

Parenting Children Living with Type 1 Diabetes: A Qualitative Study

by

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Abstract

This qualitative descriptive study explores a parent's sense of meaning and understanding in relation to the parenting of their children who are living with type 1 diabetes. A collective case study design was used and ten interviews were conducted with parents of children living with type 1 diabetes. Recruitment took place through the Winnipeg Diabetes Education and Resource for Children and Adolescents and the Juvenile Diabetes Research Foundation. Nine categories are identified using qualitative content analysis and are interpreted according to an ecological framework (Bronfenbrenner, 1979). Data was triangulated through references to field notes and to the existing literature in this area. Implications regarding training and education for children and families have been discussed.

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Parenting Children Living with Type 1 Diabetes: A Qualitative Study

CHAPTER I**Statement of the Problem**

The aim of this qualitative descriptive study was to explore a parent's sense of meaning and understanding in relation to the parenting of their children who are living with type 1 diabetes. Since little is known about the parental sense of meaning related to parenting a child living with type 1 diabetes, this study will contribute important new data on this topic. A better understanding of how the parental sense of meaning and understanding might impact parental decisions regarding care and how they might promote positive approaches to diabetes management can be useful for program planning and development. The aim of this study is, therefore, to understand a parent's sense of meaning and understanding in relation to the parenting of their children who are living with type 1 diabetes and how this might impact parental decisions regarding care as well as future program planning and development.

Key questions include:

- 1) What is the parental sense of meaning and understanding in relation to the parenting of their children living with type 1 diabetes?
- 2) What are the benefits of these as they relate to parenting?
- 3) What are the drawbacks of these as they relate to parenting?
- 4) What recommendations can be made towards improving training and education given the themes that emerge from the data?

Background

Type 1 diabetes is considered a chronic illness and is characterized by the cessation of insulin production by the pancreas (Canadian Diabetes Association [CDA],

2008). This lack of insulin leads to high levels of blood glucose and will eventually lead to death if left untreated (CDA, 2008). Type 1 diabetes is usually diagnosed in childhood (International Diabetes Federation [IDF], 2009). About 70,000 children a year develop type 1 diabetes, globally, and rates are increasing all over the world (Juvenile Diabetes Research Foundation [JDRF], 2010). While the causes of type 1 diabetes are not fully understood, people who have close family members with type 1 diabetes are at an increased risk for getting it (Nagaraja & Boyle, 2006).

The treatment of type 1 diabetes is complex. The overall aim of living with type 1 diabetes, from a medical perspective, is to keep blood glucose levels within an acceptable range as much as possible in order to reduce short and long term complications (CDA, 2008). This is done through administering insulin (American Diabetes Association [ADA], 2002). Administering insulin requires the parent and child to adjust to giving/receiving injections because insulin must be taken by syringes, insulin pen injectors, or by insulin pump therapy (CDA, 2008). Additionally, parents need to monitor their children's food intake or keep track of the carbohydrates that their children eat in order to administer the correct amount of insulin (CDA, 2008). Children must receive several injections of insulin per day and their insulin requirements change with growth, level of exercise, or due to other illnesses, therefore insulin dosage and timing is adjusted throughout life on an ongoing basis (CDA, 2008). Monitoring of blood glucose levels throughout the day is another key component in the management of type 1 diabetes because knowing blood glucose levels is necessary for making treatment-related decisions such as how much insulin to administer. These ongoing tasks require extra time

and energy of parents and can cause them a great deal of worry and stress (Sullivan-Bolyai, Deatrick, Gruppuso, Tamborlane, & Grey, 2003).

In addition, as parents strive to keep blood glucose levels within an acceptable range they must always be prepared to respond to acute complications. Hypoglycemia is an acute complication that can occur when blood glucose levels drop too low. This can happen when there is too much insulin in the blood and can be distressing and disruptive for children and their families because symptoms include poor concentration, dizziness, or loss of consciousness (Strychar, 2007). If hypoglycaemia occurs the child must eat or drink something that is high in sugar as soon as possible and may require assistance from someone else (or from emergency medical services) if they are no longer functioning well enough on their own (CDA, 2008). Conversely, hyperglycemia, or blood glucose levels that are above target levels, can occur and can lead to the need for hospitalizations if left untreated (CDA, 2008). Hyperglycemia is treated by giving insulin, making it important that parents have insulin and insulin supplies with them at all times. As a result of the complex nature of life with diabetes, parents of children living with type 1 diabetes have a high degree of responsibility (Pattison, Moledina & Barrett, 2006).

Theoretical Framework: Ecological Systems Theory

Bronfenbrenner's ecological model of development provides an interlocking description of how individuals are situated within their environment (1979). It takes into account the immediate setting (e.g. individuals and their personal values and beliefs) as well as cultural and structural factors that may cause lasting change in the way an individual perceives and responds to his or her environment. Included in the framework is the immediate environments the individual is in, or microsystem; the relationship

between those immediate environments, or mesosystem; settings in which the individual may not enter but in which events occur that may affect what happens in the individual's immediate environment, or exosystem; generalized and overarching patterns of ideology and organization of social institutions common to a culture, or macrosystem; and finally, the patterning of environmental events and transitions over the lifecourse, or chronosystem.

The interpretation of the meaning of the categories that emerged from this study used this ecological model to better understand how the parental sense of meaning is shaped within their historical and social contexts.

CHAPTER II

Review of the Literature

The literature review has been divided into two sections. The first section is a review of quantitative studies that have been done in this area. Following the review of the quantitative research in this area is a review of the qualitative research that has been done to explore the experience of parenting a child living with type 1 diabetes.

Quantitative

The quantitative literature related to parenting children living with type 1 diabetes has had a focus on exploring various factors for how these relate to diabetes management and adjustment, with blood glucose control as the primary indicator of successful management and adjustment. Factors related to how well parents adhere to medical management plans and integrate diabetes-related tasks into daily life (or adjust to life with diabetes) have been examined for their impact on blood glucose control.

Children. Most of the research examining pre-school and school-aged children's characteristics that affect the way parents manage their children's diabetes has focused on physical or physiological aspects of children. For example, children's age will affect how stringently parents can control their children's blood glucose. Even though it increases the likelihood of long-term complications targets for overall blood glucose are higher for younger children (CDA, 2008). This is due to the increased risk of hypoglycemia in pre-school aged children and the potential for long-term neurological damage (CDA, 2008). Children's age will impact the degree to which they can participate in illness management tasks. While school-aged children can participate in some aspects of illness management, such as blood glucose testing or giving self-injections, too much child

responsibility for care has been linked with poorer glycemic control (CDA, 2008; Pattison, 2006). Balancing food (which involves counting and measuring carbohydrates) with insulin and exercise, for example, may be too complex for pre-school and school-aged children to undertake. Level of hypoglycemic awareness (the degree to which one can feel the lowering of his or her blood glucose) in children with type 1 diabetes can impact daily functioning of children with type 1 diabetes. Children with low hypoglycemic awareness may experience hypoglycemia more often, which can disrupt learning at school or other activities (Pacaud, 2002).

Adolescence may present unique challenges in the parenting of children with type 1 diabetes. This is because adolescent children become more independent and parent-child disagreement over illness management or amount of time children should spend away from home may cause conflict. This conflict has been associated with less child adherence to illness management such as regular blood glucose monitoring (Dashiff, Bartolucci, Wallander, & Abdullatif, 2005; Grey et al., 2009). In contrast, adolescents from families with less conflict, better communication, and continued responsibility sharing between parents and children have been shown to have better blood glucose control through increased adherence to management plans (Whitemore et al., 2002).

An additional challenge is that children and adolescents with type 1 diabetes are at a greater risk for depression and other psychiatric disorders, which impacts illness management and glycemic control. Whitemore et al. (2002) measured depressive symptoms in 117 children with type 1 diabetes aged 12 to 16 and found that those with more depressive symptoms had significantly higher overall blood glucose levels. The presence of diagnosed psychiatric disorders (major depression, bipolar disorder, anxiety,

panic disorder) has also been found to be predictive of severe hypoglycemia in adolescents, especially for girls (Rewers et al., 2002).

While little is known about parental diabetes-related understandings and how they shape parenting practices family functioning is certainly thought to be a factor that is protective against poor mental health outcomes in children living with type 1 diabetes. For example, adolescents who had higher depressive symptoms self-reported more rigid and structured family types rather than warm and caring family types (Whitemore et al., 2002).

Parents. Parental characteristics have been found to be related to management adherence and blood glucose control in parents of children living with type 1 diabetes. Parental beliefs and diabetes-related knowledge, for example, were found to be related to how well parents follow the management plans for their younger children living with type 1 diabetes (Pattison et al., 2006). Parental self-efficacy is a psychological construct that has been found to have a positive impact on adjustment. Pattison et al. (2006) used regression analysis to measure the impact of parental self-efficacy on their children's blood glucose control and found that it did not independently predict better blood glucose control but it did predict better adjustment, or normalization, to living with type 1 diabetes. Conversely, low self-efficacy in parents has been associated with parental stress (Streisand, Swift, Wickmark, Chen, & Holmes, 2005). In parents of school-aged children lower belief in their children's ability to manage the illness was associated with better glycemic control (Pattison et al., 2006). Butler et al. (2008) measured several family factors for their impact on glycemic control and found that diabetes-specific knowledge

and lower perceived burden of care in parents of children living with type 1 diabetes predicted better glycemic control in their children.

Parenting styles have been examined using quantitative methods for their impact on quality of life for children living with type 1 diabetes. Responsive parenting styles have been found to be associated with better quality of life for children living with type 1 diabetes. Botello-Harbaum, Nansel, Haynie, Iannotti, and Simons-Morton (2008) conducted a quantitative study in which children (aged 11 to 16) completed quality of life self-reports and Authoritative Parenting Index assessments which measured parental demandingness and parental responsiveness. The aim was to measure the relationship between quality of life and parental responsiveness while controlling for other impacting variables such as family conflict. They found that responsive parenting was associated with better quality of life in children living with type 1 diabetes.

Healthcare professionals. Healthcare professionals play a role in shaping the way parents think about diabetes in their children. This is because when a child is initially diagnosed with diabetes healthcare professionals provide parents and children with an explanation of what diabetes is, giving parents and children an initial framework for understanding diabetes as an illness and how it should be treated. Care and education that is provided by healthcare professionals in Canada is primarily focused on the medical aspects of illness management with the haemoglobin A1C (a long term measure of blood glucose levels) as the primary indicator of management success. Regular appointments at pediatric diabetes clinics generally focus on management details from a medical perspective and diabetes educators provide practical knowledge to improve or maintain control over blood glucose. More specifically, diabetes education most often centers

around insulin requirements and administration, counselling on how to balance food intake with insulin, exercise, sick day management, and the prevention of diabetes-related complications (CDA, 2008). While the focus is primarily on the medical aspects of diabetes, many pediatric diabetes clinics in Canada encourage the child's extended family members to participate in diabetes education, in order to foster a team approach to the child's diabetes-related care.

As a result of the focus on maintaining glycemic control some parents have reported feeling that healthcare providers have mistakenly assumed that they are emotionally well-adjusted and coping well with the illness management demands when A1C tests are good (Bowes, Lowes, Warner, & Gregory, 2009). Yet it is important to note that some parents may not feel that they have had the opportunity to discuss their concerns because they may be reluctant to do so in front of their children who are at the appointment (Bowes et al., 2009). While there is recognition within the healthcare setting of the emotional, social, and financial impacts of the illness and of the unique situation of each child, little research has been conducted examining these links from the parental perspective.

Once children turn 18 they can no longer attend pediatric diabetes clinics and must go to adult clinics. The transition from pediatric to adult diabetes care may be a challenging time for the parents of children with type 1 diabetes because it is often associated with less management adherence in young adults with diabetes. Scott, Vallis, Charette, Murray, & Latta (2005) found that of participants aged 18 to 22 years old only 41.3% had been to an adult clinic and that the usual reasons given for reduced attendance were that they were too busy to attend. Respondents were asked to talk about their

experiences of leaving pediatric diabetes care and many of the young adults said that they missed the staff at the pediatric diabetes clinics and experienced feelings of abandonment because they had to leave as soon they became adults. When asked about what they would like in a diabetes clinic common themes of the respondents were that they would like the staff to be closer to their age (rather than much older) and to make them feel comfortable enough to talk about their personal issues.

Health disparities. Socioeconomic status plays a role in the parenting of children with type 1 diabetes. Acute complications have been found to be more common in children and individuals with lower socioeconomic status. Sawka et al. (2007) conducted a review of studies that looked at the relationship between various measures of socioeconomic status and hypoglycemia in children and adults living with type 1 diabetes in developed countries over the past 10 years. Out of nine studies eight showed an association between one or more measures of low socioeconomic status and severe hypoglycemia. There was also a relationship between hospitalizations for hypoglycemia or hyperglycemia and income levels. Booth & Hux (2003) examined a large sample of individuals with type 1 diabetes in Canada and found that those in the lowest income category were 44% more likely than those in the highest to have been hospitalized for hyperglycemia or hypoglycemia over the 7-year period of the study.

While the relationship between socioeconomic status and poor outcomes is not yet fully understood there are a few possible mediating factors. Food insecurity (poorer food quality and quantity and disruptive eating patterns) may make it more difficult for parents to treat hypoglycemia in their children and has been found among nearly half of all Canadians who fall into the lowest income category as well as in over half of those

who receive social assistance (Strychar, 2007). And while Canada has publicly funded healthcare, the costs of medications and medical supplies are not fully covered. There are programs to cover some of the costs of medication and supplies which vary from province to province but not everyone will qualify for these programs (Kwan, Razzaq, Leiter, Lillie, & Hux, 2008). Some families may not have private insurance to cover the costs of diabetes medication and supplies. Costs of supplies needed to manage type 1 diabetes and insulin-dependent type 2 diabetes have been found to be significant for families who do not have coverage (Harris et al., 2007). In a survey conducted by the Canadian Diabetes Association most respondents said they spent \$50 to \$100 per month on diabetes supplies and about one quarter of respondents said that they could not afford devices recommended by healthcare providers (Harris et al., 2007). A relationship has been found between underinsurance and poor blood glucose control because those who pay out-of-pocket for testing supplies may test their blood glucose levels (or their children's) less often in order to cut down on the cost of testing supplies (Canadian Diabetes Association [CDA], 2009). Costs of transportation and not being able to take time off from work may make it more difficult to attend regular appointments (Booth & Hux, 2003). For Canadians who do not live in or near cities access to pediatric diabetes clinics is limited (Griffis & Beauvais, 2007). Northern communities may have particularly limited access and there is still a need to develop programs to provide better service to remote areas.

Culture. The role of culture in the context of parenting children living with type 1 diabetes has not been addressed specifically. However, poorer management of chronic illness and thus increased complications has been found to be experienced in individuals

living with diabetes who do not identify with the dominant cultural understanding of illness (Shaw, Huebner, Armin, Orzech, & Vivian, 2009). Individuals from cultural backgrounds that have an understanding of an illness that is different from that of their healthcare providers' understanding may seek fewer healthcare services and comply less with treatment plans. For example, Ho and James (2006) conducted qualitative interviews with Chinese immigrants to Canada who had type 2 diabetes. They delayed beginning treatment with insulin due to having a distrust of western medicine. For the example, participants' injections were associated with greater severity of illness because in China only doctors give injections. Insulin was also associated with a feeling of failure to manage the illness. In Canada healthcare professionals focus on individual responsibility for illness management (Wong, Stewart, & Furler, 2009). However, in an Aboriginal context health and wellness are viewed as interconnected with an individual's community, spirituality, and the environment; therefore, individuals from Aboriginal communities may not view diabetes as within their individual control (Giles et al., 2007). As culture impacts an individual's diabetes management, a parent's ethnic culture may impact the way he or she interacts with healthcare and adheres to management plans, which can have an impact on diabetes-related outcomes in the child.

Family history. Some studies have included questions related to having a family history of diabetes and its relationship to glycemic control or its role in shaping illness representations and adherence to management plans in individuals living with diabetes. Pattison et al. (2006) examined the relationship between parental perceptions of diabetes and glycemic control in their children living with type 1 diabetes. The parents filled out surveys which included questions about having a family history of diabetes. While family

history of diabetes was not related to glycemic control, the parents who did have a family history of diabetes perceived the illness as more serious than the parents without a family history of diabetes. For individuals living with type 2 diabetes, having knowledge of a family history of type 2 diabetes was found to inform their diabetes-related illness representations (beliefs about the cause, outcomes, and controllability of illness).

Therefore, Scollan-Koliopoulos, O'Connell, and Walker (2005) proposed a framework to assist healthcare professionals in assessing the extent to which patient knowledge acquired through family interaction impacts illness representations and management adherence in individuals with type 2 diabetes. Scollan-Koliopoulos et al. proposed that nurses and healthcare providers ask specific questions about the family history of diabetes with the aim of helping individuals incorporate new or more current or accurate information into their existing framework.

This literature provides a breadth of information on the many factors that are important in diabetes management and blood glucose control in children living with type 1 diabetes. This literature is comprehensive in that it includes factors related to the child, parent, and community as well as socioeconomic background and culture; yet it neglects to examine or explore the parental sense of meaning and understanding and how it shapes parenting practices in the context of parenting children living with type 1 diabetes.

Qualitative Studies

Some qualitative studies have explored the experience of parenting a child living with type 1 diabetes as well as some of the social factors that impact that experience, without an emphasis on blood glucose control.

The experience of parenting a child living with type 1 diabetes. Mothers caring for pre-school aged children living with type 1 diabetes have described their experience as a constant worry about the necessary management details and described their loss of freedom as being analogous to having a newborn again (Sullivan-Bolyai et al., 2003). These mothers had to always be prepared and they could never stop thinking about their children's well-being as it related to diabetes – this meant thinking about management details such as when their children ate last and when they would eat again, how much insulin they last took and when it will peak, whether or not the children had enough supplies, their children's activity level, and how many carbohydrates were in food. When the mothers did get respite they had concerns about the caregivers knowledge and ability to care for their children.

Hatton, Canam, Thorne, and Hughes (1995) conducted a study that was aimed at uncovering parents' experience of caring for infants and toddlers with type 1 diabetes. They found that parents felt that they were responsible for keeping their children alive and also experienced stressors that were related to specific diabetes-related events over time. These events included the diagnoses of diabetes and initial hospitalization, coming home from the hospital after the diagnoses and learning to accommodate the demands of managing the diabetes, and ongoing adaptations to changes related to the child such as entering pre-school or the child becoming more oppositional towards receiving injections or having his or her food intake monitored. Parents expressed the need to continually adapt to the stressors that each new event brought on by seeking help from professionals or learning to trust others to help take care of their child.

Bowes et al. (2009) interviewed parents of children who had been living with type 1 diabetes for at least seven years. They found that while parents incorporated the illness-related demands into their daily life feelings of sadness did emerge for parents when events triggered thoughts of the time that their child was initially diagnosed or when their children's blood sugar was not well controlled. Some of the study participants also became upset during interviews when discussing events such as hospitalizations and said that watching or giving injections can still be upsetting because these events reminded them that the illness is permanent. Parents also experienced ongoing worries about what their children's future outcomes would be if blood sugars were poorly controlled and this concern was particularly salient when the children's blood sugars were high. Also identified by participants in this study was a need for more emotional support from healthcare providers. Therefore, while the parents usually incorporated diabetes care into their daily life, trigger events did not permit them to have a sense of closure.

Based on interviews with parents of children living with type 1 diabetes and the children themselves Marshall, Carter, Rose, and Brotherton (2009) described parenting in this situation as bringing change and disruption, loss of freedom, and loss of confidence as parents. In addition, the attachment relationship between parents and their children may also be disrupted because of the need to check on the children more often, even as they got older. Diabetes made families feel different and parents had to come to accept the diabetes and work towards achieving a new sense of normal.

Community interaction. Other qualitative studies have addressed some of the social aspects of parenting children living with type 1 diabetes. For example, several studies have explored parents' experiences of communicating with others about diabetes.

Kliebenstein and Broome (2000) focused on parents' experiences related to communicating with schools to facilitate their children's re-entry to school after being diagnosed with a chronic illness including type 1 diabetes. Parents identified several issues of communication related to watching for changes in the children's health status and ongoing information sharing. Parents felt that informed staff members were not always available throughout the day and that the staff did not always understand what the children needed. In the case of children living with type 1 diabetes parents felt that the school staff's response would not be quick enough if their children experienced hypoglycemia, in situations in which the children's glucose meter was kept in the principal's office. Parents wanted to be the ones to provide information to schools about the care of their children but also wanted more involvement from healthcare providers. They expressed a concern that school staff members might believe that the children were using their illness as an excuse to get out of work and felt that healthcare providers could help clarify this for the school staff.

Wennick, Lundqvist & Hallström (2009) explored parents' experiences related to informing friends and family about what diabetes is and how it should be managed. The parents in their study reported that a common source of frustration was friends' and family's misunderstanding about type 1 diabetes. Mothers reported that people would confuse type 1 diabetes with type 2 diabetes or believe that their children got diabetes as a result of eating too much sugar (Wennick et al., 2009; Wennick & Hallström, 2007). Parents also expressed having a fear that their children might experience hypoglycaemia when they were in the care of friends or family and as a result would allow blood glucose levels to remain higher than they would allow at home when their children stayed with

friends or family (Wennick et al., 2009). Neufeld, Harrison, Hughes, and Stewart (2007) examined how mothers of children with chronic illnesses perceived their interactions with healthcare providers, schools, family, and friends. Mothers caring for children with type 1 diabetes were included in this study. Some of these interactions were categorized as negative and included not being taken seriously by healthcare providers or feeling blamed for poor illness management. Ineffective interactions were classified as those interactions whereby the mothers' need for support went unrecognized or offers of help were not followed through. The mothers of children living with type 1 diabetes felt that being uncomfortable with needles prevented friends or family members from providing childcare and in some cases parents would not go to family gatherings in order to avoid making other family members feel uncomfortable.

Culture. The experience of parenting a child living with diabetes for immigrant parents has been explored. Povlsen and Ringsberg (2009) conducted a qualitative study to find out if there were differences between parents living as immigrants and those living in their native country in how they experienced learning to live with a child with type 1 diabetes. The aim was to identify problems related to cross-cultural diabetes care. They interviewed parents from Iraq, Lebanon, and Morocco who were living as immigrants in Denmark and parents living in their native country of Egypt. All of the parents in the study felt that showing compassion and understanding were the most important qualities for healthcare providers to have, especially when providing care for younger children, while the content of the diabetes education was perceived as more important when their children were teenaged. A primary difference in experience between parents living as immigrants and those living in their native country was that the immigrant parents felt

less trusting of healthcare professionals because they spoke a different language and had a different background than the doctors. The immigrant parents expressed a need to seek additional information and some sought advice from doctors in their native countries. Additionally, while the immigrant parents felt that living in Sweden provided them with better access to medical aids such as insulin and diabetes supplies they felt that they had less support (from family and friends) to help them care for their children.

Some qualitative studies have explored the way culture shapes the experience of living with diabetes. Shimizu and Paterson (2007) compared and contrasted the experiences of diabetes self-management between adults in Japan and Canada with type 1 and type 2 diabetes in order to understanding how collectivist and individualistic cultural ideals can shape the illness management experience. Shimizu and Paterson found similarities and differences in how participants from each group viewed the concept of diabetes self-management. Across both studies the participants' goal was to minimize diabetes complications. In the Japanese participants, however, healthcare providers also emphasized self-management adherence as necessary for fulfilling social roles and ensuring the well-being of their patients' significant others. Non-adherence, then, was believed to adversely affect others (Shimizu & Paterson, 2007). Canadian study participants were motivated by the desire to be able to do the things they wanted to do if their diabetes was well-managed, although they felt significant others would be positively affected as well. An additional motivation to adhere to management regimens for the participants from Japan was to maintain a good relationship with their healthcare providers.

In another example, Waldram et al. (2000) conducted a qualitative study among a group of 60 Aboriginal people in Saskatoon with type 2 diabetes. They found that many individuals who participated in the study believed that traditional Aboriginal treatments for diabetes were effective. However, after prolonged contact with healthcare providers reporting of the use of traditional treatments decreased.

Much of the quantitative literature has focused on factors impacting management adherence and blood glucose control. And while qualitative studies have explored some of the social aspects of parenting a child living with diabetes, the parent's sense of meaning and understanding in relation to parenting a child living with type 1 diabetes and how these might impact parental decisions regarding care has not yet been explored. My study will help to fill this gap.

CHAPTER III

Methodology

Study Design

A qualitative approach to collecting data was used in this study. Qualitative research aims to better understand experiences, situations, or events, by representing and interpreting them in terms of the meaning people bring to them (Denzin and Lincoln, 2005). This research involves collecting and presenting detailed descriptions about an individual's or group of individuals' experiences. Researchers are then able to gain a better understanding of the processes that an individual may go through and how these processes may lead him or her to a specific understanding or response (Grypdonck, 2006). Detailed understanding of the processes and responses of individuals of interest can be gained by conducting open-ended interviews with participants to illicit an in-depth understanding of their experiences as they relate to the study question. For this study a qualitative approach using the 'case study' was applied. This allowed for the examination of parents' discussions around their experiences and understandings around parenting their children living with type 1 diabetes. Since little research has been conducted regarding the parental sense of meaning and understanding in relation to the parenting of their children living with type 1 diabetes, a qualitative approach using open-ended interviews can help to uncover the important but yet unknown aspects of this experience.

Case study is the study of an issue or phenomenon explored through one or more cases within a bounded system (Creswell, 2007). A bounded system is the setting or context of the case which can include the physical context, the social, economic, and cultural context, as well as time (Stake, 2005). A case may constitute an individual or a

group of individuals, an organizational setting, or an event (Stake, 2005). Case studies include descriptions of the case with attention to the details of each individual who had participated. This description allows for a greater understanding of the complexity of the phenomenon that is being explored. When more than one individual, group of individuals, or setting is used to examine an issue, it is referred to as a collective case study (Creswell, 2007). In this study a collective case study design has been used to better understand the parental sense of meaning with attention to the historical, familial, and social contexts of each parenting situation. Specifically, ten interviews were sought with parents of children living with type 1 diabetes and the issue was explored across all participants.

In particular, this study was an instrumental collective case study which means that the case serves as a tool for better understanding the issue rather than examining the case because it is especially unique (Stake, 2005). The aim was to include diverse examples of parenting a child living with type 1 diabetes in order to allow for different perspectives on the issue to emerge (Stake, 2005).

The use of a case study design was suited to the research purpose of this study because the case study includes a focus and description of the context that the participants are in. Case study research is used when contextual factors are believed to influence the issue being studied (Creswell, 2007). A description of the social, historical, economic, and cultural contexts in which the study participants are situated are important because they are assumed to influence the meaning, understandings, and actions of the individuals in my study. Findings from this case study will therefore have limited transferability; however, the primary goal of a case study design is to obtain an in-depth understanding

of the case and is therefore less concerned with transferability of findings (Stake, 2005). Parents were required to remember and describe past events and this is a key objective of qualitative research - to describe the meaning and the experiences people attribute to a point of interest. The aim of my study was to explore a parent's subjective experiences and perceptions in order to uncover his or her sense of meaning and understanding in relation to the parenting of his or her child living with type 1 diabetes.

A case study design will yield large amounts of data (interview texts) and there may be issues that emerge that are not directly related to the primary research questions. As an instrumental case study, data that related to the issue being studied were the focus of the analysis; the details around the uniqueness of each participant were given less emphasis.

Ethics Protocol

An ethics protocol was prepared and approval was obtained from the University of Manitoba Joint-faculty Research Ethics Board for research with human participants. Participants were asked to sign consent forms which outlined the purpose of the study as well as potential risks associated with participation and maintaining confidentiality. In case any participant experienced significant emotional distress due to participating in the study a list of services was included with their copy of the consent form. Confidentiality throughout the data analysis process was ensured by assigning a pseudonym to each participant. Other identifying details were changed as well, in order to maintain confidentiality. Participants were made aware that publications may emerge from this data set and that every attempt would be made to reduce the possibility that they are recognizable in the text.

Recruitment and Eligibility Criteria

Parents of children living with type 1 diabetes were recruited through the Diabetes Education and Resource for Children and Adolescents (DER-CA) located in Winnipeg as well as the Juvenile Diabetes Research Foundation (JDRF), Winnipeg chapter. The DER-CA is the pediatric diabetes community clinic that provides all of the assessment and ongoing diabetes-related education for children living with diabetes and their families in the province of Manitoba. They provide services to over 500 families. The JDRF is an organization that promotes fundraising for diabetes research and awareness as well as providing information and support networks to parents and families affected by type 1 diabetes.

Originally I had planned to explore the research question parents of children living with type 1 diabetes who also had a close family history of type 1 diabetes. The aim was to explore multi-generational family illness narratives and their role in shaping the parental sense of meaning in relation to the parenting of their children living with type 1 diabetes. However, once I began the recruiting process, I found that most of the parents who were interested in participating did not fit the original criterion of having a family history of type 1 diabetes. The eligibility criteria were then changed to include parents of children living with type 1 diabetes who had a family history of either type 1 or type 2 diabetes and I made a new study poster to include this. Parents could also have diabetes themselves (see appendix D). Many of the parents, however, had no family history of either type of diabetes or in situations where they had a family history of type 2 diabetes they had little contact or awareness of their family members who had lived with type 2 diabetes. It was decided that it was best to interview the parents who responded,

and explore the parental sense of meaning without a specific focus on the aspect of family history of diabetes.

Other organizations were also invited to help with recruiting. The Maestro Project for adolescents with diabetes, in Winnipeg, sent out 300 copies of my study information in September and my poster was up at the Philippine Canadian centre, the Aboriginal Health and Wellness centre, and at Klinik on Portage where a nurse educator agreed to hand out copies to those who might be eligible. Information about the study was also handed out at the Youville Diabetes Centre. I approached the Canadian Diabetes Association and the Diabetes Research Group and they said that they were not able to help me with recruiting.

In total 10 interviews were conducted with 13 participants (see Table 1). Seven interviews were with mothers of children living with type 1 diabetes and three interviews were with mothers and fathers together. The parents' children who were living with diabetes ranged in age from seven to 17 years old and none of the parents had more than one child living with diabetes. All of the parent's children had been diagnosed with diabetes at least one year prior to the interviews and the length of time that their children had lived with diabetes ranged from one year to 13 years in length.

Table 1: Study Participants

	1	2	3	4	5	6	7	8	9	10	11	12	13
Parent Gender	F	F	M	F	F	F	F	F	M	F	F	M	F
Parent Age	40 to 50	35 to 45	35 to 45	40 to 50	30 to 40	40 to 50	30 to 40	40 to 50	40 to 50	35 to 45	30 to 45	Over 65	40 to 50
Age of Child	17	10	Same child	13	6 ½	12	8	13	Same child	13	7	Same child	12
Age of Child's Diagnoses	4	3 ½	Same child	9	5 ½	3	6	8	Same child	9	5	Same child	10 1/2
Child Gender	M	M	Same child	F	M	M	M	M	Same child	F	M	Same child	F
Family History of Diabetes	T1	T1	No	No	No	No	No	T2	No	No	T2	T2	T2
Sibling(s)	1	2	Same child	1	2	1	1	3	Same child	1	No	Same child	1

Note: These participants were couples (and parents to their children living with diabetes) and were interviewed together; 2 and 3, 8 and 9, 11 and 12.

Table 2: Pseudonyms

Participant	Parent Pseudonym	Child Pseudonym
1	Carrie	Shane
2	Haley	Sam
3	Mark	N/A
4	Vicki	Kayla
5	Cheri	Ethan
6	Lily	Charlie
7	Mandy	Tyler
8	Lynne	Jordan
9	Dave	N/A
10	Emily	Zoe
11	Amy	Austin
12	Scott	N/A
13	Lisa	Debbie

Sampling. The goal was to include a diverse sample of participants using maximum variation sampling, a sampling strategy whereby participants are chosen because they differ on specified criteria in order to gain diverse perspectives on the issue (Creswell, 2007). In this study it was considered beneficial to have a diversity of participants in the example of age and gender (that is, parents of different aged children and of male and female children), ethnicity, regional background, location of families (urban and rural dwelling), and families from different socioeconomic status. Including parents of different aged children who are living with type 1 diabetes was thought to provide an example of a variety of parenting situations. The intention to include parents from a variety of ethnic and regional backgrounds would allow for the exploration of similarities and differences in the parental sense of meaning for parents from a variety of

backgrounds. Since differences in access to healthcare and diabetes-related complications exist among children from different socioeconomic backgrounds and locations (urban versus rural) including parents who differ on these two criteria was thought to be important because access to healthcare and the experience of complications are assumed to impact the parenting of children living with type 1 diabetes. With ten interviews having been conducted for this study, not all populations have been represented, and so this study offers a more detailed window into questions that will need to be referred to a future study.

Data Collection/Interviews

The data were collected through semi-structured interviews. Parents were asked open ended questions about their experiences in parenting their children living with type 1 diabetes (see appendix A). Open-ended questions are used to collect information in qualitative research so that the issues that are the most important to the participants can be uncovered and used to help shape further questions (Creswell, 2007). This flexibility and openness to data collection allows for important yet unexplored experiences to be revealed and discussed by the participants. The interviews took place in the participants' homes, in their workplace offices, or at coffee shops. Interviews were recorded on a digital recorder and then later transcribed. Participants were interviewed once and the interviews ranged in length from one hour to one and a half hours. Field notes were also taken during each interview.

The interview questions focused on the participants' daily experiences in parenting their children who are living with type 1 diabetes. These questions centred on issues concerning managing the diabetes as well as the way in which it had impacted life

for the children and the family. Parents were asked how the diagnoses of diabetes in their children affected their experience as parents and how the diabetes has shaped their outlook on parenting or their parenting practices. It is important to note that, while each parent was asked the same core questions, the specific topics and areas of discussion during the interviews were unique to each parent, based on the areas of their lives or their children's lives that they felt were most affected by the diabetes. Parents who had a family history of diabetes were asked how their previous diabetes-related knowledge and experiences had shaped their experience as a parent to a child living with diabetes. As is common in qualitative research, questions were added as data collection progressed in response to the topics, issues, or points of interest that emerged throughout the data collection process.

Detailed field notes were taken throughout the interviews, with regard to the interview setting, process, and responses given by the participants. The notes helped guide further questions as the interviews progressed. The purpose of field notes is for the researcher to record his or her immediate response about the research process, including observations as well as his or her thoughts on analysis. "The point is to write down whatever impressions occur, that is, to react rather than to sift out what may seem important, because it is often difficult to know what will and will not be useful in the future" (Eisenhardt, 1989, p. 539). The use of field notes allows the researcher to think about what he or she is learning from the research process and to compare and contrast the differences between participants (Eisenhardt, 1989).

Data Analysis

Transcribed interviews were analysed using qualitative content analysis.

Qualitative content analysis was suited to this particular study because it is useful for analyzing the perceptions of individuals (Julien, 2008). Content analysis involves the analysis of texts with the assumption that words or phrases that occur frequently indicate that they are of importance and that groups of words or phrases reveal underlying themes or concepts (Duriau, Reger & Pfarrer, 2007). More specifically, Graneheim and Lundman (2004) state that “words, sentences, or paragraphs containing aspects related to each other through their content and context” (p. 106) are placed into codes and then categories are identified based on the relationship between the codes. Finally, a theme is developed to represent the underlying or latent sense of meaning that is found across the categories (Graneheim & Lundman, 2004). Categories and themes can be pre-determined but for this study they will be based on concepts that “emerge” from the data (Julien, 2008). The interview transcripts were read several times and persistent concepts or themes related to the primary research questions were identified and coded. Codes that contain related concepts were then placed together into their own distinct categories. A qualitative data analysis program (Nvivo8) was used to organize the data throughout the analysis process.

Rigour. In conducting qualitative research it is important to establish the trustworthiness of the methods of data collection and analysis being used by demonstrating that they are credible, dependable, and confirmable (Lincoln and Guba, 1985). According to Lincoln and Guba, several techniques can be used to increase the trustworthiness of the qualitative research process.

In my study clarification of researcher bias is necessary to help to ensure that the findings and interpretations reflect the perspectives of the participants in the study; I am the parent to a child who was diagnosed with type 1 diabetes prior to beginning this research. This position led me to develop an interest in type 1 diabetes and parenting. But, the diversity in backgrounds and professional training of my thesis committee members has brought different perspectives to the data analysis, minimizing the chance of bias from a single perspective. The thesis committee members reviewed the interview protocol prior to the data collection and debriefs between myself and my thesis supervisor occurred after the first interview had taken place to discuss the interview process, any problems/successes, and preliminary observations of findings. Data has been triangulated through the use of existing literature and the researcher field notes. In the presentation of the study's findings, sufficient excerpts of the raw data have been included to provide clarification and examples of the categories identified. All of the techniques mentioned have helped to ensure that the study findings are credible, dependable, and confirmable.

Timeline

The thesis proposal defence took place on June 4th, 2010, and an ethics proposal was submitted to the appropriate ethical review board immediately thereafter. Once ethical approval was received, the recruitment process began. The recruiting process took place between September, 2010 and January, 2011. The final thesis defence was held on July 28, 2011 with a graduation date of fall 2011.

CHAPTER IV

Findings

The findings include nine categories that correspond with the levels of the ecological system (Bronfenbrenner, 1979). They have been organized this way because it is factors within the level of the system in which the category is placed that are assumed to have most shaped the parental sense of meaning, and this will allow for a clearer interpretation. However, because an individual is assumed to be influenced by factors within multiple levels of the system simultaneously, the parental perceptions are not meant to be understood as being influenced exclusively by one level of the system. The following table identifies the categories within the levels of the ecological system.

Table 3: Categories in the Levels of the Ecological System

Microsystem
The Parent’s Emotions in Relation the Child’s Diabetes The Parent and Child Relationship
Mesosystem
Being Like Everyone Else Protecting the Children
Exosystem
Putting Faith in the Unknown
Macrosystem
Keeping it in the Family Incorporating Diabetes Into Daily Life
Chronosystem
Does Heredity Matter? The Course of the Illness Sets the Tone

Microsystem

The microsystem includes the immediate environments an individual inhabits that will influence the way a person understands and responds to the world around them. Here, I describe the impact of the diabetes on the parents' emotions and on their perceptions of themselves as parents. Also discussed is the ways in which the parents managed difficult emotions related to parenting a child living with type 1 diabetes and the relationship between the parent and child as it is shaped and influenced by the presence of the diabetes. In this way, the following categories represents a 'microsystem' in that the parents reflected on their own perception of themselves and their children - factors within their immediate environment - to understand their child's illness.

The parent's emotions in relation to the child's diabetes. At various points throughout the interviews the parents talked about the circumstances surrounding the diagnoses of type 1 diabetes in their children and many of the parents speculated about what might have caused or brought about the diabetes in their children. Most of the parents understood type 1 diabetes as a condition resulting from the cessation of insulin production, but wondered why this cessation occurred in the first place. They attributed the onset of the diabetes to factors mostly within the microsystem such as other illnesses the children may have had, to the family's immediate environment, and to events that had occurred in the family's life. This led to worry that that they may have done something to cause the diabetes.

Other health-related events that had occurred in the child's life were sometimes seen as possible factors that may have been linked to the onset of the diabetes. Lily recalled that her son Charlie had had a febrile seizure over a year before he was diagnosed with type 1 diabetes and explained that "I understand the trigger is there and

actually before he was diagnosed, about a half a year before he had a seizure...And my theory is that's what triggered it." Lynne talked about a serious ear infection and meningitis that Jordan had been diagnosed with several years before the diagnosis of diabetes. She had heard that meningitis can cause trauma to the system leading to other illnesses later on and felt this may have contributed to the diabetes.

Lisa told a story of stress and the need for her family to adjust to a lot of change as a factor precipitating the onset of the illness. They had moved away from their hometown for job opportunities which did not end up working out as well as they had hoped. Within a short time of moving away they decided to move back; however, the children had begun to adjust to their new home away. Lisa said:

I think stress. I think really, you know taking your kids and moving someplace new. And then all of a sudden, you know, within a year you're moving back and you're not. You know, it's just you take them out of another situation and then expect them to adapt, adapt, adapt. And I just I think for her I think it was really stressful. Because she was loving Halifax. She loved her friends. She loved her school. She loved everything about it. And um, you know I just remember when we put that for sale sign back up on the house in Halifax and just, they were shattered, absolutely shattered. They didn't want to move back.

Some of the factors that parents speculated may have been linked with the onset of the illness were events that had occurred many years before the diagnoses. Several of the mothers were concerned that the drugs they took during childbirth, the way they took care of themselves while they were pregnant, or their children's immunizations may have played a part in the onset of diabetes. Although Emily's daughter had been living with

diabetes for four years at the time of the interview, she was still concerned over the cause of the illness, thinking that she may have unknowingly done something to cause it, pointing to drugs taken at the time of delivery, something that she fed Zoe, or childhood immunization shots. Cheri also wondered if she ate the wrong kinds of food during her pregnancy with Ethan or whether she gave him the wrong kind of milk or formula.

Parents who speculated that they may have done something to bring about the diabetes felt a sense of guilt and wondered if they could have done something to prevent it from happening. When parents wondered if they may have contributed to an illness that could have been prevented, they expressed feelings of guilt. Cheri explained:

I think, I think, um, it's devastating as a mother because you feel guilty. Maybe you could have done something, maybe you did something. Throughout your pregnancy maybe you ate wrong, maybe you gave them the wrong food, maybe you gave them the wrong milk or formula when they were growing up and you feel an enormous sense of guilt that, that this somehow was your fault.

Bowes et al. (2009) found that recalling important events such as the time of their children's diagnoses could bring out feelings of sadness for parents and that they did not have a sense of closure around the acceptance of the diabetes. This was apparent in my study as well. However, not having a clear understanding of what caused the diabetes was a factor that may have prevented the parents from experiencing a sense of closure around the diabetes.

Finally, another factor that parents looked to as contributing to the onset of their children's diabetes was the food their children ate. Several of the parents wondered if chemicals or hormones in food played a part in their children's illnesses as well as the

increasing rates of diabetes generally. Parents felt that there have been changes in the way food is produced that are now having health consequences for their children and society in general. Scott felt strongly that something in the food was causing more children to be diagnosed with diabetes because “It spills off, all this stuff spills off and well, everything you put in your body affects it right. It’s this foreign stuff in our body. Ya, it’s all a negative base, ya.”

The conclusions parents came to about the cause of the illness has implications for their self-identity as good parents. The parental understanding of the causes shifted between those that were within the parents’ control and those that were not within parents’ control, with the latter reducing the parents’ feelings of blame for contributing to the onset of the diabetes in their children.

This category revealed that parents have illness understandings that are based on both a medical perspective of illness and their own theories of the illness’ cause. According to Bury (2001) it is common for individuals’ accounts of their personal experiences of chronic illness to include both lay and medical understandings of illness, particularly around causation. In the context of diabetes, the parents in my study held the understanding that there is a trigger or factor(s) that causes an individual’s body to begin destroying insulin-producing cells (the autoimmune response) that is not yet fully understood by the medical community. As medical professionals could not provide a complete understanding of the cause of diabetes, parents looked for non-medical understandings of the causes of their children’s diagnoses. In the case of diabetes, where medical explanations are not completely understood, parents looked for non-medical understandings of the causes of their children’s diagnoses. Most of the factors that

parents speculated could have caused the diabetes were those within the child's immediate surrounding and circumstances, such as the child's experience with previous illnesses or stress in the family. However, parents looked to factors outside the home as well when they questioned the quality of the food that is available to people in society generally.

Consistent with the findings of Sullivan-Bolyai et al. (2003), the parents who participated in my study described the experience of parenting a child living with type 1 diabetes as fraught with constant worry about their children's well-being. Parents had fears around their children having diabetes-related emergencies and about what the future would hold for their children. Their fears centred on the possibility of the child having severely low blood sugar, or on the impact that the diabetes may have on the future quality of life of their children, should long-term complications occur. The parents felt that careful monitoring of the diabetes would prevent the children from suffering from long-term complications in the future and they had to live with this pressure to keep the diabetes managed while still going about their daily lives. Parents utilized several strategies to manage their worries and fears so that they could stay positive and motivated to parent their children as best they could. Some parents chose to look at the diabetes from a more positive point of view in order to stay motivated to care for the children as well as to set a good example for them. Identifying beneficial changes resulting from the diabetes also helped them to stay positive.

Many of the parents expressed feelings of gratitude and positive changes in their life philosophy. They explained that their situation could be worse and that they were thankful that their children were not diagnosed with something more serious. Vicki

recalled that another child who had been in the hospital at the same time as her daughter had been diagnosed with a far more serious illness, saying that “in lots of ways you become thankful. And I say that, I mean the little boy that was in the hospital room next to her died I mean about 3 days after she got out of the hospital. He had cancer.” And parents looked to various aspects of their particular situations that helped them to feel that they were better prepared to look after their children than other parents in the same situation might be. For parents who worked in healthcare related occupations or had a close family member who did, they felt that this made them better able to cope than other parents; Mark said “It’s fairly simple for us, to a certain extent now because, I mean we’re both fairly comfortable with understanding diabetes. I mean she’s, Haley, is a nurse and she grew up with it and I’m a physician.” Similarly, Mandy felt that having knowledge of first aid and being comfortable with needles was an advantage and Amy and Scott felt that they were better off because they were able to overcome the feeling of guilt that many parents experience.

Parents became more focused on what they considered to be the most important aspects of their lives, such as spending time with their family or just enjoying the present moment, as well as gaining a greater sense of understanding of other people who might be going through difficulty. Lisa told the story of having gone through a great deal of hardship caring for Debbie when she was first born because she was born with neonatal diabetes that went away a few months later. She then had to struggle with disbelief and grief when Debbie was “re-diagnosed” with type 1 diabetes at age 10. After explaining the many struggles she had gone through Lisa explained that she has re-evaluated her outlook on life:

And it's funny but sometimes I think, and I know it sounds corny but I love to do yoga. Because what yoga teaches you is just to live in the moment. Breathe now, and that seems pretty simple but and that's something I used to do because I used to work a job that I was working 7 days a week and I was working 14 and 15 hour days. And you know, and I did that for 20 years. And you miss a lot but you also you sacrifice your health and you sacrifice sort of, it's, you're just driven, driven, driven. I think you just want to make it, you just want to be the best and do the best in everything right. But in the end it doesn't really matter. It's really what you got for today, you know.

Upon being asked about their future hopes for their children parents stated that they wished for good health or lack of complications, and noted that the diabetes has caused them to shift their expectations to become focused on more basic aspects of life. Similarly, Kratz, Uding, Trahms, Villareale, and Kieckhefer (2009) held discussion groups with parents of children living with a variety of chronic conditions, including diabetes, to identify challenges and strategies for coping. They found that "reframing one's perspective and adjusting expectations" (p.307) was a primary coping strategy for parents because one's way of thinking influences their emotional state. They also reported that parents of children living with chronic illnesses felt that their experience helped them to focus on the things that are the most important in life.

The parents were also able to identify benefits related to the diabetes, which helped them to take a positive outlook. Some of the parents of younger children felt that being diagnosed with diabetes made their children feel special and unique because of the extra attention they got from parents, family, teachers, or friends. The parents felt that,

since the whole family had to make adjustments in order to incorporate diabetes into their lives, such as waiting until their children living with diabetes checked their blood sugar before everyone ate dinner, their families became closer. Structure within home-life, particularly around mealtimes, was more regular and predictable due to their children's need to eat at specified times of the day and some of the parents identified this as beneficial for the family. Parents made an effort to include the whole family in the diabetes care and ensure that everyone in the family was well-informed and some of the parents felt this made the family members draw closer. Haley, who had three children, felt that as a family they all communicated better as a result of the diabetes and Mandy also felt confident that the diabetes had brought about positive changes for her family, making them work together as a team:

I don't, it's, almost feel like it hasn't negatively changed our family. It's cemented some of the positive things that we had. We used to sometimes sit in the kitchen, and we've got an eat-in kitchen, but we almost always sit at this table here (dining room), we all sit in our spots, we have a nice meal, we talk about our day, I ask open-ended questions or else I get the "no." And ah, ya, no. And you know, so um, and then we just work the diabetes into that, you know. So we're doing the insulin, we're doing the test, whatever, but um, no it's ah probably just more cemented that family meal time, and um, we're a team.

While parents of multiple children expressed that they struggled with balancing their attention between all of their children, they also felt that the siblings were closer and that the siblings without diabetes would help those who were living with it. For example,

Lisa felt that her children were closer since Debbie was diagnosed with diabetes, saying that:

Ya, and they play really well together and they're just really close. And I think a lot of that has to come to with I don't know, is it part of it them being sisters, yeah, but I think a lot of it has to come with her diagnoses as well. And ah her sister's always kind of aware with what's going on with her to. You know. I know sometimes she'll be low and she'll go Debbie you better check your blood sugar. And sure enough she'll be low.

Parenting a child living with diabetes affected a parent's emotional well-being because they wanted to know what caused the diabetes in order to feel like they had done everything they could have to keep their children healthy. They also had to find positive perspectives towards the diabetes in order to cope with the added worries, fears, and uncertainties that the diabetes brought.

The parent and child relationship. The presence of the diabetes influenced parenting and the relationship between the parents and children. One such influence related to the way that the parents responded to their children's diabetes-related needs. Because the parents had to make decisions related to the children's diabetes, the children's experiential knowledge related to diabetes became a primary source of information in making day to day management decisions. While the parents received education and diabetes-related knowledge from healthcare professionals, they also took cues from their children on an ongoing basis in order to make diabetes-related decisions. The children's experiential knowledge was, therefore, a factor in the parent's immediate environment that shaped the way that parents responded to their children. While the

children had to take their insulin, check their blood sugar, or respond to their diabetes while at school or other places, the way that played out on a day-to-day basis was usually negotiable between the children and the parents. Parents responded based on their children's needs, abilities, and moods. For younger children, for example, diabetes management at school involved parents advocating for what their children wanted, such as making sure that their children were able to monitor their blood sugar at the locations where they felt the most comfortable. Vicki told the story of how Kayla had a difficult time when she was taking a certain kind of insulin; she would get headaches from the noise in the classroom at school when her blood sugar was high, and she had the school division nurse come in and explain to the class why this was happening:

So I think that was the hardest part – was getting, and we had a hard time on the NPH. It didn't work well with her. And so she didn't stay very consistent with her readings. So I think that was the hardest part for her, how she felt physically and having to be in the classroom. But we had had the division nurse come into the classroom and give a talk to her class.

Specific information about how the children felt and how they responded to their diabetes treatment was important to the parents as they made day to day decisions related to the children.

For children who were not able to give all of their own insulin injections the physical location on which they received their injections was usually up to the children as was how much involvement the children took in diabetes management from day to day, depending on their moods and ability. In speaking about her daily life taking care of Tyler, who was nine years old, Mandy said:

But I take my cues from him and if he's having a bad day and says "this sucks and I don't want to do it." I say "It is what it is. You can't do anything about it. Let's get it over with and we're done." You know. So we do the insulin. I'll do it for him if he's not having a good day, whatever.

Scott felt that the individuals who are living with diabetes, like his son Austin, are the ones who hold the most knowledge of diabetes, and he referred to children living with diabetes as the experts who have information to share with healthcare providers, saying that "You know like this is what his, like, they're even teaching doctors you know. The same as um, I mean if you're a male doctor he can't tell you how to have a baby right. Same thing." As Scott explains in this analogy, experiencing something first-hand was considered to make someone an expert, rather than being a doctor, and it was important to listen to Austin and consider how he was feeling when they made decisions around managing the diabetes.

Diabetes also influenced the parents' relationship with their children because they had become closer to them and more aware of their needs as a result of the diabetes. This was because they had to monitor them more closely than they would have to if they did not have diabetes. Dave said that he became closer to his son because of the diabetes, explaining that:

Has it made you become more closer to your son, you know I think it has. In a different way, but it has. You know yea, you become, whether it's your daughter or your son you do become closer because of the things that you have to monitor now. You know and at the age they have to, they have to report to you more, so.

While healthcare providers gave parents an understanding of the medical aspects of diabetes and provided guidance around any ongoing concerns, parents were also informed by the children themselves, and the children's experiential knowledge helped to guide the way that the parents responded on a day to day basis. When an illness is chronic it is taken care of, or managed, by the individuals living with it, and/or their parents. Since the management of chronic illness takes place within the context of the individual's everyday life, rather than at a clinic or hospital, factors within the microsystem, such as the children's mood, are going to help guide everyday decision making around the illness.

On the other hand, while the parents looked to the children to give them cues around daily management and felt closer to their children, they also needed to ensure that their children had the knowledge and skills necessary to be able to live with diabetes without their help. This meant that they had to teach their children not only diabetes-specific knowledge but also interpersonal skills. At times, this posed an enormous challenge and became a source of anxiety for parents as well as a source of conflict between parents and children, while at other times parents felt proud that their children were doing well in managing their diabetes.

Parents shared their experiences related to their efforts to get their children more involved in daily management and the joys and frustration they experienced related to these efforts. Sometimes small steps, such as the child making a decision around how to respond based on a blood sugar number, meant that the child was making progress towards greater independence and parents could feel positive about their children's future. Other times parents told stories of their children not remembering to carry

diabetes necessities with them when they left the house, such as testing supplies or emergency sugar; events like these were a cause for worry that the children would end up in an emergency situation where they did not have what they needed to treat their low or high blood sugar.

During times when the children were going through transitions such as starting a new school or activity, or going to university, parents felt it was especially important for the children to gain the skills necessary to take care of themselves. Parents, who were used to reminding their adolescent children to prepare their food, insulin, and testing supplies, made efforts to pull back on these reminders in order to give the children the chance to do it on their own.

Preparing the children for life as adults with diabetes meant more than just teaching them to perform diabetes-related tasks. It also meant that the parents had to teach their children how to assert themselves around other people. They had to teach their children to ignore and to not worry about what their peers or teachers said or thought and to speak up for themselves when they felt that their blood sugar was going too low. When children were shy this was particularly challenging for parents. Emily, for example, expressed frustration after Zoe experienced very low blood sugars at school as a result of her reluctance to interrupt the teacher, stating that:

She doesn't like interrupting the class and she's not, she is very shy. And she doesn't have enough self-confidence to go up to the teacher and say "I'm not feeling good," or, so we had to sit down with her and the teacher and get the teacher to tell her, "You get up in the middle of the class and do whatever you have to do. If you have to go poke, if you have to eat, you just do it. Don't tell me.

If you get up I'm going to know why." But still Zoe's not very comfortable doing that. We've actually had to get mad at her and say like, "You let that go too long." And she'd say, "But the teacher was reading." And "We don't care, you have to." And so it's very hard.

For the parents of children living with type 1 diabetes in this study, teaching their children how to take care of the diabetes on their own meant that their children would have reduced short and long-term complications and, therefore, a brighter future; they would be able to have careers, get a driver's license, have children, and be able to do any other things they might want to do.

Previous research has shown that during adolescence conflict over diabetes management can occur between parents and children (Dashiff, et al, 2005; Grey et al., 2009) and this was found in my study as well. This conflict was related to parents' perceived failed efforts to teach their children to follow their diabetes care plan. Some of the parents explained that when the children got negative feedback from peers or felt self-conscious about having diabetes, they were reluctant to follow their diabetes care plan. But the parents felt that they needed to urge the children to follow through with diabetes tasks despite negative peer interactions or feeling self-conscious because they feared the children would experience negative outcomes. This reluctance on the children's part and the fear on the parents' part led to conflict as parents tried to convince their children to take the diabetes more seriously. While parents did not want to frighten their children about long-term complications, sometimes they felt that they had few alternatives but share this information with their children, in the hopes that the knowledge of the complications that can result from diabetes would convince them to follow their care

plans more closely. After Jordan had experienced negativity from his friends at a new school he stopped taking his insulin regularly, and his A1C became high, leading to conflict between him and his parents. Upon feeling frustrated that Jordan was not following his diabetes care plan at school, Dave considered letting Jordan know that he may experience long term damage to his body, saying:

And some day, I mean, if he doesn't smarten up soon, well I'm going to look at where I can take him for a tour and say "Hey, this is what's going to happen." I'm not saying "It *can* happen" I'm saying "It's *going* to happen." There's a difference. And I need to get it into his head.

The parents were also aware of the need to control their own reactions and emotions when they were around their children because their moods would affect the children's emotions as well. Just as the parents found ways to maintain a positive outlook for themselves, it was also important to help their children maintain a positive, or at least a less negative, outlook towards diabetes so that the children would not become upset or depressed. Dave spoke to the fact that keeping the blood sugar within a "normal" range is very difficult and that it is important that parents not become visibly upset when they see a high blood sugar number on the glucose meter because the child will become discouraged. He said:

You know what, you're going to have to have a waving line up and down. If you don't you're going to be on edge all the time. "Oh no, oh this is, oh." but then you're going to make that person, the diabetic, nervous. You know, then they're going to be. So they, I think you have to, you know, learn how to relax with it so that they can relax with it.

Parents realized that their children were forming ideas and understandings around what diabetes means, and sometimes parents tried to manage any negative views or misconceptions that the children might have had. The literature has shown that adolescents with diabetes are at an increased risk of depression and that family functioning is an important factor in children's and adolescents' mental health (Whitemore et al., 2002) and for some of the parents of adolescent children in this study, helping their children adopt a positive view of diabetes was important so that the children would not become depressed. For example, Emily was worried about Zoe because she became discouraged and wanted the diabetes to go away. Emily, felt that she had to do a lot of extra work to convince Zoe to view the diabetes from a more optimistic point of view and maintain the hope that it will be easier to manage in the future. Emily said:

It's a lot of, like, you really have to work hard on how she's feeling. 'Cause you don't want her to get depressed and so it's a lot of constantly telling her "You know, this is your life and you have to do this. There's no choice. You can either choose to be sad about it or we can choose to just live with it, be positive about it and know that maybe someday they'll make it so easy that you won't even know."

While the parents wanted their children to feel accepting towards the diabetes and have a positive attitude towards it, they were cautious about telling their children that there will be a cure. Instead they usually focused on aspects of their lives that might get easier due to advances in treatment, such as in technology or new types of insulin that may become available.

Parents believed that as long as their children were in their care and still living

within the home, their health would be well monitored. But they also knew that their children would have to grow up and have experiences and lives outside of the family home, so they needed to prepare them for life as adults living with diabetes. Healthcare providers influenced the parents' understanding of what the children must learn, in terms of the medical aspects of diabetes. Interactions between the parents and children were also affected by the presence of the diabetes because the parents had to help the children, as well as themselves, adopt a positive outlook. While this category was largely shaped by influences within the home environment, such as the parents' desire to help themselves and their children feel well-adjusted, factors in the exosystem such as the availability of new treatments, technology, or the hope of a cure, also shape the way a parent can put the diabetes into a positive perspective. As was evident in the example of the quote by Emily, parents could help their children to stay motivated by the hope that life with diabetes may get easier in the future should treatments improve.

The way that the parents thought about parenting was influenced by the diabetes. Parenting a child living with type 1 diabetes meant that the parents needed to be committed to giving their children the same opportunities and childhood experiences they would have had if they had not been diagnosed with diabetes. All of the parents expressed a desire and a determination to ensure that their children did not miss out on anything because they were diagnosed with diabetes. For example, although many events required much extra planning, the parents expressed that it was necessary to find ways to ensure that the children would be able to attend birthday parties, camps, sleepovers, or go out for Halloween. The parents felt that they needed to do the extra planning and work

involved in ensuring that their children could participate. Vicki felt strongly that Kayla should not miss out because of having diabetes:

And nothing is denied to her because of the diabetes. I don't want her growing up thinking she's limited in any way because she's a diabetic. Because she's not. There's nothing she can't do. And she needs to know that from us early on. And if I stopped her from going to sleep-overs or stopped her from going to summer camp or on campfires with her Girl Guide group then I'm telling her she can't do something because of the diabetes. That's not to say I haven't stopped her for other reasons, but never, I've never said to her you know (whispering) "you can't because you've got diabetes." And I never will.

Some of the parents expressed a determination to give the child an even better life, since the diagnoses. Haley said "We send him, actually, and encourage him to do even more."

Not every parent, however, could invest the same amount of time in monitoring their children at activities, such as sports, or in going to their children's classrooms to educate the other students about the diabetes, due to economic and time constraints. Socio-economic factors, therefore, shape the parental response within this category. Mothers who were able to have a flexible work schedule or take time off to help their children and the family adjust to life with diabetes, had more confidence that their children would be safe while participating in various activities. Parents who felt that they could provide their children with whatever kind of treatment options the children might want also seemed to have a greater sense of confidence. For example, Haley explained:

I'm hopeful for some other treatment but I'm also very comfortable with the treatment that's, that's available right now. Sam could have a pump. Um, he

chooses not to have a pump. He, ah, likes the good old orange-capped needles. He just, you know he doesn't even want to use a pen. Yeah, he doesn't want to dial up or anything. He just, he just likes what he likes and it is what it is and it's working for us, so yeah.

Some parents, however, admitted that their children did have to make some sacrifices as a result of having to live with diabetes even though they did not want their children to have to miss out on anything. Lynne and Dave wanted to give Jordan a break from having to take too many needles by buying him reduced sugar chocolates but stopped because of the cost of "diabetes food" saying, "They charge you twice the cost. An arm and a leg. That is, that is so unfair because you know what, it cost you enough just to have your son being a diabetic that they have to soak up every little penny you have besides that."

It was evident that, because of their drive to continue to provide their children with the same or more opportunities as children living without diabetes, parents may experience a sense of failure when they are unable to uphold this ideal, or do not have the resources to do so. Some parents expressed sadness and a sense of letting their children down when they felt they could not manage the added demands the diabetes placed on them while undertaking everyday activities. For mothers with multiple children, being able to monitor their child living with diabetes closely enough to allow them to participate in various activities was especially demanding. Several mothers identified vacations, with all of the concerns over how they might be able to respond to diabetes-related emergencies while on an airplane or in a new country, as especially difficult and frightening. Emily, for example, stressed that being a single parent to two children (one

of them being a child living with diabetes) meant that they did not go on vacation at all anymore.

Providing their children with the same experiences they would have if they were not living with diabetes was important to these parents. It helped them to feel that they are the same as other families and gave them a sense of confidence that they are good parents. Pattison et al. (2006) found that parental self-efficacy had a positive impact on adjustment, or normalization, among parents of children living with type 1 diabetes. The parents in the present study felt good about making sure that their children did not miss out on anything because of their illness. As noted by Streisand et al. (2005), parents with lower self-efficacy may experience more stress. This finding has implications for some of the parents in the present study, as not all had the same resources, in terms of time and money, to meet their children's diabetes-related needs.

Mesosystem

The mesosystem is the level of the ecological system that involves the way an event or situation affects the relationships among an individual's immediate environments. The categories within this level relate to the way that parenting a child living with type 1 diabetes affected the way that the parents thought about their children in relation to other people and communicated with others about their child and family. In some contexts the parents did not talk about their children in terms of as being ill or having a chronic illness while in others they did. The parents strove for a sense of belonging for their child and themselves, in light of the diabetes.

Being like everyone else. This category reflects the parents' efforts to have their child and family be perceived by others as the same as anyone else, not fully identifying

their child as being ill, and the need to find connection with others in the same situation. Marshall et al. (2009) found that the parents in their study did not want to define their children as having a disease or as being sick. The parents in the present study illustrated this finding. In their interactions with others in the community, these parents defined diabetes as just a characteristic of their child, rather than as a disease. The diabetes had negative social consequences for the child and the family. It was stigmatizing and this played a role in the way that parents presented the diabetes to others outside the family.

Sometimes parents spoke about parenting a child living with diabetes, versus parenting a child without diabetes, as meaning that there were just simply more tasks to perform, such as making sure sugary snacks and diabetes supplies are always on hand before going out. But they stressed that their children were the same as other children. They thought of the diabetes as a characteristic of the child. For example, Lynne described how she thinks about diabetes differently now from before Jordan was diagnosed with it:

Because it's really not a disease. No one can catch it. It's just the way your body went. So, I don't know.... before it was more of a harmful disease. Now it's more of a controllable disease. So that's why yeah, the disease word doesn't you know, um, isn't, you can't even call it a mental or physical handicap because it's neither one of those either.

The parents' need to persuade others to view diabetes as a characteristic of the child rather than as a disease reflects the way in which parents responded to other people's understanding of diabetes, which reflect the socio-cultural understanding of illness as a deviation from the normal. Therefore, factors at the macrosystem level also influenced

perceptions within this category. According to Bury (2001), chronic illness represents a disruption from the norm of society, especially a society in which health is valued, and the illness causes those affected to have to redefine who they are in the face of that disruption. For some of the parents in the present study, especially those whose children were going through adolescence and no longer felt special like they did when they were younger, diabetes threatened to change the child and thereby the family's sense of identity from normal to not normal. In various social contexts, parents had to work at presenting diabetes in a way that would minimize this threat.

Neufeld et al. (2007) found that mothers of children living with type 1 diabetes felt that needles made other people feel uncomfortable. This also was the experience of parents in the present study. Situations where children needed to take needles in public compelled parents to explain diabetes as a characteristic of the child rather than as a disease. Some of the parents told stories of feeling stigmatized as a result of their children's injections. They noticed that others would stare at them or suggest that they should not allow their children to take their insulin injection in public. This happened in restaurants, during their children's activities, and at school. All of the parents responded in a way intended to convey that their children are "regular kids" who should be allowed to take their insulin in public. Dave stressed this point in a story about a negative reaction from someone in Jordan's community. He explained that taking insulin is a regular part of life that can be done out in the open:

She was the, she was the coach and she says, "Maybe you and Jordan should go over to that washroom at the back hallway to do that." And I says, "No, we can do that right here." She said, "Well the other kids don't need to see that." I said,

“Actually the other kids do need to see that. It’s part of life.” I says, “Who’s to say this one or that one or that one is not going to have it?” you know and Jordan was sitting at the table with them and they said, “It’s not a problem. You shouldn’t need to say anything.” And I said, “No, you don’t need to say anything.” So we bumped heads from then on in and she treated him different.

The parents in this study often shifted between the concepts of diabetes as a disease versus diabetes as a characteristic of the child. In recounting times involving emergency situations, parents spoke about diabetes as an illness. They also stressed that diabetes is a serious illness to school staff, while simultaneously encouraging the children to not view themselves as different. There was a positive aspect to viewing diabetes as a disease because it could mean that the children got help, but parents like Mandy felt ambivalent about this:

Um, I in terms of treating him differently I had a really hard time with, when we got the paperwork for the disability tax credit. I said to Martin (her husband) I don’t consider it a disability. You know? And so I really struggled with that label. And, and then also at school, you know, being considered special needs. Yes, I want him to have the support he needs but do I consider him special needs? Well, the school does. Do I? I don’t know. I, I worry about that label and how that changes how people treat him.

Parents did not want to define diabetes as a disability, but they knew that more help would be available if their children had this label.

Furthermore, parents did not think of their children as being susceptible to complications in the same way as others they knew living with diabetes and this

influenced the way that they interacted with others. Negative outcomes experienced by the other people they knew with diabetes were attributed to that person's failure to take proper care of their diabetes, either due to a lack of understanding or of motivation. Some of the parents would talk about diabetes management with extended family members that there were living with diabetes. Sometimes this led to frustration when parents felt that they had valuable information to share but that others were not being receptive. In discussing interactions with her mother, who was living with type 1 diabetes, Haley said:

You asked me if I spend time talking to her and stuff but it's, I know it sounds horrible but we don't. I know that it'll go in one ear and out the other kind of thing. Like she almost zones out when I, um, when we're talking about it. Any um, sometimes she'll get upset and she'll say "You know what I can't handle this conversation today."

Because they felt that they and their children had better ways of managing diabetes the parents felt that their children would not experience the same complications as other people they knew living with diabetes such as losing an eye or toes, having kidney problems, or having severe low blood sugars.

Connecting with other families in similar situations was a factor that the parents identified as helpful to gain a sense of belonging. Participating in fundraising for improved diabetes treatment or a cure, connecting with other children and families living with diabetes, and sharing knowledge around diabetes with others was important to the parents in this study. Many of the families attended diabetes-related fundraising events and expressed a sense of pride that so many people in their lives (friends, extended family, and co-workers) were generous in contributing towards diabetes research. Some

of the children also got involved; Lisa told the story of how Debbie collected money for JDRF for her birthday one year instead of asking for gifts, and was excited to be a spokesperson for diabetes:

So that's her thinking about how she can give back. And when Angela from JDRF asked her to be the ambassador she was just like flying out of her seat. She was like "Yes, yes, yes. Mom can I?" and I'm like, "yeah of course you can" you know, so yeah.

Being able to help other families was also important to the parents. They described feeling good when they were able to help other parents of newly diagnosed children living with diabetes. They were happy to help other families who were affected by diabetes through formal organizations or through neighbourhood connections. Not long before her interview, Mandy had met a parent through her son's school whose child was recently diagnosed with type 1 diabetes:

I mean obviously I'm not an expert but um, you know, I feel like I'm in a position where I feel like I can mentor this other mom at the school. Um, and that um, ah, you know, if anyone at work, I'm a first aid representative and I consider myself the diabetes expert. So anyone with diabetes at work knows they can come to me if they have any problems.

While fundraising was considered important by many of the parents, a big part of what motivated the parents to participate in diabetes events was giving their children the opportunity to be around other people living with diabetes. Similarly, if there were other children at school or extended family members living with diabetes, this was seen as helping the children to feel less alone.

Connecting with family could also help the children feel like they are not alone. Carrie felt that Shane felt a connection with his uncle who had lived with type 1 diabetes and that, since Carrie's niece and cousin, in addition to her brother, had also had lived with type 1 diabetes the whole family shared a connection. She said, "But there, you like, suddenly it's like you have this little secret society, club you know, that you feel supported by each other because of it." As a result of her son's diagnosis, Carrie also acquired a greater sense of empathy for her brother because, after parenting a child living with diabetes, she could now understand what her brother had experienced through the years.

For some parents, knowledge sharing was important. Lisa, for example, reached out to other people in the hope that someone, upon hearing her story, may be able to explain why Debbie's diabetes recurred:

I just, so many people don't know anything about it. So I'm really trying to educate people more about it, right. In my own close circle but also people outside. People at school, people I talk to, just 'cause I'm always thinking maybe there's somebody out there that can help me figure out why this came back. So that's why I kind of always put the word out there, you know.

Scott and Amy felt that since Austin was living with diabetes, Austin had important experiential knowledge to share with other children living with it: "He'll go to help, he's helping other children, boys and girls so we're ah, we're probably gonna be doing some you know, just sharing with other people what it's like to, to connect people in this way."

Since the diabetes brought about a sense of being different, connecting with others was helpful for families. They felt that the only people who could really

understand them were other parents of children living with diabetes. This finding supports those of Coffey (2006), who found that the parents of children living with a variety of chronic illnesses, including type 1 diabetes, felt that only other parents in the same situation could really understand what they are going through, and that seeking support from other parents in the same situation was an important way to cope.

Parenting a child living with diabetes changed the way that parents interacted with the community – they needed to reach out to other parents and families in the same situation. Previous research has shown that families living with diabetes have to work towards a sense of “normal” (Marshall et al., 2009). For the participants in the present study, reaching out to other families and to organizations helped them to regain a sense of normalcy and reduce feelings of isolation.

Protecting the children. While the first category in this level of the system represents the ways that the parents advocated against looking at diabetes as an illness and strove for a sense of belonging, this category is about the situations in which the parents emphasized the seriousness of diabetes and their efforts to make sure that the children were protected from negative outcomes related to the diabetes while they were with care providers other than their parents.

The parents told stories of making efforts to protect their children from being ill-treated by others. This involved advocating for the children when other people were not understanding or accommodating their diabetes-related needs. A great deal of effort was put into informing and correcting school personnel in order to protect the children from diabetes-related emergencies or from negative social outcomes. Many of the parents went to their children’s schools and provided staff, and sometimes other students, with

information on the symptoms of low and high blood sugar and what measures to take in case of an emergency. Other parents shared stories of insisting to school staff that their children be able to test their blood sugar at their desks, instead of being required to leave the room, or be able to leave the room accompanied by a classmate when they felt that their blood sugar was low. Parents who felt that school staff were not responding appropriately often insisted that some adjustments be made at school in order to accommodate their children's diabetes-related needs. Mandy felt strongly about the need to protect Tyler:

I like, for example at the school when I felt that they weren't educating themselves enough about diabetes and what he needed at school to get through the day, I did get kind of mama bear and I phoned the nurse educator for the school and said "You need to educate your staff. I'm frustrated." And, um, and so I will ah, that's where the advocate part comes in. That, you know, I, I, when it comes to the diabetes education that maybe I can push a little more on the, but I wouldn't ask for any other special treatment, you know, because of the diabetes, so.

Mothers of younger children also went on field trips when their children were younger, or when their children had been recently diagnosed, so that they could be sure that the children would be alright while they were at school.

According to Kliebenstein and Broome (2000) communicating with schools is an important issue in parenting children living with chronic illness. However, not all of their attempts are successful. Dave and Lynn shared the story of their attempts to convince staff at Jordan's school to bend their policy requiring students to share lockers because it meant that Jordan could not keep his insulin in his locker where it would be more

accessible than it was in the school office. For Jordan, the staff's rigidity had social and physical consequences because he felt singled out when he had to go to the office to take his insulin, leading him to not take his insulin at school. This was an ongoing issue that had become quite stressful for Dave and Lynne. They felt that the school was not being accommodating because they were poorly educated about diabetes.

Some parents, however, received strong support from their children's schools. Some even made extra staff available to help monitor the children, oversee their care plans, or maintain regular communication with their parents. The level of support schools were able to give appeared to vary depending on the neighbourhood in which the children lived.

Parents expressed concern over being able to trust that others would notice and respond to cues in their children that would indicate an emergency situation. Since the parents could not be with their children all of the time, they had to teach other people about the diabetes and trust them to respond appropriately. As Hatton et al. (1995) found, trust is a prominent issue for these parents across a range of situations, such as school, visiting at friends' houses, birthday parties, and babysitting. Lily expressed her concern about sending Charlie to birthday parties: "You're leaving him alone for three, four hours, and you're assuming that maybe the people have a little bit of a clue." While the parents were committed to having their children participate in the activities they were interested in, leaving them there required taking a chance that everything would be ok.

While parents were committed to having their children participate in activities, they had to take risks in doing so and then manage their fears. Carrie described the longest trip Shane took away from home, to a camp in another province. It was planned

that Shane would visit the nurse once a day to just to check in. Carrie was reassured that since Shane could not be easily reached by telephone, she could call the nurse to make sure things are going well. However, when she phoned she was unable to reach anyone, leaving her wondering how Shane was doing; “And then I couldn’t get a hold of them. And so I’m kind of like ‘Carrie, let it go, he’s almost 17 years old. Like you, he’s not a little kid.’ But on the other hand I’m thinking, ‘Oh my gosh, oh my gosh!’”

The issue of trust also was prominent in the school context. As Kliebenstein and Broome (2000) found, some of the parents did not trust that schools would be able to respond appropriately to diabetes-related emergencies. Vicki felt that she could not trust that substitute teachers would be well informed about Kayla’s diabetes. She shared the story of Kayla having low blood sugar while running laps during a gym class when there was a substitute teacher:

But she also had a gym teacher who, who was a substitute and when Kayla asked to leave the class to go get some snacks the teacher said, “No, you can just run another lap.” And Kayla said, “No I can’t run another lap.” She (the teacher) said, “We’re not done what we’re doing. You need to finish this.”

In order to care for herself, Kayla decided to ignore her teacher’s instructions. Situations such as these eroded parents’ trust that teachers would be informed about diabetes and how to respond to an emergency.

Some parents were concerned not only about teachers’ under-reactions, but also about their over-reactions, which could cause their children embarrassment. Emily’s story of Zoe’s school experiences reflects this.

The first year she had one episode where she was sitting on the floor with the kids and just put her head down like she was falling asleep, on her friend's shoulder. And the school freaked out, like, the teacher didn't know what to do. They put her on a chair with wheels and they wheeled her down to the office. I thought we went over how to handle everything and we had that plan with the nurse. But they wheeled her all the way down to the office, they phoned me, I'm telling them, "Give her juice, give her juice!" And when I got finally to the office, the teacher was crying and she's shaking and the principal's crying. Everybody in the office is sitting there crying and they had phoned 911 by then. So when I pulled up the fire people were there already. And it wasn't even, it wasn't even a bad one. Like, it wasn't.

This situation caused embarrassment for Zoe because she did not want attention drawn to her because of the diabetes.

Some of the parents expressed frustration that their children's schools were not able to do more to help children living with type 1 diabetes, such as administering a glucagon (an injection to raise the blood sugar level) instead of calling an ambulance if the child were to go unconscious. They speculated that it is fear that prevents school staff from responding appropriately.

Sometimes when parents were not confident that others would be able to take care of their children's diabetes-related needs, they reminded themselves that they can trust the children themselves to monitor their blood sugar and follow their care plans. Instead of explaining all of the details of their children's diabetes care to other people, some parents found it easier to focus on the children's ability to do it themselves.

Parenting a child living with diabetes influenced parents' trust in, and their interactions with, their children's schools. The parents wanted their children to be integrated into the school as much as possible so that they could be cared for without feeling singled out, but parents did not always trust that this would happen. School division policies around administering medications and their approach towards chronic illness and children living with disabilities is an important factor influencing the parental perceptions within this category. In schools where the staff are well-informed around the diabetes the parents will be able to trust that their children will be alright when they are at school, but in situations where school staff are not all aware or able to respond appropriately, parents' trust is shaken.

The medical context may also shape the parental understanding around the issue of trust. Since school policies and diabetes care plans are based on medical understandings of diabetes, with a focus on controlling blood glucose, care plans may not take into account the children's experience (such as feelings of embarrassment when an ambulance is called to the school). Furthermore, because diabetes is understood as a serious medical illness, school staff may have fear around helping the children manage their blood sugar levels because these procedures are viewed as medical procedures that are beyond their competence.

Exosystem

The exosystem represents the systems that an individual is not in but which impacts the way an individual perceives and responds to their situation (Bronfenbrenner, 1979). The category within this level focuses on parental perceptions of drug companies, diabetes research, and the medical system. The following category, therefore, reflects the way environments outside those in which the parents actually enter have an impact on

their perceptions and responses.

Putting faith in the unknown. Many parents expressed distrust in the medical system and drug companies. They viewed drug companies were profiting from their children's illness because of the high cost of diabetes supplies. Some of the parents were frustrated with the cost of blood glucose testing strips and insulin pumps, for example. Lynne and Dave spent a great deal of effort looking into ways to raise money for an insulin pump, such as community legions or trying to win money through a radio call-in show because they could not afford to pay for the pump on their own.

Parents speculated that a cure will not likely be found soon because drug companies are generating such large profits from diabetes. Lisa noted that the rates of diabetes are increasing in Canada and all over the world, making it a billion dollar a year business:

But I think the drug companies, they make a lot of money by having people who have diabetes right. Insulin costs money, test strips, lancets...I think if you take away diabetes and have a cure for it there go all those drug companies and their major sources of revenue all over the world, the whole world.

Parents also wondered why, when so much money is being raised for diabetes research, there is not yet a cure, speculating that perhaps researchers are not really motivated to find one. Cheri said:

There's a lot of stuff we don't know what's going on and I completely believe in those conspiracy theories, that um, money, money rules the world. And if they don't figure out how they're going to profit from it, who knows? There may be cures for all these things that we, these horrible diseases and cancers and

everything, just until they figure out how to profit from it they're never going to release it.

Scott even speculated that people, rather than doctors, would eventually figure out what is causing diabetes, as well as other illnesses, so that people can prevent it themselves.

A parent's ability to afford diabetes treatments was also a factor influencing parental perception within this category. Parents stated that it is expensive to parent a child living with diabetes. Parents' drug plans will, therefore, influence their views of the medical system. Drug programs vary from province to province and not everyone will qualify for provincial drug programs (Kwan, Razzaq, Leiter, Lillie, & Hux, 2008). While all of the parents in the present study had some type of coverage, either through Pharmacare (the provincial program in Manitoba) or other insurance coverage, not every cost was covered, making treatment options limited for those without high incomes.

Parents who were not experiencing financial strain felt positively about the possibility of their children being able to choose their treatment options, now and in the future. Also, parents who had medical training and had been exposed to medical understandings of diabetes did not express distrust or scepticism of the medical system.

Macrosystem

The macrosystem is the level of the ecological system that involves generalized and overarching patterns of ideology and organization of social institutions common to a culture (Bronfenbrenner, 1979). In the following categories, the parents explain what it means to manage diabetes in terms of who is responsible for carrying out diabetes-related tasks as well as the way they think about diabetes in their daily life. The parents'

explanations reflect the generalized patterns of ideology in Canada and Western culture generally, as well as the organization of institutions, such as the healthcare system.

Keeping it in the family. Within this category is the parents' understanding of the responsibility for carrying out diabetes related tasks and for the outcomes related to diabetes. Until the child was ready to self-administer injections, parents were the only ones to perform them. And, since management is complex, parents did not view it as care that others could be expected to take on. As a result, when their children were with others, the parents still planned ahead and communicated with their children directly over the phone in order to manage their diabetes. Extended family did not play a primary role in caregiving for any of the families. Upon being asked if extended family members are involved in any diabetes management, Lily said:

Ah no, it's just our family, you know. We just sort of deal with things. We're not real, sort of, emotional or excitable or anything. You know, it's just like ok, he has diabetes and this is what we do. But ah, no, I've always felt it was our burden, not anybody else's so. My mom's not too bad, you know, she'll look after him. It makes her nervous. It makes people nervous, you know.

Thinking about balancing carbohydrates with insulin, exercise, or other factors was considered too complex for non-family members to think about. The parents felt that it requires others to remember too much information. In some cases, parents chose not to leave their children with family members living with diabetes. Haley, whose mother was living with type 1 diabetes, felt more comfortable leaving Sam with his paternal grandmother because management styles between Sam and his maternal grandmother were very different. Haley said that with "the other grandmother that doesn't have

diabetes it just seems more straightforward,” although neither grandmother gave injections because Sam was able to do it on his own. In other cases, family members were not supportive at all because they did not understand. Vicki’s family would eat treats in front of Kayla and this could be upsetting for her: “That they didn’t get it. They didn’t get it. They didn’t understand.”

However, many of the parents who spent time with extended family described support that they provided even if they were not involved directly with diabetes-related tasks, such as having diet soft drinks available or asking about what the children could eat and making it available. Family members also gave emotional support to the children; they praised the children for being brave and were impressed by how they were able to take a needle and check their blood sugar.

The parents felt that other people were frightened by needles, and just kept a distance. Some people had previous experience with diabetes were frightened by it. In Lily’s words, “I think the more you know, the more scared you are.” Parents explained that it was difficult to send their children out to friends’ houses or to parties because they did not want to put the burden of the diabetes onto other parents. Emily felt that Zoe did not get invited to parties because of her diabetes: “Well the one, the mom just came right out and told me she said ‘I’m too nervous to have Zoe’ and I said ‘I understand completely.’” The parents worried that something could go wrong when their children were in another person’s care and that it would be unfair to place that responsibility on them.

Leaving the children with a babysitter was not usually considered an option because it was just too much responsibility for a sitter. Mandy said, “Who will babysit

him and manage his diabetes? I can't get a 13-year-old to babysit him because I can't trust a 13-year-old to manage his carbs and his insulin." Parents also did not take trips without their children. Several of the parents talked to individuals from the JDRF and the pediatric clinic regarding this concern, wishing that there could be some type of formal service for children with diabetes, such as Cheri who suggested "a visiting nurse service that would monitor and administer insulin."

Because diabetes management was considered the primary responsibility of the immediate family, parents found it difficult to get a break, particularly parents of younger children who were unable to self-administer insulin injections. Several mothers noted that they felt guilty for wanting a break at all, since their children could never get a break from it. Parents also felt guilty when their children's blood sugars were not well controlled, since diabetes outcomes in the child were attributed to parental behaviours.

These findings support those of Neufeld et al. (2007) who found that mothers of children with chronic illnesses felt blamed for poor illness management, as well as feeling that extended family and friends were unable to help with childcare due to a discomfort with needles. Needles may be symbolic of serious health problems, so injections may be seen by many as an intervention that should only be administered by healthcare professionals or experts. As Bury (2001) stated, the medical understanding of illness and of performing medical procedures is that they are meant to be for professionals only. These beliefs may contribute to people outside the immediate family wanting to keep their distance. Furthermore, the lack of knowledge about type 1 diabetes among people generally, as noted by many of the parents in the present study, may reinforce the parents' understanding that diabetes is the family's burden.

Additionally, most of the parents felt that the children's actions, once they started managing the diabetes on their own, were the primary determinants of the diabetes-related outcomes that their children would experience. While the parents wanted their children to have happy childhoods, they also knew that they had to instill a sense of personal responsibility towards diabetes management so that they would be able to live full lives and reduce future complications.

The children could demonstrate their responsibility by taking small steps such as their checking blood sugar levels or taking insulin without being asked or reminded. For older children who wanted to spend time outside the home, demonstrating responsibility would give them the freedom to do the things that they wanted to do. Lily said, "He's going to do his own thing. At some point he'll have to take responsibility for himself and his actions and consequences, but it will still kill us watching."

As children got older, sometimes parents felt that they were running out of time; they knew that the time would soon come where they would not be with the children anymore to support them. Shane was finishing high school and thinking about going to university. This was a source of concern for his mother because he did not always make his diabetes management a priority and still needed help to keep his blood sugars down, as indicated by results of routine A1C tests. Upon reflection around what would happen in the future, in terms of Shane being able to manage his diabetes on his own, Carrie said:

You have to move on and start taking care of yourself more. And ah, so I will say "Ok, Shane, you really gotta take care of it" and then we'll go into the hospital and it's and his um, A1C will be, will be alarmingly high. And then I'll just, oh gosh! You know, I gotta get right on you again. And you know it's that constant

see-saw. How much freedom do you give him? And how much to take back.

The need for children to take responsibility for their own diabetes management and the sense of urgency around them doing so was sometimes a source of conflict between parents and children. When the blood sugars were not well controlled, the focus was on altering aspects of the children's behavior. After transitioning to high school Jordan's blood sugar became very high. Lynne and Dave described their conflict with Jordan as they encouraged him to take more responsibility: "I guess it's been more of a fight or argument. He's not following it as well...more bucking. There's just more bucking involved." Parents turned to diabetes educators for advice and guidance and these individuals would help parents to work with their children around aspects of management that were particularly difficult for the children to follow.

In some cases, parents noted factors that were preventing their children from following or taking responsibility for their diabetes plans. Some of the children did not want to inform those around them of what to do in case of low blood sugar because they felt embarrassed. Others did not check their blood sugar or take insulin when they should have because their friends were unsupportive. Jordan did not want to take insulin at lunch time (at school) because his friends became impatient, since taking insulin meant going down to the office where it was kept. Dave shared the story of how this information came up at a diabetes appointment:

Well he was in there and the nurse was saying that, I guess digging into him a little bit because of his AC1 being so high. Trying to explain things to him. And I stepped in and said "Well you know darn well what can happen." I says "You could lose kidneys, you could lose toes, you' everything." So the nurse stepped in

and she started talking about it at him too. And then he started cheering up a bit. You know, then he's, then he's, "Well it's just my friends and, you know, they didn't" and he didn't want to talk too much more and she went and got the social worker. The social worker came in and then he opened up about it more with her.

Therefore, a medical focus on control of patients' behaviour without having an understanding of their life contexts can lead to unreasonable demands being placed on individuals living with diabetes (Dickenson, 1999).

The common focus on individual responsibility reflects the Canadian medical culture in which the emphasis is primarily on control of disease through the monitoring of physiological processes (Waldram et al., 2000). Within this model, management is largely shaped by notions of individual responsibility as determinants of long term outcomes (Wong et al., 2009). In the context of diabetes, management is viewed as a personal responsibility and, as a result, negative outcomes may be attributed to the individual's commission or omission of particular behaviours, as opposed to environmental factors that may enhance or constrain the individual's ability to manage his or her diabetes. A focus on blood sugar control at diabetes appointments may reinforce the need to put more individual responsibility on the children, who may feel blamed when blood sugar control is poor. From the children's point of view, peer acceptance may be more important than blood glucose control, and this may prevent them from following through with diabetes plans.

Popular understandings of diabetes do not take into account the fact that not every child or family will have the same situation or resources. For children within school settings where other students or teachers are not well informed about the illness or where

few accommodations are made for children living with it, children may feel that they have to choose between managing their diabetes or being accepted by their peers.

Thomas, Peterson, and Goldstein (1997) found that children and adolescents would choose behaviours more consistent with peer desires than diabetes management and Pendley et al. (2002) suggested that interventions for children and teens with diabetes should involve mobilizing support from the children's friends as well as family.

Incorporating diabetes into daily life. Diabetes was understood as something that the parents needed to keep from taking over their lives. Sometimes diabetes was talked about as a kind of intrusion into family life that needed to be held at bay, in order to ensure that the child and the family would not be deprived of the full enjoyment of life. When her child was diagnosed, Mandy said that it felt like “something that was going to consume every day of our lives for the rest of our lives.” Vicki summarized this by saying, “You control it. It doesn't control you,” meaning that parenting a child living with diabetes should not be all about the illness.

For some of the parents maintaining control meant not allowing their children's lives to be taken over by medical procedures. While they still did their best to plan ahead and maintain blood sugar levels, they set limits around how much they would actually make their children test their blood sugar or correct it by taking extra insulin when it was high, whether they would get up in the night to test their children's blood sugar, whether they would restrict the foods that their children could eat, or whether they would try new types of medical treatment. The parents compared themselves with other parents of children living with diabetes, saying that the other parents were too restrictive because they would have their children constantly test their blood sugar or would now allow them

to participate in activities where there would be a risk of the children's blood sugar going too low. Carrie, for example, felt that life for another family she knew with diabetes had been taken over by the illness, and she did not want this to be the case for Shane:

She, the other mom, had said you know "We have him playing baseball. Well, he would like to play soccer but we won't let him play soccer because if he was going for the ball to go into a goal and he really went low? And he, you know, it would be more important for him to go do the goal than it would be for him to take care of his low." And meanwhile if he's playing baseball you're usually just standing there so it would be easy to pop something – sugar tablet.

Sometimes, not letting the diabetes control the family meant sacrificing optimal glycemic control. Marshall et al. (2009) also found that parents sometimes would sacrifice good glycemic control in order to regain a sense of normalcy. In the present study, some of the parents accepted that their children's blood sugar levels might not be as optimal as they could be. But setting limits on the amount of time their children would have to spend doing medical procedures was understood as a fair trade-off in order for their children to enjoy life as much as possible. Vicki knew another family wherein which the parents seemed to insist that the child's blood sugar be kept strictly on-target, and she felt that this placed unreasonable demands on the child: "I refuse to have my daughter test 15 times a day so that she can correct that many times a day. I refuse to have it control her. Now in the end maybe they'll fare better, but at what cost?"

Some of the parents commented on the need to rely on technology (blood glucose monitors) and expressed anxiety about its potential to fail and about running out of supplies. This technology increased their feeling of being controlled by the medical

aspect of diabetes. None of the children were using an insulin pump, this was something that some of the parents were considering. Dave and Lynne, who wanted to get an insulin pump for Jordan, speculated that there may be challenges to using the pump, such as kinks in the tubing. They recognized that, in the end, the pump might not work well for Jordan. Scott stated that he would not choose an insulin pump, even though for Austin the cost would be covered, because “they’re very technical. And I think they’re too technical.”

Sometimes the understanding that the children’s blood sugar could not realistically be expected to remain on target all of the time had to be explained to other people who had contact with the child. For example when one of Tyler’s teachers stated that she thought that his numbers would become “stable”, Mandy felt frustrated, explaining that stability is not the nature of diabetes. She said that “it is what it is.” For many of the parents in the present study, diabetes was something that could only be contended with, or responded to, on a moment by moment basis, rather than being “controlled.”

Some parents, however, planned to do everything that they needed to do in order to keep their children’s blood sugar under control, while still participating fully in life. They did not feel that they would ever sacrifice good glycemic control and did not resist the medical aspects of diabetes. This parenting approach appeared to reflect parents’ availability to do extra planning, such as going to the child’s classroom to speak about diabetes, being able to accompany the child to sporting (or other) activities, or jobs that gave them flexibility in their schedules. Being in this type of situation likely increased these parents’ confidence that they could keep their children’s blood sugar under control

without those efforts taking over their families' lives. Not all of the mothers, however, were able to invest this much time in these activities. Therefore, for some of the parents not letting diabetes control their lives meant resisting the medical aspects of diabetes and for others it meant accepting those aspects of the illness.

Parents did not want the diabetes to limit their children's ability to do the things they wanted to do. This is reflective of the Canadian culture which can be considered predominantly individualistic. Shimizu & Paterson (2007) found that Canadian participants in their study were motivated to adhere to diabetes plans by the desire to be able to do the things they wanted to do if their diabetes was well-managed, versus being motivated by a sense of duty towards others or because it will benefit others. However, in my study some of the parents felt that being able to do the things they wanted to do also the need to reduce adherence to medical plans.

The knowledge that a parent had around diabetes likely was shaped by the parents' occupation and background. These factors influenced their level of comfort around medicalization, including the use of medical technology. Haley and Mark, for example, both worked in health-related occupations and expressed confidence that they would be able to help Sam try out any type of treatment option he wanted. Parents who do not have the same familiarity with the healthcare system and medical knowledge may feel more sceptical about using technology because it did not seem like a "natural" part of life. According to Conrad (2005) "technology has often facilitated medicalization." (5) and those who have not been exposed to dominant medical understandings of illness may, therefore, be less likely to feel comfortable with medical technology.

Chronosystem

The chronosystem is the level that reflects an individual's history, or the patterning of events and transitions over the lifecourse (Bronfenbrenner, 1979). Within the categories in this level I describe how the early experiences in the parenting of their children living with diabetes shaped their understanding of diabetes as an illness.

Does heredity matter? Parents who had grown up with another close family member who had lived with type 1 diabetes tended to assume that the cause of their children's illness was genetic, while those without such a family history wondered more about the cause of their children's diagnoses and searched for answers. Those with a family history of diabetes (type 1 or type 2) explained that they had more knowledge of the negative outcomes of living with diabetes.

Two of the participants had a close relative who had lived with type 1 diabetes; Carrie had an older brother who had lived with it for many years, and Haley had a parent who was currently living with it. These two mothers assumed that the cause of their children's diabetes was heredity, at least in part. These mothers did not wonder about the possible causes of their children's diabetes (while the parents with no family history or with family history of type 2 diabetes did). Carrie spoke with her brother who was living with type 1 diabetes shortly before Shane was diagnosed, because Shane was becoming sick and showing symptoms of diabetes. She explained to her brother:

You know, I'm worried. I'm worried that it might be diabetes. I knew enough about the signs because I remember in school doing a project on it just because of, um, you know knowing that it was in my family, knowing about him. But not realizing at the time that it ran in families and that I could be concerned, should be concerned about it. Although as a child I remember being tested myself.

Carrie did not think about diabetes in terms of it being hereditary until her son was diagnosed, at which time, it occurred to her that it must have been caused, at least in part, by hereditary factors. For Haley, also having a close family history of type 1 diabetes, there was no questioning the cause of the illness; she assumed that it was triggered by hereditary factors.

The parents with type 2 diabetes in their family history did not see it as being related, in the hereditary sense, to their children's diagnoses of type 1 diabetes. When asked about whether or not a family history of diabetes was something that they thought about when their children were diagnosed, parents with type 2 diabetes in their families did not think that their children had been more susceptible to diabetes because of the family history. Because their children's diabetes was not attributed to genetic factors, parents with a family history of type 2 diabetes also wondered about the causes of their children's illness, just as parents without a history of diabetes did. Lisa, for instance, had a father who had lived with type 2 diabetes and did not attribute Debbie's diabetes to heredity. She felt that type 2 diabetes was nothing like type 1 since type 2 results from lifestyle factors that she understood as being "completely controllable" while this was not the case for type 1 diabetes. However, she did experience her father having serious complications of diabetes, and she did not want Debbie to know about this. Dave and Lynne (Lynne had a parent who had suffered serious complications due to type 2 diabetes as well) noted that they "know more of what can happen" and worried that the same thing could happen to Jordan. Scott and Amy also had type 2 diabetes in both their family histories and Scott's mother had died as a result of diabetes-related complications. Contrary to other parents' views of type 2 diabetes being completely different from type

1, Scott made no distinction between the types of diabetes but expressed that the illness was particularly “devastating” for people living in northern communities. Despite having a family history of type 2 diabetes, Amy did not express worry about future complications as she preferred to stay focused on day-to-day life.

In discussing their interactions with other people in the community, some of the parents explained that they felt that other people over-emphasized the genetic component of diabetes. Dave explained this point when he spoke to Jordan’s friends who did not understand diabetes, warning them that it could happen to them as well, or anyone:

You don’t ever, and you know that’s what I want to say “Don’t ever think,” and I said that to some of his friends “Don’t ever think that you won’t get this.” I says “This can happen to anybody.” And then I get some “Well, oh, it runs in the family, ain’t that how you get it?” I says “Type 1 is onset.” You know, I says “It can happen to anybody at anytime.” I says “I have no diabetes in my family. But Jordan’s became diabetic.” She (Jordan’s mother) has only type 2 in her family.

Dave felt that others mistakenly assumed that Jordan had a family history of type 1 diabetes and that they themselves would not get diabetes if they did not have a family history of it. And he did not consider type 2 to be linked to type 1 through heredity.

Ethan’s father had a cousin who had been living with type 1 diabetes for a long time and another cousin’s child was diagnosed with type 1 diabetes not long before I had interviewed Cheri. When Cheri was asked about whether or not she thought about diabetes as hereditary at the time of Ethan’s diagnosis, she said:

Um, no not in the least. Because the first cousin, you know, has had it all his life and then this one (Ethan’s father’s cousin’s child) was diagnosed after him. Well

after the second cousin was diagnosed then I thought maybe there's something on the mother's side. That's what it seems like, cause they're all directly related through my husband's mother's side of the family.

For Cheri, with the recent diagnosis of her husband's second cousin, the hereditary aspect of diabetes appeared to be more plausible.

Hereditary, therefore, influenced the way parents understood the cause of the diabetes. For the parents who had a close family history of type 1 diabetes, it was looked at as hereditary and those parents felt that this played a part in their children becoming diagnosed with diabetes while families with a history of type 2 diabetes did not see the cause of their children's diagnoses as genetic. When a parent knew another close relative with type 1 diabetes, heredity was then one of the factors in the child's immediate environment that helped to explain the cause of the diabetes in the child and there was less ambiguity around the cause of the children's diagnoses. Healthcare providers as well as the media may both also influence the way that parent think about heredity; many parents mentioned that they were asked by healthcare providers if they had a family history of type 1 diabetes and they also heard information through the media about type 2 diabetes, particularly around eating and lifestyle factors as the primarily cause of it, and that it was, therefore, not a factor contributing to their children's diagnoses of type 1 diabetes.

The course of the illness sets the tone. Some of the parents went through particularly difficult and emotional experiences close to the time when their children were first diagnosed with diabetes and they explained that this had an impact on their outlook related to parenting their children. Debbie had been born with neonatal diabetes.

Lisa was told by doctors that this was very rare and that they did not fully understand why it happened. Lisa described looking after Debbie as a newborn who was dependent on insulin as a time of intense stress, medical interventions, and uncertainty as doctors tried to determine the cause of, and an optimal treatment for the diabetes. Little support was available, making the experience of parenting an infant with diabetes more difficult. While a nurse came to the home, she did not help with insulin injections. Lisa said:

I need somebody to give insulin, right. I need somebody to, when I'm shaking like this and I'm calling my husband from work 'cause I've got a 5 pound baby and I haven't slept for months. Like literally months. I was so like, fatigued and like almost living in another zone. Like not living in, like, anywhere where I even remotely remember the person I was, which is really bizarre.

The neonatal diabetes went away before Debbie turned one, but the family was told that it could recur, which it did when Debbie was 10 years old. These early experiences, within a context characterized by a lack of knowledge about the cause of the diabetes, resulted in great confusion and uncertainty for Lisa. She wondered if Debbie's diabetes would remit again in the future. She believed that Debbie had a different form of diabetes, given its remission and recurrence. While Debbie was dependent on insulin to live, her diabetes did not appear to recur as the result of an autoimmune mediated response, which is the generally accepted cause of type 1 diabetes. Lisa stated that doctors had "done all the tests and she's not type 1." This situation affected Lisa's level of acceptance, as well as Debbie's, and increased their uncertainty about the future. Lisa explained that "I don't think she thinks she's gonna have it for the rest of her life. And I don't know that I

believe it either.” This uncertainty had an impact on the family’s sense of identity and belonging within the diabetes community:

Like even with them asking her at JDRF to be the ambassador for type 1 diabetes I say to Jen and to Sarah “You guys understand that she’s not type 1 and she’s not type 2, you know.” And she got invited to camp Briardale (a camp for children living with type 1 diabetes) I say “You know Dr. Smith she’s not type 1 or type 2, you know that.” She goes “It doesn’t matter. She still has diabetes.”

Emily explained that because Zoe had experienced very low blood sugar in which she lost consciousness and had seizures, her sense of burden and loss of spontaneity was heightened. Emily shared Stories around the surrounding circumstances of these experiences. For example, Zoe’s blood sugar became very low when they were on a vacation and it was difficult to get it back up:

And her mouth was just clamped so shut and I was trying to pry her teeth open to get it down and nothing. So then I yelled at my son to phone downstairs and they brought sugar water but she wasn’t taking anything in. so then we just decided we had to phone 911. So they came and they were, just got an IV in her and I guess some of the juice started to work and she started crying. And like, she doesn’t know when she has these. She doesn’t have any memory and doesn’t, has no recollection of what happened. So she just woke up to this guy standing over her with a needle in her arm and she panicked. So the ah, they just assessed it that she was coming out of it and we gave her more juice now that she was aware. But then she’s just sick after.

Emily felt that life had not been the same since experiencing several particularly frightening experiences of low blood sugar levels in the night. She did not sleep as well as she used to and she felt the need to be always on guard. Other parents also shared stories of their children's blood sugar becoming too low and experiences like these tended to increase feelings of guilt because they were not able to predict emergencies and because the parents worried that they gave their children too much insulin, causing their children to lose unconscious or have a seizure.

Factors in a parent's own life may contribute to the course of diabetes over time. Emily separated from Zoe's father shortly after Zoe was diagnosed. Her emotional stress added to the strain of caring for Zoe. Multiple stressors can have an impact on a parent's available energy. After Zoe had lost consciousness, she later called healthcare providers for advice: "So then I phoned the clinic and told them and they were all mad that I didn't have the, what's the name (glucagon). But at that time we had separated and I thought I would leave it with her father and I just forgot to get my own." Because Emily was managing the separation and the diabetes simultaneously, her routine was disrupted and her focus was distracted. This situation led to a sense of self-blame.

Neufeld, et al. (2007) found that mothers of children living with diabetes had support needs that often went unrecognized, and that they often felt blamed by healthcare providers for poor illness management. The findings of the present study support those conclusions and suggest that stressors that occur in a parent's life that are not directly related to their children's illness can impact diabetes-related outcomes.

CHAPTER V

Discussion

This study has demonstrated that the presence of diabetes brought new meaning to parenting for the participants and that this new meaning influenced the way that parents responded to their children's diabetes-related needs.

In the face of their children's diabetes the parents' worked to define the illness as a characteristic of the children rather than as a disease, particularly when discussing situations where the children were out in the community. Experiences of stigma – for example, when other people stared at their children or made negative comments while they took insulin – meant that others were perceiving their children as not only ill, but also as not being normal because they had to take insulin injections. An implicit sense of 'what is normal' for children pervaded the strategies that parents employed regarding their own children; for example, the children were not perceived to be normal by others because they did not conform to conventional ideas about what it means to be healthy. The parents now had the added challenge of deciding how to respond to these messages, because they may have been internalized not only for themselves but also in their children. By creating a sense in which the diabetes was a characteristic of the children rather than an illness the parents worked to re-define what it means to be normal, hopefully transferring this to their children as well. The parents accepted that the idea of 'what is normal' is important, but normal now meant that sometimes people need to inject insulin when their body does not produce it and the parents stressed that other people need to accept this definition of normal as well. Parents, therefore, pointed out that it is other people's problem if they are uncomfortable with needles and insisted that

their children be allowed to take insulin wherever they want. This translated also to strategies regarding diet, safety on school trips, going to other children's birthday parties and other 'normal' activities that children are expected to engage in without hesitation or the need for specialized care. By placing the responsibility of defining of normal onto the other's view of taking insulin, the parents worked to preserve their children's identity as regular children. A process of normalization has been well documented by other authors, when families are affected by type 1 diabetes (Marshall et al., 2009; Wennick & Hallstrom, 2007).

Parenting children with needs that were perceived as not being a normal part of life pressed the parents to put greater emphasis on the immediate family as providing daily diabetes care. The parents did not feel it was appropriate for other people to be expected to give insulin because injections and diabetes monitoring was not a regular part of life. Living with diabetes meant keeping everyone in the home informed about the diabetes and making sure that all of the family members (parents and siblings) knew what needs to be done to keep the child safe because they were the ones who could be relied on to help in an emergency situation. Sometimes parents worried that siblings of the children living with diabetes did not get fair amounts of attention and this shaped family dynamics in daily and ordinary ways. However, the parents felt that, because of the need for the family to communicate more due to the need to manage the diabetes exclusively within the family, the families drew closer. This was seen as an implicit strength for the family system.

In light of the need to regain this sense of being normal, the parents also needed to manage their own and their children's sense of belonging. They did this by getting to

know other families with diabetes and giving their children opportunities to be around other children who were living with diabetes. Their experience was considered to be one that only other parents in the same situation could understand. This created a new kind of community among families with children with diabetes, and provided families with a unique sense of belonging to this community, where recognition of similar issues likely diminished the stigma that might be felt in the mainstream world.

Furthermore, the diabetes affected the parent's sense of self and well-being as parents. The parents felt that others perceived them negatively, as parents, because they had children that were not considered to be normal and healthy. Bury (2001) states that an individual who is affected by a chronic illness will have a sense of meaning that reflects his or her moral evaluation of the illness and of the ways in which the illness changes their sense of identity in relation to family or society, and findings from my study reflect this because the diabetes caused the parents to reflect on themselves as *good* or *bad* parents. When parents speculated about the cause(s) of diabetes the sense of meaning was that others might believe that they had done something wrong or failed their children in some way, and that this failure to be good parents resulted in the children's diabetes. Some of the mothers maintained that they must have fed their children the wrong foods or took medications that they should not have, and therefore felt guilty for causing their children's diabetes. When the parents discussed interactions with others in the community, they emphasized that the cause of diabetes is unknown and it was important that other people knew that diabetes can happen to anyone's child. Explaining diabetes in this way helped to work against the idea that they were responsible for

causing their children's diabetes. The image that good parents have healthy, normal children was something that the parents had to make sense of on an ongoing basis.

Parenting a child living with diabetes brought changes to the way that the parents thought about factors outside themselves and the home environment. The healthcare system was a powerful mediator for how parenting in this situation was experienced on a daily basis. Some of the parents were frustrated with the cost of diabetes-related supplies such as blood sugar testing strips and insulin pumps and felt that it was unfair that drug companies generate profits while they struggle to provide the best possible care for their children, with limited options. Daily experiences such as paying for medical supplies, pharmacare deductibles, and specialty foods for diabetes led parents to evaluate their level of trust in the healthcare system and this is a new finding related to this parenting situation. While the parents all had some degree of coverage not all diabetes-related costs were covered and for parents who were not confident that they could provide their children with any type of treatment they might want, the sense of distrust was particularly prominent. It also indicates that diabetes becomes a different kind of disease if and when one can afford specialized services, resulting in poorer families being less able to support their children in a pursuit of 'normal childhood'. Class differences shaped what strategies were available to which parents.

The healthcare system clearly shapes the daily experience of illness in other ways. The dominant medical understanding of illness is that control is achieved through focusing on the management behaviours of the individual living with an illness (or the primary caregiver to a child living with chronic illness). And for the parents in this study, diabetes care was believed to be the primary responsibility of the parents and the

children. Parenting in this situation meant that the family needed to accept the added burden of planning and monitoring the children's diabetes. Care was considered to be too complex for other people to understand and, especially since needles were involved, it was considered to be too much responsibility for someone other than the parents and children. Findings by Sullivan et al. (2003) also revealed that mothers of young children living with type 1 diabetes felt that extended family who initially offered to help withdrew it because they were too uncomfortable with the need to give insulin injections. The healthcare system provides an understanding and language around illness management and in this situation the A1C test was a benchmark for the parents to know whether diabetes management was going well or not. When parents in this study felt that A1C tests were too high, they felt the need to put further pressure on themselves and their children to stay on top of diabetes management. The emphasis on personal responsibility for care influenced parent and child interactions on a daily basis because the parents felt that the children could demonstrate personal responsibility for care. They could do this by checking their blood sugar or taking insulin without being asked, or remembering to carry all the necessary diabetes supplies. Becoming responsible for diabetes management would also afford the children more freedom to do the things they wanted to do. In this way, individualizing diabetes as a 'personal issue' allows the health care system (and a more general social definition of good health) not to be placed into question. Social factors that contribute to the availability of healthy food, opportunities for activities, and options around diabetes care, as well as the language around heredity and what then is inevitably familial, leaves the individual parent responsible for their own child on many social and normative levels.

The emphasis on parent and child responsibility for care meant that the parents felt that diabetes-related outcomes were the result of theirs and their children's actions and that it was their fault when outcomes were poor, such as when the children's A1C was high. The parents felt guilty when blood sugars were too low or too high because it meant that they and/or the children were not managing it well enough. The need for the child to take responsibility also led to conflict between the parents and children when the parents felt that the children were not paying attention to their diabetes and following their care plans. Marshall et al. (2009) found that parents of children living with type 1 diabetes worried that their children would chose other activities over diabetes care and this caused tension between the parents and children as the children grew older and the parents had less control over diabetes management. This demonstrates how diabetes is reinforced as an individualistic problem where society and social factors are not placed into question.

Findings from the present study revealed that the diabetes brought new motivation around how the parents needed to advocate for their children in the school context. The parents identified challenges that the children faced while at school such as teachers not being well informed about a child's care plan, the child not being allowed to keep insulin nearby because the lockers were shared, or teachers over-reacting to diabetes-related complications. They then spent a great deal of time and energy communicating with school staff to ensure that their children could have care plans at school that best suited them. They also felt the need to focus on teaching their children to advocate for themselves when teachers did not understand their special requirements related to diabetes. Some parents had to insist with their children that they interrupt teachers if they

needed to, in order to treat low blood sugar, or to ignore a teacher's instructions when they did not understand that the child needed to treat low blood sugar. The education system then depended on the parents to provide training and education to its professional staff, rather than supporting systemic training for staff within the school system. This study reflects the findings of Kliebenstein and Broome (2000) who identified issues related to communication between parents and school staff and found that parents did not always feel confident that staff would respond appropriately.

The way that diabetes was understood within the school system, therefore, shaped the daily experiences of the children living with diabetes and influenced the way that parents interacted with schools. Within the schools, diabetes was viewed as a medical condition that was not seen as a regular part of life, whereas the children wanted to be perceived as normal and not have unnecessary attention drawn to the diabetes. School policies reflected the emphasis on diabetes as an illness, rather than a regular part of life, because they were focused on control over insulin and diabetes supplies and over diabetes management tasks. Some parents explained that school staff would not allow their children to have easy access to their insulin, would not administer glucagon, were not always comfortable with diabetes emergencies and, therefore, over reacted. The parents felt that these types of situations led the children to feel like there was something wrong with them, which made it more difficult for the children to manage their diabetes. The parents needed to negotiate with schools in order to adjust the details of their children's diabetes management and school policies that caused their children to feel singled out. Because diabetes within the school environment was not looked at as a normal part of life, the parents had to work to maintain diabetes care at school that

reduced the negative social consequences for the children while, at the same time, making sure that they could trust that school staff could respond to emergencies.

Because the parents knew that present blood sugar control can affect their children's future, they experienced a loss of their hopes and expectations around how their children's lives would unfold. They could no longer feel the same certainty about the type of jobs their children would be able to have, whether their children would be able to live alone, or whether they would be able to have children or get driver's licenses, for example. These life events/milestones would not likely come without some adjustments and/or challenges, especially if the children were to experience serious diabetes-related complications. In order to cope with this loss the parents had to change their outlook to become more invested in the present, rather than the future. They did this by consciously choosing to enjoy the present moment and time with their family, and being thankful that their children did not have something that they considered to be worse than diabetes. The parents had to manage feelings of fear and anxiety, on an ongoing basis, about the present and future well-being of the children. This was because the parents knew that what happens now will affect their children's future. This reflects the findings of Bowes et al. (2009) who found that parents of children living with type 1 diabetes did not have a sense of closure because of ongoing worries about how poorly controlled blood sugars might affect their children's future. The diabetes also brought uncertainty around whether their children would ever be able to live without having to inject insulin because the parents were not sure if there would be a cure in their children's lifetime. They, therefore, emphasized that advances in technology and treatments might make diabetes easier to live with, in the future. Focusing on life getting easier due to

advances in treatments helped the parents to provide their children with some degree of certainty around the way their lives might unfold.

Many of the parents in the present study felt that their children had already become depressed and discouraged by having diabetes and they had to help their children keep from becoming further discouraged. Maintaining the children's well-being in this parenting situation, therefore, involves a great deal of effort and it is imagined that this might be more than for parents of children who are not living with a chronic illness. The parents had to teach their children and themselves to develop a positive sense of meaning around the diabetes in addition to all of their non-diabetes related parenting responsibilities. Marshall et al. (2009) also found that parents of children living with type 1 diabetes worried about how their children would accept the diabetes as they got older and developed a deeper understanding of the significance of it. And these findings add new understanding around how parents respond to this sense of meaning. As mentioned, the parents in my study focused on telling their children that diabetes care will get easier in the future with advances in treatment. Some parents also explained that they were careful not to over-react to blood sugar numbers and that they emphasized with their children that they can choose to not dwell on the negative aspects of diabetes. Parents felt that if the children became depressed or discouraged they might stop managing their diabetes and then experience even more extreme negative physical and social outcomes, now or in the future. The children could experience low blood sugar when they were with their peers and this would be embarrassing, or they could have complications later on which would affect their ability to live full lives. Balancing health and wellness narratives with positive meaning about the illness becomes a daily task for parents in this situation.

Caring for a child living with type 1 diabetes meant that the parents needed to feel that they were maintaining a balance between controlling the diabetes while not allowing their lives to be all about the diabetes. The presence of the diabetes changed the way the families functioned in the sense that mealtimes and schedules became more regimented and there was a great deal more planning that had to be done on a regular basis. However, because the diabetes brought about these changes, the parents now felt the need to set limits on how much they allowed their focus to be on the many aspects of diabetes care. This meant accepting that blood sugars will not always be well controlled and that they needed to live with some degree of uncertainty around the children's future. This supports other findings that have shown that parents in this situation struggle to manage the uncertainty that the diabetes brought (Marshall et al., 2009). However findings from this study also revealed that sometimes accepting uncertainty can mean limiting the amount of time spent on the medical procedures involved in managing the diabetes. This balance then became a new skill that parents benefitted from in other areas as well. Striking a sense of normalcy through these strategies assisted their children in developing new areas of skill and strength which could serve them well in areas outside diabetes management. This skill could be translated later on in life in a way that could aid children to become resilient and strong adults, in charge not only of their diabetes, but also the rest of their lives.

The stories in this study around efforts to maintain good blood sugar control were paralleled by stories of the need to accept that, to an extent, their children's blood sugars would not always be good, that they would not let their children's lives be taken over by the medical aspects of the illness, and that they had to trust that their children would be

alright when they were not within their immediate care. These stories represent shining examples of parents guiding their children, in the instance of needing guidance regarding diabetes care, to become strong and healthy well-functioning adults contributing to society in ways they would choose in the future. The strengths and skills parents imbued in their children provided an unparalleled example for other parents as well.

Implications

By deepening our understanding of the parental sense of meaning in this parenting situation it is more possible to explore how these impact medical aspects of the condition and how social factors along with parental sense of meaning and understanding shape behavioural management of the illness. This data has indicated that social factors shape parental perceptions, which then influence behavioural management of diabetes. Based on these findings, there are some recommendations that can be made for parents and families, school staff, and healthcare providers.

Parents and Families

The parents identified benefits resulting from the diabetes such as parents and children becoming closer and siblings becoming closer, due to a greater need to monitor their children. The parents also felt that connecting with other families in similar situations helped them to feel understood and also decreased the children's feelings of being different from everyone else because they had diabetes. These are positive ways of coping that parents in this situation can utilize.

The parents explained that they put limits on the amount of time they spent, or had their children spend, performing diabetes-related tasks such as checking blood sugar and correcting high blood sugar with extra insulin. This was because they felt as though it

was taking too much away from their children's enjoyment of everyday activities.

Sometimes this meant that the children's blood sugars were not kept down as much as they could be. When parents feel overwhelmed by diabetes care it is important to ask for guidance from diabetes healthcare providers and for support from friends and family, if it is available.

This study revealed that children and parents felt that their actions alone will dictate future outcomes in terms of blood sugar control and possible future complications. As a result, parents and children felt blamed for poor outcomes, such as high blood sugars, even in situations where there were social factors outside of their immediate control that made it difficult to follow diabetes care plans. Conflict between parents and children occurred when parents felt that the children were not taking responsibility for their diabetes and some of the children felt discouraged by the diabetes. This is another situation in parents may need to ask for extra assistance from healthcare professionals because parents and children may become overwhelmed because of the diabetes. Children in adolescence may benefit from having the opportunity to speak with the social worker at regular diabetes appointments so that they have an opportunity to talk about any social and emotional concerns they have.

School System

Many issues were identified related to the children's diabetes-related experiences in the school environment. The need to go to the office to take insulin, rather than keeping it nearby was a problem that led to social and physical consequences for the child. Teachers were not always well informed about the children's diabetes care plans and this led to under or over-reacting by teachers when complications occurred. And

finally, the parents identified that the school policy of not administering glucagons injections was problematic. Principals of every school where a child living with type 1 diabetes attends should ensure that any staff that work with these students receive training and are well-informed about how to respond should a diabetes-related emergency occur. Once they reach middle school and high school, children living with type 1 diabetes would also benefit from having their own locker to keep their insulin in, or have access to another safe location that is convenient for the child to keep their insulin when they are not using it. School policies related to glucagons should be changed to allow the administration of glucagons so that children who do not want emergency services to come to the school do not have to have them called.

Nurse educators within the school division can help the schools develop a diabetes care plan that take into account the social and emotional impact that the diabetes can have on the child while they are at school. They can do this by involving the child, the parent(s), and school staff in the development and ongoing assessment of care plans in order to gain feedback regarding any issues the child might be encountering at school that are negatively impacting his or her diabetes management. This is particularly important because principals and school staff may not understanding that the children's need to feel integrated and accepted by their peers needs to be considered and balanced with appropriate diabetes care.

Healthcare Setting

The parents experienced worry about future complications, being able to teach their children to manage diabetes on their own, and concerns about what caused the diabetes. Healthcare providers need to take the time to speak to parents without the

children present because, as the parents in this study indicated, they may not want to discuss these concerns in front of their children, particularly their fear of complications. Otherwise, as Bowes et al. (2009) pointed out, healthcare providers may assumed that parents are emotionally well-adjusted. It was important for parents to have an understanding of the potential cause(s) of their children's diabetes because they felt guilty that they may have contributed to it. Diabetes as an illness is difficult to understand but healthcare providers should, in discussion with parents, provide clear information and clarify any misconceptions that parents might have. Parents need to work towards an understanding of diabetes that helps them to feel a sense of acceptance towards it and healthcare providers can help them to do this by providing the most accurate and recent information.

Healthcare professionals may be able to provide additional support to children and families by helping the child find ways to incorporate diabetes tasks into their lives in a way that fits in with the child's specific goals and life situation. Putting an emphasis on helping the children to do the things they want to do, rather than emphasizing the importance of blood sugar control, may help the children better incorporate diabetes-related tasks and ultimately lead to better diabetes outcomes. Healthcare providers can find out through discussions with the child what the child's goals are, socially, academically or in terms of other activities, so that they know what is important to the child. For example, many of the parents talked about which sports their children would play and considered the impact those sports would have on changes in the children's blood sugar. Healthcare providers can offer guidance based on monitoring diabetes

during specific activities that the children want to participate in, or are already participating in.

It was also important for the family to be able to continue with the same activities as much as possible, despite the diabetes, otherwise the parents felt discouraged because the diabetes was taking over their lives. Healthcare providers can acknowledge this and emphasize that their role is to assist families to be able to live their lives as normally as possible, rather than focusing strictly on controlling the diabetes. According to the clinical guidelines for diabetes care, approaches to chronic illness “require significant investment to create and support patients who are informed and engaged in their care” (CDA, 2008, P. s21) and healthcare providers should acquire an understanding of the activities and events in daily life that are important to the families in order to provide education around diabetes care that could be incorporated into those specific events and activities. Tailoring diabetes care to each child and family’s particular situation as well as taking into account the resources that the children and family have available to them may help families better adhere to diabetes care plans and have better outcomes. For example, parents may want flexibility in the way that diabetes is managed while families are on holidays or during special occasions; if families are going to be in one of these situations healthcare providers can help them find a way to eat and give insulin at different times of the day than usual so that the family does not feel restricted by the need to keep the same schedule. This may also help reduce the likelihood that parents or children will feel blamed when blood sugar is high and unreasonable demands will not be placed on the children or parents (Dickenson, 1999).

Parenting a child living with type 1 diabetes meant that the parents had to help their children stay positive and adhere to care plans. Interventions for families should include education for parents related to helping them respond well to their children's emotional needs as well as information on how they can get additional help for their children should they need it. Parents felt frustrated when they felt that their children were not adhering to care plans and education for parents should include a component whereby parents can learn about positive ways to increase their children's adherence.

The knowledge that when children living with diabetes feel self-conscious and unaccepted by friends and peers should inform diabetes educators and they should have ongoing discussions with children, especially as they grow to adolescence, around how having diabetes makes them feel when they are with friends and peers. This way they may be able to alert parents that something may need to be changed in the way that the children's diabetes is managed at school in order to prevent the children from experiencing negative social outcomes as well as negative diabetes-related outcomes.

Healthcare providers encourage the involvement of extended family and friends in diabetes care (DCA, 2008). However, these findings revealed that involvement from individuals outside the immediate family was actually minimal. The parents expressed a need for support so that they can get a break and healthcare providers should provide information on where parents can seek help such as through other diabetes organizations. This is important because, while research has shown that too much child responsibility is associated with poorer glycemic control (CDA, 2008; Pattison, 2006) the parents felt that they needed to put the responsibility onto the children as soon as possible, since other supports were not available.

And finally, there was scepticism expressed by some of the parents around the medical system and costs of diabetes supplies. While the parents all had some degree of coverage not all diabetes-related costs were covered. In Canada each province allocates funding for healthcare and Unger and Witkos (2005) point out that “the provinces do not agree on the importance of providing comprehensive coverage for all children. For many Canadian children, significant financial barriers exist to medication access” (p. 101). Working families with low incomes, in particular, have to pay significant out-of-pocket costs for medications and there is a need for uniform drug coverage for all children who require medical treatment in Canada.

Future Directions for Research

Because many of the concerns that were identified by the parents in the study involved the children’s experiences with diabetes in school, more research needs to be done to review school policies relating to children living with type 1 diabetes and chronic illnesses. Future research should also identify the barriers that keep school staff from fully accommodating children living with type 1 diabetes. Research aimed at identifying the experience of school staff would also be a useful way to identify the barriers that may keep staff from responding appropriately in relation to children living with diabetes as well as other chronic illnesses and disabilities. With rates of type 1 diabetes on the rise this area is particularly important.

Further research to learn how children understand and cope with diabetes in the home, school, and community, and the social factors associated with these, would be help to inform service providers as they support children living with type 1 diabetes.

Limitations

My original research question was to explore the role of family narratives in the situation where parents had grown up with a close family history of type 1 diabetes. However, I was unable to find enough participants that fit these criteria. The first two interviews I conducted were with parents who did have a close family history of type 1 diabetes and the questions they were asked at the beginning of the interviews had more of an emphasis on the family history aspect of their parenting experience. In other words, they were asked about their previous experiences growing up with diabetes in their family. The interviews, then, differed somewhat between parents. However, all of the parents were asked to talk about what is like parenting their children living with diabetes.

While the participants differed in several other ways, most were white and from a middle socioeconomic background. Many of the participants in my study were recruited through the JDRF and were parents who readily participated in fundraising activities for diabetes. This indicates a confidence to speak out, to advocate and connect with other parents, which may suggest higher levels of education or familiarity with the healthcare system. Parents from lower socioeconomic background may not participate as often in diabetes-related events because there may be costs involved in participation or it may be more difficult to get to events due to transportation or time constraints. Parents from lower socioeconomic status did not volunteer for the study. Additionally, with most of the participants being white there was not a great deal of cultural diversity among the participants.

Conclusion

This study has revealed that the parental sense of meaning intersects with medical knowledge and that both work to shape the parental perception as well as influencing the way that parents respond to their children's diabetes-related needs. Diabetes management is as much about the meaning that parents hold as it is about adhering to medical care plans. In this way, the study contributes to a deeper understanding of how our subjective interpretations shape our understanding of diabetes well outside a medical realm. Parenting a child living with diabetes also involves not only adjustments to accommodate diabetes-related tasks, but also changes in outlook and in interactions with family, community, and society. How family members and others in society communicate about illness shapes our daily lived experience, well-being and interactions with each other in a way that shapes our identity. This link between identity, self and illness becomes not only part of the fabric of communication, self and identity, but also then a significant contributing factor to management of illness.

The quantitative literature in this area has provided an understanding of the factors related to diabetes management in terms of a parent's adherence to medical advice and the degree of blood glucose control. Therefore, diabetes-related outcomes have been linked predominantly to a parent's adherence to care plans and level of medical knowledge, while the parent's understandings or experiences of illness, as shaped through social interaction, have not been considered to have much impact on the person's decisions regarding their care (Hall, 2003). My data has shown that the parental sense of diabetes-related meaning, along with medical knowledge, influence everyday decision-making related to parenting a child living with diabetes. While qualitative studies have

explored the experience of parenting a child living with type 1 diabetes, this study has added an understanding of how the parental sense of meaning plays a role in the parenting of children living with type 1 diabetes.

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Appendix A

Interview Questions

1. What was your experience growing up with diabetes in your family?
What do you know about your relative with type 1 diabetes?
2. What is it like now having a child with diabetes?
How has parenting a child living with diabetes affected life for you and the family?
3. How has growing up with diabetes shaped your experience as a parent?
4. What wishes / hopes do you have for the future of your child?

Appendix B



UNIVERSITY
OF MANITOBA

Winnipeg, Manitoba

Canada R3T 2N2

Faculty of Human Ecology
Family Social Sciences

Are you a biological parent and primary caregiver to a child living with type 1 diabetes?

&

Do you have a sibling, parent, or grandparent who is, or was, living with type 1 diabetes?

You are invited to take part in a study aimed at better understanding what it means to be a parent in this situation.

The study is entitled “The Role of Family Narratives in the Parenting of Children Living with Type 1 Diabetes.”

- You will be asked to take part in a confidential interview lasting approximately 1 to 2 hours in length, in your home or at another convenient location.
- For more information, or to volunteer to take part, please contact:

Mary Anne Nurmi, B.A. (Hons), M. Sc. (Candidate)

Department of Family Social Sciences

Email: marynurmi@yahoo.ca

Phone: 272-1618

- This study has been approved by the University of Manitoba Research Ethics Board.

Appendix C



Faculty of Human Ecology
Family Social Sciences

Winnipeg, Manitoba
Canada R3T 2N2

Are you a parent (with or without diabetes) and primary caregiver to a child living with type 1 diabetes?

&

Do you have a family history of diabetes (sibling, parent, or grandparent who is, or was, living with type 1 or 2 diabetes)?

You are invited to take part in a study aimed at better understanding what it means to be a parent in this situation.

The study is entitled “The Role of Family Narratives in the Parenting of Children Living with Type 1 Diabetes.”

- You will be asked to take part in a confidential interview lasting approximately 1 to 2 hours in length, in your home or at another convenient location.
- For more information, or to volunteer to take part, please contact:

Mary Anne Nurmi, B.A. (Hons), M. Sc. (Candidate)
Department of Family Social Sciences
Email: marynurmi@yahoo.ca
Phone: 272-1618

- This study has been approved by the University of Manitoba Research Ethics Board.

Appendix D



UNIVERSITY
OF MANITOBA

Faculty of Human Ecology
Family Social Sciences

Winnipeg, Manitoba
Canada R3T 2N2

Study Title: The Role of Family Narratives in the Parenting of Children with Type 1 Diabetes

Researcher: Mary Anne Nurmi

Research Supervisor: Dr. Kerstin Roger

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully.

The purpose of this study is to learn how parents feel that their family history of diabetes has affected their diabetes-related perceptions in relation to the parenting of their children who are living with type 1 diabetes. When a parent knows or has known a relative (sibling, aunt/uncle, parent, grandparent) with diabetes, diabetes is considered to be a part of his or her family history. As a result, a parent will have learnt something about diabetes from shared family stories and experiences. The aim of this study is to find out how parents feel that these shared family stories and experiences have influenced them and their parenting practices in relation to their children who are living with type 1 diabetes. I am also exploring how parents without a known family history of diabetes feel that the new diagnoses of diabetes in the family has influenced them and their parenting practices.

You will be asked to participate in one interview that will last approximately 1 to 2 hours. The interview will be recorded using a digital audio recorder. You will be asked open-ended questions about your family history as it relates to diabetes or about the new diagnoses of diabetes in your family. You will also be asked about your experiences in the parenting of your child who is living with type 1 diabetes. In the event that

clarification is required regarding the topics discussed in the interview, you may be contacted by the researcher to participate in a second interview.

This knowledge may help inform training for healthcare providers and families around improving diabetes management as well as increasing our understanding of child and family life with diabetes and how social factors, such as family history, shape parental perceptions and practices.

This study does not pose any foreseeable risk. However, if you feel upset by talking about events or feelings related to diabetes you may be provided with a list of services to contact for assistance, if you wish. You may enjoy having the opportunity to talk about your experiences related to caring for your child living with type 1 diabetes.

Only the primary researcher will have access to your contact information. As this study is being conducted for a Master's thesis, the research supervisor will work with the researcher on the data analysis and will have access to the interview transcript but not to your name or contact information. Thesis committee members may request to see an original interview transcript but will not have access to any names or contact information.

A transcriptionist will be used to transcribe the interview and he or she will be bound to a confidentiality agreement. Prior to transcribing the recorded interview pseudonyms will be assigned to your name and your child's name, and the names of anyone else mentioned during the interview will not be used in the transcription or final written study findings. Written study findings based on the information collected for this study will be in the form of a Master's thesis, although there is a possibility that other publications may arise from this study and findings may be presented at research conferences. Your contact information, interview recording, and interview transcription will be destroyed upon completion of the study, which is expected to be in September, 2011.

Should the disclosure of the abuse of a child or children be discovered in the course of this study, it is the researcher's responsibility to report the matter to the appropriate legal authority.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the study and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and/or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

Researcher: Mary Anne Nurmi

Phone: 272-1618

Email: marynurmi@yahoo.ca

Research Supervisor: Dr. Kerstin Roger

This research has been approved by the University of Manitoba Joint-faculty Research Ethics Board for research with human participants. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Secretariat at 474-7122. A copy of this consent form has been given to you to keep for your records and reference.

Participant's Signature _____

Date _____

Researcher's Signature

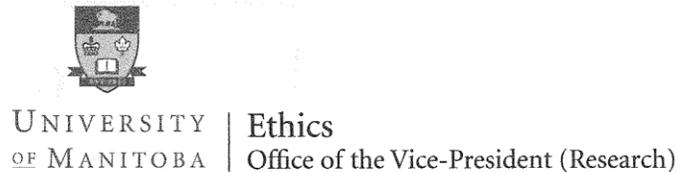
_____ **Date** _____

Services:

Klinik: 784-4090

Health Links: 788-8200

Appendix E



CTC Building
208 - 194 Dafoe Road
Winnipeg, MB R3T 2N2
Fax (204) 269-7173
www.umanitoba.ca/research

APPROVAL CERTIFICATE

July 15, 2010

TO: **Mary Anne Nurmi** (Roger)
Principal Investigator

FROM: **Wayne Taylor, Chair**
Joint-Faculty Research Ethics Board (JFREB)

Re: **Protocol #J2010:091**
"The Role of Family Narratives in the Parenting of Children Living with Type I Diabetes"

Please be advised that your above-referenced protocol has received human ethics approval by the **Joint-Faculty Research Ethics Board**, which is organized and operates according to the Tri-Council Policy Statement. This approval is valid for one year only.

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Secretariat in advance of implementation of such changes.

Please note:

- if you have funds pending human ethics approval, the auditor requires that you submit a copy of this Approval Certificate to Eveline Saurette in the Office of Research Services, (e-mail eveline_saurette@umanitoba.ca, or fax 261-0325), including the Sponsor name, before your account can be opened.
- if you have received multi-year funding for this research, responsibility lies with you to apply for and obtain Renewal Approval at the expiry of the initial one-year approval; otherwise the account will be locked.

The Research Ethics Board requests a final report for your study (available at: http://umanitoba.ca/research/ors/ethics/ors_ethics_human_REB_forms_guidelines.html) in order to be in compliance with Tri-Council Guidelines.