The Impact of Type 1 Diabetes on the Self of Adolescents and Young Adults

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Declaration:

I, Sharon Hillege certify that this work:

The Impact of Type 1 Diabetes on the Self of Adolescents and Young Adults

is original and has not been submitted for a higher degree at another institution.

Sharon Hillege
Signed: [Redacted]
Abstract

This qualitative study was designed to gain an insight into the ways in which adolescents and young adults managed “self” in their day - to - day diabetes management. It also examined the effect that illness self representations had on that management. A grounded theory approach using a symbolic interactionist framework was adopted based on 27 in- depth semi structured interviews with adolescents and young adults with diabetes.

Respondents described the effects of diabetes management on the physical, emotional, social and related selves. They also described their various illness self representations. It often took an inordinate amount of work for the respondents to manage their diabetes. This “management” work could be related to problems with their physiological control, emotional stressors, the need to be socially interactive, differing priorities or relational issues. Certainly even the most resilient respondents experienced periods of vulnerability and needed to nurture the “self”

The study generates new knowledge which builds upon the existing body of knowledge relating to the management of self in adolescents and young adults in the context of T1DM. The study established that whilst some health professionals are sensitive and cognizant of the needs of adolescents and young adults with diabetes, there is room for improvement in the way in which health professionals understand the complexities involved in diabetes management for adolescents and young adults.
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A glossary is provided of common diabetes related terms to assist the reader to understand the terminology which is used throughout the thesis.

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<td>Beta cells</td>
<td>Insulin is produced in the beta cells of the islets of Langerhans in the pancreas in response to increased levels of glucose in the blood.</td>
</tr>
<tr>
<td>Blood glucose levels</td>
<td>Level of glucose in the blood. The normal range is approximately, 3.5 to 6.8 m/mols per litre. (m/mols is million molecules).</td>
</tr>
<tr>
<td>Brittle diabetes</td>
<td>Wide fluctuations in blood glucose levels despite best possible medical management.</td>
</tr>
<tr>
<td>Dead-in-bed-syndrome</td>
<td>Unexpected death in young people with T1DM.</td>
</tr>
<tr>
<td>Diabetes Mellitus</td>
<td>From the General Practice Notebook Web Site. (<a href="http://www.gpnotebook.co.uk">http://www.gpnotebook.co.uk</a>)</td>
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<tr>
<td></td>
<td>Diabetes mellitus is a heterogeneous collection of disorders unified by a state of diminished insulin action which may result from:</td>
</tr>
<tr>
<td></td>
<td>• decreased insulin secretion</td>
</tr>
<tr>
<td></td>
<td>• a reduction in the effectiveness of secreted insulin</td>
</tr>
<tr>
<td></td>
<td>• a combination of the above</td>
</tr>
<tr>
<td></td>
<td>Diabetes mellitus, irrespective of its aetiology, is characterised by hyperglycaemia and is defined in terms of plasma glucose levels.</td>
</tr>
<tr>
<td>Diabetic Retinopathy</td>
<td>Diabetic Retinopathy is a process of change in the normal vascular structure of the retina – the part of the eye that creates visual images via light sensitive cells called rods and cones (Walker &amp; Rodgers, 2002)</td>
</tr>
<tr>
<td>Foundations, support groups etc</td>
<td>Juvenile Diabetes Research Foundation (JDRF)</td>
</tr>
<tr>
<td></td>
<td>Diabetes International (JDFI)</td>
</tr>
<tr>
<td></td>
<td>Diabetes Australia</td>
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<tr>
<td>Glycosolated haemoglobin or (HbA1c).</td>
<td>Test reflects average blood glucose levels over a two to three months period. When blood glucose is high, glucose molecules attach themselves to haemoglobin in red blood cells. If glucose levels continue to be elevated more glucose binds to the red blood cells and the glycosylated haemoglobin level is high. The usual values range from four to eight percent (Smeltzer, &amp; Bare, 1996).</td>
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<td>Term</td>
<td>Explanation</td>
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<td>Hyperglycaemia</td>
<td>Increased blood glucose levels. Hyperglycaemia, leading to ketoacidosis is a serious and life threatening state. It can occur rapidly, usually within days, as a result of consistently elevated blood glucose levels. There is no consensus about these levels but the term refers to “decompensation resulting from hyperglycaemia, acidosis and the presence of ketones” (Edge &amp; Matyka, 1997, p. 208)</td>
</tr>
<tr>
<td>Hypoglycaemia</td>
<td>A deficiency of blood glucose</td>
</tr>
<tr>
<td>Immune system in type 1 diabetes mellitus</td>
<td>Blood glucose levels are regulated by the hormone insulin, which is produced by the B cells in the islets of Langerhans in the pancreas. Evidence of an autoimmune reaction to the B cells is evident in approximately 90 per cent of people with type 1 diabetes mellitus (Krentz 2000). While the mechanism is not completely understood, it is thought that environmental factors trigger the onset of diabetes in those with an inherited predisposition (Williams and Pickup 1999). This interaction helps to explain why even in identical twins it is not always inevitable that if one twin develops type 1 diabetes, then so will the other. One twin might be exposed to the trigger, whereas the other might not. (Farley &amp; Hendry, 2002)</td>
</tr>
<tr>
<td>Insulin</td>
<td>Insulin is a naturally occurring hormone that promotes transport and entry of glucose into the cells and other tissues. It regulates glucose metabolism and lowers blood glucose level. (Williams and Pickup 1999)</td>
</tr>
<tr>
<td>Ketoacidosis (Diabetic Ketoacidosis)</td>
<td>From <a href="http://www.diseasesdatabase.com">http://www.diseasesdatabase.com</a>: &quot;Complication of diabetes resulting from severe insulin deficiency coupled with an absolute or relative increase in glucagon concentration. The metabolic acidosis is caused by the breakdown of adipose stores and resulting increased levels of free fatty acids. Glucagon accelerates the oxidation of the free fatty acids producing excess ketone bodies (ketosis).&quot;</td>
</tr>
<tr>
<td>Micro vascular complications</td>
<td>Micro vascular complications is the mechanisms by which hyperglycaemia causes microangiopathy (damage to small blood vessels) are complex. The mechanisms consist of biochemical and haemodynamic factors. It is believed that these factors are common to the pathogenesis of all diabetic microvascular complications. Hyperglycaemia causes an accumulation of sorbitol in the cells which, in turn, can cause ischaemia. The enzyme protein kinase C is also increased in hyperglycaemia. This can lead to changes in blood flow and thickening of the basement membrane of blood vessels (Williams and Pickup 1999)</td>
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<td>Term</td>
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<td>Nephropathy (Kidney failure)</td>
<td>Chronic renal, or kidney, failure occurs when both kidneys gradually cease to function. Within the kidneys are numerous tiny structures (glomeruli) that filter waste products from the blood and retain larger substances, such as proteins. Waste products and excess water then accumulate in the bladder until excreted as urine. In chronic kidney failure, the kidneys suffer progressive damage over a number of months or years. As kidney tissue is destroyed by injury or inflammation, the remaining healthy tissue compensates for the loss of function. The extra work overloads the previously undamaged portions of the kidneys, causing more damage, until eventually the entire kidney may cease to function (a condition known as end-stage renal failure). (From <a href="http://hopkinsafter50.com">http://hopkinsafter50.com</a>)</td>
</tr>
<tr>
<td>Nocturnal hypoglycaemia</td>
<td>Low blood glucose levels at night caused by more than the necessary levels of insulin dropping blood glucose levels below desired levels. Amongst other things it may also be caused by low food intake before going to bed, increased efficiency of insulin, the time frame in which the insulin may remain active (as in long acting vs short acting insulin), hormonal changes within the body affecting the efficiency of insulin, illness, stress, levels of exercise and activity before going to bed, and more.</td>
</tr>
<tr>
<td>Norm Glycaemia</td>
<td>Maintaining blood glucose levels as near to normal as possible. The normal range is 3.5 to 6.8 m/mols per litre. (m/mols is million molecules)</td>
</tr>
<tr>
<td>Recurrent hypoglycaemia</td>
<td>Persistent imbalance in the dose of insulin and the quantity of food consumed resulting in recurrent low blood glucose levels.</td>
</tr>
<tr>
<td>Type 1 diabetes or (T1DM)</td>
<td>Type 1 diabetes or (T1DM) is “a T – cell- dependent autoimmune disease characterised by infiltration and destruction of the pancreatic islets leading to absolute dependence on exogenous insulin” (Cavan, Penny, Bain &amp; Barnett 1997). This means that there is a complete insulin deficiency. The disease usually occurs in children and young adults (Dunning, 2003). About 4.9 million people worldwide have T1DM and this number appears to be rising especially amongst children (Cavallo, 2003).</td>
</tr>
<tr>
<td>Term</td>
<td>Explanation</td>
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<td>Type 2 diabetes.</td>
<td>The aetiology of T2DM is still unclear, there is a strong genetic link, since there is a definite familial pattern in its occurrence and it is often particularly prevalent in some ethnic groups. Identical twins are much more likely to both develop T2DM (Harris &amp; Zimmet, 1997, in Alberti, Zimmet, &amp; Defronzo, 1997). T2DM also occurs as a result of lifestyle factors such as lack of exercise and unhealthy eating habits, which contribute to obesity. These factors, combined with the heredity and environmental factors, cause people to develop the disease. This form of diabetes is most common, affecting 85 - 90% percent of all cases. The disease generally occurs in people over the age of forty years, although it may occur in younger people but they are not required to take insulin. If type 2 diabetes occurs in young people it is called mature onset diabetes of youth (MODY). In type 2 diabetes the pancreas does not produce sufficient insulin for the body’s requirements (insulin resistance) (Harris &amp; Zimmet, 1997 in Alberti, Zimmet, &amp; Defronzo, 1997; Diabetes Australia, 2003). “Insulin resistance is the term given to impaired biological response, to both endogenous and exogenous insulin that can be improved with weight loss” (Dunning 2003).</td>
</tr>
<tr>
<td>Vitrectomy</td>
<td>The use of a special instrument to remove the content of the vitreous chamber, that is the portion of the cavity of the eyeball behind the lens, and replace the content with sterile physiological solution (Taber’s Cyclopedic Medical Dictionary, 1997).</td>
</tr>
</tbody>
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• I would like to express my gratitude to Dr. Keith Bennett, my principal supervisor, for his patience and great insights and ability to encourage and support the completion of this project.

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Chapter 1

Overview of the Study

This chapter provides an introduction to the study and describes the motivating force behind the research as well as the need for the study. It illustrates the reason for the choice of an interpretive paradigm to investigate the role of the self in the management of insulin dependent diabetes mellitus. The official term for insulin dependent diabetes mellitus is Type I diabetes, however, for ease of reading T1DM will be used hereafter. The chapter also describes the research plan and gives a brief overview of the study and finally an outline of the content of each chapter.

1.1 Introduction

Diabetes Mellitus (DM) is the most common endocrine disorder in childhood. Almost all of cases of childhood DM are insulin dependent (Australian Institute of Health and Welfare, 2002). This occurs because the body’s immune system destroys the insulin producing beta cells in the pancreas resulting in failure of insulin production. This destruction of beta cells usually occurs in the young although it can occur in adults as well (AIHW., 2002). About 4.9 million people have T1DM worldwide and numbers appear to be rising, especially amongst children (Cavallo, 2003). For Australia, based on self reporting in 1995 about 39,400 people from all age groups had T1DM, that is about 220 per 100,000 population (AIHW., 2002). The prevalence of DM in children, adolescents and young adults in Australia is about 130 per 100,000 (Silink, 1994).
Numerous studies into T1DM focus on the biological and physiological aspects of this disease and many of these studies are of immense importance. However, there has been a more recent emphasis on the psychosocial aspects of DM, as the complexity of Diabetes management and in particular the management of T1DM has been realised. Although management in T1DM encompasses a number of factors—monitoring blood sugar levels, injecting insulin, following an appropriate diet and exercise regime—satisfactory outcomes are not necessarily guaranteed. The management of T1DM is multifaceted and requires strong determination to maintain “good glycaemic control”. Certain terminologies used in Diabetes management for example “good”, “tests” and “control” are embedded in the biomedical model of health, the common model used in Diabetes management. As such they are extremely value laden and should be used advisedly. The use of this terminology is addressed in Chapter 6.

1.2 The structure of the study

The study took place in two parts. This first study included nine adolescents between the ages of 16–20 years with T1DM and a model was developed. The second study included seven of the same respondents (now young adults) in longitudinal testing, three young adults who had experienced complications as a result of T1DM were interviewed for theoretical sampling and eight new 16–20 year old respondents who were interviewed to test the developed model. Table 1 below outlines the structure of the study.
1.3 The motivation and need for the study

The ability to manage T1DM requires a great deal of focused “work” which requires the carrying out of multiplicity of tasks. They have to inject themselves as often as four times daily and should perform blood sugars levels usually at least four times a day. They are advised to follow a low fat, low glycaemic index diet and generally eat six meals a day and also need to exercise frequently. Trying to prioritise all these needs is often very hard and is particularly difficult as one enters adolescence and young adulthood where these priorities might clash with other developmental needs and priorities.
It was how adolescents and young adults managed this “focused diabetes work” and the effect that it had on the self as well as how they represented the illness to the self that became the driving force behind this study.

It is of vital importance for the person with DM to have good physiological management of their DM; this was proven to be essential by the DM control and complications trial. This trial, was conducted in between 1983 and 1993. It included 1441 volunteers between the ages of 13 and 39 years who had had DM for one to fifteen years. The trial provided compelling evidence that there was a reduced risk of the development of retinopathy and microvascular complications if blood sugars were maintained at as near normal levels as possible (Orchard, Forrest, Ellis & Becker 1997; Morris, Boyle, McMahon, Greene, MacDonald & Newton, 1997). The trial provided conclusive evidence, not previously available to health professionals, of the need for people with all forms of DM to maintain blood glucose levels as near to normal as possible (norm glycaemia).

Nevertheless, even in this trial with a highly selected and motivated research population given ample resources and education, only five percent of the people maintained an average concentration of glycosylated haemoglobin in the target or normal range (less/equal 6.05%), that is excellent blood glucose control (Jacobson, 1996). A glycosolated haemoglobin (or HbA1c) test reflects the average blood glucose levels over a two to three months period. When blood glucose is high, glucose molecules attach themselves to haemoglobin in red blood cells. If glucose levels continue to be elevated more glucose binds to the red blood cells and the glycosylated haemoglobin level is increased. The usual values range from four to
eight percent (Smeltzer & Bare, 2004). However the target range, as mentioned previously, is less than or equal to 6.05% (Jacobson, 1996).

It takes an immense amount of work and motivation to maintain appropriate blood sugar levels and thus prevent the onset of complications. People with DM may become discouraged and may suffer burnout since:

“Few, if any, people can maintain all the tasks of diabetes care, week-in week-out and keep blood glucose and HbA1c’s in the narrow ‘normal’ range all the time. Without realistic expectations and practical strategies for managing the emotional side of diabetes, the risk of burnout is high.” (Beeney & Sharpe 2001, p.4).

I have nursed scores of people (including children, adolescents and young adults) with DM. I have observed my own daughter, who was diagnosed with T1DM at the age of four, as she has developed through childhood, into her early teens then adolescence and now adulthood. I have marvelled at how my daughter and many others have coped with this particularly onerous disease with such equanimity. I have also nursed a young woman who in her early twenties, had gone blind and had already had a kidney and pancreas transplant, yet she displayed such courage and fortitude. Newbern (1990) rightly suggests, it takes “courage and persistence … to survive diabetes” (p.36).

Questions arose in my mind as to what the effect a disease, such as DM, has on the developing self and led me to ponder about whether the way one perceived oneself affects diabetes management. It was my contention that there was a need to be sensitive to these young developing selves, as health professionals and parents, in order to assist them to negotiate the rather bumpy ride which is diabetes management.
1.4 Choice of research paradigm and explanation of terms used in the thesis

Prior to commencing this study it was necessary to decide which research paradigm might assist the researcher to explore the question/s being posed in the most appropriate manner. The initial thought was to complete a quantitative study measuring self-esteem levels and performing the Kuhn's "Who am I test"? on people with DM (Kuhn & McPartland, 1953). However, a quantitative study would not have given the in–depth understanding that was being sought.

As I wished to uncover and unravel the role of self in adolescents and young adults with T1DM, I came to the realisation early in the research process, that this topic would be better explored using a qualitative research approach. After a period of examination, I decided to use a symbolic interactionist framework to develop a grounded theory, as this framework would allow for an in-depth description of the impact that having DM has on the self of adolescents and young adults.

At this point it becomes necessary to give the definition of self that is to be used in this thesis. The decision was made to use the definition of self described by Mead and other symbolic interactionists. They describe “the development of self as a process between the I and the me” (Osborne & Van Loon, 1999, p. 80), in fact this “self is always in process”(p. 79) therefore, “personality is not fixed but fluid” (Osborne & Van Loon, 1999, p.82). This seemed a very satisfactory definition of self, as it sees self as developing and changing over time and not as being determined. A more in-depth discussion of self can be found in Chapters 2 and 3.
I was also interested in how people represented their illnesses and as I explored this, I came across the work of Nerenz and Leventhal (1983) as well as the work of Charmaz (1991). Nerenz & Leventhal (1983) acknowledged, Gutmann, Pollack, Schmidt & Dudek’s findings with cardiac patients and reflected on how these findings may be modified to describe three illness self representations present in cancer patients. They provided a valuable description of these illness self representations. The first representation being “the disease is the self, the self is the disease" where there is total involvement with the disease, it affects every aspect of human activity. The second is the encapsulated self, which means, "a component of the self is diseased, but large areas are disease free" and there is adaptation to the disease. There is an awareness of the disease, but people are still able to work, socialize and conduct life as usual. The third self representation is the "at risk self". This means “the self (total or part) faces a constant threat of outbursts of the disease" (acute and symptomatic illness). There is a permanent state of threat or potential for an acute outbreak of the disease (Nerenz and Leventhal, 1983, p 28).

Charmaz (1991) described the illness-self experience and her findings concur with the illness self representations described by Nerenz and Leventhal (1983). She indicated that "people experience serious chronic illness in three ways, as an interruption in their lives, as an intrusive illness and as an immersion in illness" (p.10). She extends this concept further and indicates that the same person may experience the disease as "interruption", "intrusion" or "immersion" (p.10). Dependent upon what is occurring in the disease process, she suggests that people can move in and out of these illness representations depending upon degeneration or remission of the disease process.
These illness self representations provided a coherent way to explore the illness \textit{self} experience in adolescents and young adults with DM. The illness self representations are described more fully in Chapter 2, Chapter 5 and Chapter 6.

1.5 The sample groups for the studies and rationale for this choice.

The sample groups were nine adolescents and young adults. There are some unique issues that surround the period of adolescence and young adulthood and there are many theories about these phases of development.

The first study included adolescents. As far back as 1904, behavioural scientists, such as Hall suggested that adolescence was a "period of disturbance of the child's self image... the age of storm and stress." (cited in Simmons, Rosenberg & Rosenberg, 1973, p. 553). Erikson (1968) proposed that adolescence was a time of identity crisis, where the child struggled to form a stable sense of self. Sociologists see adolescence as a phase of "physical maturity and social immaturity" (Davis, 1944, cited in Simmons et. al., 1973, p.554). They intimate that because of our complex social system the child achieves adult status before he/she is able to function well in adult social roles.

While the task for adolescence and young adulthood is to develop an identity, have a positive self and body image, become emotionally independent and have realistic ideas about the future (Blumberg, Lewis and Susman, 1984; Court, 1992), it is also the case as Hepperlin suggests that "children and adolescents are generally known to
be vulnerable to various physical and psychological obstacles to maturation" (1991, p.122 - 123).

Chronic illness further complicates this developmental cycle and Charmaz (1990) argues that the life restrictions imposed by chronic illness affect independence and individualism. She does, however, indicate that as long as the individual is able to exercise freedom and choice, then "suffering is reduced and self - images are maintained" (p. 1170). Since having a chronic illness, such as DM, may curtail, one’s freedom and choice, it is easy to see how it could interfere with the task of becoming an adolescent and young adult.

These issues are complexities which may occur in the lives of adolescents and young adults with DM and they provide the rationale for the samples used in this thesis investigation.

1.5.1 The sample group for the first study

The sample group were nine, 16 - 20 year old adolescents. They were chosen in the belief that this age group would display some form of uniformity of perceptions. They would possibly still be at school or university and a majority would be living at home. All of the respondents had had DM for longer than one year and most had it for two to three years when they were first interviewed. Another reason for studying this age group was because in younger children, parents, in the main, control the child’s DM and metabolic control might therefore, be determined by this parental control rather than the child's illness self representation. In mid adolescence, however, teenagers are able to take on more responsibility for the management of their disease (Court, 1992).
The rationale for choosing respondents who had been diagnosed with DM for longer than one year, was based on early studies conducted by Kovacs, Iyengar, Goldston, Stewart, Obrosky and March (1990) which indicated that in the first year after diagnosis, mild episodes of depression were experienced but, thereafter, the person seemed to adapt to the disease. It was considered that respondents would suffer less depression if they had had DM for a year or more. However, as this study progressed this was proven untrue. There are findings that indicate that adolescents and young adults may well be at risk of problems of adaptation and that this may result from low self-esteem, social dependency and poor ego development. These problems may be more widespread among both children and adolescents with DM than amongst their healthy peers (Grey, Cameron, & Thurber, 1991; Grey, Lipman, Cameron & Thurber, 1997). The issue of depression will be explored in the further chapters as some respondents had, or were suffering, from depression when they were interviewed.

1.6 Dilemmas accessing respondents

The task of accessing respondents was a difficult one. The researcher was unable to carry out the research in two large endocrinology units at prominent Sydney hospitals. At that time there was no nursing research taking place in either of the units and there was certainly no qualitative research occurring. Nursing research appeared to be scrutinised by doctors and as researcher I questioned in my mind, how much background in research doctors really had. However this issue of hegemony is perhaps best explored elsewhere and not in this thesis. I did, however, believe that I had sufficient interest and experience in the area that I was researching and was aware
of the importance of the research question being asked. After a short period of “despair” I pursued another avenue in order to gain access to respondents through a support group the Juvenile Diabetes Research Foundation. A group of nine adolescents were recruited and interviewed, the interviews were analysed in accordance with grounded theory approach, themes were elicited and some models of diabetes management were described. These models are described in Chapters 4, 5 and 6.

By this stage I had developed the research to the level of a Masters (Honours) thesis and with the encouragement of the chair of my supervisory panel transferred my candidature to the Doctor of Philosophy. This led to the second study, which provided an opportunity to explore issues arising from the first study that needed further clarification, and extend the theoretical underpinnings of the first study.

1.7 The sample group in the second study and rationale for this choice

The second study addressed the questions raised by the previous study and used a three pronged approach.

1. Seven respondents from the first study were re-interviewed - the longitudinal study (LS). Four years had passed and these adolescents were now young adults. I revisited what these respondents revealed in the first study and posed the following questions: How have things changed for you? What have brought about these changes? How do you perceive the future? The developed model and its validity was tested by giving the respondents a review of the
study to date and asking them for their feedback after an additional in-depth interview.

2. A different cohort of 16 - 20 year olds was also interviewed, to test the potential of the developed model over time – the cohort group (CG) study. Such cross - sequential extension of the study is in line with best practice in longitudinal research (Polit & Hungler,1999). Respondents for the CG study were recruited through Diabetes Australia in the main.

3. A third prong was introduced by interviewing others known to have a different illness trajectory to those already interviewed, in order to test their illness self–representations. This illness trajectory (IT) group allowed counter model arguments to be developed and expanded. In the main, given the nature of the IT study respondents, they were recruited through “snowball” sampling.

The research project was thus divided into two studies and the aims of both studies will be discussed below.

1.8 The aims of the two studies

The aim of the first study was to explore the concepts of self and illness self representations in adolescents with DM. The aims of the second study were related to the three sample groups. The longitudinal study aimed to explore change in self and illness self representations over time as the adolescents moved into young adulthood. The cohort study was completed in order to achieve cross-sequential extension of the study. The third component of the second study was to theoretically sample those
who had had a different illness trajectory, in order to test their self and illness self representations and thus to expand on counter model arguments.

All of the groups were shown the developed model once their interviews were completed and asked to comment on it. This was done in order to check the validity of the developed model.

1.9 Structure of the thesis

Chapter One, the present Chapter, provides background information relating to the study as well as the need for the study. It includes the reason for choosing an interpretive paradigm to examine the role of the self in the Diabetes management and the broad direction followed in order to accomplish the research.

Chapter Two provides a review of the literature, commencing with a description of theories of illness causation, the factors influencing beliefs about illness and disease and the nature of illness. Ideas about self and illness self representations are explored. This is followed by a historical overview of Diabetes Mellitus (DM), which includes Non Insulin Dependent Diabetes Mellitus (T2DM) and Insulin Dependent Diabetes Mellitus (T1DM), its management and the need for appropriate compliance in order to avoid complications. The final section focuses on adolescence and young adulthood and the impact of chronic illness on these stages of development with a special focus on adolescents and young adults with T1DM.

Chapter Three includes a discussion of the theoretical framework and describes some common research paradigms. The use of interpretive perspectives and more
specifically, Symbolic Interactionism as a framework for the development of Grounded Theory to describe a model of diabetes management, are discussed.

Chapter Four introduces the first study which moved the investigation towards theory development. An explanation of the research questions and aims is given and the design, implementation, data collection methodology and sampling procedures of the study are documented. Participant recruitment is described and sample characteristics and ethical issues integral to the study are discussed. Finally the way in which grounded theory methodology and procedures were applied to explore the impact that DM has on the self of adolescents is described in this chapter.

Chapter Five provides a review of study two, the research questions that were posed are stated and the analysis and findings of the longitudinal study group (LS), the illness trajectory group (IT) and the cohort group (CG), are presented, as well as the findings about the illness–self representations discovered in both Study One and Study Two.

Chapter Six includes a brief overview of the study, a detailed discussion of the developed themes and their connections to existing literature, notes the limitations of the study, and concludes with making recommendations for practice, education and research.

In summary this thesis explores the role of self and illness self representations in adolescents and young adults as they manage their DM. A qualitative, theory-building methodology is described that reflects the subjective nature of respondents’
experiences and the interpretations that they give to them. The environment in which these experiences occurred is also explored. This study’s outcomes can significantly enhance the understanding of important concepts and practices relevant to diabetes management in adolescents and young adults and provides valuable insights for nursing and health professionals.
Chapter 2

Literature Review

2.1 Introduction

This chapter reviews literature on disease causation, theories of illness and the contrast between acute and chronic illness. This will be followed by a critical discussion of what is meant by the self and by illness self representations which necessarily focuses on literature concerning the developmental aspects of adolescence, early adulthood and of selfhood. Diabetes mellitus (DM) as a chronic disease entity, the global and Australia incidence of the types of DM, with a particular focus on Type 1 Diabetes Mellitus (T1DM) is outlined. Finally, this Chapter explores the developmental processes that take place in adolescence and early adulthood with particular reference to problems faced by adolescents and young adults with T1DM.

2.2 Theories of Illness Causation

Theories of illness causation can be encapsulated under three headings - germ theory, homeostatic theories and psychosocial theories. Germ theory was developed in the late 19th century by Pasteur who suggested living micro organisms cause all infectious and contagious diseases (Wyngaarden, Smith & Bennett, 1992).

The idea of body fluids constancy, or homeostasis and its role in understanding how life is maintained was an early notion of Bernard and Cannon. They suggested that health was the “ability of the human body to keep its internal environment in an ongoing state, despite the external environmental variations that acted upon it...they considered that disease was the result
of an imbalance in the body's internal environment, or a rupture in its capacity to harmonize effectively with its external environment” (Franco, de Barros, Nogueira-Martins & Michel, 2003, p. 548). Selye, based his pioneering research on Bernard’s work that recognized the mind-body connection, when he described the general adaptation syndrome which describes stress biologically (Franco, de Barros, Nogueira-Martins & Michel, 2003). John Mason built on Selye’s research and worked in the area of psycho-endocrinology. He indicated that stress was principally a psychological rather than a physiological occurrence (Franco, de Barros, Nogueira-Martins & Michel, 2003).

Psychosocial theories attempted to integrate the psychological, social and physiological in order to explain disease. In 1953, for example, the neurologist Harold Wolff formulated the hypothesis that physiological and pathological changes unwittingly evoked stress responses which had an effect on the emotional and social environment of the person (Franco, de Barros, Nogueira-Martins & Michel, 2003).

It does not seem to matter which theory of illness causation is adhered to, since the general view is that each disease is diverse and incorporates socio-ecological, ethnic, cultural, developmental, psychological, physiological, molecular, and genetic components. This general view recognises that a person - or patient - has a disease or illness and that “disease should be not be the sole focus of the healer's attention; the patient should be” (Weiner, 1999, p. 262).

Certainly, aspects of germ theory and homeostasis are reflected in the theories behind the causation of T1DM. T1DM is caused by the destruction of the insulin-producing beta cells in the
pancreas as a result of the immune system of the body mistakenly recognizing these cells as invaders. Genetic factors are involved, but other causes also play a role in triggering the disease. These may be viral infections or dietary factors since; proteins in the diet may trigger auto-immune destruction of the beta cells (Cavan, Penny, Bain & Barnett, 1997; Alberti, Zimmet & Defronzo, 1997; Dunning, 2003).

Beyond the level of illness causation one of the most important factors about disease is what it means to the person. The drive to find meaning in illness is a strong common feature shared across cultures. Unquestionably definitions and meanings of illness differ enormously at various levels – personal, social, spiritual - and what causes deep foreboding for some people might be disregarded by others. While important to acknowledge that not every person who is sick is searching for meaning in the experience, many do hold strong beliefs about illness and these are often multi-factorial (McGrath, 1998).

2.3 Factors influencing beliefs about illness and disease
Cassell (1985) wryly notes that illness is the experience that the person has when he goes to the doctor and a disease is what he has on his way home from the doctor’s consulting room. For Cassell, disease results from a change in the biological or psychological state which leads to malfunction of a body organ or system; whereas illness is a subjective response to something a person actually encounters. It is precisely the interaction between these biological, psychological and subjective responses, which occur when a person is diagnosed with a chronic illness such as DM, that is the broad focus of this literature review, and which this study was designed to explore.
When people notice signs and symptoms they may seek to self diagnose which in turn can drive the person to seek out professional help, or conversely, they may avoid this help completely. They are, however, likely to interpret what is happening to them from within a framework of existing knowledge and beliefs. Such a framework is influenced by factors beyond the symptoms and the experience. It is likely to be socially mediated as well as contingent on personality and culture (Omeri, 1996; Andrews & Boyle, 1997; Andrews & Boyle, 1999; Helman, 2000; McGee, 2000). For example, Papadopoulos (1999) suggests that in the case of Greek Cypriots, their emerging model for health and illness appears to include the “concepts of fatalism, realism and idealism within an active-to-passive continuum”… (p.1102). Health is seen both in terms of personal responsibility, personal action as well as being determined by God. However, there is also an expression of realism, when the stresses and battles of everyday life and their effects on health are discussed (Papadopoulos 1999). Clearly each individual diagnosed with the same disease may understand their illness in a completely different way (Antonovsky, 1985).

Such understandings and beliefs about the cause and severity of their complaint can affect an individual’s health behaviours and the manner in which treatment, if any, is sought and followed. Such “intuitive” theories derive from various biomedical, sociological, and philosophical perspectives which in this context give explanatory power to the phenomena being experienced.

The anthropologist Kleinman (1980) developed an explanatory model of illness. This model provides a succinct way to look at how illness is patterned, understood and treated. He outlines how ideas about the experience of sickness and behaviours are employed by all those involved in
the clinical process and how, since explanatory models are held by both the person and the health professional, they offer explanations of the sickness and treatment. These models guide choices amongst existing remedies and therapists and cast personal and social meaning on the experience of sickness. Kleinman’s model addresses five aspects of illness which are: the aetiology of the condition, the timing and manner of onset of the symptoms, the patho-physiological processes involved, the natural history and severity of the illness and finally the appropriate treatments for the condition.

Kleinman (1980) suggests that the models adopted by lay people tend to be distinctive and unpredictable and are greatly influenced by personal factors in contrast to those models adopted by health professionals which are based on scientific logic (Kleinman, 1980; Kleinman, 1988; Helman, 2000). He also suggests that when people recognise that they have become ill they begin to ask questions-What has happened? Why has it happened? Why has it happened to them and at that particular time? What would happen if nothing were done about the problem? What should be done about the problem? Kleinman’s model suggests that patients and health professionals may adopt various perspectives concerning illness and suffering and it is particularly helpful in interpreting the culture of western medicine to others, and in performing cross-cultural comparisons.

Historically, both “practitioner” and patient accepted a supernatural explanation for illness and suffering. This is still found, amongst people from so-called “primitive” cultures, certain ethnic groups and, in fact in many non-western societies. In this explanatory model, health is seen as a balanced relationship between man and man, man and nature and man and the supernatural world.
where a disturbance of balance may manifest itself in either physical or emotional symptoms (Tamm, 1993; Helman, 2000).

The supernatural or mystical view of health in western societies was moderated in the middle ages by a theocratic view influenced primarily by the Christian church. It was accepted that God had the final authority over life and this included suffering and illness “therefore disease of the body and anguish of the soul were within God’s domain and that of His healers” (Reed, 2003, p. 6). This theocratic view of health and illness has not only influenced western civilization but continues to do so.

While people began to challenge the idea of the unity of the body and the spirit quite early the 11th and 12th centuries (Reed, 2003), the idea of the mind being differentiated from the body gained new impetus in the 17th century when Descartes published his celebrated treatise on the scientific method. Descartes considered the mind as the direct expression of God’s nature in man and that therefore the mind could not be studied scientifically (Tamm, 1993). Conversely, he considered the body to be a machine, which could be studied scientifically. While Lawler (1991) contends that this dualism is wrongly attributed to Descartes, it is generally accepted as “Cartesian dualism” (Tamm, 1993).

As medicine moved into medieval universities and became an academic discipline the explanation of disease became more naturalistic and theoretical. Those adopting this secular view were called humanists since their focus was on humans and given the increasing use of observation and reason, supernatural explanations of disease and suffering began to recede (Reed, 2003). According to this “humanistic” model, health is not a condition, but a process of
moving towards self–actualization where the person creates his or her experience of health and illness (Tamm, 1993).

Over time the mechanistic model of the human body, made up of parts which can be repaired, was split apart from the issue of suffering which was relegated to the domain of religion and philosophy (Reed, 2003). Often health professionals have been educated from a very scientific curriculum which does not pay much attention to suffering and it could be argued that inattention to suffering in present day health care professionals originates in their mission to cure the person using scientific knowledge and techniques. The biomedical model is a disease model and though many diseases can certainly be treated through this approach, it is not an entirely satisfactory model for individuals with chronic illnesses. Chronic illnesses have much to do with self-management, lifestyle choices and attitudes, and an acknowledgement of the suffering that often accompanies chronicity.

Wolpert & Anderson (2001) argue that the guidelines for treating DM are framed within the biomedical perspective as they concentrate almost exclusively on biological control with tight glycaemic control as the ultimate goal of future health. While this, ideally, is the goal of people with DM as well, other goals may have primacy in particular situations. For example, a more meaningful goal for young people with T1DM may be to prioritise their activities and focus on immediate concerns which, at times, may not include the biological dimension of tight glycaemic control. Therefore, treating adolescents and young adults with T1DM requires a much greater understanding of the factors influencing their decision-making in relation to glycaemic control.
than is constituted within a biomedical model. A broader approach is required to address these treatment goals.

Nurse-phenomenologists suggest that, while it is important to understand the biological and psychological implications of disease, it is equally important to attempt to grasp the subjective and individual nature of an illness experience. When this approach is adopted, the health professional is more likely to be able to support the person in their illness experience (Kretlow, 1991; Benner Hooper-Kyriakidis & Stannard, 1999). Locker (1981) adds to this approach by suggesting that illness is a social construct that is dependent on the way individuals evaluate their constellation of symptoms. Such a construct is “a symbolic ordering of given events or states of illness” to which the individual gives a label (1981, p. 4). He argues that illness is something that becomes a part of the person and that illness and disease are conceptually distinct with disease being a “variety of biological events such as changes in physiological, biochemical and anatomical structure and functioning” (1981, p.4). Further, he contends that it is possible for someone to suffer from a disease without being defined as being ill, such as, could be true for a person suffering from hypertension. By the same token, a person may be defined as being ill without having a detectable disease, such as, someone who is suffering from a mental illness without having any underlying pathophysiology. Furthermore he makes the case that the individual may not take any action as a result of these definitions of their condition, however constructed.

Locker’s position (1981) contrasts markedly with that of the foundation tenet of Parsons (1951), and with the several revisions of his original theory. Parsons holds that when people are
diagnosed with an illness they adopt a ‘sick role’, which legitimises withdraw from normal social role responsibilities. Since it is usually the doctor and or significant others who legitimise this “right”, the sick person is not expected to get better without assistance and, since the acceptance of the sick role is not desirable for the long term, the person is obliged to want to get well. Because of this obligation the ill person, needs to seek help (usually from a physician) and to cooperate with his or her care in order to regain wellness (Parsons, 1951). This once popular, widely accepted model of illness has, however, been heavily critiqued. Some suggest that it only applies to those with short, acute episodes of illness and it has been variously critiqued for its theoretical poverty relative to chronic and terminal illness and its social and cultural implications, arising from its strong ties to the biomedical model of health (McKay, 2003). However, it needs to be acknowledged that this model has been revised by Parsons himself, who has resiled from his original all-or-nothing position. However, it may be that remnants of his original postulations, rather than the reasons, linger longer.

Frank (1995) contends that people, who do not get well, wish to continue to believe that they will get well. For this group, whom Frank calls the “remission society” (p.82), the sick role as initially described by Parsons has little relevance. Often rather than taking on the sick role, the person might use some help-seeking behaviour to solve the problems that arise as a result of labelling that occurs with the diagnosis of a chronic or malignant disease. Locker describes this as social action, in that, “the actors construct the sense of the events, objects and state of affairs with regard to illness” (Locker, 1981, p. 4).
T1DM has a genetic base and in such cases Shiloh suggests that “genetic disorders are commonly perceived as permanent, irreversible, chronic, family-linked, stigmatizing, complex, and evocative of strong emotions, such as fear, pity, and guilt for passing the defect to offspring” (1996, p.476). Thus, T1DM may elicit an element of guilt particularly among parents because there may be a genetic link in the path of causation and this can also complicate the meaning attached to this disease.

Once the person is diagnosed with a disease or illness they start on what is termed by health sociologists as an illness career trajectory (Glaser & Strauss, 1968; Corbin & Strauss, 1991; Corbin, 1998; Miller, 2000). The illness career is determined by the length and the extent of the disease process. Thus illnesses may be defined as either acute or chronic illness (Locker, 1981; Miller, 2000).

2.4 Nature of illness

An acute illness can be described as one with a comparatively rapid onset which usually responds to appropriate treatment, is self-limiting and short term (Ignatavicius, & Workman, 2002). Acute illness may affect functioning in one or more experiential dimensions - physical, psychological or spiritual - but in general people suffer few or no complications and are able to return to their former level of performance (Crisp & Taylor, 2001). By contrast, chronic illness follows a different trajectory.

A formal definition of chronic illness is “the irreversible presence, accumulation or latency of disease states or impairments that involve the total human environment for supportive care and self care, maintenance of function and prevention of further disability” (Lubkin & Larsen, 2002,
Chronic illness may leave permanent impairment, residual physical or mental disability and non reversible pathological changes. It may require special rehabilitation and long-term medical and nursing management (Crisp & Taylor, 2001; Ignatavicius, & Workman, 2002). There are five stages of illness behaviour which are well documented and while relevant to both acute and chronic illness, they are most clearly delineated in acute illness.

2.4.1 Stages of illness behaviour

A stages of illness approach commonly includes the experience of symptoms; the assumption of the sick role; contact with medical care; the dependent client role, and finally recovery and/or rehabilitation (Register, 1987). This approach often takes little account of subjective human experience.

In contrast, the response to a diagnosis of a chronic condition consists of different and more diffuse levels of complexity of psychological and possibly, physical response, in some cases resembling a grief response, leading to chronic sorrow. This is a model that not only offers a framework for understanding responses to the diagnosis of a chronic illness, but also for the grief or sorrow that may be experienced as a response to disruptions and losses of many kinds in a person’s life. For example, people on being diagnosed with a chronic illness are more likely to experience deeper feelings of anxiety, (Gjengedal, Rustoen, Wahl, Hanestad, 2003; Kyngas,& Barlow, 1995), disbelief, anger and grief, (Eakes, Burke & Hainsworth, 1998), hope (Coleman, 2003; Reed, 2003), shame (Goffman, 1986) courage (Newbern, 1990), depression and despair (Kyngas & Barlow, 1995; Kovacs, Mukerji, Iyengar & Drash, 1995; Miller, 2000), helplessness, (Mikulincer, 1994) loneliness (Reed, 2003) and even increasing faith (Coleman, 2003).
2.4.2 Adaptation to chronic illness

Adapting to chronic illness is often long, arduous and continuous. The way in which a person adapts depends upon the type of illness, the magnitude of incapacity, and features of the person’s personality. Medically speaking, some chronic illnesses are stable. Others fluctuate in severity and symptom intensity with periodic remissions. A percentage degenerate and become end-stage (Charmaz, 1991; Ludder Jackson & Vessey, 2000). The effects of severe chronic illness are further compounded by the personal responsibility and discipline required for self-management. The degree of self efficacy or powerlessness a person experiences is affected by the unpredictability of many chronic illnesses (Turk, Rudy, & Salovey, 1986). Managing the chronic illness DM, especially T2DM, which has a more predictable course, may not pose as much difficulty if the person is able to maintain wellness, and get on with their lives. Managing T1DM, however, is often unpredictable and difficult to control. There may be multiple fluctuations even throughout a single day, that may be serious and even cause life-threatening repercussions and T1DM requires a great deal of personal responsibility in managing it. Its variability is sometimes linked to a co-existing acute illness which can lead to considerable feelings of frustration and powerlessness for the person, families and treating staff.

2.4.3 The impact of chronic illness

A chronic illness has a great impact on the self since the characteristics of chronic illnesses are that they are long–term, uncertain, and require great effort to manage. A person with a chronic illness may experience other co-existing conditions that are disproportionately intrusive on the self (Strauss, Corbin, Fagerhaugh, Glaser, Maines, Suczek & Wiener, 1984).
People with chronic illnesses can be variously impacted: household routines are affected and this may result in social isolation; the use of many ancillary services can increase expenses; body impairment caused by the chronic illness may lead to loss of activity (Ignatavicius, & Workman, 2002). People with chronic illness may not have sufficient knowledge about the disease and may, therefore, be unable to make rational health decisions, which could enable them to recover more freedom and control. This may lead to increased dependency on others for their recovery and they may experience disempowerment, accompanied by increasing vulnerability and threats to their self-image. This illness experience can cause a separation of the physical and psychological self (Crisp & Taylor, 2001).

The meaning that a person attributes to the disease has a significant effect on the way in which the person views themselves or on how others view them. For example short term illnesses might not involve significant changes in self-identity, but long term illnesses cause a substantial revision of self-identity (Miller, 2000). The psychological self becomes isolated, leading to indecision and confusion. The person is less able to plan, and feels incompetent. They also experience emotional distress, hopelessness, despair and an inability to communicate and this "lack of control seems to pervade all aspects of chronic illness” (Miller, 2000, p. 7).

Indeed, anyone who becomes ill or sustains an injury, experiences change and loss in one way or another. This loss might include changes in mental or physical function, loss of levels of independence, changes in self-image or identity and body image. The person may experience feelings of being “permanently different” and “being of less worth...almost like a defective mechanical device” (Miller, 2000, p. 11). They enter the world of the chronically ill described as
the “fourth world.” Cooper explains this “fourth world” as a place made up of millions of people who have become alienated from the ideal everyday world and who are unable or denied interaction in that world as a result of their disease and its treatment (Cooper, 1976)

Disease and injury interfere with self-image, since they distort the structure of the body and can alter body image (Bronheim, Strain and Biller, 1991). Charmaz (1983) contends that this loss of self is felt by many people with chronic illness. Drench (1994) supports this view and indicates that body image, self concept, identity and ego are very closely allied and any variation in any one of these can have a detrimental effect on the entire self.

Clearly chronic illness has an impact on the self.

This Chapter now turns to examine some ideas about the self itself and its relationship to illness.

2.5 Ideas about the self and illness

Self is obviously a complex concept and this complexity is reflected in the many views of self in philosophy and social sciences and the accompanying lack of clarity and coherence in these views. It is self-evident that the “term self is used in so many different ways in our everyday speech that it is hard to pin down what we mean by it” (Charon, 1989, p 64). For example, Kuhn & McPartland indicate that "self has been called an image, a conception, a concept, a feeling, internalization, a self looking at oneself and most commonly simply the self." (1953, p.68).

Wright (1960) suggests that the construction of a self picture is a complex which is made up of various individual characteristics that define for a person their own psychological identity (1960). Craven & Hirnle (1992, p.1242) define various concepts of self which include:
• Body image - the way in which one pictures ones body or how one feels about ones body.
• Social self - the way in which one sees oneself in their social relationships.
• Self - concept - the mental picture that one has of oneself.
• Self - esteem - the decisions that one makes regarding oneself.

They go on to suggest that identity can be described as the "organizing principle of the self" and “it is being aware of being a separate entity from others” (Craven & Hirnle, 1992, p.1243). They illustrate that if a person has a strong sense of personal identity then they have an integrated self-esteem, body image and whole self-concept.

Some researchers such as Dennett, Harre and Gergen (in Kolak & Martin, 1991) contend that there is no such thing as the self. In fact, Dennet argues that the human self that emerges from interpersonal and social interactions is not real. Harre indicates that concept of self in reality refers to nothing, and Gergen contends that the self is a fabrication.

Conversely Neisser describes five ways of knowing self:

• The ecological self – I am the person here in this place, engaged in this particular activity.
• The interpersonal self – I am the person engaged here, in this particular human interchange.
• The extended self – I am the person who had certain specific experiences, who regularly engages in certain specific and familiar routines.
• The private self - I am in principle, the only person who can feel this unique and particular experience.
The conceptual self or self-concept - draws meaning from the network of assumptions and theories in which it is embedded” (Neisser in Kolak & Martin, 1991, p. 386)

Ashmore and Jussim (1997) indicate that some ideas about self are descriptions of social roles, (e.g. mother) or internal entities (e.g. soul) or socially significant dimension, (e.g. wealth, attractiveness). They also contend that these “selves” are not usually experienced as disconnected or distinct, but are unified and of fundamental importance. They further illustrate the unity of self by indicating that “selfing” causes people to experience a “sense of otherness” whilst at the same time being an intrinsically “unifying, integrative and synthesizing process”.

The process of “selfing” they argue begins when an infant encounters the world as a subject. Once this is consolidated, then selfing (the I) works to weave a representation of the self that is the “me” (1997, pp. 56-58). This process continues into late adolescence and young adulthood. Identity becomes a desirable quality of selfhood and undeniably, society expects individual lives to display “individuated patterning suggestive of life unity and purpose” (Erikson, 1963 cited in Ashmore and Jussim, 1997, p.60).

Social relationships are very important in the development of self. Goldman and Maclean (1998) define identity as “a socially constructed phenomenon given, that one’s relationships with others shapes self-esteem, self confidence and general sense of self” (p.745). Norris (1970) also indicates, “that body image is viewed as a social creation” and that it is “intimately interdependent with personality, ego, self-image identity, and sense of worth” (cited in Drench, 1994, p 31). Thus, we see that social relationships profoundly affect the sense of personal identity or self. It is precisely these social relationships which are affected in the course of a
chronic disease as they, are often not predictable and social adjustments and readjustments have to be made (Strauss et al., 1984, p.73).

The symbolic interactionists perspective of *self*, has a very specific meaning and is very functional (Charon, 2001). The *self* does not have the same meaning as Freud’s ‘ego’. Rather the *self* is “an object, social in origin and that undergoes change like all other objects: in interaction” (Charon, 1989 p.65). “Human beings can be objects to themselves”, that is, “an object that they can name, imagine, visualise, talk about and act towards” (Hewitt, 2000, pp. 49 - 50). In symbolic interaction approaches the *self* can also be described as a process. Mead, describes, the *self* comprising of two parts, the *I* and the *Me*, the *I* being “the looking glass or reflector” and the *Me* being conceptualized, as a result of self-reflection (Meltzer, Petras, & Reynolds, 1975, p.41; Bowers, 1988; Hewitt, 2000).

Another sociologist who used social interaction to examine human interaction and whose work is pertinent to this study is Goffman. He argues that the situations where we spend most of our lives are face to face activities involving others. He indicates that people have great control over both the physical and social environment of the individual. Whilst, Goffman describes institutionalised life, this model is pertinent to all of our lives because there are a multitude of situations where people do have power and are able to manipulate *self* judgements (Goffman, 1959; Charon, 2001). For instances parents, siblings, partners and health professionals may have this effect on those with T1DM, as their judgements may lead these individuals to reject *self* or love *self*. Although these various definitions and treatments of *self* are of interest, the perspective
of self that will be used in this thesis is primarily influenced by that of Mead and arises from a symbolic interactionist perspective. This perspective will be further explored in Chapter 3.

Yet another issue which has an effect on the management of a chronic illness is the way in which the person represents illness to the self.

2.6 Illness Self-Representations

There are various ways in which people represent illness to the self. Nerenz & Leventhal, (1983, in Burish and Bradley, 1983) and as mentioned in Chapter 1, provide valuable description of these illness self representations in the following three ways:

- The first is the total self, this means, "the disease is the self, the self is the disease". There is total involvement with the disease. It affects every aspect of human activity.

- The second is the encapsulated self, this means," a component of the self is diseased, but large areas are disease free". There is adaptation to the disease. There is an awareness of the disease. These people are still able to work, socialize and conduct life as usual.

- The third is the "at risk self", this means, “the self (total or part) faces a constant threat of outbursts of the disease” (acute and symptomatic illness). There is a permanent state of threat or a potential for an acute outbreak of the disease ( Nerenz & Leventhal, 1983, in Burish and Bradley, 1983, p.28).

Charmaz (1991) also describes the illness-self experience and concurs with the illness self representations as described above by Nerenz and Leventhal by suggesting that "people experience serious chronic illness in three ways, as an interruption in their lives, as an intrusive
illness and as an immersion in illness" (p.23). Charmaz (1991, p.23) illustrates that people define the interruption stage in four ways:

- Disruption without a diagnosis.
- Rapid escalation after vague symptoms, followed by crisis.
- Stricken by severe sudden onset.
- Bad news from unexpected test results.

In this interruption stage people commonly embrace a "model of acute care" which, as mentioned previously, is the assumption of the sick role, coming in contact with medical care, taking on the dependent client role, and finally moving to recovery and/or rehabilitation (Charmaz, 1991, p.13). People adopt this model in order to prevent their lives and self-concepts from becoming inundated by the illness. In fact some practitioners believe that when clients adopt the interruption-illness-self representation they are denying their illness. However, Charmaz argues that this is not necessarily the case indicating that if people do not experience "altered bodies in their own worlds" then they can define their impairment as temporary. This might be seen as denial of reality (from the outside), but it is the reality of the person’s experience (from the inside). She does concede however, that some people stretch the "allowable" length of the acute illness, because they do not wish to acknowledge that the disease has developed into something more than an interruption (Charmaz, 1991, p.20).

The next illness self representation is referred to as an intrusive illness. Intrusive illness is defined as the "illness that demands continued attention, allotted time and forced accommodation". It threatens to dominate the "self" and the "situation" and causes uncertainty
(Charmaz, 1991, p.42-43). This may occur as a result of degeneration of the disease process or the person may find that they have to allot a good deal of time to managing their disease consistently.

The other illness self representation is where the person feels immersed in their disease. Immersion in illness changes the organization of peoples lives - their priorities change, the illness or disability stays in the foreground and it becomes an "affront" to the self (Charmaz, 1991, p.79). These people face the task of becoming dependent on others, their "social world shrinks," they are confined by illness routines, they become socially isolated, introversion occurs and people begin to question their own identity (Charmaz, 1991, p. 84). Once again this can occur at the time of diagnosis or as a result of where the person finds themselves on the disease continuum.

Charmaz, suggests that people diagnosed with a chronic illness can move “from the initial interruption to complete immersion with both the bumps and jolts and long smooth stretches” (1991, p.9). One such illness that may fit into these illness representations is T1DM and this is the direction and thrust of this thesis.

2.7 Diabetes Mellitus

A diagnosis of diabetes mellitus (DM) impacts significantly on the life of an adolescent or young adult. This section explores seminal literature on a number of issues surrounding this phenomenon. Such issues include the nature, management and complications of DM.
DM is the most commonly diagnosed metabolic disorder and it is a chronic disorder. It causes metabolic alterations and physiological changes in almost all areas of the body. It can cause long-term complications and if it is left untreated it can be life-threatening. DM is the fastest growing disease with at least 171 million people worldwide having diabetes and this figure is likely to more than double by 2030 (World Health Organisation, 2004; Wild, Roglic, Green Sicree, & King 2004). Globally 3.2 million deaths are attributed to diabetes (WHO, 2004) and is the sixth major cause of death, due to disease, in Australia. In Australia one person is diagnosed every 10 minutes and by the year 2010 it is estimated that 1.15 million Australians are likely to be affected by DM. DM is reaching epidemic proportions; with estimations that about 800,000 people have DM with about half of these people being unaware that they have it. (Diabetes Australia, 2004).

2.7.1 Overview of the history of DM.

The history of DM is extremely interesting and extends over a period of more than 3000 years. A historical overview of DM, taking excerpts from Van Rooyen (1981) and Pyke (1997) is provided in the following paragraphs.

The earliest account of DM is believed to have been in about 1500 BC. It was described as a clinical syndrome (polydipsia and polyuria) in documentation found in the Papyrus Ebers. The ancient Indians, in the fourth century BC, referred to DM as Madhumeha. They are said to have observed ants congregating around the urine of people with diabetes. In the seventh century AD, Chen Chhuan, from China, described the main characteristics of DM, including the sweet urine. Celsus in approximately 10 AD, described a painless disorder of polyuria, associated with
emaciation. In about 70 AD, Aretaeus of Cappodocia gave the disease its present Greek name. Dia, meaning through; and bainein meaning to flow and mellitus meaning honey or sweet. Avicenna, an Arab physician, in the eleventh century, described some of the degenerative changes caused by DM for example gangrene.

From 1600 to the 1900, Morton described the hereditary tendency of DM; Willis described the sweet taste of urine and prescribed a diet as a remedy and referred to the disease as “the pissing evil.” Dobson demonstrated the presence of sugar in the urine and Cawley associated DM with pancreatic pathology. Rollo described the smell of acetone on the breath of people with advanced T1DM and observed cataracts in people with DM. Clinicians, including Joslin, confirmed the importance of diet in the treatment of DM. Jager was able to produce illustrations of diabetic retinopathy using the ophthalmoscope invented by Helmholtz. Bernard demonstrated hyperglycaemia and Langerhans, who was a medical student at the time, described islet cells in the pancreas. In 1874 Kussmaul explained that air hunger and dyspnoea were caused as a result of metabolic acidosis and thus the term “Kussmaul’s breathing” persists to this day.

Von Mering and Minkowski verified the occurrence of DM as a result of a pancreatectomy and Auche confirmed that peripheral nerve damage occurred as a result of DM. Naunyn discovered the hereditary pattern and distinguished between T1DM and T2DM.

The early 1900’s saw great strides in DM management. De Meyer named the hypothetical hormone of the islet cells found in the pancreas “insuline.” Banting and Best prepared an extract from the pancreas of a dog, which when injected, produced a chemical hypoglycaemia. Collip, a biochemist was then able to refine this extract and it was administered to a fourteen year old boy, Leonard Thompson of Toronto. This discovery was a tremendous breakthrough since DM had
been a fatal disease prior to this discovery. Death was slow and although Joslin and Allen had been able to keep people alive for a period of time, they existed on a starvation diet.

Allen’s nurse described the effect that the use of insulin had on the patients.

Diabetics who had not been out of bed for weeks began to trail weakly about; clinging to the walls and the furniture…they looked like an old Flemish painter’s depiction of a resurrection after famine. It was a resurrection …a crawling stirring, as of some vague springtime (Pyke, 1997 p. 3).

The link between other endocrine systems was demonstrated when Houssay, experimenting on a frog demonstrated an improvement in DM after performing a hypophysectomy. The diverse metabolic pathways of DM were first described by Emden, Meyerhof, Cori and Krebs and Long and Lukens were able to demonstrate improvement in a cat with DM after an adrenalectomy and a syndrome call Kimmelstiel – Wilson syndrome, which is glomelurosclerosis, leading to renal failure and death was described by its co-discovers.

Research in 1930’s and 1940’s discovered the clinical distinction between the two types of DM, with Himsworth demonstrating insulin sensitivity in T1DM and insulin resistance in T2DM. Hagedorn produced the first long acting insulin, Janbon discovered the hypoglycaemic effects of sulphonamides and Ballantyne and Lowenstein described capillary micro aneurysm in the retinas of people with DM.

During the 1950’s and 1960’s advances were made to show that insulin was instrumental in the transfer of glucose through the cell membrane by Levine and glucagon was refined by Straub. Sanger documented the chemical structure of insulin in an ox and Franke and Fuchs in Germany and Loubatieres in France begin to administer oral hypoglycaemic medications. Nicol and Smith
described the chemical structure of human insulin and Berson and Yalow demonstrated the
method of radio-immune assay, which meant that minute concentration of insulin and other
hormones could be precisely and reliably measured, as well as this Zacks described the
thickening of the basal membrane of the arterioles of the skeletal muscles as a result of having
DM. During this time period further refinements in the production of insulin were made by
researchers including Katsoyannis, Zahn, Steiner and Hodgkin.

Discoveries and management of DM from the 1970’s to the 1980’s included HLA typing in
T1DM; discovering the role of insulin receptors in T2DM; developing artificial beta cells;
pancreas transplantation; the use of laser therapy for the treatment of retinopathy; discovering
how to measure the haemoglobin A1c (a measure of the average blood glucose levels over a
period of about three months) and synthesising insulin from EColi and thereby producing
synthetic human insulin (Van Rooyen, 1981). During this period of time the distinctions between
non-insulin dependent diabetes (T2DM) and insulin dependent diabetes (T1DM) became clearer
and the fact that the cause of T2DM was from an entirely different mechanism to that of T1DM.
T1DM was linked to certain HLA types as well as an autoimmune process, which is involved in
the destruction of the beta cells. Genetic influences in T2DM are even stronger than in T1DM.
In T1DM 35 % to 60 % of identical twins will both develop T1DM, whereas in T2DM between
80 – 100% of identical twins will develop T2DM (Lamb, 1997; Pyke, 1997, p. 38).

2.7.2 Blood glucose monitoring.
DM management has incorporated glucose monitoring for a long period. Mendosa (2001) gives
a fascinating overview of blood glucose monitoring. A brief summary follows.
For many years people with DM monitored glucose levels by testing their urine for the presence of glucose and administered insulin accordingly. This management proved to be fairly inaccurate and the blood glucose monitoring stick was developed in 1965 by Adams and his research team. Whilst it was useful in the approximation of blood glucose levels, most people could read the low and high levels but were not able to accurately distinguish the levels in between.

In 1970 Clemens, developed a reflectance meter to read blood glucose levels and this was soon upgraded to the more sophisticated Eyetone machine. Initially these machines were purchased by doctors to test their patient’s blood glucose levels, and often doctors were reluctant for their patients to use these meters by themselves. However, over time, it was realized that if people had these meters their DM management might improve.

Bernstein, a person with DM, who later went on to become a medical doctor, was the first person to publish a paper on home testing of blood glucose. Danowski, was the first doctor to publish information about regular blood testing in 1971. Blood glucose monitors are still in use today but the technology is based on biosensors rather than reflected light (Mendosa, 2001).

In March 2001, the FDA (US. Food and Drug Administration) approved the Glucowatch manufactured by Cynus Inc. It is a non – invasive monitor which is able to check blood glucose levels. The device looks like a wrist watch. The way it works is by pulling up body fluid from the skin using small electric currents and checking blood glucose every twenty minutes. However, there is still a need to perform conventional blood glucose monitoring as well (National Diabetes Information Clearinghouse, 2003).
2.7.3 Current research and DM management

Initially insulin was regarded as almost a cure for DM, because it had restored the people’s health. However, as people lived longer as a result of this new wonder drug, the complications that beset people with DM became more apparent (Van Rooyen, 1981; Pyke, 1997).

Currently the treatment of T1DM incorporates insulin injections and they remain the treatment for most people with T1DM. Insulin has until recently only been able to be administered intravenously and subcutaneously as it cannot be taken orally because it is destroyed by digestive enzymes. Alternative ways of administering insulin have been via insulin pumps which have mimicked a healthy pancreas. These have been available for about a quarter of a century. The early pumps were unwieldy and inconvenient; did not have programming capacities or alarm systems and had tubing problems causing occlusions and malfunctions. Recently, the pump has become more popular as a method of controlling blood glucose levels with the equipment far more sophisticated and the pump the size of a pager (Savinetti-Rose & Bolmer; 1997; Olohan, & Zappitelli, 2003). Modern pumps consist of a reservoir (generally a large syringe) containing insulin. They are battery powered and have a computer chip controller. The pump delivers insulin subcutaneously via an infusion set (catheter tubing and a needle or soft cannula).

New manufacturing techniques produce insulin “analogues” that are very short acting and rapidly absorbed. Conversely, other analogues are designed to produce a very long acting effect which is helpful in the prevention of night time hypoglycaemia. However, despite these new developments insulin is still administered in injection form. Currently, short acting inhaled insulin is being trialed worldwide as a safe and effective alternative to short acting insulin injections (Prins, 2003). Because the administration of insulin is still the method of treatment in
T1DM, it is necessary for people with T1DM to monitor their blood sugar levels frequently in order to administer accurate dosages of insulin.

Much current research into DM is focused on prevention of DM and finding a cure. The study of genetics has helped to identify the genetic variations that contribute to susceptibility for developing T1DM. In the future the ability to identify and understand the functions of genes and genetic variations might help in the discovery of ways to prevent DM, and its complications and assist in the production of a large supply of islet cells for transplantation (Dinsmoor, 2003).

Pancreas transplantation and beta cell transplantation have become realities. Worldwide about two hundred and fifty seven people have been recipients of islet transplantation (O’Connell, 2003). In October 2002 the first islet cell transplant in Australia occurred at Westmead Hospital in Sydney and three people have now had islet transplantation with two of these people no longer requiring insulin. However there is a limited supply of islet cells and there is a need to take immunosuppressive drugs to prevent rejection of the transplanted cells (O’Connell, 2003).

Pancreas and renal transplantation is only performed on people who have encountered renal failure as a result of the long term complications of DM. Islet transplantation is only available to people who have hypoglycaemic unawareness, an extremely dangerous condition, associated with long term DM where people blackout without any warning. (O’Connell, 2003).

This snippet of the history about DM illustrates the tremendous strides that have taken place in researching DM the current research. Progress in the area of treatment and prevention of DM is
being made daily, however, for the person living with DM in 2004, the reality is still that they have to manage a very complex disease, in order prevent the complications from this disease.

2.7.4 The nature of DM.

There are various forms of DM and other categories of glucose intolerance, which include T1DM, T2DM, malnutrition related DM, gestational DM (“Glucose intolerance that has its onset or recognition during pregnancy”) (Dunning, 2003, p.3) and other types of DM including those associated with certain conditions and syndromes for example pancreatic disease and certain genetic syndromes, endocrine disorders, drug or chemical induced and impaired glucose tolerance (Alberti, Zimmet & Defronzo, 1997; Court & Lamb, 1997; Dunning, 2003).

There are however, despite multiple types of DM only two major forms of DM found in western countries. Since 1997, these have been classified as Type 2 diabetes (T2DM) and Type 1 diabetes (T1DM) (Dunning, 2003; Diabetes Australia, 2004). These two major forms of DM will be explored below.

2.7.4.1 Type 2 Diabetes (T2DM)

The aetiology of Type 2 diabetes (T2DM) is still unclear however; there is a strong genetic link and a definite familial pattern in its occurrence. It is often particularly prevalent in some ethnic groups. It is also the case, as mentioned previously that identical twins are much more likely to co-develop T2DM (Harris & Zimmet, 1997 in Alberti et al., 1997). T2DM also occurs as a result of lifestyle factors such as lack of exercise and unhealthy eating habits, which contribute to obesity. These factors, combined with the heredity and environmental factors probably cause people to develop the disease. This form of DM is most common affecting 85 - 90% percent of
all cases. The disease generally occurs in people over the age of forty years, although it may occur in younger people but they are not required to take insulin. If T2DM occurs in young people it is called mature onset DM of youth (MODY).

In T2DM the pancreas does not produce sufficient insulin for the body’s requirements (Harris & Zimmet, 1997 in Alberti et al., 1997; Diabetes Australia, 2004). Such a condition is known as insulin resistance a “term given to impaired biological response to both endogenous and exogenous insulin that can be improved with weight loss” (Dunning, 2003, p.3). Thus, for people with T2DM, healthy eating and regular exercise can control blood glucose levels. Treatment with oral hypoglycaemic agents may also be employed and, if blood sugar levels cannot be controlled, then the person may finally be treated with insulin injections (Smeltzer & Bare, 2004).

2.7.4.2 Type 1 Diabetes (T1DM)

Type 1 diabetes or (T1DM) is “a T-cell-dependent autoimmune disease characterised by infiltration and destruction of the pancreatic islets leading to absolute dependence on exogenous insulin” (Cavan, Penny, Bain & Barnett, 1997, p. 109). This means that there is a complete insulin deficiency. The disease usually occurs in children and young adults (Dunning, 2003). About 4.9 million people worldwide have T1DM and this number appears to be rising especially amongst children (Cavallo, 2003).

2.7.4.3 Epidemiology and incidence of T1DM

There are worldwide incidence variations. The highest incidence of T1DM is found in Finland where the incidence is 42.9/100,000 (Lamb, 1997, p. 3) and Sardinia, Italy where the rates are
two to three times greater than those in other parts of Europe and North America. The lowest incidence is amongst Asian Indians, Chinese (in China the incidence is 0.7 / 100,000 (Lamb, 1997, p. 3) and Black Africans (Verge, 1992; Cavan, Penny, Bain & Barnett, 1997; Cavallo, 2003). In Great Britain there is a wide range of presentation of the disease from 6 / 100,000 in Southern England to 19.8 / 100,000 in Scotland. Despite incidence variations there has been a steady rise in T1DM over the past 50 years, at the rate of 3% annually. (Green & Patterson, 2001; Gale, 2002,). Multiple factors including environmental factors, such as infectious agents, infant diet, nutrition and lifestyle as well as national prosperity are all implicated in the incidence of T1DM (Patterson, Dahlquist, Soltesz & Green, 2001, Rewers & Zimmet, 2004). A large study into these issues has just begun in the United States cities, Denver, Seattle, and Augusta, three European cities; Malmo in Sweden; Turku in Finland; and Munich in Germany (Cavallo, 2003). Gale has hypothesised that the rise may be the result of what he calls the “hygiene hypothesis” (2002, p. 3359). He postulates that an over sanitised modern world, obsessed with the elimination of micro organisms, has resulted in destruction of the protective immune system factors that are found in the environment

In 1995 the Australian Institute of Health and Welfare estimated that 39,400 people from all age groups had T1DM (AIHW., 2002) and at this rate it is one of the most serious and widespread chronic diseases. About half the people develop T1DM before the age of 18; about 98% of childhood diabetes is T1DM (Silink, 1994). It is indicated that the there has been an increase in “T1DM in New South Wales over the period of 1900 – 1996 and the incidence has increased by an average of 3.2% since 1990” (Australian Institute of Health and Welfare- Diabetes, 2002, p. 8). DM is very uncommon in infancy, and preschool children have a lower incidence than school
going children (although some countries have reported an increase in incidence in children under five). The incidence peaks in early adolescence and then declines in the remainder of adolescent years (Lamb, 1997).

There appear to be seasonal factors and gender factors involved. The diagnosis is more commonly made in winter when viral respiratory tract infections are prevalent. The incidence is higher in males in countries where the incidence is high (for example in Finland), while females are more likely to be at greater risk where the incidence is low. The incidence appears to be age related with a higher incidence reported in older males. It is postulated that this is related to the presence of increased male hormones (Lamb, 1997). Over and above the aetiology, epidemiology, environmental and genetic factors associated with T1DM this thesis focuses on the day to day management of DM and now moves in this direction.

2.7.5 Managing T1DM.

Given various discussion about the nature of chronic illness in general it is not surprising that the management of T1DM places heavy daily demands on people. DM impinges on quality of life. Even though quality of life is said to be improved by resilience because of protective factors “such as high self esteem, internal locus of control” (Lawford & Eiser 2001, p. 214) and by positive coping skills and social relationships, it is still considered burdensome, and requires major modification of lifestyle (Tref, Wade, Pine, Weinstock 2003). These life style demands include insulin injections, an individualised dietary plan, with a balance between protein, fat and carbohydrates. This plan is modified to meet the needs of the client, in order to encourage long–term compliance (rather than a diabetic diet) (Gehling, 2001). However, in spite of this plan,
nutrition therapy best practices remain controversial and evidence shows that adherence to this therapy is poor, unless the client is extremely motivated (Buccino, Murray, Farmer, Assor & Daneman, 2004). It is essential to balance exercise, food intake and insulin dosage and/or urine and blood testing (Satin, La Greca, Zigo, Skyler, 1989; Gehling, 2001). Thus we see that, maintaining a healthy range of blood glucose values is more complex than simply balancing the three major elements of management - food, physical activity and insulin-since people with DM have acute complications associated with the disease. The most common of these complications is hypoglycaemia, which can cause seizures and loss of consciousness. Another complication may be ketoacidosis (Edge & Matyka, 1997). This occurs as a result of severe insulin deficiency, when cells unable to absorb glucose, metabolise protein and fat for energy this resulting in a catabolic process causing loss of muscle mass and elevated concentrations of fatty acids stores (Saladin, 1998). Both hypoglycaemia and ketoacidosis can occur very rapidly. Hypoglycaemia may occur in isolated episodes where there is an imbalance of food, insulin and exercise or as a result of gastroenteritis. Recurrent hypoglycaemia is the (“persistent imbalance in the dose of insulin and the quantity of food consumed and in addition of exercise as a further variable”) and it may occur daily (Edge & Matyka, 1997, p. 204).

Nocturnal hypoglycaemia occurs in 34–80 % of people with T1DM with many of these episodes being asymptomatic. However, there is a concern that the ‘dead-in-bed-syndrome’ (unexpected death in young people with T1DM) may be as a result of undiagnosed nocturnal hypoglycaemia (Edge & Matyka, 1997).

Hyperglycaemia at the level which leads to ketoacidosis is a serious life threatening state. It can occur rapidly, usually within days, as a result of consistently elevated blood glucose levels. There is no consensus about these levels but the term refers to “decompensation resulting from
hyperglycaemia, acidosis and the presence of ketones” (Edge & Matyka, 1997, p. 208).

Complications which may occur as a result of diabetic ketoacidosis are hypokalaemia (a deficiency of potassium ions in the blood, less than 3.5 mEq/L) (Saladin, 1998, p.1077), aspiration pneumonia and the largest risk - cerebral oedema (swelling of the brain due to increased fluid in the cerebral cells) (Monohan & Neighbors, 1998, p. 82). This last condition often accounts for the mortality rate among people with T1DM and occurs most commonly in those under 20 years of age (Edge & Matyka, 1997; Dunning, 2003).

Another phenomenon found in DM management is brittle DM, which refers to wide fluctuations in blood glucose levels despite best possible medical management. The causes of brittle DM are multifactorial. Some prefer to ascribe this phenomenon to socio-psychological factors alone, such as, anger, non acceptance of DM, difficult relationships and sexual abuse, but this is not sufficient since related physical causes may be impaired insulin response, poor communication skills which makes self care and education difficult, drug addiction, gastroparesis or coeliac disease conditions leading to poor food absorption, seizure disorders, an inappropriate medical regime, the presence of other endocrine disorders, eating disorders and unrecognised hypoglycaemia (Dunning, 2003).

People with T1DM (and T2DM as well) are susceptible to a whole array of further DM complications including blindness, kidney failure, varied neuropathies, peripheral vascular disease and foot problems. These complications occur at a much younger age in those with T1DM (AIHW., 2002). Complications of diabetes such as retinopathy have a significant impact
on quality of life (Huang, Palta, Allen, LeCaire, D’Alessio 2004) as a result of loss of independence, mobility, leisure and the ability to self-care (Coyne et al., 2004). Therefore, it becomes necessary for the person with DM, to not only integrate treatment regimes into their daily lives, but also to live with the constant threat of the actual onset of DM complications and obviously the treatment of DM, in its most serious form, may encroach upon work, emotional and physical well-being, personal relationships, and social interaction. While this is true for all people with DM, the focus of this thesis is on adolescents and young adults with T1DM. For these respondents the task is more onerous because of the need to manage age-specific developmental tasks which are in themselves unrelated to DM, but which add to the complexity of disease management. These tasks may include development of greater autonomy and independence as well as separation from the family in adolescence, and the development of family and work roles in early adulthood (Welch, Jacobson, & Polonsky, 1997). The adolescent and the young adult group are the focus of this thesis and the developmental phases of adolescence and early adulthood must be integrated into the way in which T1DM is viewed among these age groups.

2.8 Adolescence and Young Adulthood

2.8.1 Adolescence

Adolescence is a relatively modern concept that has evolved in western cultures. From as early as the beginning of the twentieth century, adolescence has been marked out as a stage of physical, social and intra-psychic development worthy of attention by various disciplines.
Adolescence can be defined as “the stage of psychological development between the start of puberty and the time the individual accepts the full responsibility of being an adult in a given society” (Sternberg, 1997, p. 90). It is a “transitional developmental period between childhood and adulthood characterised by more biological, psychological and role changes than any other stage of life except infancy” (Feldman & Elliott, 1990, p.410).

There have been various theories of adolescence, dating back as far as 1904 where Hall (1904) (in Simmons et al., 1973) indicated that adolescence was a "period of disturbance of the child's self image...the age of storm and stress”. Erikson argued that it was a period where, there may be an identity crisis where the dialectic between identity and role confusion is played out, and where the child now "struggles for stable sense of self." (Erikson, 1959, cited in Simmons et al., 1973; Erikson, 1950). He postulated that this may occur because the child strives to differentiate him/herself from their parents and their beliefs.

Sociologists see adolescence as a phase of "physical maturity and social immaturity" (Davis, 1944, cited in Simmons et al., 1973) where, in our complex social system, the child achieves physical adulthood before he /she is able to function well in adult social roles (Blumberg, Lewis & Susman, 1984, in Eisenberg, Sutkin & Jansen, 1984). This stage of development is a decisive period in establishing life long positive and risky health-related behaviours. These risk – related behaviours may be: inappropriate use of alcohol, which is commonly associated with unsafe sexual practices, unwanted pregnancy, drink driving resulting in accidents, fights and criminal behaviour. There is also an increased incidence smoking (particularly in young women), suicide and illegal drugs use in adolescence. (Better Heath Channel, 2001) and these behaviours occur
whether adolescents have a chronic illness or not (Andrews & Boyle, 1999; McMurray, 2003). More importantly it is a critical period where developmental and health trajectories can be significantly altered in both positive and negative ways (Guthrie, Loveland – Cherry, Frey & Dielman, 1994; Holmbeck, 2002). Often the adolescent is expected to make decisions about their future that they have not even conceptualized (Blumberg, Lewis & Susman, 1984).

There are multiple conceptualizations of adolescence—psychological, sociological, biological and cultural. Many developmental theorists have addressed development across the lifespan such as Kohlberg, Piaget and Selman (Sternberg, 1997). One of the best known, and most often referred to theories of life-span development is that of Erik Erikson. While not without critics for the primarily male-centred nature of his work and inability of this approach to incorporate both culture and cohort effects, the approach stands as enduring and in terms of this thesis both appropriate, and intuitively appealing. A brief overview of Erikson’s eight stages of psychosocial development, as used in this thesis, will be outlined with the cautions, and recognising the limitations, mentioned above.

Erikson believed that it was essential to satisfactorily achieve eight stages of development in order to successfully manage “life” and for the transition between stages to relatively “trouble-free”. Erikson proposes four stages of childhood development accounting for a very short period of the entire life-span. These stages reflect the influence of Freudian theorisation and in particular his early working with Anna Freud. In adolescence and early adulthood Erikson proposes two stages within which dialectics of “identity versus role confusion” and “intimacy versus isolation” are the dominant tasks. In adolescence he proposes there begins a conscious search for identity and the processes by which separation from the moral and ethical prescripts of
parents become dominant—a process “becoming one’s own man” (sic). Thus there is a shift in the parent-child relationship and the adolescent is permitted to move in and out of this dependent and independent role (Wright & Leahey, 2000). In young adulthood attention is directed to settling down, finding a mate, consolidating identity and directing attention to the external world of earning a living. The seventh stage of middle adulthood is one which is characterised by the ability to care (generatively) with the final stage, old age / maturity as one where the developmental challenge is to accept one’s whole life and to reflect on it in a positive way (Erikson, 1968; Wright & Leahey, 2000).

2.8.2 Young adulthood

As noted, for Erikson young adulthood is a time of resolving the dialectic between intimacy and isolation (Erikson, 1950; 1956; Sternberg, 1997). Unlike the more dramatic changes that occur in adolescence the transition into adulthood is a gentle one and often overlooked (Vaillant, 1977). It is however an important time in people lives, they are making crucial choices about social, vocational and geographic matters and in western culture at least, these choices form a matrix from which the adult self begins to emerge. The young adult self emerges with new forms and functions, characterised by a more ambivalent self which can be considered as both tentative and constant with some self characteristics that will endure while others will change (Vaillant, 1977). As Erikson (1950) notes there is an unconscious solidifying of disposition and behaviours with changes involving changes in approach towards success and failure, accomplishment and disappointment, choosing to be leader or a follower and winning or losing. The “separation-individuation process” is a life long one that may entail the inherent danger of loss at every stage
of independence. There is a need as an adult to redefine self and relationships with significant people at “critical affect-laden junctures” (Mahler, 1973, p. 135; Nemiroff & Colarusso, 1990).

It is argued that young adulthood is a decisive turning point in developing self identity (Blos, 1971) particularly focused on the search for authentic intimacy with people of his/her own age (Erikson, 1950).

2.8.3 The Impact of chronic illness

It is not difficult to see how a chronic illness may interfere with the task of being and becoming an adolescent, and progressing to young adulthood. After all in the normal view adolescent development is a difficult enough task in itself. Yet most adolescents are not consistently confronted by a serious and life threatening illness as is the case in adolescents with chronic illness, such as DM (Robinson, Snowden, Tatersall, 1995) where there is never a time when it is not looming in the background and where the need for constant vigilance is moving from parent-centred to self-centred.

It needs to be acknowledged at this point, that parents and families play a vital role in the management of T1DM from a psychosocial, cultural and economic perspective. The psychosocial effect on the family is pronounced. The family experiences disequilibrium as result of the diagnosis and progression of the chronic illness in their child. (Heitinen, & Kyngas, 1998) This can have a profound effect on the family structure as there might be a need to shift roles and responsibilities and at times of crisis the emotional and physical needs of all the family might not be met (Meleski, 2002). Many families are able to draw support, at these times, from relatives,
friends, health professionals, organisations (particularly support groups) and religious and spiritual sources (Eakes, Burke & Hainsworth, 1998).

The impact of T1DM on families is not necessarily a constant impact across cultures and ethnicities. A study of 30 Greek children with T1DM suggested that treatment regimes needed to be mediated by certain family characteristics which included: “enmeshed relationships, ambiguous roles and rules, break down of hierarchy, coalition between mother and patient, absence of father’s involvement and ‘infantilization’ of the suffering child”. In addition, siblings took on parental roles and the families displayed signs of social exclusion (Tsamparli & Kounenou 2004 p.1646). McGee (2000) and Wright & Leahey (2000) support this view and suggest that there is a need to be aware of “differences in family beliefs and values” and that nurses need to ‘alter their “ethnic filters’” (Wright & Leahey, 2000, p.81). However, it is of interest to note that, studies conducted by Weller & Baer (2001) indicated that there was a high level of concordance concerning beliefs about illnesses, including diabetes. This means that there is a high degree of shared meaning across populations with very little disparity resulting from regional or ethnic diversity.

Finally, the estimated cost of managing diabetes per year, is $2774 per person in Australia (McCarthy, Zimmet, Dalton, Segal & Wellborn, 1996; Rassmussen, Wellard and Nankervis, 2001) and this burden is borne largely by the family.

It is precisely because of this dependence on the family that there is some ambivalence in the transition towards independence and the increased social and emotional responsibility in adolescence and young adulthood (Kyngas, Hentinen & Barlow, 1998).
Court (1992), mirroring the general thrust of the developmental psychologists, suggests that the tasks of adolescence include developing an identity, having a positive self and body image, having realistic ideas about the future and becoming emotionally independent. Yet having a chronic illness such as DM can take its toll on body image and self image thus making the task of becoming emotionally independent difficult (Pletsch, Johnson, Tosi, Thurston, & Riesh, 1991). Charmaz argues that the life restrictions imposed by chronic illness affect independence and individualism, but that as long as the individual is able exercise freedom and choice, then "suffering is reduced and self-images are maintained" (Charmaz, 1983, p.170).

Hepperlin indicates that working with adolescents “is a challenge which is probably not matched by any other stage’ (1991, p. 122) and that "children and adolescents are generally known to be vulnerable to various physical and psychological obstacles to maturation.” (p. 123). The presence of a chronic illness such as T1DM could well be considered an obstacle to achieving this maturation.

2.8.4 Adolescents and young adults with T1DM.

Waley and Wong (1995) suggest that children diagnosed with DM before adolescence, appear to accept their DM more easily than adolescents. They suggest that this is because they may not place as much stress on perfection and the need to be the same as their peers is not as significant. However, for those diagnosed in adolescence, denial of the existence of DM and refusing to take their insulin or do blood tests may occur. At the very time when the search for identity is the foremost developmental task “diabetes makes the youngster different when conformity and sameness are desired; having the disease emphasizes vulnerability and imperfection when the
search for identity is the foremost developmental task” (Waley & Wong, 1995, p. 1785). In other words “with respect to chronic illness, management of a disease is at odds with normal adolescent strivings” (Holmbeck, Johnson, Wills, Mc Keron, Rose, Erklin, & Kemper, 2002, p.411) and it is suggested that “adherence to medical regimens decreases from childhood to adolescence” (p.411).

In a study of American adolescents with T1DM, it was found that adolescents did weigh up the costs and benefits of adhering to their DM regimen. Sometimes they chose not to adhere in order to be able to interact more fully with their peer group (Brooks – Gunn, 1993). Adolescents have also been known to fabricate their blood sugar results to keep their parents and the health professionals happy (Court, 1992). Charmaz (1983) argues that health professionals themselves often alienate young people by using devaluing statements such as, “have you been a good boy today”, “have you taken your medications”, “are you doing what the doctor tells you” and when spoken to in a demeaning way, as though the person were a "puppy dog or four year old", (pp. 172,177).

In adolescence, there is a decreased sensitivity to insulin, as a result of an increase in growth hormone, requiring periodic upward adjustments in insulin dosage (Court, 1992, Madsen, Roisman & Collins, 2002). Increased insulin dosage can lead to weight gain (Neumark-Sztainer, Patterson, Mellin & Ackard, 2002) which is often resented and eating disorders may occur in teenagers with DM (Waley & Wong, 1995). There is consensus among a number of researchers that eating problems occur frequently amongst young women with T1DM ( Rodin & Daneman, 1992; Rydall, Rodin, Olmsted, Devenyi, & Daneman, 1997; Jones, Lawson, Daneman, Olmsted,
& Rodin, 2000; Colton, Olmsted, Daneman, Rydall & Rodin, 2004) with eating disorders identified in up to 20% of insulin-dependent females (Rodin, Daneman, Johnson, Kenshole, & Garfinkel, 1985; Rodin, Craven, Littlefield, Murray, & Daneman, 1991; Jones et al., 2000;). Although disordered eating has been found to occur more frequently in females it does also occur in males with T1DM (Neumark-Sztainer, Patterson, Mellin & Ackard, 2002).

It is acknowledged that adolescents and young adults may deliberately omit their insulin in order to counterbalance the effect of food that has been eaten or to achieve weight loss (Crow, Keel & Kendall, 1998; Colton, et al., 2004)). Other researchers indicate that 12%–40% of young women with T1DM admit to insulin omission for weight loss purposes and 60%–80% admit to binge eating (La Greca, Schwarz, & Satin, 1987; Rydall et al., 1997; Stancin, Link, & Reuter, 1989). These unhealthy weight control practices are of particular concern because they lead to poorer metabolic control and this has a flow on effect causing micro vascular complications including retinopathy, nephropathy and other health complications (Daneman, Olmsted, Rydall, Maharaj, & Rodin, 1998; Rydall, Rodin, Olmsted, Devenyi, & Daneman, 1997; Neumark- Sztainer, Patterson, Mellin & Ackard, 2002). This combination of dietary control in order to adhere to normal DM nutritional guidelines, as well as the weight gain that occurs as a result of the onset of insulin therapy (or of the need for increased doses of insulin), may create an alternating cycle of self-control, binge eating, and possibly purging in girls feeling overwhelmed by the need to control their weight, to achieve a peer-referenced bodily appearance (Rodin & Daneman, 1992).

It is estimated that five to seven percent of adolescents abuse alcohol and if these adolescents have DM as well then serious hypoglycaemia (low blood sugars) may result, as excessive alcohol
intake induces hypoglycaemia (Sulway, 1992; Roberts, 2004). The consequences of hypoglycaemia outline a range of problems facing young people with insulin-dependence. Teenagers are frequently involved in erratic eating behaviour; they eat at unusual times and may consistently consume "junk" food. (Court, 1992). Where this occurs, diabetic control declines and if this period is prolonged then complications as a result of hyperglycaemia may occur (Walker, 1991). Unfortunately simply knowing this may only increase stress levels rather than lead to changes in behaviour (Kyngas & Barlow, 1995). The adolescent who hates their DM may also feel guilty because they are not able to, or are disinclined to, conform to a strict management plan.

Conversely there are other adolescents who do comply with their regime, but by doing so may exact a heavy price in psychological adjustment. In mid-adolescence teenagers are able to take on more responsibility for self-management, but they may still be somewhat unreliable. Smoking, which causes increased risk of complications in DM, is common in adolescence. Already referred to above, weight control is often a problem in adolescent girls and those with DM are no different to their peers in choosing to smoke in order to control their weight. About one third of all adolescents HbA1c's, (a blood test which is able to indicate how well the blood sugar levels have been controlled over about a three month period) are elevated and it is at this age that early signs of microvascular complications can surface even though some of these complications may be reversed by appropriate blood sugar control (Court, 1992).

Increased levels of social anxiety, depression and loneliness are prevalent in adolescence (Milne, Garrison, Addy, McKeown, Jackson, Cuffe, Waller, 1995; Lustman, Clouse, Griffith, Carney, & Freedland, 1997) and this may be related to peer victimization as a result of being seen as
“different” in childhood (Storch, et al., 2004, p.468). Such affective disorders experienced in childhood and adolescence are more likely to continue into young adulthood (Rao, Ryan, Birmaher, Dahl, Williamson, Kaufman, Rao, Nelson, 1995). Additionally, both poor psychological adjustment and metabolic control may worsen with age (Kovacs, 1985; Grey, Cameron and Thurber, 1991) which is why it is imperative to attempt to alter developmental and health trajectories in adolescence so that they can be significantly changed at this time to prevent negative outcomes in later ages. (Guthrie, Loveland–Cherry, Frey & Dielman, 1994; Holmbeck, 2002).

Much interest has focused on the physical outcomes of children with T1DM as they progress through adolescence to adult life as can be seen from the plethora of articles relating to the physiological management of T1DM but less attention has been given to psychosocial outcomes (Goldman, & Maclean, 1998; Wolpert & Anderson, 2001). As mentioned previously Erikson 1950, suggests that the successful negotiation of each stage of development is important for people in order for them to fully enjoy life. Young adults can be regarded as being in a state of transition from dependence to independence. Lower self esteem in those with T1DM has been shown to interfere with their metabolic control (Kovacs, Mukerji, Iyengar & Drash, 1995; Johnston-Brooks, Lewis & Garg, 2002) and low self esteem has been recognised as a probable predisposing factor for psychiatric disorders such as depression in adulthood (Gledhill, Rangel, & Gerralda, 2000).

Another issue which confronts adolescents and young adults in the context of chronic illness and insulin dependence is the thought of becoming a burden. Charmaz (1991, p.188) cites a young
physician who had DM who had fears about the future. He indicated that the thought of living on social security and, eventually, of being a disabled old man with DM frightened him indeed more so than death itself. Closely related to the issue of burden, is the need for adolescents and young adults to become financially and intrapsychically/psychologically independent of their parents.

As a chronic illness, T1DM may possibly interfere with individuation among teens (Rodin, Daneman, & de Groot, 1993; Maharaj, Rodin, Connolly, Olmsted, & Daneman, 2001).

According to Holmbeck, Johnson, Wills, Mc Keron, Rose, Erklin & Kemper (2002) too much parental control during adolescence is linked to reduced levels of independence. This in turn is related to higher levels of problem behaviour, manifested as rebellion against medical regimes - regimes which can be construed by adolescents as another form of parental control.

Adherence to a strict management plan, which includes multiple injections of insulin daily, as well as the need to frequently monitor blood glucose levels, regular exercise, adherence to a nutritional plan which places emphasis on regularity in the timing, the amount and types of food eaten, is required to control and limit severe complications of T1DM. This is difficult for many teenagers and young adults (Daneman & Frank, 1996) and frequently involves the shared effort of the family (Hauser & Solomon, 1985). Consequently, having DM may increase reliance on parents at the very time that teenagers and young adults are striving to assert greater independence. This heightened dependence, as well as parental apprehension about the illness, may intensify the normal conflict that can occur between adolescents and young adults and their parents. This can have a detrimental effect on the negotiation of independence and challenge the adolescents or young adult’s ability to develop a separate self (Rodin et al., 1993).
Shaben, (1993) illustrates how uncertainty has a detrimental effect on identity when he describes adolescents with kidney transplants. The constant uncertainty of kidney rejection made them especially vulnerable to the detrimental effects of a non-integrated identity. Their development towards an integrated identity was hampered to the extent that psychological and emotional adaptation may be impaired. Similarly, the adolescent and young adult with DM is also faced with constant uncertainty and has to work hard to manage their DM and, therefore, the same outcome probably generalises to them.

2.9 Summary

This literature review has outlined DM and described its medical management. It has illustrated some ideas of illness theory, explored theories about self, and examined illness self representations. It has briefly overviewed the critical aspects of the complex developmental processes of adolescence and early adulthood and has explored the particular problems faced by adolescents and young adults with DM. Adolescence is widely recognised as a developmental stage fraught with difficulties - social pressure from peers and reference groups, confusion about the self and identity. It is the stage of growth and development which might be called ‘normal’ but which is often experienced as “horrible”. It is made even worse by having a chronic illness, such as T1DM, that has to be managed, albeit with medical and often family guidance and support. The review has uncovered the constraints that an illness such as DM has on the whole person and this is the focus of this thesis. Following a thorough search, I have identified a lack of Australian studies detailing the experience of adolescents and young adults as they strive to come to terms with a chronic illness in the midst of significant life transitions. The study
reported here was designed to address the gap by investigating the impact of T1DM on the self of adolescents and young adults. In its broadest form this thesis seeks to understand the impact that DM has on the selves of adolescents and young adults, to explore these effects on the person with DM, and to understand the implications that this has for health professionals’ involved DM management. This question is explored using a grounded theory approach and a symbolic interactionist framework. The following Chapter provides explication and justification of the study’s methodology.
Chapter 3

The Theoretical Framework

This chapter begins by illustrating the necessity for using a theoretical framework; this is followed by a brief debate surrounding qualitative research. It then discusses common research paradigms, and gives a thorough overview of symbolic interactionism and grounded theory, the theoretical and methodological approaches adopted in this thesis.

3.1 Introduction

The primary task for a researcher is to choose a theory or model that will accommodate their research question since “theory is an attempt to describe, organize or explain a phenomenon or group of phenomena of a discipline in language that is appropriate to the discipline” (Roberts & Taylor, 2002, p. 62).

It is a truism that theories are used in nursing and health in an attempt to describe and explain nursing and health issues (Roberts & Taylor, 2002). Over time many theoretical frameworks have been developed in nursing. Examples of these are Peplau’s (1952) interpersonal relations model; Henderson’s (1966) fourteen needs model; Rogers’ (1970) unitary man model; Roy’s (1980) adaptation model; Orem’s (1995) self care deficit nursing theory; and Neuman’s (1995) systems model, to name just a few (Roberts & Taylor, 2002; Cormack, 2000). Leininger’s theory of Culture Care Diversity and Universality (1967, 1970, 2002, 2004) also has relevance to this study. Adolescents and
young adults are a culture of their own with values and beliefs that need to be known by health professional who become involved in their care and management. Knowing culture care diversities held by adolescents will facilitate care managements relating to TIDM. Using culture constructs from anthropological perspective and care from a nursing perspective, Leininger suggests that nurses are unable to provide significant, therapeutic, worthwhile or holistic care, without including culturally based transcultural nursing skills and knowledge (2002).

The nursing research theories most frequently used are those that contain accurate definitions of concepts, making them useful frameworks for research. Nursing theories are usually divided into two major groups-grand theories and middle range theories (Roberts & Taylor, 2002), which do nothing more than circumscribe the degree of generality associated with them.

Historically, nursing research does not have a good track record of using theoretical frameworks. Internationally about half of the published articles in nursing journals use nursing theory frameworks with many only making use of a theory or model as an organizing framework, rather than engaging in any questioning of the theory or the model. In Australia, only about a quarter of all the published nursing articles use a theoretical framework, and they are most commonly behavioural science frameworks and Orem’s (1995) self-care deficit nursing theory (Roberts & Taylor, 2002).

Nursing, like many human focussed disciplines, uses a variety of research methodologies but increasingly, various qualitative approaches, such as phenomenology, historical
research, hermeneutics, critical analysis and grounded theory to have been adopted and used to produce nursing-based theory (Roberts & Taylor, 2002). Of these theory generating approaches many have used grounded theory. Such researchers are Field and Morse 1985, who explored chronic illness; Sandelowski (1986), who explored infertility; Lawler (1991) who explored “how body is managed by nurses in their work in our culture” (p.1) and Annells (1997c) who explored the difficult topic of flatus. Browne, Minichiello & Plummer (2002) used grounded theory to develop new ways of approaching the area of clinical consultation when a person had a sexually transmitted disease, and Fenwick, Barclay and Schmied (2001) explored the way nurses supported mothers to take up mothering in the neonatal nursery using this methodology (Borbasi, Jackson & Langford, 2004).

Certainly the methodological approach of any study, including the way in which the data are analysed, should be compatible with the chosen model or theoretical framework. For example in the current study the researcher is using a symbolic interactionist framework to inform and develop a grounded theory. Grounded theory has its own specific method of data analysis. The symbolic interactionist framework provides a structure for writing up the study, which includes the way in which the literature review is done and how the results and the discussion are presented. When a framework is properly utilized it is interwoven into all parts of the study (Roberts & Taylor, 2002; Crookes & Davies, 2004).

This study explored the role of self in adolescents and young adults with diabetes using a grounded theory methodology and a symbolic interactionist framework to develop a
model about how young people manage themselves and their diabetes. In the path to outline how this question is addressed I now turn to explicate some issues surrounding qualitative research. This is done in order to locate the use of a qualitative paradigm for this thesis in a situated way.

3.2 Qualitative Research.

Qualitative research is, “a systematic, interactive, subjective approach used to describe life experiences and give them meaning” (Crookes & Davies, 2004, p.326). It is also used to develop theory inductively, by studying the world from the participants’ perspectives, and attempts to describe these aspects of phenomena (Clifford, 1994).

Caution is, however, required, this is particularly so if quantitative and qualitative research is thought of as being totally distinct, as there are "some remnants of one in the other". Both can use deductive and inductive reasoning and both require “scientific” designs in order to be methodically sound and rigorous (Roberts & Taylor, 2002, p. 100). It is a common error to assume that all qualitative researchers share the identical assumptions. Positivist, post positivist, and post structural differences also shape the discourse of qualitative research. (Denzin & Lincoln, 2000, p. 10) just as they do quantitative research. There is at best, only an artificial division between the two paradigms and some researchers try to master these divisions by including the best of both traditions into their research designs (Porter, 1996; Denzin & Lincoln, 2000). Indeed a number of research approaches, from the interpretive and critical paradigms, which
ostensibly rely on non-mathematical judgements, also use quantitative techniques for data analysis (Higgs & Cant, 1998; Roberts & Taylor, 2002).

Indeed grounded theory, the qualitative design used in this study, has some shared characteristics with quantitative research such as using terms like hypotheses and variables (Roberts & Taylor, 2002) and it is suggested that grounded theory “lies on the cusp” between quantitative and qualitative research (Roberts & Taylor, 2002 p.103). Charmaz (2000) describes Glaser, Strauss, as the “fathers” of grounded theory, and Corbin as having “positivist-objectivist leanings” (p. 374). Grounded Theory is used widely as an interpretive strategy because it provides specific steps “to follow that are closely aligned with the canons of good science” (Denzin & Lincoln, 2000, p. 374).

Developmentally qualitative research “has a long distinguished and sometimes anguished history in human disciplines” (Denzin & Lincoln, 2000, p. 1). Debates in the 1960s and 1970s by scholars such as Henderson (1964), Kratz (1978) and others following them in the 1980s and 1990s have ensured that qualitative nursing research has ‘come of age’. It now holds a highly regarded place in the new millennium (Roberts & Taylor, 2002, p. 310). Morse, an eminent nursing scholar, rightly states, that a qualitative study needs to be considered as “a study complete in itself… the cringe has gone from nursing scholarship and research about whether qualitative research is “good enough” (Morse, 1991, p.19). Morgan, rightly suggests that we often select particular methodologies because we either have a "manifest or latent conception" as to what we are trying to do in
our research (1983, p.19). Within the qualitative approach various research paradigms can be used to study the subjects’ viewpoint. Some of these will be discussed below.

3.2.1 Some common research paradigms in qualitative research

Interpretive paradigms have their origins in social anthropology, sociology and psychology (Lowenberg, 1993; Streubert & Carpenter, 1999; Denzin & Lincoln, 2000). The overriding goal of these paradigms is to interpret meaning (Jones & Borbasi, 2003). They include phenomenology, ethnography, hermeneutics, and the paradigm that will be used in this study, symbolic interactionism.

Phenomenology is a philosophical movement (first described by European philosophers) as well as a scientific method of inquiry. It has evolved over time into a variety of theoretical and procedural extensions (Mitchell & Cody, 1993; Madjar & Walton 1999; Jones & Borbasi, 2003). It can also be described as the study of the various kinds of consciousness, as well as differences of consciousness (Merleau – Ponty, 1962). Phenomenology holds an appeal for nurses for this very reason because it attempts to overcome Cartesian Dualism through this idea of “bodily consciousness” (Madjar & Walton 1999, p.4). It explores the ways in which people understand the world in which they live (Minechello, Aroni, Timewell & Alexander, 1995). Crotty (1996, p.2) argues that whilst the term “phenomenology” is generally accepted as “the movement stemming from Husserl, it was used in many different senses before Husserl and even now is used by people in different ways”. He contends that the phenomenologies, (especially that
form stemming from North America) have suffered severe mutation. Thus, the words “experience”, “phenomena”, “reduction”, “ bracketing” and “intentionality” have taken on a different meaning than that espoused by the original phenomenological movement.

Whilst indicating that there is scope for this new phenomenology he merely suggests that it should be labelled as such, rather than being oblivious of the difference.

Ethnography is the observation of the activity of members of a specific social group, and the description and appraisal of their activities (Minichiello et al., 1995). The basis of ethnography as a paradigm, is to uncover shared meanings of a cultural group using such methods as participant observation, interviewing and thick (that is, meaning rich) description (Mitchell & Cody, 1993; Streubert & Carpenter, 1999).

Hermeneutics is the theory of practice and interpretation. The word is derived from Hermes, the Greek God, whose task was to explicate messages from Zeus and other Gods to ordinary mortals (Van Manen, 1990). Historically, hermeneutics is a theory of interpretation, especially of sacred and classical manuscripts (Schleiermacher, 1977). Hermeneutic phenomenology tries to incorporate both terms into the methodology. It is descriptive (phenomenological) because it allows the phenomenon or phenomena to speak for themselves and interpretive because it is impossible to have such a thing as “uninterpreted phenomena” (Van Manen, 1990, p.180). Hermeneutics is the study of understanding, and concentrates on the task of understanding symbols, of which language is an example. It is concerned with the understanding of the person from that person’s
perspective rather than the scientist’s standpoint. The development of contemporary hermeneutics is ascribed to Heidegger (Jones & Borbasi, 2003).

Symbolic interactionism is a perspective in social psychology that emphasizes the nature and meaning of an interaction and how this meaning is derived. It is the study of self-society relationships as a process of symbolic communication between people and it focuses on the acting person rather than on the social system (Bowers, 1988; Minichiello et al., 1995; Hewitt, 2000; Charon, 2001). This means that a social situation has meaning only in the way people define and interpret what is happening and people react to their personal interpretations of that specific situation (Chenitz & Swanson, 1986). According to Charon (1989, pp.22, 23) symbolic interaction has four central ideas

- People constantly interact “hence, a more dynamic and human being emerges, rather than an actor merely responding to others”.
- “The human being is understood as acting in the present influenced not by what happened in the past but by what is happening now” (although the past is recalled in the present).
- The “interaction is not simply happening between people but also what is happening within the individual”.
- The human being is more “unpredictable and active in his or her world than other perspectives” (Charon, 1989, p. 23). That is, people have their own particular social situations and therefore, very divergent views about the same situation. This means that people may not have shared perspectives about a particular interaction or situation (Polgar & Thomas, 2000).
Various people associated with the so called Chicago school, have been involved in the development of symbolic interactionism. These include, Mead, Park, Thomas, Everett, Hughes, Blumer and Becker. However, the concepts of symbolic interactionism are best articulated by the work of Blumer (Bowers, 1988; Hewitt, 2000; Charon, 2001). A more detailed description of symbolic interaction will follow later in this chapter as it underlies the development and model “formation” of this thesis. At this point it is necessary to understand the rationale for using a qualitative design by examining the assumptions underlying qualitative research.

3.2.2 The primary assumption of qualitative research and its critics.

Societies, particularly those of the West, have had a desire to “find a reality which is absolute, outside of the human condition” (Rothwell, 1998, p.21). This is evidenced in the method of scientific thought, and the need to separate subjective from objective reality. Over time, this strong objectivist orientation has led to a well-formed counter reaction (Rothwell, 1998 ) that proposes that science, whether natural or social, is a product of human culture and human history that came out of the “Lebenswelt” (the life world) that is, the world in which we live meet and interact with others (Husserl, 1970 cited in Higgs, 1997). This move towards “interpretive interaction” has been a very significant shift in science since it takes for granted the subject matter, found in everyday life, and focuses on these issues as a form of inquiry. It guides reflection on the meanings, purposes, objectives, emotions and feelings of interactive, self reflective individuals and categorically rejects a decentred structuralist theory of society and self. It
indicates that the person finds meaning in relationships in their every day world and in the practices that make that world meaningful and understandable (Higgs, 1997). Qualitative approaches are not without their critics and originate predominantly from those who believe that quantitative research is more reputable and more accurate (Higgs & Cant, 1998). Historically, it is suggested that quantitative methods have produced verifiable scientific answers resulting from “hard data”. Whereas, qualitative approaches produce “soft data”, which is incapable of providing adequate answers and is therefore, not instrumental in generating change (Clifford, 1994, pp. 716 – 721).

Undeniably, valid criticisms of qualitative research which hinge around its “credibility, fittingness, auditability and confirmability ” have been raised (Sandelowski, 1986, pp. 33 – 35). These criticisms can, however, be annulled by having a “clear decision trail’, which other investigators can follow. They include checking the “representiveness” of the data, triangulation, (Beck, 1993, p.265) checking descriptions and theories, trying to discount or refute conclusions from the data and authenticating the findings with the respondents themselves (Denzin & Lincoln, 2000; Roberts & Taylor, 2002). Such a decision trail is demonstrated in the conduct of this research.

Qualitative and quantitative research answer a range of questions however, many research questions relating to social science and nursing are better addressed by the use of a qualitative research where an attempt is made to gain insights into the respondents’ subjective experience. (Clifford, 1994; Higgs, 1997; Polgar & Thomas, 2000). This thesis is one such instance, since it aims to explore the meaning of a condition from the
person’s perspective, in the milieu of the family and within a specific social context (Polgar & Thomas, 2000). In particular the core research question of this study is: what impact does diabetes have on the self of adolescents and young adults as they interact in their world. A subjective approach using narrative language is adopted with a symbolic interactionist framework used to develop a grounded theory concerning the role of self in adolescents and young adults with diabetes.

3.3 An overview of symbolic interactionism

George Herbert Mead was a social psychologist credited with the development of symbolic interactionism. Herbert Blumer, was a doctoral student of Mead’s, who further explicated his theories and was the first to use the term “symbolic interactionism” (Chenitz & Swanson, 1986; Patton, 2002). Blumer’s interpretation of Mead’s work provides an understanding of symbolic interactionism.

Mead taught philosophy at the University of Chicago and was only recognized posthumously for the original contributions he made to the field of social psychology. He did not publish a single book and only had a few major publications. Other sociologists, social psychologists and philosophers of note, who influenced and / or who was influenced by symbolic interactionism, were James, Cooley, Pierce, Park, Thomas and Dewey (Crowley & Mitchell, 1994).

Strauss suggests:

Almost exclusively sociologists lit upon Mead’s ideas about socialization. They were impressed by his concepts of “generalized others” and the “socialized self”. This was the case because these ideas held some appeal for the sociologists of the nineteen twenties and thirties” as they needed some other way of describing
behaviour rather than the prevalent “biological explanations of behaviour (1969, p. xii).

Thus we see that symbolic interactionism was reactionary, developing in opposition to the dominant “grand”, functionalist theories of the mid-nineteenth century.

Functionalism suggests that the (social) world exists as a whole unit or system made up of interrelated, functioning parts. Symbolic interactionism diverges from functionalism in both the theoretical and moral domain, since its underlying assumptions are that society is an ordered, integrated and naturally evolving totality (Bowers, 1988).

The objections to functionalist theory were that it was considered to be fundamentally normative, judgmental and rigid (Friedrichs, 1970 cited in Bowers, 1988). It did not account for rapid social change and it gave the impression that social life was more rational and orderly than was empirically borne out. It focussed on role expectations as internalizing norms and did address the thinking, feeling individual. Functionalists do not view the individual as an active participant in the social process and therefore, the individual was seen to be determined rather than the determiner (Bowers, 1988; Charon, 2001).

In contrast symbolic interactionists focus on the acting individual rather than on the social system and analysis originates with the acting individual rather than the larger social group. The way in which the analysis occurs is in an upward movement commencing with the individual up through social groups, organizations and institutions, rather than a downward movement to the individual. Unlike the functionalists, who
commence with a theory and then endeavoured to prove it empirically, interactionists begin from an empirical stance and then construct theories (Bowers, 1988).

The fundamental assumptions of symbolic interactionism are that people act towards things or objects, wittingly or unwittingly, on the basis of the meanings that those particular things have for them. These meanings occur as a result of social interaction in human society and are utilised and handled through the interpretive action adopted by each person in dealing with the objects or things he / she confronts (Blumer, 1969;; Hewitt, 2000; Charon, 2001). This means that a social situation has meaning only in the way people define and explain an event. People do not respond to objective aspects of their surroundings but, in fact, their actions are mediated by their personal interpretations of the situation. Therefore their actions are based on their past experiences and distinctive social situations. People may interpret the same situation in different ways and act in conflicting fashions (Polgar & Thomas, 2000; Hewitt, 2000). The symbolic interactionist perspective is useful in social and health care settings, because it allows for the exploration of different perceptions of events since “shared perspectives” among people cannot be taken for granted (Polgar & Thomas, 2000, p. 110).

Symbolic interactionism implies that the person confronts a world that they must interpret in order to act. Therefore, the symbolic interactionist views reality as the knowing gained through people’s perception of their social world which can only be discovered by empirically exploring that world (Blumer, 1969; Streubert & Carpenter, 1999). The symbolic interactionist perspective uses a two-fold approach to research. The first is to become familiar with the group under study to gain as comprehensive and accurate a
representation as possible. The second is to determine systematic relationships in order to create a theory about the group, behaviour or phenomenon under study (Blumer, 1969; Streubert & Carpenter, 1999). Grounded theory is firmly established in symbolic interactionism.

A symbolic interactionist framework is valuable for exploring the role of self in interaction with others, and the interaction of adolescents and young adults with their disease (diabetes). Since this study uses grounded theory processes and incorporates symbolic interaction as its orientating standpoint, it allows for the investigation of meaning of self in the context of the person living with diabetes. This occurs because using the symbolic interactionist perspective allows the researcher to look at “a reality” of how the adolescent and young adult negotiates the self in the management of their diabetes and the subsequent development of a grounded theory about the self in adolescents and young adults with diabetes.

Since symbolic interactionism describes pivotal ideas such as “the self”, “the world” and “social action” (Meltzer Petras & Reynolds, 1975) it is necessary to understand and explore the meanings of these concepts.

3.3.1 The Self and the generalized other

Symbolic interactionism deals with the concept of self. Mead, (1934), described the self as being comprised of two parts, the I and the Me, with the I being “the looking glass or reflector” and the "Me" being conceptualised, as a result of self-reflection (Mead, 1934, cited in Meltzer et al., 1975, p. 41).
The self involves two phases. The I phase and the Me phase. The I phase is the first, unprepared, unorganised aspect of human experience, which is undisciplined, unconfined and undirected. The Me phase is moderated by the attitudes and definitions of what is acceptable behaviour within the dominant group, that is the “generalized other” as described by Mead (Blumer, 1969; Osborne & Van Loon, 1999; Hewitt, 2000; Charon, 2001). In any given situation the behaviour of the Me is tempered by the expectations of the “generalized other” (this could be health professionals, parents or significant others) (Blumer, 1969; Meltzer, 1975 in Manis & Meltzer, 1975;). Therefore, the self is socially constructed and the me part of self is continually being constructed (Hewitt, 2000; Charon, 2001). This process commences at birth and is ongoing as the person is exposed to and interprets social cues from the social milieu (Bowers, 1988; Hewitt, 2000).

Faberman (1985) indicates that people alter their actions to the single as well as the general “other”. Berger and Luckmann, 1990, describe these “others” as being part of a continuum, at the one end are those “others” with whom we frequently and intensively interact in intimate interaction. At the other end are the nameless “others” with whom we will never have any intimate interaction. They suggest that these interactions are essential aspects of everyday reality.

The self can then be described as an aggregation of all earlier social interaction as interpreted and integrated by the I. The self is never a complete entity, rather it is continually evolving. This is referred to as “temporality” in symbolic interactionism and
relates to Mead’s attempt to address the concept of permanence and change (Strauss, 1969). Temporality can be described by reference to the notion that “the past and the future are often defined with respect to an emerging present” (Meltzer et al., 1975, p.27). This implies that the meaning of a situation changes over time since individuals are orientated towards the future and, therefore, re interpret the past in terms of the present or future projects and goals. The self that I am now, is not the self that I will be in the future, or what I was in the past. And whilst my present and future selves reflect my past selves, it is continuously being reinterpreted as a result of continual social interaction (Bowers, 1988; Charon, 2001). This concept of temporality is important and fitting to this study as respondents were interviewed at varying times after their diagnosis and throughout the duration of their illness. The longitudinal study group were adolescents at the time of their first interview and had moved into adulthood in the second interview therefore, these respondents were likely to reinterpret the past in terms of the present or future projects and goals.

Then obviously the self, and how it interacts with a social world, is pertinent to this study and is briefly discussed below.

3.3.2 The social world and objects

The social world is considered by symbolic interactionists as the world within which we live. It is important to understand that the term used for world, is the social world. It is the experienced or interpreted world rather than the physical world, described as the “object world” (Meltzer, Petras & Reynolds, 1975, p.61; Bowers, 1988). The objects in this “object world” should not to be thought of only as physical substances, since to the interactionist an object can be anything which affects the self - physical as well as
abstract concepts, (Meltzer, et al., 1975; Bowers, 1988; Hewitt, 2000). For example, fear is no less an object, than the injection that might provoke that fear. Objects may have no intrinsic meaning but rather their significance is derived from how people respond to them and this may be described as that persons' **experienced or interpreted world**.

Therefore, what is reality for one person at a given point in time and in a specific context may be a different reality to others. In fact the same person may interpret, the same object, differently at another moment in time and in a different context (Bowers, 1988). Even though it is important to acknowledge that people experience different “object worlds”, it is equally important to recognise that people can experience “object worlds” of shared meaning (Charon, 2001).

Shared meaning comes about as a result of socialization. Socialization occurs within the context of the family, school, friends, the church, work colleagues and the whole community. These groups have shared meanings, or “shared object worlds”, which increases homogeneity in both understanding and action and which permits us to correctly anticipate the behaviour of others around us (Bowers, 1988; Hewitt, 2000).

A further issue for the symbolic interactionist is the notion that things are “real in their consequences” (Thomas, 1928, cited in Bowers, 1988). Bowers, 1988 uses the social status of women as an example by arguing that, if we think that women are intellectually inferior to men, the consequences are that women will become intellectually inferior to men. The perception becomes a social reality through women socially constructing themselves to be of lower intellectual status.
A similar effect is seen with adolescents who are considered non-compliant or not coping with their diabetes by health professionals and others. If a negative attitude is displayed towards adolescents who are “non-compliant” this it has a profound effect and often leads to a re-construction of their view of self. This then has a flow on effect with regards to their diabetes management. These issues will be discussed in further chapters.

3.3.3 Social action in the social world

Social action takes place in the social world by using verbal and non verbal gestures, which can be considered objects in our social world (Bowers, 1988). Thus social worlds, it is suggested, are the repeated actions of shared possibility and shared understanding as symbolic engagement spread out over time and space (Crowley & Mitchell, 1994; Lupton & Najman, 1995). When we interact using objects that have shared meaning our interaction is predictable and meaningful. However, it is equally true that if those objects do not have shared meaning then misunderstanding and conflict can occur (Bowers, 1988).

Thus, we see in brief, that the main tenets of symbolic interactionism revolve around the concepts of the self, the world and social action. These concepts form a useful framework for underpinning a grounded theory about self. However, there are also criticisms of symbolic interactionism.
3.4 Criticisms of symbolic interactionism

Meltzer et al., (1975) makes a number of criticisms of Mead’s social psychology as described by Blumer. He comments that the main concepts are “vague and fuzzy” and argues that this might have occurred because Mead did not actually write up most of the published theory. Criticisms also revolve around Mead’s descriptions of the major concepts in symbolic interactionism for example, the concept of “impulses” is not clearly defined. Kolb (1944 cited in Manis and Meltzer, 1975) indicates that the I concept is unclear and is not as well defined as the me concept and the I concept does not seem to have limits. Becker & Barnes (1961) conversely support the view of the “impulsive” I, (my italics) because it avoids the “sociological determinism of human conduct” (p.203).

There is also a criticism (Manis and Meltzer, 1975) that the use of the term “generalized other” seems to be oversimplified and assumes a “single universal generalized other …rather than different levels of generality”. They also raise issues around the concepts of “object and image” and suggest that the two concepts are used interchangeably whereas it is probable that what was meant was that the “images were mental representations of objects” (p.19).

Other criticisms, articulated by Blumer himself, are that symbolic interaction “constitutes a purely analytical scheme which lacks content” (p.20). Mead, it is suggested, merely describes “human conduct” rather than explaining why the specific behaviours occur. Blumer is also critical of the framework since sentiment and emotions, which are found
in social interactions, are not addressed nor are the unconscious and the subconscious (Blumer, 1969; Charon, 2001). Mead’s theory is also criticized because is does not provide specifications or recommendations on techniques to enable the study of human behaviour (Blumer, 1969; Hewitt, 2000; Charon, 2001).

Other critics maintain that symbolic interactionism is not contextual, and that it describes a conservative naive representation of social reality; that it is philosophically biased (Denzin & Lincoln, 2000), culturally bound, “uncritical and apolitical,” and “that it lacks a proper appreciation of social organization and social structure” (Meltzer et al., 1975, p. 97).

Many of these criticisms relate to how the social world is to be investigated from a symbolic interactionist perspective and the development and wide use of grounded theory in large part overcomes these criticisms.

3.5 Overview of grounded theory

Glaser and Strauss initially developed grounded theory in 1967. They described the theory as “the discovery of theory from the data systematically obtained from social research” (Llewellyn, 1997, p. 27). They indicated that this permitted them to arrive at “theory fitting to its hypothetical aim” (Smith & Biley, 1997, p.17).

Grounded theory arose as a response to the emerging criticism that held that qualitative research was unscientific by virtue of its abandonment of controlled experiments and that
it seemed to embrace interpretation. Glaser and Strauss, both sociologists, came from different philosophic and research environments with the contributions of both to the development of this methodology of equal importance. Glaser developed his skills in quantitative research methods at Columbia University and later, when he was engaged in some qualitative research, he saw the need for a well constructed, formulated, organised set of procedures for both coding and testing hypotheses produced during the qualitative research process. On the other hand, the Chicago school of thought (interpretive interactionism), strongly shaped Strauss’ view of research. The University of Chicago had a long tradition of pioneering and devising qualitative research approaches (Strauss & Corbin, 1990; Smith & Biley, 1997).

Whilst working together on a piece of qualitative research exploring the perceptions of dying, Glaser and Strauss realized that in order to develop this particular form of research they needed to go into the field to find out what was happening (Strauss & Corbin, 1990). This reinforced the belief that theory needed to be grounded in reality, in order to develop knowledge in a particular discipline. They proposed that the nature of experience and enduring in dying patients, was constantly evolving as these patients played an active part in shaping the environment in which they lived (Glaser & Strauss, 1968). This led them to propose that, change, process, variability, the intricacy of life, as well as issues such as meaningfulness and action, were significant in understanding this specific research phenomena (Strauss & Corbin, 1990). Thus, they devised a theory that was grounded in the reality of the social milieu, rather than interpretation (Smith & Biley, 1997).
Grounded theory, and in particular its framework of symbolic interaction, were initially firmly based in the social sciences, and as mentioned previously, it was developed in an attempt to gain “scientific” respectability for qualitative research. As a result, the traditions of sociology and social psychology have been particularly shaped by the development of grounded theory (Llewellyn, 1997). Nevertheless, the work of Glaser and Strauss has had a crucial impact on nursing research, because nurse scholars found it a credible way of conducting research in order to understand how humans perceive their social world and how that world could be discovered and examined empirically (Roberts & Taylor, 2002). Indeed Glaser has founded the Grounded Theory Institute, which provides lectures, workshops and seminars, in order to provide a structure for researchers to learn how to perform grounded theory (Glaser 1998).

Grounded theory requires the researcher to become familiar with the group under study in order to gain as extensive and legitimate a picture of their world as possible (Smith & Biley, 1997). It also describes how to discover an orderly sequence, which enables the formulation of theory about a group, behaviour or phenomenon. The developed theory offers predictability, that is, if similar conditions occur then similar outcomes can be predicted. It also provides a useful way to reveal information about a problem that is little understood. It is, therefore, a very satisfactory method to employ to explore nursing issues (Smith & Biley, 1997) such as that addressed in this thesis.
3.6 The Research Methodology

The research methodology, which is used in this study, is grounded theory. This approach will be discussed below. Grounded theory has derived its name because it starts from the ground and builds up to an effective theory. It does this in an inductive way, by theorising about the data which have been gathered during the course of the research and tries to make sense of what people have recounted about their experiences (Roberts & Taylor, 2002).

3.6.1 Differing views about Grounded Theory

Currently there are differing views about grounded theory. The “classic” grounded theory was introduced in 1967 by Glaser and Strauss, but since then there have been many modifications and variations of the method (Annells, 2003).

Melia, examined these differing views and concluded that they were based on differences of opinion about grounded theory which had occurred between Glaser and Strauss, indicating that, Glaser felt that, Strauss was using a new methodology, however, Strauss believed that his methodology was the “true” grounded theory (1996). This is a view supported by Stern (1994), who argued that although both Glaser and Strauss thought that they meant the same thing by grounded theory, they had very different ideas about its actual constitution. This only became apparent when they published separately. It is suggested that this different approach arose because Glaser and Strauss ask different questions of the data (Stern, 1994).
The two sociologists then went on to teach their students, their own particular way thus, in the face of this lack of precision many researchers resort to saying that have used a modified methodology, so as to avoid the indictment of inaccuracy (Smith & Biley, 1997). Annells (2003) clarifies this problem by suggesting that the different versions simply reflect disparate ideas about how the data is analysed to the point that a theory is developed. She suggests that in practice, grounded theory adopts three data analysis approaches:

- Firstly, is the objectivist approach (that is, using the facts without the misrepresentation which may result if personal feelings or bias are allowed to influence the research.
- Secondly, it can simply lean towards an objectivist approach (Schneider, Elliott, LoBiondo-Wood & Haber, 2003)
- Thirdly, it may adopt a constructivist approach (that is, “the view that the nature of reality is local, that multiple constructions comprise reality and that the knower is subjectively linked to what can be known” (Hall & Callery, 2001, p. 261; Annells, 2003).

However, these “constructions are not more or less true or more or less informed or sophisticated” (Hall & Callery, 2001, p. 258). A grounded theorist is not bound by either the objectivist or constructivist approach and they usually adopt a perspective according to their own philosophical view (Annells, 1997a; Annells, 1997b; Annells, 2003).
Despite analytical differences, most would agree that grounded theory follows a set of agreed methodological steps: data gathering and reference to literature; integration of data collection and analysis; concurrent data gathering and analysis. These methodological steps will be discussed below.

3.6.2 Data Gathering and references to literature

There are differing ways of collecting data and contradictory views about how and when to refer to literature. Data are collected in many ways. It may be as simple as asking flexible open-ended questions or by using a combination of methods, such as observation, interviewing, video recording or audio-taping. The data are collected in an attempt to thoroughly investigate the topic under study. It is recorded and transcribed to produce narrative/linguistic material for analysis. Because of the amount of data collected, it can be confusing in the early stages of a study. Strauss indicates it is necessary to begin to focus early in the research process (Cormack, 2000). This is achieved by organising and analysing data at an early stage which enables the researcher to identify areas that need to be clarified in ensuing interviews or observations.

Grounded theory does not progress in a linear manner. Rather it is a repetitive approach and the researcher continuously returns to the data in order to examine issues that surface and to collect new data where it is appropriate. This process is termed constant comparative analysis (Cormack, 2000).

It is commonly argued that grounded theory researchers need to avoid preconceptions in order not to bring bias to the data (Roberts & Taylor, 2002). However, within nursing
research, questions are often based on the nurses’ personal, as well as, nursing practice experience, including information gleaned from literature. Many nurse researchers are very aware of the literature and the gaps in it (Roberts & Taylor, 2002) yet; it appears that they are often discouraged for the sake of methodological “purity”, from allowing this knowledge to influence their research and what will be discovered. They are encouraged not to have preconceived ideas and only to consult pertinent literature discerningly (Smith & Biley, 1997; Glaser & Holton, 2004).

It has been argued that the literature is particularly useful when a person has limited knowledge in an area in which they wish to become more familiar (Crookes & Davies, 2004) but it could be equally argued that comprehension of the phenomena positively influences the manner in which the research is conducted and understood (Mitchell & Cody, 1993). Thus, while it is clear that there are differing views about how and when to refer to literature when conducting grounded theory research many models, determined and influenced by the flow of the research process are adopted in practice. In this study, a literature review was conducted, prior to the commencement of the study to explore the issues surrounding the broad area this was continued throughout the study in order to explicate the findings as they emerged in the analysis - a thoroughly repetitive approach.

3.6.3 Integration of data collection and analysis

As mentioned previously there are various ways of performing grounded theory research which (Llewellyn, 1997, p. 32) calls “variations on a theme” and this includes the way the collected data is integrated and analysed. For example, Glaser, in particular, gives less focus to the data, which he considers more as a basis for conceptualising ideas and
tentative hypotheses. His objective is to move immediately to abstraction and creation of ideas (Glaser, 1992, 1998, 2001). Whereas, Strauss gives an immense amount of attention to the data focussing on every illustration to investigate every possibility and then from these instances, seeks further comparable and contrasting samples to progressively build up discernible categories and their relationships (Strauss & Corbin, 1998).

Bowers (1988) whilst acknowledging the various steps in grounded theory (including the literature review phase, the question/hypothesis creation phase, and data accumulation and analysis phase) indicates that they all happen concurrently rather than as a sequence of different steps or phases. She argues that it is this continual process of data analysis that guides the elaboration of interview questions and sample choice, and can indeed lead to a change in the data collection and the respondents who are sampled.

Although, Strauss and Corbin (1990) provide a step-by-step procedure of how to perform a grounded theory study, they also caution about the danger of working and reasoning in a linear, sequential fashion. Thus, we see in the area of data collection integration and analysis that grounded theory offers multiple ways of proceeding as there as no mandatory rules (Walker, 1996; Strauss & Corbin, 1998).

Analysis of the data usually commences as soon as the first interview has been completed. The researcher tries to discover what the respondent’s world is really like, how it is created and experienced. Initially this is a tentative examination of different
aspects that the researcher perceives as important or interesting. These phenomena are labelled according to the potential relevance that they have to the subject area, and this is referred to as open coding. (Glaser & Holton 2004) Indexes are often created line-by-line or even word-by-word. Every transcript, together with field notes is examined and the researcher asks questions of these transcripts: “What is going on here?” “What are important issues or areas of interest?” “What are all the processes at work in this world?” (Smith & Biley, 1997, p. 20; Glaser & Holton 2004). The process of coding is not simple and often analysts may need to make changes to the codes until there is an accurate fit (Smith & Biley, 1997). The process continues with concurrent data gathering and analysis. As the analysis proceeds, categories are developed when a number of substantive codes are consolidated into a higher level of abstraction. In this process, certain common characteristics begin to be described in the emerging categories - these could include aspects about the person, the occurrence, the circumstances or the phenomena (Benton, 1996). Grounded theory does not depend on the number of times a phenomenon occurs, rather on collecting potentially meaningful notions which, when teased out, develop into categories. At the end of this process of abstraction some concepts may be excluded from the final analysis, not as unimportant but, rather, as a reflection of the “thickness” of the data and the impossibility to report on everything that occurs in a subject area.

3.6.4 Concurrent data gathering and analysis

As coding continues and more data is collected, the analysis needs to become more refined and as the study proceeds there is a move to greater abstraction and conceptualisation (Bowers, 1988; Walker, 1996; Smith & Biley, 1997). This is done by
using the constant comparative method which entails a comparison of occurrences, and this then allows for the formulation of categories. The coded concepts become more refined and they are then extended. This refining is accomplished by using an indexing method, memo writing and category integration (Benton, 1996; Smith & Biley, 1997). Once substantive codes have been developed they are condensed into categories which are then subsumed into emergent categories. A point is attained where the collecting of further data no longer advances new concepts this stage is called category saturation (Benton, 1996). The issue of saturation however is also subject of debate and some grounded theorists consider the term elastic (Denzin & Lincoln, 2000). Other grounded theorist avoid saying that they have reached this point (Annells, 2003). However, there is a time when the analyst will define each concept giving concise reasons why each incident has been covered in a specific code using verbatim quotes from the data in order to explain the categories by example. This process allows for a richer and more complex understanding of the nature of the phenomenon being examined (Benton, 1996).

Whilst this is taking place the analyst also writes theoretical memos. These record thoughts, questions and hypothesis and they are written down in order to keep track of thoughts and decision making processes throughout the study. Memo writing should commence as soon as the first data is collected and when coding and analysis commences. Initially the memos may be superficial, but then they become more abstract as more and more codes, categories and properties are uncovered. It is a good way to discover emerging concepts and their interrelationships (Benton, 1996; Smith & Biley, 1997).
Finally, a well-designed grounded theory should be testable and verified with the respondents. The grounded theory can also be peer reviewed by those who have some understanding and experience in the area. The theory is confirmed when the respondents or peers give an affirmative response to the findings and recognize them as being similar to their own experience (Walker, 1996). In the present study this was implemented. Respondents in the Second Study were all asked to comment on the grounded theory which had been developed from that data collected in the initial interviews in Study One. This was done to test the auditability, credibility, validity and reliability of the developed models, which are cardinal issues surrounding qualitative research (Morse, Barrett, Mayan, Olson & Spiers, 2002)

3.7 Testing the validity of the theory

Some notions can only be explored using qualitative methods. This may suggest that theories that are derived from qualitative methodologies “may not lend themselves to having …credibility ….due to the extent of their inherent abstraction” (Mc Kenna, 1997 cited in Cutcliffe & Mc Kenna, 1999, p. 374). However it was the intent of Glaser and Strauss at the inception of the development of grounded theory in 1967 to gain scientific respectability for qualitative research. While the idea of empirical testing can seem to be at odds with the concept of using a qualitative methodology, Guba and Lincoln (1981) would argue that qualitative data is credible because others are able to recognize their own experiences after merely reading about them.
This is supported by current researchers who indicate that, “the researcher should describe the social world with such vividness that you could imagine yourself there and that… you could almost literally see and hear its people” (Wimpenny & Gass, 2000, p. 1491). They argue further that because of the “constant comparison and reduction” which occurs in grounded theory, a “well integrated theory” is developed (Wimpenny & Gass, 2000, p. 1491) with accurate concepts that come directly from the empirical research (Cutcliffe & Mc Kenna, 1999).

Obviously, grounded theory is not without its critics and some of these will be discussed below.

3.7.1 Criticisms of grounded theory.

Criticisms of grounded theory come from those who believe that it has a very positivist slant. There are those who believe that much of grounded theory research carried out does adhere to strict methodological guidelines and still others, who struggle to know what those methodological guidelines are.

Charmaz, indicates, that postmodernists and poststructuralists, such as Denzin, Richardson, and Van Maanen, denounce positivistic and objectivist views reflected in grounded theory (Charmaz, 2000). Certainly Glaser and Strauss have been criticized for using “quantitative terminology” and “sociological language” difficult for other disciplines to understand (Stern, 1985; Keddy, Sims & Stern, 1996; Coyne, 1997). In a similar vein Thorne (1991) claims that grounded theory is biased against naturalism and relativism, and that only emerging theory are considered to be meaningful.
Other criticisms, primarily methodological, come from grounded theorist themselves, who indicate that researchers often do not follow each step of the process correctly - a view that Glaser and Strauss believed was fundamental to the development of a grounded theory. (Smith & Biley, 1997). This criticism is further elaborated by Skodol-Wilson & Hutchinson (1996) who indicate that there are often methodological transgressions that contravene the philosophy and methodology of grounded theory. They describe these issues as a muddling of qualitative methods and generational erosion, which they attribute to the differences of opinion between Glaser and Strauss (see Section 3.6.1, for review).

Skodol-Wilson & Hutchinson (1996) also describe three other perceived flaws in grounded theory research. They are premature closure, being overly generic and containing imported concepts. Premature closure, they describe as “underanalysis” (p.80), which leads to some useful descriptions but not to grounded theory. They describe the term “overly generic”, as meaning, that the concepts are so wide-ranging that they could be relevant to any experience or phenomenon. They argue that this does not produce a satisfactory grounded theory, nor does it add to theoretical knowledge of a substantive area (p.81). Thirdly, they believe that imported concepts occur when the novice grounded theorist does not suspend prejudices, disciplinary viewpoints and previous impressions when examining the data, thus, failing to provide a unique and grounded interpretation.
There are indeed some thorny methodological issues in the use of grounded theory approaches. Cutcliffe (2000) gives a lucid outline of the methodological issues that are a dilemma to those using grounded theory. He indicates that there are some opposing views and unresolved issues around what constitutes a grounded theory, as well as, the process of grounded theory. As an example, he points to how, sampling is described by Glaser, Strauss, Becker, Sandelowski et al., and Coyne) as theoretical rather than purposeful because it is driven from the emerging theory. Purposeful sampling involves a deliberate decision to sample a specific group with some notion in mind of what you wish to achieve, whereas theoretical sampling has no predetermined target. They argue that this is precisely why the grounded theory researcher seeks out further interviews and data to elucidate concepts (Glaser & Strauss, 1967; Glaser, 1978; Sandelowski et al., 1992; Becker, 1993; Cutcliffe, 2000). Lincoln & Guba and Morse suggest that theoretical and purposeful samplings are in fact one and the same thing. (Lincoln & Guba, 1985; Morse, 1991; Cutcliffe, 2000). Yet other ground theorists indicate that all types of sampling can be called purposeful sampling (Morse, 1991; Baker, Wuest & Stern, 1992; Cutcliffe, 2000; Patton, 2002).

Olshansky (1996) moves the argument even further indicating that although grounded theory has traditionally been seen as the foundation for subsequent research, extension of grounded theory can be made. Olshansky believes that the fundamentals of a provisional or initial theory can be further explored for the purpose of refining these theories by identifying the various cases and conditions in which they are useful. This goal is best
achieved by well planned and executed studies which focus on particular phenomena. In this way a theory is generated with considerable scientific and practical value to health.

Charmaz explores three criticisms of grounded theory. The first is, that it curtails access to the subjects’ world and reduces an understanding of their experiences. Secondly it diminishes representation of both the social and subjective experience. Thirdly, it depends on the observer’s authority as expert and proposes a set of objectivist procedures on which analysis hinges (Charmaz, 2000).

It is because of these issues cited above, that Cutcliffe, stresses the need to clarify issues of sampling, creativity and reflexivity, the literature and precision in grounded theory and the need to describe exactly how the grounded theory is performed (2000).

What are some of the methodological processes which can help to overcome the major criticisms?

3.7.2 Criticisms addressed

Coyne, springs to the defence of Glaser and Strauss indicating that when grounded theory was developed, it needed to be couched in language that quantitative researchers would find acceptable, because the quantitative paradigm was pre-eminent at the time (1997).

Cutcliffe (2000) suggests that the methodological differences inherent in grounded theory are indeed confusing to the novice researcher noting that if researchers are able to explain their sampling strategy in an appropriate manner, it minimizes any confusion and improves the quality of the research. It also prevents method “slurring” and provides a
clearer picture of the use of theoretical sampling in nursing research. He further explains that providing that researchers state what they have done and how they did it, straying outside of the boundaries of one particular version is less of an issue than limiting the potential depth of understanding that strict adherence to one version would produce.

Charmaz gives similar advice and indicates that grounded theory strategies do not need to be rigid and prescriptive. She illustrates that focusing on meaning, deepens rather than curtails, interpretive understanding. She asserts that grounded theory procedures can be undertaken without adopting the positivist bias of the earlier proponents of grounded theory, whilst still recognising that there certainly is a continuum between objectivist and constructivist grounded theory (Charmaz, 2000).

In choosing grounded theory as the methodological process for this thesis, I followed as researcher, this advice. I chose to ask of the data “What is happening here?” as advocated by Glaser (1978). I also asked “What if?” of the data, as suggested by Corbin and Strauss (1990). For instance, I was led by the data to ask “what would the respondents’ response be if they were not from a self-help group such as The Juvenile Diabetes Research Foundation or Diabetes Australia?” I was also led by the data to conduct a longitudinal study of a group of respondents to try to understand how the meaning of their diabetes changed over time as they moved from adolescence into adulthood. The initial grounded theory was tested with a new group of respondents to explore whether it would still be relevant to a cohort of similar age to the initial respondents and to those who had experienced some complications as a result of having diabetes. I also chose respondents
who had a broad knowledge in a general area of diabetes, as advocated by Morse (1991). Additionally, both theoretical and purposeful sampling were used to develop the grounded theory and theory testing was done on the illness self-representations of adolescents and young adults with diabetes, as these self representations had been developed by Charmaz in her grounded theory work on chronic illness. Pragmatic language rather than metaphorical language was used to label the core processes as advocated by Charmaz (1990) and Walker (1996). Finally, a constructivist approach was pursued. This approach tries to define how subjects construct their realities. It does not propose generalisable truth - rather it provides hypotheses and concepts that other researchers can transport to similar research problems and to other substantive fields (Charmaz, 2000). The researcher has, as Charmaz, 2000 (p.523) recommends, tried to “construct an image of a reality, not the reality – that is objective, true and external.”

A symbolic interactionist framework has been used to develop a grounded theory, as it assisted with “meaning and emergence” and supplemented the “abundant unfolding of sensitizing impressions” (Charmaz, 2000, p. 513).

3.7.3 Summary of the studies theoretical perspectives

Qualitative and quantitative research approaches answer a range of questions. However, many research questions relating to nursing and social sciences are better addressed by using a qualitative research approach (Clifford, 1994; Higgs, 1997; Polgar & Thomas, 2000). Debates by scholars from the 1960s to the 1990s, have ensured that qualitative nursing has ‘come of age’ and has secured a highly regarded place not only in the 1990s but into the new millennium (Roberts & Taylor, 2002, p. 310).
This thesis reflects the researcher’s account of the meaning of *self* in the context of diabetes management which was explored using a grounded theory approach underpinned by a symbolic interactionist framework. The next chapter will present the way in which grounded theory methodology and procedures were applied in this study.
Chapter 4

The research parameters, the conduct and the findings of Study One.

4.1 Introduction

Any investigative study must begin with one or more research questions to be answered and this leads the researcher to clarify study aims. An appropriate design must be chosen so that the study can be implemented effectively. In interpretive studies, the goal is in-depth exploration of issues surrounding particular phenomena. To achieve this goal, suitable respondents are recruited and interviewed and/or observed so that phenomena become clearer and informant voices may be heard. All interaction with environment, respondents and data, including analysis, interpretation and verification of findings must adhere to the strictest standards of rigour. This chapter describes and explains the research parameters (question and aims), the conduct of Study One, and the findings.

4.2 The research question and the research aims

The research question for Study One was “What roles do self and illness self representations play in diabetes management in adolescents?” This question was investigated by teasing out data bearing in the following five aims.

1. To examine what effect having T1DM has on the self of adolescents.

2. To investigate whether the descriptions of self and illness self-representations constituted adequate and authentic explanations of these phenomena. These concepts were explored following foundational work of Gutmann, Pollack,

3. To explore whether these descriptions exhaustively represent the varieties of illness self-representations or if not, to explore what other ways are available to represent illness to the self.

4. To explore any illness self-representations and derived self–representations which became evident through content analysis of data from open-ended interviews. This was done in order to understand the interactions that may be occurring between other aspects of self. Further, to explore whether these illness self representations change if other aspects of self (i.e. the physical, emotional, social and related selves) also change.

5. Finally, to investigate whether differences exist in the psychological and sociological contexts of adolescents who hold differing illness self–representations? This aim involved uncovering what was occurring in the world of each respondent and determining whether life-context had an impact on the way a respondent represented that illness.

4.3 Design, implementation and choice of data collection method

The choice of methodology, as discussed in the previous chapter, was to use grounded theory with a symbolic interactionist framework to develop a grounded theory which helped explain the role of self and illness self-representations in diabetes management in adolescents.
4.4 Criteria for the sampling procedure and participant recruitment

The respondents needed to be in mid-adolescence and to have had T1DM for longer than one year and indeed most had had T1DM for two to three years when they were interviewed.

The rationale for this sampling frame, as mentioned in Chapter one, was because in childhood and early adolescence DM control is more the domain of parents, or is at least shared between parent and child. For this reason, metabolic control might not be determined by the child's aspects of “self” or illness self-representation. However in mid adolescence teenagers often take on more responsibility for the management of their disease (Court, 1992). Adolescence is difficult to define, but it is frequently defined as beginning with puberty and ending with the achievement of some level of independence (Edelman & Mandle, 1998). Consequently, young people aged between sixteen and twenty years of age were selected in the belief that they were an age group that would display some form of uniformity of perceptions. Since they would probably still be at school or university, a majority would still be living at home with their parents, but be moving towards a certain level of independence.

The reason for choosing respondents, who had been diagnosed with T1DM for longer than one year, was based on studies conducted by Kovacs, Iyengar, Goldston, Stewart, Obrosky & March (1990), and Grey, Cameron & Thurber (1994) which indicated that in the first year after diagnosis, mild episodes of depression were experienced but, thereafter, the person seemed to adapt to the disease. Therefore, it was considered that the depression would be less likely to impact on the respondents and subsequently
skew the developed model if they had had the disease for one year or longer. This however proved not to be true. As the study progressed it was evident that some respondents had suffered, or were suffering from depression, when they were interviewed, this is revisited again in chapter 6.

Respondents meeting the age and time since diagnosis requirements, were sought through the Diabetes Youth Foundation in NSW. It would have been desirable to have the sample balanced by informants not involved in a support group because the literature suggests that there is a higher level of compliance with treatment goals among those who join support groups (Laudet, Magura, Cleland, Vogel, Knight, 2003; Chun, 2002). However, it was not possible to access adolescents and young adults with diabetes through clinics or endocrinology practices for a variety of reasons mentioned in Chapter 1.

4.5 Ethical considerations.

The project’s ethics application for Study One was submitted to the Human Ethics Review Committee at the University of Western Sydney (Approval Number HERC 1994/46). In accordance with the ethical protocol for conduct of the study, all tape recordings, transcripts and respondent names and addresses were kept and will remain in a secure place, in my office. In order to maintain anonymity, respondents’ names were changed to numbers and, where people’s names or places are mentioned, these have been omitted, disguised or substituted with an X. The preliminary and final findings where individuals might have been identified were not discussed outside the student-supervisor relationship.
4.6 Recruitment of respondents

In summary inclusion criteria were as follows: the respondents need to be in mid-adolescence (ranging in age from 16-20 years) and have had, T1DM for longer than one year. The respondents for Study One were recruited from The Juvenile Diabetes Research Foundation (from whom written permission was sought) as they had access to a database of people in these age groups.

The Board of Juvenile Diabetes Research Foundation met (written permission was given by the Board) and they agreed to distribute the flyers (Appendix 1) containing information about the study and information for parents, (since although the respondents were all over the age of sixteen it was considered a courtesy to inform the parents and gain their consent). Those that were sent flyers returned their response slips to the researcher if they were interested in being part of the study. They were then contacted by phone, the purpose of the study was explained further and interviews were arranged at times and in locations that suited the respondents. Nine respondents, both males and females, with ages ranging from sixteen to twenty years of age, agreed to be interviewed. Prior to the interviews, the respondents were given the information sheet to read again (Appendix 2), further explanations were given if they were necessary and a written consent was obtained (Appendix 3). It was also made clear to the respondents that they could withdraw from the study at any time they wished with counselling available in the event of psycho-emotional distress. They were also assured of confidentiality, alongside anonymity.
4.7 Interviews.

The interviews were audio taped (after gaining verbal permission from the respondents) because it is a reliable way to obtain a complete and accurate record of an interview, particularly if supported by interviewer note-taking. It enables the interviewer to develop rapport and to listen attentively so that recursive questioning could occur. Recording the raw data allowed for the material to be available for further in-depth analysis. An accurate record is achieved because both the questions and answers are recorded (Minichiello, Aroni, Timewell & Alexander, 1995).

Two important lessons were learned in this process. The first was to step out of the helping, advising role of nurse and into the role of researcher. The second, perhaps more important, was the need to develop mastery of open-ended interviewing, especially with regard to the use of probes and of recursive questioning.

Audiotapes can give an enduring voice recording, but the impact of body language is lost (Minichiello et al., 1995). This was overcome by noting some of the body language in a book kept for memo writing. Since the researcher is not a typist or an expert transcriber, a transcriber was employed who was able to interpret inflection and pauses (Minichiello, et al., 1995). Brief notes were made during the interviews and following the interviews more in-depth notes were made. The interview tapes were replayed several times, the sense of each interview being compared with interview notes and the transcribed material so that very little, if any, of the meaning of the interview was lost.
The length of the interviews was between one to one and half hours with the possibility of a follow-up interview for clarification, if necessary, with the informant’s consent.

Audiotaped interviews were completed with all of the nine respondents and transcribed verbatim. The guidelines for data analysis in grounded theory methodology were followed from the initial interview in that, the collection of data and analysis occurred concurrently. Occasionally, when a brief interval between one interview and the next was unavoidable, the researcher returned to analysis as soon as possible. The interview transcripts and field notes were carefully examined and line-by-line indexes were created to reflect what issues of interest and importance were being expressed.

The goal at this stage of data analysis was to discover what the world of the respondents was really like and how it was created and experienced. This examination began by tentatively exploring the various phenomena through manual coding with constant comparison of segments of an interview and with other interviews, initially as well as recursively (Strauss & Corbin, 1990, 1998). Some of these phenomena became more important. These phenomena were then labelled according to their potential relevance to the impact of T1DM on the respondent’s self, as well as to the subject area. In this way processes of increasing significance in the worlds of the respondents were identified. It is common to generate a considerable number of codes from transcribed data as well as from a researcher’s analytical and theoretical memos. This is encouraged in order to open the data up to the fullest and most intensive scrutiny. Without journaling and memo writing, meaningful analysis
would be difficult and defending one’s conclusions and generating a thesis would be rendered impossible (Strauss & Corbin, 1990, 1998).

4.8 The Settings

Informants were given a choice of where they would prefer to be interviewed. Most respondents were interviewed in the privacy of their own homes, and only one interview took place in my work office, at the respondent’s request. Only one respondent was accompanied by her mother the rest were unaccompanied. All gave consent to audio taping and were advised that recording could be interrupted or terminated if this was desired.

4.9 Technical difficulties

Taking note of whether the tape recorder was switched on was important as well as taking note of when it was time to turn the tape over or to change the tape. In one instance, the tape had finished and about ten minutes of a very informative interview was lost. It became difficult to remember what had been said requiring a further phone call to the respondent. Another issue was that of noisy environments, this made transcription of the tapes very difficult.

There was also the possibility that the tape recording proved intrusive and inhibited either the interviewer or interviewee, although I do not on reflection, think it greatly impinged on the information shared.
4.10 Study One

The interviews consisted of semi-structured, open-ended questions (for examples, refer to Appendix 4). Their purpose was to invite respondents to describe what it was like to have T1DM so that the researcher might be able to discover what impact living with T1DM had on the respondent.

As the analysis proceeded with each successive interview, reflection on the literal meaning of words was done. These words were clustered and these clusters became consolidated into higher levels of abstraction (Benton, 1996; Holloway & Wheeler, 1996). Thus, clustering of strongly related codes was subsumed into appropriately labelled themes (Strauss & Corbin, 1990, 1998). Determining the relevance of each code, its relationship to other codes and the suitability of codes (Streubert & Carpenter, 1999) and category labels was a time consuming, trial-and-error process.

Certain common characteristics became more evident in the themes including aspects about the respondent’s ‘self’. With adequate data support, these aspects were labelled the physical, emotional, social and related self. A data-generated definition and description of these ‘selves’ occurs later in this chapter.

After these self themes had been discovered in the data, the researcher in searching the literature for these themes as is appropriate in the ground theory research, discovered a study completed by Ternulf Nyhlin, 1990. In her study of forty eight adults with T1DM, she described a grounded theory model which describes how the respondents managed emotionally, physically as well as how they managed the health care system.
and the social factors that impinged their lives. It was reinforcing to discover these findings as they substantiated the findings in the current study.

It became important to recognise that the number of times a phenomenon occurred was less important, in the context of this study, than other meaningful ideas. These were explored and developed into themes and as a consequence, some concepts were excluded from the final analysis, primarily because it was necessary to focus on what was pertinent to this specific study. Finally saturation (Streubert & Carpenter, 1999, p. 317) was reached at that point where new concepts were no longer evident.

During this entire research process theoretical memos were being written in order to record thoughts, questions and hypothesis. Memo writing (Strauss & Corbin, 1990) enabled these and procedural decisions to be justified and tracked throughout the study. Memo writing commenced as soon as the first data were collected. Initially the memos were superficial, but eventually gained depth and maturity - as more and more codes, themes and properties – were uncovered. Towards the end of the interview, each was asked to respond to twenty statements in the “Who am I?” test (Appendix 7) developed by Kuhn to help identify the ‘salient self’ (Kuhn & McPartland, 1953, p.68). This assumes that the most important aspects of who ‘I’ am will be mentioned first on the statement list. If, for example, their first response was - “I am a diabetic”, this was taken to indicate that the T1DM condition had a higher level of importance to them than if they responded in this way lower down the scale (Kuhn & McPartland, 1953; Charon, 2001) In this addition, I was trying to elicit the significance to them of having T1DM, to see if this compared with the way the respondents represented their illness. The analysis and findings from Study One are described below.
4.10.1 The analysis and findings from Study One

During data analysis particularly strong themes relating to the way informants managed their T1DM were noted. They were faced with managing their physical, social, emotional and relational (the effect on the family and relationships) selves. In the following pages, an overview of the analysis and findings of Study One is provided. It demonstrates how the core themes were discovered and how this led to the development of a grounded theory of developing the self over time in the context of T1DM. This theory describes how adolescents manage themselves within the context of their disease. Segments of actual data are included throughout to substantiate the analysis process for the reader along with a series of diagrams depicting the developmental process of the concepts and their relationships. Each diagram will be followed by descriptive comments. One of these concepts is called the equilibrium dilemma.

The equilibrium dilemma is described in three steps. The first step is *protecting the self in the “now” and balancing needs*. The second step is *losing focus*, which leads to getting ‘off track’ or losing direction, and the third step is *regaining focus*. This loss of focus could be as a result of changing priorities, the “worldview” lens of those with T1DM, in Figure 1, is the same as those without diabetes. The lens changes as the person is confronted with more immediate priorities. In those with T1DM priorities might not always include appropriate diabetes management. Thus, in the person with T1DM, loss of focus occurs for numerous reasons which may include, becoming disillusioned and frustrated, becoming depressed, and fearing hypoglycaemia, or
simply because of conflicting demands. Regaining focus might occur as a result of gaining more self efficacy or some action might be taken when manifestation of the symptoms occur in a friend or in one’s self (Becker, 1974). The goal, described in Figure 1, is maintaining optimum control of blood sugars while having a balanced lifestyle and maintaining an integrated self. The three steps occur in a cyclic fashion with the ultimate goal of preserving the self.
Step 1: Protecting “self” and balancing needs

Step 2: Losing focus
Goal: Optimum control of blood sugars balanced with lifestyle and maintaining an integrated self

Step 3: Regaining focus

The lenses represent the numerous reasons and conflicting demands which cause the person to lose focus as well as regain focus.

Figure 1 The equilibrium dilemma
The first step is *protecting the self in the “now”*. This encompasses monitoring the physical *self*, the emotional *self*, the social *self* and the related *self* and trying very hard to balance the needs of each aspect of *self*. The second step is when the person *loses focus* for numerous reasons and the third step is *regaining the focus*.

Other important sub-themes that came to the foreground were:

- **Disclosing** - the way adolescents with T1DM are known to others, that is the presentation of *self* / labelling, who they tell that they have T1DM, what they tell, why they tell and when they tell. This theme addresses the control of flow of information about the diabetic *self*;

- **Effect on life** - how they perceived having T1DM affected their lives, their future, their career and their hope of cure.

- **Adolescent development** - how the disease affected activities, diet, and the way they experienced moving through adolescence towards adulthood.

These core themes of *self* all appeared to interact, that is, what had an effect on the management of the physical *self*, also effected the emotional, the social or the relational *selves*. There was a ‘flow on effect’ to the sub-themes of: disclosing, effect on life, diet, activity effect and adolescent development. Any of these aspects could interfere with the all round management of the disease.

In summary, data analysis revealed that many issues impacted on the way these respondents managed the physical self, the emotional self, the social self and the related self and the interrelated sub-themes. The first the step in the substantive theory is protecting the *self* in the (now).
4.10.2 Protecting the *self* in the in the “now” and trying to balance needs

The adolescent with T1DM endeavours to protect the *self* and strives to maintain a balance of the physical, emotional, social and related selves. These *self*- protecting themes may be depicted as a “Rain Cloud” (Figure 2)

**Figure 2 T1DM depicted as a Rain Cloud. The adolescent with T1DM uses the protective umbrella of disciplined *self* management.**

![Diagram of a Rain Cloud with protective umbrella featuring BSL’s, Insulin, Diet, and Exercise]

*Self* protecting themes can also be depicted as a ‘Balancing Scale’

**Figure 3 Balancing T1DM with the needs of ‘*self*’**
The reason for choosing these particular images is because T1DM is always looming, like a cloud on the horizon, in the background even if the respondent is employing protective behaviours. The respondent is never able to completely rid themselves of this “cloud”, or the “rainstorm” it might produce. However, they can take several protective measures such as using the monitoring “umbrella” of performing their blood sugar levels, giving their insulin injections, adhering to their diet and exercising. Simultaneously, they attempt to balance the physical, the emotional the social and the related selves in order to stop the T1DM from “raining” on them and causing them to become overwhelmed and therefore immersed in the disease.

4.10.2.1 The physical self

In this context the “physical self” may be described as all the physical work that is entailed in preserving the physical self.

A feature of the interviews was the concept of temporality as described in symbolic interactionism (Strauss, 1969; Charon, 2001; Kenworthy, Snowley & Gilling, 1996). This concept illustrates that time is an intangible aspect of our experience. We are “locked into a constant present that is immediately past and the future seems to flow past us as we watch.” (Kenworthy, Snowley & Gilling, 1996, p. 46). People tend to think of time in a linear way, however our present is in fact “sliding along a line, converting future into past and we are marooned in the present” (Kenworthy, Snowley & Gilling, 1996, p. 46). Whilst externally and physically this linear conception of time might be useful, psychologically we may conceive of time very differently. Our brains allow us to remember the past and anticipate the future and this enriches our present from both directions. In fact our past “rolls up like a carpet behind us always
at our heels” (Kenworthy, Snowley & Gilling 1996, p. 46; Charon, 2001) and this effects the way we think and behave in the present.

This concept of temporality was evident throughout the interviews. There was a thread starting in the past, and continuing into the present and the future and it affected how the person with T1DM managed their disease. The thread of the past began with the build up to the diagnosis, the diagnosis that in most cases included a period of hospitalization, and sometimes readmission for restabilization. This can be seen in the following data extracts.

4.10.2.2 The physical self in the past: Pre-diagnosis, diagnosis, readmissions

There is usually a period of illness or weight loss, polydipsia and polyuria prior to diagnosis; this is well described by this respondent:

...leading up to being told.... that I had diabetes, there was [the] awful experience... drinking a lot and... Losing a lot of weight and always having to... make pit stops to the toilet.... I just went to the doctor and they did a test and said.... you may have diabetes, I think we’d better get you down to the hospital (Respondent 2).

The diagnosis occurs and sometimes a sense of relief follows, “I remember when I was diagnosed... having to have injections and things like that ...I was pretty sick when I was young so I just thought of it as another medicine that I had to have.... I don't know that it made much difference”. This sense of relief occurs when a name is finally given to the symptoms that the person has been experiencing and they do not mind taking the medicine because it makes them feel better.
Then what follows is trying to understand what the disease is all about. “Ah, well when I first got diabetes I didn’t really know anything about it ... I suppose no one does...” (Respondent 1).

The person goes on to develop a sort of “uneasy truce” with the disease:

I adapted quickly to it cause I knew you couldn’t get rid of it so there’s no point trying to think... it was going to go away ... I didn’t like ... what I had to do, injections and stuff at first but gradually I just got used to doing them ... it just became sort of like second nature... (Respondent 7)

They learn to cope with the interruptions it causes. “I just got on with my life and did what normal people did ...”. Many respondents indicated that diet change was not really a problem:

The change of food didn’t really worry me much ...it wasn’t that hard dealing with my diet and things...I didn’t really eat much sugar food or anything before anyway so the change of diet... didn’t really affect us much either (Respondent 4).

However, the fear of needles was more of a problem: “the fear of having to give myself a needle ... I sort of … made myself do it, in hospital, cause I wanted to get out; I hated the place so I made myself do it”. One respondent was quite adept at giving her needle but then, one day just couldn't do it [give my needle]: No way ... I got my five year old brother to do it”.

Only a few respondents had to return to hospital, for restabilsation: “One time was for restabilsation... I think both times just for a check up ...”. The length of stay varied: “I think [for] about ten days and the other was about a week” Another respondent needed restabilsation after a trip to England: “I was really sick and I had to go into hospital overnight to get everything down” Yet another respondent became ill and
needed restabilisation; “I was throwing up a lot ... they just wanted me to go into hospital to make sure nothing was wrong...”.

4.10.2.3 The Present: Becoming a “Monitor”

After the initial diagnosis the person begins to understand what T1DM is. They are also in the process of developing an “uneasy truce” with the disease. From there, they appreciate the need to move on and become a “monitor” of the disease in the present: They become a monitor: -

• of blood sugar levels
• of charting
• of being able to recognise “highs or lows” (hypoglycaemia and hyperglycaemia)
• of injection giving
• of the effects of hypoglycaemia
• checking that they are carrying glucose
• as well as the impact of other illnesses and their potential impact on T1DM.

Each of these was reflected in the data.

4.10.2.3.1 Monitoring blood sugar levels and charting

Once diagnosed, as mentioned previously, the person is then required to monitor the physical control of their disease. Some find that they do this task automatically: “I check them [blood sugars] every time I do my shot or if I feel low or high”. They also record their blood sugar readings and some do this very well “At first it was a bit annoying ... now I just automatically do it, I don’t think about what I’m doing...”.
Some have blood sugar machines with memory banks: “and I just leave it there and whenever I go to Dr[X] ...he just pulls the memory out’.

4.10.2.3.2 Monitoring the “Highs and the Lows”

All the respondents suggested that they were able to feel when they became hypoglycaemic or hyperglycaemic. “When it’s low [BSL] I can feel it... but it is mostly always high so I have always been able to tell the difference... when I am sort of high I drink a lot”, and again: “I know, I can feel it within myself, if I'm having a low, if I'm having a high you know... you get to know what your body does at a certain level and you know when you've got to check it.” Some respondents are able illustrate how they are able to tell the difference between hypoglycaemia and hyperglycaemia.

When I'm high I'm thirsty,[I] can sometimes get a headache[I], just... don't feel so well,... when I'm hypo I have shaky hands... sometimes I feel really... I feel... annoyed (Respondent 4).

As well as this they indicate that:

[You ] can't really concentrate at all, you just feel like lying down and staying still but you can't, ... cause you're just constantly shaking, dizzy ... it all depends on how low though ... but... if I'm high, [I am] very thirsty, very warm and sweaty, dizzy, and lethargic, ... you just can't be bothered doing much at all (Respondent 5).

I start getting tingly round the lips [with hypoglycaemia]... my highs... I don’t generally feel it unless it’s really[high] ... I find that sometimes I get in a really hyperactive type mood just before I go low (Respondent 9).

Some say that they are able to tell by looking at their urine: “if you're high, your urine is clear but if you're low it’s really yellow”.

These are all cues which the respondents believe indicate their blood sugar level.

Some choose to check their blood sugar levels at this point by performing a blood sugar test.
4.10.2.3.3 Monitoring of injection giving

Many of the respondents gave themselves all the injections they needed to have. Some had to give 2 two injections per day and others had 4 four injections a day and but they were not too concerned about having to do this. “I don’t worry... You get used to it in a way”.

4.10.2.3.4 Monitoring the effects of hypoglycaemia

Many respondents had some form of glucose or money (to purchase sweets), with them at most times to prevent themselves from becoming hypoglycaemic. “Well I usually have barley sugar in my [pocket], [and] I have a can of lemonade in my locker” or money to buy “lollies,” “I usually just take money and they let me go to the canteen when I have to”.

4.10.2.3.5 Monitoring the effects of other illnesses on T1DM

When the respondents become ill there is an increasing need to monitor the impact of the illness on their T1DM. Frequently their blood sugars increased dramatically. “...When I get sick or something ...like the flu, I mean it's 10 times worse because you've got...diabetes and you get more fatigue and high blood sugar”. However, hypoglycaemia can be a problem as well: “when you get ... the gastric, [you have to go to the doctor because] you want to have the Maxalon needle [so that you stop being] sick and you can like keep your blood sugar level at a good rate, and you don't have hypos”. The problem also exists where the respondents fluctuate between hypoglycaemia and hyperglycaemia: “I had a bad hypo and I was sick and I slept from dinner then I got high blood sugar”. 
In summary the respondents were attempting to manage their physical self and T1DM in the present and expressed hopes for the future as in the following section.

4.10.2.4 The future: The hope of the “imminent cure” and the career

The respondents’ priorities were to live and enjoy life in the present but this was also tempered by the wish to be in control, predominantly of the physical self (so as to avoid suffering the indignity that often accompanies hypoglycaemia). This was done with an eye on the future, wanting to maintain optimum health in anticipation of an imminent cure:

Well I think diabetes ... control is important because ...if they do ever find a cure... the people that are healthy...I think [would ] be the first people to actually receive the cure, and also if it, involves a transplant of some sort ... that they would be able to take [it] a lot better, so with good control of diabetes... I think future prospects ... to be one of the first for the cures ... would be pretty high ... also I feel a lot better if I’m in control of it as well. (Respondent 7)

Some respondents were hoping the cure would be there before they entered the work force: “I am hoping for a cure before I have to do anything like that, hopefully in about 5 years maybe”. Most respondents felt that having T1DM encroached on their career options: “Yeah it will, because I won't be able to do something like, like [air] hostessing”. A few respondents wanted to enter either the armed forces or the police but were unable to do this: “Yeah, cause I want to do forensic pathology ... most people go through the Police Force. Another said: “I wanted to join the police force - they said no... with diabetes you can’t - army is the same”. However, many were resilient enough to work their way around these barriers and said: “… but you can go through the Department of Health [to do forensic pathology] cause you're not meant
to be in the Police Force”. Another said: “[I] think really there’s a way of getting round it if I really, really want to do it”. The respondents were not only managing the physical self but also the emotional self.

4.10.2.5 The emotional self

The emotional self, in this context, can be described as the impact having T1DM has on the emotions, i.e., how the respondents feel about having T1DM as well as the stressors that effect T1DM control. There was the same thread through their narratives - starting in the past, continuing into both the present and the future that affected how the adolescent with T1DM managed their emotional self

4.10.2.5.1 The emotional self in the past, present and future

For some respondents the first response was one of disbelief: “[I was] hoping it was not me or that it wasn't sort of for... life”, and again: “It's the biggest shock I ever ha, ... I was crying and I told mum and she couldn't believe it”. Another respondent said: [for about a] “week I was just saying, oh my gosh what’s happening here... I’m 13... I’m not supposed to be doing this... I just felt really out of whack with everyone else ... and I hated being on the diet”.

This disbelief is followed by anger: “I was so angry... I thought he was joking! [but] he was serious! (Laugh). There seems to be a sense of feeling cheated: “I wasn’t supposed to get this ... I was supposed to go through high school you know, just being normal like everyone else”. Then in order to gain some control the respondents begin to become interested in what they have to do: “After a while I thought you know, you've [got] to be interested ... finding out what could happen “
Other respondents suggested that they: shrugged it off, really...just sort of put it behind me... it never really hit me... [I] didn’t really worry about it ...it’s a weird time”.

One respondent illustrated the fear of needles and the added responsibility in this way:

It was more the fear of having to give myself a needle... I sort of like made myself do it in hospital, cause I wanted to get out, I hated the place so I made myself do it... [I] suppose it made me grow up a lot ...I was 16, I didn’t really care about what I did ... there’s a lot of... responsibility, you’ve got to remember to have your injections, cause I used to forget, still do occasionally [and remember to take it with you], if you’re going out somewhere (Respondent 9).

In the present, developing the “uneasy truce” is evident. This was explained in the following way: “Now when I look back I can’t sort of see myself as a non-diabetic”.

Another said: “There’s one weird thing though, I hate that word [diabetes] - Yeah can’t stand it, I can’t say it often, I don’t really like saying it at all ... I just can’t stand that word”. When asked whether it was the word or the diabetes, he disliked he indicated he was not sure. He appeared to have a real sense of ambivalence about the diabetes. He went on to explain it in this manner:

don’t really like them both I don’t know why, it’s weird... I don’t think it’s just ‘cause I’ve got it either, it’s strange, I just don’t like saying that...[word] Oh I don’t really mind having the disease, it’s the word I hate, I just can’t stand that word ...I don’t know what it is (Respondent 8).

The respondents did not like being pitied by others: “ they look at you in a different light, like .oh you poor thing, you're diseased (laugh)”.

In the future there is a sense of hope for a cure, a feeling that: “if I can hold on and maintain good control then my chances are very good for a cure”. “Like if they do ever find a cure... [the] people that are healthy... [will] be one of the first for the
cures... [my] prospects[I] think would be pretty high”. Another respondent said: “I’m hoping for a cure before I have to... [start a career]. This is also mixed with a sense of frustration because the cure seems to be taking so long:

oh, well, you know I’ve got this disease, do something about it, you know... then you get these magazines that come from JDF and you hear these things ...I went crazy one night because this guy was on “Real Life” and he had that pancreas transplant... and I just went yes, a disease that can be cured!.... they keep saying, 2 years... - I don't think so. Now it's within 10 years you know (Respondent 2).

4.10.2.6 The social self

The social self in this context may be described as the way that having T1DM has impacted social relationships with others. Once again there was a thread of the past, the present and the future running through data on the social self.

4.10.2.6.1 The social self in the past, present and future

Most respondents had good social relationships in the past. Friendships were in most cases not affected because the respondent had T1DM: “Surprisingly I did have support from a lot of my friends and, I did have a friend who’d had diabetes too...that was useful ... she kind of talked to me”. This same respondent had, had a boyfriend who was very understanding:

He understood all the time and... it was really good because... some guys do not understand about anything, I mean, they're not very understanding about that time of the month let alone you know having a disease (Respondent 2).

Another respondent found that their peers were eager to be tested for their own blood glucose/sugar levels themselves:
When I was at school... they were really good ... it was more a case of oh, take my blood sugar ... they all wanted to have their blood sugar tested and see what it was like after they had a can of coke and things. (Respondent 9).

Most respondents have experienced positive relationships in the present. Some liked their friends to be aware that they have T1DM so that they are able to assist them if they become hypoglycaemic:

I'm very open about it with my friends, cause I feel that they should know and it makes it easier for them so they don't start panicking when things go wrong, ... cause I shake and my eyes go glassy so most of the time people can tell and tell me to get juice and stuff (Respondent 3).

Some even indicated that their friendships might have been strengthened because they had developed T1DM:

There's another girl at school who I'd never really met ... I knew her ... she's in my grade and I didn't really know her much before and she... got diabetes I think just last year, and I became really friendly with her just through diabetes... A lot of other people have got closer to me, I don't know if it's because of diabetes but I think a lot more people probably care about me now (Respondent 7).

However other respondents are wary about whom they tell about their T1DM:

“I don't like to tell [anybody]... I think some, my very close friends would know that but some of my other friends wouldn't know”. Another respondent said: “I have ... a close-knit of friends and we know usually do all things together so, I don’t really go out very much... with a lot of people that really don’t really know me”.

Most respondents indicated that teachers were very good about them having T1DM but some encountered problems, usually easily solved by explanation: “I pulled out
jelly beans ... I was eating them and my teacher goes, if you're eating you've got to share it with the whole class... I went outside and had a word with him”.

Most respondents were content with relationships and their future prospect for securing a good career. Quite a few of the male respondents had not really thought about the consequences of having children, partly because of their age and perhaps because of their gender. This was in marked contrast to female respondents, all of whom had thought about having children.

Those that had thought about having children, both male and female respondents, were concerned about their children developing T1DM: “I wouldn't want to have a kid that had diabetes cause I'd much rather not have diabetes. I used to think I'd adopt a child but I don't know”. Another said that he would be concerned about his children having T1DM, but it would not really stop him from having children. One respondent said: “I would be concerned; I would know that it doesn’t really affect their lives that much and I would make sure that, they would eat properly”. Another respondent said: “before I have children I suppose I’m hoping for a cure so I’m just sort of not thinking about that sort of thing”. Yet another other sub-set of respondents were more concerned about trying to maintain good blood sugar control:

I don’t think [I am] necessarily concerned about passing the disease on but ... about keeping it [the diabetes] controlled ... that’s a major worry ... you don’t want to do damage [to the foetus] cause your sugars go out of control (Respondent 4).
4.10.2.7 The related *self*

In this context the related *self* can be understood as the relationship between the respondent and their parents and their siblings. The presence of a chronic illness often leads to conflict developing between the respondent and close family members (their parents and siblings). Ludder Jackson and Vessey, 2000, indicate that having a child with a chronic illness can lead to a "situational crisis". Hymovich.1981, (cited in Ludder Jackson and Vessey, 2000) states that "the attempt to regain equilibrium either leaves the family stronger, weaker or dissolved" (p13).

4.10.2.7.1 The related *self* in the past, present and future.

The initial response of parents is usually one of shock, and worry: “*They were worried. [about whether both they and I] could look after me*”. Again: “*well, my mum was very upset*”. Many respondents mentioned that their parents were shocked although they had suspected they [the respondents] had T1DM: *they were shocked ... but they were the ones who actually thought it was that [I had T1DM]*”. There is also the feeling of not wanting to explain over and over again all that is involved in having T1DM; this was explained well by one respondent:

> I didn't really want to go up to dad's after I'd been diagnosed ... I knew I was going to get 50 million questions ...You sit there and you've got to explain to them. I gave them some sheets ... the hypo sheets and the hyper sheets ... and I just said read those and it tells you what to do ... but no, I had to explain it, ... cause I'd have hypos during the night ... but the thing was the hypo always wakes me up in time for me to understand what's going on. (Respondent 2).

Many siblings began to have the same food at the same time as the respondents and this led to complaints. There was also the feeling that too much attention was being paid to the diabetic siblings because they were given different food or drinks:
He sort of became a diabetic when I became one ... eating at the same time and the same food ... thinking back I got treated as the spoilt brat because I [was] getting more attention from mum and dad, but he tried as to as best he could…” (Respondent 1).

I know my brothers and sisters used to complain about not having stuff like sugar....I’ll have fizzy drink...that used to be a lot bigger than the poppa so...they didn't like that. (Respondent 4).

Most of the interviews for Study One took place before the advent of Humalog and other insulins which do not require the half an hour wait for food. Many respondents did not wait for about half an hour before they ate their meals once they had given their insulin. Their mums in particular were concerned about this. “Mum's always telling me I should do that but.....” Another respondent said: “we used to but now ... we have early morning lessons a lot, sometimes I only wait 10 - 15 minutes, even 5 minutes but mum’s ... trying to get me back on to 1/2 hour before.”

Parents often ask about the respondent’s blood sugar levels and this could be annoying to some the respondents:

Well, my dad, whenever ... I am hypo and I'm in the kitchen drinking something, he always has to ask me... are you hypo ... and if I'm drinking something I would have thought it would be really obvious that I am hypo and so I just hate that question  (Respondent 4)..

However, some respondents simply see it as being concerned and not really interfering:

Well mum, mum checks on me quite a bit but I feel that [it] makes her feel a lot better... no one else really does it that much. Dad does it a few times but nothing much, he does that just to please mum and make sure it’s fine (Respondent 7).
Siblings seemed to react because of the change of diet that parents instituted for all the family but as time wore on they seemed to settle down: “I know my brothers and sisters used to complain about not having stuff like sugar and stuff like that ... that's got a lot slacker now that I'm a bit older”. This seemed to occur because parents began to realize that the other children did not need to be on the same diet as the respondents and they did not want to cause resentment.

Respondents did not mention how their parents or siblings perceived the future. There was a sense of concern by the related others about the respondents illustrated by “Mum worries a bit,” and again: “my mum in particular... she goes, oh have you given yourself your insulin?” I believe that the reason for this worry is both for the immediate safety of the respondent and the impact that lack of control of T1DM may have on the future of the respondent.

There was a sense of anticipation of a cure, both by respondents and their families, as suggested by the following comment, which I believe would include those related to the respondent. This perception is probably verified by the following statement:

Mum got excited once because I was so good ... [I] went down to my doctor and he had my blood test and he said you have a non-diabetic reading ... mum naturally thought that was it! I don't have it any more” (Respondent 2).

In summary, the respondents try to protect “the self” in the “now” by monitoring the physical, emotional, social and related selves and trying to balance all of these needs. However, this is not always the case because illness or any number of stressors can intervene and the respondent begins to lose focus in their attempts to protect self.
4.10.3 Losing focus

This is the second step in the equilibrium dilemma as previously depicted in Figure 1 above. This entails losing focus. It leads to getting off track in terms of the management of T1DM. Losing this focus has a flow on effect.

The T1DM, "cloud" becomes a more “ominous storm cloud”. The T1DM may begin to dominate the self i.e. the collective selves or separate selves the physical, the emotional, the social and the relational selves.

T1DM can have an effect on the self, but conversely, how the physical, emotional, social and related selves are managed can have an effect on the T1DM. For example, other things that have an influence on the physical, emotional, social and related selves are:-

- The effects of other illness, for example, an infection such as influenza.

- Adolescent developmental issues, including the struggle to develop an independent identity, and critical physiological changes, such as increased growth hormone and progesterone levels, which have an effect on being able to control blood sugar levels.

- Balancing the diet can be problematic because, although it is less restrictive than in earlier years and contemporary recommendations make compliance easier, many adolescents love to live on “junk” foods and to eat meals at irregular times. Those with T1DM are no exception. This can have a significant effect on blood sugar control as well as cholesterol levels.
Life effect (refer to Figure 4a below) can be explained by the effect that having T1DM has on a number of areas of the respondent’s life such as career options; the planning that must precede social activities; balancing diet, nutrition and exercise; the tedium of maintaining a stable blood glucose level (Lundman, Asplund & Norberg, 1988; Ternulf Nyhlin, 1990; Beeney & Sharpe, 2001) and coping with incidental illness and its disruptive effects on glucose balance.

**Figure 4a T1DM depicted as an Ominous Rain Cloud**

T1DM is an additional burden at times when one or more of the selves is experiencing a significant stressor. The ominous rain cloud represents a metaphorical storm which may blow up at any time for any or all of the ‘selves’ This can either have a flow on effect with regards to adolescent development, diet, life effect, activity effect or disclosing. Or this storm may have resulted from these sub themes.
An example might be: the presence of excessive growth hormone in adolescent development can interfere with physical management of T1DM as insulin resistance occurs. This can lead to frustration and affect the emotional *self*, parents may feel the respondent is not managing their T1DM well and this might be a source of friction for the related *self*. The person may become depressed and decide not to socialise and this has an effect on the social *self*.

4.10.3.1 Losing focus and its impact on the physical *self*

Study respondents did not like to feel ‘out of control’ which can be the effect of a hypoglycaemic episode. They tried to avoid becoming hypoglycaemic at all costs, even if this meant having an elevated blood glucose level (See Figure.5). The distractions of ‘life effects’ may lead to a loss of focus and thus loss of direction. This is very well described by respondents in regards to testing and charting blood sugar levels, why they skip injections, how they feel about having injections, how they feel when they become hypoglycaemic or hyperglycaemic.

Charting and doing blood sugars is found to be time-consuming, frustrating and painful. The respondents gave voice to this as follows:

“I find writing in the book a hassle ... I often don't write in months and then I lose a few of them and some of them ... tend to be a bit fictitious... I don't do readings a lot”.

The time constraints are also a big problem: “... you've got to get up ... 15 minutes earlier... because you're so slow in the morning, if you want to do your blood sugar levels ... I just, can't keep up with it all”. Performing blood sugars can be painful and
this prevents respondents from doing them: “I've even got this callous on my finger from doing it one too many times on the same spot ... it's not that appealing, stabbing you finger every day. I do it every now and then just to make sure that things are alright”. The respondents take their insulin: “…because if I don't do it [have insulin]... I don't feel so good... but blood sugars I really don't need them, to stay well”. The constant testing is frustrating: “ you know having to find out how high or low or whatever, was just ... you know. [shaking his head]”. This causes the respondents to lose heart and they reduce the amount of blood sugars they do and even write down fictitious results: “... if I have ... a week off, [doing blood sugars] if I do ... I’d probably just write a couple down (laugh)”. Another respondent described the problem in this way: “I was really good for the first year and a half, I used to do blood sugars ... twice and three times a day every day without fail - I don't any more”. Another said: “I mean the blood sugars and all - I'm the worse person in the world ...I do 'em occasionally.”

Most respondents did give their insulin but some found this difficult with their job and they felt not giving their insulin was their only way to work around their T1DM.

Well there was twice when I was at [a show] doing some stuff and I just didn't do a dinner needle, because a hypo I can't work with because I am weak and can't do anything, but when I'm high I can't really feel it, apart from being thirsty and a glass of water now and then that will be fine (Respondent 1).

Some respondents found it difficult to give their insulin when they went out with a group of friends: “...sometimes I take the syringe with me when I go out, I really [said very quietly as though afraid someone else was listening]: never do injections much when I go out”. Another described it in this way: “...I know a couple of times I haven’t given it [my injection] cause I ... don’t want to leave, type of thing, I don’t want to have to go and say oh I’ve just got to go for a minute”.
Some respondents do not give their injection before examinations because they indicate that it is very difficult if you become hypoglycaemic in an examination:

Well if, I am stressed ... during exams, I'll often eat more ... to make sure that I am high so that I don't go hypo ... and if, I'm scared that I'm going to go hypo in the morning, sometimes[I’ll] not have my injection of a night, cause I'd rather go high than go hypo (Respondent 4).

Others hated all needles for example, when questioned about needles for testing cholesterol levels or having other injections. They did not like any injections but they had to have their insulin, as they realised that it was a life or death situation: “I hate them (laughter)... people often say, don’t you hate needles - yeah I hate needles but I'm used to giving these needles too, it’s a fact of life - if I don’t do it, I’m not going to be here”.

They often felt that people expect them not to dislike having insulin injection or other injections, because they have T1DM

I hate needles... they go, you're a diabetic! And I go ... but that's just a little needle ... this one goes in about ... 5 cm and it's about 2 cm thick (laugh) ... it's real painful! ... Its funny how people say oh how can you be scared of needles? Just like everybody else, I suppose (Respondent 2).

Some respondents even experienced times when they had a real inability to give their needle: “…I was really good at giving myself the needles, no problem at all ... then one day just couldn't do it... got my five year old brother to do it”. Another said “I just make myself do it and I just sort of wait a while and wait till I’ve built up a bit of confidence”.
Respondents were able to describe how they felt when their blood sugars were high or low and how they managed these scenarios. They also describe a sense of losing physical control when they become hypoglycaemic. This is a situation that the respondents did not like at all: “... I don't like it very much, like cause I know that I'm out of control of myself ...I don't like the fact of knowing that I could really hurt myself ... if no one else is around”. This same sense of weakness and being out of control, during a hypoglycaemic episode is expressed in the following ways: “because a hypo I can't work with because I am weak and can't do anything”. Another respondent noted: “I can tell everyone what to do, get me this, get me that, but I couldn't, [get sweet food or drink] cause I couldn't do it myself”. Again another respondent says she has to be forced to eat and drink: “... I'm shaking and my eyes go glassy.... then you need to get juice with sugar....and make me drink even if I don't want to ... I really don't want to eat... [I feel like saying] don’t put that in my mouth”.
There appears to be a subjective level of knowing about what the respondents’ blood sugar levels are, therefore, quite frequently, the respondents do not feel the need to do them. This is referred to as blood glucose estimation or body listening (Cox, Clarke, Gonder-Frederick, Pohl, Hoover, Snyder, Zimbelman, Carter, Bobbitt, & Pennebaker, 1985; Freund, Johnson, Rosenbloom, Alexander & Hansen, 1986; Price, 1993; Meltzer, Johnson, Pappachan, & Silverstein, 2003.) This is body listening is expressed by the respondents when they indicate: “... I can feel it within myself, if I'm having a low, if I'm having a high you know ... you get to know what your body does at a certain level and you know when you've got to check it” and again, “it’s pretty hard to describe but I get this sort of feeling inside, I can’t really describe it very well but I can tell”. Taking all the above issues into account it becomes clear why the respondents are at risk of losing their focus on the physical self and thus experience a loss of direction in managing their condition.

4.10.3.2 Losing focus and its impact on the emotional self

Emotions such as pity, embarrassment, aggression, anger, frustration and feeling out of control and having to depend on others, are expressed as issues which caused respondents to become discouraged and lose direction. Many respondents do not wish to tell others that they have T1DM because: “they look at you in a different light, like oh you poor thing, you're diseased, (laugh)... if there’s no need for them to know ... I don't tell 'em because ... it, sounds like ... I want some attention”. There is a sense of embarrassment about telling people that you have T1DM: “I find it hard to tell people that I am a diabetic and then grab a needle out and do it there, sort of thing”. The respondents only told people who needed to know that they had T1DM. People such as close friends, sometimes employers, and if they were worried about becoming
hypoglycaemic they might tell somebody but only so that would be able to assist them, not because they really wanted to tell them. There is also a great deal of embarrassment and frustration about the way in which hypoglycaemia takes away the sense of control and their independence:

[You] lose control of your body and your mind and you have to let everybody else think and react for you and pray that there’s someone there that knows what they’re doing ... it’s, it’s weird to know that I can go kind of crazy ... when I’m older ... I can’t just move into a flat by myself ... I’ve got to have someone there that understands everything about me and is willing to take the responsibility of me you know (Respondent 2).

Respondents say they do not know what is happening and cannot remember what has happened after a hypoglycaemic episode:

I often forget, I don’t remember it afterwards. I had a bad hypo after an exam one day, I was coming home from school, [with] a friend ... a friend drove us to [X] ... I don’t remember anything from [X] on ... she ... let me have some lunch and then I was fine .... I didn’t remember getting out of the car [and] I walked from where she dropped us into the shops” (Respondent 4).

Respondent 6 noted:

No. the bad ones, I can remember little bits of them but most of the time I can’t remember I might have a flash in the middle ... cause I can remember telling this guy off, after he like carried me into a room, (laugh) ... that’s the only thing I can remember, and I thought, did I dream that or did I really say that - I’m so sorry! You know.

They are also concerned about how they may have behaved when they are hypoglycaemic:

I can be really weird ... when I flip out - I can be either aggressive, [or] I can be a little child” and another said “I went so aggressive ... I can’t eat ... I couldn’t suck it or anything cause it was just so sweet ... they nearly took me to hospital cause I was being so unco-operative (laugh) Respondent 9.
The way in which T1DM controls their lives is well explained by these respondents in this way:

[It] sort of does control you... you have to think about it before you do things... like eating, which is a classical example, you always have to think....chocolaty stuff ... and … pizza, even, so you have to really be careful about that sort of stuff” (Respondent 5).

Yeah it does. [control your life] I hadn't really thought about it, but it does because ... I mean most of the time ...[ my blood sugars are] not going to go down real quick, I can usually go and handle it, but I’ve always got to rely on someone that knows something about it … I’m really scared that one day I’m not going to have any one round me that knows anything or knows that I’m a diabetic... I’m out somewhere I’d rather be a little high than a little low because if people don’t know how to handle the situation they’ll just freak or something (Respondent 6).

Another respondent stated:

I have terrible a time with my sugar levels most of the time I go into exams I’m 20, and that annoys me so much cause I can’t concentrate, [on] anything I do... I wouldn’t have a clue how ...fix it up, only by giving myself more insulin ... then I don’t want to have a hypo (Respondent 2).

Faced with a situation of stress or illness, which either increased or decreased blood sugar levels and when there was very little that they can do to change that, their frustrations become evident. This data leads to a better understanding of factors which cause the respondents to lose direction of the emotional self.
4.10.3.3 Losing focus and its impact on the social self

Respondents did recognise that T1DM did have an effect on their social relationships and they did not like that at all. They liked to be part of their peer group and did not like being seen as different. This caused some to stay at home while others tried very hard to fit in, even if that meant juggling their diabetes lifestyle. Some found that it affected friendships. Some people such as teachers and nurses appear to have been more of a hindrance than a support.

In the words of one respondent:

I still don't go out much I don't know whether it is because I don't like going out or because I am diabetic and I have to get back all the time and that sort of stuff “ and another said, when you're going out with everyone ... I found it very difficult and I just got lazy. I said I'm not going out, forget it, couldn't be bothered because I had to take the insulin and I'd have to make sure that I'd do this and don't do that. (Respondent 1).

Another respondent indicated that after experiencing quite a few hypoglycaemic episodes at school her friends became frustrated with her: “after a while everybody kind of got sick of feeling sorry for me and like helping me out and they just said that I was faking it ... that hurt... some people don't quite understand.” (Respondent 2).

Several respondents encountered problems with teachers not understanding about having to eat in class and a school nurse who seemed to lack understanding:

He was a stubborn man and a teacher that I didn't like at all... he said you're not eating in my class. I said I've got to, I've got diabetes, ... the whole class [is] backing me up... 10 minutes later... I'm flippin’ out... I taught him a lesson and no worries since (Respondent 2).

and:
I mean there's this annoying nurse at school, ... she goes on how I should have my glucometer with me I've told her before and, that I don't need to bring it... my doctor [says so] ... you can't ... sprain your ankle ...she's going to ask you what your blood sugar level is ... it can be really annoying (Respondent 2).

Respondents do not like to put their friends out and this can occur. One respondent described how if he had not had enough to eat and had done a lot of exercise: “...[it] makes me feel like am I going to survive it ... it'll worry me so therefore ... I do have to put other people out saying oh I’ve got to go do this [eat] and they get ...a bit angry with it”.

In summary, these narratives help us to recognize how negative social interactions can cause the respondents to lose focus.

4.10.3.4 Losing focus and its impact on the related self

Sometimes problems occur between parents and siblings and this is often due to frustration because of the side effects of having T1DM. One respondent described how difficult it was to travel with her father because she needed to go to the toilet frequently: “Dad was understanding at first, but then after a while ... I'm having to go the toilet a lot, he was, saying...“Oh God”. It made me feel, they had no idea, I mean I can't help this ... it makes you feel awful”.

The respondents particularly disliked being asked about how their diabetes was rather how they were.

I think it was my uncle or my aunty ... oh how’s your diabetes going? And I just went - what about me? How about how I'm going, who cares about my diabetes ... that's a part of me, it's not me being a part of it. (Respondent 2).
Adolescence is a difficult time for those with chronic illness and their parents, because, while needing to gain their independence, they also realise that their parents care. One respondent described this way: “She tries to [help control my blood sugars] (laugh)... she will ask sometimes but ... it’s more or less up to me now”.

So we see that numerous issues can derail the efforts of adolescents in the management of their T1DM and cause them to lose direction. They feel frustrated with the continual monitoring; they become embarrassed about having to divulge that they have T1DM. As well as this, they are concerned about how they may respond when they become hypoglycaemic and, therefore, prefer their blood sugars to be a bit higher: “I’d rather be a little high than a little low because if people don’t know how to handle the situation they’ll just freak or something”. These respondents wanted to be accepted socially and they sometimes feel that they do not fit in because of the restraints imposed on them as a result of their T1DM, especially the fact that they have to eat so regularly: “I do have to put other people out saying oh I’ve got to go do this [eat]”. Some respondents feel that their T1DM may negatively bias an employer and choose not to disclose this information:

*I mean if ... you tell them when they employ you ... some people are biased, they think, well, is she going to be a health risk and ... sue me for something, not letting her out to lunch or something ... you’re so embarrassed by ... diabetes ... I was filling out a form for something ... I didn't fill it in because I was sick of people being biased* (Respondent 2).
Adolescent development can interfere with diabetes control just wanting to be part of the group and not different as well as developing independence: “When I first had my diabetes, it wasn't very difficult ... as I got older... it is becoming more difficult because I wanted to go to parties and I'd have to take an injection with me which is really difficult... [before] mum used to make sure I did them .... I do it myself now.”

Female respondents said that it was difficult to control their blood sugars when they menstruated and this can be a real source of frustration and disincentive to control their blood sugars: “just before [I menstruate] ... I feel like I should eat heaps so that's probably why they [the blood sugar levels] do go up... then when I get them I don't eat at all so then they go down again ... I just don't feel hungry when I first get them”.

Often the respondents did not like having to follow a diet: “I hate it so much! ... I just go off it [the diet] every now and then - Most of the time I don’t really care ... I should, ... I dunno, it’s, it’s hard watching what you eat”.

Before the respondents do any activities they have to plan well ahead of time and there is always the unknown that can complicate life for the respondents for example if they do a lot of exercise they need more food to prevent them for becoming hypoglycaemic:

“I was involved in Venturers ... just so many things I had to think of, like I had to make sure I had enough insulin, needles ... [you had] take all your own food and everything, cause it was a 3 day hike ... and I had ... pockets full of dried fruit bars ... it was just, trying to think would you have enough. You didn't know how much you’d need...how much exercise we were going to do (Respondent 6).

Whilst most of the respondent interviewed did not have complications as a result of having T1DM, many attended “complications clinics.” The focus of these clinics is
the prevention of potential complications, which while commendable, many found
confrontational. The respondent may feel coerced into conforming and in adolescence
this could be counterproductive, a feeling of another “parent” watching over them and
this may lead to rebellion. One respondent had already developed cataracts even
though she was still in her teens:

*I was actually diagnosed ...with them ... only about 7 months after I’d actually
been diagnosed with diabetes in the first place they’re normally caused by
uncontrolled blood sugars ... they think it was a long period before I was
diagnosed and ... that’s what caused it because juvenile cataracts are really
rare*. (Respondent 9).

The respondents are continually reminded of the fact that complications from T1DM
can occur at a relatively young age and this leads to competing realities occurring.
These realities are living life in the present and being in physical control even if this
means having higher blood sugars, so as to avert the problems that accompany
hypoglycaemia. At the same time trying to maintain optimum physical health to avoid
complications occurring which jeopardise their long term health, as well their chance
of receiving the anticipated “imminent cure”. Thus they try to once again to regain
focus.

4.10.4 Regaining the focus

When the respondents are reminded about the need to control their blood sugars,
usually by their doctor or by having a severe hypoglycaemic or hyperglycaemic
episode, or some complication of T1DM or a poor test result, they really try hard to do
this: “...he [the doctor] tells you ... you sort of know it but, I dunno I suppose he like
underlines the main things that you need to do, like, with me I’m sort of not as stable
as I used to be, like I’m up and down.”
The respondents try to focus on the goal to control the physical, emotional, social and related self. The way in which the respondents try to regain control of the physical self is to revert back to becoming a good “monitor” of their blood sugars, diet, exercise and insulin.

4.10.4.1 Regaining control of the physical self

The respondents become more thorough about performing blood sugar levels, increasing their exercise levels, sticking to their diet and giving their insulin correctly:

“If I'm feeling really good or I've just been to the doctor I usually do 2 or 3 [blood sugars] a day”. They watch their diet. “I watch what I eat ... also like exercising, I have to make sure... I've got the right levels”. Again: “…I was so good and I didn't touch anything [wrong food] ...” and administering insulin correctly: “we used to [wait for half an hour before eating, after having insulin] …mum’s, I think, is trying to get me back on to [waiting ] 1/2 hour before”. Therefore the respondents make a concerted effort to control their blood sugars.

4.10.4.2 Regaining control of the emotional self

They decide to disclose that they have T1DM: “probably so if I got low blood sugar that they'd know what to do and it would be easier for me and people around”. The striving to remain healthy is reignited because... if they do ever find a cure... the people who have diabetes who are healthy would I think...be the first people to actually receive the cure”. The respondents try to regain control of the emotional self by being proactive.
4.10.4.3 Regaining control of the social *self*

They confide more readily in their friends: “*I'm very open about it with my friends, cause I feel that they should know and it makes it easier for them so they don't start panicking when things go wrong ...*”. They adjust to life: “*I just got on with my life and did what normal people did*”.

4.10.4.4 Regaining control of the related *self*

The respondents realise that their parents predominantly check on them not to irritate but to reassure themselves that the respondents are fine: “*mum checks just make sure it's fine*”. They also find that often siblings: “*care when something goes wrong*” rather than resenting them.

In summary as mentioned in the opening paragraphs of the analysis and findings section, when the respondents were first diagnosed with T1DM they tried to protect the *self* and balance all their needs. They are confronted with competing realities which are captured in Figure 5, below.
Figure 5: Competing realities for young people with T1DM

Then, for numerous reasons, people with T1DM appear to lose focus, and finally, they try to regain focus. This is a cyclic process described in (The equilibrium dilemma) and it occurs over and over throughout the course of their lives. There is no fixed duration of these steps and while some may lose focus for longer periods of time than others, the respondents strive to maintain control of their physical, emotional social and related selves.

The purpose of the study was to discover what effect T1DM had on the self and to try to understand what it was like to be an adolescent with T1DM. This led to the development of a substantive theory described as the equilibrium dilemma. A grounded theory which was testable and verifying was developed. This substantive theory helped to explain the role of self in the management of T1DM in adolescents.

The model, which was developed, was a defensible one. However it raised a number of questions crucial to the study.

These questions were:

- Firstly, to what degree were the illness representations linked to this age group?
• Secondly, to what degree did the model required moderation, because of the
developmental process of adolescence in general? (eg. independence, peer
group, age group, depression etc )
• Finally, to what degree was “hope of a cure” voiced by the individual
adolescent in their interviews?
These issues were explored in the Study Two which is described in Chapter 5.
Chapter 5

The Findings from the Longitudinal, Illness Trajectory and Cohort groups in Study Two and Illness self representations

5.1 Introduction:

In the previous chapter a grounded theory was developed. This chapter engages in theory testing and modification of this developed model. This chapter reports on revisiting the original group of respondents to check and explore further how the grounded theory stands up over time - the Longitudinal study (LS). It also engages in theory testing with a smaller group of respondents whose illness has not followed a similar path as other respondents—the Illness trajectory study (IT). It also explores cohort testing - the cohort study (CG). These findings will be recorded together with the IT group since these findings, contrary to expectation, were more similar to the IT group than those in LS group since many of the respondents had already experienced some complications as a result of having diabetes and this factor was more likely to have an impact on the selves of those with diabetes. This Chapter also describes the research questions and aims, demonstrates the design and implementation, data collection, methodology and sampling procedures. In addition, participant recruitment, sample characteristics and ethical issues are outlined. Finally, the Chapter illustrates the manner in which grounded theory methodology and procedures were applied to both investigate the impact that T1DM has on the self of adolescents and young adults over time-Longitudinal study group (LS), the Illness Trajectory Group (IT) and the Cohort Group (CG). This Chapter will also describe the illness self representations held by the respondents.
5.2 Study Two

In November 1997, my candidature was transferred to the Doctor of Philosophy. In February, 1998 ethical approval was sought for this study.

5.2.1 Ethical Approval

Ethical approval was again sought and approval gained (HERC 1998/14), once an information sheets (Appendices 5 and 6) were provided to informants explaining Study Two and including contact details of a qualified counsellor should participants become distressed when revisiting the impact on them of T1DM. Once again in order to maintain anonymity, responding names were changed to corresponding numbers from study one for the Longitudinal Study group (LS) and the Illness Trajectory (IT) and first initials and grouping initials for Cohort Group (CG). Where people’s names or places are mentioned in reported transcripts, these have been omitted, disguised or substituted with an X. The findings were not discussed outside the student-supervisor relationship.

This allowed for the questions raised by the previous study to be addressed by using a three-pronged approach. The structure of the study is revisited in Table 1.
### Table 1: Structure of the Study

<table>
<thead>
<tr>
<th>Study One</th>
<th>Study Two</th>
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| Longitudinal testing | Longitudinal group  
Seven of the original nine (now young adults) respondents were re-interviewed |
| Theoretical sampling | Illness trajectory group  
Three young adults who had experienced complications as a result of T1DM and therefore not followed the same illness trajectory as the other respondents were interviewed |
| Cohort testing | Cohort group  
Eight new 16 – 20 year olds interviewed to test the developed model |

| Nine 16 – 20 year olds with T1DM were interviewed and the model developed |
| Longitudinal group  
Seven of the original nine (now young adults) respondents were re-interviewed |
| Illness trajectory group  
Three young adults who had experienced complications as a result of T1DM and therefore not followed the same illness trajectory as the other respondents were interviewed |
| Cohort testing | Cohort group  
Eight new 16 – 20 year olds interviewed to test the developed model |

#### 5.2.2 The research questions and the research process

1. Seven of the original nine respondents were re-interviewed. Four years had passed and these adolescents were now young adults. After a further in-depth interview had been completed, the developed model and its validity were tested by giving the respondents a review of the study to date and asking them for their feedback. The purpose of the interviews was to revisit what these respondents had previously discussed. They were asked:

- How have things changed for you?
- What do you think has brought about these changes?
- What would you like to do in the future? (See Appendix 9).
2. The researcher then interviewed another cohort (n=8) of 16-20 year olds to test the potential of the developed model over time. As mentioned previously such cross-sequential extension of the study is in line with best practice in longitudinal research (Polit & Hungler, 1999).

3. Data was gathered from others (n=3) with a different illness trajectory as a further way of theory testing. This different illness trajectory meant that these respondents had experienced complications as a result of having T1DM, which had caused greater life disruptions for them than for those already interviewed. This was done to test their illness self-representations and to expand on counter model arguments by comparing people with the same illness, but under different circumstances.

5.2.3 Participant recruitment

Seven of the original respondents agreed to be re-interviewed. The illness trajectory groups (IT) were gained through snowballing. Respondents for the cohort group (CG) were gained from the relevant database at Diabetes Australia. The Board met, (written permission was given by the Board), and they agreed to distribute flyers seeking respondents for the study (Appendix 8). Those that were sent flyers returned their response slips to the researcher if they were interested in being part of the study. They were then contacted by phone. The purpose of the study was further explained and interviews were arranged at times to suit the respondents.

The researcher completed six additional interviews to see how they might be able to inform the study about T1DM in adolescence and young adulthood. These additional interviews included an interview conducted by mail with a man, (now deceased), in his mid sixties at the time of the interview. He was living in Holland and had multiple
complications from T1DM, which he had contracted when he was four years of age. Two internet interviews were completed with interviewees from the United States of America who responded to an e-mail to the Insulin-Pumpers Support Group. One was a forty year old female doctor who was diagnosed at age eleven and a twenty four year old man diagnosed with T1DM at nineteen years of age. This was done to try to understand if there were different treatment modalities in these other countries and whether they had an impact on the self. The effect of duration of the disease process was also explored.

An additional informant was a 24-year-old Australian female unconnected to any diabetes support group with T1DM, who did not fall into any of the above groups i.e. the longitudinal study, the illness trajectory group or the cohort group. Further interviews were conducted with the parents of two developmentally disabled boys with T1DM. In total thirty three interviews were completed. The findings from the additional interviews were not included in this study however, and only twenty seven interviews were cited verbatim as they were most relevant because of their lucid conceptualizations of the experience of managing T1DM in adolescence and young adulthood.

In summary, informants in the longitudinal study were interviewed twice, once in the Study One and then in the longitudinal study in Study Two. The illness trajectory and cohort respondents were interviewed only once and formed part of Study Two.

This second investigation included a longitudinal study, which focuses on the concept of temporality. By way of review, humans are always acting in the present (Charon,
2001), however, “our present is sliding along a line converting future into past and we are marooned in the present” (Kenworthy, Snowley & Gilling, 1996, p. 46). Thus we remember our past and envisage our future but act in the present; this is one of the central ideas of the symbolic interactionist framework (Charon, 2001; Kenworthy, Snowley & Gilling, 1996; Hewitt, 2000). I am obviously interested in the longitudinal study in how the past (Study One) is acted on in the present (Study Two).

Cohort testing was done by interviewing a new group of 16 - 20 year olds to test the developed model over time. Such a cross-sequential approach can potentially identify how historical factors, changes in treatment options and so on, can invalidate part or all of a time-bounded grounded theory.

Theoretical sampling was achieved by interviewing a group of respondents who had followed different illness trajectories.

The resulting data led to the refinement of the developed model and to the final form of the grounded theory of diabetic self-management. This in turn, led to the development of a substantive theory, which helps to explain how adolescents and young adults manage themselves and their T1DM.

5.3 The organization of the findings

The themes are described under the same three headings as those in the Study One

- Managing the physical, social, emotional and related selves.
- The way the person with T1DM is known to others.
• How they perceived T1DM affected their lives, their future, their career and the cure, as well as how the disease affected activities, their diet, and adolescent and adult development

As mentioned in the previous chapter these themes all appeared to interact, that is, what had an effect on the management of the physical self, also affects the emotional self, the social self or the related selves. The data strongly reveals a flow - on effect to the sub-themes - disclosing, diet, life effect, activity effect and adolescent or adult development. It was clear that any of these aspects could interfere with all - round management of the disease.

The similarities and differences in the findings of the longitudinal, the illness trajectory and the cohort group will now be outlined. The findings from the (LS) are described first. This is followed by those from the (IT) and the (CG).

5.4 The longitudinal study group – the physical self, past, present and future.

The longitudinal study group consisted of seven out of the nine respondents interviewed in the Study One. The first theme explored will be the physical self, past, present, future.

5.4.1. Change over time for physical self

In the past, Study One respondents were struggling to maintain control of the physical self but there had been further changes over the four years in the way the respondents were managing their physical self which impacted on the present.
In the present, respondents were still trying to control the physical self by monitoring blood sugars and giving their insulin as they had done previously. The changes that had occurred in diabetes management for the respondents in the longitudinal group compared to Study One were:-

- There had been changes in the insulin regimes and blood glucose monitoring.
- Respondents were more likely to have prioritized work and study highly (which often meant a problem with diabetic control).
- Respondents indicated that they were not experiencing as many hypoglycaemic episodes as before, and were often more likely to rely on how they “felt” to administer insulin rather than first performing blood sugars.
- They were more likely to experience high blood sugars rather than low blood sugars and some were experiencing changes in the way hypoglycaemic episodes were experienced, with fewer early warning signs.
- There was also a change in their view on a diabetes cure which they still felt might occur but they questioned how soon this may occur and whether they would be the recipients of the cure.

In the present the respondents, as in Study One, continued with some monitoring their blood glucose levels.

5.4.1.1 Monitoring blood sugar levels and charting

Monitoring of blood sugars and charting were, in the main, often omitted or done infrequently, and this related to increasing familiarity with tell-tale symptoms. Good examples of this issue were expressed by two respondents. Respondent 6 stated that being able to identify florid episodes of ‘hypos’ (low blood glucose levels) or ‘hypers’ (high blood glucose levels) experientially made testing and charting
“pointless”, however they continued to have their injections, and tested a little more regularly prior to visiting the doctor. Similarly, Respondent 7 relied on “spot checks”, roughly one per week, and over the year blood sugars had been satisfactory.

However, one respondent, who had become a registered nurse, was triggered to become more vigilant with increasing exposure to patients with DM:

I'm watching things more carefully … so that makes it easier … back then I think I was only monitoring, if you were lucky, twice a day, whereas now it's at least 3 or 4 times a day… I tend to know even if I don't monitor it, I can usually guess what it would be, knowing what I've eaten and things like that so… I look at people [with T1DM who have suffered from complications and say [I] want to keep my legs and [I] don’t want ulcers, and [I want ]…to be able to have kids and have healthy kids [and]…that means keeping well controlled… preventing those complications as much as possible (Respondent 9).

Most of the respondents indicated that they relied on physical sensations as a guide to blood sugar levels, and in any case, were more likely to have high blood sugar levels. They administered their insulin according to these sensations rather than depending on glucometer readings. Some respondents, however, reported either not getting the usual early warning signs of impending hypoglycaemic attacks, or of having to recognise their late onset in a hurry:

I won't even feel it and I found that was very difficult, I got to a stage, this is probably within the last two years ...before ...I couldn't even recognize it, my hands didn't shake anymore, I didn’t feel the hot/cold sort of sensation... the only time I'd start to recognize it was when my legs would start to go, I'd start to get really weak in the knees, and ...it was just all of a sudden ... someone would notice... because I was slurring my speech and ... the symptoms weren’t as recognizable as they used to be ... I used to get really early signs, like I would start to shake a [with a BSL of ] five, you know but now I don't really get any signs until I'm about three (Respondent 2)
5.4.1.2 Monitoring of injection giving: Changes in insulin regimes

Quite a few of the respondents had had their insulin regimes changed. Some appeared to be satisfied with the change but others were struggling to manage. Even those that were satisfied indicated that a bit of juggling was needed to maintain blood sugar levels at optimum levels. Others sometimes do not take their insulin, as Respondent 1 said: “I don't do a needle for lunch and I don't have lunch ... I'm still not looking after myself as well as I should... and then I skip one needle, I skip one test, I start skipping a few more tests”.

Some respondents did not know how to resolve the problem of trying to fit their diabetes management regime into a new career:

I'm not too sure [how to resolve the problem], cause I don't know many people that work in ... the hospitality industry with [T1DM] ... I sort of played round a bit, reducing my insulin and maybe ... having my lunch a lot earlier than at lunchtime but ... what I find when I do that is I get high after lunch ... it just doesn't seem to balance out and if I don't eat before lunch time I go low ... it's just too hard and even if I have reduced my insulin because I'm up and working as well, my blood sugar levels go low too so it's just really hard to find my balance and stuff at the moment...(Respondent 3)

Respondent 6 was really struggling because she had moved to a country area and felt that they lacked expertise in the area of T1DM, and that she could do better herself:

... and being a small country town the GP wouldn't refer me over to a specialist because he felt that he could handle it ... then... he didn't come and visit me for two of the days while I was in hospital so I'm thinking, what am I doing here ... I know more than the nurses ... I've got a diabetic sort of specialist, not an endocrinologist ... up there which is as good as it gets ... I've been going to Newcastle which is 2 two hours down the road ...so now I'm under Dr. X ... they've chopped and changed my insulin ... so much in the last couple of months because they all reckon they know what's best [I] don't like being ...on Mixtard ... I don't like that at all...you just can't control it ...and if you want to do some exercise [I can adjust separate doses]... if I need to where it's really next to impossible to adjust a mixture... I never really had a problem
It appears that some insulin changes were more satisfactory than others and control remained a continual and demanding balancing act.

5.4.1.3 Monitoring the effects of hypoglycaemia and taking action.

Respondents had to be constantly vigilant about becoming hypoglycaemic.

Respondent 9 avoided a hypoglycaemic episode by having chocolate when she got home: “I work an evening and it’s... really busy... when I get home, [I will have some] chocolate”. Respondent 6 had a hypoglycaemic episode at work. She related what happened in this way:

I was actually sitting at my desk and I thought I've got to get that poppa [soft drink] out of the fridge and I slowly walked out, by the time I'd sat down, I had the poppa open... I couldn't respond to anyone outside, all I could respond to was me going okay now just suck the damn thing (laugh)... I just had to get something in me, I knew I had to and I couldn't focus on anything that was happening around me. (Respondent 6).

A hypoglycaemic episode takes away the ability to work well and concentrate on necessary tasks; this causes respondents to feel frustrated. It exerts a more immediate demand for monitoring and action than does a high blood sugar level. What is even more evident is that respondents appeared relatively indifferent to hyperglycaemic episodes, whereas, to clinicians, hyperglycaemia is just as urgently in need of control and may be damaging in the middle to long term. Respondents appeared to make this choice on the basis of their personal and work priorities.
5.4.1.4 Monitoring the effects of other illnesses and their impact on T1DM

Experiencing another illness as well as having T1DM often interferes with metabolic control of T1DM. Most of the respondents had not had other illnesses but one remarked that she had developed a chronic bowel complaint and any acute episode of this had interfered with T1DM management.

…they thought I had coeliac disease… [but it was some] sort of a bacterial/virus… I just couldn't shake which was probably due to the T1DM, …that was a major problem at the time but that's all fixed up now…[it] made me feel rather ill and in a lot of pain cause they did biopsies as well and…[I was] a day patient, … under sedation when they did it…[I was on] a lot of antibiotics it affected my eating, so…my blood sugars would drop and sometimes before I was on the antibiotics … must have been a little infection because I was going through a high [hyperglycaemic] stage (Respondent 2)

There had been a change in the way the respondents viewed the future—while not despairing they were less optimistic about a cure.

One respondent remained optimistic about a future cure:

I still think …it's gonna happen … I think it'll be, maximum five years … maybe to prevent it or maybe even cure outright… I'm pretty optimistic that in ten years, they'll have an outright cure for it cause they're just making such advances”… they can identify which genes and things are affected …so I'm pretty sure they'll have a cure …there's a lot of money being spent on it (Respondent 3).

For most respondents, the expectation of an imminent cure had faded. They were less hopeful in their lifetime and thought it would be beyond their financial means.

“I don't see anything… a cure it'd probably be costly too… I would think not in my lifetime I don't necessarily feel that there will be a cure, well within…the next 20 years.”

Respondent 9 remarked,
I'm not hanging out for it...they may never find one like that's going to help me... they're talking about preventative things ... that's not going to help me so [I have to] deal with what I've got now.

Respondent 5 remarked

If the cure comes that's fantastic but how many ... millions of diabetics are there in the world ... at the end of the day is there enough for me? ... is it too expensive?

Respondents expressed the need to change their priorities. Most were struggling with trying to manage increasing responsibilities - work, and or work plus university or study commitments - and were trying to find a reasonable compromise that would let them function adequately. Respondent 3 worked in a restaurant and was finding it very hard to control blood sugar levels because it meant preparing and serving food at the same time that it was necessary to eat. The issue was described in the following way:

[If I work an] 8 hour shifts and 10 hour shifts and that means it's gonna cover at least 2 of my meals a day and I just found it hard ... to keep my blood sugar readings down and ... my insulin levels and stuff and it's been quite hard and I still haven't managed to work it out and I've been ... full time for nearly a month now ... also I'm not playing as much sport now either.

There was often a need to focus on the immediate priority and this might cause a respondent to focus less on the physiological control of their T1DM and more on perceived important issues.

For one respondent it was a need to concentrate on both work and university which caused a struggle with physiological management of the T1DM.

I think ... uni was the worst one cause ... sometimes during the day... sometimes at night ... I was all over the place ... I was working two jobs plus going to uni at one stage [so when I was home that was the only time that ]... I was basically doing my diabetes stuff (Respondent 7)

As well, other respondents suggested that unpredictable work hours, meal and tea breaks, missed meals, delayed injections (with often predictable hypoglycaemia
episodes), all interfered with their diabetes management. Many spoke of this as a need to focus on the present, best summed up in the words of respondent 1:

I don't really look into the future and I don't look at what's happened too many times… I live for now … but for the future … I hope to get my name …[as] almost a household name [in] the industry … I hope to … live a long time and… know people are enjoying my work and…know about me.

There was also a change of view about their career. Whilst a few said that having T1DM had not impinged on their choice of a career most had to work around it in their career. This was well described by Respondent 9 who had become a registered nurse. She was working in an intensive care unit and felt that this unit was better than working in the wards for regularity of meal times.

It's such a small area, if I feel I need something to eat, I just go and help myself whereas on the ward your bags are locked away. [Here] we don't have lockers, everything's just under the desk and there's a fridge right there so if I feel I need something it's right there, I don't have …to juggle 12 patients and get away and get something to eat at the same time (Respondent 9)

Whilst this situation was a more manageable one for her, she still had to find the time to eat.

However, Respondent 1 found it almost impossible to work around his T1DM and just went without food:

I don't have the time for lunch … and sometimes I just forget to eat, it's not as though I'm sitting here thinking I'm really hungry but I can't afford the time …I'll just forget to eat, I'll look at my watch, it'll be like 5 o'clock and I think it's too late to have anything now, just wait for dinner …I just simply forget to eat, a lot of people don't understand … I just forget.

Another respondent indicated how difficult he found it to work in a restaurant. He found that the times when he needed to be available to the customers cut across his own meal times and this then caused him to struggle with carrying trays of food when he was hypoglycaemic, because his hands became very shaky.
(Respondent 2) felt that because she mentioned that she had T1DM it was harder for prospective employers to see her as suitable:

*I'm very, very positive of that because I found [if it] was [on the] applications, I wouldn't even get to the interview ... if I said [I had T1DM whilst] I was having the interview and it was going really well ... generally a question in a job interview, is there anything you'd like to add [and I said] well I'm a diabetic but I'm very well controlled and there is certainly no problem with it at all, I would find that the interview would drop off then.*

In summary there had been changes in the physical *self* over time. This had occurred because of changes in blood glucose monitoring, insulin regimes, work and career commitments and a less optimistic view about a cure. The next section examines how the emotional *self* is holding up over time.

5.5 The emotional *self*

In Study One respondents described how they felt about having T1DM. Over time respondents now speak of T1DM being more deeply incorporated into their being, by making statements like this: “*I mean I don't even think of it ... it's just a part of me... not even, a problem*”.

5.5.1 Change over time for the emotional *self*

In the past, Respondents in the Study One had indicated how shocked they were about the initial diagnosis, but indicated that they had “come to terms with it”. However, when they were re-interviewed, they were still living with T1DM in what I have called, an “uneasy truce”, but they were undeniably moving forward with their lives as shown in the statements below.

In the present, how respondents felt about having T1DM is described well by Respondent 2 who stated it was not difficult having T1DM and yet there was still a
struggle to control it. There was a sense of discounting in her narrative, of self-
comforting through minimising the difficulties encountered in managing her
condition: “I feel that … I'm pretty much on top of things … if things get all out of
control it's usually my fault because I've slacked off or … eaten something that I
shouldn't have” and “the only problem was getting to a bathroom. However, while
discounting the pain and pins and needles in her legs as … nothing, … I mean I don't
even think of it [ the T1DM] … it's just a part of me … not a problem you know, and at
the same time she mused that:

... the only problem you ever have is getting sore finger tips really and bruises
all over your stomach and legs, [laugh] that's it... So no one sees, you know,
the tops of your legs or your stomach so it's not noticeable; and again: I don't
find T1DM that difficult at all... it's just like you know getting up and brushing
your teeth in the morning. She goes on to say: I'm not that good at
controlling myself. I've got this thing, I think it's more of a psychological
thing really. I mean I should probably have some counselling about it or
something but I think it's more of a fact that because I'm not allowed to have
it, I have it (Respondent 2)

This cognitive dissonance, that is the internal conflict that occurs when people feel
that their behaviour is inconsistent with their intentions or values” (Anspaugh,
Hamrick & Rosato, 2000, p. 15), is often reflected in the interviews. Many
respondents say that they have come to terms with their T1DM yet their narratives
seem to indicate more of an “uneasy truce”.

One respondent described how holding down a full time job was stressful and how
this could have an impact on a person with T1DM.

I can't handle stress because it just sends my sugars sky high, [I am] more
blessed that I have a, a full time job rather than nothing? … ideally I would
really prefer three-day a week job [so] that I could physically and
emotionally [get]… on top of it … when I'm high I can't work... when I'm low I
can't work … the [diabetes] educator said that 65 or 70% of my readings are
above 16, cause I just can't control what I'm doing, I mean I'm trying my
hardest but it's just not happening for me … I'm hopeless at work… I can do
the basic things but when I have to really sit down and think about things…
you're really got to keep pushing yourself … [I] can't do it… [I get] immense
headaches … my eyes have been really affected it's all contributing factors …I'm on a computer all the time, it's just so hard to …just to focus at the screen (Respondent 6).

Many of the respondents said that they lived in the present and really did not think much about the future. Their hopes for the future hinged around careers and having children both within a context, for most, of reduced hopes of a cure.

I live for the present, as to the future I don't really spend a great deal of time thinking about the future, I sort of live for now … the few things that I do think about for the future is my career and where I'm going to be, I don't really see myself …exactly where I'm going to be, but I just see myself being more than where I am now … I do hope for a cure … sure, everyone does … [I would like to] maybe in the future move on and do an MBA, but I'd like to still work while I'm at uni, I'd like to sort of have a bit of money … lying around to use (Respondent 8)

Further to this: “… well I reckon that I will be successful in what I want to do … I am hoping that say, in a year when everything settles, maybe two years, you know I'll look after myself a fair bit better (Respondent 5) and… “I'd like to be able to have kids … have healthy kids” (Respondent 9)

In summary there had been changes in the emotional self over time. This had occurred because people had become more focused on their careers and relationships and less optimistic about a cure. The next section examines how the social self is holding up over time.

5.6 The Social Self

The social self reflects how T1DM has impacted social relationships with others. Once again there was a thread of the past and the present and the future running through the social self.
5.6.1 Changes over time for the social self

In the past most respondents tried to accommodate T1DM within their social context and had few if any problems socializing. One fairly reserved respondent indicated that he was now more outgoing:

When I am out and about… once I get to know them then… I'll start to be really outrageous and really out there at the parties… but no I have changed …I do socialize a lot more (Respondent 1)

In the present changes had taken place in risk-taking behaviours for some of the respondents. This arose as they became aware of the impact risk taking behaviour had on them physiologically. It also arose when, because of work commitments, they just did not have the time to spend on social activities, which had been destabilizing:

I've suppose I've had to change a lot… I am more vigilant… whereas previously I'd eat whenever I felt like it (laugh) basically… so it's like work and stuff keeps you busy so you know, sort of focused… things like drinking alcohol… it was very social… we used to go out… two and three times a week, whereas now I just don't have the time and you know, just a lot more aware of what I'm doing (Respondent 9).

Moving out of home also impacts on how people were able to manage their T1DM in the present for the social self. These changes often moved the person from joint management towards independence. This is not always an easy transition. One respondent described very well.

[I] moved up to T… my whole diet and plan completely changed because mum wasn't cooking any more, so now I have to… try and take control… you just don't come home, sit in front of the TV, say dinner's on the table and come and eat, you've… got to do it all you know… my diabetes got into a state of total uncontrol, and I ended up in hospital for 5 five days couple of months ago… I was stressed, … I had no friends up there, moving to a different place… I think it was harder for a diabetic to move out of home than anyone else (Respondent 6).
Conversely another respondent was really happy living on her own and said “I've moved out of home… living on my own … I'm not waiting for other people to eat dinner… I … suit my lifestyle” (Respondent 9).

Moving the social self towards independence was a feature of this group of respondents. Respondent 7 said “I went on the Fairstar … it's not often you get something like that and it was with school friends too so it was good…Mum was pretty worried about it … as you would be I suppose… the things we did didn't really affect what I had to do for my T1DM”. This same respondent was ready to move even farther a field on his own.

Once again most of the respondents were optimistic about the future - securing a good career or, if they were already pursuing a career, being successful, and considering having children sometime in the future. One indicated that was one of the reasons that she was trying to control her blood sugars adequately… I'd like to be able to have kids … have healthy kids (Respondent 9)

By way of summary changes had occurred for the social self over time. This had been brought about by a reduction, for some, in risk taking behaviours, changes in domicile, the move from joint management of DM towards independence and shift in focus towards relationships and careers. The next section examines how the related self is holding up over time.

5.7 The related self – past, present and future:

The related self is characterized as the relationship between a respondent, their parent/s and siblings. Respondents had now moved on, and just as the possibility of
conflict had existed with parents and siblings, it could now occur with a partner as well.

5.7.1 Change over time for the related self

For one respondent, who had married, the past included a need to prioritise and organise her wedding. This had caused her to place the appropriate management of her T1DM on hold, while another respondent suggested that the strictness of his parents had caused him to rebel and he had developed a pattern of buying and consuming food that was not good for him.

It was presently, still difficult for those who lived at home as their parent, partners or siblings interfered in their T1DM management. One respondent believed his autonomous management of his condition to be constantly challenged by his partner as well as by his mother.

Ten years ago … when I first got diabetes [my mother would say] you wake up at this time every time and you do this every time and that sort of thing, …unfortunately [my partner] has also cottoned on to her story of diabetes … we’re probably both wrong and there’s something else in the middle … mum says that I should have breakfast every single morning… I don’t like having breakfast at all … well I should do a needle but a very small needle, something to counteract the coffee and slice of toast, and not the three portions that I used to be forced to have … then if I want to have a big breakfast which I probably do once every two weeks… then I can do more insulin … instead of being forced to do something I don’t want to do … she’s still living [in the past of 10 or 13 years ago, where I had to have lunch at this time and she’ll still hassle me, saying did you have lunch? … she’s saying you’re stupid, you’re killing yourself … she doesn’t listen … … my partner is always asking me if am I okay… have I had something to eat, all that sort of stuff, … it gets to me. (Respondent 1).

Another respondent did not mind if his parents nagged him, because he felt that they knew what they were talking about and were doing it for his own good, but he did not like interference from his fiancé’s family:
my fiancé, her family they don't really know much about it … they're more on the joking side of it, you're a diabetic, sorry, you can't have it … her mother says … you'd better not have that, you know you're a diabetic… I know what I'm doing and then she'll argue, she'll say no you don't, … she'll sort of pull me up from what people have told her (Respondent 7).

Respondent 2 found that siblings could also be difficult:

_I have a lot of problems with my brothers … with diet drinks … I drink a lot of Pepsi Max (diet cola) and there'll be normal drinks in the fridge, and they will always drink mine, see they've got the choice, they can have either one, I can only have one, and this is a continuing [problem for me] … he tries to hurt my feelings by throwing my disease up in my face._

Overall respondents were cautiously optimistic, although some were fatalistic about themselves, the related others and the future.

One respondent who was getting married in a year’s time saw the future in this way:

_“I reckon that I will be successful in what I want to do … I don't think diabetes will have too many negative implications for] me, cause I am hoping that say in a year when everything settles, maybe two years … I'll look after myself a fair bit better”._

Another respondent appeared rather fatalistic and complained about the pressure brought to bear on him by his mum and partner. When talking figuratively about using the protective umbrella of disciplined self-management (See Section 4.10.2) said : “_looking to the future my suit's [meaning his body is] probably going to be ruined and kind of have to be thrown away earlier than what it should be, but [I am] living for now, I don't really mind, and I'm sure when my suit [meaning his body] has to be thrown out I'm going to think, I was stupid I should have used that umbrella._

In summary changes had taken place in the related _self_ over time as a result of marriage, interference in DM management by partners, parents and siblings and the degree of optimism and fatalism the respondents experienced. The next section
examines how focus on the goal of optimum diabetes management, balanced lifestyle and an maintaining an integrated self, is lost.

5.8 Losing focus.

This second step in the cyclic process (See the Equilibrium Dilemma Figure 1, Chapter 4), often entails getting off-track in terms of physiological management. This can have a flow on effect to all of the selves. Conversely, what effects the emotional, social and related selves can effect DM management.

5.8.1 Losing focus and its impact on the physical self

Respondents described losing focus by not monitoring their blood sugars levels or giving all their needles. Respondent 1 described it in this way:

I skip one needle, I skip one test, I start skipping a few more tests and hey it didn't hurt to skip all those tests, let's just forget about the whole thing. And it's not a conscious thing ... I've been good enough, it's time to be naughty [and] I slip back down again and [then] I think I've hit rock bottom, let's get back up there and it goes straight up and now it slides down again, goes straight up and then it slides down again and sometimes it gets up half the way and slides down really fast and sometimes it's, it goes all the way up and [I say] this is the last time I ever do anything wrong.

Working and playing sport also interfered with physical management of T1DM:

I've had a few occasions where I've had to go straight from soccer to work and that makes it hard for me to have dinner and stuff cause if I work at night I usually have dinner before I go to work ... but other times I don't have time and I won't be eating till a lot later in the night so then it stuffs up the rest of the night (Respondent 3).
5.8.2 Losing focus and its impact on the emotional self

Respondents found that stress affected their blood sugar levels and that in many instances they could not do much about the situation. This led to them avoiding doing blood sugars and avoiding seeing doctors.

Respondent 6 indicated the effect that stress had on her blood sugars in the following way:

*I don't cope with stress at all, and my diabetes doesn't cope with stress [it] snowballs, … I can't handle stress because it just sends my sugars sky high, …ideally I would really prefer three day a week job that I could physically and emotionally... keep on top of it but it's not gonna happen so you know you sort of keep on going.*

Analysis revealed other demotivating triggers, this same respondent indicated that she did not want to be reminded that her blood sugars were high.

*I mean sometimes I don't bother to do them [ blood sugars] when I'm having a high reading … I know that I'm high... I don't want to be reminded that I'm high ...[I] don't want to be reminded that I'm high ... I couldn't do a thing about it and I wasn't prepared to, I had so many other things that I needed to concentrate on.*

… and:

*I hated going to see my specialist down in [the city] ... couldn't stand him because he always just said you're not doing good enough, I said how would you know ... it was really frustrating...I mean he's apparently really good and excellent ... all he wanted to see was for me to do better but I couldn't do better because that's me ...I'm sure that he did try to encourage me in his way but it wasn't communicated to me ... I just wanted to live a good life, normal life  [and just recently I had ]... a specialist appointment ... I completely forgot, had too many things on and I still haven't called him to make another one ... I mean I know what he's going to say that he's only there for ... moral support ... [but I find it frustrating because] I'm...[ trying to control my blood sugars]*

Another respondent had not seen her endocrinologist for an extended period nor had she had her regular eye tests.
Well I'm seeing [Dr J]... I haven't seen her probably for a year and a half... I dearly love [Dr J] but she's in the most awkward place ... it's just not feasible for me to be going there anymore, it's too much time, I don't have it, I'm very busy with my study now so... I haven't had an eye test probably in 2 two years ...I was having ...a little bit of trouble focusing ...so I have to go and have all that ... done while I'm on holidays ...I have a lot of trouble with sores, healing, I knocked my hand ...a couple of weeks ago and it was rather red and awful and green looking and it was only just a scrape... I'm yet to go the doctor about this...I have these, I get these aches in my legs that are rather horrible... now I just don't want to go anymore go ... because basically there hasn't been a need to [to see the doctor] and also she's a little strict and I don't keep a catalogue because it's just too much time consuming and to sit down and write down and write down insulin dosages ...I just don't have the time to do all THAT... so I'm pretty laid back about it all (Respondent 2).

Another respondent spoke about the same issue of avoiding seeing his endocrinologist:

I don't see the doctor a great deal for two reasons, I don't do a lot of readings ...just find it a hassle to do readings I probably should do a lot more ... the reason for going to see the doctor is for the doctor to look at the readings and I don't have readings and there's no point spending $60, $70 on him to say ... do more readings cause I know I should ... [the other is I am] busy ...I had to cancel an appointment two weeks ago because I was going to B... but sometimes when I cancel it's because there's just no point in going (Respondent 1).

Another respondent speaking about exercise said: “I don't swim anymore ... I have time to do it but [I], don't have the motivation to do it” (Respondent 3).

5.8.3 Losing focus and its impact on the social **self**

Sometimes the social group might not help the person to control their blood sugars because of the expectations of the group. As in the case of respondent 5 “**every so often I would, [like to go snow boarding with my friends] ... they go down have heaps of drinking and ...snowboarding the whole day, and I think to myself well I want to go but should I?” On the other hand sometimes the social group frustrated the respondent because they would try to tell the respondent what to do even if they had T1DM themselves:
Some people don't understand the fact that I need to have sugar sometimes, they understand you're not allowed to have sugar, and you're not allowed fat when I have something sweet they don't understand there's all these really old ladies who have got type 2 diabetes in the church, and they always say have you had dinner yet I don't eat dinner till 7.30, oh well I eat my dinner at 5, well that's you, that's not me (laugh) [they are] only looking out for my best interests but yeah (Respondent 6)

5.8.4 Losing focus and its impact on the related self

Parents and partners become fearful when respondents were having problems with diabetes management or are not monitoring themselves as appropriately as they believe that they should. This causes frustration and conflict in the relationship:

my doctor informed me that I've got some minor problems a couple of years ago they wouldn't even be detected but they've detected them and start working on it now we can reverse the problem but mum hears minor problems and that's where her hearing stops then she goes off on this big tangent, you've already killed yourself once, you're going to keep going down the spiral and because she then goes on and on and on about the fact that I'm killing myself I do the [converse] I'll keep doing whatever I have been doing I will consciously screw myself up even more even though it's a minor, reversible problem detected now because technology has improved, she then hears the first thing and runs with that think the word is retinopathy that's minor which is reversible then there's something, I think wrong with my kidneys it was very minor and reversible, for the eyes and the kidneys I'm on a tablet Respondent 1

This respondent saw this disease progression as minor yet it would be recognized by parents, partners and health professionals as significant. Conflict is inevitable.

Losing of focus on the goal (optimum DM management) does have and effect on the multiple selves and conversely experiencing a problem with one of the other selves has an impact on DM management.
5.9 Regaining focus of the physical, emotional, social and the related selves

Chapter Four discussed how the respondents in Study One were reminded about their need to control their blood sugars, usually by their doctor or by having a severe hypoglycaemic or hyperglycaemic episode, some complication of T1DM or a poor test result. This remains true over time where Study Two (LS) respondents often try to regain focus - but this might not last for very long. Most were able to identify what generally caused them to try to regain focus.

The support of a related person can motivate the person to try to **regain focus of the physical self**: “my parents are always pulling me up when I need to be pulled up, although I don’t always listen, they’re always … nagging in a way but … it’s good, I like being nagged every so often”. Conversely, another respondent who lived on her own said she was: “…more vigilant…don’t drink as much … and a lot more careful about what I eat and things like that…whereas previously I’d eat whenever I felt like it”.

One respondent, whose blood glucose control was severely impacted by stress, described how she **regained focus of the emotional self**: “I’d say there’s times when work’s really busy [and I am] just tired and stressed…but usually then I get to a point where I go, okay, time to snap out of it …[ and try to deal with the stress].

One respondent explained how she had **regained focus of her social self**: She had drunk quite a lot whilst at university but now she had changed her behaviour quite dramatically:

…my habits have changed a lot … I am more vigilant… [ I am] lot more careful about what I eat …things like drinking alcohol…It was very social, we used to go out 2 two and three times a week…now I just don’t have the time …[I am ] just a lot more aware of what I’m doing…actually drink differently
[not as often, not as much, and no spirits]… I'm lucky if I drink once a month… there's not all the other people around, influencing me to have a drink.
(Respondent 9)

Regaining control of the related self was well illustrated by Respondent 1, who indicated that his partner tried to encourage him to look after himself and he did often attempt to do this:

B [my partner] often makes me think that I [should control my blood sugars better] and …sometimes when I get sore legs … why are they sore, it's because of diabetes, I should be looking after myself and then I'll look after myself for, it could be a few days, it could be a couple of weeks. (Respondent 1)

Sometimes a related person encourages the respondent to try to care for themselves more appropriately. Despite this, although the related person can encourage the respondent, ultimately the responsibility remains with the respondent. The respondents in the longitudinal group were in various cycles of T1DM management. Many were in a phase where they were trying to regain focus and struggling to manage their T1DM.

Finally, the LS group did display change over time. They were attempting to adopt the protective behaviors of self management. However, this required more effort as the focus of their priorities were on nurturing relationships and careers, which often meant that more immediate priorities were addressed and this might not include adequate DM management.
Table 2 The similarities and differences found in the longitudinal group

<table>
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<td>The equilibrium dilemma remained the same.</td>
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<tr>
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<td>• The protective umbrella of self management still occurred but much greater effort required.</td>
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<td>• Step 2 losing focus and getting off track</td>
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<td>• Step 3 Regaining focus</td>
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<td>• Protecting the selves by adopting the protective umbrella of disciplined self – management.</td>
<td>These changes were:</td>
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<tr>
<td>• Balancing T1DM with need of self (physical, emotional, social and related)</td>
<td>• Changes in insulin dosages and number of injections.</td>
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<tr>
<td>Physical, social emotional and related selves interact with adolescent development, diet life effect, activity effect and disclosing However diabetes management becomes more difficult when and this is represented by ominous rain cloud, which may blow up at any time for any or all of the ‘selves’ This can either have a flow on effect with regards to adolescent development, diet, life effect, activity effect or disclosing or the converse may be true.</td>
<td>• Changes from joint management to individual management of T1DM this had an effect on diet, activity effect and life effect. Less likely to keep doctors appointments and perform blood glucose levels.</td>
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<td>The competing realities for young diabetics through time</td>
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<td>• Changes in hypoglycaemic episodes but most were more likely to be hyperglycaemic than hypoglycaemic.</td>
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<td>• Being in physical control, even with higher blood sugars, but at the same time wanting to maintain optimum health for the imminent cure.</td>
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<td></td>
<td>• One person had experienced minor complications as a result of having T1DM.</td>
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<td>The next part of this study includes the findings from and Cohort group (CG) and the illness trajectory group (IT).</td>
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The Cohort Group consisted of eight, 16 – 20 year olds who were interviewed to test the potential of the developed model over time. Some of the findings were similar, yet others were markedly different to Study One.

The similarities were:-

- The frustrations of having to eat when you were not hungry.
- Not doing as many blood sugar levels as they should, with the possible exception of one respondent who was doing between 6-8 blood sugars per day and was seeing a psychologist because of her extreme anxiety about becoming hypoglycaemic.
- They were working really hard to maintain blood sugar levels and experiencing frustration when sometimes in spite of what they did their blood sugars were either elevated or too low.
- The loss of focus of the various selves and then regaining focus of the selves.
- All the groups relied on ‘body listening’. By this is meant being aware of how they felt both when they were hypoglycaemic (or hyperglycaemic). Most suggested that they were able tell relatively well what their blood sugar levels were, although there were times when they were unable to decide. Many administered insulin on the basis of this ‘listening’ rather than on testing blood sugar level. One revealed relying solely on this stored sense memory after a brief period of using a glucometer.

The differences were:-

- Three out of the eight respondents had been diagnosed when they were very young and could not really remember their response to their diagnosis.
• As well as this, four out of the eight had experienced complications as a result of having T1DM. The complications experienced by this group included, early retinopathy, neuropathy, hypoglycaemic unawareness, insulin resistance and hypertension.

• Five out of the eight had experienced other illnesses some of which also impacted on their T1DM. These included aortic cellulitis, a tumour, coeliac disease, cysts on the back and the neck, spinal surgery for scoliosis, eating disorders, and polycystic ovaries.

• The respondent with polycystic ovaries (with resulting very high levels of testosterone) needed large doses of insulin “…I was on 94 units of insulin a day and they’ve taken it down to about, just under 60 by putting me on the tablet… testosterone was eating up the rest [of the insulin] and by putting me on the Diaformin (an oral hypoglycaemic drug), it means less insulin… it’s made my blood sugars a lot more even” (Respondent M2 CG).

• One respondent had had a near-drowning experience as a result of having a hypoglycaemic event whilst in the bath. She had lost her sensitivity to hypoglycaemic episodes. This also had other implications for her as her parents did not want her to bath or travel on a train on her own and this restricted her freedom.

• Another difference was that the Cohort Group was much less enthusiastic about the hope of a cure.

These differences were in strong contrast to the Longitudinal Group, (you will remember that these were the same respondents from Study One who were re-interviewed for Study Two), who were all able to remember how they felt about their
condition, having been diagnosed at an older age. Only one person in the Study One had experienced the complications of cataracts as a result of having T1DM. Additionally, in the initial interviews for Study One, only one respondent had another condition, which was thyroid disease.

Only two respondents in follow-up interviews of the Longitudinal Group (after four years), had experienced problems. One had some early retinopathy and nephropathy and another had had a viral gastrointestinal infection which had upset her T1DM control for a period of time.

In the main the Longitudinal Group had only experienced minor illnesses or mild complications.

The cohort interviews were carried out to test the validity of the findings in the Study One, with some exceptions, the experience of the Cohort Group was more closely aligned to those of the Illness Trajectory Group, having already experienced complications as a result of their T1DM and these findings will therefore be reported together with the IT group. Although, there are differing viewpoints concerning the terminology used, when describing how to ensure rigour in a study. This thesis relied on (Morse, Barrett, Mayan, Olson, & Spiers, 2002) who argue the need to return to the use of the terminology “reliability and validity” for qualitative research to ensure the rigour that is used in conventional science.

There were three respondents in the illness trajectory (IT) group. Some of their experiences were similar to those in Study One and those in Study Two (LS) and the Cohort group (CG). The same themes found in Study One were found in the illness trajectory group (IT). There were however; recurring themes found in the data in IT group and CG that were different to LS group.
5.10 The Illness Trajectory (IT) and Cohort Group (CG)-the physical self, past, present and future.

The findings will be discussed under the same themes. These themes are: managing the physical, the social, and the related (the effect on the family and relationships) and the emotional selves, within the time-frames of past, present and future.

5.10.1 The Physical Self

The respondents both groups were trying to control the physical self by monitoring blood sugars in some way and giving their insulin. They described a similar journey of diagnosis, trying to come to terms with having T1DM and attempting to manage the physical, emotional social and related selves. In each of the following sections, data has been summarized by the writer.

5.10.1.1 The Physical self in the past and present

Respondents initially appeared to cope very well with the diagnosis of T1DM and in the past they were even commended for the way in which they managed their T1DM. However, this was not true in reality. The initial adventure soon became an onerous task.

Respondent 1 IT: You're 13, you're kind of like a soldier and you take everything like a challenge … and then on the other hand I was also just grateful that I was feeling better, [no] constant thirst any more … lethargy had gone and I was able to do things again … they told me …I'd have to inject so they asked me to try an injection on an orange … then I started straight away injecting on myself, my mum didn't do it. The early years of high school [were] easy, [too]

Diagnosed at age seven, Respondent 2 IT felt that T1DM was more exciting than traumatic, although confused by the rules about eating. She quickly learned to give her own injections and test her urine although the novelty of this soon wore off.
Respondent 3 IT recalled:

... when I was diagnosed, [I] took it on the chin like right little trooper and was so good they had me counselling other kids and all sorts of miraculous things and thought I was just fabulous. I also had just the most incredible support anybody could want. My best friend at the time who was also 10 volunteered her own tummy for me to practice injections on which I think is just amazing ... I had a wonderful family.

When this change from adventure to onerous task took place the respondents found it very hard to tell others that they were not coping:

I didn’t feel that I could say after 3 years, because the basic assumption is, well she’s had it for 3 years, she must be coping better, I didn’t feel I was able to turn around and say, help, I am not coping anymore, I need this to go away and that made it really difficult. (Respondent 3 IT)

The respondents who were older when diagnosed, described the experience prior to diagnosis of becoming aware that they were not well, and of sensing their parents’ fears, complicated by, the shock of the diagnosis and finally, of learning to manage T1DM. Early management was initially shared between respondents and their parents, with the age of their independent self-care ranging between eight and sixteen years. However, others in this group came to grips with testing and injecting almost from the beginning.

The respondents varied in the way they were managing the physical self in the present. Some achieved satisfactory control with one or two blood sugar tests, while others were meticulous with these, without reaching a good level of control at any time “[I did] everything right and it didn’t work, I’ve never been controlled” (Respondent K CG).

5.10.1.1.1 Monitoring blood sugar levels and charting.

Attitudes of respondents regarding testing, injecting and recording reflected a range of views and practices in that some were fully compliant with these, while others chose
certain compromises to fit their inclinations and life-styles. Most of the respondents acknowledge fudging their urine and blood sugar results.

The IT respondents described what they did in the past:

I remember CHEATING … I don't even remember doing a proper urine test, [I would] just run it under water and saying look mum the colour is blue which was negative… [in] later years I think … I was pretty bad… I remember being constantly thirsty so that's an obvious indication of high blood sugar (Respondent 1 IT)

Respondent 3 (IT) said:

I always had bad control, even when I was … 10 and didn't do any of the evil things that I do now or have done in my life (laughter) …even my hours were regular, the food was healthy, there was no smoke, no drink, no nothing that would alter any kind of blood control and I was still all over the shop all the time

Respondent 2 (IT) said: “I think what I remember of primary school with diabetes … it did set me apart from the other kids.” She really did not like this and avoided doing blood sugars and insulin injections if it made her stand out from the crowd.

Respondent 3 IT indicated that in the past she really wasn't testing often at all and “I was eating so often that I would have been running permanently high… between the ages of sort of 18 and 22: “I was doing the bare minimum to stay alive, it was insulin and that was it, I ate what I wanted, I wasn't really exercising much… I ate all the time and I never tested my blood” and IT Respondent 2 indicated that she made up her blood sugars all the time: ...

“I remember one appointment [with the doctor] I had every single spot filled in… I could have left a few spare, it was just so obvious and they were all just so neat and… he said … some kids think … they have to fill in all the gaps just so it looks perfect …I actually didn't do many blood sugar tests through my teens … I never did it… I never tested

Respondent 1 (IT) also acknowledged that she did not monitor her blood sugars levels very well and also fabricated her results.
5.10.1.1.2 Monitoring the effects of hypoglycaemia and taking action

Blood sugar highs and lows were monitored by respondents in two ways: by testing and by developing a sense of what was happening in their bodies and acting upon those sensations, particularly in relation to hypoglycaemic episodes. Further, learning how to interpret varied sensation and adapt their insulin dosages were trial-and-error processes which did not always have successful outcomes. For example, a dangerously low blood sugar level in a respondent went unrecognised, possibly because it affected her ability to think critically about what was happening. However, another respondent tested her blood sugars 6-8 times a day because she was fearful of hypoglycaemia … my blood sugar levels; I do them too much…. I worry that I’m going to go low (Respondent M CG). This was an exception to the cohort response on this issue.

One respondent said that she had never collapsed or fitted having a hypoglycaemic episode and that she had previously had a very caring partner who assisted her when she became hypoglycaemic. She said:

I've never collapsed from a hypo… never had a fit … the worst moments are the night hypos, especially if you're, in a … new relationship … in the middle of an intimate moment or you wake up in the middle of the night sweating and, thrashing about and your partner thinks you're trying to kill them…you need to find somebody who's willing to accept that, I was very lucky in my last relationship I had a major hypo on our third date and he ran out the door to go and buy me sugar (Respondent 3 IT).

Respondent 2 IT said: “[I have] always been lucky … my hypos have never been bad, I've always been able to get a lot of warning … never been anywhere near to losing consciousness or, so I can always take care of them myself, I don't need assistance.”

Respondent 1 IT said that when she became hypoglycaemic it affected her moods and ultimately her marriage. She said:
You can't tell me that I'm moody ... there's a classic thing about diabetics not accepting...[their] low blood sugar and my partner used to say ... look you're having a hypo, go and eat something ... I'd say no I am not having a hypo, this is a real argument here, it's not because I'm in a hypo that we're arguing... in retrospect I may have been low at those times when we were arguing

5.10.1.1.3 Monitoring of injection giving.

Some acknowledged a real fear of injections by any route, including venipunctures and intravenous infusions which are all part of diabetes management in young people. Whilst for some respondents it was easy to begin doing their injections, and to give them consistently, for others, having to increase the number of injections to a clinically safe level was very difficult. This led to hospital admissions for blood sugar level stabilization, to cycles of instability, and to increased resistance to injections required for any reason (such as tetanus prophylaxis) carrying with it the likelihood of severe diabetes and other complications.

In the past some respondents did not always administer their insulin; one respondent went without insulin for two reasons.

in my first year [at boarding school]... I didn't like taking my shots in front of the other girls ... I used to do it ... in one of the dorm mistresses rooms, and a couple of times [I could not] be bothered ... organizing it, I just went without my shots and you feel dreadful when you do that ... I can only remember skipping shots probably in that first year of boarding school, and then I didn't do it again until I was about 20 years old ... I was skipping ... insulin shots to lose weight which a lot of young female diabetics do.

Respondent 1 IT described what she had done about injections over time, recalling:

“I got a steady boyfriend in the last year of high school and he knew about my diabetes but I never talked about it with him, he knew nothing and I certainly never did tests or injections in front of him.” On another occasion she backpacked around Europe with a friend: ... “I'd take thousands of syringes but in the end I'd reuse one syringe for about a week ... at first ... you're really keen and you're good and you use
a syringe a day, [then you] ended up … injecting with blunt needles” and at times she indicated that she was: “a bit of a compulsive over eater … “I’d get into a depression of some sort and I’d over eat, seek company in food and then I’d … inject huge amounts of insulin to compensate.”

A respondent simply stopped having her injections all together: I think I just got sick of it and I wanted to be like every other kid but I don’t think what I realized is every other kid’s got a problem as well, so... I was in hospital I think for a week and a half. while another preferred to be the only one giving her injections: other people just aren’t allowed to give me injections, I give my own.

5.10.1.1.4 Monitoring the effects of hypoglycaemia and taking action

Most respondents preferred to live with blood sugar levels slightly higher than the norm, finding this gave them a stronger sense of diabetes control, that is, they perceived their lives were more at risk of disruption and threat with hypoglycaemic episodes such as drowning as noted in data earlier. This finding was emphasized by those leading physically active lives and was common to all respondent groups.

5.10.1.1.5 Monitoring the effects of other illnesses and their impact on T1DM

It is widely understood that diabetes complicates some conditions, for example, infection, gastrointestinal tract problems, allergy, surgery and trauma, or a requirement for dental extractions, and may precipitate other illnesses such as insulin resistance and delayed wound healing. In such cases, effective treatment can become challenging and problematic. Most of the respondents had had an experience of one or other physical problem. Some reported being disbelieved, as one respondent who had been hospitalized 13 times for an unknown complaint indicated
… one of my endocrinologists … refused to believe that I was actually taking my insulin, he was utterly convinced that this was happening because I was not being a compliant diabetic … so I was in X Hospital for a week and that was the main time when they tried to stabilize me and it didn't work obviously … after this episode with the endocrinologist…I actually left his care. I was very unhappy with him and so was my mother (Respondent K CG). She was really offended by this accusation.

Having others illnesses or procedures are usually more complex as a result of having T1DM. One respondent said

_I've been in hospital … having wisdom teeth out and tonsils … that always takes a lot more when you've got T1DM cause you have to have everything okay with that. I've been, I was in hospital from the age of 10 to 16 every year, for something or other … I had to have a Glucagon injection because I'd gone unconscious and I'm allergic to Glucagon so I was in hospital for that, another time I just had really bad gastro and illness and I couldn't, I wasn't absorbing anything and I was just really sick so I needed to be on a drip._ (Respondent B CG).

Eating disorders and depression have a profound effect on T1DM management.

These issues have been discussed in Chapter 2 and will be revisited in the discussion Chapter 6. One respondent described how in the past she had skipped her insulin injections, saying:

_eating disorders and skipping blood sugars … can lead to some fairly bad control and … you find a lot of young women [skip their needles]… basically it's a form of bulimia because you're doing something destructive to your body to lose weight, whether it be vomiting or missing your insulin shots …I found a lot of diabetics that overeat because you lose all sense of when you're hungry [because]when you're not hungry … you're forced to eat at certain times and certain amounts, so you lose a sense of when you are actually full …and you also have these strange situations where your blood sugar drops and you feel so hungry you could eat a horse…so there's sort of problems with over eating too_ (Respondent 1 IT).

Another respondent said:

_I [was a]… binge eater … [for about]-nine years … I was always terrified of going to the endocrinologist because … your HBA1c is like an exam result and
I just knew that I was going to be scolded and I would make up my blood sugar results and all kinds of things, and then I remember one appointment I actually kept, I went in and there was a locum there, a lady, and I was about 16 and the only part I remember of the whole consultation was when she weighed me and she screamed, she said your doctor told you to lose weight and you've put on two kilos and I just ran out crying and didn't go back for years … I was so self conscious of my weight anyway I would try, … I'd get moments of inspiration and I'd think right, now I'm going to eat healthily, I'm going to lose weight, I'm going to exercise and then old habits would come back because I didn't have ongoing support … at 17 I wound up in Intensive care with ketoacidosis because … I went on a diet programme… I desperately wanted to be slim for my 18th birthday … I did lose a lot of weight and I also got ketoacidosis and wound up with a central line …I'm sure that's done [damage]… I also now have retinopathy and have just experienced my first bleed (Respondent 3 IT).

Another respondent described her compulsive eating in this way:

I was a bit of a compulsive over eater… I'd get into a depression … I'd over eat, seek company in food and then I'd go and inject huge amounts of insulin to compensate, never actually threw up the food like a bulimic but I'd inject huge amounts of insulin … I was in the clinic … for about 2 or 3 weeks, got things under control again… then sure enough that all sort of creeps back … 3 to 6 months later … I fought that for about I don't know 5 to 6 to 7 years (Respondent 1 IT).

It is evident that the interaction of other problems such as an eating disorder and depression significantly interfere with the management of T1DM.

When interviewed (in the present) all of these respondents were working really hard at maintaining control of their T1DM. However; they were struggling to keep their blood sugar levels in control. One respondent said: “To be honest, my blood sugars are so all over the place, that I couldn't …say, I couldn't detect a pattern …[but] I'm generally taking a lot better care of myself now” (Respondent 3 IT).

Another respondent said:

Looking back on it … I wish I could still do the urine tests because that was … twice a day, now I test [my blood] sometimes 5 sometimes 6 times a day and I think … where's the quality of life there, I don't go anywhere without my blood glucose machine, it goes everywhere with me, in fact I have two, just in
case I leave one somewhere… I always have one at my mum's place (Respondent 1 IT).

The same respondent had just returned from a doctor’s visit:

*My doctor has said that she wasn't really, happy with my overall HBA1c, it was 9 [elevated] (three months ago) now it's gone up to 10… I agree that's not good … I've been in a state of flux with my living arrangements, I haven't been doing my normal exercise routine, I've had relationship problems …[and] working situation problems so I've had a lot of stress so I think that's the result … the rise in my HBA1c and I think I can do something about it but by the same token, I'm depressed because … I have to do another injection … my overall outlook at the moment is fairly bleak, I'm really worried about my eyes.* (Respondent 1 IT)

Another respondent was hoping to get a travel–working visa and was frustrated because she said: “*They're making me go for medical test after medical test [at] one stage they told me I'd have to get an HbA1c of 5.5 or under, which only 5% of diabetics can get.*

Respondents were really attempting to control their blood sugars but were continuously fighting extraneous forces that produced stressors and this in turn caused their blood sugars to become elevated.

When considering the future, there was a sense of less optimism amongst both groups about a future cure and they felt that if a cure was found it would be costly. There was also a sense of frustration that magazines sensationalized the aspect of cure when in reality only trials were taking place. There was considerable pessimism that any cure would be too late, too costly, and possibly unsuitable for their type of diabetes. While they did not relinquish all hope, they did not really expect a cure. Only one respondent in the IT group spoke about cure and said with some despair that there seemed to be no hope:
I've come to that conclusion as well in my lifetime I won't see it yet when I was diagnosed the doctors had said to my parents, I always use this as a quote, "oh don't worry X is one of the lucky ones because in her thirties, there'll be a cure", hello... no cure yet (Respondent 1 IT).

Most respondents in the Cohort Group said that if they not had T1DM they might have followed another career path but they still felt that they were doing what they wanted to do. Many felt that having T1DM had affected their HSC and university results, with a flow-on effect on career choices. The stress of examinations frequently led to hypoglycaemic episodes and their sequelae (confusion, sleepiness, migraines, diarrhoea) before or during an examination. This clearly impacted on their future careers, even when they had been given appropriate special consideration such as an average of previous marks, or being able to test their blood sugar and take remedial action during an examination.

I actually went hypo in a couple of my HSC exams ... one HSC exam I actually had to leave because I just wasn't coming out of this hypo and that really stressed me out, ...uni you just have stress [its] ...pretty stressful a lot of the time and it's very full on so my exam periods tend to make me go utterly out of control (Respondent K CG).

Another respondent said:

I had a hypo before my HSC exam last year, and that affected my performance... I just woke up low... well my mum says that she came in to wake me up and about half hour later I was hypo...[I] was okay when she woke me up but then half hour later I was hypo, I can't really remember it that well... I ... did the exam and had massive migraines and diarrhoea as a result of the hypo, and I got an illness misadventure form and my assessment mark... I had 2 exams on that day... I had one in the morning and one in the afternoon (Respondent S CG).

Still another said:

actually had one [a hypoglycaemic episode] in my Higher School Certificate, my English exam, but they just gave me the average because I had special [consideration], I was sitting by myself doing the exams so I could test my blood sugar in the middle and if it was under 4 they gave me 10 minutes to get it up and if it was still under 4 they gave me an average cause they said [my mark] would be affected (Respondent M2 CG).
Discussing the future and careers were one of the most difficult issues for the IT respondents because of the complications that they had suffered. All the respondents had suffered from varying degrees of retinopathy. One respondent said…

*I totally lost interest in, pursuing something career wise … I wanted to [and did] travel … have fun … go and do things … see the world … I was scared I wouldn’t be able to when I was older … I had some wonderful experiences traveling … I went all over Europe and to North Africa and Canada and … little bit of Asia … [But now] Especially … since it intensified in the last two years and, where I could have lost my eyesight … it’s real difficult to think about career and I didn’t want to start something that I was never going to be able to go through with it … the last couple of years have made me very nervous about … the future … I’ve lost confidence in being able to keep a full time job … I’ve been working for my father at the moment, and I can take time off any time with him … the last job … I used up all my sick days within two months … a … real issue if you’ve a career to follow, I … made the decision for the next year to try not to worry about it too much and just enjoy myself see how this relationship pans out … I deserve some fun after the past year … in the back of my mind I sort of think … I have a lot of potential, I was very … bright at school … [it] was a big part of my ego … my self worth … part of my identity I was top of the class, I was smart, and I haven’t had that since I left school, that’s been taken away from me … I haven’t pursued anything career [wise] (Respondent 2 IT).

Respondent 1 IT spoke about her career this way:

[I] … got a job straight away, [after traveling overseas] … went back to study … I felt that I was never able to hold down my study … and [manage] THE DIABETES … I kept … having to be restabilized at the end of each year.”

She indicated that when her blood sugars were constantly unstable she could not concentrate and, therefore, found studying extremely difficult. This had led her to be unsuccessful in her attempts. Another issue was the times she needed to be at university.

“…studying part time you get … to leave work at 4 o’clock, lectures were at night between six and ten pm … to FIT DIABETES around that … TOTALLY … I just let it [the diabetes] go out the window … I was
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busy driving to uni … I'd get there right on the dot of six, last thing I was going to do was get some food into my stomach …[I’d be] eating at ten o’clock at night and totally stupid for the diabetic…snacking in between …[on]…really unhealthy food…but I was never the type of person that really worried about not finishing my courses … I always managed to land on my feet with a job …I’d … bluff my way through things… if I didn't have the T1DM I would have finished because it really does throw just another element on top of your whole life …

Respondent 1 IT later said sadly: … “you know, no eyesight, no job, no relationship that I can hold down it was basically black, the future looked [black].”

The respondents in both groups, but especially the IT group, were struggling to manage the physical self and because there is interrelatedness between having to deal with difficult complications and manage T1DM in a normal way, this has a flow on effect to the other selves. The next self that will be explored is the emotional self.

5.11 The Emotional self

The issue about how the respondents described what they felt about having T1DM has been addressed previously. Most respondents were shocked when they were diagnosed, and a number hated needle pricks and injections, but realized they could not hide from it. Some said that they had come to terms with their T1DM and said “everything they taught me I understood and I just coped with it” However, whilst some were coping, for most it was still an uneasy truce and a constant struggle. The respondents initially tried to, as one respondent put it to take the T1DM on the “chin. But fairly soon it became difficult to manage their T1DM.

Because, in the past, all of the respondents seemed to take the diagnosis so well it was difficult for them to acknowledge when they were no longer coping. Respondents
articulated this very well: “for the first couple of years … I was actually the model diabetic and another said

I was praised so highly for taking it so well, I didn't feel that [after 3 years] I could say … help I'm not coping anymore, I need this to go away, and that made it really, really difficult…diabetics do tend to shoot themselves in the foot, because we don’t want people to know that we're not coping … [we don’t say] look this is a right shit, and I'm not dealing with it and I'm angry and I'm frustrated [we] don't want to be seen to be a whinger…as a child I remember my doctor was astounded because she said you must be thinking why me, and I looked at her and I said well, why not me… I think that's really quite profound for a 10 year old … I just had a delayed reaction… when I was 17 I found myself …more often thinking, I've had enough, why… do I have to do it (Respondent 3 IT).

These respondents then began to suffer from depression and they developed eating disorders.

I was also unbeknownst to me, quite seriously depressed for the first couple of years [at university]… I just didn't really enjoy myself … I… was really, was quite severely obsessed with food and … paranoid, I felt people were looking me and saying gosh isn't she fat … I look back now and I think why would they care, why would they say anything but at the time I, it would terrify me to walk across the concourse, and I think … that's really sad (Respondent 3 IT).

Respondent K CG said “I basically stopped eating for three months, I was never actually diagnosed with anorexia but I was seeing a social worker and I was scaring hell out of my family, I dropped I think 20 kilos in that time, and since then I've had some trouble with binge eating and a little bit of bulimia.

The above respondent believed she had developed an eating disorder because her doctor refused to believe she was taking her insulin. She felt the only way to make him believe was to change the only thing she could, was her weight.

Depression and eating disorders were a major problem for all the respondents in the IT group. This described well in the following verbatim:

I'd [visit] mum [who would say] my breath smells of ketones… I always associate those periods with depression… I'd go into hospital …they'd stabilize me, I'd come back out and be all refreshed again… I remember doing that …once a year, which was absolutely crazy when you think about it. I also suffered in those years an eating disorder, I felt that, having been denied
certain foods when I was a young kid ... I was a bit of a compulsive over eater ... I'd get into a depression ... I'd over-eat, seek company in food. She fought this compulsive eating and depression for about seven years (Respondent 1 IT).

One respondent said that when she was depressive, suicidal and had an eating disorder she skipped injections to lose weight, bringing herself to the verge of ketoacidosis and requiring more than one hospitalization.

Of the three IT respondents, one had just had a retinal bleed when I interviewed her. Another had just returned from her doctor's visit and had been told that her HbA1c's were too high. The third was recovering from severe neuropathy and hoping to travel overseas. They were all feeling extremely vulnerable (in the present).

One respondent disclosed her distress at having her first retinal bleed after having approximately 4,000 painful laser treatments on her right eye, and about 2,000 on the left, and believing that her treatment had been successfully completed.

...on Saturday night it happened ... I just noticed that my vision was getting worse and worse ... I've had a headache ... since that night... the bleeding itself puts a bit of extra pressure on the eye ... or ... it's just a psychological thing because I'm looking at blood 24 hours a day [maybe if] you see blood you feel pain... I think it's also ... eye strain because you have to concentrate that much more to read and... to see things clearly ... I have been a, bit of a teary ... it's quite scary...I feel angry that it's happened (Respondent 3 IT).

She felt that she had misunderstood the function of laser treatments and said:  

I thought that when you had laser it actually burnt the vessels off ... [but they] ... burn around where the vessels are growing to kill the chemistry which makes the vessels grow ... I'm worried because I don't know if there's going to be permanent damage ... scar tissue ... [or a]...vitrectomy ... I worry about my job performance, it's affected my balance and my judgment ... [and] ... peripheral vision (Respondent 3 IT).

As a result of the retinopathy she was not able to drive a car. She missed driving and had lost her independence: “it irritates me that if I have something
for work, I either have to catch a cab or I have to have somebody else drive me … it's a loss of independence”. The retinopathy had affected her night vision as well.

The same respondent was dealing with the fact that she will not be able to have children:

When I first developed kidney disease, I was told I wasn't going to be able to have children, or that it was not likely I'd be able to have children … I hadn't realized until that point how desperately I wanted [them] and I think a big part of that is the choice is taken away, as a female it's your birthright that you will be able to have kids [it] was devastating … [that] brings all kinds of social … emotional costs … thinking … I'm never going to fall in love, nobody's going to want me if I'm on dialysis, what if a man loves me but he wants children and I can't give them to him… people say … if that happens he wasn't the right man for you anyway, …it's a real fear and a lot of people have that fear with diabetes on its own, what if nobody wants me because they think I'm sick and I'm diseased and that's ...a big hurdle I think in society is that people don't understand enough about T1DM at all (Respondent 3 IT).

Respondent 1IT also mentioned that she was depressed because she had just returned from seeing her doctor and she had discovered that her HbA1c’s were even more elevated. She was frustrated about this and said that she had been experiencing upheaval in her relationship and work situation. She indicated that stress elevated her blood glucose levels. She expressed concern about having to give herself another injection. She was also concerned about the progression of the retinopathy, nephropathy and her elevated blood pressure and said “my overall outlook at the moment is fairly bleak.”

She confided tearfully:

I think if I hadn't had …my psychiatrist to help me, and the anti depressants I think the option of suicide had come up [numerous times] … [I was] 30, …when it happened … [I have] no hope with having children… all my friends are married with children....I grieved …. the loss of my eyesight at the end of
last year God, everything’s coming at once… no eyesight, no job, no relationship that I can hold down, I mean it was basically black, the future looked black you know (Respondent 1 IT).

The third respondent was recovering from a severe illness and felt that she had become very reliant on her parents. She had also met a young man and was nervous about their relationship:

I don't know how I would have coped, [without my parents] … that's scary … I was so independent … not scared of anything, … at the moment …I feel so dependent … I don't know how I'd cope without the safety net…. She felt that she needed to gain some independence…break some bonds with my parents, regain my self confidence … sorting out where I want to go with my life. (Respondent 2 IT)

Respondent 2 IT was also dealing with the complex issue of having children. She noted that her boyfriend wanted children, but that she wasn’t ready to conceive and was very aware of the potential problems of T1DM in pregnancy for herself and the child—with diabetes in her partner’s family as well. She expressed doubts about being able to care for a child while looking after herself. She was also worried that she was placing too much hope in this new relationship.

For those in the IT group having to struggle with blood sugar control, being fearful of relationship failure, grieving over loss of career and of not being able to have children or fearing what might happen if one had a child, as well as the loss of vision in the future caused these respondents to struggle emotionally.

Some, although not all respondents in the CG, were struggling with their emotional selves. Stress was a universal constant. It sent blood levels up in some and down in others. One respondent indicated that stress affected most areas of her life, particularly her diabetes management and forward planning at any level. Another, two respondents with stress-related, unpredictable hypoglycaemic effects, felt chronic
apprehension and preferred to maintain hyperglycaemia which gave them a sense of control.

Stress and fear of hypoglycaemia have an unmistakable effect on emotional self of some respondents.

Some respondents in the CG were cautiously optimistic about the future. One felt confident in biotechnology advances in early detection of complications. Male respondents seemed far less concerned about having children with T1DM for that reason: “I’d just try and make sure it got detected, have them tested, at an early age.”

Most of the female respondents were concerned about having children. Some would not let T1DM stop them “…I love kids,” while others were really unsure.

…but as I get older I mean I don’t want to have kids and have them, pass on my genes, of having T1DM …and because my T1DM is not controlled, any effects of my blood sugar on a foetus [would be disastrous]… I just don’t think I could cope with a child as well as myself, at the moment (Respondent K CG).

The emotional self clearly had an impact on the T1DM and conversely the T1DM had an impact on the emotional self.

The effect of T1DM on the social self and vice versa is explored below.

5.12 The social self

T1DM impacts on social relationships. Once again there was a thread of the past and the present and the future running through the social self. Most of the respondents had experienced good social relationships in the past, were enjoying them in the present and were content about relationships in the future.

The respondents in the IT group all spoke of friends, in the past, influencing them in the area of drugs and alcohol; one said: “I think it affected my overall care of myself
“...my friends ... discovering the world of drugs and alcohol ... all the things that most teenagers find out about at some point ... it happened when I was 17 and 18.”

Another recalled:

I remember [it] being ... crazy times ... I went to university ... there were lots of parties, all my friends were on drugs, ... I mean dope, marijuana, speed, all of that I tried .... I mean who's not going to try it and I'm the type of kid where I think, once I discovered that I could be a little bit naughty with my diabetes control and nothing would happen (Respondent 1 IT).

The third respondent found social interaction quite difficult and later began to drink and take drugs:

...it was very difficult to talk to me about it [diabetes] not sure if it started when I was in primary school when I got into my teens... got the feeling ... when I was about ten [I] never knew anyone else who was diabetic, ... mum sent me to one kid’s [diabetes] camps when I was quite young, about nine ...I hated it... I didn't, [get] involved in anything to do with diabetes... I mean I was different, it set me apart as it was and I didn't want to have to go into this group of ...diabetics (Respondent 2 IT)

Later on this respondent got involved with drugs and alcohol:

at school it was alcohol ... not drugs until I left school... I would binge drink every weekend when I was traveling overseas it was more often than that, a lot of drinking ...didn't really take a lot of drugs... that was only every so often more marijuana than anything, didn't really get into taking speed or, the trips or anything like that .... I suppose the biggest involvement I've had with drugs is when they were prescribed, but I did actually get quite addicted last year [The respondent became addicted to the painkillers administered for severe neuropathy]... I [also] social smoked for a little while. (Respondent 2 IT)

The same respondent, who had previously, been reluctant to talk about T1DM earlier had become more comfortable about talking about her diabetes over time. Another respondent had recovered from her eating disorder and now was able to deal with it openly. She said she would tell friends about her diabetes and its associated difficulties, to educate them ... so I tell anyone who'll listen basically. (Respondent 3 IT). She further indicated that diabetes is socially constraining because even close
friends who are sympathetic seem to overreact when insulin is either due or overdue:

“... do we need to drive you, do you need to go somewhere ... in that respect they tend to over react and think, gosh, something’s going to happen to her and we better rush her off to the hospital”. (Respondent 3 IT)

Another respondent said socializing it was really difficult because even friends did not realize the seriousness of the disease but some were very supportive:

  your friends, don't really think it's as serious as what it is, [and] psychologically that is so hard because you want to go out and join them, you want to go out ... you want to be normal ...[you say] I had a bit of laser surgery on my eyes last year but hey I'm fine now and I can come out with you but then you know you'd go to smoky atmosphere [ which is not good for your eyes] I'm a social person [but I]...put off friends ...I'd say I just don't feel like talking ... hang up abruptly ... cancel appointments. I have a couple of close friends who really understood and I even went out a couple of times and they'd hold me by the hand [and say at a kerb or stairs] step ... you can only sort of share that with really close friends, you didn't really want to tell others, [it] was really hard. (Respondent 1 IT)

Respondent M2CG also found friends were very helpful:

  My friends could actually get the signal that I was going, ...[to] collapse in class ...[only recently] I've been able to tell when the hypos are coming on, I've had it for so long that the signals just wouldn't come, I'd just be out like that, but a few of my friends, they could tell with my eyes, whereas I couldn't tell ....I had problem [with] a teacher[who] threatened [me]...but one of my friends came in and (laugh) sort of rescued me. (Respondent M2CG)

However this same respondent sometimes found social relationships difficult and disliked the effect that their hypoglycaemic episodes had on their social relationships and said that she became violent …

  I was in infant’s school ... I had a violent one ... I was throwing things at teachers and students (laughter)... I don't know what it makes me feel because they look at you funny and people stare at you for days saying that's not who you are, and they're worried that it could happen at any time...a lot of people I found tried to avoid me after I've had one ....When I was little a lot of people just thought I was weird... when you're five or six they, you just don't have any grasp of it ...as you got older people got more understanding once they found out what actually was wrong with you, you couldn't do anything about it, but
a lot of the time people thought you were just putting it on (Respondent M2CG).

And again this respondent said:

... people I thought were my friends ...would say I was doing it on purpose, trying to get out of things ... a lot of them not understanding the problems that I was having ... especially when I had one in an exam, they said that I did it on purpose and that actually put me into tears, makes you feel like they don't know me, like they didn't understand, they didn't want to understand, they just were taking it at surface value as if I'm just fainting on purpose. (Respondent M2CG)

Another respondent described social difficulties that were just as complex:

I don't know if it's because of the eating disorder or I have a problem with people watching me eat, so if I go hypo having to stuff my face...with lollies and sugar gives me a bit of a complex, especially ... because I am quite a large person is a polite way to put it...I felt that people were judging me... she's overweight, she shouldn't be eating that, or that's disgusting, how can someone eat so much sugar ... some people in class used to get jealous ... how come she's allowed to eat in class ...why can't I eat in class, particularly in science laboratories and stuff where you're not supposed to eat at all (Respondent K CG).

This same respondent found moving out of home made diabetes management more difficult. She had to learn to be herself, cope with new domestic tasks, shop and cook for herself, become disciplined about university study, and try to make new friends, as well as manage her T1DM in changed and stressful circumstances.

I was over eating, binge eating, because I tend to have this little theory that everyone needs one escape mechanism and obviously cigarettes aren't going to be my escape mechanism, alcohol can't really be my escape mechanism, and therefore food kind of just fills in the gap (Respondent K CG).

It is clear that the respondents had problems with some in their social circles understanding the implications of T1DM and the need to attend to diabetes management. Yet they also wanted to be involved in the everyday social activities without people over-reacting. This frequently made social interaction complex and difficult to negotiate.
"It makes me scared a lot of the time because I don't know what's going to happen, where I'm going to be, who's going to be there with me ... but no one from uni has ever actually had to [assist during a hypoglycaemic episode] so I find that I like it better when my blood sugar's high than when it's low, just because there's no threat of a hypo (Respondent M2 CG).

One respondent felt that not only were others checking on her but that she needed to check on herself:

you can't really just let your hair down and have a good time ....I've been going out on Friday nights to the pub with a group of friends and we don't tend to stay in one pub, we tend to move from pub to pub and I'm the designated driver, and because I'm out... I tend to feel I have to do a blood test before I get in the car behind the wheel particularly when I have eight people in the back seat and then everyone else in the car goes [what are your blood sugars] (Respondent K CG).

She was also upset that members of the diabetes management team would be discussing private things about her, that every doctor who ever saw her had full access to her medical history. She felt powerless, excluded, angry and resentful at what she perceived to be a breach of a one-on-one trust relationship with health professionals. She strongly objected to a team discussing her in her absence.

Wrestling with the social self in the present had a significant impact on their diabetes management since what happened to the respondents in the present had social implications for the future.

Some respondents were confident about their social selves in the future while others were concerned because of the instability of their T1DM in this regard and much of what might happen in the future was uncertain. The IT respondents were most guarded about their social future, possibly due to the social as well as the physical constraints linked T1DM complications. T1DM can have both positive and negative effects on relationships and the converse is true as well.
5.13 The related self

The relationship between the respondent and their parents, siblings and partners can be strained by the realities of T1DM although for some it had been a bonding experience. All parents were understandably very distressed when their children were diagnosed with T1DM and while some conflict was still inevitable, respondents were able to acknowledge a more mature understanding of their family’s concerns for them.

One respondent whose father had T1DM said his father wept when he was diagnosed:

I'd never seen him do that so I thought oh it's pretty serious. I still try to keep a light hearted approach to it all...He might have first thought that I would blame him for it, but I wasn't going to do that cause it's, not the type of thing that people should get held down by having, he's lived like that all his life and he's coped and he's fantastic but different people deal with different things different ways...I guess at first he would have felt a bit guilty...once it happened it sort of gave us something to talk about...compare... readings and stuff like that ... plus ... I couldn't have been in a better situation cause my Dad works in a hospital so he had a lot of background and my mum's a dietician (Respondent M CG).

The same respondent also said that his mum started teaching him how to manage his T1DM because “it's hard to learn everything in a week in a hospital”

One respondent said:

Mum didn't like it at all (laugh) ... I think dad just saw it as another thing that's come along and have to deal with and mum did in a sense as well, but I think ...she didn’t like needles very much, I think that was mum's problem, but I think dad and mum both gave me injections (Respondent B CG).

A consistent theme of family responses to the diagnosis was initial shock and distress, parental education regarding diet and injections, intrusion of the T1DM eating routine into family mealtimes, and siblings occasionally carping about the attention and special treatment afforded respondents.

The stressors of diabetes management had memorably impacted the relationships in the past.
One respondent spoke of her mother’s hassling and occasional lack of trust, another of his mother taking control of testing and injections, then handing the responsibility back to her: “mum trusts me and then at other points [she asks]… have you done [your blood sugars] only my mum that hassles me, she’s the only one.” One respondent said of his mother:

mum first handed me the responsibility of doing it I mucked up and she took it away from me again so and then when I got to become aware of what I was doing before I said can I just do it again and again Mum's always saying keep controlled, you'll regret it when you get some complications. This same respondent said: Mum tells me to do stuff but most of the time she doesn't know what's going on and what I've done and what I've eaten (Respondent J CG).

One respondent had no problem telling boyfriends about her T1DM. Another said that his girlfriend knew his diagnosis, that she could watch finger-pricks, but not injections.

Still another respondent was positive about relationships. As someone with sales skills, he was able to sell the positive aspects of his personality, and to educate his companions about both positive and negative aspects.

One respondent mentioned that previously she did not share how she felt about her T1DM with her family:

I've started to think a lot about it in the last couple of years… before that I never thought of the impact it had on my family, it was always just me, me, me, I could only think of the impact it was having on me and I actually didn't like discussing it with them… didn't want them involved … anything to do with diabetes I would just back off … I mean you could ask my mother, it was very difficult to talk to me about it. (Respondent 2 IT)

Another respondent indicated that she initially:

… had a wonderful family and lots of love and lots of support, [but] dad just ran away, he doesn't deal well with sickness at all… he's hardly been sick ever in his life so… I know they were both devastated but mum who has rheumatoid arthritis was the primary carer, she was the one who read all the books and learnt how to do injections who really understood the whole process of diabetes I think my sister who was 13 at the time wasn't that concerned, she
just wanted to know if it was going to kill me and when she found that no it wasn’t, she was pretty cool with that ... she used to get irritated with all my family asking me questions and fussing over me and saying can you eat this, do you have to eat now, have you done your blood tests, and so she made a conscious effort not to talk to me about it but if I chose to talk to her she was happy to listen...(Respondent 3 IT)

But then when this respondent’s parent separated initially, she did not think that it really bothered her that much at the time:

[But] evidently [it] did … I don't really think it bothered my sister at all, she said yeah cool, whatever you want to do, make yourself happy and I so much wanted to be like that and apparently that's what I said when my father said look I'm leaving and I said whatever makes you happy and that's kind of in my personality, but...at 17 when my parents split up [I became a] full blown binge eater battled with that for nine years. (Respondent 3 IT)

One respondent really felt that having T1DM did have an impact on her marriage which lasted three years, and had been marked by a repeated fights and reconciliations. Recalling the arguments, she recognized how difficult it is for a partner to live with someone with mood swings related to fluctuating blood sugar levels, while:

I'd like to say I've never suffered mood swings, but I do ... your family can tell ... you put your back up and, and you get your defense mechanisms happening ... there's a classic thing about diabetics not accepting when they're low blood sugar... he used to argue with me when he knew I was low but he'd also say oh look you're having a hypo, go and eat something and I'd say no I am not having a hypo, this is a real argument here, it's not because I'm in a hypo that we're arguing. In retrospect I may have been low at those times when we were arguing, the mood swings started it, the mood swings got worse, the blood sugars got worse while we were in the argument ... it's a catch 22, just getting worse and worse, so I divorced four years later(Respondent 1 IT).

This same respondent tried to share her treatment regime with a new partner, but swung between wanting this and getting into an argument triggered by a blood sugar above the normal limits, and his inevitable question, “Why?” …but how do you explain [that you had something extra for afternoon tea] to a non-diabetic, and even one that loves you very much (Respondent 1 IT).
Another respondent had a problem with a partner who was helpful but controlling.  

*in my last relationship ... I had a major hypo on our third date and he ran out the door to go and buy me sugar the poor dear but he liked to know where my strips were and he would constantly say to me have you done a test...as a more mature person now, I understand it's out of care and out of love and part of it was wonderful because he would actually do my test for me, he'd sometimes wake me up in the middle of the night he would prick my finger and sometimes say you're low, and he'd put some lollies in my mouth I'd go back to sleep and he'd be saying chew, chew, and he would...really look after me in that way which was just superb but on the down side some of it was a bit too invasive, and a bit too, 'no this is my disease-you can't take control of it'.*(Respondent 3 IT).

Another respondent was also less enthusiastic. A boyfriend she really liked got sick each time she tested her blood and she said: “...it's, *(laugh)* not fabulous to try and form any kind of relationships.”

Clearly, the impact of T1DM on relationships can cause strain that may result in those relationships floundering or failing. This then places additional pressure on the person with T1DM and they can perceive themselves as failures as well.

One respondent spoke, *(in the present)*, of the importance of her parents when she was confronted the complications as result of having T1DM. Academically she had done extremely well at school but depression and T1DM complications have interfered with her career goals. From being independent, confident and optimistic, traveling overseas alone, she now had conflicting needs for strong family support: *...I don’t know how I’d cope without the safety net, it’s kind of scary ... yet sensed the desire to regain self-confidence, loosen her child-parent bonds, and sort out her life*(Respondent 2 IT).
Another respondent spoke of her family and especially her mother in the following way:

...The future looks black ... no relationship that I can hold down ... you end up coping and staying on because ... I come from a really strong family background where ... your family is everything so I guess that's what stops you [suiciding] in the end, but if I hadn't had that strong, family thing I would have ended it ages ago ... those three months when I was blind, mum took me everywhere (Respondent 1IT).

The support of families is imperative for these respondents, but there was the constant struggle between dependence and retaining some independence.

Most of the respondent in the CG seemed to be satisfied with the related self in the future, or made no comment about the future at all. However, respondents in the IT group barely touched on relationships in the future; since they were struggling to cope with the present. Only one respondent was hoping that her relationship would work out but was afraid to be too optimistic. It was very clear that all respondents felt the need for some level family support in the future. The respondents described how they had lost focus in their DM management, this is discussed below.

5.14 Losing focus

As previously explained the second step in the cyclic process (Figure 1 The Equilibrium dilemma in Chapter 4), entails losing focus. It leads to getting off track in terms of diabetes management. T1DM can have an effect on the self, but conversely, how one manages the physical, emotional, social and related selves can have an effect on the T1DM. Some respondents in the CG were not finding it too difficult to manage their T1DM although most had experienced times when they had lost focus on the physical emotional, social and related selves, but those in the IT group were finding diabetes management very difficult.
5.14.1 Losing focus and its impact on the physical self

This took various but predictable forms such as not injecting insulin and having to be hospitalized; becoming metabolically unstable without knowing why or no matter how much effort went into self-management; or never achieving reasonable blood sugar control with resulting despair and regressive behaviours which aggravated others (an issue re-visited below), which had major impacts on the emotional and social self.

In the IT group this cyclic process for one respondent was compounded by teasing by adolescent boys at school, developing a negative body image, binge eating, parents separating, not testing at all for three years, drinking alcohol, smoking marijuana and generally not looking after herself, over a period of three years, and trying to manage without family or peer support. Losing focus is well illustrated in the following excerpt:

I was always terrified of going to the endocrinologist because ... your HBA1c is like an exam result and I just knew that I was going to be scolded and I would make up my blood sugar results, I remember one appointment I actually kept, I went in and there was a locum there, a lady, and I was about 16 and the only part I remember of the whole consultation was when she weighed me and she screamed, 'Your doctor told you to lose weight and you've put on 2 kilos!' and I just ran out crying and didn't go back for years because I was so self conscious of my weight I was 16 ... I just thought ...I can't deal with this so I ... didn't go back for a long time ... I would try ... [to be sensible, eat well, exercise, and lose weight]... then old habits would come back because I didn't have ongoing support. I think, that was the problem, I didn't know anybody else with T1DM, I didn't meet anybody else who had it until I was ... twenty three, and I don't know how I ever got by without it, and for a long time I never thought I needed any support, and that made it really, really difficult... at 17, I wound up in intensive care with ketoacidosis [as a result of using a meal replacement programme ...to be slim for my 18th birthday and I did lose a lot of weight and I also got ketoacidosis and wound up with a central line and all sorts of things, which was ...a, bit of a nightmare and taught me a big, a big lesson, and I'm sure that's done ... some damage... I now have retinopathy a haemorrhage in my right eye means I can't see properly... it's irritating, the laser treatment hurts ... it wipes you out (Respondent 3IT)
Respondent 1 IT recalled an earlier period of cheating on testing, being non-compliant yet constantly thirsty: “so that’s an obvious indication of high blood sugar”.

Another respondent said that testing and giving injections would have disrupted her boarding school activities: “I just didn’t want to make a fuss.” She also cheated on her diet and manufactured her testing results. Her doctor commented gently: “… some kids think you have … to fill in all the gaps just so it looks perfect…. I actually didn’t do many blood sugar tests…through my teens … I never did it, I never tested”.

(Respondent 2 IT).

These narratives make it clear that the respondents lost focus of the physical self with a resultant major impact on their physical wellbeing.

5.14.2 Losing focus and its impact on the emotional self

Stress was both a cause and a consequence of unstable blood sugar levels. It affected every aspect of respondents’ lives: their eating, their planning, their activity patterns, the way they were able to function at work or study or in social situations. Thus it was relatively easy to lose focus on an emotional level. The respondents often found trying to manage T1DM as well as cope with stress, depression and eating disorders very difficult.

I felt that having been denied certain foods when I was a young kid and not really being told … you can have anything but just in moderation … it was pathetic because the foods you could have freely were things like lettuce, celery, carrots. I saw a couple of counsellors about an eating disorder, I went into a clinic once … I’d get into a depression … I’d over eat, seek company in food and then I’d go and inject huge amounts of insulin to compensate, never actually threw up the food like a bulimic … I was in the clinic … for about two or three weeks, got things under control again, left, everything fine but then sure enough that all sort of creeps back, you know three to six months later so I reckon I fought that for about …five to seven years. And: … I definitely
associate the stress with getting out of control with my diabetes… it certainly sends blood sugars up (Respondent 1 IT).

Respondent 2 IT verified that stress was also a very important factor in diabetes management. In her case, it was the stress of the higher school certificate (HSC), fainting before an important examination, followed by two years of depression. Despite this, she passed her first and second year university subjects, but a major period of stress, shock and guilt occasioned by the sudden cardiac death of her grandmother. This coincided with a totally unexpected diagnosis, at age 20, of retinopathy. She had associated such complications with older people, had avoided reading about them. She continued:

Most young people [are not] really aware of [their] own mortality… you don’t expect to have these sorts of health problems at my age … the retinopathy was pretty early stages … they weren’t doing anything at that stage … so I basically… forgot about it for about… 3 years … I did a lot of traveling during that time [I put diabetes] on the sidelines, just, just enough to keep me going and I also started skipping injections, to lose weight… I started doing that chronically from about age of 20 … I only stopped doing it when I got ill at the start of last year… I mean it didn’t all just suddenly happen … I’d been going downhill for a long time … I actually ended up in hospital a couple of times so on the verge of ketoacidosis.

The same respondent found the stress of a five-day working week and missing her ‘shots’ on and off over several years affected her blood sugars so badly that she left her job, moved back home and tried to get back on track. She developed wide-spread neuropathies but found it difficult when no-one believed her symptoms.

I had it from the neck down, and I was in such unbelievable pain and yet because … they couldn’t find anything wrong … they kept trying to send me to a psychiatrist … they couldn’t believe I was in all this pain … I couldn’t believe it was psychosomatic… mum … kept taking me to doctor after doctor and after doctor, we just didn’t stopped looking because … I wasn’t sleeping, and I was crying all day and all night, and I was in the foetal position… we’d actually been trying to get in to see [Dr.X] for about a month and a half and
couldn't get an appointment ... finally got into see him, I didn't really have an idea that it had to do with my diabetes ... I was in there two minutes and he knew what it was and it was an acute severe type of neuropathy, and I went straight into hospital (Respondent 2 IT).

Initially, prescribed medication gave no relief. She agreed to try morphine for relief of insomnia and for her severe pain “... a good and a bad thing ...”, but after six months, had an established opiate addiction, a major loss of affect, motivation and memory. This was exacerbated by sudden withdrawal of the opiates without cognitive behavioural therapy. She remained in severe pain for two months.

She also expressed feelings of suicidal ideation:

...I can remember thinking about suicide when I was in my teens but never really seriously. I think a lot of teens go through that... [when I] got into my early twenties I would have quite severe depressive stages where I think I could have probably done something ... did actually, cut my wrists up a couple of times... I didn't, I mean it...I feel it was more of a form of self abuse, cutting myself up ... I hated myself ... I didn't feel like a strong person 'cause I wasn't dealing with this and it went on and I wasn't looking after myself ... the first thing someone says to you when you're sick is you've been a naughty girl, I still get that (Respondent 2 IT)

There is a special need for doctors to remain non–judgmental:

I've been quite lucky because I've had two very wonderful specialists... they were never, not even slightly, judgmental just ... accepted what control I had ... what my HBAIc was and tried to advise me to help me along with making it better, you know, never any sort of, any guilt ... most of our sessions talking about, about me, and what I was doing and what I was doing at school and what my family was doing and ...very little of the time was spent on physiological needs, more of it was actually spent on, on how I was doing. (Respondent 2 IT)

One of the respondents speaking about her parent’s divorce said she coped by blocking it out with eating and watching television:

I'm not sure where the food came in, I think that's probably just a rebellion from being restricted for so long ... It's quite logical really that you take it out on food, well I'm going to have this and I'm going to eat 10 of them and I would watch the television, it would be hand to mouth, immediate stimulus and then you don't think; and so I escaped my problems that way, anything I didn't really want to deal with was pushed back (Respondent 3 IT).
Another respondent indicated that with grieving the loss of fertility, the loss of her eyesight, and feeling worthless without a relationship or job, the option of suicide had come up many times. “If I hadn’t had that strong family thing I would have ended it.”

Clearly grief, loss and depression had severely impacted the emotional selves of the IT respondents. Loss of focus had repercussion for the social selves of the respondents and their DM management.

5.14.3 Losing focus and its impact on the social self

Respondents did not really want people to know about their T1DM as they felt this would make them feel different. As respondent 2 IT said: “I didn’t like taking my shots in front of the other girls … and a couple of times I just went without my shots …” the respondents in the IT group experimented with drugs and alcohol throughout their teenage years, as well as sugary foods. They resented having to live tied to a diabetes management routine, oscillating between not taking care of themselves and overcompensating.

In the CG, one respondent was embarrassed by her behaviour when she was hypoglycaemic and preferred to have higher blood sugars. She felt others thought she was: “weird” and ‘putting it on’” and would stare at her “for days”. She felt intensely uncomfortable and pessimistic about her social self.

5.14.4 Losing focus of the related self

When the parents of respondent 3 IT divorced, she lost direction and become non-compliant with diabetes management, due to depression, loneliness and an eating disorder (Respondent 3 IT).
Respondent 2 IT did not share how she felt about her T1DM with her family and also reflected it was better for parents to look after their children, rather than place them in boarding school:

[It] probably wasn't such a good thing for me because … I think your parents would be more likely to watch over what you were doing … the one nurse there and the dorm. mistress … did watch over me … I don't think they fully understood diabetes as much as my parents did … I really wasn't looking after myself…in essence that made me even more secluded in diabetes because my parents weren't with me most of the time… the most I did for myself was take my shots and, and go see the specialist because the appointment was made by my mother or the nurse and they took me and I had to go (Respondent 2 IT).

One respondent in the CG had an extremely low sensitivity to hypoglycaemia. Since this had resulted in a near-tragedy, her family instituted protective regimes, leaving her with very little independence. They held her hand in the shower (baths were not allowed), and she had to tell her family where she was going, when she would arrive and how and when she would be returning. Respondents were very aware of the burdens unstable diabetes placed on those in relationships with them.

5.15 Regaining focus on the physical, emotional, social and the related selves

Although respondents worked hard to either maintain focus or regain focus of the physical emotional, social and related selves those in the IT group were going through such tumultuous times, physically, emotionally, socially and relationally that some were struggling to regain control of all aspects of self. They were trying to regain control of the physical self. One respondent said that she really never had good blood sugars: She said that her blood sugars were still: “all over the place”… and that she could not “detect a pattern” in the blood glucose readings, but that she was “generally taking a lot better care of [herself] now.”
The following data segments are characteristic of the interaction between the physical, social, emotional and related selves:

*My overall HBAIc, it was months ago, now it's gone up to ten... I agree that's not good [but]... I've been in a state of flux with my living arrangements, [not] doing my normal exercise routine, I've had relationship problems, I've had the working situation problems so I've had a lot of stress so I think that's the result of my, the rise in my HBAIc and I think I can do something about it but ... I'm depressed because ... I've come back and the overall suggestion was that I have to do another [additional daily] injection (Respondent1 IT).*

As mentioned earlier, when a previously non-compliant respondent in the IT group tried to regain control of her blood sugars, the result was a severe neuropathy, a rare side effect of rapid blood sugar correction. Treatment with long-term morphine led to physical dependence which she had now overcome. This whole series of problems had caused her to leave her job, move home, become dependent on her parents, with the results already noted. Interrelatedness between the physical, emotional, social and related selves is profoundly affected by T1DM and there is a reciprocal and simultaneous impact of the self on T1DM. The loss of independence which occurs when T1DM complications arise, such as retinopathy, is reported in findings by Walker & Rodgers (2002) who also indicate that people lose their jobs, and ability to drive as well as to self-care.

Respondent B (CG) “*was just sick of it and decided that [I would not have my injections]... I wanted to be like every other kid... I had to have counselling ... not that I thought I really needed but obviously I did.*” Counselling helped the respondent realize: “*that it is something” she had to do “get over it and move on.*” This helped the respondent regain control of both the physical self and the emotional self.
One respondent achieved control of his emotional self by comparing his situation with that of a friend. While having T1DM was depressing, he would rather have T1DM than cancer:

\[ \textit{it happened to a friend of mine \ldots he had cancer his whole life\ldots thought it went away, thought that they'd cured it, came back it killed him, I mean there's so many restrictions with T1DM [but] you'd rather have T1DM} \] (Respondent J CG).

Another respondent had started developing new friendships which had helped her and she was happy because they had supported her in losing weight.

One respondent received a great deal of help from a friend:

\[ I've got a very good friend who's 45, who has helped me cause she's diabetic and she's had it since she was nineteen, but even she said she didn't understand the problem that I was having at school because she didn't have to go through school with it she was able to relate to me and say this is what you do, this is how you can solve the problems you're having, explaining to people, just tell them straight out you're diabetic, this is what to expect, cause I had problems through school \ldots I'm very shy, I don't like telling people I'm diabetic, I found that it's just got to happen\ldots she was able to help me more than my parents cause she understood it and my parents understood that as well \] (Respondent M2 CG).

Social support and mentoring helps the respondents to regain control of the social self.

One respondent was really upset that her family were overprotective but said she could now understand why this was so because she always suffered from very severe hypoglycaemia. She had come to acknowledge that they were very frightened because she had experience a near drowning as a result of hypoglycaemia and they feared that this or some other unpredictable event might happen again. She now understood that this overprotective behaviour was because they loved her and did not wish her to be harmed.

In summary, T1DM has a significant, sometimes life-changing and profound impact on the physical, emotional, social and related selves. Some respondents are able to manage these selves and their T1DM effectively but more often than not, it places an inordinate amount of stress on the person, their primary carers and closest friends.
There is a resulting loss of focus and control of their several selves and their diabetes management, which is not always able to be regained.

Table 3 is provided as an overview of the findings from the IT group.

**Table 3: Similarities and differences between Study One and the IT Group – Study Two**

<table>
<thead>
<tr>
<th>Study One</th>
<th>Study Two: Illness trajectory group findings</th>
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<tbody>
<tr>
<td>The equilibrium dilemma,</td>
<td>The equilibrium dilemma remained the same</td>
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<tr>
<td>- Step 1 protecting the selves in the “now” and balancing needs</td>
<td>- The protective umbrella of self management still occurred but required great effort</td>
</tr>
<tr>
<td>- Step 2 losing focus and getting off track</td>
<td>- Balancing the needs of T1DM with the self remained the same</td>
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<tr>
<td>- Step 3 Regaining focus</td>
<td>- The selves / development/ diet/ life effect/ activity effect and disclosing had changed and this often meant that T1DM was more difficult to manage. Recurring themes were found in the data in this illness trajectory group. They were different from those in the longitudinal group. Eating disorders were also found in the cohort group. Diabetes complications which were found in the longitudinal group and the cohort group. These complications did have a profound impact on respondents in both the illness trajectory group and the cohort group. The findings were:</td>
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<tr>
<td>- Protecting the selves by adopting the protective umbrella of disciplined self – management</td>
<td>- Each person had experienced an eating disorder.</td>
</tr>
<tr>
<td>- Balancing T1DM with need of self (physical, emotional, social and related)</td>
<td>- They had become involved in the use of drugs and alcohol to quite a large degree.</td>
</tr>
<tr>
<td>- Physical, social, emotional and related selves interact with adolescent development/ diet/ life effect/ activity effect and disclosing. Diabetes management becomes more difficult and this is represented by ominous rain cloud, a metaphorical storm, which may blow up at any time for any or all of the ‘selves’ This storm can either result from problems with adolescent development, diet, life effect, activity effect or disclosing or when problems arise for the physical, emotional or social selves.</td>
<td>- All respondents had experienced clinical depression.</td>
</tr>
<tr>
<td>- The competing realities for young diabetics through time</td>
<td>- They had found managing T1DM VERY DIFFICULT from very early in the diabetes management process.</td>
</tr>
<tr>
<td>- Past – coming to terms with the diagnosis</td>
<td>- There had been extended periods of time when little or no attention was paid to the physical management of the T1DM.</td>
</tr>
<tr>
<td>- Present – priority</td>
<td>- They had experienced major complications as a result of having T1DM.</td>
</tr>
<tr>
<td>- Living in the present</td>
<td>- The competing realities for young diabetics through time</td>
</tr>
<tr>
<td>- Being in physical control, even with higher blood sugars, but at the same time wanting to maintain optimum health for the imminent cure.</td>
<td>- In the Past diabetes management had been difficult to negotiate.</td>
</tr>
<tr>
<td>- Future – Cure and career.</td>
<td>- The Present was difficult as well, they were continuously having to cope with the realities of the impact of the diabetes complications on their lives.</td>
</tr>
<tr>
<td>- Extended periods of time when little or no attention was paid to the physical management of the T1DM.</td>
<td>- The Future was very uncertain there was no hope of a cure and careers were all but lost as a result of the diabetes complications.</td>
</tr>
</tbody>
</table>
A discussion on the way in which the respondents represented their illness follows below.

5.16 Illness self representations

It will be recalled that after the respondents had completed their interview they were asked to rate where on the “Who am I scale” they would rate their T1DM. Most of the respondents rated themselves between one and ten, with some rating their T1DM as high as between one and three, others between five and six, one at ten with one indicating that if T1DM was on the scale, it would not rate high at all. This rating on the scale did not really correlate with the words chosen to describe the illness self representation.

The respondents were also shown the words “interruption”, “intrusion” and “immersion” and when discussing them only one respondent in the Study One saw the disease as intrusive. The majority saw the disease as an interruption, but there were times when they became immersed in the disease. This was especially true of those who were struggling with severe complications as a result of having T1DM or at times when blood sugar control was unmanageable or the respondents were not coping with other issues influencing their emotional, social and related selves. The T1DM then became overwhelming, but most of the time the respondents saw T1DM as merely an interruption in their lives. One person however who appeared to managing his T1DM very well and not struggling with complications said he was continually immersed in his disease as it was part of him. Another said he felt that he saw his disease as an interruption because if he saw it as more than that, then, he
would have to improve his diabetes management and the disease would become more intrusive.

In summary most of the respondents viewed their illness as an interruption unless they were struggling to control one or more of the areas of *self*. At these times they either found the disease intrusive or felt that they were immersed in the disease. This is graphically represented in Figure 6 below.

![Illness self representation model](image)

**Figure 6 Illness self representations**

Therefore the illness *self* representations were adequate and "real," that is, they did hold meaning in the experience of adolescents and young adults with T1DM. They did represent exhaustively the various illness self representations, although one or two respondents suggested a word less than an interruption, the word was a “hassle.”

These illness representations are relevant to adolescents and young adults and they
can be generalized to a specific illness, in particular, T1DM. Certainly differences did exist in the psychological and sociological contexts of adolescents and young adults who hold differing illness self-representations. A discussion and conclusion concerning the study findings, which includes those concerning illness self-representation and comparison data from Study One and Two, follows in Chapter 6.
Chapter 6

Discussion and Conclusion

6.1 Introduction

The findings from this study indicate that people with T1DM need to work at controlling the disease; this finding will be explored in this Chapter. For a few respondents the task of “diabetes work” did not appear to be too onerous but, for most, the monitoring of the physical, emotional, social and related selves required hard work in attempting to balance all of these needs. Most respondents lost focus of their diabetes management for numerous reasons and struggled to regain focus. The Chapter begins with a brief overview, of pertinent study findings presented within a framework of actions and attitudes that may either hinder or assist the young person in their efforts to manage their diabetes. This is followed by a discussion of developed model of selves over time, and an exploration of some of the challenges of diabetes management. A possible explanation of why respondents might represent T1DM as an interruption, as intrusive or why they may become immersed in the disease is given. A discussion concerning the effect of the biomedical model of care follows with emphasis on the need for individualised care and setting realistic goals. It draws on and summarises literature relevant to the role of the health care professional, patient education and models of self management. Finally the Chapter addresses the limitations of the study and suggests conclusions which can be drawn from the study and outlines where and how the findings can be applied and makes recommendations for further study.
6.2 Overview

The series of linked studies reported in this thesis centred on respondents’ experiences of living with T1DM. In doing so it uncovered not only the struggles of these young people to manage the condition, but also the considerable personal strengths they brought to the task.

The researcher was struck by the fortitude shown by all respondents as they managed their particular situations in relation to this complex disease. There was a constant need for vigilance if any gains were to be made. In the main, respondents were resolute in attempting to keep the disease from overwhelming them, even those who had suffered complications as a result of having diabetes. In so doing, many demonstrated an admirable resilience in the face of disappointments.

There was a need for recognition by others (including professional carers) of their vulnerability. They needed, at times, a substantial level of professional and personal support. For some, appropriate recognition and support were not readily available. Investigating the effect of diabetes on the self has led the researcher to conclude, therefore, that young people negotiating this disabling disease on a daily basis have had to call up considerable motivation.

In the following paragraphs, new insights into the impact of T1DM on the self are presented, in terms of what hinders and what helps the self.
6.2.1 The physical self: what helps and what hinders.

The researcher was able to confirm with respondents that the problem in the area of physical management is not so much the impact of diabetes on the *self*, but the impact that endeavouring to manage the diabetes has on the *self*. Respondents identified interventions, instances or issues as either self-confirming or self-disconfirming. Included in these instances are those that are confirming of the physical *self* that is, when life is manageable and blood sugars are manageable. Self-disconfirmation occurs when in spite of good monitoring, blood sugars remain unmanageable, thus making life unmanageable. Confirmation or disconfirmation is essentially an intrapsychic process. Respondents felt a sense of achievement if they were able to manage or reverse unsatisfactory blood sugars or HbA1c results; this led to a greater sense of self efficacy, which then became a self-confirming experience. Conversely the inability to manage or reverse unsatisfactory blood sugar results became a self-disconfirming event.

6.2.2 The Emotional self: what helps and what hinders.

When the emotional *self* feels in control there is increased self esteem and self-efficacy, both of which are confirming to the *self*. Disconfirmation of the emotional *self* occurs when life is out of control, for what ever reason, for example sadness or anxiety which might lead to depression or pessimism with a flow-on effect where motivation is hard to muster. An example of this was seen when one respondent, from the illness trajectory group, who had been struggling with an extremely painful undiagnosed polyneuritis, was considered to have a psychiatric disorder, she felt so disconfirmed that she contemplated suicide. However when she finally found an
endocrinologist who was able to diagnose the problem and support her in her recovery she felt affirmed.

6.2.3 The Social self: what helps and what hinders

The social self feels confirmed when it experiences support from people such as friends, associates and health professionals. Most of the respondents felt supported by their friends and indicated that if they disclosed the fact of having diabetes, it was to these friends, because they could rely on them for support when they were experiencing, a hypoglycaemic episode or needed to inject themselves and have regular meals. B from the LS (longitudinal study) group and G and B from the IT (illness trajectory) group spoke of the nurturing and supportive role their endocrinologist played in their lives, illustrating that the endocrinologist did not set the goal posts too high and encouraged them to achieve their own best goals. A negative sense of self and disconfirmation was reported as occurring when K from the CG (cohort group) and S and from the IT group, had negative experiences with doctors who had not believed them when they had presented with legitimate physical illnesses and they had been referred to psychiatric care. Respondent 2 from the LS group and M2 from the CG found what they called “supposed” friends as being unhelpful when they indicated that they were faking their hypoglycaemia in order to gain attention this lack of social support is undermining of self.

6.2.4. The Related self: what helps and what hinders

The related self feels confirmed when relationships with parents, partners and siblings are warm and supportive, for example, M from the (LS) group, found his parents very supportive and encouraging, as did G and S from the IT group who suggested that they could not have managed life without their parents and B in the IT group spoke of
how nurtured she felt when her partner was able to support and assist her when experiencing night time hypoglycaemia. The converse leaves the related self feeling destitute and unsupported, such as in an instances when K from the (CG), felt her father was not supportive and S from the IT group indicated that she has been sent to boarding school at an early age and that her parents would have been the more appropriate people to assist her with her early diabetes management and when respondent 1 from the LS group and B and G from the IT group had found their domineering, controlling partners unhelpful.

6.2 5 The Model of self over time

In Study One a model was developed to describe the role of self in the diabetes management of adolescents. These ‘multiple selves’ were described in Chapter 4 as the physical, emotional, social and related selves. The ‘multiple selves’ model developed in the present study is now considered in relation to utility over time.

- physical self - remains the same in terms of trying to monitor the T1DM, time constraints appear to make more in roads into regular monitoring.
- emotional self - for some was under great stress
- social self - many had formed new friendships while others were yet to do so.
- related self - becoming more independent was not always simple for either the person with T1DM or for the parent. There is a sense of the person with T1DM sometimes wanting to relinquish control back to the parent and on other occasions fiercely wanting independence rather like wanting to take a holiday from the responsibilities, but as the data clearly demonstrates, there are no holidays from T1DM.
6.2.6 The challenges of diabetes management

Whilst each person must face individual challenges in diabetes self-management, respondents in this study all experienced some problems with compliance.

Each respondent had both unique and common responses to being diagnosed with T1DM. Most were shocked. Overtime some indicate that they had adapted to the T1DM, many others lived with T1DM in some sort of an uneasy truce, while others pretended it was not there and did the minimal amount of work to keep the effects of T1DM at bay. Some focused on their treatment regime and worked diligently at trying to maintain appropriate control however, the degree of effort put into diabetes management did not always determine the outcome.

6.2.7 The interaction of the selves and important findings of the study.

It is possible for the same person to feel confirmed in one area of self but disconfirmed in another area and it depends on this rather tenuous balance whether the person or (self) feels affirmed or rejected.

6.2.8 Disciplined self-management

In the model depicting diabetes as a rain cloud (Figure 2) the adolescent and young adult with diabetes use the protective umbrella of disciplined self-management. This model works well and resilience makes an important contribution. Thus when the person feels loved and supported then the physical, emotional, social and related selves all feel accepted, by friends, family and health care professionals. This support increases the resilience reflected in disciplined self-management. Therefore even if
the physical, emotional, social or related selves are experiencing difficulty or disequilibrium the respondent is still able to have a stable view of self - if approval and support are available.

Respondents are able to describe the disease as an interruption in their lives and they are generally able as (Figure 3-describes) to maintain a balance or perhaps an uneasy truce between the diabetes and the physical, emotional and social and related selves. As this global self, is more and more compromised - by the presence of severe diabetes complications, difficult physiological management, disapproval of and withdrawal of support by family, friends and professional carers - they might still cling to the concept of the disease as an interruption in order to try to prevent the threat to self-integrity.

When the person is no longer able to maintain the balance of all these selves the diabetes may be depicted as the ominous rain cloud (Figure 4b). This model has been extended to include adult development.
Diabetes is an additional burden at times when one or more of the selves are experiencing a significant stressor. This can lead to despair and depression in some and they may suffer from isolation and alienation which leads to a loss of connectedness with people (explored later in the chapter) (Younger, 1995). In order to avoid this depression, some resort to hyperbolic discounting or denial or defensiveness in order to move forward - mentioned later in this Chapter. This may result in a failure to care about any aspect of the self, as well as to lose focus, as noted in the Equilibrium Dilemma model (outlined in Figure 1, Chapter 4).
6.2.9 The reasons for viewing the disease as interruptive, intrusive and immersive: what helps and what hinders

It seems that there might be two reasons to represent the disease as an interruption in respondents’ lives. This might occur because when things truly are going well the disease is, in their reality, only an interruption or conversely this might mean that by keeping the disease at arm’s length it permits the young person a semblance of self-integration. Respondents varied in their experience of living with diabetes, and in the degree to which they regarded managing it as burdensome. Some respondents indicated that the concept of ‘interruption’ was too extreme to describe the management demands of the disease. Yet some of these respondents who were experiencing very good control of the physical, emotional, social and related selves described the disease as intrusive or immersing. This might be occurring because of the way the respondents represented the illness to self. They may represent, "the disease as the self, the self as the disease" which causes them to have total involvement with the disease because it effects every aspect of human activity or they may consider that "the self (total or part) faces a constant threat of outbursts of the disease" (acute and symptomatic illness). They may feel that there is permanent or a potential threat for an acute outbreak of the disease (Nerenz & Leventhal, 1983, p.28).

In contrast, other respondents in the longitudinal, cohort and the illness trajectory group sometimes described having diabetes as being immersed in the disease or its being an intrusive disease because they were struggling to manage the overwhelming nature of their disease. Charmaz (1991) illustrates that this might occur because the same person may experience the disease as "interruption", "intrusion" or "immersion", dependent on what is occurring in the disease process and that people can move in and
out of these illness representations depending on degeneration or remission of the disease process (Charmaz, 1991, p.10).

Urquhart, Law, Kelly, Huey, & Summerbell (2002) in a study into the regulatory role played by illness representations in diabetes management, do not accept that illness beliefs significantly affect diabetes self-management, but rather that having a sense of control in self-management is an important predictor of psychological well being. They suggest the use of cognitive techniques to modify behaviour that leads to disengagement from diabetes management.

For the respondents in this study, the difference between managing well and feeling overwhelmed was related to the presence of severe diabetes complications, the ability to maintain appropriate diabetes management of the selves, but in particular being able to achieve good BSL control. Many of the respondents, as mentioned previously, were extremely resilient and showed personal hardiness.

6.3 Personal resilience and hardiness and the concept of learned helplessness

The concept of resilience is an interesting one, similar to transformation and adaptation. Polk defines it as “the ability to transform disaster into a growth experience and move forward” (Polk, 1997, p.1). A resilient person is considered to be a person with a healthy sense of self and self efficacy, one who is determined and able to find meaning and manageability in life (Hunter & Chandler, 1999). The concept of hardiness, gleaned from agriculture refers to the ability of crops to endure adverse climatic conditions, and is closely aligned to resilience. This concept has
been extrapolated to health and illness. It describes aspects of personality that buffer the effects of stress (Low, 1996). In fact research studies indicate that personal health models are recognised as important positive determinants of self care (Hampson, Glascow & Toobert, 1990; Hampson, Glascow & Foster, 1995; Glasow, Hampson, Stryker, Ruggiero, 1997; Skinner, White, Johnson & Hixenbaugh, 1999; Skinner & Hampson 1998, 2001).

However, research completed by Hunter & Chandler (1999) identified that resilience in children and adolescents can lead to psychopathology and psychosocial maladaptation. They go on to cite Higgins (1994) who theorised that when resilient children reached adulthood they often became socially and emotionally maladaptive. Similarly they cite Luthar & Zigler’s (1991) findings, that some resilient adolescents showed high scores on depression and anxiety scales. These adolescents indicated that they considered themselves to be resilient because they disconnected from others they could not trust; they were isolated because they had inadequate or no social support and insulated because the emotional pain was too much to bear. The question then is posed: is resilience a healthy state? (Hunter & Chandler, 1999). They answer this rhetorical question by suggesting that resilient children can survive almost anything but, that the world may not like the outcome. Indeed Skinner, Hampson & Fife-Shaw (2002) reported from their research involving three hundred and fifty eight people with T1DM that a hardy personality did not in fact indicate the ability to manage diabetes but, rather people’s personal health beliefs.

Thus, any positive attribute such as self sufficiency, can become maladaptive if applied with excessive zeal (by either the person themselves or a significant other).
Many of the respondents mentioned throughout this study had displayed a great deal of resilience and hardiness when attempting to maintain appropriate diabetes management, but despite their best efforts they were unsuccessful and this may have caused them to adopt learned helplessness as a coping mechanism.

Seligman, Maier & Geer (1968) first described learned helplessness in dogs that were given inescapable electric shocks. This caused them to resign themselves to passively accepting these traumatic shocks. In 1972, Seligman studied the behavioural and psychological effects on humans who were exposed to uncontrollable traumatic effects and described the phenomenon of learned helplessness.

Generally people have structured plans for attaining a goal, but when they are blocked by uncontrollable failure, this causes a discrepancy between the imagined construction of successful performance and the inability to achieve a goal. They encounter helplessness training as a result of the constant thwarting of personal goals (Lazarus, 1991). Kutter, Delameter & Santiago (1990) in a study of fifty children with T1DM, describe learned helplessness as being associated with depression and poor metabolic control. They indicated that some of their study respondents adhered well to their diabetes management regime and still had poor metabolic control and others who adhered poorly to their diabetes regime were still able to maintain good blood glucose control. They offered various reasons for this - endogenous hormonal factors and an ineffective or erroneous regime. Some of the current study respondents might well feel thwarted from achieving their goal of good metabolic control because, despite their best efforts, they were unable to control their blood glucose levels and this uncontrollable failure may have led to a form of “learned helplessness”. Therefore, encouraging hardy behaviour in sick persons may cause them to disregard medical
advice in their pursuit of independence (Lee, 1983 cited in Low, 1996). Since threats to self-integrity cause people to re-evaluate how they negotiate life (Paterson, et al., 1999) respondents in this current study found unexpected hypoglycaemic events jeopardized their physical control and chose to maintain higher than normal blood glucose levels. Additionally encouraging people with chronic illness to develop hardiness may be judgmental since if they are unable to display this behaviour in the face of stressful situations, they may be considered deficient and this could effectively lead to victim blaming (Low, 1996).

Therefore, the idea of resilience may not reflect a person who is adaptable, flexible and competent in overcoming adversity. Rather it may be a survival tactic. It could however, be argued that it may be possible to harness the strength of resilience and produce healthy resilience - developing trust, connection competence and ego resilience (Hunter & Chandler, 1999).

There are, however, two opposing theoretical positions in relation to task failure found in the literature. The first position is that dwelling on failure (self-focusing on one’s shortcomings in a task) produces negative emotions, which people prefer to avoid, thereby maintaining their emotional equilibrium (Pyszczynski & Greenberg, 1985-1986 cited in Mikulincer, 1994). The alternative position, proposed by Janoff-Bulman & Brickman (1982, in Mikulincer, 1994) is that people do not give up after one failure, and that most people are able to persist even after a large number of failures…in fact failure may enhance rather than reduce self-focus. Individuals vary in their desires and ability to self-focus in failure. A positive value must be placed on the task associated with the failure with at least some likelihood of rectifying the problem, before self-focusing will occur. On the other hand, low-value tasks offer no
incentive to expend coping and self-focusing energy (Janoff-Bulman & Brickman, 1982, in Mikulincer, 1994). Interestingly, either of these positions could have relevance to the current study respondents.

Another aspect found in the data was that of body listening.

6.4 Body listening

Many of the respondents relied at times on body listening to determine what their blood sugar levels were, rather than performing blood glucose tests. Price (1993) explored this phenomenon of body listening amongst 18 insulin dependent adults and suggested that it was important to acknowledge that it was a way of “knowing one’s body” and could be “affirming to the person” and suggested that “the greatest fear…of the expert patient” was that “this expert knowledge” would be “discounted and less - than – expert interventions” would be given (p 51). Price encouraged body listening and indicated that it might be very helpful in assessing and preventing hypoglycaemia.

However, studies into predictions of accuracy and error rates in blood glucose estimation indicated that people have varied success in estimating their own blood sugar levels (Eastman, Johnson, Silverstein, Spillar & McCullam, 1983; Cox, Clarke, Gonder-Frederick, Pohl, Hoover, Snyder, 1985; Freund, Johnson, Rosenbloom, Alexander & Hansen, 1986; Nurick & Johnson, 1991; Ruggiero, Kairys, Fritz & Wood, 1991). There was less accuracy amongst children compared to adolescents (Eastman, et al., 1983) and adolescents generally experienced less accuracy than adults (Cox et al., 1985; Nurick & Johnson, 1991; Ruggiero et al., 1991). There was also revealing gender differences in body listening, with adolescent girls able to
estimate blood glucose levels more accurately than their male counterparts (Freund, et al., 1986) and adult men able to estimate blood glucose levels more accurately than women (Cox, et al., 1985). Meltzer, Johnson, Pappachan & Silverstein (2003) also found that blood glucose estimations were only accurate about thirty seven percent of the time, and that girls and older adolescents had a higher level of accuracy than boys and younger adolescents. They voiced concern about inappropriate self-medication resulting from the difficulty that people with T1DM had in estimating blood glucose levels accurately.

Evidence suggests that maintaining norm glycaemia reduces the incidence of diabetes complications (Orchard, Forrest, Ellis & Becker, 1997; Morris, Boyle, McMahon, Greene, MacDonald & Newton, 1997). Therefore the use of blood glucose monitoring to determine blood sugar levels is encouraged. However, determining the levels of blood glucose is somewhat time-consuming, requires a person to prick their fingers often up to four times or more a day, and sets the person apart from his / her non diabetic peers. As well as this, as mentioned before, it is sometimes the case that diabetes defies management logic and it is almost impossible to control. Outcomes, therefore, do not necessarily conform to a neat formula, no matter how well–reasoned.

6.5 Metabolic control

It seems logical that if you do not produce insulin then by administering insulin, judiciously exercising, and balancing your dietary intake, blood sugar control should follow. This, however, is far from true, particularly in the case of brittle diabetes (wide fluctuations in blood glucose levels despite best possible medical management). The causes of brittle diabetes are multifactorial (Dunning, 2003). These causes may
be physiological or psychosocial as mentioned in Chapter 2. Having brittle diabetes makes diabetes management very complex and may cause the person with T1DM to become discouraged as in the cases of three respondents in the cohort group (K and M1, M2) and all in the illness trajectory group.

Sometimes, metabolic control was further complicated by the inability of the respondents to give their injections and perform blood glucose tests. While some respondents overcame this fear and summoned up the courage and skills to do them, others really struggled to overcome the phobia of giving themselves injections and finger pricking (Snoek, Mollema, Heine, Bouter & Van Ploeg, 1997).

Some who do everything to control their blood sugars still find it almost impossible to maintain norm glycaemia, some struggle to administer their insulin and others-who do not seem to have to work as hard, on diabetes management—seem to have better blood sugar control. These marked differences could well be because some respondents still produce small remnants of insulin and because some people are less susceptible to the effects of stress which is known to impair insulin sensitivity (Nagengast, 1989; Moberg, 1994).

6.5.1 Hypoglycaemia

Those involved in the diabetes complications trial reported severe hypoglycaemia to be three times higher in the intensive therapy groups than in the conventional therapy groups (Teucher & Reinli, 1994; Bulsara, Holman, Davis & Jones, 2004; Pacaud, 2004). Severe hypoglycaemia is defined as “neuroglycopenia that renders the patient
unable to self treat because of mental confusion, incoordination, lethargy, or unconsciousness” (Gonder- Frederick, Cox, Kovatchev, Schlundt, & Clarke, 1997, p. 661). Severe hypoglycaemia can have very frightening and negative outcomes which range from feeling nervous, sweating and hunger, to confusion, weakness, seizures and coma. This can lead to social embarrassment, accidents and even death (Ritholz & Jacobson, 1998). These sequelae cause the person with T1DM increased anxiety levels if they are prone to hypoglycaemia (Wredling, Theorell, Roll, Lins & Adamson, 1992) and they become discouraged from pursuing intensive insulin therapy. This was true for most of the respondents, and in particular for M1(CG), who performed multiple blood sugars and needed counselling because of her extreme anxiety, and M2 (CG) who had experienced a near drowning as a result of hypoglycaemia and who was subsequently constantly monitored by family and friends. Most of the other respondents did not like the lack of control that occurred with hypoglycaemia. This then becomes a major barrier to improving diabetes control. It is not easy to prevent hypoglycaemia since insulin regimes are not perfect and the person may administer excess insulin from time to time (Ritholz & Jacobson, 1998; Gonder- Frederick, et.al., 1997).

Ritholz and Jacobson (1998) contend that this fear of hypoglycaemia is not a new phenomenon. Medical records of the world famous Elliott Joslin (late nineteenth century endocrinologist) indicate the conflict between the need for control of the diabetes and its inherent complications, and the struggle for normality and the incorporation of a sense of self in relation to the disease. Tight control of blood sugars may reduce complications that result from hyperglycaemia but this may have some negative personal consequences that cannot be underestimated.
It is the case that the mortality rate of children with T1DM as a result of diabetic ketoacidosis is still excessive (Edge, 1999). However, the issue of ‘dead-in-bed’ syndrome (a situation where young people with T1DM are found dead in the morning when there has been no evidence of illness or abnormal glucose control) is equally frightening. It is possible for a young person on multiple dose insulin to make a mistake with their insulin dosage. If they suffer from hypoglycaemic unawareness then they might not wake up in time to take action to prevent the hypoglycaemia leading to unconsciousness, cardiac arrhythmias and possible death (Kramer, Fasching, Madl, Schneider, Damjancic, Waldhausl, Irsigler & Grimm, 1998; Weston & Gill, 1997; Hanas, 1997).

While some contend that there is no difference between the attentional functioning of people with T1DM, with or without a history of severe hypoglycaemia (Snoek, et.al.,1998), other literature indicates that, with the use of more modern tests such as magnetic resonance imaging of the brain, people are at risk of hypoglycaemic – induced brain damage (Fanelli, Paramore, Hershey, Terkamp, Ovalle, Craft, & Cryer, 1998; Kovatchev, Cox, Gonder- Frederick, Young – Hyman, Schlundt, & Clarke, 1998; McCall, 1997; Amiel, 1997; Perros & Frier, 1997; Perros, Deary, Sellar, Best & Frier, 1997; Wredling, Levander, Adamson, Lins, 1990).

This thesis has made it clear that people with T1DM face a daunting task - they are encouraged to remain norm glycaemic to prevent the long–term complications of DM, and at the same time avoid hypoglycaemia. From the person with T1DM’s perspective the psychological costs of persistent hypoglycaemia can vary from mild
inconvenience to phobic avoidance of low blood glucose levels. The real possibility of hypoglycaemia is a consequence of insulin therapy, but fear of hypoglycaemia can prevent people from striving for good control. This problem, as discussed in Chapter 2, (p.42), is compounded by hypoglycaemic unawareness (Kwasi, Sherwin, Murphy, Kerr, 1996). Since many of these management problems seem, from the outside, quite onerous it is of interest to note that many of the respondents saw their T1DM as only an interruption in their lives.

6.6 T1DM as an interruption

It is surprising that although a person might have experienced quite substantial complications as a result of having T1DM they still represented their illness as an interruption in their lives and struggled to follow a strict diabetes management regime. Why this is so might be explained from one or other theories about illness and illness management. A range of these theoretical explanations is outlined below.

6.6.1 Self–perception and beliefs about illness

Wichowski and Kubsch (1997) offer some useful insights into why T1DM may only be viewed as an interruption. They suggest that in childhood self-perception is not distorted by beliefs about illness. Children perceive themselves as being “normal” even though they have a chronic disease or disability. They further suggest that this might be as a result of the child always having had the disorder or contracting the disease at an early age. Therefore their current health status is the norm and they do not perceive themselves as ill (Wichowski and Kubsch, 1997). This seems to be supported by a study conducted by Hester (1987), a paediatric nurse, who found that
both diabetic and healthy children viewed themselves as ‘well’ and that illness was not a prominent theme in the conversations of these children with T1DM. Hester’s conclusion was that these children had not internalized illness as part of their self-concept.

A view put forward by Coombs & Snygg (1959) is that people think and behave according to the concepts they hold about themselves and their abilities. It follows that self-perception is a major determinant of both thoughts and behaviours. In order to preserve psychic integrity every person tries to achieve, at least, an adequate perception of self.

Charmaz (1991) puts forward a similar view and indicates that if people do not experience "altered bodies in their own worlds" they are able to define their disease as short-lived. While this might be seen as denial of reality, she argues that it is the reality of the person’s experience. Charmaz does concede that some people stretch the "allowable" length of the acute illness, because they do not wish to acknowledge that the disease has developed into something more than an interruption (Charmaz, 1991, p. 20). This may be because people who perceive themselves as ill or disabled experience a state of “dis-equilibrium in the self concept” (Roy & Andrews, 1991, p. 45) and people may use various strategies to maintain consistent self-organization and to avoid the discomfort of psychic dis-equilibrium.

6.6.2 The perception of the need to change behaviour.

Another reason why illness might be represented as an interruption is that before people become motivated to change their behaviour they must first believe that they are susceptible to illness, perhaps to the point of acknowledging poor lifestyle habits
or non-compliance with a medical regime. They must also believe that the illness could have serious repercussions if it continues untreated. Additionally, the person must believe that the treatment plan will have definite benefits.

Sometimes a sign or action is needed to produce the necessary aroused emotions and resultant attitudinal and behavioural changes - this could be the development of the feared illness by a friend or the manifestation of the symptoms in one’s self (Becker, 1974; Anspaugh, Hamrick & Rosato, 2000) or, in the context of the present discussion, the retinopathy and nephropathy reported by a number of study respondents after several years of being asymptomatic.

6.6.3 The transtheoretical model of behaviour change

The transtheoretical model of behaviour change described by Anspaugh, Hamrick & Rosato (2000) might be useful to describe this phenomenon of viewing the disease as an interruption. It may provide a reason for why so many of the respondents simply did not perform their blood sugar levels, prior to administering insulin.

This model consists of six stages, pre-contemplation, contemplation, preparation, action, maintenance and termination stages.

The pre-contemplation stage is where individuals have no intention of changing in the future, may have no idea of the health risks associated with their behaviour or have a sense of hopelessness about their situation since they might have tried to change unsuccessfully. They resort to denial or defensiveness in order to move forward. The contemplation stage occurs when people have an awareness of
problem behaviour and begin to consider seriously changing that behaviour. It is possible to remain in the contemplation stage for years because, to make the change, requires more effort than the person is willing to expend or the rewards of the current behaviour outweigh the benefits of the changed behaviour. In this stage people may experience “cognitive dissonance”, which is internal conflict accompanied by emotional arousal - an individual is aware of inconsistencies between current behaviour and the need to change. In the **preparation stage**, action is planned - an individual, is convinced of the need to change. In the **action stage** people are making visible changes and putting considerable energy into these changes. The **maintenance stage** follows - for consolidation of behavioural patterns to occur, rewards or satisfaction must be evidenced. The **termination stage** occurs where the problem behaviour is no longer tempting. Unless consolidation takes place, people will relapse and return to the pre-contemplation or contemplation stages.

An all-or-nothing mindset is unhelpful when positive health-related behaviours are in the process of being consolidated. Such a negative perspective has a profound demotivating effect if goals are unrealistic, or are not achieved as quickly, or to the desired extent (Anspaugh, Hamrick & Rosato, 2000). Therefore health professionals act wisely when they assist their clients to develop goals that are both achievable and specific to the client’s situation and context. Many of the respondents interviewed were still in the pre-contemplation and contemplation stages. Either because they unwilling or unable, maybe because of other perceived more important priorities, to put in the considerable effort required to change, or because they had tried and failed.
6.6.4 The Sick Role Theory

The Sick Role Theory (originally proposed by sociologist Talcott Parsons in the 1950’s), modified several times since, and misunderstood by many!) is perhaps another explanation for the experience of diabetes as an interruption. This theory suggests that non–compliant people have not adopted the sick role. They may be experiencing “sick–role failure or sick role conflict”. They fail to demonstrate behaviours appropriate to their stage of illness on the health or illness continuum. Such people would most likely not follow physicians’ orders and / or refuse treatment and medication (Wichowski & Kubsch, 1997, p. 551). Many of the respondents had long periods where they had not focused on diabetes management, perhaps because they did not view themselves as being sick and were focussing on other priorities.

6 6.5 The Hyperbolic Discounting Theory

Another reason for describing T1DM as an ‘interruption’ may be related to the Hyperbolic Discounting Theory described by Ainslie (2001). Ainslie describes discounting curves in connection with additive behaviours. He bases his theory on the mathematical hyperbolic curve suggesting that people devalue future goods (in this context read health complications) proportionately to their delay; and this discount curve is hyperbolic. It could then mean that those with T1DM might tend to devalue future events that is, the problem of diabetes complications, believing that they are very distant events. According to Chapman, Brewer, Coups, Brownlee, Leventhal & Leventhal (2001) numerous studies illustrate that very little weight is given to future outcomes by those with, or at risk for chronic illness, and this accounts for the fact that people do not adopt preventative health behaviours or become involved in future minded activities. Kirby, Petry & Bickel (1999) in a study of people with heroin
addiction indicated that they had very ‘high discounting rates’ in terms of dire consequences - for example, the threat of jail, losing the custody of their children and even the threat of premature death from AIDS.

6.6.6 Defensive avoidance

Respondents in this study may have been employing defensive avoidance. Lowenstein, Weber, Hsee & Welsh (2001) argue that to induce guilt and anxiety is counterproductive since it not only adds to the burden carried, but may also induce a defensive reaction called “defensive avoidance” where people ward off exposure to the content of the message resulting in information avoidance and risk mitigation. In fact, some literature suggests that breast self-examination may induce anticipatory anxiety about cancer and, therefore, women do not examine their breasts (2001, p. 13).

Oliver (2003) describes a similar concept called the Allais paradox, where people weigh up outcomes in terms certainty and probability. His study participants made health decisions on the basis of certainty and probability.

Defensive avoidance and the Allais paradox might also account for the attitudes of some of this study’s respondents who, even when faced with the consequences of diabetes complications, still are not persuaded to manage their T1DM more strictly and why they choose not to perform blood sugar levels, administer their injections, or visit their doctor.
Some of these theories may account for why those that were already dealing with the complications of T1DM only saw their disease as an interruption. They may also account for some of the risk taking behaviours adopted by some of the respondents, such as becoming involved in drug taking. The experience of T1DM as intrusion and immersion is discussed below.

6.7 T1DM as an intrusion or being immersed in your T1DM.

Most respondents indicated that at times of hopelessness or depression their disease was intrusive or that they felt immersed in the disease.

6.7.1 Depression and the *self*

Many of the respondents reported that they had or were suffering from depression. This high prevalence and incidence of depression has been validated by a number of authors (Grey, Cameron & Thurber, 1991; Kovacs, Goldston, Obrosky, Scott & Bonar, 1997; Jacobson & Weinger, 1998) and this might be because adolescents and young adults with T1DM are at risk because of the demands of their condition (Grey, Lipman, Cameron & Thurber, 1997) or may result from low self-esteem, social dependency and poor ego development. Gilbert & Gilbert (2003) argue that a sense of defeat and entrapment related to unsuccessful efforts to control their blood sugar levels may lead people to become depressed. Other reasons as to why this might occur are discussed below.

Discovering, accepting and being comfortable with one’s ‘true self’ are major tasks of adolescence. That is, the goal at this stage of psychosocial development is to find a
clear identity, and eventually to understand and accept their individuality and uniqueness. A negative outcome leads to role confusion (Erikson, 1968). Success results from open, sometimes painful and protracted interactions with the emergent self and with others, and a growing confidence which allows young people to feel competent in facing life challenges. For some, this is a hard-won outcome which may entail significant struggle. Erikson (1959) makes it clear that the process of transition though psychosocial developmental stages is far from cut-and-dried. Unresolved conflicts or remnants from a past stage (or stages) may continue to linger. In the present context of this discussion of young people struggling with diabetes management, comfortable role transition can be inhibited by uncompromising clinical or social pressures to achieve full compliance where this is not individually possible. A lack of personal authenticity occurs when there is a lack of autonomy, and results in feelings of helplessness, frustration shame and anger (Howard & Callero, 1991) - all precursors to depression.

Harter (1997) when describing self and identity suggests that, “if significant others” [in this study, read clinicians, family and close friends] ignore, reject, devalue or actively denigrate one’s ‘authentic self’ (p.100) … then individuals (whether children, adolescents, adults male or female) will be driven to suppress the true self and to display manifestations of false self behaviour. Harter goes on to comment that such behaviours are motivated by attempts to obtain approval, to avoid rejection in order to maintain some form of connection - “Paradoxically, however, efforts to sustain a relationship and please others that require a distortion of the self, not only leads to disconnection from one’s true self but disconnection from significant others since they also prevent an authentic relationship” (Harter, 1997, p 100). Often the respondents
were trying to please the health professionals and perhaps their parents, but when they were unable to achieve or sustain appropriate diabetes management, they were often told that they were not trying hard enough. They felt that despite their best efforts they were unsuccessful and this led to discouragement.

This lack of a voice in a relationship can lead a person to devalue self which may cause people to reflect a false, more acceptable self. Kolligan (1990, cited in Ashmore & Jussim, 1997) reports that this perceived fraudulence in adults, results in self criticism and depressive tendencies. It is conceivable therefore that continual non acceptance by health professionals would lead to fabricating of blood sugar results so as avoid the lack of approval of those who adolescents and young adults seek to impress. Significant others may not understand what it is like to live with T1DM and, as is reflected in this thesis, may lead the person with T1DM to become disconnected from those that devalue them.

Paterson, Thorne, Crawford, & Tarko (1999) assert that threats to self integrity arise when negative challenges or unsatisfactory experiences occur. For example, they point to study participants being ‘accused of cheating’ by health care professionals because of their blood glucose levels, even though they had been adhering to their treatment regimes. These participants indicated that they “no longer had faith that [the physician] knew what was right for them” (Paterson et al., 1999, p.794). For respondents in the present study what was important to them was the trust that they had in their health care professional and that they understood them as a person not just as a diabetic. This was also found to be true in the study of Paterson et al., (1999).
Many of the respondents described in this thesis had a similar experience. They had not passed the “test” which would reward them with approval from powerful health professionals. This disconnection resulting from loss of confidence in clinicians and others acting as advisors could lead young people with T1DM to action the non-compliance they are being accused of - missing clinical appointments, not being careful with diet, not exercising - because they are unable to meet the standards set by unaffected others, since they are not acknowledged as individuals who are more complex than the simple sum of their blood sugars and the outcome may be periods of depression.

The highest levels of false self-behaviour are those reported by adolescents who are receiving relatively low levels of support which they feel is conditional. The assumption is that the higher the level at which they achieve results that please the health professional, the more support they will receive. This causes them to feel hopeless about pleasing others and this in turn causes them to suppress their true selves. Symbolic interactionists suggest that incorporation of certain attitudes that others hold about the self, which do not reflect one’s own experience, may cause an individual to engage in actions designed to please or impress others. This can be so even if actions violate ones sense of core self. A common reason for failing to express one’s true self is that this real self has not been, and will not be, given approval or acceptance by significant others. Implicit in this situation is the tension between the one’s sense of true self and the false self that is being manifested (Harter, 1997) and this could lead to depression in the respondents.
For the young person with T1DM the normal challenges and difficulties of moving through the age-specific developmental tasks of adolescence and young adulthood are complicated by the essentials of incorporating treatment regimes into their daily lives, and coping with the potential threat, or actual onset, of diabetes complications. It is therefore not surprising that some people with T1DM express feelings of emotional distress. They also struggle with motivation as they try to negotiate their diabetes management and express feelings of ‘guilt, discouragement and of being overwhelmed’ in this process. Some people present with overt psychiatric disorders such as major depression and eating disorders which present in poor glycaemic control. People with T1DM who are non-responders potentially represent persons with greater diabetes management problems (Welch, Jacobson & Polonsky, 1997) since they are more likely to suffer from diabetes complications as a result of not focusing on adequate blood glucose control.

From this study, the researcher is unclear whether it is possible to incorporate “the enemy within” into the self. It is unclear whether this is a good thing to do because by surrendering the T1DM may become engulfing. In fact the respondents represent the self in their language and they say things like “my diabetes”, “my insulin”, “my needle” “my diet” and “my blood sugar levels”, almost because they have no option. Indeed, “diabetes is not a condition that individuals accept and manage once and for all the process is continuous…people continuously have to “renegotiate the relationship between diabetes and the self.” (Goldman & Maclean, 1998, p.746) and this process is described in this current study as an “uneasy truce. This ‘uneasy truce’ between ‘the self and T1DM involves emotional, relational and spiritual disharmony
which could lead to depression. Another issue emanating from the data was that of suicide and eating disorders.

6.7.2 Suicide

Adolescents and young adults, who wish to maintain the integrity of their true self, but who continuously receive negative feedback, will, as a survival technique, abstract themselves from the situation. Being unable to actualise the self authentically is a real cause for concern because, both in theory and research, such a situation is associated with very low self esteem (both global and relational), a sense of hopelessness and depression, even leading to self destructive behaviours (Harter, 1997). In worst-case scenarios, suicide, as well as other anti-social behaviours, may occur. Some respondents in the current study had contemplated and attempted suicide when their health and life situation seemed untenable.

6.7.3 Eating disorders

Four respondents in the study mentioned their struggle with eating disorders. Eating disorders occur in female adolescents with T1DM twice as often as amongst their non-diabetic peers (Jones, et al., 2000). It is of interest to note that the incidence of eating disorders reported in a research study, suggest that one third of teenage girls with T1DM may suffer from eating disorders such as anorexia nervosa and bulimia (Rydall, et al., 1997).

Issues which may predispose adolescents and young adults in general, to eating disorders are weight gain caused by the multiple dose insulin therapy, dietary restrictions and a co-existing continual preoccupation with food. This preoccupation, impacts on activities of daily living, as well as interfering with geniality and social
relationships. Food amount and type, and associated restrictions may become the main source of conflict with both parents and health professionals. In a number of cases the deliberate choice to suspend or reduce their insulin is a common symptom underlying an eating disorder. More than one third of the teenage girls with T1DM admitted to under dosing their insulin in order to lose weight (Felix, 1998). The combination of all these variables can lead to poor metabolic control and increase the risk of microvascular complications (Franzese, Valerio, Buono, Mozzillo, Gritti & Lucariello, 2002).

Thus, reluctance to comply with diabetic management regimes can be framed within three personal perspectives. The first is that those with T1DM know there own bodily responses best, and respond accordingly. The second perspective is that each responds differently to T1DM and their response is not necessarily a textbook response. Finally people with T1DM have a practical knowledge of their bodies which is unique and this uniqueness is poorly understood by those without diabetes. Chronic illness (and in particular T1DM) is imbued with different symbolic meanings for the sufferer and the carer or significant other. That meaning to a Significant Other who inevitably becomes an ‘outsider’ might be quite different to that of the ‘insider’ (i.e. person with T1DM). The way in which an illness must be managed might be quite sensible to the outsider and in fact, it might be empirically proven to work. This, however, does not guarantee that the insider finds the management sensible or even practical. The skill of diabetes management is to be able to maintain the integrated self whilst running what can seem to be the marathon of life. There is a need to understand the person not as a “diabetic” but as a person who incidentally has diabetes, and who requires individualised care.
6.8 The effect of the biomedical model of care

The research findings of this present study have implications for all health professionals who work with people with T1DM, an area still dominated by the language of a seemingly authoritarian biomedical model.

For example, we speak of control, complications trials, diabetes management, regulating, modifying diet, insulin and exercise regime, the national diabetes strategy and implementation plan and the national diabetes task force. This terminology makes people with diabetes feel “more like they are taking an exam to be passed or failed” (Beeney & Sharpe, 2001, p.4). In adolescence and young adulthood there is a struggle to discover the self. A self that, at times, may be very tentative, and lacking in confidence and each time they do not ‘pass’ a blood glucose test these unconfident selves may feel a failure.

The Diabetes Control and Complications Trial provides incontrovertible empirical evidence of the importance of good control of blood sugar levels to avoid serious complications that can occur in poorly controlled diabetes. However, when the focus of professional care is only one aspect of the young person’s self i.e. the physical (reflected in passing the HbA1c test) and ignores the impact that conflicts raging in the other selves have on physiological control, the myth of the biomedical model of care as adequate is perpetuated.

If young people with T1DM can only feel valued by their health professionals when they can demonstrate ‘good’ results, rather than for continuing to strive for some normality on many fronts, they may be feeling additionally stigmatized, that is,
beyond the indignity which accompanies having T1DM in the first place. This could lead to further difficulties in diabetes management.

Margarete Sandelowski (1999) whose more recent work has focused on the often dehumanizing influence of technology in health care, stated “technologies hold multiple meanings to various human users who see its potential for serving particular ends… technologies are what they are not only by virtue of what they are physically and materially but also by virtue of what they become in a particular user context” (p.40). Applied in the context of this present discussion, her comments could suggest that glucometer readings and Hb A1c’s, for the health professional (doctor and nurse) may not only be a way of monitoring how a person is controlling their blood sugars, but may also constitute a form of salient control. For the respondent, it could reinforce his/her responsibility for blood glucose levels, inducing a sense of guilt and culpability if, or when, the health professional pronounces them unsatisfactory.

While some level of need for approval is present at this developmental stage there is also the desire to break away from parental (or parent-figure, as in health professional) authority and to seek their own identity. This authority may be rejected by the very people that health professionals are seeking to assist and reflects the aversion young people have towards visiting health professionals.

The dominant developmental task in adolescence involves moving towards autonomy and this is best achieved in the “context of meaningful relationships with significant others” (Ashmore & Jussim, 1997, p.98). Yet another issue is the abrupt transfer of care from the paediatric to the adult setting.
6.8.1 The abrupt transfer of care

A reason why informants in the study, specifically those in the adolescent and young adult groups with T1DM, often stop visiting their clinics or doctors is the abrupt transfer to the adult sector with little choice of doctor. In Australia, there is a tendency to transfer the adolescent to adult diabetes clinics as soon as nominal adulthood is reached (Colagiuri, 1998). Having developed a rapport with their paediatrician, who is often the person who helped them to deal with the crisis of diagnosis, they are transferred to another doctor, usually without discussion or consultation. They are uncomfortable with having to interact with someone new, and suffer the insecurity of losing a significant and supportive clinician. Somewhat akin to the migration process, they arrive in new territory, looking backwards to what was, in some respects mourning the loss of the familiar, and being expected to conform to a new regime.

As children, they had developed good rapport with their paediatric doctor, over a long period, where there was a friendly family approach. On suddenly being dislocated from this security, and possibly not being evaluated as sufficiently mature, independent and ready to deal with this transition, they lacked readiness to take on the responsibility of self-management (Fleming, Carter & Gillibrand, 2002; Sawyer, Blair & Bowes, 1997; Frank, 1992).

A current study is being conducted into this issue in South Australia. Preliminary findings are that often these adolescents and young adults had not had recent diabetes education and their insulin regimes were changed to more intensive regimes when they were transferred to adult care. The researchers concluded that these young
people needed to be supported through this period of change and that gaps in the system needed to be identified to make the transition a more satisfactory process (Visentin, Sonnack, Taylor, Koch, Kralik, Howard & Dennes, 2003).

Previously, although they were involved in their diabetes management they could at times lean on significant others for support and help was forthcoming. Now, however, because they felt rushed from childhood into adulthood, they were more often than not expected to behave as fully independent young adults. This was frightening and intimidating especially at a time when they not only had to manage their T1DM, in a more stringent environment, but they are also involved in the search for self (Visentin, et al., 2003).

Increasingly, health professionals are aware of holistic and developmentally-focused approaches in service provision. Such principles as acknowledging that clients function in more than one context, that they are more complex entities than a diagnostic label could suggest, and embracing the value of effective interpersonal communication and support may gradually turn the biomedical tide toward more empathetic management styles. These complex styles are particularly desirable for young people with T1DM. Experts in the management of diabetes now readily acknowledge that past good control may not necessarily continue. What may not be so well understood is the need to meet and validate the person wherever they are on the continuum of ‘good’ and ‘not-so-good results’ - a “walk a mile in my shoes” philosophy - as the findings from this present study suggest.
6.9 Individualised diabetes care

Living with diabetes has major social implications. This is an important issue in diabetes management and being cognisant of this can improve diabetes education and treatment (Tildesley & Johns, 2004). Rather than attempting to make individuals fit into a fixed educational framework, it would be of greater importance to understand the uniqueness of each individual’s needs and attempt to work towards meeting these needs (Goldman & Maclean, 1998).

Diabetes management strategies and responses to clients cannot, therefore, be based on any assumption of linearity, that is, in anticipation of continuing good and uncomplicated outcomes. Not only that, but each meeting of a young person with T1DM with a health professional can have different meanings and may require exploration of particular issues, depending on current concerns of the individuals (Goldman & Maclean, 1998).

Emotional arousal, resulting from the threat of complications may cause short term focus. Then, as time goes on, the relevance of the perceived task diminishes as blood sugars become more and more uncontrollable and the person loses focus of the goal. This may explain the cyclic model that people experience when trying to control their blood glucose levels.

How then can this loss of focus cycle that occurs in The Equilibrium Dilemma be broken? Simply the health professional needs be supportive and to set realistic goals.
6.9.1 Setting realistic goals.

Anspaugh, Hamrick & Rosato (2000) assert that setting unachievable goals undermines any achievable results. People should be assessed to see what is achievable for them as an individual in terms of their health goals. While it is desirable for all with T1DM to sustain the least possible damage the question arises whether this ideal is realistic for everyone. The essential conflict is between surviving in the “now” and dealing with complications later.

This is well represented by the Competing Realities Model (Figure 5 in Chapter 4.). The reality of profound hypoglycaemia and possibly coma or death in the “now” competes with the reality of diabetes complications “later”. Each study respondent faced a difficult choice between present quality of life, with some choosing to live with a high or higher - than normal blood sugar level and some quality of life, while others chose the potential for longevity and with it, the risk of profound hypoglycaemia. The latter choice was more likely to be associated with a history of minor hypoglycaemic episodes; the former with fear of or actual experience of hypoglycaemic insensitivity or of an unstable diabetes profile.

For some, especially in the illness trajectory group, complications just did not seem to be a reality until they were confronted with them. The issue of diabetes complications confronts these young fragile selves as a constant struggle. Sometimes, to keep some of the self intact they ignore some of the other realities.
6.9.2 Interventions – Are they achievable?

In the Diabetes Control and Complications (DCCT), with a large group of carefully selected highly motivated research participants provided “with ample resources and education only 5% maintained an average concentration of glycosylated haemoglobin in the target or normal range (less/equal 6.05%)” (Jacobson, 1996, p.1249). Maintaining blood glucose at these levels can delay the onset and slow the development of microvascular complications, however, if only a relatively small number are able to achieve this goal, the task is intimidating and it must be asked at what cost to those young people with T1DM who struggle for any sort of control.

In this thesis many of the respondents (especially those in the IT group and some in the CG group) indicated that initially they had taken on the task of diabetes management with great enthusiasm, but in spite of their best efforts they had not been successful in achieving appropriate blood glucose control. It therefore becomes imperative that the goals that people with T1DM are expected to reach are realistic and achievable.

Some theorists would argue that people are transformed by chronic illness, suggesting that the experience of enduring is an introspective process, with much to be discovered which may lead to personal growth - a growth where this restructuring of the illness experience leads to a restructuring of the self (Charmaz, 1991; Strauss & Corbin, 1988).

Conversely, Thorne (1990) refers to ‘constructive non compliance’ because some people may choose not to ‘normalize’ (i.e. adapt or conform) since they may be
concerned that it prevents them from forming authentic identities (Thorne, 1990). This might be particularly true of adolescents and young adults with T1DM who are seeking to develop their own unique identity in the face of its unarguable chronicity.

The fact that, so many of the respondents interviewed indicated that their disease was an interruption could be understood in several ways. They were able to manage the disease and did not become immersed in the disease. Alternately they found it difficult to manage the disease and while it did not impinge on their lifestyle too much (they had not yet developed complications of diabetes) they were able to keep the disease at arms length.

6.9.3 Control, transformation–or both?

In the context of the present discussion, this term control should be understood as a developing sense of personal control in adversity or chronicity. Whilst Johnson & Morse (1990) describe this transformative process in terms of adaptation (learning to live with the illness and regaining control in the process) this essentially depends on the reason for the transformation - whether it is self-initiated or develops in response to the expectations of others? The expectation of others could result in unwanted pressure and an undermining of whatever control the person has been able to achieve. Newman & Moch (1991) indicate that people in their study of people with heart disease, who had experienced transformation, had less need for control than other participants.

Many writers propose that the self is restructured to integrate the constraints imposed by chronic illness; this is deemed necessary before one can accept and come to terms
with the illness. In reality this restructuring and integration might only last until the
next insult to the self is experienced, either as a result of further intrusion of the
T1DM on the self, or perhaps some personally disconfirming interaction with family,
friends and health professionals. According to symbolic interactionists, this is
because self concept grows out of social (i.e. symbolic) interaction and is contingent
on social interaction for its maintenance (Turner & Billings, 1991). One’s personal
identity is often confirmed by our choice of situations and activities.

In applying these concepts to young people with T1DM, two things are important to
consider. Firstly, disconfirmation of the self in the midst of managing an extremely
complex illness may lead to prioritizing self-protective strategies. Both
disconfirmation and self-protection drain emotional and physical resources, leading to
stress-induced blood sugar level distortion and further cyclic psychological and
metabolic destabilization. Secondly, identity is an intra-psychic phenomenon, the
development of which may usefully be regarded as ‘work in progress’, particularly so
in adolescents and young adults. While this has a hopeful aspect - an optimistic view
of humanity as being open to change and further development - the young person with
T1DM may not be able to avoid the onset of physical complications if too much time
passes.

The respondents in this study suppress emotions at great emotional cost often as a
result of the powerful influence of negative thoughts and expectations about
themselves and the future. In order to prevent negative possibilities for the self, the
person spends a substantial amount of time thinking and worrying about them,
fortifying themselves against them and planning and rehearsing strategies to prevent
them. If they are unable to protect themselves they may experience depression,
learned helplessness, withdrawal, misuse of alcohol or drugs and display other related
maladaptive responses. This might mean that the respondent withdraws from treatment by missing medical appointments or ceases blood testing or discontinues their insulin, since they are a constant reminder of failure.

The health care system can be difficult to negotiate and health care professionals have limited knowledge about an individual person’s condition. This problem can be compounded by insensitivity and disregard of the person’s needs for sympathy, support and validation. Young people with T1DM are in the ambiguous position of needing others and yet having to carry the private burden of protecting themselves during social interaction. Nurses are particularly well–placed professionally to work with their patients in developing strategies to reduce the distress experienced by the patient. (Dewar, 2001). This advantage unfortunately is off-set in a stretched and overburdened health care system (Lumby, 2001). In essence the writer concurs with Paterson et al., (1999), who believe that people with T1DM should not be categorized into transformed and untransformed, and rather they should be seen as evolving people.

We have addressed the changes that occurred in the selves of the respondents over time, and some of the complex issues involved in diabetes management. Some theories and reasons as to why T1DM might be represented as an interruption or why some might consider it intrusive or be immersed in the disease have also been suggested. The ineffectiveness of the biomedical model for the management of T1DM has been discussed and suggestions have been offered as to how to accommodate the unique needs of young people with T1DM who are courageously attempting to manage the complexities of a progressive and chronic illness, and making sense of their equally complex selves. It is important for health professionals
to understand these realities and display sensitivity towards those with whom they work.

6.10 The role of the health professional in diabetes care

Those who enter the health professions do so for a number of reasons, but one reason might be the desire to solve problems. There is a tendency for health professionals to be action-oriented and there is an expectation of undemanding compliance and co-operation from the person but, often the process of learning about health and cultural beliefs, requires the health professional to think about the individual's search for meaning (Omeri, 1996; Andrews & Boyle, 1997; McGrath, 1998; Andrews & Boyle, 1999; McGee, 2000; Wright & Leahey, 2000). Exploring the meaning of the illness, for an individual “requires a role shift from clinician as expert and doer to that of listener and learner” (McGrath, 1998, p. 29).

While health professionals are usually extremely busy, there is a need to be patient and empathic (Lumby, 2001). In fact, self-monitoring and reflective practice are necessary requirements in contemporary clinicians if they are to guard against alienating their clients. Health professionals need to be able to nurture the client until each is ready to assume control once more, and not to place such high expectations on that person that in order to retain some level of personal integration, they break away from the clinical relationship.
Respondents, in this thesis, spoke very highly of those health professionals who were nurturing, and were critical of those working in a biomedical model of care. They spoke of ‘nurturers’ whose focus was the effect of the disease and the treatment on the individual and who were overtly supportive. They also called up images of those therapists who were less nurturing, who appeared to listen but in reality did not, whose interest was solely on how often blood sugars were tested and how much insulin was needed, and who offered little in the way of validation of the person’s struggles or their growing self-knowledge.

Some of those in the longitudinal group who appeared resilient at first interview were indeed really struggling to still balance all the needs as they moved into early adulthood. This was true of those in the cohort group and the illness trajectory group as well. Thus there is a need to rethink some of our views about diabetic management.

Health professionals, and in particular doctors, usually place great emphasis on glycaemic control management of diabetes; which generally means advising the person about the need to improve their physiological management. Most patient education materials focus on intensive diabetes management largely compiled from the health provider’s viewpoint, with a focus on strict glucose control as the primary target. Intensive insulin treatment is rigorous and demanding. It presents a long term goal, but these apparent benefits do not take into account the fact that, many people with DM are more concerned about the strenuous imposition that intensive treatment entails and they lose sight of the possible future benefits (Wolpert & Anderson, 2001).
The theory of miscarried helping (Coyne, Wortman & Lehman, 1988 cited in Wolpert & Anderson, 2001) is instructive on this point. It is a style of well-intentioned helping where those efforts to assist or motivate another person lead, ironically, to situations which over time are constraining to the receiver of ‘help.’ For example, if someone is too persistent in making suggestions, a possible response could be irritation and resentment and an aversion to any advice. This theory illustrates that when long term goals are over-emphasised a cycle of negative interactions which are counterproductive can ensue. Optimal self care is then compromised.

There is need for the person to have a sense of autonomy in deciding their goals. Health care providers need to explore with their clients goals that are broader than simply glycaemic control. When guidelines for managing diabetes in young adults are framed from the medical perspective they concentrate almost exclusively on biological control which means tight glycaemic control with the ultimate goal being future health. Whilst this is a goal shared by young people, a more immediate concern for them is to prioritise life activities which, at the time may not always include strict glycaemic controls.

In order to prevent ‘miscarried help’ any person’s goals need to be incorporated into the treatment plan. As such, this is a generic principle in health education and management. Very importantly, goals or targets which are too ambitious and overlook the realities of life set people up for failure which then has an impact on the sense of success, competence and engagement with the self-management tasks related to their condition. Unfortunately, even though it is well-established that intensive glycaemic control can prevent microvascular complications of diabetes, these goals are rarely
achieved in clinical practice. Imposing treatment targets without incorporating the person in goal-setting destroys motivation and involvement and ultimately undermines any attempt at improved glycaemic control. A regime which is flexible, attainable and fits in with the person’s life is much more likely to be followed (Wolpert & Anderson, 2001).

6.10.1 Theory and practice of health education

One of the most important roles of nurses and other health professionals is providing health education (Downie, Tannahill & Tannahill, 1996). However, historically health education has been imbedded in an ‘authority model’ derived from the biomedical viewpoint which has a focus on disease prevention. This is seen by some as having a negative focus (Naidoo & Willis, 2000). Health promotion, however, is seen more positively as it involves health education but also includes an understanding of the environmental and societal issues that adversely affect peoples’ health (Mackintosh, 1996; Gonder-Frederick, Cox, Ritterband, 2002). Thus health education is seen as reductionist and biomedical. Nurses, often mistakenly consider themselves to be health promoters when they might well be traditional health educators (Norton, 1998; Whitehead, 2001). Often health education is based on teaching materials which are resourced by government funding, targeted at specific health issues and are therefore outcome focussed, health is thus seen as a commodity (Seedhouse, 1986, Mc Murray, 2003). As well as this, these programmes are often viewed as paternalistic and coercive (Brown & Piper, 1995; Stubblefield, 1997).

The challenges that face health educators are that there are no simple answers to complex phenomena (McQueen, 2000). Health education is largely unsuccessful because discrepancies exist between clients’ behaviours and beliefs (Dines, 1994). To
overcome these pitfalls clients should be given the option to choose their own priorities (Norton, 1998).

The contemporary goal of diabetes management as mentioned frequently is to maintain blood glucose levels as close to norm glycaemia as possible. Various education models for diabetes management have been developed to achieve this goal.

6.10.2 Models of Self management of diabetes

- Health Belief models and social-cognitive models: Many studies have demonstrated that personal-health belief and self-efficacy are predictive of self care (Brownlee-Duffeck, Peterson, Simmonds, Goldstein, Kilo & Hotte, 1987; McCaul, Glasgow & Shafer, 1987; Hampson, Glasgow & Strycker, 2000). The criticisms of these models are that health beliefs vary over lifespan development. Adolescents tend not to focus on long-term complications of diabetes rather they focus on short term needs. (Skinner & Hampson, 1999). Internal (personal) or external locus of control is often considered as a moderating influence in diabetes management, however, confounding finding with this construct, have been reported, since a sense of personal autonomy does not necessarily mean conforming to a tight medical regime which might offer negative feedback for non-compliant behaviours (Peyrot & Rubin, 1994).

- Compliance and adherence models: it often suggested these models are appropriate to assist in diabetes management. However, they have been criticised as being simplistic (Glasgow & Eakin, 1998), because they do not consider the variability that occurs in diabetes management over time and some aspects of diabetes management are more difficult to follow for some people than for others (Gonder-Frederick, Cox, Ritterband, 2002).
• Several effective interventions which improve patient coping are coping-skills training (Grey, Boland, Davidson, Li, & Tamborlane, 2000); stress management programmes (Broadway, Delameter, Tomakowsky & Gutai, 1993; Mendez & Belendez, 1997) and quality of life assessment (Polonsky, 2000).

• Current models of diabetes management focus more on education, counselling and empowering the person (Feste & Anderson, 1995; Anderson, Funnell, Carlson, Saleh-Statin, Cradock & Skinner, 2000; Gonder-Frederick, Cox & Ritterband, 2002). These models are favoured since they rely on empowering the person with the skills and resources required to carry out self care within the context of personal choice, rather than exerting pressure to comply with prescriptive recommendations (Gonder-Frederick, Cox & Ritterband, 2002; Politi & Trofino, 2003). Provision of interactive treatment is well suited to web based treatment interventions because it allows for people to be better informed although, this needs to be done with caution as knowledge and awareness do not necessarily eventuate in behavioural change and although the use of the internet is potentially beneficial it will possibly not be replaced by face-to-face care (Ritteband, Gonder-Frederick, Cox, Clifton, West & Borowitz, 2003).
6.11 Limitations of the study

Limitations of a qualitative study may be both conceptual and methodological and this might reduce the auditability, credibility, reliability and fittingness. However, in this thesis the questions of auditability, creditability, reliability and fittingness have been answered when respondents concurred with the models and attested that it reflected their experience.

Methodological limitations revolve around the methodology and the appropriateness of the research question and the aptness of the audit trial. Many of the respondents were from the support groups Juvenile Diabetes Research Foundation and Diabetes Australia, as mentioned in previous chapters. Literature suggests that there is a higher level of compliance with treatment goals among those who join support groups (Chun, 2002; Laudet, Magura, Cleland, Vogel & Knight, 2003), however, this was mediated by interviews conducted with those that were not from support groups.

Researcher bias may have been a limitation, as a nurse, researcher and a parent of a child (now adult) with diabetes. Despite endeavours made not to allow my various ‘roles’ to colour interpretations, this tacit knowledge and related assumptions, may have constrained some interpretations.

6.12 Conclusion

The aim of this study was to achieve an understanding of the role of self in adolescents and young adults with diabetes and its implications for health professionals. The objective was to use a symbolic interactionist framework to
develop a grounded theory model of the role of self in diabetes management in adolescents and young adults. This unique study is important because there are no other grounded theory studies in Australia or elsewhere which have explored the role of self in diabetes management of adolescent and young adults and their illness self-representations. Consequently, the present study makes a valuable contribution to the knowledge of the effects of diabetes management on the selves of adolescents and young adults. The findings inform parents, practice nurses and other health professionals and could be used to educate them about the psychoemotional fragility of young people with diabetes.

It is important to understand the characteristics of child, adolescent and young adult psychology and to remind ourselves that Eriksonian perspectives, the main theorist relied upon to inform this study, believed that it was essential to effectively achieve all stages of life span development in order to successfully manage the transition to the next stage. Erikson (1968), argued that adolescence was a period where an identity crisis could occur and that this could lead to identity versus role confusion, where the adolescent struggled for stable sense of self. This study certainly found that the presence of the chronic illness T1DM, did affect the respondents’ sense of self.

There is a need to rethink some of our views about diabetic management. The core agenda of a majority of doctors, is usually the technical management of diabetes, this generally means cautioning the person about their need to do to improve glycaemic control. However as mentioned previously there is a need for patient-provider goal-setting in order to encourage adherence in people with diabetes (Wolpert & Anderson, 2001; Ciechanowski, Katon, Russo & Walker, 2001). Diabetes care should adopt a holistic approach to care rather than relying solely on the medical model (Marshall, Fleming, Gillibrand & Carter, 2002).
6.13 Recommendations for further research could include:

- The completion of a needs analysis of young people living with T1DM in Australia.
- More research into individualised care for adolescents and young adults living with diabetes.
- Research into patient satisfaction in diabetes education for adolescents and young adults.
- Research into active listening and the development of diabetes specific programmes for mentoring and coaching, that is, a need to learn from and with each other in order to provide consistent motivation for young people living with diabetes.
- A qualitative comparative study with informants from among diabetes nurse educators on their experiences with a) adults with T1DM and b) young people with T1DM.
- At some further date a plan to investigate the parental perspective of living with a young person with T1DM.

This further research could build a body of knowledge in this area of diabetes management.

Final reflection

This study set out to explore the impact of diabetes on the *self* of adolescents and young adults. It provides a theory securely grounded in the data and informed by symbolic interactionism which is congruent with the respondents’ experience of
diabetes management. It provides a credible way of understanding the impact of diabetes management on the self of young people and illustrates the need for parents, family, friends and particularly health professionals to provide supportive, sensitive, holistic care for those on the tortuous journey of diabetes management.


Beeney, L., & Sharpe, L. (2001). Diabetes burnout: how to stop the daily grind from bringing you down. *Conquest,* Autumn, 4-5.


Sandelowski, M. 1999 More than meets the eye: Foetal ultrasonography as cultural instrument. *Conference proceedings from the 5th International Qualitative Health Conference, 7th – 10th April 1999*, The University of Newcastle, Faculty of Nursing, Newcastle, Australia. 40.


Visentin, K., Sonnack, D., Taylor, J., Koch, T., Kralik, D., Howard N., & Dennes, L. (2003) Towards the development of a model of diabetes care for young adults with type 1 diabetes who are making the transition from children’s to adult health care services, Manuscript in progress. Royal District Nursing Service (SA Inc.).


My name is Sharon Hillege and I am a registered nurse and a graduate student at The University of Western Sydney, Nepean undertaking research for the Master of Nursing.

I am interested in adolescents and the effect that having diabetes has had on them and their life experiences. Their experience, at this time, is important to understand so that nurses working in the area of diabetes can learn how to provide them with the best possible care. I am conducting interviews with adolescents between the ages of sixteen to eighteen years who have had diabetes for at least three years. The interviews will take about one hour each and can be held in your own home or my home depending on where your child feels most comfortable. This choice will be discussed with your child when the appointment is made. The interview will consist of a discussion of their experience and although it is possible that this may cause some stress most people find it a helpful experience.

Any information obtained will be confidential and kept in a secure place. I will be the only person who will have access to the information they provide. When the research is written up no individual participants will be able to be identified as their name and address will not be attached to the interview material. When the research is completed, I will send your child a summary of the findings.

I can assure them that whether they decide to participate or not, or whether they change their mind later it will make no difference to the care that they receive. I would like you as parents to be aware that your child will be involved in this project. If you have any further questions please do not hesitate to call me.

Sharon Hillege Telephone number: 831 - 6305

Appendix 1

Are you 16 - 20 years old ?

Have you had Diabetes for 3 or more years ?

Can we talk ?
INFORMATION SHEET
FOR 16 TO 20 YEAR OLDS.

MY NAME IS SHARON HILLEGE AND I AM A REGISTERED NURSE AND A GRADUATE STUDENT AT THE UNIVERSITY OF WESTERN SYDNEY, NEPEAN UNDERTAKING RESEARCH FOR THE MASTER OF NURSING (HONOURS).

- I AM INTERESTED IN THE EFFECT THAT HAVING DIABETES HAS HAD ON YOU AND YOUR LIFE EXPERIENCES.
- I AM INTERESTED IN CONDUCTING INTERVIEWS WITH SIXTEEN TO EIGHTEEN YEAR OLDS WHO HAVE HAD DIABETES FOR AT LEAST THREE YEARS.
- THE INTERVIEWS WILL TAKE ABOUT ONE HOUR
- VENUE: YOUR HOME OR MINE DEPENDING ON WHERE YOU FEEL MOST COMFORTABLE.
- THE INTERVIEW WILL CONSIST OF A DISCUSSION OF YOUR EXPERIENCE AND ALTHOUGH IT IS POSSIBLE THAT THIS MAY CAUSE SOME STRESS MOST PEOPLE FIND IT A HELPFUL EXPERIENCE.
- ANY INFORMATION OBTAINED WILL BE CONFIDENTIAL AND KEPT IN A SECURE PLACE. I WILL BE THE ONLY PERSON WHO WILL HAVE ACCESS TO THE INFORMATION YOU PROVIDE.
- WHEN THE RESEARCH IS WRITTEN UP NO INDIVIDUAL PARTICIPANTS WILL BE ABLE TO BE IDENTIFIED AS YOUR NAME AND ADDRESS WILL NOT BE ATTACHED TO THE INTERVIEW MATERIAL.

- WHEN THE RESEARCH IS COMPLETED I WILL SEND YOU A SUMMARY OF THE FINDINGS.
- WHEN I HAVE SPOKEN TO YOU AND GIVEN YOU MORE DETAILS ABOUT THE INTERVIEW, IF YOU DECIDE TO PARTICIPATE I WANT TO ASSURE YOU THAT YOU MAY DISCONTINUE AT ANY TIME. THIS RESEARCH IS NOT CONNECTED IN ANY WAY TO ANY DIABETIC CLINIC OR WARD OR ASSOCIATION.
- I WOULD ALSO LIKE TO RECEIVE PERMISSION FROM ONE OF YOUR PARENTS IF YOU ARE STILL DEPENDENT ON THEM (PARENTS INFORMATION SHEET INCLUDED).

IF YOU ARE INTERESTED IN FINDING OUT MORE ABOUT THIS PROJECT I WOULD LIKE YOU TO RETURN THE TEAR OFF SECTION TO ME IN THE SELF ADDRESSED ENVELOPE INCLUDED. I WILL CONTACT YOU SOON AFTER RECEIVING THIS INFORMATION.

THANK YOU, I LOOK FORWARD TO MEETING YOU SOON,

SHARON HILLEGE

TEL: 831 – 6305
Appendix 2

INFORMATION SHEET

My name is Sharon Hillege and I am a registered nurse and a graduate student at The University of Western Sydney, Nepean undertaking research for the Master of Nursing. I am interested in adolescents and the effect that having diabetes has had on them and their life experiences. Your experience, at this time, is important to understand so that nurses working in the area of diabetes can learn how to provide you with the best possible care. I am conducting interviews with adolescents between the ages of sixteen to eighteen years who have had diabetes for at least three years. The interviews will take about one hour each and can be held in the wards, the clinic or in your own home depending on where you feel most comfortable, this choice will be discussed with you when the appointment is made. The interview will consist of a discussion of your experience and although it is possible that this may cause some stress most people find it a helpful experience.

Any information obtained will be confidential and kept in a secure place. I will be the only person who will have access to the information you provide. When the research is written up no individual participants will be able to be identified as your name and address will not be attached to the interview material.

I want to assure you that you may discontinue at any time. This research is not connected in any way to the diabetic clinic or ward or association.

I can assure you that whether you decide to participate or not, or whether you change your mind later it will make no difference to the care that you receive. I would also like to receive permission from your one of your parents if you are still dependent on them.

Sharon Hillege Telephone number: 831 - 6305
Appendix 3

CONSENT FORM

I, ................................................................. (name) agree to take part in the research being conducted by Sharon Hillege through The University of Western Sydney, Nepean.

I understand that my involvement will include an interview of about one hour
I understand that I may discontinue my involvement at any time and that this will in no way affect my care that I receive.

I have read the information sheet and understand what is required of me in the research project.

Signed ..........................................................

Date............................................................
Appendix 4

Sign Consent Form
Sign Information Form

Name
Address
Age
Duration of Diabetes
Remember to switch on Recorder

Could you tell me about your experience of having diabetes? Perhaps we could start from your diagnosis or from your earliest memories?

Effect did the diagnosis have on you?
- Response of your parents to the diagnosis?
- Illness episodes related to having diabetes.
- How do you find having to attend clinics?
- Explain to me how you would tell a friend how you give an injection?
- How do you transport your insulin. Do you take it to school. Do you take lollies to school?
- Can you feel hi’s and lows
- Do you find some lollies too sweet?
- Do you remember what is happening when you have hypos?
- What do you feel like when you have a hypop? (out of control) dependent on others
- What impact has having diabetes had on:
  - Schooling and problems with teachers?
  - Sport?
  - Entertainment?
  - Friendships? (support or shunning)
  - Relationships?
  - Impact on career options.
  - Siblings feelings
- Thoughts of having children?
- Any complications from having this disease?
- How often does having diabetes have an effect on what you do?
- How time consuming is having diabetes and controlling?
- Do people ever ask about your diabetes instead of asking how you are?
- Do you fine having to explain about having diabetes embarrassing, ever labelled?
- Any problems having to do blood sugars or giving insulin?
- How has your blood sugar control been?
- Do you feel you are always being checked on?
- How do you feel about other needles?
- How would you rate on the "who am I scale"?
- Would you tell me you had diabetes in normal conversation?
- After viewing the pictures if the person suggests that they alternate between self representations ask them what is occurring contextually to them.

Show developed model and ask some questions
Appendix 5

INFORMATION SHEET FOR LONGITUDINAL STUDY GROUP

As you will remember, my name is Sharon Hillege and I am a registered nurse and a graduate student at The University of Western Sydney, Nepean. I am undertaking research for the Doctor of Philosophy (Nursing).

In previous interviews, you very kindly gave me information about the effect that having diabetes has had on you and your life. I would like to re-interview you to ask you about the changes that have taken place in your life, since our last interview. This will give me some insight into the changes that have occurred as you have moved from adolescence into adulthood.

Although talking about your diabetes may cause some stress, most people find it a helpful experience. Should you wish to use a counselling service the telephone number is 9552 – 9900 and ask to speak to a counsellor? I have written a review of the study, which I will discuss with you after the interview.

Any information obtained will be confidential and kept in a secure place. I will be the only person who will have access to the information you provide. When the research is written up no individual participants will be able to be identified as your name and address will not be attached to the interview material.

If you decide to participate I want to assure you that you may discontinue at any time. This research is not connected in any way to the diabetic clinic or ward or association. I can assure you that whether you decide to participate or not, or whether you change your mind later it will make no difference to the care that you receive.

Sharon Hillege Telephone number (H) 9831 6305 (W) 93519665
Appendix 6

INFORMATION SHEET FOR COHORT AND ILLNESS TRAJECTORY GROUP

My name is Sharon Hillege and I am a registered nurse and a graduate student at The University of Western Sydney, Nepean. I am undertaking research for the Doctor of Philosophy (Nursing)
I am interested in the effect that having diabetes has had your life experiences. Your experience, at this time, is important to understand so that nurses working in the area of diabetes can learn how to provide you with the best possible care. I am conducting interviews with adolescents and young adults between the ages of sixteen to twenty years who have had diabetes for at least three years. The interviews will take about one hour each and can be held in the wards, the clinic or in your own home depending on where you feel most comfortable, this choice will be discussed with you when the appointment is made. The interview will consist of a discussion of your experience and although it is possible that this may cause some stress most people find it a helpful experience. Should you wish to use a counselling service the telephone number is 9552 – 9900 and ask to speak to a counsellor?

Any information obtained will be confidential and kept in a secure place. I will be the only person who will have access to the information you provide. When the research is written up no individual participants will be able to be identified as your name and address will not be attached to the interview material.
I want to assure you that you may discontinue at any time. This research is not connected in any way to the diabetic clinic or ward or association.
I can assure you that whether you decide to participate or not, or whether you change your mind later it will make no difference to the care that you receive. I would also like to receive permission from your one of your parents if you are still dependent on them.

Sharon Hillege Telephone number (H) 9831 6305 (W) 93519665
Appendix 7
The Kuhn Twenty Statements test

I am statements

1. __________________________________________
2. __________________________________________
3. __________________________________________
4. __________________________________________
5. __________________________________________
6. __________________________________________
7. __________________________________________
8. __________________________________________
9. __________________________________________
10. __________________________________________
11. __________________________________________
12. __________________________________________
13. __________________________________________
14. __________________________________________
15. __________________________________________
16. __________________________________________
17. __________________________________________
18. __________________________________________
19. __________________________________________
20. __________________________________________
Appendix 8

On the tightrope
Appendix 8
I see diabetes as:

- An interruption
- Intrusive

I am immersed in it
Appendix 9

Guidelines and questions for longitudinal group Study 2

Read Information Form
Sign Consent Form

Name
Address
Age
Duration of Diabetes

Remember to switch on Recorder

- Don’t tell me what you think I want to hear, tell me what it is really like
- Tell me a couple of stories what has happened since we last met?
- What was it like to move away from home and parents?
- What are some of the milestones in the past years and can you tell me about these?
- Tell me how things have been with you and your diabetes?
- Tell me sometimes when you do not do your blood sugars is it because you have had enough (tedium) or is there any other reason?
- Any things you find a real hassle about having diabetes?
- Do you sometimes avoid seeing the doctor or are you too busy?
- Do you see yourself as a Diabetic or a person who happens to have diabetes?
- Can you remember what it was like not to have diabetes?
- How are your social relationships now?
- Previously you spoke about your career how has having diabetes impacted on your career choice?
- Do you have a job and how has having diabetes impacted on that
- How do you feel about telling people that you have was this a problem is this still so or have things changed and if so why have they changed
- Are you able to do any exercise
- Previously we spoke about the hope of a cure is this still so and if not why has this changed?
- Any complications from having diabetes
- Thinking back what do you think has changed since we last spoke and why do you think they are so important?

Give hand out on review of the study / interpret findings
Ask questions about whether you agree/ disagree with the findings?
Ask these questions in depth, could you give examples.
Do you still think about having diabetes in the same way?
Appendix 10

Conference presentation
July 1994 Poster Presentation

*The Self in Adolescents with Diabetes: The Implications for Child and Family Nursing*
*International Congress for Nursing Research "The Adventure of Nursing Practice Through Research a Brave New World"11th July to 13th July 1994*
How will this information help people with diabetes?

Sharing your life experience is important to help doctors, nurses and other health professionals working in the area of diabetes to better understand the implications of diabetes and to provide you with the best possible care.

Would you like to share your experience of what it is like to have Diabetes

Can we talk?
INFORMATION SHEET

MY NAME IS SHARON HILLEGE AND I AM A REGISTERED NURSE AND A GRADUATE STUDENT AT THE UNIVERSITY OF WESTERN SYDNEY, NEPEAN UNDERTAKING RESEARCH FOR THE DOCTOR OF PHILOSOPHY (NURSING).

- I AM INTERESTED IN THE EFFECT THAT HAVING DIABETES HAS HAD ON YOU AND YOUR LIFE EXPERIENCES.
- THE INTERVIEWS WILL TAKE ABOUT ONE HOUR
- VENUE: YOUR HOME OR MINE OR ANY OTHER VENUE DEPENDING ON WHERE YOU FEEL MOST COMFORTABLE.
- THE INTERVIEW WILL CONSIST OF A DISCUSSION OF YOUR EXPERIENCE AND ALTHOUGH IT IS POSSIBLE THAT THIS MAY CAUSE SOME STRESS MOST PEOPLE FIND IT A HELPFUL EXPERIENCE.
- ANY INFORMATION OBTAINED WILL BE CONFIDENTIAL AND KEPT IN A SECURE PLACE. I WILL BE THE ONLY PERSON WHO WILL HAVE ACCESS TO THE INFORMATION YOU PROVIDE.
- WHEN THE RESEARCH IS WRITTEN UP NO INDIVIDUAL PARTICIPANTS WILL BE ABLE TO BE IDENTIFIED AS YOUR NAME AND ADDRESS WILL NOT BE ATTACHED TO THE INTERVIEW MATERIAL.
- WHEN THE RESEARCH IS COMPLETED I WILL SEND YOU A SUMMARY OF THE FINDINGS.

WHEN I HAVE SPOKEN TO YOU AND GIVEN YOU MORE DETAILS ABOUT THE INTERVIEW, IF YOU DECIDE TO PARTICIPATE I WANT TO ASSURE YOU THAT YOU MAY DISCONTINUE AT ANY TIME. THIS RESEARCH IS NOT CONNECTED IN ANY WAY TO ANY DIABETIC CLINIC, DOCTOR, WARD OR ASSOCIATION.

IF YOU ARE INTERESTED IN FINDING OUT MORE ABOUT THIS PROJECT I WOULD LIKE YOU TO RETURN THE TEAR OFF SECTION TO ME IN THE SELF ADDRESSED ENVELOPE INCLUDED. I WILL CONTACT YOU SOON AFTER RECEIVING THIS INFORMATION.

THANK YOU, I LOOK FORWARD TO MEETING YOU SOON.

SHARON HILLEGE

★ TELEPHONE NUMBER 9831 – 6305 (h) 9351 - 9665 (w)
Appendix 12

Case studies developed for teaching

Young people with Diabetes: Three Case Studies

Case Study 1.

You are the diabetes educator at Green Valley Base Hospital and are planning to attend a five-day continuing education course offered in your local Health Service Area. Today, however, Cassandra has an appointment with you in the Out-Patients Clinic. Cassandra has been attending your Clinic for nine years. She was diagnosed as a diabetic at four years of age. Her blood sugar control during her childhood years has been relatively good. Now that she is going through puberty, her blood sugars are becoming very unstable. She is becoming very despondent since it appears that no matter what she does and however hard she tries to control her blood sugars they remain elevated prior to menstruation.

She is becoming very upset and verbalises that it is probably not worth adhering to her diet or carrying out the four blood sugar levels she does each day.

1. Why does puberty affect her blood sugar levels in this way?
2. You are aware of the advice you would normally give regarding testing blood sugar levels and adhering to her diet. Are there other issues you might explore with Cassandra first?
3. How could you try to address her feelings?
Case Study 2:
Wayne is an 18 year old with diabetes. He was diagnosed when he was six years of age. He has played a great deal of sport and been able to maintain his blood sugars relatively well. He is in his final year at school and since he is a very capable student and has a tremendous love for animals he is hoping to study veterinary sciences. To be able to enter the course he must achieve a very high academic score.

Having to submit assessment tasks and concentrate on his studies puts him under a great deal of stress. His glycosylated haemoglobin levels, which have generally been in the good range, are now ranging at between 8-10 Percent

------------------------------------------------------------------------------------
1. Wayne approaches you as the diabetes educator, for advice. What would your advice be? What are your rationales for the advice you give?
Case Study 3.
Claire was diagnosed with diabetes at the age of three. She is now eighteen. Early in adolescence, she rebelled against the control that having diabetes had on her life. She avoided testing her blood glucose levels, and frequently missed giving her insulin. She has been in and out of hospital with ketoacidosis.

Unfortunately constantly elevated blood sugar levels have led to complications. She has early changes in the retina, mild renal failure and ulcers on both legs that are not healing.

She is admitted for blood glucose stabilisation and wound care to the medical ward where you work as a recently graduated Registered Nurse.

1. Why has Claire developed these complications?.
2. What nursing strategies could you develop with Claire to facilitate stabilisation of her condition?.
3. How would you prioritise these?
4. What resources (other staff or material) could you explore to assist you in providing appropriate health care for Claire?
Case studies developed by Sharon Patricia Hillege R/N CM BHS Nursing (CSU).
Senior Lecturer, School of Nursing (NSW)
Australian Catholic University
PO Box 968
40 Edward Street
North Sydney NSW 2059 AUSTRALIA
Phone: 61 2 9739 2382
Fax: 61 2 9739 2075
SUGGESTED ANSWERS AND REFERENCES.

Case study 1

1. Puberty is a period of turbulence, when there is a tension between dependence and independence as well as this Growth Hormone and hormones such as testosterone, oestrogen and progestin cause insulin resistance to occur.

2. Once she is aware of the fact that insulin resistance might be a problem and she and she is given advise concerning insulin resistance, she might feel more reassured. Sometimes advocating a reduction in blood glucose monitoring for a short period can assist.

3. If she is feeling disheartened she could be encouraged to understand that it is not unusual to feel a sense of frustration and disappointment, when metabolic control is difficult. Active listening and sensitivity would assist Cassandra and prevent burnout.

Supporting references

Beeney, L., & Sharpe, L. (2001). Diabetes burnout: how to stop the daily grind from bringing you down. Conquest, Autumn, 4 - 5.


**Case Study 2:**

**Answer**

The advise given to Wayne is that

- Stress can adversely affect blood sugar control.
- Encouragement and active listening would assist him.
- Stress management programmes could be recommended if available.

**Supporting references**


Case study 3

1. Microvascular complications occur as a result of long-term hyperglycaemia
2. Try to understand why Claire is not taking her insulin and testing her blood glucose levels. One of the signs of an eating disorder is missing insulin injection or the patient may be phobic about injections and finger pricks.
3. Try to understand what is occurring in Claire’s life.
   a) Encourage her to try to commence taking her insulin again.
   b) Encourage her that improved glycaemic control can curtail microvascular complications.
   c) Explain treatment is available for the treatment of retinopathy and nephropathy.
   d) There is a glucowatch which is becoming more accurate at assessing blood glucose and it is non-invasive.
   e) Testing is being carried out on inhaled insulin and the trials are successful.
4. Counselling would assist Claire to renegotiate her diabetes management

Resources supplied below.

Supporting references


