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*Dissertation submitted towards MFamMed. Dept. Family Medicine
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Monograph Format

Title

***A QUALITATIVE STUDY ON THE EXPERIENCES OF
MOTHERS OF ADOLESCENTS WITH TYPE I DIABETES
MELLITUS***

Statement of original unpublished work

I hereby confirm that this research is based on independent work by the author, and that neither the whole nor part of it has been submitted for another degree to any other university. Furthermore this work has not been reported or published prior to registration for this degree.

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Table of Contents

<i>Acknowledgements</i>	3
<i>Abstract</i>	4
1. <i>Literature review</i>	6
2. <i>Methodology</i>	17
3. <i>Results – Individual Interviews</i>	24
I. Interview 1 (Mother – Margaret, Son – Deon)	
II. Interview 2 (Mother – Hilary, Daughter – Karen)	
III. Interview 3 (Mother – Adele, Son – Bruce)	
IV. Interview 4 (Mother – Sheila, Daughter – Lauren)	
V. Interview 5 (Mother – Shireen, Daughter – Saskia)	
VI. Interview 6 (Mother – Lindsey, Daughter – Carrie)	
VII. Interview 7 (Mother – Bianca, Son – Stuart)	
4. <i>Results – Global Themes</i>	125
I. Negotiating Identity	
II. Fate and Agency	
III. Food as expression of family dynamic	
IV. Resilience	
V. The Triad of Glycaemic control, adolescent autonomy and maternal affect	
5. <i>Discussion and Conclusion</i>	146
I. Limitations of this study	
II. Correlation with the literature	
III. Concluding discussion	
6. <i>Personal reflections</i>	156
<i>Bibliography</i>	160
<i>Appendices</i>	166
I. The protocol	
II. Research Instrument: The McGill illness narrative interview	
III. Short Note on the McGill illness narrative interview	
IV. Organising topics utilised in thematic analysis	
V. Ethics approval	
VI. Consent form	

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Abstract

Study Rationale

Type 1 diabetes is an important chronic endocrine illness of adolescence. It presents a range of unique and difficult to manage problems by virtue of the developmental challenges that face adolescents. Medical services are often ill equipped to deal with this patient group while the complicated management regimes necessary for glycaemic control has far ranging and potentially adverse psychosocial effects on the adolescent and their family. These challenges are experienced directly by the family, arguably the most important proximate influence in the adolescents' life. Psychosocial factors are pivotal in not only managing metabolic control but also in determining healthy family function and quality of life. This compels health workers who treat diabetic adolescents to comprehensively understand the families they work with. While there has been much research into the psychosocial aspects of adolescents with Type I diabetes, there is far less on the way that families and specifically parents experience this chronic illness in family life. Mothers are usually the most important caregivers within this context, taking the lead in co-ordinating and managing the health care needs of their families. The aim of this study is to gain further understanding of how families, specifically mothers make sense and incorporate their experiences into their broader comprehension of how Type I diabetes has affected themselves and their families.

Methods

This was a qualitative study based on semi-structured interviews. Seven mothers of adolescents with Type 1 diabetes were interviewed. Their transcribed interviews were subject to a thematic analysis yielding a detailed in-depth case study of each interview and an analysis of the global themes evident from the data as a whole.

Results

Global themes that emerged include (i) The importance for adolescent, mother and family to negotiate a normalising identity amidst the challenges of diabetes.

(ii) The concepts of fate and agency in explaining the existential dimension of the illness. (iii) The symbolic potency of food as an expression of family dynamics.

(iv) Resilience as a unifying concept to understand how mothers and their families cope to varying degrees with the challenges presented by diabetes. (v) The inextricably bound interconnected dynamics of glycaemic control, adolescent autonomy and maternal affect.

Discussion and Conclusion

The centrality of mothers in managing their adolescent's diabetes was confirmed, revealed in a broad range of feelings, concerns, values, belief systems and ways of coping. The experiences of mothers could be broadly understood to follow two trends, either as externalising (describing their experiences through the focal point of their child) or internalising (describing themselves as the focal point of the narrative) These broad categories were useful as a means to understand family functioning and revealing of mother-adolescent relationships. The experience of diabetes in a family is revealed principally as a social phenomena defined by the quality and style of relationships, belief and value systems and modes of resilience.

Chapter One

Literature Review

Approach to the search

A PubMed search was conducted, incorporating search terms either used singly or in combination including: “Chronic Illness”, “Type I diabetes”, “qualitative”, “narrative”, “autonomy”, “parenting”, “experience”, “explanatory”, “conflict” and “morbidity”. When analysing the findings of the research, important topics revealed were searched for. Key words included “Personality”, “co-morbidity”, “resilience” and “adolescent development”. Google scholar was used as an adjunct to PubMed. References in located articles were reviewed with incorporation of suitable articles.

I was interested in articles that would yield contemporary research on adolescent development; both normal and in the context of chronic illness. Further to this, I sought articles more specific to Type 1 diabetes in adolescence. My particular subjects of interest included how diabetes in the adolescent impacted on the family and the experience of the mother. I wanted to know what the literature said on the impact of diabetes on parental relationships, parent-adolescent relationships and how these reciprocally affected glycaemic control.

Areas of debate I was interested in included whether families with diabetic adolescents experienced significant psychological morbidity directly related to managing diabetes and what factors could protect against these. I was also interested in how parents and adolescents negotiated age appropriate autonomy needs and to what degree diabetes contributed to family conflict and impaired quality of life within the family. The subject of both vulnerability and resilience in dealing with adolescent diabetes was of interest too.

Criteria for inclusion

Articles from peer reviewed English language journals covering the subject areas discussed above were included. I preferentially selected those articles that were not too theory laden, had broad applicability and provided an overview of the relevant subjects. Both medical and nursing journals were prominent when articles were selected. I preferred to exclude older articles published before 2000, though this was not the case for those thought to be especially relevant.

Global context

Type 1 diabetes is an autoimmune disease characterised by the destruction of pancreatic beta cells resulting in an absolute deficiency of insulin in the body. The disorder has a strong genetic component but the factors which trigger the onset of clinical disease remains largely unknown. (1) Type 1 diabetes characteristically requires treatment with exogenous insulin. It is different from Type 2 diabetes in that the latter, though partly genetic, is a disease primarily of the bodies' metabolic process, characterised by relative insulin paucity and by insulin resistance. It usually presents in middle age, associated with other metabolic conditions such as obesity, hyperlipidaemia and hypertension, and is strongly associated with lifestyle factors such as poor diet and lack of exercise. (2)

Children and adolescents are increasingly diagnosed with Type 2 diabetes, the result of the high prevalence of obesity and inactivity in these populations. These factors are unrelated to the prevalence and incidence of Type 1 diabetes, which is a distinct entity, and the subject of this study.

Type 1 diabetes is one of the most common endocrine and metabolic conditions in childhood and adolescence and is rapidly increasing around the world, with an overall annual incidence of 3%. (3) Globally it is estimated that 480 000 children under the age of 15 have Type 1 diabetes. This is an incidence of approximately 0.02%. (4) There are about 78 000 new cases every year. If present trends continue, it is estimated that there will be a doubling of new cases in Europe by

2020. (4) Unfortunately data for the rest of the world, and in particular the developing world (South Africa included) is difficult to obtain. (3)

Recognition of importance of adolescent diabetes

Institutional weaknesses, lack of integration at the fault line of paediatric and adult medical services and the complexity of team based management programs has resulted, historically, in neglect of healthcare needs for adolescents with Type 1 diabetes. (5) Adolescence is a critical period when long term health trajectories are established and when early signs of diabetic complications can first manifest. Intensive glycaemic control has a considerable impact on morbidity and mortality. (6)(7) Adolescents with Type 1 diabetes must confront unique challenges in their efforts to achieve adherence and glycaemic control during a time of rapid developmental change, when carers are striving to encourage independence and self-management. These particular health challenges have recently been recognised and prioritised. (8)(9)(10)(11) Careful guidelines for care have been specifically laid out for this particular patient group. The updated ISPAD Consensus Guidelines 2009 recognises the profound importance of the psychosocial milieu in providing care for the adolescent with type I diabetes. (11)

Definitions

Adolescence is a transitional developmental period between childhood and adulthood characterized by profound biological, psychological and social role change. (12)(13) Many researchers have divided adolescence into three developmental periods, entailing early adolescence, (ages 10-13) middle adolescence (ages 14-17) and later adolescence (18 – early 20's) Transition from adolescence into adulthood has traditionally been defined in terms of marriage, starting a family and entering the work force but is increasingly delayed in contemporary society, the instability of this period giving rise to the term 'emerging adulthood'. (14)

Adolescent development

A complex range of developmental tasks needs to be completed throughout adolescence including managing bodily changes, emerging sexuality and negotiating intimate relationships. Striving towards a coherent self-identity sees relational influence extend from the family of origin to the broader peer group. It is a period of heightened self-awareness and involvement, with a fear of failure alternating with a sense of high self-expectation. The emotional world of the adolescent can be characterised by feelings of alienation, accompanied by close scrutiny of inner experience. A sense of feeling invulnerable may predominate, leading to a rejection of parental control or authority that discounts potential risks to their future health and potentially complicate management of a chronic illness. (15) Academic demands, geographic moves, career decisions and financial stressors all potentially distract from the close attention required to treat a chronic illness.

Risk taking in adolescence is likely to be normative, biologically driven and perhaps inevitable. Developmental neuroscience has identified dramatic changes to the adolescent brain during puberty, when remodelling of the brain's dopaminergic system leads to increased reward seeking, especially in the presence of peers. This correlates with the increase in risk taking seen in early adolescence. (16) As a general rule adolescents and young adults are far more likely than adults over 25 to binge drink, smoke cigarettes, have casual sexual partners, engage in violent or other criminal behaviour and suffer fatal or serious automobile accidents, usually related to the influence of alcohol. Consequences of preventable self-inflicted behaviour are the greatest risk to the well being of young people in industrialized societies. (17) These problems can compound the challenges of any coexisting chronic health condition.

In the latter part of adolescence, risk taking diminishes, as changes in the brain's cognitive control system widens the individual's capacity for self-regulation.

During this time the adolescent transits from a pattern of “concrete thinking” to a more adult perspective that incorporates time perspectives and consequences of actions. (13)

Encouragingly some general conclusions have emerged from studies on problematic behaviour in adolescents. These help to get a more balanced perspective. They include the necessity to distinguish between occasional experimentation and enduring patterns of troublesome behaviour, the identification that many behavioural problems are not specific to adolescence but herald back to childhood and that most problems encountered by adolescents are transient with few long-term repercussions. (17) Adolescence can be a vulnerable time but should not be over dramatized.

Diabetes in Adolescence

Chronic disease has wide ranging and reciprocal effects on adolescent development. These are inclusive of the psychological, social and physical domains. (18)

Diabetes brings its own unique challenges. In order to manage Type 1 diabetes the adolescent must watch what they eat, how they exercise, must carefully monitor their glucose levels and administer a complex regime of medication, usually insulin. In addition they must integrate the short-term problems of hypoglycaemia with the longer-term complications of poor glycaemic control. (19) All this is over and above normal age appropriate adolescent developmental tasks. These requirements can have a significant effect on their normal developmental progress to autonomous adulthood, because moves towards independence, including peer-congruent risk-taking may be at odds with the requirements for good glycaemic control and may place the adolescent at risk for adverse health consequences. (12)(20)(21) The requirement for good control and the hyper-vigilance of their parents give the adolescent fewer options to test boundaries and experiment. (22) Evidence suggests that as the adolescent assumes greater autonomy for diabetic self-care, glucose control worsens.

(23)(24)(25)

Numerous other factors come into play. Biological variables include hormonal fluctuations, the insulin resistance of puberty, diet variation, growth spurts, and physical exertion. These can all contribute to worsening metabolic control in Type 1 diabetes. (26)(27) Insulin requirements therefore fluctuate. In addition, peer pressure and risk taking may expose the adolescent to sexually transmitted diseases, inappropriate dietary choices, and substance misuse. Emotional and behavioural problems are more frequent in adolescents with diabetes with almost double the frequency of anorexia nervosa in females. (28)(29) Binge eating, and manipulation of insulin doses to control weight is particularly common. (29) Overall, older adolescents with Type 1 diabetes experience more psychological distress than their non-diabetic peer group which is associated with poorer glycaemic control. (26)(30)

Adolescents with diabetes face institutional challenges to their health provision. Structural problems exist within the framework of care for diabetic adolescents. (8)(9) Medical care of the adolescent is often neglected as it falls outside the framework of both Adult Medicine and traditional Paediatric care. Health care services that are sensitive to the unique developmental and transitional context of adolescence are often non-existent or poorly developed, with profound implications for clinic follow up and adherence to complex management regimes. Recent efforts to heighten awareness, formulate policy and construct guidelines attempt to rectify this situation. (5)(7)(11)

The family and adolescence

The most enduring, influential and secure relationships experienced during adolescence are within the matrix of the family. These relationships need to adapt during the period of adolescence. How they change and the degree to which they are necessarily a focus of conflict has been an area of hot debate within academia over the last few decades. (31) The dominant perception that adolescence is a period of turbulence and chaos continues to hold sway amongst contemporary

popular literature and the social media. Teenagers are typified as difficult to understand, truculent, angry and ungrateful. Popular thought dictates that if your teenager is not rebelling there may indeed be something wrong with their development.

Recent research in this area paints a more nuanced picture. (31) Low grade conflict characterized by squabbling and bickering increases, particularly in early adolescence and time spent together with parents and children decreases. Open familial conflict with extreme alienation, active rejection of adult values and rebellion to authority are the exception and seen more frequently when mental health problems co-exist in the adolescent or parent. (17)(32) It appears that the key to understanding intergenerational conflict during this time is to recognize that adolescents and parents have very different expectations and experiences of social scripts and conventions. How one defines conflict becomes very important. In addition, parents and adolescents interpret and are disturbed by conflict in different ways. Parents, particularly mothers, who are most involved at the 'coalface,' appear to be more negatively affected by disagreements and struggles whereas adolescents are able to dismiss them with greater ease. (33)

The question of whether parenting style influences adolescent socialization has been strongly influenced by the work of Diana Baumrind (34) whose seminal studies of parental influences on child and adolescent competence and maturity have been borne out by recent research. Her original formulation compared three qualitatively distinct typologies of parenting control modulated by "responsiveness" (the extent to which a parent responds to a child's need) and "demandingness" (the extent to which the parent expects more mature and responsible behaviour from their child). Using these two dimensions, the three different typologies included.

Permissive (low demandingness with high responsiveness)

Authoritarian (high demandingness with low responsiveness)

Authoritative (moderate demandingness with moderate responsiveness)

Contemporary research bears out that the authoritative parenting style is associated with a wide range of psychological and social advantages in adolescence. (32)(35)(36)

Sibling relationships are important too. Overall adjustment during adolescence is positively influenced by better relationships with siblings, though problem behaviours such as early sexual activity or drug use may be a risk factor for younger siblings. (32)

Ecological perspectives on adolescent development, initially developed by Bronfenbrenner dominate contemporary research. These stress the interactive nature of a complex mix of forces that determine human development, accounting for different contexts and signal a move away from single linear environmental influences. (17)

Bronfenbrenner's Ecological systems theory applied to adolescent development can be broken up into five main sources.

1. *Microsystem*: Institutions and groups that most directly impact on adolescent development.
2. *Mesosystem*: Connections between microsystems or contexts.
3. *Exosystem*: Links to the social setting but with no immediate active role.
4. *Macrosystem*: Cultural beliefs and context of individual and society
5. *Chronosystem*: The plotting of the time course relative to the transitions and events that pattern.

In the context of adolescent diabetes the most important factors include the parent-child dyad, genetic influences, socio-cultural modulators and co-existing mental and physical morbidity. (17) Of these, parenting style is one of the more important. (37)

Diabetes and the family

Family context is integral to the management and care of the adolescent diabetic. It is within the crucible of the family, that the young adolescent negotiates their autonomy, and assumes greater responsibility for their self-care as they enter into late adolescence and early adulthood.

Psychosocial factors play a significant role in the family management of diabetes. (38)(39) The dynamic between family and diabetes is bilateral and reciprocal. Considerable demands are placed on the family in caring for a child with a chronic illness. Compared to families with healthy adolescents, families caring for an adolescent with diabetes portray their interactions as more structured, less cohesive and stimulating. (40) Care-giving burden can be significant and impact on the mental health of parents. Parenting children with diabetes brings a higher perceived burden and emotional distress in both mothers and fathers, though the mother is disproportionately affected. (41) There is also a greater potential for marital disharmony amongst parents of a Type I diabetic, with parents of affected adolescents exhibiting less marital integration compared to parents of those without diabetes. (42)

Nocturnal blood glucose measurements and long-term health concerns were important causes of emotional distress. It has been shown that reducing perceived parental burden does enhance glycaemic control. (35)

The style of parenting is important. Constructive family function characterized by a high degree of cohesion, flexibility and organization is associated with better glycaemic control and well-adjusted adolescent disease management. (43)(44)(40) Ideally a parenting style that adopts an authoritative style with high levels of receptivity and high demands for mature behaviour within a warm caring environment appear best suited to treat any chronic disease. (34)(45) An involved relationship that fosters self-sufficiency has positive effects on adherence and metabolic control, (46)(47)(48) whereas parental over-involvement with care has the potential to antagonize autonomy-seeking

adolescents and foster conflict within the family. (49) It has been found that the manner in which parents demonstrate involvement, notably a collaborative style low in conflict, is more important than the amount of responsibility taken. Family style of communication not only impacts directly on glycaemic control but on the adolescent's perceived quality of life. (50)

The central role of the Mother

As the primary carers of their children with Type 1 Diabetes mothers shoulder the greatest burden of care and are the more likely of the two parents to experience emotional distress. (51)(52)(53) Mothers of children with chronic illnesses are more likely to exhibit psychopathological symptoms. Mothers were found to have impaired well being when there were wide discrepancies in perceptions of competence and independence between them and their adolescent children (54) Parental psychological distress including maternal anxiety has adverse implications for adolescent glycaemic control. (55)(52) Maternal separation anxiety may lead to heightened parental attachment behaviour and adversely influence the development of cognitive autonomy and self care in adolescents. (56).

The need for this study

Research is accumulating in areas that look at how parental style and involvement impact on quality of life, glycaemic control and the general health status of adolescents with Type 1 diabetes. It is just beginning to look at the differences between paternal and maternal functioning within the family. (45)(47)(51)(53)

Mothers are at the epicentre of their families' health needs and bear much of the psychological impact this imparts. They are in the best position to describe the reciprocal influences of diabetes and adolescent development within the family context. Overall however, the research on mothers is sparse and poorly developed. There is a growing awareness of the mental health burden of looking after adolescents with Type 1 diabetes but very little, if anything, on the subject of mother's experiences. Specifically, there is little about their belief systems, their

ideas about how best to manage their children, what their primary concerns and fears are and how they perceive the illness impacts on their own lives. Other areas of importance pertaining to their role as primary carers of an adolescent with diabetes include their changing role-identities, impact on their relationships and how they deal with the loss of their child's health. There is also little on the subject of how mothers engage with their developing teenager's requirement for autonomy and how the tensions of this dynamic play out within the context of Type 1 diabetes. Furthermore, there is a pressing need to look beyond the various factors that can adversely influence glycaemic control and quality of life measures, and turn attention to those factors that promote resilience and facilitate healthy adaptation to Type 1 diabetes.

The importance of this information cannot be underestimated as it bears directly on their own and families' quality of life and on the relationships they build with health care providers.

An aim of this study is contribute to the understanding of what mothers go through, what they experience, and how they make sense of the many demands an adolescent with Type 1 diabetes presents. I hope to present a detailed picture through a rich in-depth inquiry and fine bore analysis of how they perceive their (and their families) life experiences. This would contribute to furthering understanding of these mothers; discern hidden dynamics, create further bridges to empathy and gain insight into the way these mothers facilitate resilience within their families.

The health personnel who help such families are often working with time restraints that compel them to prioritise the technical challenges managing diabetes presents. Interventions in the family on communication and parenting styles, information sharing and counselling with regards parent-adolescent interaction all have the capacity to improve glycaemic control and quality of life. (48) Access to the deeper levels of the mothers' experience would add value and provide information invaluable to optimal patient care.

Chapter Two

Methodology

The study took place between August 2011 and December 2011. Ethics approval was received from the UCT Ethics Committee in August 2011.

Study Design

The study was in the form of semi-structured interviews of between 1 and 2 hours duration. If this time was not sufficient, a second interview was scheduled. The aim was to facilitate a narrative that revealed the mothers explanatory worlds as they pertained to diabetes, and to share how they viewed the impact of diabetes on themselves, the development of their adolescent children and on their families.

Recruitment

Sampling was purposive; my purpose to locate mothers of children with Type I diabetes between the ages of 13 and 21. I recruited subjects through paediatricians, endocrinologists and paediatric endocrinologists in the Western Cape. I also contacted the Red-Cross adolescent diabetic clinic.

Each prospective participant was identified and contacted by the referral source, and asked if they would like to participate. I contacted them if they agreed, and set up a time to meet, usually in a coffee shop, (one subject was interviewed at home) at which time full consent was taken and signed and the interview was recorded. Confidentiality was assured, and permission was requested to share research information, including elements of the transcribed interviews with my academic supervisors. All names were changed and aliases given to protect the identity of the participants and their families. The participants were interviewed alone, without the presence of their partners or children.

Eight participants were interviewed, one of whom was excluded because the audio recorder failed, and the researcher was unable to transcribe this interview. This number was settled on after saturation of the subject was achieved.

There was no payment provided and travel expenses were borne by the participants themselves. I paid for any beverages consumed during the interview. I explained to all subjects that I was a medical practitioner, was interviewing in my capacity as researcher and would therefore not be in a position to give any medical advice. I also disclosed that I was an Insulin Dependent Diabetic. There were occasional questions posed to me of a medical nature, or asking about my own personal experience. I answered these questions simply and transparently, but abstained from giving any medical recommendations, or length personal comment.

I explained that research findings arising from the interviews would possibly be published and disseminated in different forums. (E.g. talks to the diabetic association, journal articles).

Each participant was told that they would be contacted when the study was complete, and given the opportunity to get feedback from its conclusions.

Inclusion Criteria

Participants needed to be the mothers and primary care givers of their children. Competency in English was a prerequisite. They needed to have the capacity to understand and give consent. Their children should have been diagnosed a minimum of 12 months previously so that there was time to get over the initial shock of the diagnosis, stabilise management and have a slightly longer period of time from which to draw experience.

Patients from my own practice were excluded. It was thought that they would find it too difficult to separate my role as researcher from that of their doctor. One

interview was discarded as it failed to record, and therefore could not be transcribed.

Interview design

The interviews aimed for a free flowing story that captured the narrative of the teller's experience in their own terms and from their own perspective but with some direction pertinent to the research objectives.

In order to help structure the interview, a questionnaire was developed, loosely adapted from the McGill Illness Narrative Interview Schedule. (*Appendix II*)

The McGill Illness Narrative Interview is a semi-structured qualitative interview schedule designed by a team of clinicians and researchers from McGill University, (with anthropology, social work, medical and mental health backgrounds) to elicit illness narratives in cross cultural health research. (58)

It was initially developed to explore individuals' illness experience in a study examining health-seeking behaviour and use of mental health services amongst those with medically unexplained symptoms in Ethiopia, and primary care settings in Israel. It was subsequently adapted to be used in a variety of medical environments, including after-care of myocardial infarction, hyperemesis gravidarum and breast-feeding. (59)

I adapted it for my purpose, with a particular focus on the mothers' narrative of the origins of the illness and the impact of diabetes on the developing adolescent, on the mother herself, and on the family as a whole.

Pilot Study

I initially interviewed Mrs K in her home with a view to assessing how the semi-structured questionnaire would work within the structure of the interview and to

roughly gauge what type of areas we would be concentrating on most. I also asked for direct feedback on those areas that seemed most salient.

From this I determined the following.

- An overly structured approach to interviewing with many direct questions would hamper the natural flow of the narrative.
- The time of first diagnosis and the immediate aftermath are remembered in great detail, with strong beliefs surrounding it.
- There may be obstacles for a mother to talk openly about the more difficult areas of glycaemic control, particularly if they have a strong motivation to present themselves and their families in a positive way.
- Other family members are intrinsically involved, including the father and siblings and there may be good reasons for a similar study including them.
- An estimate of between an hour and an hour and a half was appropriate to cover the needs of the interview.
- The questions were salient, comprehensible and appropriate, eliciting a richly responsive narrative.

Data Collection and Management

I recorded all interviews with an iPhone, and transcribed them myself. Files were kept in a secure password protected file on my personal computer. Copies were kept on a secure hard-drive and the original recordings were deleted.

Data Analysis

Gaining familiarity with the interviews.

All the interviews were read, firstly to gain a 'feel' of them, then to generate a long list of ideas.

Identifying Organising Topics

These ideas were grouped together into what I called Organising topics. These were chosen to reflect the main areas covered within the interviews, the concerns of the research question and the areas of importance suggested by the literature. *(Appendix IV)*

Coding the Organising Topics

These Organising Topics were then broken down further into subtopics, reflecting the different dimensions they covered.

Finding the Organising Topics in the text

I then returned to each interview text and marked by letter where these Organising Topics, (or any of their subdivisions) could be found. At this stage, applicability was widely interpreted. Many times, a part of the narrative would embrace different organising topics simultaneously.

The narrative fragments reflecting each Organising Topic were copied and pasted and grouped together for each interview.

Shuttling between the data of the transcribed interviews and Organising Topics allowed a sifting of information, an iterative process that helped to break the data down into different segments, thus revealing novel dimensions. Relationships between the Organising Topics as they cut across the different interviews yielded further information. It was hoped that moving between the interviews and Organising topics using the constant comparative methodology would generate new perspectives on the data.

Generation of Organising Themes

From the transcribed interviews and the sifted Organising Topics, Organising Themes were identified for each interview. These Organising Themes bring together the most salient, emotionally weighted and frequently mentioned aspects of each interview. Narrative elements are also incorporated resulting in a detailed self-contained case study for each interview.

Generation of Global Themes

Global overarching themes are identified, and discussed in a separate chapter following on from the individual case studies. The Global Themes are guided and influenced by the Organizing Themes derived from the individual case studies. They reflect groups of ideas that exhibit continuity and consistency across the interviews, and which are revealing of the mothers' experiences of their developing adolescent children within the context of their families and the illness of diabetes. They are a further step of integrative abstraction beyond the Organizing Themes found within each individual interview.

Finding validity

Recruitment was carried out over a large catchment area and was designed to yield a heterogeneous group thus minimising that chance of non-representative samples of the greater population of mothers with Type 1 diabetic children. The questionnaire was guided by a validated questionnaire, the McGill Illness Narrative interview schedule and a pilot study was carried out to refine the final interviews. The same person, thus facilitating a close and immersive relationship with the data, carried out interview transcription and analysis. This ensured consistency across the samples. Topics and themes identified were reliably represented in the data by many salient examples taken directly from the transcribed interviews. While the researcher worked alone, he gained valuable advice from his supervisors. There was no time, neither were the resources available to get a comprehensive review of these themes by a disinterested third party.

Presentation of Findings

Each of the seven interviews are presented as an in-depth internal case study. All names have been changed. The salient themes representing each interview are presented and discussed separately from each other. Thereafter a single chapter will gather together the Global Themes, derived from an iterative process of data analysis and representing a higher abstract order of interpretation and analysis. The conclusion will contain the limitations on the study, their correlation with the literature and further synthesis and interpretation of salient points derived from the study. Lastly I suggest possible future directions.

Chapter Three

Results – individual interviews

Interview 1

**Mother - Margaret
Son - Deon**

Deon was diagnosed with diabetes when he was 9 years old and was 20 years old at the time of the interview. His brother, who is 3 years older is a recovering drug addict in remission and is HIV positive. Much of the families' lives have been orientated around drug rehabilitation and Narcotics Anonymous. To compound her problems, her husband is in treatment for a haematological malignancy. Margaret has taken care of Deon's diabetic needs herself - she feels that her husband has never been able to give her the support she needs. Deon has at one time or another been diagnosed with various allergies, attention deficit disorder, sensory integration problems and learning problems. His mother describes an enduring pattern of poor care of his diabetes, risky activities and poor insight into his condition. This has elicited a response in her to search widely for someone with whom he could have a therapeutic relationship and help bring order to his diabetic control. She has elicited help from many individuals, but has yet to answer the two dominating questions in her narrative. Why is her son like he is and what can be done about it?

(I) A Child set apart

"...and that's why I am giving you the picture, and he has always been a different child..."

Children with chronic illnesses are often perceived and treated differently from their peers, and none more than those with diabetes. They are marked by their different diets, requirement to inject and test their blood glucose levels and to lead a more controlled life.

Adolescents with diabetes need to navigate the tension between being normal and being different. Margaret, by marking out her son as different or 'set apart' satisfies a wide range of explanatory drives that allow her to find meaning and preserve the integrity of her narrative.

From the very beginning Deon was different in ways that marked him out as unique and special, but also as particularly troubled and distressed. He was never a normal child.

"...but I have to say, that Deon has always been very different to an average child, my first child was an average child, born easily, happy chappy, normal, what the books say..."

His difference manifests as a type of vulnerability. He is weaker, more physically at risk. He has multiple allergies, grew up on goat's milk rather than ordinary milk and always had overdeveloped senses, including his hearing, (*"in the autistic spectrum"*) so that it was difficult for him to tolerate being near other people. He required a carefully tended environment.

"...Apart from all the sensitivity and the vulnerability of Deon from when he was born and all those nine years, you know, those 9 years already made us treat him very differently to every other mother treating her children..."

His mother explains how he was ultra-sensitive to the batteries of his diabetic pump and that complaints of fatigue and exhaustion were only relieved once they put battery blockers around them. She also recounts how he had difficulty breathing and it was only after she had carried out extensive research and found he was allergic to the formaldehyde impregnated in the new wooden cabinet in his room that he improved. He was also sensitive to the cell phone tower near to his High School.

“...Same with the cell phone tower at Camps Bay High school. He used to wear a what are they called, a tachyon, used to wear it in his pocket, so everything about Deon has been different, the sensitivity, that he has to wear a tachyon in his pocket...”

He seemed sensitive to esoteric and unexpected stimuli, whether they were chemicals, inhaled substances, ingested substances, emotions or even technology.

“...he always has at least one day off of going to school, if he does a 5 day week, he is phenomenal, he is always tired, he can never cope with ... it's the sensory input I think, it gets too much, the civilization, all the technology, he loves technology, as all the youngsters do, but its all overwhelming for his system...”

This set of core beliefs underpins Margaret's understanding of why Deon got diabetes. Whereas other parents defend their children's normality the particular pressures brought to bear on Margaret's narrative call for a different response.

Deon's sensitivity makes him vulnerable to illness. Margaret believes that this underlying weakness makes him particularly prone to emotional stress and that emotional deregulation is what destroyed his pancreas and gave him diabetes.

“...I almost feel that he created the diabetes from anxiety. The anxiety of the person caused the diabetes. It's possible it triggered the whole thing, but I do believe that how he acquired diabetes at 9 years, being over anxious, over

sensitive, maybe unhappy in his being, not satisfied, that's what I think on that angle ..."

Deon's learning and sensory difficulties (he is diagnosed with ADD and dyslexia before the age of nine) require many different therapists and therapies. This accounts for the vast energy expended by the family and his mother in particular in getting him the help they believe he needs. Wrestling control of the diabetes was the most challenging of all, and throughout adolescence was the site for major conflict.

Mom admits that ...

"He was also a very difficult and challenging child."

Though a vulnerable and sensitive child, he nevertheless exerted an overwhelming power by virtue of the time and effort required to manage his many problems. In this way he exemplified paradoxically, a certain kind of raw strength.

"...he was conceived on the loop, this child has been determined to live ... he was just determined to be part of our lives..."

Margaret holds the belief that Deon was fated to be their son and she his mother. This predetermined, fated existence helps to answer the silent though menacing question; what if Deon had been a different child? A healthy child? a less problematic child? If something is meant to be, then clearly there is a reason behind it, even if this reason is opaque.

The whole family revolves around Deon. He is the central focus and as a result wields a disproportionate influence and power in the family unit. This further marks him out.

*“...because the focus is on the child who is diabetic, so now you are, you think, I have two children one a 12 year old and one a 9 year old, **all** the focus on the 9 year old...”*

Those concepts of being difficult, different and challenging, also translate as - Deon being a *special child*. He is set apart in ways that make him unique and therefore worthy of all the attention.

“...I love him and hug him and tell him he is my special child, and he is so different, you know, he knows he is different and special...”

His specialness is extrapolated further to the realms of the almost magical. Margaret attributes superhuman-like qualities to him.

“...and I do believe that he is psychic or has the ability to be psychic, even though he denies anything ... he always has antennae out there, like a little not-earthling kid...”

Margaret’s narrative demonstrates her ambivalence in reconciling what she recognizes in her son as unique, remarkable and full of potential with the intense challenge and difficulty that he presents to her. She loves and is steadfastly dedicated to him, but at the same time, questions whether she would have had another child if he were her first.

“...and when I had Deon, well, I must be honest, had I had Deon first, I never would have had another child. It was unbelievable...”

The stakes however are set because she cannot run away. His life is on the line by virtue of the diabetes.

Short Summary

The central theme of Dean as a special child has many dimensions, including his physical and emotional vulnerability, the difficult and challenging problem of glycaemic control, the power he exerts over the family and his mother in particular and his extra-ordinary qualities she describes. It is an important organizing theme because it functions as both explanation and expiation for both cause and current dilemmas faced in managing his illness. In the tussle to carve out an identity for her son, Margaret has opted for an explanatory framework that emphasizes difference rather than sameness. This is unusual as most parents in this study have emphasized, or hoped to emphasize the relative normality of their child. But perhaps Margaret has no choice, as she cannot pretend that Deon is like other children. Indeed, his failure to take responsibility, his frequently uncontrolled sugar levels, and his antisocial behaviour, (discussed below) all substantiate the narrative of his apartness.

(II) A Mother's fate – a pre-determined destiny.

"I do believe that in a strange way, he has been sent to me for me to look after him."

Running through this narrative is Margaret's belief that her role as Deon's mother is somehow predetermined. This is a substantiation of her identity and lends congruence to her role. A particular child like Deon requires the particular kind of mother she can be. This thought may reassuringly answer the important existential question; "why did I have this difficult and challenging child?" The answer is simple – it was meant to be.

"...and I think there is a lot to be said, a lot to be said that he was conceived, and that I am his mother. I believed that I had to be his mother, even as much as the vaccinations are concerned, but I had to learn my journey before I had him..."

This reality allows Margaret to understand her own medical history prior to Deon's birth - when she struggled to manage Ulcerative Colitis.

"...When I was pregnant with the oldest boy, who was 12 year old when Deon diagnosed. I had ulcerative colitis, and I was really really ill, and they put me on cortisone. I was 7 months pregnant when this happened, and they put me on salizopyrine, and they did all the things, the genuine pig tests, at GSH, and the lot, and nothing helped, and in the end I went to Rheinhard Linder and that's how I met him, and well here I sit today, having had Ulcerative Colitis, and I'm not on anything, so, but, it took three years, then it took a lot of psychotherapy, because I realized that he has got me so far, that I now needed to get myself further, so that's the background that I come from..."

From her own experience with Ulcerative Colitis, Margaret learnt that standard medical treatments don't always work and that one often has to seek

unconventional alternatives to heal. She concludes that healing is only possible by taking full responsibility and understanding oneself emotionally.

“...I don’t know, I really don’t know, having had the ulcerative colitis, I realized that a lot of that illness was from stress and emotional disorder, the fact, the gift that I have learnt about psychology is an enormous... that has helped me to cope in my life...”

The challenge of looking after Deon was something she was prepared for by her previous experiences, which not only gave her confidence, but also provided a framework for her relationship with healthcare providers. Her first port of call when Deon became ill, prior to the formal diagnosis of diabetes was her Homeopath.

“...let’s try before we go onto insulin, as the insulin will disguise anything that’s there, and we did it, and that was a very stressful time because everybody was saying, how can you let your child’s sugars run so high how can you do this too him and whatever, but we did it for about 10 days, or 8 days, or something, and then we succumbed...”

Margaret’s view of medical professionals constitutes a mixture of trust and suspicion, depending on circumstances and her needs. She is convinced that her determination not to vaccinate her son prevented him from being autistic and she sees this as further proof that there was some force at play predetermining her protective role in his life.

“...As well as when I had Deon, having learnt what I learnt about homeopathy I did not vaccinate Deon, I gave him only polio drops, and I do believe that in a strange way, he has been sent to me for me to look after him because I do believe almost in way, that he, had he had vaccinations he would have been more autistic, I think, what I have read about vaccinations has since affirmed it. But this is my side...”

There is a *post hoc ergo propter hoc* reasoning where associations are taken as causal. The proximity, salience and personal emotional resonance of these associations confirm their metaphorical power.

Margaret's journey is a personal one, even if it is within the crucible of the wider family. This in part, is a reflection of her husbands taking a secondary role in the care of Deon's diabetes. Indeed, at the time of my talking to her he is ill himself with a serious haematological malignancy, further compounding her stress, and her lack of support in managing Deon.

"...John was always on the outside, he never jumped in and learnt how to care for Deon. I've always been the carer, all my life, so I did it quite capably so, because I had to, when I look at Sarah and Clive, my friends, Sarah goes to the appointments with the doctor, Sarah knows how the pump works, how the insulin works, what an up and a down is, what the levels are, I just envy her having that support, which I have never had, but so is life, and I think it has much to do with the fact, psychologically, that deep inside John did not want to have children, and I wanted to have children..."

"...I often wonder how do children choose their parents, not children but souls, that to me is all very interesting..."

Margaret has followed a journey, and her narrative describes a path of self-actualization bred through her own illness and the problems she has faced with Deon. She has demonstrated a persistence and creativity in finding care, notwithstanding the obstacles. (Including the non-involvement of her husband.)

"...I don't know, it's a soul journey, and I don't know if I am right on my angle, its just how I feel and I look at it all as a gift, because it has to be a gift, because that's how it has to be, maybe some people could turn round and say well look at it as a curse, but its not because that's how you learn, that's what life's about, why look at the negative? And there is so much love there, and

there is so much... ja so much underlying, that is treasure but it is a hard treasure to live with, it's a hard treasure to deal with, you know..."

Margaret presents a coherent explanatory world that has provided a framework for dealing with the unique challenges posed by her child. She demonstrates the complex personal challenges faced by parents in the care of their children, the creative solutions and resources required to meet them.

"...Well, I think that's become my philosophy, as I have grown older and wiser, heh heh heh, by force (laughter) though I must say I wouldn't change much in my life if I had it all over again, as funny as it is, because I have learnt so much through them you know..."

Short Summary

The theme of predestination captures Margaret's belief that she was meant to be her son's mother, that there was no-one else who could do it, that she was uniquely prepared by her experience with Ulcerative Colitis. The internal integrity of her role fulfils an arc of growth achieved by the meeting of personal challenges in her life. Furthermore it helps to answer the question of why her son has diabetes, and why indeed she got the Ulcerative Colitis. There is a matrix of interconnected meaning in the world.

(III) What is wrong with my son?

“...I promise you, it’s like, he is the biggest screwball now...”

“...I don’t know if it is denial, I don’t know if it is disabilities learning wise, I don’t know... but he now is so appalling at managing his diabetes that every morning I wake him up, and read his level and give him the amount that he needs to rectify...”

Margaret cannot understand why her son cannot look after himself. Much of the interview is a recounting of how Deon seems incapable of responsible self-care. He is non-engaging with health professionals, doesn’t test his sugars and seems indiscriminate in what he eats. He seems unwilling to listen to anyone and recently had started taking soft drugs. One could argue that he was otherwise being a normal teenager. His mother struggles with this possibility. In her eyes he seems to lack the capacity to care for himself, and she doesn’t know why.

“...He was living in a flat in Sea Point, sharing it with his brother, but his brother wasn’t there at the time, and he actually cooked his pump (Insulin) in the microwave, with the lasagne from Woolworths, the lasagne that he had stolen from my fridge at home. He stuck it in the microwave because he was low and he cooked the R32 000 pump because he was low... And then he proceeded to eat the lasagne that was full of the chemicals from the machine...”

She is uncertain. Is this learnt behaviour from his brother? Is it the ADD? Is it a form of autism? Or is it just terribly bad behaviour?

“... so I take out the glucometer and put it in front of him on the table, and he does it, and he is HI, but he was going to walk out the door and he is prepared to walk out to go to work for 4 hours like that. What is it? Is it the ADD? Is it the dyslexia? Is it the drugs? Is it saying it’s not normal? He is buying into it somewhere along the line, and he needs to go speak to someone about himself, but until he gets there, cos I’ve tried and I’ve tried and I’ve tried...”

There is frustration and anger and a sense of feeling manipulated.

“...he doesn't communicate, he will talk to me, he will go for days, and do his own thing then he will pull me in, but he does stuff that is so stupidly not normal like his sugar levels over the last 24 hours, hi, hi 33. And then he pulls you in, brings himself back to having a relationship, and he does it with me and he does it with his brother, and then he pushes you away...”

Not only do these activities put Deon in danger but they provide no basis for the handover of responsibility from his mother. Efforts to foster autonomy in her son have failed. She continues to bear the burden of responsibility and this fuels her anger.

Drawing on a rich and available metaphorical substrate, she compares diabetes to drug addiction. Her older son has battled a severe drug problem and has been in rehab several times. A few years earlier he had contracted HIV from a dirty needle. She has seen that both conditions are associated with behavioural patterns of failure to look after the physical self, wilful irresponsibility and danger of death. Above all, both are pathological diagnoses, medical conditions that partially relieve the sufferer from agency, thus exiating him from some responsibility. According to this reasoning they are victims of something beyond their control.

“...but I don't know if it is only the diabetes, but because the diabetes is so similar to drug addiction, in essence they have to look after themselves, no-one else can do it, it's exactly the same... it's a disease, it is not by choice, the by choice was trying it, and after that you are addicted, and after that there is the understanding that they have to come to the stage in their lives, hit the bottom line, or hit rock bottom before they can look after themselves, if they are ever going to, and so is diabetes...”

Margaret recounts many instances of how she monitored Dean, gave him the right food, watched over him and took responsibility where he didn't. Her anger seeps through the words of her narrative. The burden of responsibility is a heavy one. Like with drug addiction, she is forced into a situation where she must now practice tough love. There is only so much more she can do.

"...so I woke up one morning at 5 or 6 in the morning and he still wasn't home, so I double locked the door so he could not get in. He came and banged on the door, so angry, saying let me in, and I want to get in, this must have been about maybe 6, 7 in the morning, and I said go away, go and find somewhere else to sleep. I am sick of being woken up with you all night in the early hours of the morning, worrying about where you are, etc. etc I didn't really have a long conversation through the door, the very next thing he does, is he goes along, and he gets stones from outside on the property, and he smashes the bedroom, the bathroom windows, he throws the stones through the bathroom windows, he then climbs round to the level like this, even higher, to my bedroom window, and he smashes with his foot the sliding door in, and I said to him go away or I will phone the police. By this time I have phoned the Camps Bay watch people, and they sent the police round and I led them around to the side of the house, and they came round and handcuffed him to my balcony and took him to jail and I put him in jail, diabetic and all because I just said I have had enough of this disrespectful behaviour. I don't know if it's got anything to do with diabetes. I think its got to do with drugs and diabetes and maybe alcohol, or maybe rebellion, or maybe his father being so ill in hospital, or his brother being in rehab, you know enormous lot to deal with, and then of course he was in a cell in Camps Bay and I had to decide if I wanted to lay a charge or not, and I laid a charge, and he kept calling from the cell saying...I took down food, and I took down insulin and I said, he is a diabetic, here's his stuff, and of course they couldn't put it in

the cell with him, because of the needles and the whole thing, and he kept calling, come Mom, come, calling me back, and I walked and I laid a charge against him, and in the end I had to negotiate, this is how you behave, this was a big wake up that he got. I just wouldn't take it anymore..."

In this case, the divergence of understanding, and the failure to communicate is played out with terrible consequences.

This frustration at not being able to reach her son with the help she extends is poignantly contrasted in a chance interaction with a young under-privileged girl whose greatest wish is to understand her own diabetes further.

"...And here she is talking to me, a foreigner at the side of the road, and maybe she is listening to me and saying her mother doesn't understand and here you are saying to me what would you tell someone who has a person with diabetes, and I say, let them own it themselves, and I admire that little kid for trying to find out..."

Short Summary

Margaret considers Deon to be a "screwball". She expresses anger and frustration, cannot understand why he does not take care of himself. She asks herself whether he is responsible or if he suffers from some condition that makes him who he is. She invokes the metaphor of a drug addict, an illness that would at least absolve him of some of the responsibility. In this way she is trying to lift blame, preserve hope. She looks for causes elsewhere and finds the possibly in Asperger Syndrome. Ultimately she concludes that she is part of the problem, that tough love is the only option. Her anger spills over culminating in one episode when she leaves him overnight in a prison cell. She cannot understand why he does not want to help himself.

(IV) A Mother's Quest – A narrative of searching

“...as far as I'm concerned knowledge is power, when I go there I talk to people I go to support groups, I go to counsellors to find out, I am still on a mission to find who is the right person to help me with Deon...”

In his book *The Wounded Storyteller*, Arthur Frank (57) conceptualizes three core narrative templates in which stories about illness can be told. Restitution templates envisage a return to pre-morbid health and are stories of loss and restoration. Chaos narratives lead nowhere, cannot envisage an ending or resolution and are immersed in the despair of defeat.

There is much in Margaret's narrative that reads like the third type of narrative template - that of the Quest.

Margaret's narrative recognizes that something has been irrevocably lost – Deon's pre-diabetic healthy state. But he is unable to reach a new steady state of equilibrium, unable to take responsibility for glycaemic control and is trapped seemingly in a directionless vortex of destruction. If we were to speak to Deon, we may elicit a Chaos narrative but his mother's belief is more systematized. Her experiences have taught her that you can find answers by going out into the world. She is looking not for restitution but for a type of transformation. A state whereby her son (and by extension, herself) can effectively, be saved.

“...teach me the practical stuff and ... I know what I know, and understand it, and would rather ask other peoples advice, you know, and that's what I do, that's what I did a lot...”

Margaret seeks help from disparate sources. They range from western medical doctors to homeopaths, psychologists, support groups and the wider fringes of those who seemingly operate with magical powers. She enlists the help of a woman from Llandudno who waves a wand and passes a machine over Deon's body to search for allergies. She consults with specialists in Asperger's syndrome,

and attends a support group for Autism in Tygerberg. She never gives up hope and even contemplates the telephone number of a putative mentor, an inspirational outdoors type, given to her by a stranger in a restaurant.

“...and I said to her, give me your number, because one day...because he needs a mentor...one day he could meet someone who would empower him, it would be amazing, not someone to analyse him, someone who looks after himself, ja...”

There is a steadfast determination to answer those deep questions concerning the well being of her son. She has convinced herself that she just hasn't found the right person to connect with her son yet. It's a matter of continuing the quest. In this way the on-going search protects her need for hope that something can be done. Underlying all this is the sense that a mother should never give up on her son no matter the adverse circumstances, and could never attribute solely to him agency for his misdemeanours.

But she is continually frustrated on her path...

“...Well what I want to say is, Michelle Carrihill has been fantastic, and had a rap session with us and it went very well, but we have never got to the bottom of why he cannot manage his diabetes and I do believe that after Jana's appointment, it was actually the ADD, that he cannot manage it himself, he cannot manage it himself, it's the time management, its being aware that he needs to read, sometimes he injects without even reading, and then he hits lows...”

The quest is a lonely one, not shared by her husband. Deon defaults from therapy, refuses to comply, is surly and unappreciative, and doesn't take much advice from anyone.

Still his mother continues in her search.

“...But that’s what I have done my whole life, tried to put him in situations where something can enable him, that he would pick up on it and go forward, so what do you do...”

“...Yes, but why can’t he manage himself, to keep his diabetes on an even keel. Help....”

Margaret’s quest is an on-going one, motivated by the need to answer key questions about her son’s condition and to help him. One could argue that her quest has provided little to help her son’s current poor control. She nevertheless has provided herself with a coherent and meaningful framework within which to situate her role as the mother to her difficult child.

Short Summary

Margaret is on a quest to answer two key questions. Why is my son the way he is? And how can I best help him? The implicit unstated third question however, is about how she can help herself cope with this situation.

On causation: Is this Deon’s adolescence, rebellion, learning difficulty, ADD, dyslexia, autism or addictive behaviour? Is it learnt behaviour or is he just a useless “screwball” who cannot be helped? Margaret’s restless search covers a wide field and while her questions remain for the most part unanswered. She is nevertheless supported on her own journey and finds a broad framework of meaning that provides her with support, comfort and occasional possible tantalizing answers to her questions. The quest continues.

Interview 2

Mother - Hilary Daughter - Karen

Karen was 15 years when diagnosed and is 16 at the time of the interview. She has a brother 4 years older and a sister 3 years younger. Notably, her father had a brother who died from insulin dependant diabetes in his early twenties. They have a close knit mutually supportive family. Hilary is very involved in Karen's management and is generally optimistic with a positive approach to the effect the diabetes has had on the family unit. Karen is well integrated at school, plays many sports and has an active social life. They have regular contact with a wide circle of friends and family, and have good relations with a diverse group of health professionals who constitute their support team. Hilary described hardly any conflict with Karen, who is able to responsibly look after her diabetes. It has been a difficult year for the family as Karen has been sick with a variety of diabetic related incidents, at times severely so. This has put a financial strain on the family. Nevertheless Hilary maintains a positive demeanour and gains great strength from her Christian faith and an active involvement with the Church.

(I) Food as a mediator of Family Unity – Family as crucible for Care

The family unit - its interdependent function and its adaptation to the everyday reality of Karen's diabetes is a central trope through the interview. Hilary expresses the changes through the eyes of the family; how it adapted, benefited and acted as a support structure. The family, as described by Hilary was the crucible of care, and the vehicle through which mutual support, glycaemic control and Karen's care could be mediated.

A diagnosis of diabetes disrupts entrenched patterns of behaviour in the family of the affected adolescent. Food lies at the heart of every family, be it as an expression of care, a consolidator of routine, a ritual that unites members at important times or a means of teaching about the basics of healthy living.

"...so we got carbo counting from the Thursday, it completely and utterly changed everything in our household. I had to go home, emptied out, cos I decided right from word dot, that she was no different to anyone else in the household..."

Hilary is determined to integrate Karen within the family, not to allow her to be marginalized; everyone had to change to a diabetic friendly diet. Hilary takes a strong leadership role in chaperoning her family through the transition. It becomes a project of health, knowledge and even fun. The family are taught the value of carbo-counting. Shopping trips, family outings, and routine mealtimes at the dinner table change considerably.

"... I have all these other men who like to eat lots but it can only do them good as well, so, right from the first day, whatever Karen eats we eat, I chucked out everything that has more than 15 grams of carbs, we did the whole carb counting thing, what used to take us 15 minutes running into a shop, now

literally, still today, because there are so many new products coming out, we read every single label..."

The family has become more mindfully health conscious in their approach to eating. It's brought them closer, rather than dividing them. There is a shared perspective that as a family they have grown through their ordeal.

"...and I think it has bought the family together in that sense, we have always been a close family, but I think the thing with food has taught us not to just walk into a shop and take anything off the shelf when we never ever used to think about it, every single thing that we buy is thought about..."

The change in their diet is an immediately available conduit through which to communicate about the diabetes and about health matters in general.

"...And we actually spoke about it round the dinner table on Tuesday night and even my daughter, she said, she has seen such a big change in us, okay so she is also growing up through it all, but she said, we have always been a close family, but its brought us even closer, and health wise its been a fantastic thing..."

Hilary's husband, Ben, is involved with food preparation and helps to share the division of labour. Food preparation is a means by which responsibility is shared between the parents. This is particularly important, as their 12 year old has Asperger's syndrome and requires time-consuming care.

"...my husband, has been incredible, he cooks at night, my 12 year old is an Asperger's so I spend a lot of time in the afternoon going to therapy with him. My husband has his own business, and he can come home at like 4 o'clock so that Karen can like eat, he starts cooking, so by 6 o'clock, everyone starts eating, everyone has eaten..."

Inclusivity within the family includes care of the other siblings, who often struggle because the diabetic child is usually the centre of attention.

Matthew, Karen's younger brother with Asperger's couldn't understand why he wasn't allowed to inject. He felt excluded, enjoying less of the attention than previously, so he was included in a way that promoted knowledge and shifted some attention to him.

"...I would say my youngest, because he is 12... so we had to educate, because he was so scared, its not like we have these huge big needles anymore, or anything, and he didn't know what it was, and why he couldn't use it, and why is Karen doing it every day, why can't I do it, but I said, you really don't want to do this every day, and we had to, in a very different way, explain it to Matthew, and he actually, and what I did was I made him do a speech on it at school, when you got to do your oral. Now he is grade 6, he was grade 5 then and I said, if you want to understand about it, lets do a little talk on it and you can go and give it and if you think you are confident enough to give it... and he did it, and the teacher actually phoned me and said, you know I come from a diabetic family, and I have just learnt more from Matthew... it was quite funny – so he has more of an understanding of it..."

David took the role of the caring older brother.

"...David, I think was just highly concerned, you know, he is the older brother, um, so like if she was going out, he was like, Mom, do you want me to go along just to check? For the first couple of months that she went, for the first 6 weeks that she went somewhere, he would pop in just to check she was ok, without her knowing and she actually liked having him there in a sense, because if something goes wrong, if she is not feeling good, then she can just come home, he can drive, you know..."

Both siblings are integrated into the family in ways that help to alleviate alienation and consolidate the care necessary for a coherent mutually supportive approach to the diabetes.

Hilary is emphatic about the unwavering support and care available to Karen, a secure environment suggestive of consistency and transparency.

“...we did it all together right from word dot, she knows she can come to anyone of us if she needs help with anything whether its nutrition, whether its advice, whatever it is, she knows she can come to any one of us in the family and we will be there to help, so its just that constant support...”

There is a self-identification as their being a close family, and a clear indication that the diabetes has brought them even closer. In this way, diabetes is formulated as a challenge to be overcome, reinforcing the family values of unity, transparency, unquestionable mutual support and care. Hilary is articulating a form of active engagement and demonstrating an example of resilience within the family unit.

“...so I think our whole conversation has changed, its become more mature and its through the diabetes, its through the management of this disease...”

Short Summary

In Hilary's detailed descriptions, the family unit acts as the prism through which her daughter's diabetes is mediated. Food is the conduit for discussion about diabetes - the main area of change in the family and a place where responsibilities are delegated. The family has become healthier and more united, often through the medium of their shared diet. There is care to manage the asymmetries caused by the presence of a diabetic sibling. Overall, the interdependency created has resulted in a more unified, communicative and supportive family. There is a mutual understanding that they have all benefited from the experience. Hilary proudly affirms her family.

(II) Social connectivity – A foundation for care

A wide supportive network encompassing friends, family and healthcare workers forms a recurring theme in the narrative.

“...we are a very sociable family. We are quite a large family, if we have a braai, or a big lunch or whatever, Karen is always taken into account, which is so nice, because you can go to places where people just don’t give a damn, and she has to find her way around that, and just in our family circle, there must be 47 of us. Everybody, knows that Karen has her diabetes and everyone has tried to bring in a dish...”

The widespread acceptance and assistance helps to remove any stigma of her diabetes.

There is however fear amongst her peers and friends.

“...so that I think a lot of her friends were scared and the parents were even more scared, because she went through a period of a series of very low readings...”

This resulted in some changes to her social life.

“... alot of them have holiday houses, and she was invited away like literally for every holiday for long periods. She hasn’t had that since she has had the diabetes, she might go away for a weekend now, but that is almost as far as the parents can handle it. I don’t, you know, they try, but it’s definitely not like it was...”

Recognition of this is dealt with proactively as an opportunity to educate, eradicate stigma and normalize relationships for Karen amongst her peers.

“...there were 9 little girls in her group, and I invited all of the parents over, and all of her friends, and I said, this is it, and we laid out this little picture box on diabetes, and if something goes wrong with Karen, these are the processes you must follow..., if something goes wrong with Karen, this is what you do. It took away the fear from some of the parents, we were just absolutely astonished at just how many people were absolutely ignorant of diabetes...”

A large extended family abroad provides the possibility of extra support and opens up options for Karen if she were to travel.

“...It’s just if, if she goes overseas, my brother lives in Beijing, and I know my sister-in-law will look after her, but will she be able to get the kind of foods that she knows the carb counts to over there...”

Productive and appreciated contacts are made with medical helpers, including nurses, dieticians and doctors. Hilary is seemingly effective in reaching out for the help she needs and effusive in her praise for those who have helped her.

“...Dr Dave, is just amazing we absolutely love him, he was just so nurturing and explained it, we knew nothing really, I went in thinking I can do this...what I must say he was and still is absolute incredible, I can phone him anytime, I can send him a message to say I need to speak to you now, and he is available, and I think that has been a godsend...”

Short Summary

By Hilary’s account, Karen is fortunate to come from a very large and supportive family. This enhances support and helps to remove stigma. It also helps the immediate family to feel less isolated and know that Karen can spread her wings under the care of trusted relatives who know her very well. Hilary seems to know instinctively that the contacts and management partners she liaises with are very important. She values and creates meaningful appreciated bonds with a variety of

health care workers. She is also proactive in anticipating problems amongst her daughters peer group.

(III) Navigating anxiety in a parallel world of Glucose control.

A central theme running through this narrative was that of scrutiny and control. Already the relationship between Hilary and Karen is close, but the diabetes brings them closer. Hilary watches Karen's glucose levels very carefully. The connection between anxiety, glycaemic control and close scrutiny is a dominant theme throughout.

A life with diabetes entails restrictions. A central concern of parents is the amount of latitude they give adolescents to take risks.

From the beginning Karen learns that her life is going to change.

"... when she was diagnosed Dr Dave said to her, ok kid, I want to tell you now, whatever tattoos you have now, they the only ones you going to have, what ever piercings you've got, those are thing, and your drinking career, if it hasn't started, then its not going to start....right from the word go..."

Carbo-counting is the method taught by dieticians of tallying the glycaemic value of foods as a means to calculate the amount of insulin required.

"...she got her carbon counting, we did the first round of carbo counting, then we did the second round of carbo counting. We haven't done the third round yet..."

There is a long list of what she can and can't do. A whole new set of rules for her to follow. Because she still needs some caretaking, her mother will be very involved in watching and monitoring her.

"... but actually you know very little, anyway, so she got at on the 13 July that she was diagnosed, and Lara came and spent the whole afternoon, of that day with us, then she was going, Karen can't eat citrus, she can't eat this, she can't eat that she can't eat this, and I have all of my type II diabetic books and I'm thinking this quite strange, I was getting quite confused and I was getting petrified..."

Sugar lows can happen quickly and unpredictably and result in sudden dangerous changes in the body. This is the burden that a parent carries when they take responsibility for their child. Monitoring glucose levels can be very anxiety provoking.

"...it's not good for her to have too many lows, you got to keep it on an average, I mean most of last year she was between 4 and 6, which was absolutely brilliant, she has started having really low lows, her lowest one was 1.4, but she can feel it, which is a good thing..."

Hilary takes a very proactive approach in assuming control of the diabetes. A whole new language characterized by blood test values, injection units and administration times mediate this preoccupation with assuming control.

"...I think her first hba1c that was done was 11.5 or something um, that was after the first three months that we saw him, then it went to 9.4, then it went down to 5.9 so we have kept it low. It has just started to climb now, she is having another hba1c done on Monday, Um but she thinks because she is coming out of the honeymoon phase, she has been taking, she is injecting 4 times a day, in the morning at 7, 1, 6 and her 9 o clock Levemir. I would say that the whole of last year it was between 4 and 6 units she was injecting..."

A parent will usually be more risk averse than their adolescent child. A vital challenge to the mother-daughter dyad is to negotiate the relative differences in their perception of risk. For some this can be well aligned, for others more poorly. Much depends on the nature of the relationship they have together.

"...We always had a close kind of relationship, its just become a more of a nurturing type of relationship, far me, long at her, why has she got circles around her yes, when I wouldn't ever have thought about that 18 months ago, or looking her colour has changed, this morning, I mean my whole look of her, is from a health perspective. I can immediately see if she has lost weight, because she is quite slim anyway and it's a constant. How can we get her to pick up a little weight now because what we have found, is that if she goes underneath 53kg, that's when she gets sick, so we try to keep her above 53kg..."

The preoccupation with glycaemic control exerts a strong influence on the nature of the relationship between mother and child, and hones the acuity of Hilary's surveillance monitoring.

"...I think I have changed in that I am so much more aware of where she is at, who she is with, are they feeding her correctly I mean I would have thought about it before, but now, my constant thought, she can go away for the weekend and I'll be thinking, do they say they have everything but do they have lo GI bread, do they have baby potatoes, you know, my concern has become tenfold more, because we are wanting to keep the levels like they are, obviously in the future they are going to change once she gets out of her honeymoon period..."

As her daughter starts to socialize, a whole new range of threats, unremarkable in the absence of diabetes, start to raise their heads. Eating out is a problem and Hilary is very engaged in organizing and co-ordinating the right food, even from at a distance.

"...she was invited to a whole lot of dances last year, and with her eating at 6 o'clock, even if it was an hour later, wasn't taking her to the time when she could eat, so we were delaying her food the whole day, and phoning Doctor Dave, she hasn't eaten yet, and now she has to take her Levimir and then what I started doing is phoning the function room she was going to and saying,

listen, I've got a diabetic daughter, she has to eat by this time, she has to have a diabetic meal, they were extremely accommodating..."

We hear how as time goes by, as Karen graduates to greater independence, she relies less and less on her mother to organize food, and is able to take her own control.

"...Dr Dave will say to me just slow down a bit, just calm down, you are being a little bit too strict, but I just feel, she is at that age now she has to learn this for herself, she has to learn that for herself, she is 17 years now, she has gone from going to movies with her friends to going out to dinner with her friends..."

She gently chides her mother when she sees her becoming over vigilant.

"...I'm not measuring that at all, because I think she I will say to me, Mom like if I have walked in twice, she will say, you have already checked in on me, just leave me alone..."

"...I'll go and slide her door over, and she will say, Mom, I'm breathing or just go away, I'm fine, you know..."

Short Summary

This theme captures the relationship and language of glucose control and how it mediates the competing dynamics of managing a mother's fear and promoting adolescent autonomy. This negotiated control starts out in the hands of the mother and is accompanied by close scrutiny of values and numbers. These are a measure of success and ways to prevent a drop into hypoglycaemia. The mother exerts control, in part to keep her own fears at bay while her daughter may have other priorities. The transfer of responsibility is critical. Karen assumes this responsibility, facilitated by her good relationship with her mother. Hilary can relax. She is lucky, as she says, fortunate not to have to worry. Her and her husband are proud of their daughter and able to feel confident that she can look

after herself. Nevertheless, fear is ever present; university, overseas travel, marriage and children all lie ahead.

(IV) Negotiating difference – a new normal

“I am a diabetic and always will be”

Coming to terms with an illness that separates you from an age-appropriate norm expresses a central paradox of adolescent psychology - the need to be set apart from others and develop as an individual, yet simultaneously to adhere to group norms.

This theme is echoed in Karen and her families' determination to see her living as normal a life as possible, and yet still be assertive in developing a strong identity as someone with diabetes.

From the beginning, Karen takes responsibility for the management of her diabetes and is mostly forthright and transparent about her diagnosis. She shows a strong determination to integrate herself fully into her environment. She plays sport, participates fully in school and has a wide circle of friends.

From the beginning Karen wanted to take control.

“... let her give herself the first injection, she insisted, she said, that mommy, if this has happened to me, I'm going to do it, I am going to conquer it, its going to be my little battle, I'm going to do it on my own, and I mean, it was absolutely mind boggling, because she never once cried, she just handled it so beautifully...”

Karen's family changed to accommodate her needs, so that she would not appear so different - a diabetic friendly diet became the family norm.

“...we always said, we not going to let this diabetes rule you, you are going to rule the diabetes, but there are situations where it still actually rules you, um

no matter how you try to get around it, so we got carbo-counting from the Thursday, it completely and utterly changed everything in our household. I had to go home, emptied out, cos I decided right from word dot, that she was no different to anyone else in the household..."

However, it is inescapable that differences emerge, not only dietary changes and adaptations to the new technologies; the insulin and test kits, but a vast medicalization of life, with numerous medical contacts that before would have been unheard of. All these have the capacity to reinforce the idea of the sick self.

"...I think it has been huge, from never even been sick to now when we walk through Constantiaberg, she says, hello home, hello I'm home, all the doctors knew her, all the nurse knew her..."

At first Karen, very keen to make her diabetes 'invisible' was reluctant to meet with the other diabetic child at her school.

"...you know how they hated to see my injections, now they don't even notice, so it just becomes invisible, and that's the way she wants it, she doesn't want to be known as this diabetic child, um, I mean, she knows that there are only two in Springfield, and she knows who the girl is, and even though we tried to get her to communicate with the girl and that, she wasn't interested, she didn't want anyone to know that she was diabetic. Ja, or really, and since then she has become friends with her..."

Karen is described as strongly independent, and assertive in her management of diabetes within her social sphere.

"...She is extremely independent and she just lets her friends know, if they say they want to go out for pizza's tonight, she says, hello guys, I can't, I can only eat two slices of pizza, why don't we go, over to Primi Piatti, where I know I can get my salad ..."

She is discreet in injecting, and will generally not talk openly about her diabetes with those she doesn't know. One could imagine an adolescent with less confidence finding it difficult to be assertive about their needs.

But there remains a deep ambivalence about being different.

"...she said last night, because someone asked her, how do you feel about being a diabetic, and she said, I don't look at myself as being a diabetic, I'm just like everybody else, she doesn't want to be seen as a diabetic..."

She is curious and motivated enough to go to a diabetic association meeting but is concerned that it would turn out to be a group of pitying self-identifying sufferers.

"...you know, I'm a diabetic, she said to me on our way there, Mom, this isn't going to be like an AA meeting, I'm not going to have to stand up and say, My name is Karen and I'm a diabetic..."

She places limits to how far the diabetes will affect her life. She reserves the right, to clearly mark how far the technologies of glucose control will intrude onto her body.

"...she is adamant that she will never have the pump, and Dr Dave is saying to her, don't say that, she says no she is not going to have anything put on her beautiful flatboard stomach..."

Her consumer's class is a place where she has been particularly aware of differences - much of the baking and cooking is done with sugar. She is assertive in negotiating some equality for those unable to eat sugar.

"...she does consumers on a Friday where they do cooking and baking and like today, they can choose what they want to do, and they can cook with a partner, and she said, no ways, I have been cooking what you want to cook, today we are doing diabetic, and they are doing diabetic carrot cake, um..."

By helping to educate her fellow scholars, and teachers at consumers, she felt she was breaking a path for those with diabetes who follow her.

Her self esteem and positive identity as a young person with diabetes was furthered by her playing a key role in helping another young recently diagnosed scholar. At first he was reluctant to ask for help, but then one night they received a phone call.

“...it was 10 o’ clock at night, and he said, can I talk to you, I need to talk to someone who is my age and she chatted to him for I don’t know how long and went and met him...”

Karen forms a close relationship with him and her help is warmly acknowledged.

“...his family brought her a stunning little diamond cluster in the shape of a heart, just to say that she has this heart of gold and this mentoring that she is giving him is just unbelievable and they really really appreciate, so she is very good with helping others, its made her grow...”

Karen is also influenced in her thoughts about her future. Her experiences have sensitized her to want to help others.

“...as soon as she got diabetes, she said, I would love to go and do dietetics, or nutrition, or whatever, but because she doesn’t have the science, she can’t do it so what we going to do now is choose her courses, and she wants to go into business management, perhaps a food magazine, or something through that line...”

Karen is challenged one day when spotted by a fellow scholar eating something sweet.

“...So her first question was, why are you eating that? Karen said, but I can, so she said, haven’t you got diabetes anymore, so Karen said, I’ve got diabetes, and I will have it for the rest of my life, its not going to go away....”

Karen needs to come to terms with the reality that she has a significant life-changing condition that is with her for life.

Short Summary

Karen is encouraged to consider herself a normal person who happens to have diabetes. Her condition is normalized within the family environment and her peer group is educated by her parents. She takes it upon herself to bring a sugar-free cooking method into the consumer’s curriculum. Nevertheless there is ambivalence in being openly identified when injecting, not wanting to be known primarily as a diabetic and being uncertain of contact with other diabetics who may reinforce negative stereotypes for her. She marks the limit of where the technologies of diabetes will intrude on her body by refusing to wear an insulin pump. Nevertheless, her activist stance, altruism, enthusiasm to educate herself and take responsibility for her own management suggest a successful integration of diabetes into an otherwise normal adolescent identity.

(v) Upbeat Positivity

“...so Ja, if I had to put it in two words, it’s be positive, don’t look at the negative, because as soon as you look at the negative, it pushes them down, it pushes their levels up...”

Throughout her narrative, Hilary maintains a bustling positive outlook while striking a proactive extravert stance, placing emphasis on the benefits of their experience. She expresses pride in her daughter’s able way of coping with her diabetes, has glowing words for her involved husband and heaps copious praise on the health professionals. She comes across as a warm and outgoing person, seldom critical, full of energy.

“...I think her whole persona changed, and for me as a mom, she has made me unbelievable proud in the way she has handled it, for my husband as well, through the way she has handled this, being in hospital so much, when he has told friends or clients or whatever, he says, it sounds like Karen has handled this so well...”

The mien of positivity has the capacity to overcome a variety of challenges posed by diabetes. With humour and an action based approach Hilary is able to lead the family through a transition where they must change eating patterns, learn new forms of behaviour and educate themselves about this new illness. The wide variety of therapists and the enduring working relationships she has formed seems to attest to her social and organizational skills.

On advice she would give other mothers with a newly diagnosed child with diabetes:

“...just be positive, my whole thing is that if I had been negative in any way, it would have affected her, I just, the whole time, from the minute it happened, we are here for you, the whole family is here for you, we are all behind you, we going to be with you every step of the way. We actually had such fun the one

day chucking everything out of the cupboards, we made a whole family thing of it, but it was just, we did it all together right from word dot..."

Positivity is a way of committing to her family, and of communicating an attitude that will give her daughter the best possible chance of overcoming the challenges of diabetes.

"...It's just comfort, giving nurturing, she hasn't, I think in a year, there has been nearly 3 or 4 times that she has been really down, and its just being there, sitting with her, talking, and telling her the positives that can come out of it, not the negatives, she is a beautiful girl and nothing will hold her back..."

She supports her child, holding her through her difficult times and provides a framework through which the family as a whole can interpret their experience with the illness. It has changed them all for the better.

"...And we actually spoke about it round the dinner table on Tuesday night and even my daughter she said, she has seen such a big change in us, okay so she is also growing up through it all, but she said, we have always been a close family, but its brought us even closer, and health wise its been a fantastic thing..."

We even hear of how other families without diabetes look to them as role models in healthy living.

This positive frame helps to create a sense of meaning and purpose to the seemingly arbitrary appearance of diabetes. It exemplifies Frank's narrative of transcendence. (57) An overcoming of the challenge that allows those affected to re-emerge transformed for the better, having suffered an ordeal that has a heuristic element to it. There is a religious quality to this process, one that is substantiated by an acceptance that things happen for a reason, and that no-one is given anything that they cannot handle. It's a belief, in this case bounded by Hilary and her families' strong Christian faith.

“...We are Christians and I strongly believe that God thought we were the right people to give this too, to cope with it, and just pray. My husband and I are very strong in our faith and we hopefully have put that across to our children, and she knows, if she needs anything, if I am not around she can just pray and God will be there for her, and, so it's like an enveloping presence around our family...”

Positivity is intricately tied in with a form of redemptive faith, powerful in its ability to convey meaning and support.

“...from the time she took her first injection, like she had made a deal, with herself, that it wasn't going to let her down, and through that it helped me. I think, I couldn't believe what I think I was looking at, my girl, this is something that is going to be with you for the rest of your life, you are going to be injecting, you are going to go to your grave one day, there will never be a moment, in your life when you are not going to have this. She was not thinking about that, she was just thinking I've got it and I'm going to move on...”

However, as the last theme depicts, this positivity is held with an all too keen awareness of the danger that diabetes poses. The theme of positivity can only be fully understood in the light of the threat to which it is a response.

Short Summary

A central philosophy reflected in the mode of Hilary's narrative is the upbeat positive tone and proactive stance she takes in dealing with the diabetes. It is a way of life and reflection of her faith that she provides leadership and creates a framework for care and communication. It is tempered by a very real understanding of the gravity of her daughter's illness. It may be in part an idealized view, but its pragmatic effectiveness, by Hilary's account seems clear.

(VI) The Proximity of Death

“...I needed to get over that, and I needed to ask every possible question to confirm my fears that she wasn’t going to die...”

The theme of Karen’s mortality and the threat of death is a central pivot around which the narrative moves.

The early history of the family includes her husband’s brother who died at the age of 19 with diabetes. Death from this illness is already a reality that has been experienced by the family.

“...OK, I’m married to an Afrikaans guy, Ben, and his brother got diabetes when he was 21, no, he was 19 when he got it. He got married, and they got pregnant, and they had a child, and he died, the week that they had the child... of diabetes...”

From the beginning Hilary worried that her child was going to succumb to the disease...

“...My whole thought process from the time we were in Langebaan was that...my child is going to die, it’s like this death thing had been put over her head and my brother in law had died from it...”

There was a pervasive fear that she could suddenly die.

“...I would say... even up until 6 months ago, because she was running into those lows all the time, my fear was that I would walk into her bedroom and she would be gone ...”

A hypoglycaemic attack or sudden lowering of her blood sugar could happen at any time.

"...But on Tuesday it was so quick, we were sitting, were laughing, we were talking to him and all of a sudden she went quiet, and Joel (endocrinologist) looked at her, and I looked at Joel, and she just went straight away, and she was like shaking, and her heart beat hadn't gone up, but her blood pressure had dropped..."

Of rapid onset and unpredictable, they could come at any moment and prompted the fear of a coma.

"...and of course there was the whole concern of her then going into a coma with that as well, so there was that constant worry, um, in the beginning, I sort of got over it..."

In strong contrast to the positive shade conferred on their overall experience, the last year with Karen was characterized by almost continuous bad health, often with hospitalization and the prospect of a fatal diagnosis. In the interim, they ran out of medical aid and depleted their savings.

"...He said it was her sciatica nerve, that happened 6 times last year, literally every month, every month, and it took her, so long to put her weight back on, every time we were, aaah, she put on a kilogram, yay, lets throw a party – (with no sugar!) um, and then something would go, she got bronchitis, she got pneumonia in her left lung, she got this thing, 6 times and when ever she got that, her system would go completely low, and then in December, we went up to Plett and we were camping, and we got a bacterial infection, from the water, and she got, you know when they sick...a nasogastric tube, she had blisters going from her mouth, all the way down into her stomach, she had three huge ulcers. He actually called me in and showed me. It was terrible, and she couldn't eat, literally for three weeks, so we were having to mush everything that she had, that obviously, it changed the whole GI (glycaemic index) because we were mashing it, or whatever, she had that and it was a huge fright, and then before we went away... they don't know whether it was

linked. That was at the end of December. At the beginning of December, she developed, it was like bunches of grapes in her groin and they thought she had lymphoma. It was huge bunches, you could literally feel them from the outside, they were at least about 3 centimetres each, and there were 5 on the one, 7 on the other, and they gave her antibiotics, and they went down and they went away..."

Short Summary

Hilary describes the hardships they have endured, their challenges a stark contrast to the positive mien of her narrative. Karen has been very sick with numerous hospital admissions. They have used up their medical aid funds and depleted their savings. In the background is the memory of Hilary's husband's brother who died of diabetes. Each hypoglycaemic attack that Karen experiences carries with it the threat of a coma, and possibly death. The emphasis on family, positivity, unity and religious spirituality can only be truly understood and appreciated in the light of this ever-present danger.

Interview 3

Mother - Adele Son - Bruce

Bruce was diagnosed when he was 16 months old. He is 16 at the time of the interview. He has a twin sister and a brother 2 years older than himself. Adele's husband is a businessman. Trevor, Bruce's older brother is also a Type 1 diabetic, but Adele chooses to spend the entire time talking about Bruce. This is because Bruce poses a more difficult challenge to her and her husband. He has learning, attention deficit disorder and many difficulties with controlling his diabetes. Trevor on the other hand is a model student, takes full control of his diabetes and elicits little anxiety. Much of the narrative expresses the anger and frustration that both Adele and her husband feel in trying to organise the life of their son, including helping him to take responsibility for his diabetes. The on-going frustration leaks over into conflict within the parental relationship. The interview ends with Adele asking me if I know of a good adult endocrinologist that Bruce can see. I am left feeling that she is still looking for answers to help meet the challenge of her son's diabetic condition.

(I) Conflicting Priorities – The Irresponsible Adolescent

Adele has two children with insulin dependent diabetes but she chooses almost exclusively to talk about Bruce, her younger child, rather than Lee, the older. Lee is 18 years old, and Bruce is currently 16. They have a sister Carly, who is 15.

Bruce is described as being out of control most of the time and seemingly unable to control his blood sugar levels. It is only recently that his mother has stopped injecting him, late in the normal life of an adolescent with diabetes. His actions and activities do not inspire confidence in his parents.

Adele cites an example of when he ‘cooked the books’ in order to make it look as if his blood glucose control was better than it really was.

“...he started doing his own readings. I didn’t check, I won’t go back, suddenly, I just thought his readings are just too good, so I go back to his machine, and for the whole month he was 21, HI, 7, 9, 33, HI.¹ He was fiddling the books, so you see, everything has just, more control, more control, more control...”

The responsibility in handling injections, testing regularly, balancing food and exercise with sugar levels and above all keeping in contact with his parents are indicative of responsible diabetic self-care.

In this regard, Adele has little confidence in Bruce’s abilities.

“...When he plays in goal, he has to take his medic alert bracelet off, then he leaves it in the goals. Why does he have to take it off when he is playing goalie...so now I’ve got to order another one, and he has lost two phones, and he lends out games and they don’t come back, and uuuh (sigh), it just keeps on going...”

¹ The desired glucose levels would be between 5 and 7mmol/l.

She feels that he prioritizes the wrong things. He is at present very concerned with bulking up his weight and so has put a lot of effort into making himself look bigger and has asked to see a dietician.

“...I think with Bruce, he is desperate to be bigger, I said, my boy, look how you have filled out. He wears three tops on top of one another. You have seen him go out now, under there will be at least 3, 2 long sleeve tops and a short sleeve, to look bulkier, and I argue every morning with him about it and I try not to... but when I see the school shirt like this because its so tight, because he has so many clothes underneath him, I just, please Bruce your body...but he just doesn't see it. I said you are going to be taller than Lee, you can see that, but the more you run with high sugars the less weight you are going to put on...”

It is a typical example of how a teenager's concerns are at odds with a mother's worries. While Bruce is increasingly self-aware of his body - immediate concerns in the life of an adolescent, the long-term implications of high blood sugar levels are what pre-occupy his mother. These different perspectives are a source for frustration and the breakdown in trust between mother and son.

Short Summary

Bruce's inability to look after his sugar levels retards his progress into autonomous maturity. This results in an increasing amount of anxiety as he ventures beyond the home, where his mother has less control over his management. They hold divergent views over priorities. Bruce seems unconscious and uncaring of his diabetic control while his mother is made anxious and angry by his lack of responsibility. She does not have the trust that he can look after himself. Her concern and frustration is evident in that she talks exclusively about Bruce rather than her older son, also a Type I diabetic, who is able to control his diabetes well.

(II) The Spatial relationship of Control

There is a spatial element to the relationship between mother and son and the cultivation of autonomous diabetic management.

“...if you control your sugars, that’s all you have to do, you can wander around Pinelands, you can go to Jake, you can sleep over at Andiles’, but until you do that ...I mean I am a nervous wreck...”

Distance translates into anxiety unless mediated by bridges that are able to reassure of behaviour that would herald good control.

Bruce’s irresponsibility with his cell phone undermines Adele’s confidence that he is able to look after himself. This may not be direct evidence of bad control, but the ability to communicate and reassure acts as a surrogate.

“...and if he goes away I would say to him, what have you had, so I can see what he has eaten. He never phoned, he never phoned, and eventually I got hold of him through someone else, and it turned out, that because he has lost so many cell phones, we made him take an old one of ours, but that wasn’t cool...”

It is another example of how a teenager’s priorities often conflict with that of the parent. His parents give him one of their phones after he has lost yet another of his own, but still there is no contact from him. Bruce explains later, that he was embarrassed by having an ‘uncool’ phone and this prevented him from phoning them.

When Bruce goes away it is potentially a time of great anxiety and threat to his parents. Anything can happen, his sugars can go out of control or he may not inject properly. The normal anxiety parents experience when their children test the waters of independence is compounded by the perception that Bruce is irresponsible.

“... he doesn't tell us that when he comes back, so he comes back, I'm out, Rory comes to pick him up, and by this stage we are neurotic, both of us, we don't know what his sugars are. I get my daughter to go onto mixit, to get hold of one of the girls that's on camp, is he okay, um, so what would have been a relatively pleasant weekend for us, turned into mayhem...”

Distance, therefore must be mediated by proxies for control and responsibility.

“...you know, Bruce has just been on a camp now, and we said, my boy, you can go, school camp, um, one of the teachers going had a nephew who was diabetic, she was also the home economics teacher, I went and chatted to her first, Mister B was going, I am comfortable with him, and I went and talked to them and said, Bruce is 16, he knows, he has got to phone us, because now he is doing, they were at Noordehoek...”

Opening up distance between Bruce and his parents is therefore an exercise in managing his parent's anxiety as much as ensuring that he is safe.

“...since he met him here, his dad has a medical background, Dave, and he, I really trust Bruce with, and he has been invited to go up in December (To Knysna) , to go up with Jake, and then for Jake to come back with him. And, I'm pushing for it...”

“...I kept in contact with Dave, who kept an eye on them all the time, he said mom, “I'm having the time of my life”, and you know, it saddened me, that that's where he is having the time of his life, you know, so I am pushing for it...”

Adele knows how important these times away are for her son and realizes she must work hard against the grain of her own anxieties.

Similarly, she has identified the more responsible amongst her son's friends she feels she can trust Bruce with.

“...even though he is with boys who are slightly younger, they have a lot more freedom than he does, so I will say things like, he has a friend in the township, who he has had since he was two, so Jayson will come and stay here in the holidays, and that suits me, because I know Jayson is sensible, its almost like Jayson is my security blanket, when Bruce goes out, if I know he is with Jayson, I know that nothing can go wrong...”

Adele is aware that she allows Bruce less freedom compared to the others. This added scrutiny takes its toll.

Short Summary

This theme identifies a spatial element to the anxiety resulting from lack of control of Bruce’s glucose levels. As he goes further afield his parents become more worried about him. Their lack of faith in his abilities to self-care requires them to invest trust in surrogate care-givers such as Dave, a friend who lives in Knysna, or Jayson, Bruce’s reliable friend. Distance also lends opportunities to foster autonomy, is a proxy measure for parental anxiety and therefore requires careful organization. It’s a focus for some of the deepest sources of parental fear surrounding an adolescent with or without diabetes.

(III) Out of Control Emotions – A self-critical response.

“...but with Bruce, it was the most horrific thing I have probably ever been through because he was only 16 months old, the other one was just nearly three, and he had a twin sister as well, so suddenly our whole world just exploded...”

The initial diagnosis was a huge shock, arriving over and above another 16 month baby and a toddler, with all the challenges of injecting a baby and monitoring sugar levels. It was overwhelming from the very beginning.

“...he frightened me, he screamed non-stop, how I didn't land up in a mental institution...”

Adele's response was to be pedantic in her management.

“...I say it's changed my life, I have become an absolute control freak, I can't help it, and I use that word control freak...”

This was also necessary, because she received little help from her husband, who more often than not had difficulty coping.

“...Ed falls apart, and I go into control mode...”

Adele reflects on how their parental efforts and responses to diabetic management had a deleterious effect on Bruce. She feels that she over-mothers him and that perhaps things would have been different if she had responded differently.

“...A friend of mine has a very different take on him She adores him, she has known him since she was born, and she has said to me, Bruce's problems stem from you and Rory...him not growing, and not, he is not like the other two. I don't let him be as free and easy as the other two because I constantly worry about him...”

Her frustration and anger emerges in her interactions with Bruce over his lack of responsibility.

“...He wants to put on weight, he wants to bulk out, to be big, but why can't I get through to him with that, I said if your blood sugars are balanced, you will put on weight, all you doing is weeing... and then of course I start screaming...ALL YOU ARE DOING ARE JUST WEEING IT OUT...WHEN ARE YOU GOING TO REALISE, and it sets the tone for home, everyone is oh god, Bruce has done it again...”

“...but I mean, how long can we go on like this, I say to him, I shout at him, I'm gong to take you to Groote Schuur, I'm going to show you those children on dialysis, just so you can see what it looks like...”

Short Summary

Adele is self-critical when reflecting on her management of her son. She characterizes herself as a control freak, feels guilty that he would have been better had she not “over-mothered” and acknowledges how her underlying frustration often results in angry confrontations with him.

(IV) Conflict with Her Husband

“I don’t think he has ever recovered”

“...I will say that, my husband and I fell about completely. He cried and said, we will have to put him in a home because we can’t look after him...”

From the beginning, while it was incredibly difficult for them both, her husband Ed totally fell apart. This shifted the pressure onto Adele to be the one who kept things together.

“...Ed falls apart, and I go into control mode, and as I say, I’ve got good friends, you know, one popped in and she had a magazine that had something on diabetes in, and she came and sat with me, at the Vincent Palotti. People were fantastic, no um, I was frightened, but I knew Ed was falling apart and I had to keep him going...”

The experience had an indelible effect on their lives as young parents.

“...when I look back at pictures, of the family, do I see how traumatized we both were. We used to go to the beach every Sunday, winter or summer, whatever, we are beach people and if I look back at those pictures, you will see pictures of Carly, Bruce’s sister, and Lee, the older boy running on the beach, and you will see my husband sitting on the beach, with Bruce, his arms around him, and, I don’t think he has ever recovered from that...”

Both parents responded in very different ways and often disagree on approaches. Adele’s husband became withdrawn, was often worried, and seemed unable to mobilize effective management. This left Adele to mostly cope alone.

She reflected, that perhaps her husband was not meant to have such a thing happen to him.

“...I don’t think that Ed, his family lifestyle and being brought up, you know, this was probably the wrong person for this too happen to. I really have to say this honestly to you, he wasn’t built to cope with this kind of thing...”

Adele feels that Ed reacts out of fear. He often loses his temper and becomes confrontational.

“...Ed is basically threatening him again, and its out of fear again, ‘if you don’t start wearing your bracelet, we will cancel your trip to Plet’, and I know where its coming from, its I don’t really want you to go...”

They often disagree about the right course of action to take in his management.

“...He is a teenager, its not cool, and Ed went berserk, and I listened and told him Ed, tell him why you are shouting at him, its because you care, for him, I’m not punishing you...”

Short Summary

This particular theme illustrates how the cumulative trauma of a challenging chronic illness in the family can have far reaching effects on the parents. The extra stress placed on them, the discordant coping mechanisms, the burden of responsibility and the conflict that may arise out of these differences exert significant strain to a marriage. Fear both unites them and has the potential to push them apart.

Interview 4

Mother - Sheila Daughter - Lauren

Lauren was diagnosed when she was 6 years old and is 15 years old at the time of the interview. She has a sister who is 9 years older than her. Sheila worked throughout motherhood in the nursing profession. Her husband is a policeman also working night duties. Sheila is the only non-Caucasian mother interviewed whose first language is Afrikaans. She answers questions simply with little elaboration and is at times tearful. She seems full of unprocessed emotion. She describes many difficulties in looking after her daughter including stigma and blame from the treating doctors, disagreements with her husband, accusations by family and non-co-operation by her daughter. She cannot understand why her daughter will not recognise that she has an illness that requires careful management. Her daughter is socially very withdrawn. There is no feeling of resolution or integration about this narrative, rather a feeling of displaced anger and unresolved sadness.

(I) Anger and Impotence - A disconnect between daughter and mother

"...I am getting angry...because I thought maybe she is bigger now, that's what I thought..."

Sheila's relationship with her daughter is characterized by anger and frustration. Her expectation is that by her current age Lauren should be taking responsibility for looking after her diabetes. This has not been the case so her mother must continue to carry the burden of responsibility.

"...I just want her to be better and to eat right, that is my challenge. But it is difficult. She doesn't see it that way. She doesn't care about being a diabetic..."

Lauren seems unable to look after her own condition. Sheila perceives her as not caring about her illness and not agreeing about this important priority. Lauren is frequently admitted to hospital, does not regularly test her blood glucose nor self-administer insulin correctly.

"...She never talks about it, never tells the friends or anybody, doesn't even want me to tell the family that she has diabetes and sometimes I will notice that she is high a lot of times, and last year I noticed that she doesn't inject, as I say, I am working and my husband is working, so she only injects in the morning, and then in the lunch time she just doesn't eat..."

The pressure is all the greater because Sheila works and cannot be around during the day to monitor her daughters glucose levels. When she is present the control is better but when absent, glucose control goes awry. Sheila feels responsible for this. It's a responsibility that she has few others to share with.

Lauren's aunt, a devout Christian influences her to believe that prayer will cure diabetes. This adds to the discrepancy in how mother and daughter think about the diabetes and compounds her bad control.

"...She is behaving as if she doesn't have diabetes, I even went to the new school to talk to the secretary about the injection because Sister Starck said that she has to inject in the afternoon, second break, at 12 o' clock, ...she still doesn't do it, she still doesn't do it..."

This creates a rift between Lauren and her mother. Because her mother carries the responsibility, so too does she carry the blame for when things go wrong. This forces her to be stricter, to trust her daughter less and subject her to greater scrutiny. This creates further rifts in the relationship with her daughter.

"...But its very difficult, my husband used to give her money, and she used to go to the shops and buy herself slap-chips, or, sweets, I found a lot of sweets under the bed, empty papers, stuff like that, its very difficult, and I'm angry because she is young to understand, but you have to look after yourself. She says that I am too strict..."

She implores her daughter to take more responsibility, to be more curious and gather knowledge about her illness.

"...I will always tell Lauren, you must look after yourself, I am not going to, if the doctors ask a question, I am not going to answer any questions. I want you to answer the questions, but she never talks..."

Short Summary

The consistent theme reflecting the mother and daughter relationship is that of the mother's anger and the daughter's silence and withdrawal. Sheila is reluctant to hand over responsibility for diabetic care to her daughter, both because she is in denial over her condition and because she seems not to want to look after

herself properly. The most visible aspect of Laurens poor glycaemic control; the frequent hospital admissions, compounds Sheila's feeling of impotence. Her work and lack of social support further fans the anger that Sheila feels for Lauren's wilful refusal to look after herself.

(II) Guilt: Did neglect cause her daughters diabetes?

Sheila expresses self-reproach when talking about the origins of her daughter's diabetes. She questions whether she was somehow responsible by virtue of her neglect of her infant daughter. Guilt for acts of omission is common in parents of children with chronic disease.

"...Because she used to stay with the father, I was working, and the father was working night duty. When she was a baby, he used to look after her, how can I say it, I thought maybe, if I should have let someone else look after, a day mother or maybe, when he was sleeping. What is she doing did she get her breakfast, her lunch, and I was thinking that..."

As a working mother she is caught between the demands of providing for her family and the needs of her child. Though her daughter only developed diabetes at an older age, the thought that she wasn't there in her formative first few weeks is conflated into responsibility for causing Lauren's diabetes.

"...I was just thinking, she was, I went back to work when she was only 8 weeks old, I am thinking I should have stayed at home a little bit longer, but she only developed diabetes when she was 6 years old..."

Sheila concedes that other transitions at the time that could also have been responsible.

"...We just moved from the strand at that time, we moved to Bellville, and she was in a crèche up until 6 years old, and that was the first time she had been in a crèche, but I don't know..."

Though she understands that her daughter needs to take control of herself, Sheila still recognizes that even at present, she is only under good control when she is on leave from work and able to directly supervise her. This invariably compounds her guilt, as poor control is a direct result of her absence.

"...Ja, ja, even if I am at work its difficult, because the times that I am on leave, I used to sit with her, writing the sugars, and doing the food, I think I did everything. When I am not around everything gets worse..."

Her family is critical of her approach to her daughter's diabetes. She both blames herself and is blamed by others for Lauren's management.

"...I explained it to them (her family), I always explained to my husband...they think its her fault if she...they blame it on her, because she doesn't eat right, she doesn't inject, and then I explain to them... and they think I tick her off at any stage..."

Sheila imposes criticism on herself.

"...Maybe I am too strict, because I just want her to look after herself, inject, and eat right. I just want her to do it but..."

Sheila takes the medical staffs questioning, after the multiple admissions as a direct interrogation of her parenting capability.

"...they always used to ask, is there a problem at home? I was quite shocked, how can they ask? What do they mean? Because I am working and we are good parents to her..."

Short Summary

The struggle for control, the frequent admissions to hospital and the very obvious self-neglect by her child reflects on Sheila, who is particularly sensitive to external criticism, an amplification of the guilt she already feels. She feels that her neglect of her infant daughter may have contributed to her getting diabetes at a later age. Though not openly acknowledged, it is possible that her position as a nursing sister sets her up to feel sensitive about her parental responsibilities for a medical condition. She defends herself against what she sees as unfair criticism, but the vein of guilt runs deep nevertheless.

(III) Dissatisfaction with Medical Staff

Sheila's narrative is marked by a consistent dissatisfaction with the medical care she received.

"...I was not happy, you know, you know when she was first diagnosed we went to Red Cross (hospital) and after a while, I took her out and we went to a paediatrician privately, but our medical aid was exhausted and so we went back to Red Cross, but what I have noticed from a medical point of view, is that the insulin Red Cross put her on was too much and I was a bit worried. When we went to a paediatrician and the paediatrician, decreased the insulin, and I wasn't comfortable, the insulin was on 10, and now he has started her on 3, and every time I said, but doctor are you sure, I was a bit like, how can I question the doctor, and I said, but doctor, but she has been for all these years on Actrapid, and now you have put her on 3 units - is that not going to affect her sugars? and he said, but no, that is the right dosage, and eventually it was proven that he was right, when I took her back again to Red Cross, they continued with a lower dosage, so there I was a bit uncertain..."

Observed inconsistencies and disappointed expectations from Red Cross Hospital, a centre for excellence in her eyes, dilutes her trust in their management.

“...I felt I was in the dark, because I was unsure now, what’s happening now. I asked myself how, can Red Cross give such high dosages, and they are the best diabetes institution, because the paediatrician, he referred us to Red Cross, he still told me, don’t worry, they are the best...the best medical treatment...”

Sheila felt the information she was given was unreliable, and that the staff, rather than being supportive were critical, blaming her for the poor control of her daughter.

“...I wasn’t happy with the doctor at GSH at all because, he gave me the impression that it was our fault...they always used to ask, is there a problem at home, I was quite shocked, how can they ask, what do they mean, because I am working, and we are good parents to her...”

The result is that Sheila withdrew from interacting meaningfully with the medical staff, afraid of their criticism, not expecting constructive help. She would take her child for immediate care when admission was necessary but communication had otherwise totally broken down.

“...but after that, I decided, I just want my child to be helped, so she wasn’t admitted this year a lot. I think twice this year, and I don’t even bother to ask the doctors and the sisters anything, because of the questions in the past...”

Short Summary

Dissatisfaction with medical staff, a feeling of not being taken seriously, a perception of inconsistent information and communication, and implicit criticism all contribute to a breakdown in the relationship between Sheila and those who are in the best position to help her – the medical staff of Red Cross hospital. This breach fostered the feeling that she was alone and compounds the pre-existing problem of limited social support experienced by Sheila and her family.

(IV) Silence and Isolation

Notable in Sheila's narrative compared to the other interviews in this study was her restricted range of expression – she gave short answers and pared down responses to my questions. It was difficult to elicit an extended discussion on many of the issues, the most detail given was related to the disappointment she felt at Red Cross Hospital. Similarly, the depth of reflection on her daughter's illness was lean in detail and not animated by examples of situations or experiences reflecting of family life, so common in the other narratives.

When asked about her response to the diagnosis of Lauren's diabetes she responded with tears.

“...I just thought no man...no man, it can't be.... (tears) [I reassure at this stage] I thought I'm over it, but I think I'm not...”

“...I couldn't believe it...(gathering herself) it was a bit difficult because I was working, and I had to drop her off in the morning and show the teachers how to give the injections and everything...” (still crying)

My impression was that there was still much about the illness that was unspoken, with strong emotions very close to the surface.

The relative simplicity and frequent silences throughout the interview were emblematic of the social isolation and difficulty that their family was experiencing in dealing with the diabetes.

Both of Lauren's parents were working and their other daughter did not take much of an interest in engaging with her sister. When I asked about the affect of diabetes on her sibling, Sheila replies.

“...I don't know, I never ask her how she feels...I really don't know...I don't know, I don't think she is worried about her because, um, she walks home from

school, and I will tell her from the morning, if Lauren is not well, then I will tell her, I think you must go fetch her from school, and then she just don't worry to fetch her... things like that..."

There does not appear to be a deep level of engagement within the family over the diabetes. Similarly, when Sheila reflects on Lauren's private thoughts about the origins of her diabetes she replies.

"...I once asked her about her illness... "What do you think about?" then she, I think she believes that, she still believes that it can go away...I do have an aunt, she is very Christian, and she will always tell her, you must pray, you must pray, then your sugar will go away..."

Apart from the mistaken belief about her condition (already discussed above) it seems that deep communication with her children about the diabetes is rare.

She discusses the dietary changes consequent to the family once Lauren had diabetes.

"...we never exclude her when I was cooking, I was always talking about healthy eating, diet and food, and not to eat sweets and chips and junk food and stuff like that..."

She doesn't describe in any detail how things changed, or that there was any systemic attempt to draw the family into a new way of life. She may have counselled Lauren, but there is little detail on much more.

There is little support, family are far away and uncommunicative and medical services have proven themselves unreliable. It's only her work colleagues who have been helpful.

"...I didn't get support from my family, because we don't have, we don't stay so close to each other, but I think from my colleagues, um, I work at the old

Johannes Marais hospital, and there was a diabetic sister, and she used to come to my house, and explain to Lauren, to her father, to all of us, everything about the diabetes, I got a lot of support from her..."

Lauren does not have a wide circle of friends and is not integrated well into a social community. She is also increasingly isolated from her immediate family.

"...She never goes out with us anymore. Things like that, she just wants to be by herself. She doesn't have a lot of friends, I think, because she used to go and visit her cousins for the weekend, but then when she comes back she lands up in hospital on the Monday, so, that shows me she never injected, we tried to let her go out, but, she just don't do it..."

Her parents have removed her from a normal high school and placed her in a technical school.

"...She didn't do well, just before she had to go to high school we put her in a technical school. That school is specially for children with all types of illness, I thought it would be easier for her in this school..."

Difficulties in school consequent to the diabetes, (days missed, poor concentration) have contributed to her being downgraded to a special needs environment. Her diabetes has become a handicap directly affecting her academic prospects.

Short Summary

The paucity of detail and frequent silences in the interview mirror the difficulties that Sheila's family experience with Lauren and her diabetes. Social isolation, poor communication and a fragmented narrative that is notable for a lack in a unified family identity reflects the lack of a shared coherent conception of how to manage the diabetes.

Interview 5

Mother - Shireen Daughter - Saskia

Saskia was 10 years old when diagnosed and is 14 years old at the time of the interview. She has two sisters, one 3 years younger and the other 2 years older. Shireen's husband is a professional and described as very attentive to their family. She is full of praise for him and her daughters, particularly Saskia, who she regards as a special child. Saskia is an all-rounder; a leader at school, academically sound and very good at sports. Her mother describes them as very fortunate to have a daughter like her and that she was the best suited of all her children to have diabetes. They are a hands-on, closely knit family united by a strong Christian faith. Shireen is a positive woman who presents a picture of an integrated family with a wide range of resources utilized in coping with diabetes.

(I) A higher power to explain her daughter's Diabetes

"What is meant for you won't go past you"

Shireen's understanding of why her daughter has diabetes is governed by a coherent and consistent set of thoughts linking the illness with the will of a greater power beyond their control. As a self-identifying Christian, she believes strongly in an omniscient mover whose decisions are rational, even if not wholly transparent.

Saskia was born prematurely and there was a threat that she was going to die.

"...So they had her in the ICU in the paediatric ward because she was too sick to be with the neonatal babies, and at one stage she stopped breathing and the nurses were counting up to 16 and by that stage I just walked out the room, and I remember saying oh god, um, she is yours in the first place, and if you have to take her I will understand..."

Shireen submits to powers beyond her control, she does not tussle with the nuances of agency, trusting in god's ineffable will. This sets the scene for how she will make sense of her daughter's diabetes.

Of all her children, Shireen regards Saskia as the most responsible, and the one to whom the responsibilities of managing diabetes would come most naturally.

"...She is a special child, she is just, out of my three children would I choose to, if I had to choose who was going to get it, Saskia is definitely the right one, but I also believe that Saskia got it because she can handle it..."

This makes her a special child, different from the others, loaded with greater hardships to conquer. There must be great reassurance in the thought that there

is a meaningful reason for why she has the illness, and that by the same logic, she is well equipped to deal with it in the future.

“...I don’t believe that god gives you less or more than what you can handle, even at the time if you can’t see the bigger picture, that eventually you will see it, and um, and I just look at the people that we have encountered on this journey...”

The thought that the diabetes was meant for Saskia hints at a purpose, perhaps related to Saskia’s capacity to teach others, to help them in some way.

“...but Saskia, I almost felt that she is actually, that people learn from her, that I learn from her, and um, she definitely teaches me things, I believe that what is meant for you won’t go past you...”

Shireen has had other more specific thoughts about the origin of the diabetes. One of these thoughts, a common thread through many of the narratives was the theory of a “shock” of some kind.

“...Yes, Ah, and I think initially, because I thought it was shock, because I heard when John Burnham, he is a chiropractor, and he drowned in his pool, and I think a month later, his son Tommy was diagnosed, and he is only 6...”

She was concerned that Saskia had been exposed to a shock shortly before her diagnosis.

“...A month before she was diagnosed, we lost a very close friend to cancer, and she came...out of the three children, she was the only one who wanted to say goodbye to her, and she actually kissed her, kissed her on her cheek, she had lung cancer so she wasn’t even, aware of what was going on around her, and then she died the next day, and Saskia was very upset, and she was also 10, so initially I thought that, perhaps it was because of the shock...”

Shireen's implicit suggestion is that Saskia is more caring than her other children, in keeping with her view of her as a special child. Contact with the dying woman induced an experience that disturbed her equilibrium and possibly lead directly to her illness. Though Shireen will ultimately discard this line of reasoning, she still feels some responsibility for exposing her daughter to this stress.

Shireen is also conscious of how other people will immediately jump to conclusions and confer blame by assuming that she didn't feed her family properly.

"...I think a lot of people cos they are unaware put the blame on you they say like did you eat a lot of sugar, all of those things, so you look, oh gosh, look did we do something, did we do, but I think that was an issue, now I don't think like that anymore because I know better. Ja, I think that initial thing was what could I have done differently, and could I have protected her from this..."

The thought that she somehow contributed to the cause of the diabetes, troubled her with guilt at first. In the beginning she was plagued by questions.

"...and you think, and why me? And why her? And why did it happen, and could I have done something?..."

She has put these thoughts behind her. Personal volitional acts no longer play a part in her explanatory system.

She does however believe that a physical cause could also be implicated.

"...and then viral was probably the last thing that I thought of, and so, now I think it probably was viral..."

Short Summary

The dominant explanatory paradigm running through this narrative references an internally congruent omniscient power. She believes that her daughter's getting the diabetes was no coincidence, that she was the best suited of all her children to get it and that there is probably some greater good that can come out of it, in part justifying its *raison d'être*. This paradigm has overcome an earlier systemic thought infused with more personal blame that emphasized the theory of some causative sudden shock. Shireen concurrently believes that a virus caused the illness, a proximal physical cause that does not exclude the possibility of an omniscient power. Numerous seemingly contradictory explanations are considered simultaneously.

(II) The Family Unit Strengthened by the Diabetes

Shireen's point of reference through her narrative is her family. It is an organizing concept around which she reflects on the changes brought about by the diabetes and overshadows in importance her own personal journey.

She describes how the diagnosis immediately focused the family on each other. They became very insular and grew closer together.

"...Um, we as a family, definitely became more aware of each other, and a lot closer, and and and, like um initially we didn't do anything without each other, but actually up until last week it was the longest, she went away on a school camp and was away for three nights, three nights and four days, um, Molly slept in her bed, Lolo then slept in Molly's bed, um, they have become, the oldest two have definitely become incredibly close..."

The dietary habits of the whole family, and all the children in particular changed. This was not always so easy for their youngest daughter Lolo, who adapted nevertheless.

“...the kids would have a sort of a lunch box before, would be a coco-pops bar, a chocolate muffin, a white bread sandwich and an apple juice, and now...they always had vegetables, ...but now it’s a GI sandwich whole wheat or brown roll, um, with cucumber, lettuce tomato, baby tomato, celery, and would always have a salad, biltong sticks, and ja, no more muffins, no more biscuits. We don’t have juice, we just have water, and if we do, then maybe I buy ice tea but that’s about the only thing, its very seldom, they know we just have water, and only whole wheat or brown rice or those kind of things, and now, as a family if we go somewhere and have white bread, we say, we don’t know how we ate that before. Because it’s terrible, ja, so basically, that way we definitely changed the way we eat...”

Shireen describes how Saskia has become the fulcrum around which the family organizes itself. The other members of the family are very aware of her health status and respond accordingly when needed.

“...Um, I think we...ummm I think we, not rely on each other, but are willing to do things for each other for the benefit of others, which is quite a thing, now that I am saying it, the other two, like we wake up, in the morning, and we say, Saskia is having a low, and I’m making lunch for the kids or whatever, then I will say, Molly can you make lunch for Saskia’s low, or could you get me the (testing) kit, and its almost like everybody stops, and we’ll rally around what needs to be done for Saskia, and then when she has stopped we will just continue again, its quite amazing really ...well we, like being late, or not being ready on time, it almost doesn’t matter because if Saskia is fine, then we can carry on, so...”

Saskia’s siblings are aware that more attention is given to their sister.

“...we have had times when the other two have said to me, and its happened maybe twice...’mommy, you care more about Saskia than you do about us’...”

Nevertheless they work well as a unit, anticipating each other's needs and making compromises for each other. They have grown increasingly close and strengthened as a unit.

"...I think our family, since Saskia has been diagnosed, is definitely tighter, and we are a very strong family, and um, and, also, ja, incredible love, and incredible support, and because of Saskia, and maybe because of Saskia, sometimes we go the extra mile for the other two..."

The overall effect of the diabetes has been positive.

"...and I look at this and I think that maybe as a family, we are better people for it..."

Their Christian faith unifies the family and cannot be fully separated from their response to the diabetes. They experience it together and it binds them into a solid unit.

"... I think also my faith has been really strong, I have said you know what, maybe its the way you feel with it, as a family, and as a unit, and I think also, we just recently changed churches and we went to, and it was the first time we were there, and it was communion, and um, there were hands being raised, and my oldest daughter, her eyes were getting bigger and bigger and my husband nudged her, and said, just imagine you are in the golden circle at a concert. And then they said those who would like to come up for communion, and I asked, what is Saskia going to do now, and she got up and I was just like, and Megan sat there, and I was just like, I was so proud of her, because I think independently, they are, they are not scared to be who they are, so, that way, her faith..."

Shireen's family and her faith are intelligible systems through which she can draw meaning from her experiences.

Short Summary

The dominant viewpoint in Shireen's narrative is through the lens of family. The challenge of the diabetes, the changes enacted, the dietary details and responses of her husband and other two daughters describes a world whereby the whole is always more than the sum of its individual parts. The positive effects of the diabetes on the family reflect those values of family communication, cohesion, mutual support and the spirit of compromise - facets that she describes with a pride echoed in her children's participation in their Christian faith.

(III) The Salve of a Responsible child - "we are so lucky"

Shireen describes Saskia in near adulatory terms. She constantly affirms her and expresses how lucky they are because of her approach to the diabetes. Like all mothers in this study, Shireen has shouldered the burden of worry about Saskia's health, but because of the character of her daughter much of this stress has been taken away from her.

"...we are so lucky, because she is an incredibly responsible child, she has a good heart, very diligent and conscientious and so she will, and also she is aware, like I will say, Sas, I think we are going off the rails a bit, so she will say, Mom I agree with you..."

She does not take credit but rather gives thanks for her fortune in having a responsible communicative daughter.

She details the ways in which Saskia from the very beginning took responsibility for her illness.

"...from day one she showed Saskia how to inject herself, that first 7 units into her bum, and then Ginelle showed her how to do it into her tummy and from that moment she has been doing it herself. It's amazing..."

She describes how Saskia is able to respond flexibly to different situations.

“...as Saskia has got older, and she has been able to say, right well actually I can have that and I will just take a couple of extra units, or I will be fine, or I will choose not to have that - she can make those decisions herself now...”

Responsibility has been thrust on Saskia. She has risen to the challenge and taken some of the pressure off Shireen.

“...Oh yes, absolutely, because she has had to be more responsible, she has had to take her own life in her hands, and I mean, I have never had to inject her, I have done her finger pricking when I can't wake her up, but not, never to inject her, and I think, almost, that is a responsibility that has been taken away from me, that she is able to do all that on her own, but she is definitely a lot more responsible, because I think, she has gone through these life-threatening moments...”

A mark of her daughter's ability to look after herself is that she knows her limitations.

“...like yesterday, she had school swimming and she was meant to go to squad, and she said, mom, I think I need to do my homework and I will go tomorrow. Fine Sas, so that way she knows her limitations...”

“...The camp that she went on now, they went away for 4 days on the Breede and one of the teachers said that on the Thursday, Saskia chose not to go on the rapids because she wasn't feeling well, she chose to stay at home and slept for an hour and just chatted with the teachers, and was able to make that decision, she is not irresponsible...”

The good control and responsible behaviour demonstrated by Saskia removes the burden of blame and any poor reflection on Shireen's parenting. She expresses

how hard it feels to be powerless to take away her child's problem - a potential source of guilt. She realizes that the key to Saskia's development is to facilitate her autonomy.

"...Don't blame yourself, as hard as it is, try so much, cos you want to take it away from them, try to give them more responsibility, looking back, in hindsight and from people I have seen try to take it on themselves, um, and, I would say, give them that responsibility, let them be responsible, because they will only benefit from it, and I think so will you, it never leaves you..."

Her talk is peppered with affirmation reflecting the high regard she has for Saskia.

"...She is amazing, she really is, she is an incredible child, no, we really are fortunate..."

Short Summary

The mothers in this study all feel the burden of responsibility to look after and protect their children. Shireen expresses how lucky she feels and in very affirming terms describes the ways in which Saskia is able to take responsibility for her own glycaemic control. Saskia has taken care of her own injecting from a young age, can adapt to different circumstances and knows her limitations. Shireen's confidence in her daughter relieves her, not only of some anxiety, but also of any possibility that she has failed her daughter as a parent.

(IV) Integration of a diabetic Identity – as normal adolescent

Saskia has integrated herself into her social peer group as a normal adolescent who happens to have diabetes. There is little in the narrative to suggest any hardship or problems consequent to the diabetes. She has performed well at school; this Shireen thinks could have protected her against diabetes related negative perceptions of her.

“...She is an achiever and, ag, she is a peer mediator, team leader, a SRC leader, and instructor, a swimming captain, all those things. Because she has been an achiever, they don’t feel sorry for her, she says, don’t feel sorry for me because I can do it...”

She has avoided playing the role of victim to the diabetes.

One of the greatest factors in allowing Saskia to lead a normal life has been the consistent infusion of insulin provided by an Insulin pump.

“...she would rather have the pump than go back to injecting all the time, I think it is also less invasive, I think being on the pump, she has definitely led more of a normal life...”

Nevertheless, the testing and injecting can potentially attract attention. She is okay with the insulin pump port visible when she is on the beach but is more circumspect when injecting at a restaurant.

“...Ja, I’ve asked her, she really does, she won’t tell anybody, now she went to the beach a couple of weekends ago, and, um, she had a bikini on, and I was like worried, especially now as summer, and I thought I hope she can always be like this, she has her port, and I mean, it looks like a cell phone with a wire attached to it, so, you know, she, and most of her friends know, most of her people know, she doesn’t talk about it, or she won’t you know, volunteer it to anybody, and if we are, say out in a restaurant having dinner, she will keep her kit on her lap, and do her finger prick under the table...”

Having the diabetes has provided an opportunity for her to help similarly affected adolescents.

“...even the people we have been able to help, she has been amazing, there was a girl last year who was diagnosed, and, she came home, well actually, I got the telephone call first from the school and they said, would you mind if we gave your number out, and I said not at all. And we phoned this couple and Saskia and I went to go and see them. And Saskia spent more time talking to the parents than I did. She was saying and so this would happen, then that would happen, and you would feel scared and sometimes you Wow! ...”

These altruistic actions have the capacity, in the tradition of the wounded healer, to transform something potentially negative into the affirming activity of helping others. It can thereby promote self-esteem, create further social connections and empower Saskia.

Shireen worries that as a responsible young person, as someone who generally likes to be in control and comes from a family of responsible parents, that she will be too well behaved. Her daughter reassures her...though not that convincingly.

“...And also, this term she got a ‘B’ for behaviour, and I said, Saskia, you got a ‘B’, what happened? and she said, I know mom, sometimes I can talk to much, or I can do this, or I can do that. Yes, go Sas, be like that, because she is very much not a control freak, but she definitely likes all her ducks in a row, and ah, I mean, my husband was a head boy, I was a prefect, so we are both quite beraard people, whereas my oldest one, all she wants to do is have a gap year after school, and she doesn’t have a clue what she wants to do. I mean she even said the other day, are you going to smoke when you are older, and she said, of course not, why would you want to do that, and she said, Lolo you’re not, I’m not even going there, I mean, neither of us do, so where does that come from. Its nice to see her sometimes jump out of the box, but perhaps her diabetes holds her back...”

Shireen feels that both the extra responsibility required of diabetes, and the fear that her sugar levels will go awry prevent Saskia from pushing herself enough.

Overall, Saskia appears to have successfully integrated the diabetes into her life, such that she copes with it and sees it as a fundamental part of her identity.

“...Ja, no, no, no, she also, I have asked her, if I could take it away from you, would you want me to, and she said, no mom, I don’t think so, because this is who I am, and so...”

Short Summary

Shireen describes her daughter as socially outgoing, bright, sporty, engaged in leadership and popular at school. It is likely that these characteristics overlap with those that facilitate her good diabetic control. It suggests a strong self-esteem reflected by her mothers affirming comments. In this context Saskia is not too self-conscious about its visibility and therefore is successfully able to integrate diabetes into her identity. Her altruistic activities and ability to perform so well at school reinforce this, as does her absorption into her family where her diet and way of life are normalized. Diabetes becomes part of who she is.

(V) Engaged Mothering – “It never leaves you”

Shireen’s narrative is remarkable for the detailed descriptions she gives, detailing her close engagement with her family and specifically the planning and logistics involved with managing the diabetes. She is deeply immersed in the life of her daughter and her management.

She describes what it was like when Saskia started on the Insulin Pump.

“...I almost feel like we are starting at scratch again with meal plans and writing everything out, and we are having a run when the oldest one has been baking a lot, and so we will say Molly, slow down on making those brownies, and also me, I do hotdogs at school on a Friday for fundraising, for the grade 7s, and it was easier to give Saskia a hot dog than give her lunch because Fridays were a mare (nightmare) and now we have to get up a little earlier to make sure that Saskia has got her lunch pack because she actually needs to eat better...”

She describes some of the planning prior to Saskia going away for a weekend.

“...Well, we have, um, gosh she has a separate cooler bag, and everything gets packed in there, a spare kit, extra insulin and then there is a whole letter that goes with, um, explaining everything that happened, and also, two of her closest friends, actually three of them, know exactly what to do if something happens, we have spoken to them. I do feel terrible sometimes...”

Shireen sees it as her responsibility. It is her role to watch her daughters back and feels guilty when other people have to help with this.

“...because I almost put the responsibility on them, and I said, when they are going away, now Look after Sas! and they... no we will Shireen we will. You must see a bit of fear, oh god, I hope nothing happens on my watch. Ja but, I

think that something has happened and they were there, and they dealt with it and um, ja..."

Shireen describes a time when Saskia had a severe hypoglycaemic attack when on a weekend camp. Saskia had become confused and faint but was helped to recovery by her teachers. Shireen's response to this event highlights her close connection and feeling of responsibility for her child and specifically her impotence in not being there.

"... In some ways I was almost a little angry that it happened with them, and it didn't happen with me, because it was like, I should have been there, and I, and it wouldn't have happened if I was there, and because I would have been checking on her, and I told them, exactly everything, and this is what happens, I could see she was very shy, and she we got into the car, and she burst into tears, and I said, what happened, and she said, I passed out Mama and I couldn't do anything. I felt so helpless..."

She acknowledges that she carries most of the emotional burden of care in the family.

"...but definitely, emotionally, I think I carry a lot more than Andrew does, and no disrespect, but I think men can compartmentalize things, but with woman, we keep it all the time..."

When it comes to the deeper levels of trust required to discuss or deal with the more difficult aspects of diabetes, Saskia will turn to her mother.

"...if she has to change her needle, and she is busy doing something else, she will say, Mom, can you just change my needle for me, and I will say, with pleasure, but she will never ask Andrew, because not that she knows that he won't do it, she knows I will do it, and it will be fine, like as I say, we went to the doctor, and she says, I prefer it when you come with me because you know which questions to ask..."

Short Summary

Shireen's engagement with her child is total and immersive, an emotional binding that translates into her spending much time with her on diabetic related issues, requires her to change routines and engage in elaborate logistical plans. Her close attention to detail in the narrative both belies her single-minded involvement, her fine emotional tuning to her daughters needs and a proactive management stance. She is motivated to educate the parents at the school, liaise with a host of medical professionals, learn about insulin regimes and lead the entire family into a new way of life while exuding a positive attitude and encouraging upbeat mien.

Interview 6

Mother - Lindsey
Daughter - Carrie

Carrie was 9 years old when diagnosed and is 18 years old at the time of the interview. Lindsey has another daughter who is 5 years older than Carrie. Lindsey and her husband go into denial for at least a year after the diagnosis, ignoring it as if it hadn't happened, before they begin to take it more seriously. Carrie is described as a responsible girl, perhaps too responsible, who since diagnosis has become obsessed with food to the point of planning to become a dietician. Her life changed when she got the insulin pump, which has made glucose control much easier for all of them.

(I) A Question of Origins

The co-existence of Physical and Emotional explanatory models.

Lindsey balances up her thoughts on what caused her daughter to get Diabetes. She juggles different types of explanations concurrently.

She considers that from a physical point of view, it was simply a virus.

“...I mean, the only thing I can think of from a physical point of view, is that I presume it was the virus which I think she got. Her body,... this is what I’m thinking, the body, the immune system made a mistake and attacked her pancreas...”

But, this explanation alone is insufficient. There must be an emotional explanation too.

“...from an emotional point of view, I think that we all get something in our lives that either make us different, I think we are actually lucky to get things, whatever they are, you know, maybe, whatever it is, and it depends on how you use that in either positive or negative ways. I do think, I mean, she is a highly intelligent child. I would have liked to see her do something that is in the...If she does become a chef, be a chef that works around...”

In this formulation, an illness is rationalized as something that confers unique characteristics to the effected person and gives them the opportunity, through hardship, to either elevate themselves and become better people for it - or not. The forces of volition and fate are thus allocated. The test of a person is how they choose to utilize the condition they have been given. Lindsey hopes that Carrie will use her knowledge of diabetes to help others in a career that she develops in the future.

“...She got it because she can use it in some positive way in the future, she has, I mean through all these kind of things, became a youth leader, I mean I think it was something that kept her quite motivated at one stage – to help other people...”

Lindsey describes how she is put on the spot when her child has asked her why she has diabetes.

“...I mean she did question it, why did I? ...Who knows what everybody gets? Some people get cancer, some people get other things. You know, which could be worse...”

The task of a parent in explaining to their child why they have to carry the weight of a chronic disease is difficult. It is easy to understand how a parent would wish to put a positive spin on this reason, to try fashion some meaningful explanation that has the capacity to empower their child and imbue her with hope.

“...How do you explain that, what can you explain to your child, each one has your own cross to bear, and each one has their own thing in life that is unique to them, and obviously there is a greater plan, I mean I reckon that, I mean, we just try to be very positive about it...”

An explanation with a deeper meaning, one that answers the question on an existential level is more satisfying.

“...She is very spiritual, and I think she has come to terms with that, and that there is a reason for that, and she can go ahead, you know, whatever it is it will come clear to her, and whatever it is, what her path is, but ja, it is a question at one stage, when a child looks at you and says um, ja okay, you know when you are at that time when your mother is not that clever, you know...”

Lindsey recognizes that she is limited in providing all the answers. She cannot fully explain to her daughter why she has diabetes.

Short Summary

Lindsey entertains different types of explanatory models about the origins of diabetes concurrently. She recognizes that on a physical level a virus may have initiated an autoimmune event that destroyed the beta cells of her daughters pancreas but the explanatory potency of this theory is insufficient. On an emotional level, or perhaps on a spiritual level, as she describes it, she requires a reason for why her daughter specifically got this illness. She reasons that each person will get something, and through this they have the opportunity to help others and become better people. In this way, Carrie's diabetes makes her unique, puts her in a position to help others and is indicative of a greater plan for her beyond the mundane realities of everyday life. Ultimately however, Lindsey concedes that she is limited, and cannot definitively answer her daughter's questions on causation.

(II) Pervasive Guilt

"...But things do go wrong, and you do blame yourself, it does depend on other things..."

Feelings of guilt are pervasive in the orbit of diabetes. Parents describe feeling guilty because of the hereditary aspect of the illness and as Lindsey admits, when the glucose levels are out of control.

"...Hereditary, and yet we can't find it anywhere, and I was only when he got over that that it was also fine, there are a lot of emotions around, ja, and when the sugars are a little high, you blame yourself, and you say, you should have done this and this, but you can't really, and you really do..."

Lindsey understands that guilt operates on a level beyond their control. She knows that the guilt they feel is inappropriate for the situation, but she still feels it anyway.

Children feel the guilt too. They don't want to put extra stress on the parents and often feel that they are somehow to blame for the diabetes - or for the poor control.

"...oh that's another thing, the kids also start to feel guilty, when their sugars go wrong, and I always try to say to her, we know certain times when it is your fault, but sometimes you would do the same thing as yesterday and its different and I think that was a very important thing as well, for parent of a kid, was not to make that kid feel guilty..."

Lindsey acknowledges her responsibility to try reduce any guilt felt by their child.

It's less easy to assuage the guilt felt by her husband.

“...And it won't go away! those are the kind of frustrations I think a parent has, and then I think my husband felt very much that maybe it was something he had given her, and no matter how often I tried to explain it wasn't so...”

Guilt goes hand in hand with blame. The social group may add an extra-burden by their ignorance, by insinuating, or even openly blaming parents for causing their child's diabetes by feeding them a sugary diet.

“...I think one of the harder things as well was that people get confused between type I and type II diabetes. And they tend to say, you know, sort of blame on the parents... “oh, why did you give them so many sweets and chocolates”, and meanwhile its got nothing to do with that, its all about lifestyle, so I think there is a lot of frustrations amongst parents trying to explain to people who don't know the difference, and just lobbing them into one.. oh yes, she should start eating properly and it will all go away, you want to say, she does eat properly! And it won't go away! those are the kind of frustrations I think a parent has...”

Siblings who are particularly sensitive may also carry a burden of responsibility. Carrie's sister Simone worried silently about her sisters well being when her parents left them alone.

“...she actually became very very concerned about Carrie because of her total responsibility, because they would often be alone at home, not for long periods of time, but then Candice would think this was her responsibility, and I didn't realize until much later how she was worrying about it...”

Short Summary

It is impossible not to get big glucose fluctuations in adolescent diabetics on at least some occasions. Because of their transmissible genetic material and the environment they have created for their children, parents are particularly prone to feeling guilty for different aspects of their child's diabetes. This guilt can be

contributed to by the ignorance and intrusiveness of external parties, and added to by a child's own guilt. In this case, one can see guilt as a central theme running through the narrative.

(III) An Identity forged through Diabetes

The adolescent with diabetes is forced to integrate the illness into the way they see themselves. Some adolescents deny its importance, underplay its role in their lives and therefore delay the time when it can be fully integrated into their identities.

Carrie is highly ambivalent about it. At first it marked her out as special and unique. There was a novelty element to it all, and it garnered her attention, both favourable and unfavourable.

"...she had had enough of it, it wasn't going away, and I think she had come to the realization that it wasn't going away, and I think at first, at school, and I say besides the teasing, the first year she had it everyone made her feel very important, um, so she felt, I've got something that is different to everyone else, but then she got to the point where people were ignoring it because they are used to it, and the novelty is gone, but she's still got it..."

After the novelty had worn off, she still had to deal with the day-to-day reality.

"...so it was difficult, puberty was very difficult, when they are older they get to the stage when they just don't want this thing, they don't want to be different, you know..."

As a younger scholar, Carrie had been bullied and taunted on the playground.

"...I think there was a whole lot of teasing at school. Like they used to take her lunch and smash it into the ground and stamp on it, and tell her, and she used

to shout at them I might die if I don't eat, so we had quite a bit of that. The teachers tried very hard to explain to people. She came home one day and said no body wants to play with me, and I said why, and she said, no because um, they say I have to inject myself every day because I have AIDS. And this actually came from a parent I discovered, a parent told my parent not to play with my child because she injects herself..."

This perhaps may have added to her reluctance to be identified as diabetic, to wear this identity openly. She didn't want to fully admit it to others or to herself.

"...At one stage, she actually didn't want to be known as a diabetic, she didn't want to associate with other diabetics, we could never get out of her why this was, she didn't want to be a diabetic. I think in my opinion, she always had this secret, wish that it would just go away..."

Nevertheless, she made progress assimilating her diabetes into her identity. The right nomenclature played a part. She had a condition, not a potentially stigmatizing illness that marked her out as vulnerable and sickly.

"...Yes, ja, and also she knows ... what to they call it, not an illness thing ... a condition, the condition, very well, she understands it inside and out, she made it her business, they studied it at school, she showed everybody at school, she did an oral on it, she made it her business to know as much as possible, I have never had to inject her, never, I mean as I say, she took that needle and that was that, she doesn't want anyone else to inject her..."

Part of taking responsibility for her diabetes, was to be knowledgeable, transparent and perform the behaviours of diabetics, namely testing and injecting.

An adolescent with diabetes could become too responsible. Carrie's mother is pleased that Carrie is so responsible, but concerned that she has taken it too far.

“...So, that was quite strange, so we have been very very lucky, she is extremely responsible, way too responsible for her age, I think that is another side of the diabetes, because they become very responsible, not that there is anything wrong with it, but we want the kids to be responsible but you know...”

She is not participating in some of the age appropriate behaviour of her peers, though often for good reason. Instead she plays the role of the responsible friend.

“...she still doesn't drink, she says I mean, I hope it wasn't me that frightened her, I don't really know that the effects are of alcohol on diabetes, except I know, it does push the sugars up, and then suddenly drops them, she is quite scared of that, quite scared of going into a coma...”

Lindsey was concerned that amongst her peers Carrie was being identified as the responsible rescuer, a role that would create resentment and anger in her in the long run.

“...you know all her friends are partying at the moment, she doesn't much party, she is the one who stays sober, and looks after everybody else, and even when they were very young, you know the kids these days, get up to nonsense parents go out and whatever, and she was always the one, everyone else was drinking and falling over, and she was seeing that they got to the bathroom, got to the bedroom, whatever, and eventually I said, and she was hating it, resenting it, and so I said to her, you just mustn't play nursemaid to them, if they fall down the stairs they fall down the stairs...”

It may be that Carrie uses the 'responsibility' necessary to control diabetes as a means of avoiding the anxiety of age-congruent boundary pushing.

It is not uncommon for adolescents who under normal conditions have to watch what they eat quite carefully, become quite preoccupied with its role in their lives.

“...Um, we don't know that, it's just that there is definitely an obsession with food. You know, her sister gets quite cross with her, you know partying is about food, entertaining is about food, when you are unhappy you eat, when you are happy you eat, you eat all the time, so, I mean, look at our family heritage, we like to eat...”

“...I must say, why I say about the obsession with food is that she wants to become a dietician one day, and she has put on a lot of weight, and she is obsessed with food, its like the opposite of anorexia, if she is unhappy, she is in the fridge, and I know it runs in my family, but it is quite bad, and um, I don't think the diabetes helps a lot, because before she didn't really care about food, food was never that important...”

Diabetes is a portal into a complex relationship with food. Planning to be a dietician would be a direct influence of how diabetes and a preoccupation with food in particular, has influenced the career planning of a young adolescent.

Short Summary

Diabetes is an inescapable influence on the development of the adolescent character. Notwithstanding her early traumatic experiences of being stigmatized, Carrie has had to integrate diabetes into her sense of self; she is knowledgeable and able to perform all the necessary activities it entails. She reconciles her identity as a normal teenager with that of someone with a 'condition' and negotiates age appropriate risk taking, often involving alcohol with a care not required of other teenagers. Her mother worries about her being too responsible, taking on a caretaker role to her irresponsible peers. She also describes how food has become increasingly important in her life, to the point that she plans a career as a dietician.

(IV) Managing Fear

Fear is the primal emotion that runs through this narrative and links many other themes together. The management of diabetes on a biochemical level is about the control of glucose levels. On a more human level it is about the management of fear.

“... so it was huge, and at first it all quite frightened me, you know, talking about the ... if you don't control it, what's going to happen, and I think the huge thing that happened to my child, is because she had to eat a snack, you have to have breakfast, you have to have lunch, you have to have a snack, you know in the old days they used to inject before the pump...”

Fear can arise from many sources: not knowing when the glucose levels will fall or rise, uncertainty of the consequences of these fluctuations, confusion around the intricate rules of eating and how you co-ordinate injections with meal times. The fears of not getting it right and the consequences thereof all spread anxiety and fear.

“...very tricky to keep the sugars right, you know, it went low, then you had to eat more, but I think at first, at first we got a helluva shock, then we said ok, we got all the books, I mean I, read books this thick and this big...”

The fear of adverse events and of not knowing what to do creates a massive impetus to learn, read all she can, network and educate her family.

“...the closest we ever got to going into a coma was when they were driving to our weekend house and she was sleeping in our car, and the cat was sleeping on top of her, and then I turned around and the cat was sopping wet, and I turned around and thought how weird, and when I looked down, and she started to scream, and when I looked down, she was just wet wet wet like that and I had to force her...”

Hypoglycaemic attacks are particularly feared. Parents wonder how they will affect their children, - whether they are harmful.

A time of particular fear is sleep. Lindsey recounts a story of a young boy who participated in a research project with them.

"...Um, Ja, one of the boys we met when we were testing, you know testing different insulins, one of those things we had done, you know, and I know one of the boys went to sleep the one night, and didn't wake up the next morning. And that shocked me..."

Sleep is a time of worry for Carrie too.

"... before the diabetes she was fine, and then when she came, when she had to have a snack, before she went to bed...she was very very fearful of dying..."

Blood glucose levels can fall precipitously, and if asleep Carrie would not be able to sense this drop.

"...I would just unexpectedly sit up, think something was wrong and she would be like her blood count would be 1 or something and she would be shaking and not knowing where she is, but she just never woke up..."

This fear called for extraordinary precautions.

"...she used to make me promise to wake her up at 1 in the morning when she was sleeping, so I used to do that, for years, for years, and afterwards she was quite low, although we prepared very well the night before, as I say, during puberty, sometimes it was just not controllable..."

It was only when she went on the pump and her night time glucose levels stabilized that Lindsey could sleep soundly.

Lindsey understands how powerful her fear and worry is. She tries to manage it, does not want to be dictated to by this fear and become the stereotypical anxiety driven mom. In this humorous anecdote Lindsey describes how she overcompensated, not wanting to come across as panicky so she exposes her daughter to a diabetic camp well before the norm.

“...she was about a year into it, they were having the school camp, so I thought, I mustn't be one of these petrified parents, and I must send her on the camp. And, one of the teachers who are going, but one thing I said, she must have a cell phone on her, and she must be able to phone in the evening, and the teachers said fine...so she would phone me, and I asked, what are your sugars now, what did you do this afternoon, and I would try to calculate, how much snack she would have and how much insulin and then I would worry the whole night, but I left her, because I didn't want her to feel that different. I mean, it was years later that a parent with a child the same age as mine said, aaaah, I am letting him go for the first camp. So I said, oh, which camp, a diabetic camp, you are letting him go for the first time to a diabetic camp, oh dear I thought everybody was just letting them go to camp. I discovered later on that I obviously let her go to things quite earlier, out of fear of being a panicky parent, you know...it always worked out well...”

Stories of other young diabetic adults serve as potent reminders to stay well controlled.

“...I know there was one girl who as at res UCT, and she always told the girls next door to come and check on her if she hadn't come about, and she said no she is fine, and they went to two lectures and come lunch, only then did they realize that she hadn't come to any lectures. And they came down, and she was in a coma, and they took her away, but they said we came to fetch her and she said she was ok, and she said, that for her that was scary...”

Horror stories such as these make an impression, and reinforce the proximity of danger. There is the story of an ex-headgirl who went to university and whose

sugars went wildly out of control as a result of her partying, and a young man who fell into a hypoglycaemic coma after a drinking binge. As a result, Lindsey is fearful of the possible dangers to her daughter but knows how important it is to hand over control and suppress her fears. Carrie will soon go off to study.

“...there comes a time when as a parent you got to say, you got to be out the house, and I can't check her sugars everyday, check, check, check, check, check, so it really is up to her, she is going to Stellenbosch university next year, to do a BComm in management and I said, before she goes she her father says so she is going to live on her own, I mean in the res, because she has got to be responsible, but it's a huge thing for a parent...”

Fear is internally calibrated against glucose levels and the capacity of the adolescent to take responsibility for their own control.

Short Summary

Fear is vested in Lindsey's concerns about the specifics of gaining control, especially in the beginning, and about aspects of her daughter's future, but mostly about the sudden abrupt and unpredictability of low glucose attacks. Sleep is a particular time of danger, both for mother and daughter and various strategies are laid out to address these. Horror stories of other young people whose control falls apart when they leave home serve as warnings. Lindsey understands that she can only do the best she can to equip Carrie to deal with the outside world and that she must suppress her own anxieties in order to grow.

Interview 7

Mother - Bianca Son - Stuart

Stuart was 11 ½ years old when diagnosed and was 17 years old at the time of the interview. Bianca, his mother was 7 months pregnant at the time of diagnosis - her third child, a boy born a few weeks after. They also have a daughter 2 years older than Stuart. It was a very stressful time. During the first six months her father developed a brain tumour, mother developed breast cancer and Stuart's best friend died. She describes the time after diagnosis as a "time of shock", "living in limbo" and "living from day to day." Bianca and her husband Tom frantically looked for cures but these as they found out, don't exist. Bianca entered into what she called a period of "darkness" for approximately 5 years. About a year after diagnosis she was treated for depression with an antidepressant but stopped this after 2 months. It was only when introduced to a bible group by a friend that she found a place where her pain could be assuaged, an outlet for the suffering she had been through. Since then she has seen a huge improvement in her state of mind. Specifically, she has come to realise how casting her son in the role of 'victim' had a detrimental effect on how they treated him. She continues to harbour regrets about this.

(I) Creating A Victim mentality

Influence of Parental Perceptions.

Throughout her narrative Bianca reflects on the damage done and mistakes made in how they perceived and treated their son Stuart. From the time he developed diabetes they felt that he had been ill-fated, rendered vulnerable and was unlike other normal children.

The existential question of why he developed the illness was unanswered for a very long time.

"...You know initially there was a lot, I wouldn't say anger, but I think there was a lot of why him? Why us? um, you know and it was that sort of, not anger but disillusionment..."

Bianca acknowledges how difficult it was for them as parents to deal with the illness, and how it acted as an impediment to treating him like everyone else. She has developed the awareness that their perceptions had a negative effect on him.

"...It's very hard as parents, to actually, certainly for us, when we look at Stuart, very difficult to actually consider him a normal kid like everyone else, and it is an issue, it is a hurdle, and it is something, and it does actually once again superimpose on him..."

She elaborates further on how their negativity about the illness and their son had enduring repercussions on how he viewed himself.

"...I think he felt that everything was just going against him and everyone was against him, and everything went wrong in his life, we couldn't see... just to be honest with you, we also felt that way, we also couldn't see the good things that were happening, we also focused on everything that was going wrong, that seemed to be unfair, and that created definitely a mentality for him that was hard for him to shake and only after so many years now that we realize,

that I've realized, what I have done, now I am trying to actually undo all of that, and it's a nightmare..."

Their focus on his problems overshadowed any tendency to normalize Stuart's condition. He would verbalize, quite understandably, the wish not to have the diabetes, but instead of seeing this as a normal developmental inner struggle, it would serve to further reinforce his parent's fears.

"...twice he has responded back in a moment of anger, or whatever "I wish I was normal, just like everyone else. He has said those exact words a few times, which also has created a bit of stress in our lives because we automatically think, there are issues, there are issues, he is not feeling normal, not normal like everyone else, which he is..."

Bianca has struggled with the tension between acting on loving, maternal impulses that seek to protect, and standing back to allow her son to fend for himself. The message signalled in an environment of excessive worry is that there is something excessive to worry about.

"...And it can be any situation, and you can actually make a difference for your child, without even realizing, you can be compassionate and loving and a good mother, but actually what you are doing is that you are making them feel worse and worse and worse but you are stressing them out, and its becoming huge in the child..."

She gives an example of how they would respond to a sugar low on the sports field.

"...he is very sporty so he will often come before a game, after a game or whatever and say I'm low, I'm low, I'm low, and everyone goes ... there is this a whole big thing like, everybody is frantically running around trying to sort him, to fix him, and I have become so aware of the fact that now, its wrong, its bad, because you know its almost like trying to validate him to tell him its

okay, we all love you, we all understand, and we are all here, and actually its not helping him become mature about the whole thing..."

As a result, Bianca feels that her son developed the negative mentality of a victim.

"...my son has felt victimized, a mentality, this is what happens so be aware and don't go down that road. You know, stop that process so that it doesn't negatively affect your child who grows up with that mentality..."

The understanding that how you perceive, and therefore treat your child will impact widely on his self-esteem and capacity to adjust to the diabetes has been among the most important aspects of self-understanding Bianca has gained through her experience with her son. She still questions whether this dynamic is unavoidable.

"...We do need to let go of the stigma though, because you do put a stigma over your children, and I don't know if its possible not to..."

Short Summary

Bianca voices regret and feels responsible for the way in which they perceived and treated Stuart once he developed diabetes. They persistently felt sorry for him and thought of him as not normal, to be pitied and looked after. It was a response that she feels was restrictive and emphasized his vulnerability, inducing panic in those around him. As a result, Bianca feels he internalized the thought that he was a victim. She feels she has done something wrong for all the right reasons, namely her maternal desire to care for her vulnerable son. There is also a sense that their underlying negative response to the diabetes contributed to an overall lack of control and desperation that pervaded their lives.

(II) Narrative of Revelation – A Spiritual Transformation

Bianca traces a narrative with a linear trajectory beginning with the chaos and trauma of the diagnosis. She will describe how after a period of emotional darkness, she found a way to understand and give meaning to her inner struggles in coping with her sons diabetes.

The beginning was a time of numerous life-altering losses.

“...from that point, well a lot of things happen to a family after that, it was six months of hell, that was the start of really a very bad period which Stuart was also affected quite badly by, you know my dad, developed a brain tumour a month later, which had to be removed and he went into a coma, and my mother developed cancer three months later, and then Stuart lost his best friend, 5 months later 2 days before Christmas, so it was a terrible state, so actually at that stage, my memory of those first 6 months is just chaos, all over, the baby, all the illnesses, it was just insane...”

She could not cope, was depressed, crying all the time and not functioning fully within the family. She was feeling increasingly guilty that her son was feeling responsible for her despair.

“...at the time I was very emotional just wanted a cure, wanted to wake up the next morning and wish it was just a dream, it wasn't happening. And I think it was, it was crazy, because of all the things that went down in our family at the time, his illness was the one that, kind of it was the one that affected everyone the most. I mean my father – he nearly died, actually it was so bad, but, when looking back at all that went down, that was the one thing that every one can't really get over. You do get on, you do get better, you do accept, but there is still the one thing that is the shock that you can't let go, for everyone, even extended family I would say, feel that, ja, and just it has been a time period of shock. I don't know, probably 4 of the 6 ½ years, when I was just living in limbo, just kind of not feeling, just you know existing, going from

day to day to day, just surviving, just taking each day to survive, and then I got to a space where I had to get over this thing..."

Bianca eventually turned to a therapist for help. By her account it was the first time that she began to understand some of the dynamics accounting for her distress.

"...I went to a psychologist for a while just for a few sessions and there were just a few things she said to me which triggered something in my head, things like my behaviour. How I felt about the illness, things, you know, to be aware of. How I actually respond to a low or a high, or when I am in peoples company. How I respond when I bring up the whole diabetes thing all the time, because before it was just a coping mechanism, a way of just getting it out, and then it stopped and I became more aware of my behaviour. It didn't just change; it's very difficult to break the behaviour. I still struggle with it. Every time he is running on a hockey field and shouts 'Mom, I'm having a low', I think what should I do? What should I do? Your instincts you can't instantly change, ag, that was the start, actually being shown UP..."

The therapy helped her gain insight but did not answer the fundamental existential question of why diabetes had affected their family.

"...I didn't enjoy the experience I must be honest. It did help a little with the crying and the outbursts, but it didn't help in the long run, because there still wasn't working through, you know it was just numbing everything. There was no numbing everything and getting past that why us, why him, why why, you know..."

She then went to a bible group with a friend.

"...I also joined a bible study group, a friend of mine took me to a bible study group, and actually that was really my turning point. In the bible study there was an area of healing, you know, wounds and healing and pain and suffering

and, I realized that's what I felt. Like, not that god had done this to Stuart, but that he...I felt like it was something that happened because it needed to bring about a change in me, a change of my mind, a change of my focus, and that really, spiritually, I have grown immensely in the last year, and that is where I go for a lot of my comfort, a lot of my wisdom, and it has all made more sense, to be really honest, it has really made more sense..."

She describes her journey in the terms of an enlightening revelation.

"...my faith has just changed, become stronger, more active and I think for really, for the 5 years, from Stuart's illness to last year, there wasn't much going on spiritually, like I say, I was in just darkness really, and then there was that moment of bringing me out, waking me up..."

In her faith she has found an acknowledgement of her suffering, a way of understanding why Stuart developed diabetes, and that's part of its reason, was so that it could effect a beneficial change on her.

"...I think in that there is a lot of healing, if you yourself can talk about it, get it off your chest I think there is healing in that..."

Finally she was able to find some peace, and put behind her what she describes as a negative approach, the time before the awakening. She has gained more clarity in how she has contributed to the mind-set of victimization and focused hard at remedying this.

"...Everything is absolutely making more sense, and my whole approach is more positive, the way I try to guide Stuart is far more positive, trying to break those victimization mind-sets that we have, that he has, and trying to get him to a space where we are focusing more on the good that is going on his life, and there is so much that is good, he is a very gifted kid, he is very bright, there is so much of that we were crowding with all our negativity, we just weren't seeing all of that, and it impacted on him..."

Short Summary

Bianca describes the trauma and chaos of the first several months after her son's diagnosis with diabetes. She and her family continued to struggle for a long time afterwards, notably with the existential question of why they were given the ordeal. She became depressed, and saw a psychologist who helped her to develop insight into her situation. But, it was only with the Bible Group, and her introduction into the Christian faith that she could truly express her pain and find healing. She is unequivocal that this was a turning point in her development, allowing her to see the past clearly, and adopt a more positive role in her child's life. This narrative trajectory completes an arc from chaos and despair, to a revelation that changed her outlook on the world, and with this new vision gave her a greater emotional equilibrium.

(III) A Frenetic style of Glucose Control

Parental involvement with Stuart's glucose levels is characterized by constant drama, emotional expressiveness and a frenetic style. This running theme is a further reflection of how out of control and traumatized the family were during the early years after diagnosis.

"...it did throw us into an emotional state of trauma, because we did start becoming fanatical about highs and lows, and about night-times, and food, we were constantly behind him to show that his every need was looked after, there was always food around, at night time we would wake up, sometime twice, we really went to the extreme, because of lack of knowledge..."

Poorly controlled blood sugar levels caused widespread stress and parental anxiety. This was predicated on the fear of not knowing what would happen next. Would he have a coma? A seizure?

"...We are stressing out basically about control, his control is very erratic, and I think the point he misses is that, because he hasn't had a collapse or a seizure, because he can feel the highs and the lows at the moment he thinks he is just doing fine and he is under control but what he doesn't realize is that those high's and lows can have dire consequences..."

The worries for what could happen elicit anxious counter-productive responses from Bianca and her husband.

"...I think with us, it's a different mind set, we think it's a different mind set, what can happen, these are the consequences, and it goes whish, straight over his head, and sometimes I try the shock mode, which does not work, I actually think it does more damage. He is now walking around without his medic alert because he lost it for about the third time. He doesn't worry if it isn't on his arm, and then I keep on saying to him, you know...If you have an accident, no one knows you are a diabetic and how to treat you and you can DIE... I say things like that..."

Parents and child are not in agreement about how to manage the diabetes. They assign different priorities and don't have the same long term worry about the complications. This fundamental lack of control reduces both Bianca and her husband to strategies that emphasize catastrophic consequences.

"...You know, my husband actually gets a lot more frustrated with him, and quickly, and he will challenge him on it, 'and you are not looking after yourself, we must get you to the doctor, and check your hba1c, and we must, do this', and he will just attack, which I don't think Stuart likes, I think he takes it as an attack and he ignores it, which is exactly what it is - me on the other hand, I will go and talk, and then I just talk, and I talk and I talk and I talk and he gets to the stage when he gets to the stage when he will just say, I wish that she will be quiet. I try and overdo the whole talking, analysing, loving, supportive, I'm there for you, I understand, and so he gets irritated with that as well..."

They increasingly have no impact, which only makes them more desperate.

“...no impact, so I think my husband and I at the moment really have no impact, and I feel it, I can feel that out of control no impact...”

Bianca understands that her frenetic control is an expression of the vulnerability they project onto him, and the fear they have for his illness. What seems clear from this narrative is that Stuart himself doesn't actually share that same fear, and his resistance may be a very healthy rebellion to his environment.

Bianca realizes that she has to change their style of communication, hand over more responsibility. But this is hard.

“...I am so aware of their wanting to be independent, when you have a kid that's got an illness its so hard, actually, just to break that mind-set and allow them to move off and... you know he went to a cricket tour overseas last year, for three weeks, the whole family climbed on a plane and went with, you know, ... can't let him go for three weeks, but actually we have to, we have to...but actually it's the fear that when he is there, he will have an experience and no-one around you actually knows what to do...”

It is only by getting control of her own fear that she will be able to feel comfortable and help facilitate Stuart's independence.

Short Summary

Bianca and her husband mostly feel out of control when it comes to managing Stuarts glucose levels. Parents and child do not share the same concerns, and as a result have not formed a working partnership characterized by open communication. Out of this emerges the pattern of interaction over glucose control – frenetic, and marked by emotionality and despair at not getting it right.

Both parents become stressed and anxious which aggravates their confrontational approach and further worsens the problem.

Chapter Four

Results - Global Themes

(I) Negotiating Identity

Chiselling out a new identity that merges the many changes that diabetes brings to a family is a running theme throughout the interviews studied. The way a diabetic adolescent injects, eats differently, monitors and takes care of her body has profound social consequences. The adjustments to managing diabetes are social, as well as biological.

On one level, the adolescent must come to terms with the behaviour, attitude and life long commitment that diabetes thrusts upon them while negotiating the cognitive, social and psychological demands intrinsic to their developmental age.

On another level, their families need to make the adjustments required to integrate the adolescent and steer the family into a path that self identifies in a different way, in order to allow for the management of diabetes.

On a third level, parents, and particularly mothers need to adjust for their hopes, expectations and experiences of managing their teenage child.

Their ability to integrate these different levels of identity management will impact on the adolescent's diabetic management and quality of life.

A mothers view: Normal or not?

The mothers in this study are concerned with their child's 'normality' and differed widely in their view of how 'normal' they were. Hilary (interview2) and Shireen (interview5) were similar in that they viewed their children as essentially normal teenagers with the condition of diabetes, requiring special management but no different from their peers in any other fundamental way.

Hilary (interview2) makes every effort to adapt the family around Karen. Dietary changes emphasize health rather than illness, and contribute to their identity as a united, self-confident family - strong in the belief that they have grown in their experience. Similarly a large accepting extended family acknowledges and accommodates Karen, mitigating any potential for social stigma. Hilary actively educates friends and school contacts, thus helping to normalize perceptions of the illness. Shireen (interview5) also describes how her family adapted around the diabetic needs of Saskia, with emphasis on a positive healthy family identity rather than that of an ill person who needs to be cared for. Nevertheless it's clear that Saskia is different and her siblings are sensitive to the extra attention she receives.

Margaret (interview1) and Bianca (interview7) hold different views on their child, describing a 'spoiled' or non-normal identity.

Margaret (interview1) regards Deon as special and different, and definitely not normal. This view arises directly from his consistent behavioural problems; difficulty with glucose control, resistance to taking responsibility for his health and his many other associated unusual health problems. Marking his identity this way serves a potent explanatory function and marks him as special in a way that preserves something positive, almost supra-human - something valuable that justifies all the effort that has gone into his management. In this instance not being normal is a positive valuation.

Bianca (interview7) reflects on how she and her husband contributed to Bruce's spoiled identity as a damaged, vulnerable and ill-fated child, and thus contributed to its making. When they looked at him they were unable to see a normal child. She reflects on how realization of this changed the way they related to him and how emphasizing the positive and not over-reacting to his glucose fluctuations have helped to normalize their relationship and perception of him.

The way in which mothers consider the identity of their child; normal or abnormal is related to how closely their lives approximate to their non-diabetic peers and to the hopes and expectations of their parents. Most diabetic adolescents regard themselves as normal so a departure from this, a contrary identity, should be a warning sign of enduring problems.

An interesting facet of these narratives was the dynamic relationship between the mother's identity and the way they represented those of their children. A greater discordance around management usually implies divergent perspectives on many aspects of the condition between mother and teenager. The personal challenges to the mother and to her sense of self are subsequently greater. Both Margaret and Bianca's more conflict heavy narratives are dominated by their own personal stories of overcoming challenges, in contrast to Shireen, Adele and Hilary who narrate through the eyes of their family and their daughters. Sheila does not give a clear sense of herself or her daughter signifying problems with narrative coherence and identity management.

An adolescent view

The adolescents, according to their mothers, also differ widely in how they integrate their diabetes into everyday life. The examples of Karen (interview2) and Saskia (interview5) parallel that of their family experience. Both are teenagers who participate fully and often excel at school in academic, sporting and leadership domains. Karen acknowledges how her diabetes has changed her, reflecting on how Constantiaberg Hospital has become a second home and exhibits a reluctance to over-identify with other diabetic teenagers. She is however openly disclosing of her condition, discreet in her self-management and active in her commitment to educating others about diabetes. She is conscious of how far she will let the technologies of diabetes mark her, refusing to wear a diabetic pump on her slim body. Saskia, like Karen actively manages her diabetes, is outgoing, extravert and not too self-conscious (she wears a pump to the beach) She, like Karen, views herself as a normal person with diabetes, though both still live with the on-going identity juggle this entails.

In Carrie (interview6) we see a more ambivalent view. She manages her diabetes and integrates it into her day-to-day life but we get a sense from her mother that there is more ambivalence and struggle. She was teased and stigmatized as a younger person, and still questions why she should have the condition. Nevertheless, she takes active responsibility for her self-management and refers to Diabetes as a condition rather than an illness. She has internalized aspects of diabetes to a degree that worries her mother. She self-identifies as the 'responsible' one amongst her friends, taking care of them when they are partying, and has career aspirations as a dietician.

Deon (interview 1), Bruce (interview3) and Lauren (interview4) all appear not to have integrated their diabetic condition. Their denial manifests in behaviour that appears contrary to minimal self-caring strategies expected of a diabetic. They are certainly aware of the diabetes but not functional, a cause for conflict and strife within their families.

Achieving a stable identity that incorporates their diabetic condition would entail acceptance of the behaviours necessary to keep well. Bruce (interview3) significantly is concerned about how he looks, in that he wants to appear more muscular, but keeps losing his medic-alert bracelet, that identifying feature of this condition. He loses regularly misplaces or loses his phone, symptomatic of a wish not to be in communication about his diabetes with his anxious mother. It is not hard to understand that many adolescents don't want their condition, and ignoring it is a good way to pretend it doesn't exist. However, their ability to mature and develop is contingent on their taking care of themselves. Lauren's (interview4) lack of curiosity and refusal to openly acknowledge her condition as well as her relative isolation from her peers all factors mitigating against a stable and positive diabetic identity.

Managing identity, on all levels, be it the adolescent, the mother or the family, is an attempt to balance out a desired world that embodies hope and progress through life's stages, against that of illness, a profound interruption in the normal

flow of things. The idea of normal defends against the latter, and in itself helps foster a better outlook and quality of life.

Short Summary

The negotiated identities of mother and child are deeply consequential to how diabetes is managed. The study reveals the preoccupation and tension between the normality hoped for and often achieved and the very real differences that separate them from their peers. Adolescents are in the process of developing their own self-contained identities; seeking that which sets them apart yet paradoxically cleave closely to the norms of their peer group. The mothers in this study notice how their children juggle these conflicting demands of the self by trying to be 'normal, but different' at the same time.

Chronic medical conditions interfere with the expected trajectories of everyday life. They require adaptations of the social environment and the self in order to adjust for these changes. It is of critical interest to mothers that their children with diabetes fit into the normal scale and each in this study attempts this integration. Being able to minimize pathological self-perception and promote self-esteem, personal growth and functional behaviour is an ideal, not always attainable, especially if complicating co-morbidities such as learning difficulties or adverse environmental conditions prevail.

The core challenge of the adolescent is to integrate their new identity as diabetic into a normal conception of the self that provides a foundation upon which to communicate about and take responsibility for their health. The conflict evident in the interviews is most pronounced where this has not happened and particularly when there are discordant views on diabetic management between mother and teenager. A high level of discordance exerts a disproportionate pressure on the focus and substance of how mothers generate a coherent identity for themselves and for their children.

(II) Fate and Agency

A fundamental question addressed by all mothers was that of whether the diabetes was caused by something they had no control over or whether in fact they retain agency. This is pertinent to the initiating cause of diabetes and the enduring struggle to achieve glycaemic control. In other words, was this disease fated? Or are they as parents responsible for it?

I will discuss below three different dimensions of this theme.

1. The role of guilt and blame.
2. Integrating meaning
3. The role of fortune

Guilt and Blame

The two areas of responsibility consistently questioned by mothers is the degree to which they are responsible for the causation of diabetes and for managing glucose control well enough. As the parent of an adolescent still in their charge, they assume responsibility, understanding the important implications for both immediate and long-term health outcomes.

Margaret (interview1) has a son who is unable to regulate his own behaviour and in her opinion take responsibility. She asks herself continuously whether Deon has some kind of underlying condition that would explain this, be it autism, Asperger's disease, learning disability or the influence of his older brother. She compares diabetes to drug addiction, a disease that would allow less culpability on the part of her son and by implication, possibly by herself too. There is judgment implicit in her talk of her son. She calls him a "total screwball" but continues to struggle with the question of how much responsibility to apportion him for his behaviour.

Adele, (interview3) Sheila, (interview4) Shireen (interview5) and Bianca (interview7) all voice some degree of guilt about their own culpability.

Adele is self-critical about her controlling tendency to over-mother and feels guilty about the negative impact on her son's behaviour. Sheila feels she may have contributed to her daughter's illness by not being present when she was an infant, and an angry guilt infuses her reflections on how Lauren's glucose level is only controlled when she is around. Shireen describes how initially she blamed herself for exposing her daughter Saskia to the 'shock' of a terminally ill friend and that this may have had some causative influence on the disease. Bianca expressed guilt and self-castigation for the negative way in which she and her husband reacted to their son Stuart's diabetes, specifically in how they treated him as a 'victim' and helped perpetuate a victim-like mentality until they were able to get sufficient insight to move beyond this. Even though psychotherapy and becoming reborn (Christian) had helped immeasurably, she still blamed herself for the damage inflicted by their mind-set.

Adele (interview6) expresses how many mothers feel uncontrolled glucose levels in their child made them feel guilty. As a parent she feels responsible and therefore takes on the blame when sugar levels go awry. Adele also describes how Carrie feels guilty if her glucose levels go up.

Compounding this is the guilt that many parents feel for transmitting the genetic material that could have contributed to their child becoming diabetic.

Many of the mothers described the critical eye of family members and others on the outside, and the sensitivity of being blamed by those who don't fully understand the condition.

Guilt is the phenomena to which we take personal responsibility and feel directly to blame. Culpability is at its core, and the degree to which this is felt will influence how mothers treat their child.

Shame is a more social phenomena; a direct reflection of how we feel about ourselves in our interactions with others.

The presence of these strong emotions reveals the extent to which diabetes causes disturbances in relationships, as well as in glucose homeostasis. Its in this sphere that much suffering can occur.

Integrating Meaning

The degree to which answers to the important questions of causation and influence can be found outside of the bounds of human control seemed to predict whether a mother presented an integrated positive account of their child's diabetes, and to correlate their own positive affect in the interview.

The idea that 'things happen for a reason', or the theory of predestination; that there is a wider plan into which their child diabetes neatly fits, was a powerful unifying theme found through most of the interviews.

Five of the interviewees, to different degrees, held religious beliefs that expressed the idea that there is a positive force, (a Christian god) whose omnipotent and all embracing power over the world exists as a power, orientated towards the greater good.

Hilary (interview2) felt that they where given the illness because they were the right people to handle it, that god would not give you something you cannot handle and that in this thought lies hope and faith in their ability to continue to deal with the challenges coming their way. Shireen (interview5) felt it was no coincidence that Saskia got diabetes as she was the best suited of all her children to get it, that her fate was in gods hands from a very early age and that there is the potential of a greater good to come out of all this. Out of hardship can come redemption. Similarly, Lindsey (interview6), while not overtly religious in her tone, also believes that things happen for a reason, and that through illness, there is an opportunity to learn, be challenged as a human being and have the best

brought out of you, often with the potential to help others around you. Bianca (interview7) took a more personal view of healing, one infused by her new found Christian faith; that it was through surrendering to the bigger power one could find healing and acceptance and bring to an end the interminable inner questioning of why their ordeal had happened to them.

Margaret (interview1) does not come from a Christian background or refer to a Christian god. She has a more heterogeneous New Age like amalgam of beliefs, yet they are based firmly in the organizing idea that things happen for a reason. She believes that she was predestined to be Deon's mother, prepared by her own experience with ulcerative colitis. The unfolding of events in her life explains why she needed to suffer ulcerative colitis in the first place. Her healing journey has been an amalgam of serendipitous meetings and proactive striving.

What is noteworthy about Sheila (interview4) is that of all the interviews, hers was the least integrated, most emotionally raw account. She acutely felt both her and her daughter's limited abilities to control the diabetes and raged against the medical services that she felt let her down. There was little evident in the way of an all embracing, supra-human power that may have allowed her respite.

It would be unfair to say that because so many of the mothers held views of powers larger than themselves that they were passive. The vast majority actively engaged with their faith and were very proactive in the management of their adolescent's diabetes. A belief in fateful forces in no way suggests passivity and lack of agency. If anything, the conclusion can be drawn that the mothers hold multiple and co-existing belief systems, and draw on these for different explanatory needs.

The role of fortune: "We are so lucky" – or not

Amongst the interviews, those mothers whose children took responsibility for their control and engaged with their diabetes, described themselves invariably as lucky, while those whose children were poorly controlled felt more burdened,

strived to find out what was wrong and often felt themselves complicit in this unsatisfactory state of affairs.

The concept of luck is tied in with fate, part of the great roulette wheel of life that you either score on or don't. Hilary (interview2) feels lucky that Karen takes responsibility, and fortunate to have such a well-integrated child. Shireen (interview5) similarly has confidence in Saskia's ability to look after herself and feels fortunate that some of the anxiety of her glucose control has been taken away from her. Lindsey (interview6) also expresses how lucky she feels to have a daughter who knows how to look after herself.

In the face of good fortune it's a social convention not to claim too much responsibility, and this may be the case here, attributing to fate what is really the product of nurturing and constructive child rearing. But, it's truly possible that luck does play a large part in that personality, genetics, external influences and numerous other factors are outside anyone's control.

The impact of poor control such as with Deon (interview1), Sheila, (interview2) Adele (interview3) and Bianca (interview7) compel action. Agency then becomes a practical necessity, but opens up the possibility of personal responsibility for failing to act in the right way.

Agency is more apparent when something must be done to correct a disturbance, but is less obvious when things work out relatively smoothly.

Short Summary

The theme of Fate and Agency collects to it many of the underlying thoughts of the mothers interviewed. To varying degrees ideas of control, proximal or distal where juggled and balanced. To defer to a greater power allowed an assuaging of guilt, integrated the reality into how the world should be, and provided, even if rather tenuously, some kind of existential reason for the presence of diabetes in their family. It also helped to facilitate hope, by turning something negative into

something positive and affirming. This dynamic confirms that mothers in these interviews generally were not satisfied with proximal biological explanations but sought affirming emotional and spiritually integrative accounts. However, the practical day to day challenges of everyday life required practical approaches, and there was no one who doubted the grubby daily effort needed to control sugars and lifestyle. Agency, proactivity, intensive engagement with the process is the norm (to varying degrees).

(III) Food as expression of family dynamic

Food and eating are central to the routine activities of any family and carry powerful symbolic significance. Diabetes is a failure of the body to assimilate that most basic building block of nutrition – carbohydrates. The relationship with food therefore changes dramatically with a diagnosis of diabetes, and therefore is a powerful prism revealing how different families adapt and function.

Two main trends in mother's discussions of food is either as a unifier whereby different aspects of eating fulfil a productive role in overcoming the challenges of diabetes, or as a divider, a marker for conflict and distress, often out of disagreement or dismay at the way in which the wrong foods are eaten.

However, to limit interpretation to this bipolarity is to ignore the subtle differentiators between families that result in different relationships to food: Namely, the gender and age of their child, their economic, educational and professional status, and family size.

Hilary (interview2) and Shireen (interview3) give the most detailed accounts of the role food plays in their families lives. There is a strong connection between the central role of the family in Hilary's life and food. She is intimately familiar with the diabetic dietary needs and has steered her whole family to adapt. Food has become a vehicle for family unity promoting valuable mealtime conversations, mutual support and compromise so that Karen does not feel alone or different. At

family events everyone thoughtfully brings something Karen can eat. Similarly, Shireen's family has also become more unified around the changes they have made, reflecting compromise and self-sacrifice and a re-orientation towards healthy living.

Food for these two families has acted as a catalyst for positive change, and is a metaphor within their respective narratives for family unity, togetherness and growth.

This is in strong contrast with Sheila (*interview4*) whose narrative is characterized by low family involvement reflected in the sparse descriptions of food. As a working mom she is not able to dedicate the kind of time to her family she would like. Her spare account describes no change made to the family diet subsequent to Lauren's diagnosis, but she insisted that she never excluded her and was always telling her about healthy eating.

Lindsey (*interview6*) describes how many of her initial fears concentrated on food. She was overwhelmed at all the rules concerning food. Food can therefore be a site of fear. Something dangerous. If you give the wrong food, sugar levels will rise and there will be adverse health consequences. She is also concerned that her daughter is obsessed with food, has become overweight, and is planning a career as a dietician. Food as danger is made explicit by suggestions of family members that Carrie got diabetes because of the high amount of sugar in their diet.

Food and foodstuffs can be symbolic of the divisiveness and conflict that can occur when there are disagreements about correct lifestyle management. Sheila (*interview4*) gets angry with her child for eating the wrong things. Adele (*interview3*) rages at her son Bruce when he insists on seeing a dietician to get the right protein shake to gain weight, but doesn't seem to take any concern of his glucose control and Margaret (*interview1*) regards her son's stealing of a lasagne from her fridge, only to microwave it and his insulin pump at the same time as emblematic of his total lack of ability to care for himself. Margaret's narrative, for all its detail is surprisingly lacking in detail about food preparation and meal

times. This reflects her son's parallel life, not united with the rest of the family over a meal or shared concern with healthy eating even though they are living in the same house. If she mentions food at all, it's to point out his irresponsibility – missing meals, not eating according to insulin regimes, eating at the wrong times.

Food is often a surrogate for care, and most mothers describe the lengths they go to when their adolescent leaves for a weekend or holiday break. The preparation, attention to detail and level of instruction to teachers expresses an amalgam of love, care, anxiety and responsibility all mixed in as the adolescent departs the controlled environment of their home.

Short Summary

Many of the family dynamics elicited by having a diabetic adolescent in the house are captured within these narratives by the symbolic entity of food. The talk of food, its preparation, its caloric value, its quantities, the setting it takes place in function as a language in itself containing a multiplicity of meanings. These include that of unifying the family, promoting health, wellness and hope as well as the divisiveness of conflict when family members clash over different approaches to lifestyle management.

Food, while being necessary for life, in diabetes, also harbours the possibility of sickness and death. It has strongly bimodal symbolic value. Too much of the wrong food raises the sugar levels in the blood resulting in long term complications.

One could argue that an over-involvement with the mechanics of eating, i.e. the carbo-counting, the low GI, the food labels, helps to defer the anxiety of potentially uncontrollable diabetes. The relationship with food is therefore a metaphor for the relationship with risk. It becomes an important index for how fearfully a family tries to keep glucose levels under control.

(IV) Resilience

Resilience is the ability to endure and grow through adverse circumstances. These mothers and families display remarkable qualities often under great duress. Some have greater resources than others, some have greater talents, yet others are overpowered by the stresses they encounter. Though all of the mothers interviewed have adolescents with Type 1 diabetes, they are not the same. Each situation is unique and those that appear to be coping the best may not be those with the most reserves of resilience. This overarching theme gathers those factors that serve as buffers for the mothers and adolescents dealing with diabetes in their families.

From these interviews I draw signs of resilience from evidence of unified families exhibiting competence, minimal conflict and an environment of growth, even in the face of hardship. This doesn't however exclude situations high in family conflict, as these mothers also draw on deep resources to maintain themselves and go on.

The capacity to find meaning

Hilary (interview2), Shireen (interview5) and Bianca (interview7) all have strong spiritual, and specifically Christian beliefs that provide significant help in meeting the challenges that diabetes poses to their families. The reassurance of a higher good - even if they don't fully understand it, the presence of some higher purpose and the belief that things happen for a reason all shine an optimistic light on their predicament. Bianca initially went through a period of depression and despair before she was introduced to a bible group and Christianity. This connection helped her immensely, both to validate her suffering and to create a meaningful context to understand it in.

Margaret (interview1) holds an amalgam of New Age type beliefs, characterized by a non-specific higher power determining that all things happen for a reason, and that her role as mother to a child with type 1 diabetes was somehow meant to be. Though there is significant conflict in her relationship with her son, it is through her own efforts and belief in a motivating force in the world that she retains her perseverance and faith.

Lindsey (interview6) does not dwell on a particular religious belief system, but also draws meaning from the illness, explaining that out of bad things come good, and that there is some underlying reason for it occurring in the first place.

Many of the mothers, even when at their lowest ebb hold beliefs that could be described as having an optimism bias. Often causes are derived from conclusions (e.g. if something happens, there must be a reason for it) and small gains are emphasized at the expense of bigger losses. This propensity is echoed in the general value of positive thinking discussed below, and reveals an intrinsic form of human resilience that requires a modicum of denial and delusion to allow sufficient removal from reality, in order to carve out desired possibilities for the future.

Social connectivity

Hilary (interview2), Shireen (interview5), Lindsey (interview6) all have close-knit families, providing mutual support and offering strength. Family unity and growth are considered valuable resources in which they take pride. Hilary and Shireen have large extended families with a very wide network of friends. This support protects them from isolation and provides a valuable emotional resource. Friends are a valuable source of support for Adele (interview3) while Bianca (interview7) was introduced to the bible group through a friend.

Margaret (*interview1*) a gregarious and extravert woman also actively seeks support within a wide network of friends, though is estranged from her relatives who have a different more religious philosophy of life.

This contrasts with Sheila (*interview4*) whose work colleagues provide her social support. She and her daughter are socially isolated from friends and family. Lauren, introverted by nature with little indication of a wide circle of friends may be disadvantaged in not developing the communication skills and confidence that comes from a close peer group.

Social engagement plays a prominent role in the life of any family, but is of particular importance when a child has a chronic illness like diabetes. Diabetes is revealed in these narratives as a profoundly social condition, affecting

interactions, presentation to others, considerations of diet and travels beyond the home. Those in the study with complex social networks benefit by getting to know themselves and their illness through the mirror their peers provide, whilst those who are relatively isolated don't have similar avenues to build self-esteem and engage fully with the world around them.

Help-seeking behaviour

The mothers interviewed exhibit different styles and patterns of health-seeking behaviour. The character of this trait will determine the quality of the care for their children and provide the mothers with information and support in their own personal challenges.

The most helpfully therapeutic relationships with health care providers are characterised by a strong attachment, easy accessibility, regular contact and a perception of empathic connection. Hilary (*interview2*) and Shireen (*interview5*) cultivate strong reciprocal bonds with different members of the health team, including an endocrinologist, dietician and diabetic educator. Their health care interaction is active and outwardly seeking, rather than passive and receptive.

Margaret (*interview1*) throws her net very widely in looking for help. A central theme of her narrative is the inability to find the right help for her son, so she seeks far and wide, both within and outside the medical community. Her optimism that there is always potentially someone who can help infuses her with hope, and supports her on her journey. Nevertheless, the instability and variability of the help she seeks belies the chaotic status of her son's diabetic management.

Mother's help seeking patterns are linked with their underlying beliefs and affective states. They can be seen as a litmus test of the equilibrium within the family and the functionality of the interaction with their child. Interactions with medical staff, such as experienced by Sheila (*interview4*) are characterised by hostility and suspicion. She finds them judgemental and unhelpful and has withdrawn from any meaningful engagement. This reinforces and propagates the feeling of isolation and anger that pervades her narrative.

Bianca (*interview7*) has little contact with medical staff and feels that her personal efforts in research have been the most useful. She feels that medical personal could have been better in preparing her for the challenges that lay ahead.

The way in which parents cultivate and interact with health care providers is a useful indirect measure of how functional their management strategies are. It is also a notable predictor of the quality of support they get. It reinforces the central premise that good quality relationships, be they with family, friends or healthcare workers, fortifies families and provides useful support in managing chronic disease.

Fostering positivity - Leadership

The capacity to lead: get things done, create unity and inspire positive energy within the family, to provide motivation and effect behaviour change is a skill that not all the mothers possess. Hilary (*interview2*) articulates a positive philosophy that provides a framework for her families approach to the diabetes. It's even more noteworthy considering the physical difficulties Karen has gone through.

Margaret, (*interview1*) Adele, (*interview3*) Shireen (*interview5*) and Lindsey (*interview6*) all demonstrate a proactive approach to sourcing information, liaising with the school, interacting with friends and parents, and fostering a supportive diabetic friendly environment. This rubs off on their children, who are also engaged in helping other children with diabetes (Saskia, Carrie, Karen) Altruistic behaviour helps cultivate self-esteem.

Unmitigated positivity can be a problem, because it may signify a delusional state of mind, in denial about the realities of the problem faced. There is strong evidence however that the human default mode is to over-estimate the brighter side of things, a natural feature of human resilience that is very much in evidence here. Those mothers who were more positive tended also to have more integrated and unified families, suggesting an association between expressed positivity and leadership skills. The family with a child who is diabetic is best conceived of as a team, needing to confront obstacles and overcome them. This is no different from any family, but is particularly focused in the presence of a chronic illness.

Good communication skills

Hilary (interview2), Shireen (interview5) and Lindsey (interview6) are all fortunate to enjoy open and flexible communication with their adolescents. This facilitates transparency, reduces hostility and allows for a negotiated approach to conflict resolution. Most importantly it allows each access to the others thoughts with regards to diabetic self-care behaviour and allows them to develop a shared commitment to solving the challenges of glycaemic control.

In contrast Margaret, (interview1) Adele, (interview3) Sheila, (interview4) and Bianca (interview7) do not have communicative relationships with their children. The result is often differing priorities, divergent goals and conflict-ridden tussles. These minor domestic skirmishes are common enough during adolescence, but when enduring and health threatening become more serious.

Poor communication sets in motion a negative cycle, that then bring on a penumbra of difficulties, each perpetuated by the inability the solve ever deepening problems as they arise.

The most communicative of the relationships in these narratives is between mothers and daughters, provoking the questions about why this could be the case. One could tentatively suggest that this arises from the earlier social maturity experienced by girls at this age; their closer adherence to family norms or greater sensitivity to their mothers needs. It's a time when boys are usually separating from their mothers and less likely to want to promote close communicative relationships. Also, it's possible that there is a higher incidence of co-existent learning difficulties putting boys at a disadvantage.

Short Summary

The mothers in this study are united in that they all face significant challenges in coming to terms with and managing their children's diabetic condition. There are many common strands in their difficulties, but also issues unique to each of them. There is a definite correlation between those mothers who demonstrate features consistent with resilience and family parameters of good health and it is interesting to note how faith, social support and a proactive engagement with

health professionals translates positively into the individual lives of the families examined. In the small sample of this project a positive attitude is closely associated with families who present as united, hopeful and low in expressed conflict.

(V) The triad of Glycaemic Control, Adolescent Autonomy and Maternal Affect

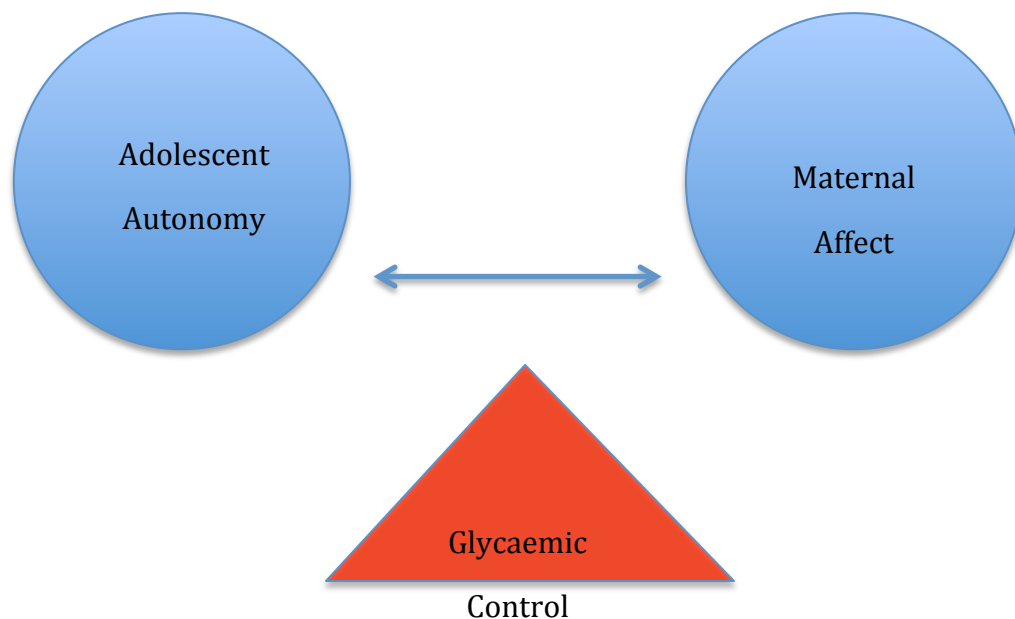
This theme explores the interconnectedness of maternal emotion with their child's autonomy seeking, mediated by their glucose control.

These three dynamics connect the central emotive foundation points of each narrative. They act as the pivot around which so much else revolves.

Glycaemic Control: This is the ultimate predictor of risk. It's measurability and direct relationship to immediate and long-term health complications as well as administrated insulin quantities, places it centre stage in the human dramas described in the interviews.

Maternal Affect: The mental state of the mother is related directly to the glucose levels, or what they are anticipated to be. Too high, and there are health problems in the future, too low and a hypoglycaemic attack may happen. Like the worlds currencies pegging to the dollar, the mother's mental state cleaves closely to the glycaemic control of their children.

Adolescent Autonomy: Adolescent development demands greater independence from the close care of their parents. This entails distance, time away from home, and increasing self-reliance. Maternal anxiety is sensitive to increases in the autonomy of the adolescent, modulated by the level of glucose control.



I will expand further on this interconnected tripartite theme in the rest of this section.

Autonomy is the goal of both mother and child. But it's not that simple, otherwise there would be uniform agreement over achieving good glycaemic control. Good control facilitates the trust of the parents that allows the child to go further and further afield. Geographic displacement from the family home is pivotal to winnowing out new avenues of independence for the exploring teenager.

Both Hilary (*interview2*) and Shireen (*interview5*) detail how closely they follow their daughters' glucose levels. Their narratives are strewn with the nomenclature of control – numbers and measures represented by glucometer readings, HbA1C levels, Insulin doses and carbo-counts. Their engagement is very close, an approach that paradoxically both reassures and reinforces the underlying anxiety it is trying to keep at bay.

A pulsing vein of fear underlies this very close engagement. Management of diabetes is especially reliant on numbers and measures which can give a false reassurance because of the inherent unpredictability of blood glucose levels. Sudden changes in glycaemic levels, unconsciousness and even death are the

spectres that haunt these mothers' minds. You can never do enough; absolute control is always out of reach. This dynamic maintains high levels of anxiety creating a trap of trying ever more close control. However, too much control can become obsessive and suffocating, and it's the adolescents' tolerance for this, and the quality of the parent-child relationship that helps to make it functional. Both Hilary and Shireen are involved WITH their daughters in both proximal control (in the household) and distal control (away from home - scrutiny of social venues, packed food, telephone calls) As long as they are reassured, the spectre of anxiety can be kept at bay, until such time as they can tolerate less control and withdraw their involvement.

Trust is the lubricant that facilitates a teenager successfully exerting her autonomy. The quality of the relationship characterised by trust and transparency helps to assuage maternal anxiety, create positive feelings and confer confidence to their children.

The role of technology to help optimise control and assuage anxiety is well illustrated by Lindsey (*interview6*) who is notably less anxious once her daughter Carrie gets an insulin pump. The pump supplies a steady dose of insulin thus protecting Carrie from sudden drops in glucose levels. For many years Lindsey would wake up as a routine, in the early hours of the morning to test her daughters blood sugar levels while she was asleep. This practice reassured Carrie that she could go to sleep safely (sleep is often a time of heightened fear) but was a steep burden for Lindsey to maintain. Mother and daughter find liberation from their fear in the pump.

The fear that is engendered by diabetes, experienced differently by mothers and their children, can be seen as an parallel entity, linked to glucose control that also needs to be actively managed. The difference is that it is unspoken and nebulous, unlike the glucose levels that are tangible and measurable. It is a heavy burden to be alone in managing these dual dimensions of diabetes, and engenders anger and resentment if not shared, either with a husband or with the adolescent. Margaret (*interview1*) is angry and frustrated at Deon's continual inability to regulate his sugar. The burden of responsibility is carried by her alone. Her communication

with her son is sporadic and unsatisfactory. Her inability to work with him reaches a head, neatly captured in the account of his incarceration in the Camps Bay police station late one night. She loses her temper and refuses to be manipulated any longer.

Adele (interview3) has little confidence in her son to go into the world and look after himself. Her anger and frustration, compounded by disagreements with her husband, builds and occasionally erupts.

Anger is a consequence of unmitigated anxiety. The mothers resent their children or partners who have not helped to carry the load. Sheila (interview4) is angry with her daughter for not assuming responsibility commensurate with her age, and with medical staff and family members who aggravate the situation by blaming her for her daughter's poor control.

Short Summary

Anxiety and fear can be seen in these narratives as a third force behind the more tangible measures of glucose control and adolescent autonomy seeking. The more difficult the glucose levels are to control the harder for a parent to stand back and allow unhindered separation of their child. Attempts to control glucose levels entail greater parental involvement at a time when the adolescent should be developing greater autonomy. Frustration and anger can boil over, complicating the already problematic relationships with these adolescents, promoting a spiral of silence and mistrust. Mothers describe how divisions with their partners can creep into their relationships and drive a wedge between them whereas good control in the adolescent appears to have widespread positive effects on family function.

Chapter Five

Discussion and Conclusion

Limitations of this study

In this study I planned to interview a heterogeneous sample of mothers of adolescents with Type 1 diabetes. As it turned out participants were demographically similar with no opportunity to widen increase sample diversity. With the exception of one, all were Caucasian of middle or higher income brackets. African, rural, unmarried mothers and patients from other minorities were not represented.

Recruiting centres were given the entry criteria for the study and asked to help me with as diverse a sample as possible. In the process of participant selection the specialists and staff at Red Cross hospital may have selected people they thought would be more willing and available to be interviewed, thus selecting for those who were more gregarious, verbally expressive and interested in diabetes. This may have excluded those not able to travel to the interview, those whose language skills were poor or those whose level of education and interest was low. The result may have been a sample skewed towards that part of the studied population who are more verbal and more culturally and economically similar.

Access to participants was highly dependent on the co-operation of specialists and staff at Red Cross Hospital diabetic clinic. Response to my request for help recruiting participants for the trial met with varying degrees of interest and assistance, thus limiting access to certain populations.

This is a study of the mother's experiences and therefore it is their subjective opinions that are being studied. Nevertheless this does not prevent emergence of response bias; these mothers may have been influenced in ways that led them away from an accurate representation of their opinions and experiences.

Mothers may have been sensitive to the presumed value judgements of the researcher, a dynamic possibly compounded by his being a medical doctor. This may have influenced them to paint a rosier picture of their family than they truly felt or to give a more bio-medically orientated account. Conversely its also possible that speaking to a medical professional would put them more at ease facilitating an honest and psychologically transparent account.

Disclosing that I was an Insulin dependant diabetic may have also influenced participant response. An advantage is that mothers may have felt more comfortable with opening up to someone who understood the condition so intimately. Conversely, I would need to be aware of investigator bias as the result of any preconceived ideas borne from my close association with the subject. This possibility compelled me to reflect on my own circumstances, to try understand how my own particular subjectivity could influence me. While understanding that my aim was not to totally eradicate subjectivity, a deeper conscious awareness was a preferable state in which to ensure a greater validity in the study. The results of my reflections can be found in Chapter 7.

Correlation with the literature

Given the small sample size and the qualitative nature of the interviews, it is difficult to make direct comparisons but much of what was found in the interviews correlated with the current literature.

The areas of salience identified by the ISPAD consensus guidelines were clearly described in the interviews. (11) The difficulties managing glycaemic levels in adolescence compared to childhood was remarked on by most of the mothers. It was confirmed that the developmental challenges of adolescence including risk taking, independence seeking and managing their own diabetic control demanded a sustained dedication from the whole family, mothers in particular. Some of the mothers in the study experienced problems with continuity of care and interactions with providers, confirming the difficulties of complex management

involving large health care teams at a time when the adolescent is transiting to an adult service provider model. (7)(8)

Family style appeared to make a difference, with authoritative parents enjoying better overall glycaemic control and quality of life compared to authoritarian or permissive parents in the study. This conforms to Baumrind's widely validated predictions of parental efficacy. (32)(34)(35)(36) Actively involved mothers who set clear boundaries on the important issues and who were able to openly communicate in an environment of trust were more comfortable managing diabetes and found it easier to hand over responsibility to their children.

An authoritative family style also seemed to predict better control and better attitudes towards diabetes. These families were more structured but it was not possible to confirm if they were less cohesive or stimulating (40) Anxiety arising from autonomy related behaviours was usually directly related to conflict over adolescent responsibility, bearing out the reciprocal relationship between controlling behaviour and poor adolescent glycaemic control. (49)(50)(56) The narratives also supported the findings that greater discrepancies in perceptions of adolescent competence and independence were associated with poorer well being for mothers. (54)

In this study poor glycaemic control appeared to be associated with conflict, both between parent and child and between parents. This reflects the literatures position that conflict is more likely when glycaemic control is poor, though overall the literature does not conclude that the mere presence of Type 1 diabetes causes more conflict amongst parents. (51)(43)(44)

Though they were recruited specifically for this reason, it nevertheless held up that overwhelmingly, mothers provided the bulk of care for their diabetic adolescents, and fathers were much more peripherally involved. (51) In this study mothers appeared to bear most of the caregiver burden and the stress that goes with. It was often the mother who helped her spouse cope with the stresses of diagnosis and management.

Bronfenbrenner's ecological perspective on the many reciprocal ways in which diabetes affects adolescent development is born out by the rich descriptions of family life in this study. The mother's narratives gather the multiple interweaving elements of their microsystem in a naturalistic way, incorporating their home and school lives, their peer groups, social worlds, sporting endeavours, sibling interactions and family dynamics, amongst others. These are all integrated within the context of their social and cultural setting. The detailed exposition of their lives allows one to see a coherent picture of family life emerge. (32)(35)

Concluding Discussion

Mothers are the axis around which a family revolves and are the principal intermediary for care with the medical team. The findings from this study, strengthens the supposition that mothers' experiences and responses are of singular importance to the medical professionals who treat them.

These findings cast a bright light on the world inhabited by the women found deep in the trenches of family life with Type 1 diabetes. The mothers interviewed express a broad range of feelings, concerns, values, belief systems and ways of coping. What is clear is that diabetes in their families has wrought massive changes in each family member, the family as a unit and the mother in particular. The mothers in the study, drawing on the resources available to them, have responded in different ways. Some families appear to have adapted better than others, reporting less conflict, better quality of life, better family unity and successful attainment of adolescent developmental milestones. Others have struggled. An important task for the researcher is to define what separates these two groups and investigate that which can ultimately help.

It is difficult to underestimate the profound changes wrought to a mother's life by the advent of diabetes. Their needs can easily be neglected while dealing with the practical challenges of glycaemic management.

It is notable from these interviews how mothers juggled their own inner worlds with the needs of their families. Important emotions below the surface include anger, guilt, fear and anxiety, as well as the positive correlates of hope, pride and joy. Conflict over control and the handling of autonomy links these emotions, and fear of unwanted outcomes is at the epicentre.

In their emergent narratives mothers interweave their personal stories with those of their adolescent children. The success of this alignment has implications for diabetic management.

To further interpret and synthesize the stories told by the mothers of Type 1 diabetics I have adapted a perspective known as ‘narrative point of view’, which in fiction writing describes the narrator’s position to the story being told. In the case of these mothers it defines their direction and focus – around which the events they describe revolves. (60)(61)

There are those mothers who view their experience through the focal point of their child (externalising)² and those that view their experience with themselves as the focal point of the narrative. (internalising)

I do not posit these categories as polar dichotomies, but rather as ways of understanding the dominant position from which the voice of the narrator emerges. It gives useful information and is a potentially important port of entry into the worlds of mothers in the normal course of their clinical assessments when presenting their adolescent children for health checks.

Those that tend towards externalising have the following characteristics:

- Their child with diabetes is the central actor of their narrative.
- Descriptions of their own experiences tend to be closely associated with that of their child.

²My own nomenclature used to elaborate the “narrative point of view” mode of interpretation.

- They often describe wide and complex social networks of which their children are an integral part.
- The trajectory of the narrative is centred on their family and child adapting to the changes necessary in diabetes.
- The child is well integrated into their social milieu and generally takes responsibility for their diabetic control.
- Though there may be concerns about their child's current functioning, they tended to be anxious about future concerns.
- There is less focus on maternal affect.
- They display a highly detailed knowledge of the diabetic adolescent's life in terms of their dietary and insulin needs.

While those that are internalising have the following characteristics.

- They mostly talked about their own emotional states.
- The narrative is often heavily infused with strong emotions detailing their personal journey through their experience.
- The teenage child was more peripheral with less detailed descriptions of their lives, including diets and lifestyles.
- There was less talk about integration into complex social networks though they may describe either the absence of these or problems with them.
- Their concerns often relate to current problems rather than longer-term issues.
- They are more likely to be experiencing or recently experienced greater psychological stress.

The differentiation between externalising and internalising narratives pinpoints areas of conflict and struggle. It supplies clues about their resilience, quality of life, social function, level of involvement with their children and whether the mother is experiencing significant mental health morbidity.

The externalizing narratives tend to be more sociable, more networked, more extravert and gregarious, and more likely to be creating an environment where

the adolescent can be successfully integrated. This pattern can facilitate opportunities for both teenager and family to establish a strong identity.

The internalizing narrative with its focus on the mother signifies a departure from the trajectory of the adolescents' narrative, a disparity that may reflect underlying conflict, distress and poor glycaemic control. Particularly in early and middle adolescence the mother and child are usually on the same parallel path with the child pulling forward, a normative move to independence while the parent keeps a safe following distance behind. A distinctly different narrative on the part of the mother may give evidence to a breakdown of the partnership required to effectively manage the diabetes.

All members of a health care team will talk to mothers about their adolescents. The perspective described here could provide an accessible route to learn how aligned mother and teenage child are in their mutual quest for diabetic control.

The management of diabetes is a complex task requiring many members of a team to work in concert towards better outcomes. Traditionally this has been monitored in Hba1c measures, though more recently also in other measures of morbidity such as quality of life and mental health. This study contributes towards reconceptualising diabetes in adolescence as a social condition, both in the relational way described by those most intimately affected by it (62) and by virtue of the implicated social determinants of desirable health outcomes.

The mothers in the study experience diabetes in relational ways and employ relational strategies to overcome the challenges it poses. Maintaining a normal social identity, integrating into a peer group, achieving at school, being part of a nurturing family and even facilitating transfer of knowledge, be it from diabetic specialists or to ignorant peers entails negotiating social variables. Furthermore, it is the social assets they have at their disposal that helps predict how successfully a family handles the illness. In keeping with the extensive literature

on social determinants of health, variables of education, financial status, community support, occupational status and access to medical treatment all play their vital role. (63)

The metaphor of food is a consistent theme through the narratives and is a useful means to understanding the social cartography of a family. (64) Food carries social information about who is being served, when and how it is prepared, what it contains, who is eating together and how dangerous or safe the food is to the consumer. Food is a form of communication and an important interface between medical professionals and families managing diabetes. Communication about food can alert health professionals to important social information and act as a vector for teaching vital social skills.

These narratives suggest there is a complex matrix of causes contributing to better adolescent glycaemic control and family adaptation. The familial capacity for resilience and social capital are clearly beneficial and bears witness to prior research on resilience in families. (65)(66)(67) The study confirms the value of an authoritative family style but other more intrinsic, less modifiable factors are important too. Personality and comorbidity appear here to be important determinants in how adolescents respond to chronic disease. Certain personalities may be greater risk takers, be extraverted or introverted, more or less empathic, organized or disorganized, more or less requiring of peer validation. Personality appears to be an important determinant of healthy outcomes in chronic disease (68), but there is little work on how it pertains to diabetes in adolescence. (69)

Other illnesses, particularly those that may impair the capacity to integrate new information, such as learning disorders or attention deficit disorders can strongly determine an adolescent's ability to manage their diabetes. There is some suggestion that there is an association with Type 1 diabetes in children and lower

intellectual performance. (70) The complex interplay of diabetes and cognitive function in adolescence warrants further study.

This study also raises the possibility that gender may play a role in glycaemic control. Is there a difference between the genders in their diabetic management? The distinctive difference between a mother-son and mother-daughter relationship at this age, and the relative absence of the father in many instances may suggest there would be a difference. In this study most mothers had close relationships with their daughters, while those with their sons were more ambivalent. Research in this area suggests that health outcomes are worse amongst females compared to male adolescents, but more studies are required for greater clarity. (71)

The success of mothers in presenting a coherent account of managing their families was dependant on their ability to find framing narratives of meaning projecting a vision of hope, positivity, agency and control. In this study, a Christian orientation was closely associated with other indices of family health, supporting previous studies that correlate Religious practices with better health outcomes. (72)

The more successful explanatory narratives facilitated a means of understanding why their child had diabetes, and why the diabetes had happened to their family. An optimism bias characterised by *post hoc ergo procto hoc* thinking,³ though logically fallible, was widely used. Optimism bias is often associated with an underestimation of personal risk, (73) but in the case of these families it was linked with a proactive positive and affirming perspective that appeared to improve their health management strategies.

This raises the question of whether such approaches can or should be facilitated by medical teams. It was evident that many of the most powerful modes of healing lay outside the remit of medical management (community/spiritual/religious

³ Whereby a cause is assumed from co-existence of a proximal coincidence. (e.g. My daughter has diabetes because she is the one most suited of my children to get it.)

involvement). Nevertheless close attention to the component qualities of resilience rather than a “what’s broken” pathology orientated approach may be helpful when preparing families to thrive under adverse conditions.

What seems clear is that each adolescent-family unit bring unique characteristics to an illness that exerts a set of familiar behavioural and management challenges. A more finely tuned understanding of the interaction of co-morbidity, personality and gender would help to identify which families and adolescents are requiring intervention. Further research is also required to define more clearly what social markers could be used to identify families at most risk, as well as which skills and tools could be usefully employed in facilitating the important role of providing leadership and team building within the family. Further research could help elucidate the role played by discrete factors including school achievement, social integration, peer acceptance, bullying, sport participation, prayer or belief in a higher entity.

This particular study looked at the mothers of adolescents with Type 1 diabetes. Families would also benefit from similar studies on the experiences of fathers and siblings. Although an authoritative parenting style appeared optimal, different adolescent characteristics may call for different responses. This fine-tuning that recognizes variability amongst teenage characteristics would benefit from further study.

This study served to highlight and interrogate the complex explanatory worlds of mothers looking after adolescents with Type 1 diabetes. Mothers are the centre of a complex range of social interactions and usually provide the leadership and team building necessary for the management of diabetes within the family. This study contributes by furthering our understanding of how they provide a meaningful explanatory system by which to explain the illness, take measures to integrate their child into their family, school and wider society, and negotiate the anxiety that comes with helping their teenage children navigate towards independent self-care as they prepare for adulthood.

Chapter Six

Personal Reflections

I feel it is important to reflect a little on how my own experiences with diabetes have intersected with this study. It is ultimately through the lens of our subjectivity that we interact with the world. I considered it important for me to confront my own history and spend some time interrogating both how my background influenced my approach to this study and how the study impacted on me.

I only contracted diabetes in my early 30's so was not a diabetic during my adolescence. I was however the sibling of a younger brother (by three years) who developed Type I diabetes (IDDM) when he was thirteen years old, a father who developed IDDM in his early 30's and an uncle (maternal) also with IDDM from his early teens. Diabetes, you could say, was a family business. We were all Type I diabetics – in our minds, the best possible kind. We were the elites of the diabetic world. Struck young by a clean immunological salvo without the messiness of the metabolic syndrome, high blood pressure and sagging pendulous bellies. It was fated that I too would develop this condition and so when my day came I accepted it with calm resignation; the pursuing cloud had finally emptied its load. So now all the males in the family had diabetes. If you were not a diabetic at our dinner table you had every right to feel marginalised.

My father was first diagnosed in his thirtieth year when I was five years old. I have a memory of him lying in a dim room for several days and then I developed nightmares. It was only much later that my mother told me about what they thought caused those nightmares – I thought he was going to die. But he didn't. He got well and remained strong and stoical. He injected with big harpoon like needles that required sterilisation every day, archaic instruments by the standards of today's micro-fine disposable needles that barely cleave the skin as they deliver their subcutaneous load. I now have them box-framed in my study.

Throughout, my father, brother and uncle have proved shining examples of how to overcome diabetes and lead busy and active lives. But it was impossible as an adolescent to escape the changes wrought on our family by my brother's diagnosis. It was a difficult time for my parents as they each struggled in their own way to come to

terms with it. My mother bore the brunt of organizing and co-ordinating my brother Russell's care and dealing with the challenges of fluctuating glucose levels during his teenage years. The vast majority of what they went through passed over my own fuzzy teenage radar. I was too busy growing up myself, but as the years passed, it was with a little more clarity that I could come to understand their ordeal. How they had to pro-actively co-ordinate care, support my brother, retain hope and encouragement and not succumb when things were not working out.

I learnt later that my brother would question my mother as to why it was him and not me who had the diabetes. For my part, I remember feeling awful for him but was not entirely sure why. I tried to inject in sympathy. I still remember the sticking clicking sound as I spread rather than pinched the skin to slide the unfamiliar needle in.

But I had my own adolescent preoccupations as my brother endured his struggles, getting immeasurable support from my parents, my mother in particular and an invaluable camaraderie with a friend of his own age at school who also had diabetes. The Diabetes Association, doctors, nurses, researchers and family all pitched in. He continues to be slim, fit and disciplined, more so than myself at times when it comes to eating the right things. We recently celebrated the birth of his first child, a little boy. A proud moment.

There is something about living with a chronic disease that blinds you to its ultimate implications. You live with it all the time so it becomes camouflaged into everyday life. You don't want to think of the negative effects, difference between you and a non-diabetic, the added hassle factor - there is a strong will to normalise experiences. This has been helped for me by having a family who integrated diabetes, seldom complained, lived productive lives and so provided an exemplary template for me. Not everyone is so fortunate.

So it is clear that I have lived through many aspects of diabetes - as a family member, brother and son. With this comes a natural empathy for the families who have the challenge of looking after an adolescent with diabetes. It takes dealing with the everyday practicalities of living with diabetes to understand what it is like for others to live with the parallel life of monitoring, controlling and remaining in touch with that

which others take for granted. The struggles and on-going challenges of integrating diabetes into everyday life are made invisible by everyday routines, but they are not insignificant.

I initially wanted to undertake research on the adolescents themselves. Before I had started the study, I spoke to Dr Arreti Philotheou, who had worked with adolescents at Red Cross for many years. She suggested an alternative - speaking to the mothers. It was an important but neglected area of research. I thought this was an excellent idea.

My experience with diabetes would have invariably affected how I approached the mothers I interviewed. I had not spoken recently to my own mother about her recollection of my brother's adolescent years from over 25 years ago and chose to discuss it once the study was complete. I didn't want her story to overshadow that of the respondents. She shared how difficult her experience was and how she mourned for 6 months, also how guilty she felt, somehow irrationally, that she was responsible for it happening. But, she coped and did everything she could. The study shone a new light on me on the courage of these mothers, mine included, in the face of this unremitting adversity.

Besides the wish to understand further a condition that has had such a mark on my family, I was also interested quite specifically in the general dynamics in families and the lives of adolescents.

Families are like islands unto themselves. There is something slightly mysterious about how they work, how they cohere together. I was curious, like an explorer of new lands, wondering at their organisation, structures and modes of communication. Similarly, I had an interest in the lives of adolescents, an area that as family physicians we receive little training in and are often challenged by in clinical practice. I wanted to learn more. This curiosity culminated in a study that also satisfied a fundamental interest in human stories with the subject matter of mothers, families, adolescents and diabetes

When it came to the interviews I was repeatedly surprised by the mother's responses. Each case was unique, each family set apart from any other. I tried to put aside

conscious pre-conceived ideas arising from my own experiences and was wary of projection. I didn't want any focus on myself. Nevertheless I agreed to share some of my story if the mothers interviewed asked directly. They were reassured, and I think opened up more easily knowing I too had experienced what it was like to live with the condition.

How did the interviews affect me? I engaged intensely with the interviews of these mothers during the different phases of the study, hearing their voices, listening carefully to their words and thinking about their stories. I was filled with admiration for their selflessness and resilience, their sheer maternal tenacity in coping with the grubby realities of diabetes in the real world. I was impressed by their emotional frankness and their deep commitment to family.

I have come away with a renewed sympathy for the unique challenges posed to these families and how they meet them with persistence and creative resilience. I was also struck by how diabetes is ultimately secondary in importance to the values, circumstances, strokes of fate and fortune, personalities and unique family characteristics that determines how things turn out. In this way, diabetes is like any other obstacle that happens to confront a family.

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PROPOSAL

A Study of the Explanatory Models utilized by mothers of adolescents with Type I diabetes.

A Proposal for dissertation thesis to complete MFamMed.
Department of Family Medicine and Primary Care.
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Table of Contents (for Protocol)

Title.....	1
Synopsis.....	3
Literature Review.....	4
Research Question.....	7
Background.....	7
Hypothesis and Motivation.....	7
Aims and Objectives.....	8
Methodology.....	9
Study Design and Study Population.....	9
Sampling Method.....	9
Exclusion/Inclusion criteria.....	9
Pilot Study.....	10
Instrument.....	10
Data Collection and Management.....	10
Data Analysis.....	10
Ethical Considerations.....	11
Proposed Budget.....	12
Timetable.....	12
Bibliography.....	13
 <i>Appendix II</i>	
McGill illness interview Schedule (see at end of this document.)	
 <i>Appendix III</i>	
Short note on the McGill Illness interview schedule (see appendix at end of document)	
 <i>Appendix VI</i>	
Consent for participation in the research Study (see appendix at end of document)	

Synopsis

Type 1 diabetes is a common adolescent endocrine problem, and set to increase globally. It occupies an awkward place between paediatric and adult medicine, such that both provision of care and research are in short supply.

Adolescence is marked by transition and turbulence along physical, psychological, social, academic and geographical domains. This makes it especially hard to manage chronic illnesses, of which Type I diabetes presents particular challenges.

A developmental approach that takes into account the rapid life changes, and particular challenges facing adolescents, within the context of a multidisciplinary team (including the parents) is best suited for optimal care.

Diabetic control in young adolescents is correlated strongly with psychosocial context, and this in turn places a burden on the primary caregivers, usually the parents, who are intimately tied in with the management of all aspects of care.

The role of parents thus remains very important notwithstanding the increasing autonomy claims of young adults. It is a pivotal aspect of care that the health team have good relationships with parents, and understand the context of care in which adolescent diabetics find themselves.

Explanatory models have been utilised in an attempt to gain access to the rich substrata of beliefs, ideas, and knowledge held by patients and their carers with regards to the illnesses they manage.

The McGill Illness Narrative Interview schedule is a useful method of gaining access to the explanatory systems that underpin those encountering illness and disease.

A qualitative study on the experiences of mothers of Type I adolescent diabetics, is undertaken with the aims of deepening our understanding of their beliefs, knowledge and attitudes surrounding this complex illness.

Literature Review

Epidemiology

Type I diabetes is one of the most common endocrine and metabolic conditions in childhood and adolescence and is rapidly increasing around the world, with an overall annual incidence of 3%. (1) Globally it is estimated that 480 000 children under the age of 15 have type I diabetes with 78 000 new cases every year. If present trends continue, it is estimated that there will be a doubling of new cases in Europe by 2020. (2) Data for the rest of the world and in particular the developing world, South Africa included is difficult to obtain. (1)

Recognition of importance of adolescent diabetes (short statement of fact)

The needs of adolescents with Type I diabetes have historically been ignored. (3) Adolescence is a critical period when long term health trajectories are established and when early signs of diabetic complications can first manifest. Intensive glycaemic control has a considerable impact on morbidity and mortality. (4)(5) Adolescents with Type I diabetes must confront unique challenges in their efforts to achieve adherence and glycaemic control during a time of rapid developmental change when carers are striving to encourage independence and self-management. These have recently been recognised and prioritised. (6)(7)(8)(10) Careful guidelines for care have been specifically laid out for this particular patient group. (9) The updated ISPAD Consensus Guidelines 2009 recognises the profound importance of the psychosocial milieu in providing care for the adolescent with Type I diabetes. (10)

Adolescent development demands

Adolescence is a transitional developmental period between childhood and adulthood characterized by profound biological, psychological and social role change. (11)(9) Cognitive changes occur such that the young adolescent transits from a pattern of “concrete thinking” to a more adult perspective that incorporates time perspectives and consequences of actions. (10) Normal developmental tasks include managing bodily changes, emerging sexuality and negotiating intimate relationships. A striving for a strong self-identity sets them apart from their family of origin while promoting bonds within their peer group. It is a period of heightened self-awareness and involvement, with a fear of failure alternating with a sense of high self-expectation. The emotional world of the adolescent is often characterised by feelings of alienation, accompanied by close scrutiny of inner experience. A sense of feeling invulnerable may predominate, leading to a rejection of parental control or authority that discounts potential risks to their future health and potentially complicate management of a chronic illness. (12) Academic demands, geographic moves, career decisions and financial stressors all potentially distract from the close attention required to treat a chronic illness. (13)

The demands of diabetes on the adolescent

In order to manage Type I diabetes the adolescent must watch what they eat, how they exercise, and must carefully monitor their glucose levels and administer a complex regime of medication; usually insulin. (14) In addition they must integrate the short-term problems of hypoglycaemia with the longer-term complications of poor glycaemic control. (15) All this is over and above normal age appropriate adolescent developmental tasks. These requirements can have a significant effect on their normal developmental progress to autonomous adulthood, because while their moves towards independence, including risk-taking, may be peer-congruent, they may be at odds with the requirements for good glycaemic control. (10)(31) The requirement for good control and the hyper-vigilance of their parents give them fewer options to rebel. (16) Evidence suggests that as the older adolescent assumes greater autonomy for diabetic self-care, glycaemia control worsens. (17)(18)

Numerous other factors come into play. (32) Physical changes include hormonal fluctuations, the insulin resistance of puberty, diet variation, growth spurts, and physical exertion. Insulin requirements therefore fluctuate. In addition, peer pressure and risk taking may expose the adolescent to sexually transmitted diseases, inappropriate dietary choices, and substance misuse. Emotional and behavioural problems are more frequent in adolescents with diabetes (19)(20), with almost double the frequency of anorexia nervosa in females. Binge eating, and manipulation of insulin doses to control weight is particularly common. (21)

Structural problems exist within the framework of care for diabetic adolescents. (7)(8) Medical care of the adolescent is often neglected, as it falls outside the framework of both Adult Medicine and traditional Paediatric care. Adolescent care services, sensitive to its unique developmental and transitional context are often non-existent or poorly developed, with profound implications for clinic follow up and adherence to complex management regimes. Efforts to heighten awareness, formulate policy and construct guidelines attempt to rectify this situation. (3)(6)(10)

The family and Adolescent diabetes

Family context is integral to the management and care of the adolescent diabetic. It is within the crucible of the family that the young adolescent negotiates their autonomy and assumes greater responsibility for their self-care as they enter into late adolescence and early adulthood. Psychosocial factors play a significant role in the family management of diabetes. (20)(22). The dynamic between family and diabetes is bilateral and reciprocal. Considerable demands are placed on the family in caring for a child with a chronic illness. Compared to families with healthy adolescents, families caring for an adolescent with diabetes portray their interactions as more structured, and less cohesive and stimulating. (23) Care-giving burden can be significant and impact on the mental health of parents. Parental psychological distress including maternal anxiety has adverse implications for adolescent glycaemic control. (24)(25) Parental over-involvement

with care has the potential to antagonize autonomy-seeking adolescents and foster conflict within the family. (33)

However, constructive family function characterized by a high degree of cohesion, flexibility and organization is associated with better glycaemic control and well-adjusted adolescent disease management. (26)(27)(23) Ideally a parenting style that incorporates an authoritative style, with high levels of receptivity and high demands for mature behaviour within a warm caring environment appear best suited to treat any chronic disease. (30) An involved relationship that fosters self-sufficiency has positive effects on adherence and metabolic control. (28)(29)

Summing up.

The adolescent is best seen as part of the greater family system, in which the bulk of day-to-day care occurs. Care of the adolescent with Type I diabetes places high demands both on the adolescent and their families with the capacity to stress and deregulate family systems. Psychosocial factors are pivotal in not only managing metabolic control but also in determining healthy family function and quality of life. This compels health workers who treat diabetic adolescents to comprehensively understand the families they work with. While there has been much research into the psychosocial aspects of adolescents with type I diabetes, there is far less on the way that families and specifically, parents experience this chronic illness in family life.

The aim of this study is to gain further understanding of how families, specifically mothers, make sense, and incorporate their experiences into their broader comprehension of how Type I diabetes has affected themselves and their families.

Research Question.

What are Mothers' perceptions of the impact of Type I diabetes on their adolescent Diabetic children and on their families?

Sub-questions:

1. What are mother's ideas and beliefs about the origin, effect and consequences of type I Diabetes on their adolescent child?
2. What are their ideas and beliefs about the impact of type I Diabetes on the family?
3. What perceptions do they have with regards the impact that diabetes has had on the developmental challenges facing their Diabetic Adolescent children?
4. How do mothers perceive the impact of their family on the management of their diabetic child?

Background

Adolescent Diabetes is important, on the rise, and a common endocrine illness. Diabetes in the adolescent provides a range of unique and difficult to manage problems by virtue of the particular challenges that face adolescents.

Medical services seem ill prepared for the challenges faced by this patient group. The complicated management regime necessary for glycaemic control has far ranging and potentially adverse psychosocial effects on the adolescent and the family, which in turn exert further stress on the family structure, with ever worsening metabolic consequences for the child. In short, adolescent diabetes challenges the integrity of healthy families, places high demands on them, with the potential for a wide range of psychosocial adverse consequences.

Hypothesis / Motivation

Diabetes can interfere with the normal functioning of a family, requiring them to consistently balance and consider the threat of the illness to their children.

Health care workers involved with adolescent care would benefit from an in-depth understanding of the ideas and belief systems that could potentially influence behaviours, such as management adherence, health seeking and the pursuit of healthy lifestyles within the context of the family and the developmental nature of adolescence.

The **direct** motivations are therefore to contribute to an improvement in the quality of care of the adolescent and their family, and thus add to the body of research, which indirectly may improve indices of glycaemic control.

In addition, behavioural interventions are increasingly being used to help families to deal with the psychosocial stressors within families. This information would

help to further guide development of such interventions, and help to formulate areas which could be studied further in a more focused way.

On a more **exploratory** level, the aim is to delve into the world of the family as experienced through the eyes of the parent, specifically the mother, in order to reveal the world-view of that family and explore the belief systems that underpin it.

On a more **humanistic** level, the study of narrative and explanatory systems allows a direct window into the world of families dealing with diabetes in their own words rather than the dominating discourse of management strategies, glycaemic control indices and outcome measurements.

Aims and Objectives

By fulfilling its objective of describing and analysing the experiences of the selected mothers, the study aims to contribute to a deeper understanding of the role diabetes plays in the life of families and developing adolescents. The twin guiding assumptions through the study is that the family is the central unit in which adolescent diabetes is managed, and that the transitional, developmental nature of adolescence is pivotal in defining the dynamic that occurs between family members.

Methodology

Study Design and Study Population

- Semi-Structured interview comprising of two separate one-hour contacts.
- One reason for splitting the interviews is to sensitize the interviewees over time to the subject material, and to facilitate a trusting environment with the interviewer.
- The first interview would aim to open discussion with a very non-structured approach, and with as few prompts as possible utilizing the first half of the interview schedule.
- The second interview will benefit from the time lapse, hopefully during which time subjects reflect and deepen their thoughts about the topics under discussion. Issues brought up on discussion during the first interview can be developed and deepened during the second.
- Interviews will be one-on-one with mothers of adolescents with type I diabetes.
- The mothers would not be interviewed in the presence of their partners or children.
- Interviews would occur at the convenience of the subjects at their own homes, at the hospital or at the diabetic clinic.

Sampling Method

- Purposive sampling method to maximize variation. Subjects should therefore range widely in socio-economic status, geography and cultural backgrounds. Paediatricians and Endocrinologists would be asked to select patients who could speak English, and these patients would then be approached telephonically, and asked if they were willing to volunteer to be part of the study.
- A limitation is that non-English speakers would be excluded from the study, and therefore contributes to selection bias.

Inclusion criteria

- Mothers should be the primary care giver in their family. Their adolescent should have received a diagnosis at least 2 years ago so that there has been some time to stabilize management and form a broadly based experiential perception.
- Mothers should be able fully understand the nature of the investigation and have the capacity to give consent.
- At the time of the interview their children should be between ages of 15 and 22. The experiences of developmental change in mid to late adolescence should be fresh in their minds.
- The adolescents should have been given the diagnosis of diabetes before the age of 15, so that mothers are able to comment on the transition through mid to late adolescence.

- A maximum number of 8 patients would be interviewed, or until saturation of subject matter occurred.
- It will be fully explained that though the investigator is a medical doctor, he is interviewing in his capacity as investigator, with no mandate for a clinical intervention.

Exclusion Criteria

- The adolescent of the mothers interviewed as a significant physical or mental co-morbidity besides Diabetes.
- Mothers for whom the investigator was the primary health care provider

Pilot Study

- The interview schedule would be discussed with a specialist in the area of Adolescent Diabetes. The questions and approach clarified and made suitable for the studied population group.
- The pilot study with a representative mother of an adolescent diabetic would aim towards reviewing the interview schedule, checking for coherence, comprehensibility, time feasibility and appropriateness of questions.

Instruments

- The McGill Illness Narrative interview is a tool developed to carry out cross-cultural analyses of Illness Explanatory models. It draws heavily on the pioneering work of Kleinman (34), Mishler and Weiss (35) in this field. It departs in trying to assess the non-linear ways in which patients connect their associations, and thus form their ideas about disease.
- Further information on the McGill Illness Narrative Questionnaire is given in the appendix.
- The Structure of the McGill Questionnaire is loosely retained, and made appropriate to the study question with appropriate changes. These changes reflect an underlying interest in the themes of how adolescent developmental challenges affect their diabetes, and how families and their diabetic adolescents reciprocally influence each other.
- The questionnaire is used as a guide to a more open discussion, rather than a rigid instrument that will demand specific answers in a question and answer format.

Data Collection and Management

All interviews will be digitally recorded and then transcribed. Files would be coded and stored on the hard-drive of the investigator. The investigator and the transcriber would be the only people to handle the original interview files. The transcriber is a professional transcriber, who is trained in the area of confidentiality and information management.

Data Analysis

Thematic Analysis will be the analytic method of use. (36) Though this method is thought by some to be a non-specific method used across more particular theoretical approaches, I prefer to take the open approach, that acknowledges its flexibility, and sees it as relatively free of one any one narrow approach (e.g. grounded theory, discourse analysis or narrative analysis)

In keeping with the process of Thematic Analysis, once transcribed, the data corpus will be divided into data sets, and systematically coded collating the data relevant to each code. These codes will then be grouped into potential themes, and expanded into relevant subthemes, before a 'thematic map' of the data set can be generated. The analysis will draw on the implicit understanding that the data is a narrative that represents a narrative that constitutes an explanatory system organizing the integration of diabetes into the family and the life of the adolescent.

Ethics Considerations

A comprehensive consent form (see appendix VI) will explain the study in full to the research subject.

Participants will be deemed to have the capacity to give consent for the study by both the paediatric endocrinologist and the investigator prior to their being successfully enrolled in the study.

The consent form will cover the following topics.

- The purpose of the study.
- The method and process
- The potential risks and discomforts to the patient.
- The potential benefits to the subject and to society.
- Dispersal of research results.
- Reimbursement
- Confidentiality
- Opportunities to withdraw from the study
- Important contact information.

Confidentiality will be particularly stressed, with a full description of how information will be disseminated, who will be exposed to it, and how anonymity will be ensured.

It will be carefully explained that the investigator, though a medical doctor, will be functioning purely in his role as researcher and not be taking any responsibility for clinical care. Any important issues regarding medical management will be communicated directly to the referring Paediatric Endocrinologist.

In the event of the subject showing mental distress during the interview, the interview will be stopped, with the appropriate steps taken to calm and contain

the subject. If the distress is significant enough, a friend or close relative would be contacted, and a referral made to the subjects' primary care doctor.

If there is any sign of Child Abuse, this will be discussed with the referring medical facility, and networks appropriate to the area where the patient is living will be activated.

During the study and its writing up, supervisors to the researcher will have direct contact with all aspects of the process. Thereafter, on completion, every effort will be made to disseminate the results to those most likely to benefit. These will include doctors, nurses, diabetic educators, diabetic adolescents and their families. This could take the form of direct communication, educational talks or published material both in lay, and professional journals.

Proposed Budget

Costs will include the following.

Time taken off from Clinical work of the investigator.

Transport costs to the subject's homes.

Cost of professional transcription:

There is no finance available to pay subjects for their transport. The Interviewer will endeavour to either interview at hospital or clinic environments where the subjects would be anyway, or at their homes, at their convenience.

Total amount: Approximately: R5000

Timetable

<u>June & July</u>	(Proposal is passed by UCT ethics committee)
<u>July</u>	(recruitment and beginning of interviews)
<u>August</u>	(Interviews and transcription completed. Commence Analysis)
<u>September & October</u>	(Thematic analysis complete)
<u>November & December</u>	(Review and completion of Writing up)

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Appendix II

Adapted McGill Illness Narrative Interview (MINI)

Section 1. Initial Illness Narrative

Could you tell me the story of your child's illness from the very beginning?

How did you first know there was a problem?

Could you tell me more about your experiences?

What happened when the diagnosis was made?

What happened after that...?

Did you seek help? Who did you see?

What was most useful in helping you during this time?

If you saw a medical doctor, can you tell me about it, and what happened after?

Did you have tests, how was that experience?

What treatments were there?

Section 2. Prototype Narrative

Has anything similar, or comparable to the Diabetes happened in the past to your family?

In what way would that past health problem be similar or different from the Diabetes?

Has anybody you have known ever experienced a similar health problem?

Have you had contact through television, magazines, radio, books, with anyone who had a similar condition?

How is your condition different from this?

Has there ever been an event in the family that has been similar to this?

Section 3. Explanatory Model Narrative

Have you had any thoughts after our last meeting?

Is there anything you would like to add?

Do you have any other term or expression in the family that describes the diabetes?

What do you think caused the diabetes in your child?

Are there any other causes that you think may have played a role?

Why did the diabetes start when it did?

What happened inside the child's body to explain the diabetes?

Is there something in your family, or your work, or in your social life that could explain the diabetes?

What do you think happens to people who have diabetes?

How do you think people react to your child because of the diabetes?

Who else do you know that has diabetes, how is your child's diabetes different?

Section 4. Impact on Life

How has the diabetes changed the way you think about yourself as a parent/mother?

How has it made you change the way you think about life in general?

What has helped you most during this time?

How have your friends and family related to you during this time?

Has any type of belief or activities helped you through this period in your life?

What do you think is the role of the parent in looking after the adolescent diabetic?

How has the diabetes in the family changed the way you live...and as a family?

What positive effects has the experience had on you?

What negative effects has the experience had?

What are your fears for your child?

How do you think their diabetes affected their adolescence?

School

Peers

Sport

Academic

Development

Intimate relations

What have been the biggest obstacles in having a child with diabetes?

Appendix III

Short note on the McGill Illness Narrative Interview

The McGill Illness Narrative Interview is a semi-structured qualitative interview schedule designed by a team of clinicians and researchers from McGill University, (with Anthropology, Social work, Medical and Mental Health backgrounds) to elicit Illness narratives in Health Research.

It was initially developed to explore individuals' illness experience in a study examining health-seeking behaviour and use of mental health services amongst those with medically unexplained symptoms in Ethiopia, and primary care settings in Israel. It was subsequently adapted to be used in a variety of medical environments, including after care of myocardial infarction, Hyperemesis Gravidarum and breast-feeding.

Its theoretical basis is organized around an understanding that lay accounts of illness experience are not formed in logical and coherent schemas of causal attribution, and are rather multi-representational, complex and often internally inconsistent and contradictory. Its design therefore seeks to understand illness experience as it is related in lay accounts by concentrating on three distinct types of cognitive reasoning used in representations of symptoms or illness.

Explanatory Model: A basic narrative of symptoms and illness experience organized along temporally contiguous events, with associations that are overtly and clearly causal in nature.

Prototypes: Reflect core associative domains, defined by previous experiences, those of family members or friends, the mass media or popular representations.

Chain-complexes: These are ways in which explanatory models held by a person will link salient elements of the narrative together, and may include causal attributions, expectations, or value systems. These are often outside of awareness.

The MINI (McGill Illness Narrative Schedule) is an instrument which has been subjected to close scrutiny, gone through a number of iterations and been used in a wide variety of medical contexts. It is explicitly aimed for use in multi-cultural environments, and is designed to capture the complex way in which cognitive organization of illness influences peoples' narrative of their experience.

On a most basic level these are factors salient to my study, but my primary aim is to elicit the experiences of Mothers, not to specifically analyse them according to the cognitive constructs reflected in the MINI. Nevertheless the structure is very useful in fulfilling my aims and I have thus modified the questionnaire accordingly.

Modifications made include the following.

1. Time: I have compressed the questions to allow for more time for the open-ended elements of subjects response. Questions that are repetitious are pruned down.
2. Applicability: Semi-structured questions are adjusted to focus on the subject of the study.
3. The section of the interview schedule focusing on health seeking behaviours is omitted.
4. An additional area examining the impact of diabetes on Adolescent life was included in my questionnaire.

Organising topics utilised in thematic analysis.

A. Explanatory systems

- a. Predisposing factors to risk of diabetes
- b. Theories of causation.
- c. Maternal philosophy or values guiding her life.

B. Effect on the Family

- a. *Chaos and Change*
 - i. Adapting to new reality
 - ii. Diet changes
- b. *Social Management relative to others.*
 - i. Exclusion from other families
 - ii. Inclusion/acceptance
 - iii. Being a normal family
- c. *Framing of the effect on the family*
 - i. Positive
 - ii. Negative
 - iii. Financial
 - iv. Advice to other families.
- d. *Siblings*
- e. *Husband*
- f. *Parental/family style*
- g. *Comorbidity in the family/adolescent*
- h. *Family Conflict*

C. Control - Glycaemic

- a. Responsibility
 - i. Irresponsible
 - ii. Responsible
 - iii. Blame and guilt
 - iv. Importance of transferring Responsibility
- b. Technology
 - i. Testing/values
 - ii. Injecting
 - iii. Pump

D. Adolescent Milestones

- a. Peer relationships
- b. Rebellious/Acquiescent/quest for independence
- c. Camps and Outings
- d. Stigma/social

- e. Identity
- f. Risk Taking
- g. Career, ambitions, future planning.
- h. Relationship with food.
- i. Role of Sport

E. Fear

- a. Hypo-glycaemic attacks
- b. Practical fears (what to do?)
- c. Managing own and others fears
- d. Fears of future
- e. Thoughts of death

F. Mother – Child Relationship

- a. Communication/connection
- b. Expression of opinion/emotion about diabetic child
- c. Characterization of child (description – non value laden)
- d. Fostering independence balancing dependence.
- e. Proactivity in Action/Involvement of the mother
- f. Resilience of mother in the face of difficulties

G. Sources of Support

- a. Doctors and other medical personal
- b. Hospitals
- c. Nurses
- d. Friends
- e. School
- f. Media or Internet
- g. Support groups

Appendix V

Ethics Approval : University of Cape Town Ethics Committee.



UNIVERSITY OF CAPE TOWN

Health Sciences Faculty
Faculty of Health Sciences Research Ethics Committee
Room E52-24 Groote Schuur Hospital Old Main Building
Observatory 7925
Telephone [021] 406 6338 • Facsimile [021] 406 6411
e-mail: sumayah.ariefdien@uct.ac.za

18 August 2011

HREC REF: 326/2011

Dr A Smith
School of Public Health & Family Medicine
Falmouth Building
FHS

Dear Dr Smith

PROJECT TITLE: A STUDY OF THE EXPLANATORY MODELS UTILIZED BY MOTHERS OF ADOLESCENTS WITH TYPE 1 DIABETES.

Thank you for addressing the queries raised by the HREC.

It is a pleasure to inform you that the Ethics Committee has **formally approved** the above-mentioned study.

Approval is granted for one year till the 28 August 2012.

Please submit a progress form, using the standardised Annual Report Form (FHS016), if the study continues beyond the approval period. Please submit a Standard Closure form (FHS010) if the study is completed within the approval period.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please quote the REC. REF in all your correspondence.

Yours sincerely

Signed by candidate

PROFESSOR M BLOCKMAN
CHAIRPERSON, HSF HUMAN ETHICS

Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938

sAriefdien

Appendix VI.

Consent form

University of Cape Town
CONSENT TO PARTICIPATE IN RESEARCH

A Study of the Explanatory Models utilized by Mothers of Adolescents with Type I Diabetes.

You are being asked to participate in a research study conducted by Dr. Anthony Smith in completion of his Masters degree in Family Medicine at the University of Cape Town. The study investigates the experiences of mothers of adolescents who have Type 1 Diabetes. You have been selected because you fit into the particular group involved in this study.

Purpose of the study:

The purpose is to understand what mothers of Adolescents with diabetes believe about the illness affects their child and family. It is thought that with a better understanding health workers can provide better care to Adolescents and their families.

Procedures

If you agree to volunteer to participate in this study, you will be asked to do the following:

The investigator will interview the subject on two separate occasions for a total of one hour each time. The interview will be a combination of long and short questions. The interview will be audiotaped, so that a detailed study can be made later on. The interviews are structured like this so that you have a chance to think about some of the questions between the two interviews.

Potential Risks and Discomforts

There are no clear risks in this study, though it may be uncomfortable to talk about certain subjects because they may relate to areas that are sensitive or are of an emotional nature. You will only be asked to share that with which you are comfortable.

The interviewer appreciates and will endeavour to respect your time.

Potential benefits to subjects and/or society:

There are no direct benefits to you in volunteering for this study. However, in the longer run, and indirectly, there will be benefits to those families and adolescents

who must cope with diabetes. Possible benefits include a better understanding of the subject for health care workers who care for them. Though the investigator is a medical doctor, the aim of the interview is to collect information for research, rather than to treat problems.

Dispersal of Study Findings:

The results of the study will be communicated to you if you wish. Others who would see the results would include those examining the thesis and those who are involved in providing health care for diabetic adolescents. Information may be published in a medical journal.

Payment for participation

There is no specific payment for participation in the study.

Confidentiality

Any information that you give will remain confidential and you will remain unidentified throughout. Any identifying information will be removed. The primary interviews will be available to the primary interviewer and a professional transcriber only. This holds true for any written or oral presentation of the study material.

Participation and withdrawal

You can choose to volunteer in this study or not. If you have volunteered, you may withdraw at any time of your choosing. You retain the right to not answer any question that you find disagreeable or unacceptable.

Identification of the investigator

Dr Anthony Craig Smith
501 The Regent
19-33 Regent Road
Sea Point
8005
(021) 4347755
0824684569
ant_tony@mweb.co.za

Rights of research subjects

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact the Research Office at the Faculty of Health Sciences at the University of Cape Town at 021 650 4015.

SIGNATURE OF RESEARCH SUBJECT OR LEGAL REPRESENTATIVE.

The information above was described to me by _____ in English and I am in command of this language or it was satisfactorily translated to me. I was given the opportunity to ask questions and these questions were answered to *my* satisfaction.

I hereby consent voluntarily to participate in this study. I have been given a copy of this form.

Name of Subject/Participant

Signature of Subject/Participant or Legal Representative

Date

SIGNATURE OF INVESTIGATOR

I declare that I explained the information given in this document to _____ [*name of the subject/participant*]. [*He/she*] was encouraged and given ample time to ask me any questions. This conversation was conducted in [*Afrikaans/*English/*Xhosa/*Other*] and [*no translator was used/this conversation was translated into*

_____ by _____].

Signature of Investigator

Date