

**Parents' experiences when their child is diagnosed with type 1 diabetes
and one parent also has type 1 diabetes: A qualitative study**



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“It always seems impossible until it is done.”

Nelson Mandela

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Abstract

Type 1 Diabetes (T1D) is one of the most common childhood chronic conditions worldwide, with the incidence increasing, particularly in children aged <15years of age. T1D requires intensive management to maintain good glycaemic control and prevent diabetes-related complications, thereby improving quality of life. A diagnosis of T1D in a child is overwhelming as it leads to a rapid change in lifestyle, bringing both physical and psychosocial challenges, for the child and the whole family. Family situations and circumstances are very different and are expected to have some effect on how T1D is managed. Understanding the family impact and providing adequate support is essential for families to manage and adjust to T1D.

The aim of this project was to explore parents' perspectives of their experience and needs when their child is diagnosed with T1D and, to determine if also having a parent with T1D has an influence on their acceptance, adaption, and management of their child's condition. The purpose of this study was to fill a void in the current literature, by providing insight into different family situations and challenges, regarding what impact a parent with T1D may have on their child when he/she is diagnosed with T1D. Information collected was in relation to the T1D parents' previous experiences, knowledge, and management of their T1D and the overall effect on family adjustment.

A purposeful sample of parents was recruited from a diabetes clinic within a research facility. The inclusion criteria included children aged <16 years and diagnosed with T1D between the years 2013 - 2016 and where one of their parents also had T1D. Using a qualitative methodology, ten face to face interviews with parents were conducted. Interviews were recorded and transcribed. Using open coding and NVivo software, data was explored using inductive thematic analysis. Five themes were identified from the data which included: 'T1D child'; 'Parents'; 'Acquisition of knowledge'; Challenges living with T1D; and 'Our new life'.

Findings from this study supported other studies; parents display many emotions when their child is diagnosed with T1D, these include being shocked, overwhelmed, saddened, and worried. Parents grieve for the loss of their healthy child, their freedom, and the life they knew. Furthermore, parents had fears related to short and long-term complications and effective diabetes management for their child. Additionally, this study identified that parents had mixed feelings about being treated as newly diagnosed families and that recognition of the T1D parent was important to acknowledge what they knew about living with this chronic condition. Furthermore, although the child's diagnosis of T1D was difficult, all parents used this as an opportunity to learn new knowledge. Parents with T1D felt empowered by this and improved their diabetes management to ensure they were good role models for their children and family.

This study identified a strong connection between the T1D parent and T1D child, regarding the choice of insulin regimen and the use of technology. This parent/child relationship had influenced the management of both the child and parent with T1D and the overall adjustment of the family. It was recognised that families with a parent and child with T1D, do face unique challenges regarding management and the support these parents received was limited. Psychological support was identified as an essential element for wellbeing.

Findings highlighted the challenges parents and families face when a child is diagnosed with T1D with the additional unique insight into how having a parent also with T1D, influences the acquisition of knowledge, their own and their child's diabetes management and the adjustment to a new life. These findings can be used to better inform professional health staff working with families with more than one family member living with T1D about the challenges these families face, to ensure effective and individualised care is delivered.

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List of Abbreviations

DCCT Diabetes Control and Complication Trial

BGL Blood Glucose Level

CSII Continuous Subcutaneous Insulin Infusion

DKA Diabetic Ketoacidosis

GP General Practitioner

HbA1c Glycosylated Haemoglobin

ISPAD International Society of Paediatric and Adolescent Diabetes

MDI Multiple Daily Injections

T1D Type 1 Diabetes

T2D Type 2 Diabetes

Chapter One – Introduction

This study aimed to explore parents' perspective of their experience and needs when their child is diagnosed with Type 1 Diabetes (T1D) and to determine if also having a parent with T1D has an influence on their acceptance, adaption, and management of their child's condition.

This chapter defines what diabetes is with an explanation of the two main types, type 1 diabetes, and type 2 diabetes. This chapter provides a more in-depth explanation of T1D, including information on diagnosis, management, and genetic predisposition. Furthermore, an overview of the international and national prevalence of this condition will provide insight into the importance of this research.

1.1 Diabetes

The term diabetes describes a complex metabolic disorder characterised by chronic hyperglycaemia which results from deficiencies in insulin secretion, insulin action or both.^{1, 2} The result is a reduction in insulin action on target tissues which leads to the abnormal metabolism of carbohydrate, fat, and protein,^{3, 4} resulting in hyperglycaemia or high levels of glucose in the blood. Symptoms of marked hyperglycaemia include polyuria (increased urination), polydipsia (increased thirst), polyphagia (increased appetite), blurred vision, weight loss, and fatigue.^{1, 4, 5}

In the short term, prolonged or severe hyperglycaemia caused by high glucose levels and low insulin levels in the blood leads to lipolysis, a metabolic imbalance, where ketones accumulate in the blood and can result in an acute life-threatening emergency known as diabetic ketoacidosis (DKA).^{5, 6} Approximately 15 - 70% of all newly diagnosed infants and children present with DKA and this is often related to a delay in recognition of symptoms resulting in a delay in diagnosis.⁶

In the long term, continued hyperglycaemia can lead to damage to the micro and macrovascular blood vessels, of the heart, eyes, kidneys, and nerves, manifesting as cardiovascular

disease (CVD), retinopathy (eye disease), nephropathy (kidney disease) and neuropathy (nerve damage).⁷ Impairment of growth, cognitive and behavioural difficulties and increased or recurrent infections have been associated with chronic hyperglycaemia.^{1, 3}

Diabetes is characterised into two broad etiopathogenetic categories: Type 1 diabetes (T1D) is described as a heterogeneous chronic autoimmune disease, having both genetic and environmental contributions. It causes organ-specific, immune-mediated destruction of insulin-producing beta (β) cells in the islet of Langerhans within the pancreas, resulting in an absolute insulin deficiency.^{3, 8-10} It is estimated that T1D accounts for 5 - 10% of all people with diabetes, and currently there is no cure.^{2, 5, 11} Type 2 diabetes (T2D), however, results from a combination of inadequate secretion of insulin and resistance to the action of insulin. T2D has a strong genetic component and is attributed to lifestyle, lack of physical activity and obesity.^{1, 3, 8} For the purpose of this thesis, T1D will be discussed in detail.

1.2 Type 1 Diabetes

T1D can be diagnosed at any age and is one of the most common childhood chronic conditions, with a high prevalence noted between 5 - 7 years of age and again at age 10 - 14 during puberty.^{8, 12} Children typically present with the classic symptoms, including polyuria and polydipsia, polyphagia and weight loss and are often quite unwell.³ Diagnosis is confirmed following the measurement of plasma glucose concentrations, either in a fasting state or two hours post food. A glycated haemoglobin test (HbA1c) which reflects the overall average plasma glucose level over an eight to twelve week period can also be used.^{2, 3, 13} At this point, it is considered essential to commence immediate exogenous insulin replacement to correct hyperglycaemia and prevent DKA. Furthermore, it has been established that commencing intensive insulin therapy early may assist in the preservation of the individual's endogenous insulin production, potentially preventing

complications such as retinopathy and may reduce severe hypoglycaemia at later stages of the disease thus improving morbidity.^{6, 12}

The aetiology of T1D remains unclear, however, the prevailing paradigm is that there is a complex relationship between environmental factors and genetic predisposition, activating an autoimmune response destroying the β -cells leading to an absolute dependency on exogenous insulin.^{2, 14} Epidemiological studies have identified strong evidence that environmental factors such as seasonal changes, enteroviruses, and infant and adolescent diets, including levels of vitamin D may have a potential bearing on the development of T1D. As a result, increased attention to the role of the gut microbe and the hygiene hypothesis has been investigated as potentially influencing the risk of the development of T1D.^{12, 14-16}

T1D is included as one of more than 80 conditions to have an autoimmune aetiology.¹⁶ In T1D the autoantibodies associated are the serological biomarkers of β -cell autoimmunity and include glutamic acid decarboxylase 65 (GAD) or tyrosine phosphate IA-2 and IA2 β and ZnT8.^{3, 11, 16} The presence of these antibodies is a strong predictor of disease with the appearance of at least one β -cell autoantibody, but usually more than one, are detected in 70 - 90% of individuals at diagnosis.^{4, 5} The presence of IAA and ZnT8 is more often noted in children under 10 years of age with the order of appearance being related to an individual's genotype.³ Susceptibility to T1D has also be determined by genetic determinants and is associated with high risk haplotypes or alleles. Individuals who have the presence of particular HLA-DR-DQ haplotypes are known to have an increased risk of developing T1D.^{5, 11} Children born with what has been identified as a high-risk genotype, equal approximately 50% of children who develop T1D by the age of five.^{3, 17}

In recent years considerable research has been completed around genetics in order to comprehend and determine the predisposition of risk within families and to better understand the progression of T1D.¹⁶ This has seen major advances in the prediction of the onset, the course and

the outcomes of illness, however, also raises complex practical, emotional and psychological issues for families when the condition is not accompanied by a curative treatment.¹⁸ It is acknowledged that parents who pass on a genetic trait to their child, can feel personally responsible, and struggle with negative emotions, particularly associated with acute illness management, or overcompensate in an attempt to improve the situation.^{19,20} The mode of inheritance of a genetic condition has both social and psychological consequences associated with feelings of guilt and blame and can have an impact on family functioning if not addressed adequately.^{20,21}

Although more than 85% of individuals diagnosed with T1D do not have a family history of the disease, there is evidence of high familial clustering,^{8, 17} with first degree relatives having a higher risk of developing T1D compared with unrelated individuals in the general population.^{1, 2} Among first degree relatives, siblings are at a higher risk of developing T1D. Siblings of children with onset of T1D before the age of five have a three-to five-fold greater cumulative risk of developing T1D by the age of 20 compared with siblings of children diagnosed between 5 and 15 years of age.²²⁻²⁴ Additionally, children with a family history of T1D tend to be younger at the age of onset. The offspring of affected mothers have a 2 - 3% risk compared to an offspring of affected fathers which have a higher risk, about 7%,^{8, 17} with preferential transmission from father to daughter.²²⁻²⁴

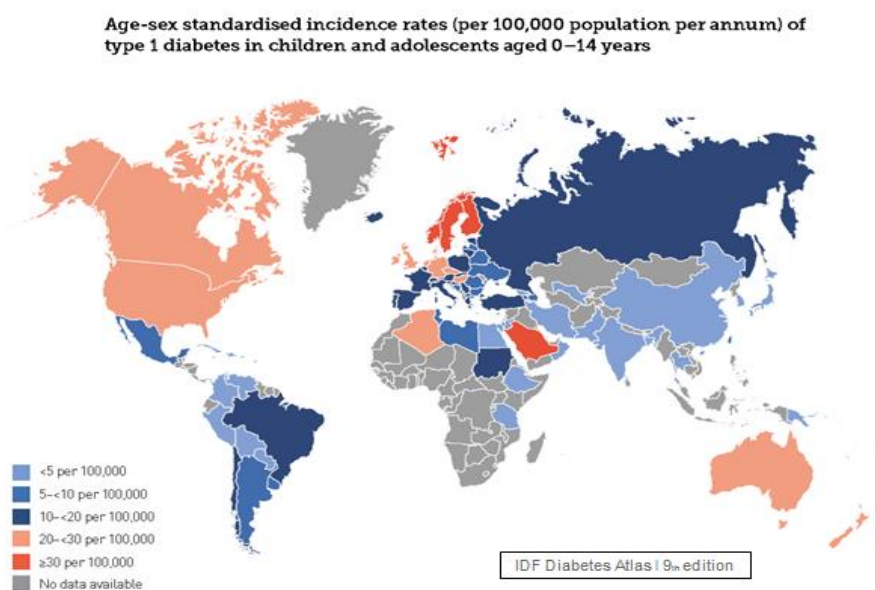
1.3 Incidence

The incidence of diabetes is increasing worldwide with the number of individuals diagnosed with T1D accounting for 5 - 10% of the population. Of these individuals, more than 90% are children and adolescents.^{2, 3} In 1988, the EURODIAB (EUROpe and DIABetes) program, a collaborative network that gathered information about T1D prevalence across many centres in Europe, was established.^{8, 25} Additionally, in 1990, The World Health Organisation (WHO) initiated a multinational project, the DIAMOND Project, which was designed to address the public health implications of T1D and to gather worldwide data on the incidence of T1D among children ≤ 14 years

of age.^{8, 26} These international population-based registries are pivotal in facilitating the collection of reliable data on the worldwide incidence of T1D and are used to monitor the global trends of standardised data by age, gender, and geographic location.²⁷

In 1990 - 1999, the DIAMOND project group found increases in T1D incidence in every region except Central America and the West Indies.²⁸ Furthermore, in Europe between 1989 - 1998, Central and European countries' rates of incidence differed significantly, although, showed evidence of the highest incidence in the youngest age group.^{8, 28} Data from these registries indicate that the worldwide incidence of T1D has been increasing in almost all populations for several decades and shows an overall annual increase of T1D to be around 3% with trends remaining higher in the younger age groups (0-14 years).^{14, 29} Finland has the highest incidence rates of T1D (>60 cases per 100 000 people each year) while China, India, and Venezuela have the lowest incidence (around 0.1 cases per 100 000 people each year).^{12, 29} There is considerable variability of incidence seen worldwide, between countries, within countries, and between different ethnic groups, see Figure 1.^{3, 25, 26, 29}

Figure 1. Global Incidence of T1D in children and adolescents ages 0-14 years. (IDF Diabetes Atlas²⁹)



In Australia, the incidence of T1D is similar across all states with 2,742 individuals being diagnosed with T1D in 2017. This equates to 12 cases per 100,000 populations. The incidence rate of diagnosis was higher in males (14 cases per 100,000) than females (10 cases per 100,000), and of those diagnosed, 61% were under 25 years of age, peaking among those 10 - 19 years.³⁰ In Australia, published data regarding increasing incidence rates for children aged 0-14 years indicate variability between states, by sex and age (see figure 2 & 3), with a slightly higher incidence rate in males than females, a similar pattern to that which is observed globally.³⁰⁻³²

Figure 2. Incidence of T1D of Males and Females (AIHW 2017 ³⁰)

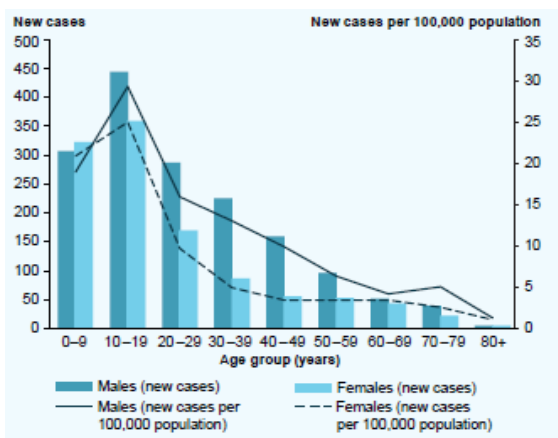
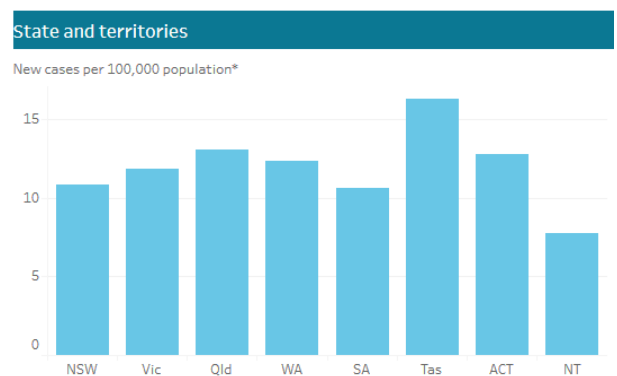


Figure 3. Incidence of T1D by States and Territories (AIHW 2017 ³⁰)



1.4 Management

Currently, there is no cure for T1D. Individuals must learn to manage this complex, time-consuming condition indefinitely. Successful management involves maintaining effective glycaemic control, which has been identified by the Diabetes Control and Complication Trial (DCCT) to reduce the potential for long term complications associated with diabetes⁷. The most important goal of management is to maintain good glycaemic control to reduce both long term and short-term complications.

International and national guidelines recommend self-monitoring of blood glucose at least 3 - 4 times per day, and for intensive treatment, between 6 - 10 per day ³³ regardless of whether

multiple daily injections (MDI) or continuous subcutaneous insulin infusion (CSII) is used.^{5, 34, 35} Self-monitoring of blood glucose provides immediate information to accurately assess glycaemic level and allows for the delivery of optimal insulin treatment to maintain a suitable HbA1c measure. HbA1c is a measure used to provide information and evaluate the effectiveness of the individual's diabetes management over three months.³⁶ Effective glycaemic control and reduction in potential complications have a wide-ranging benefit resulting in a positive effect on both physical, psychosocial aspects and family functioning, thereby reducing health care costs.^{37, 38}

According to the national standards, the key goals of diabetes care is to encourage effective self-management to improve clinical outcomes, health status and quality of life.³⁴ It is widely recognised that education is the foundation for good diabetes care, therefore maintaining up to date knowledge and skills will provide confidence and is therefore considered essential for the successful management of T1D.^{39, 40} Diabetes self-management education consists of a collaborative approach to provide knowledge and skills that enable individuals to understand their condition and modify their lifestyle and behaviour to maximise their health.^{38, 41} Additionally, diabetes self-management support includes nutritional therapy, physical activity, smoking cessation counselling, and psychosocial care.³⁴ These goals should be measured and monitored routinely as part of diabetes care.

For children, T1D management is more complex and the responsibility for care falls on their parents. Parents are accountable for the child's day to day diabetes management and monitoring, as well as managing physical challenges such as the growth and development of their child, varying physical activities, and dietary challenges associated with young children.^{42, 43} Due to the continuous demands of T1D management for their child, parents have been noted to experience increased levels of stress and anxiety and are at an increased risk of developing psychological distress.^{44, 45} Parents of children with T1D need on-going diabetes education with particular attention directed to

psychological support. Education and support need to be learner-centred and adaptable to varying family situations and individual needs.

1.5 Significance of the Study

This project was initiated after discussions with clinic staff following a succession of newly diagnosed children who also had a parent with T1D. Staff recalled that parents had questions regarding the risks of developing T1D in other children. Some parents expressed feelings of guilt and blame related to their child's diagnosis. Staff questioned whether these families required or could benefit from an alternative approach to support, information, and service delivery.

A review of literature was completed, and it was determined that there was very limited information regarding the experiences of parents with T1D when their child is diagnosed with T1D. Therefore, this research was undertaken to develop an understanding of the experiences of these families and to determine what specific information and support these families needed.

It is expected that the outcomes of this qualitative research will provide practical information to assist with providing continued targeted care to families. Additionally, this research will add to the paucity of information and complement other qualitative work regarding understanding parents' need for information and support when their child is diagnosed with T1D.

Positioning of the Researcher

The researcher is a registered general nurse (RGN) with thirty years of nursing experience, including eighteen years of general surgical nursing. In 2007 she completed a post-graduate diploma in health promotion and pursued a career in nursing research. In 2008 she commenced working as a research nurse in immunology and vaccine research, and in 2012 changed to T1D research. The researcher is currently employed as a clinical research nurse in diabetes research, working on clinical

trials and observational studies with families with T1D. The researcher has not been involved in qualitative research previously and with an interest in this, type 1 diabetes and how chronic illness impacts families, motivated her to pursue this research project. As a clinical research nurse, the researcher is not involved in any clinical care of the participants involved in this research project.

1.6 Study Aim

This study aimed to explore parents' perspective of their experience and needs when their child is diagnosed with T1D and, to determine if also having a parent with T1D has an influence on their acceptance, adaption, and management of their child's condition.

1.7 Study Questions

- 1) What are the experiences of parents when their child is diagnosed with T1D and one parent also has T1D?
- 2) How does pre-existing knowledge affect the experience of parents when their child is diagnosed with T1D and one parent also has T1D?
- 3) What support and services parents felt they required when their child is diagnosed with T1D one parent also has T1D?

1.8 Outline of Thesis

This thesis is organised into six chapters. This introductory chapter has provided an overview of the research topic, including an outline of diabetes and specifically T1D. The description of worldwide and national incidence provides insight into the rising rates of T1D. The information has been provided on the diagnosis and management of T1D in young children and adolescents to assist in understanding the research topic and the significance of this study.

Chapter two is a review of the literature around the diagnosis of a child with T1D, discussing the model of care. It describes T1D as a chronic condition and the need for targeted education and support to encourage self-management and the maintenance of good glycaemic control. It highlights the genetic predisposition for the development of T1D and addresses the impact of a diagnosis on parents.

Chapter three describes the research design, methodology, and analysis process used in this study. A qualitative research approach was undertaken. All participants were purposively recruited from a diabetes clinic and attended face to face interviews. Data storage and ethical considerations are outlined.

Chapter four discusses the results of the study in detail. Thematic analysis was used to identify themes and create a thematic map to capture and explain the parents' experience of having a child diagnosed with T1D, including participant quotes.

Chapter five incorporates a discussion about the findings in connection with current literature and identified themes. A socioecological framework will be used to demonstrate the interrelationship of the parents, child and their environment and the influence these have on each other. This chapter includes strengths and limitations identified in this study and highlights the recommendations arising from these findings.

The final chapter summarises the pertinent findings of the study in relation to the research questions and the overall aim of the study. It highlights information that could be used by health professionals to deliver patient and family centred diabetes education and management. This will ensure a holistic approach to caring for children diagnosed with T1D who also have a parent with T1D.

Chapter Two – Literature Review

An extensive review of the literature was undertaken before conducting this study to determine what information was available regarding parents' experiences when their child is diagnosed with T1D and a parent also has T1D. A broad number of databases were accessed to search for relevant and current literature, these included PubMed, CINAHL, Web of Science, Medline and Psych INFO, and in-text citations were also accessed. Key phrases used were: Parents experiences with T1D; managing children diagnosed with T1D; T1D and family dynamics; Parents with T1D; genetics influences of T1D; and adults with T1D, the only exclusion was non-English articles. No research studies were found specifically on being a parent with T1D or being a parent with T1D and having a child with T1D.

A narrative style literature review was therefore adapted, as specific research was not available to answer this research question. The available literature was brought together to present a broad perspective of the underlying topic, added to as the study progressed and organised in a chronological order. ^{46, 47}

2.1 Model of Care

The international and national guidelines for diabetes management for children and adolescents includes a framework designed to ensure comprehensive and efficient diabetes services are provided and accessible to all ^{2, 35} The main aims of these frameworks include: improving quality of life for people with diabetes, preventing or slowing the progression of complications, reducing the inequality in service provision to regional and remote areas, and to promote new technologies to improve health outcomes. ^{2, 35}

The current model of care stipulates that all children and adolescents diagnosis with T1D are seen at a specialised medical facility for management. ^{2, 35} Initial treatment and hospitalisation are

determined by the child's condition on presentation to the hospital, with medical intervention and insulin therapy commenced as needed.^{48, 49} Often children with a new diagnosis of T1D are quite unwell with symptoms of acute DKA and so require admission to hospital. The length of stay in hospital, however, is variable between countries and is related to the medical condition of the child, the parents' ability and confidence to safely manage their child's condition and social factors^{48, 50, 51} Parents are encouraged to remain in hospital with the child as they are required to commence immediate education on how to manage their child's condition safely and effectively. This is done with the support of a multidisciplinary diabetes team to ensure optimal care for individuals and families.⁵² The multidisciplinary team includes endocrinologists, diabetes educators, dieticians, social work services, teacher liaison, and psychologists.

During the child's admission to hospital, parents complete approximately 10 hours of specific, targeted diabetes education over seven days. This involves training on daily management, including insulin adjustments, nutrition and diet, exercise and management of short-term complications and is delivered by the specialised diabetes team. Due to the complexity of this condition, this intense learning is often overwhelming for both the child and their parents, and adds to the emotional distress.⁵³ Hospitalisation adds an extra level of stress to parents and family due to the separation of other family members and the need to coordinate family and work commitments. On discharge, parents often experience additional grief, distress and a sense of reluctance with the realisation that they are facing the responsibility of managing their child with this life-long condition at home.⁵⁴ The requirement to restructure their everyday family life to accommodate their child's diabetes and the lack of confidence they feel in their ability to care for their child, particularly with respect to keeping their child safe.⁵⁴⁻⁵⁶

The recognition of challenges associated with hospitalisation and the resultant increased medical costs has prompted growing support for children who are diagnosed with T1D and are

clinically well, to be managed as outpatients by a specialised team following stabilisation.^{57, 58} This model is referred to as ambulatory care, and includes early discharge from hospital within a few days with the education and insulin management being completed in the home or as outpatients in a specialised diabetes service.^{48, 50} Outcomes of studies have supported this model as a safe and alternative way of managing children who are clinically well post-diagnosis, with no significant impact on parents' diabetes knowledge, glycaemic control or parent and family psychosocial outcomes.^{48, 50, 51}

For children and adolescents, long term diabetes management is primarily managed in an outpatient setting. The emphasis is on regular attendance to clinic appointments to support the child and family to ensure the maintenance of optimal glucose control, to provide support with insulin therapy and technology and to monitor risk factors for acute and chronic complications. Moreover, the overall goal is to provide care that will result in normal growth and development and promote the feeling of empowerment to self-management successfully, resulting in a good quality of life.^{2, 35}

2.2 The Role of Health Professionals

It is well recognised that the role of the diabetes health professional team is extremely important following a diagnosis of T1D, particularly in children.^{37, 59} This multidisciplinary team includes endocrinologists, diabetes nurse educators, dieticians, social work services, teacher liaison, and psychologists. Their role is varied and challenging in that, they manage a life threatening condition, provide continual education and support for the child and/ or parent, and assist individuals to negotiate the emotional, social and financial determinants associated with this chronic condition. Each of these professionals have specialised training in diabetes and work together, sharing the same philosophy and goals for patient centred care.^{37, 59}

Health professionals are perfectly placed to assist the child and their parents normalise and adapt to their new lives with early intervention being considered essential to the success of this adaptation.⁵⁹ Acknowledging that parents experienced anxiety and depressive symptoms at the time of their child's diagnosis health professionals need to assess the parents coping and psychological needs within the first few appointments post-diagnosis to enable early intervention.^{59, 60} It is recognised that all Individuals, particularly parents of children with T1D, need to be provided with the skills and support to manage the psychological impact of diabetes to enable them to deal more effectively with the demands imposed by the chronic condition and to ensure adjustment.⁶¹

Education is recognised to be one of the most important aspect of diabetes management and is acknowledged as having a beneficial effect on maintaining effective glycaemic control and improving psychological outcomes.³⁷ However, knowledge alone is limited in its ability to promote changes, the individual themselves need the desire and motivation to make changes to improve their care.⁶¹ The health professional again has a crucial role in trying to understand these dynamics, and must maintaining an open, positive rapport with the child and their parents to gain insight into the family composition, the stresses, and available resources, to be able to provide effective patient centred diabetes management. ^{37, 59} Parents report that non-judgmental medical and nursing support is essential and that the unique circumstances of each family must be understood to provide supportive, patient-centred care. ⁵⁵ This also includes taking into consideration the recognition of previous knowledge and experiences, both positive and negative, that parents may have, and their preconceived ideas regarding diabetes management.

2.3 Living with a Chronic Condition

A diagnosis of a chronic condition, such as T1D, is a stressful life event for parents and the whole family and is known to provoke an emotional reaction that resembles that of bereavement. Feelings of fear, anger, guilt, blame, frustration, helplessness, hopelessness, sorrow, despair, and

even profound grief are often reported.^{62, 63} The classic stages of grief are progressing from anger and denial to bargaining and depression and finally, resolution or acceptance.^{52, 64} Researchers propose that parents of chronically ill children such as T1D have feelings of unresolved grief and although parents may adjust and adapt to the condition; they rarely reach acceptance.⁶² Feelings of sadness re-emerge when blood glucose levels are not well controlled, throughout difficult transitions or conflicts and when parents recall their child's diagnosis or significant health concerns.^{65, 66} Without the resolution of grief, poor adjustment to the diagnosis may result in triggering problems such as overprotectiveness, chaotic family adaptability and lack of conflict resolution⁶⁷

A diagnosis of T1D occurs with little warning, requiring parents and families to make multiple life changes in a very short time.⁶⁰ As a result of this, parents report high levels of anxiety, feelings of shock, fear, and distress.⁴⁵ Parents also feel overwhelmed by the amount of new information, they feel saddened at the loss of health of their child and fear of hypoglycaemia.^{55, 66} The realisation of the intense daily responsibilities and the related lifelong management both short term and long-term complications and the potential of shortened life expectancy is an additional stressor.^{53, 60, 64}

Parenting a child with T1D is demanding. In addition to the normal physical, mental, emotional and behavioural challenges childhood brings, their chronic condition involves complex medical decisions, technical procedures, and time-consuming management.^{2, 68, 69} While children and adolescents with T1D are encouraged to take some responsibility for their condition, the intensive life-threatening nature of this condition means that they often remain dependent on their parents and caregivers to help manage their condition satisfactorily.^{42, 52} As a result, the parent may experience a feeling of burden with the responsibility of daily, time-consuming care, particularly for young children^{68, 70} often resulting in diabetes distress. Diabetes distress has been identified in both children with T1D and their parents and is a general term that refers to the emotional burden and

stress of living with this chronic condition, including the frustrations associated with daily self-care and management and the need for continual vigilance.^{68, 71-74}

Parents have a major influence on their child's wellbeing and play an important role in how the child adjusts to their diagnosis and the management of their chronic condition.^{75, 76} Additionally, it has been observed that the amount and quality of parental involvement in T1D management correlate to treatment adherence and quality of life.⁷⁶ Mothers are acknowledged as bearing a greater portion of the responsibility for their T1D child's management.⁷⁰ It has been reported that the mother/child relationship can be affected as a result of strict dietary restrictions and performing painful procedures as part of the child's diabetes management.⁵⁵

Fathers have not previously been represented in research regarding their role in the child's management of T1D, but changes in socioeconomic and societies growing perceptions and expectations have seen a change in the level of involvement. It has been noted in some studies that fathers involvement has a positive influence on strengthening overall family functioning by assisting their partner through support and easing the burden of care, resulting in improved parent relationships.^{77, 78} Additionally, they have been described as having a greater influence than mothers on their child's adjustment to having diabetes and have a positive influence on diabetes management.^{79, 80}

2.4 Family Impact

Families both affect and are affected by the presence of a child with a chronic condition.⁸¹ Parents play an important role in the development of the family's ability to cope and adapt to the diagnosis of T1D. Children are affected by the quality of their experiences and the wellbeing of others around them. Therefore, how a situation is perceived by an individual is strongly linked to how that person responds to that situation.⁸²⁻⁸⁴ Warm positive parent-child relationships, where

parents are involved in the lives of their children and provide guidance, play a substantial role in minimising the effects of stress for children and this results in better outcomes for managing a chronic condition.⁸⁵

How the family views the impact of T1D and how T1D is integrated into the family can directly or indirectly improve the child's adaption to the condition and improved glycaemic control.^{59, 86} There is a growing body of evidence that greater family cohesion and less family conflict are linked to better adjustment in children with chronic conditions.⁸⁴ Edwards (1987)⁸⁷ believes each family views and manages the severity of the situation differently and this may be related to the symbolic meaning of the event, the availability of resources, other concurrent stressors and the families' repertoire of coping responses which can influence how a family perceives a threatening event such as a diagnosis of T1D.⁸⁷ This includes managing the siblings of children with chronic conditions who have been acknowledged as being susceptible to distress, as they often do not understand the condition but are nevertheless faced with the lifestyle changes it brings.⁸⁶ Without appropriate education, the sibling may fear that they are at risk of 'catching' diabetes or they are the cause of it. As parents are required to dedicate a considerable amount of time caring for the child with T1D, this can result in sibling rivalry and jealousy.⁵²

The promotion of support groups is important, particularly for mothers, as research shows that participation in a support group can help mothers feel understood and that they learn from others and talk and be heard, thereby lessening feelings of isolation.⁵⁴ Support of family members has been considered crucial for adaption to positive diabetes behaviours of children with T1D.⁸⁸

T1D is a complex metabolic condition most commonly diagnosed in childhood and is known to have a complex relationship between the environment and genetic predisposition. Managing children with type 1 diabetes is difficult with the responsibility falling on the parents to maintain adequate glycaemic levels to prevent both short term and long-term complications. These demands

can lead to parents having increased levels of anxiety and distress. For parents already living with type 1 diabetes, this demand increases when their child is diagnosed with T1D. Additionally feeling of fear and guilt may also be evident. For successful management of individuals with T1D, physical and psychological support and education needs to be readily available.

2.5 Summary

This chapter has given a synopsis of the literature outlining the model of care, the management of T1D, the role of the health care professionals and the family impact of living with a chronic condition. The following chapter will describe the methodological framework used including the research design, the recruitment process, and the data collection and analysis.

Chapter 3 – Methodology

In the previous chapter, the current literature was reviewed regarding the impact a diagnosis of T1D has on the whole family and the importance of the multidisciplinary diabetes team in the effective management of T1D was highlighted. Although there is literature regarding parental experience at diagnosis, there is a paucity of information regarding the experiences of parents when their child is diagnosed with T1D and one parent already has T1D. This chapter will provide an overview of the methodological framework used for this study, the research design, participant selection, and recruitment procedures. Data collection methods including the development of an interview guide and the data analysis process are explained. Ethical issues are considered, and trustworthiness is addressed throughout the chapter.

3.1 Research Approach

Qualitative research is a generic term for a range of research approaches that differ in their theoretical assumptions, the understanding of the phenomenon under investigation and the methodological approach.⁸⁹ Historically, qualitative research has been critiqued as lacking scientific rigor, as it was seen as subjective, anecdotal, subject to researcher bias and lacking generalisability.⁹⁰ In recent years, however, qualitative research has received growing attention in social sciences as a reputable and valid form of social inquiry. It claims to describe life worlds from the behaviour and point of view of the people who live in this world.^{89, 91}

The aim, therefore, of qualitative research is to understand people's lived experience from the perspective of the people themselves, their perception, and the meaning, and interpretation of experiences. This is referred to as the insider (emic) perspective.⁹¹ As human experiences and individual reactions to these experiences are complex, it is only possible to completely understand them through a holistic, real-life perspective.⁹² The researcher, positioned in the research process,

must also acknowledge that their background and experiences will shape the undertaking of the study and the interpretation and analysis of the data.⁹³

This study was underpinned by a constructivist paradigm which accentuates that our previous knowledge influences how we perceive and use new knowledge.⁹⁴ We engage in a learning process and with each new experience our knowledge increases. How we interpret or react to that knowledge and those experiences change over time, creating new knowledge.⁹⁵ The constructivist paradigm assumes a relativist ontology (there are multiple realities), a transactional and subjectivist epistemology (participant and researcher co-create knowledge and understandings), and a naturalistic (in the natural world) set of methodological procedures.^{94,96} Ontology refers to a branch of philosophy that is concerned with the nature of reality and what can be known about it.⁹⁴ Individuals' experiences do not create a single reality or truth but instead, provide information about the world around us, not how it is but, rather, how people interpret it.^{92,97}

Epistemologically, a constructivist paradigm assumes that knowledge is generated as the research proceeds. As such, it recognises the importance of the interaction between the researcher and participant and what is being explored. Transactions between participant and researcher are continual and subjective, being guided by previous knowledge and experiences generating new knowledge.⁹⁴ The 'realities' taken to exist depend upon the transaction between the researcher and participant, in the particular context in which the encounter between them takes place.⁹⁸

Methodologically, qualitative inquiry allows for that encounter to take place and involves a systematic exploration of detailed experiences and/or understandings told by participants with lived experience and/or knowledge of the issue under investigation.⁹¹ There are four conditions that are foundational for a study underpinned by a constructivist paradigm to be considered meaningful. These are 1) the use of qualitative research methods, 2) meeting the participants in their natural setting, 3) humans being the key research instrument and, as such should be able to respond to

changing contexts and 4) using the emic perspective, within the research encounter.⁹¹ To demonstrate methodological soundness and adequacy for this project, Lincoln and Guba's (1985) concept of trustworthiness was utilised. The four criteria of credibility, dependability, confirmability, and transferability will be addressed throughout the chapter.

To further explore the parents lived experience, and in the context of the constructivist paradigm, a socioecological model will be used to demonstrate the interconnection of the individual and environmental factors that influence the individual's experience and the impact each layer has on the health outcomes, behaviour and well-being.⁹⁹⁻¹⁰¹ A socioecological model (SEM) is a visual interpretation of the relationships between the layers and will be used to discuss the findings from this study. These socioecological models are detailed and demonstrate that not only are there multiple levels of influence that exist but also that these levels are interactive and reinforcing.⁹⁹

3.2 Research Design

The site on which the research project was undertaken is a diabetes clinic in a research facility. This department currently cares for more than 1000 children with T1D, with more than one hundred new patients diagnosed with T1D each year. The Diabetes Department employs the International Society for Paediatric and Adolescent Diabetes (ISPAD) guidelines as a framework for their model of care.¹⁰² This framework provides a comprehensive, accessible and efficient provision of coordinated diabetes services for all children who are diagnosed with T1D before the age of 16 years and their families. Specific care is provided using a multidisciplinary approach, providing specialised short and long-term care through continuous education, medical and psychological care from paediatric endocrinologists, diabetes educators, dieticians, social workers, and psychologists. This state-wide service is available to families living in the metropolitan areas as well as regional and remote areas of the state.

3.3 Participants and Recruitment

3.3.1 Participant Selection

The diabetes department maintains a children's diabetes database, a comprehensive prospective database that records demographic and medical information of all children diagnosed with T1D and their families to whom services are provided. Permission was sought and granted from the hospital's Human Research Ethics Committee to use this database to purposively select potential families for this study. Purposive sampling is a non-random, deliberate choice of selected individuals, groups or organisations that are rich in knowledge or experienced in the topic being explored.¹⁰³ These information rich-cases are deemed to provide the greatest insight into the research question and the inherent bias of selection contributes to its efficiency and credibility.⁹⁶ A strength of qualitative research is its potential to explore a topic in-depth and participant selection is central to the credibility of the study.¹⁰⁴

The database was used to identify parents of children diagnosed with T1D between the years of January 2013 to December 2015 with one of these parents also having a T1D diagnosis. A second condition was that families were required to still be attending the diabetes department for their child's diabetes care. This database search yielded twelve potential families or parent sets.

The child's medical records were reviewed to ensure their eligibility. While there were no exclusion criteria documented, it was agreed by the researcher and supervisors, following this review that three families should not be contacted. One child's family was noted to be having significant and current family problems, while the other two children had experienced the death of their father, the parent with T1D.

In qualitative research, the numbers of participants required are smaller than in quantitative research. To determine adequate sample size in qualitative research, many researchers refer to the

concept of interviewing to redundancy or to saturation. Redundancy is when all thoughts, ideas and beliefs are repeated multiple times without new information emerging and interviewing to saturation is where all questions have been explored with no new themes emerging.^{104,105} However it is becoming more evident that to determine the size of the sample, other aspects need to be considered including the nature of the phenomenon, its concrete versus subjective nature, the amount of complexity and scope of the phenomenon and how much is already known about the topic.¹⁰⁶ Additionally, information about study aim, sample specificity, theoretical background, quality of dialogue and strategy for analysis, has also been acknowledge as important when determining a sample size.¹⁰⁷

Malterud et al (2016) have developed a model of information power which indicates that sufficient information power can be obtained with fewer participants if the aim is narrow, the combination of participants is highly specific, if the research is supported by an established theory, if the interview dialogue is strong and analysis includes longitudinal in-depth exploration.¹⁰⁷ In this study we believed the sample size was adequate and we achieved both saturation and high information power. The aim of the research was narrow, participant who participated were well informed with specific knowledge and diverse experiences in relation to the research question and an established theory was used. The interview data collected was lengthy and informative and we believed the participants felt comfortable sharing their experiences honestly. The analysis included in-depth analysis of narratives which illustrated a pattern of experiences with no new concepts or themes being identified by the end of interviewing.

It was determined that, following the initial data analysis of seven interviews, more participants would be needed as new themes were still being identified and required further exploration. An amended protocol was submitted to the ethics committee extending the recruitment criteria to include the year 2016. Following approval of the amendment, the database

was again accessed, and another three parent sets were identified. The final number of interviews completed was ten which included, seven separate parent interviews and three interviews, where both the non-T1D and the T1D parents attended together. One of these joint interviews was completed via Skype. More detail regarding the interviews follows.

3.3.2 Recruitment

The inclusion criteria for the child's T1D diagnosis was between the years 2013 - 2016 (inclusive). This was selected as it was considered that the diabetes diagnosis experience needed to be recent enough to be remembered in extensive detail. Additionally, enough time had elapsed for families to have developed their diabetes management routine and the family to be more comfortable with the emotional and family issues associated with their child's diagnosis.

Each parent was invited to participate separately in the study via a recruitment letter (Appendix A) which included a participant information sheet and a consent form (Appendix B) sent directly to their residential address. Parents were asked to send back the lower portion of the letter in a prepaid, self-addressed envelope indicating their interest in participating in the study. It was hoped that both parents from the same family would agree to participate to ensure rich data collection from those parents' experience; however, it was not an inclusion criteria. There was only one parent from the parent couples, which declined to be interviewed.

Those parents who agreed to participate were then followed up via phone or email to ensure they fully understood the research intention and to provide them with the opportunity to ask any questions. At this time a suitable date, time and venue were organised with participants, for the completion of the interview. Those parents who did not respond to the original invitation letter were also contacted via email or phone to confirm the receipt of the letter and to officially document

their choice not to participate in the study. The two main reasons cited by the parents for non-participation were the time restraints imposed and disinterest in participating in research.

3.4 Data Collection

3.4.1 Development of Interview Guide

A review of the current literature highlighted known difficulties associated with a child being diagnosed with T1D, but there was a paucity of information relating to any association of a parent and their child with T1D. An interview guide was developed comprising questions and prompts addressing the known difficulties of a child's diagnosis and more specific questions relating directly to the T1D diagnosis of the parent and the impact this had on the parents, the child and their siblings.

Questions and prompts focused on topics, including diagnosis, emotions, hospitalisation, and management. It followed a consistent and systematic chronology from pre-diagnosis to post-diagnosis. The interview questions were semi-structured which allowed for the sequencing of questions to be different for all participants and were dependent on the process of the interview and the responses of the participant.¹⁰⁸ All of the questions in the interview guide were answered by all participants.

To test whether the questions were appropriate and would generate the information required to explore the research question, the interview guide was trialled on two parent sets selected from the diabetes database. The families met the same inclusion criteria as outlined in the research project but were selected from those with a T1D diagnosis in the previous year (2012). Four participants signed a consent form agreeing to test the interview guide and included both the parents with T1D and the parents without T1D. Each parent was interviewed separately and on different days. Test interviews were audio-recorded and transcribed verbatim. The researcher read

and reread transcripts and using Braun & Clarke's (2006) six-step framework approach identified patterns or themes within the data that were important or interesting.¹⁰⁹ Each test interview was analysed prior to the next interview being undertaken. This enabled the researcher in consultation with the supervisors, to refine the guide based on responses from parents to ensure the interview questions adequately addressed the research question. There was minimal alteration needed to the interview guide following these test interviews, with the addition of only one prompt incorporating the concept of parents with T1D being acknowledged for also having this chronic condition. (See Appendix C for interview guide)

In qualitative research, dependability refers to the consistency and accuracy of the data collection, including the constancy of data collection over the study and between participants.¹⁰⁸ To ensure the dependability of this data collection, the researcher undertook interview training with team members experienced in conducting face-to-face interviews and used the test interviews to modify and refine interviewing techniques. The same researcher conducted all the interviews including the test interviews.

3.4.2 Participant Demographics

Transferability makes research meaningful and is one of the major challenges of qualitative research. It refers to the degree to which the research can be applied to other contexts, situations or settings.⁹⁰ This is achieved by using rich descriptions of the research setting and participant's characteristics.¹¹⁰ In order for researchers to determine if this project applies to other settings, a detailed description of the research site and participants' characteristics was compiled and is reported in this thesis.

Participant details were collected via a short demographic questionnaire (Appendix D) and included information about the parents including their age, education level, and work status. Other

information gathered included the number of children and adults living in the same house and information related to the child and parent with T1D, including their date of diagnosis and current diabetes management regimen.

For the ease of discussion throughout this thesis, we will use the following abbreviations of identifying individuals in this study and in no way are they meant as labels. 'T1D parent' - Parent who has type 1 diabetes, 'T1D child' - child with type 1 diabetes and 'Non-T1D parent' as the parent who does not have the condition.

3.4.3 Interviews

In the last two decades, research interviewing has become the most common form of data collection in qualitative research and is widely used in conducting field studies and ethnographic research.^{108, 111} Interviews are a useful way for researchers to learn about the world of others but require 'a respect for and curiosity about what people say and a systematic effort to hear and understand what people tell you' (Rubin & Rubin, 1995, p.17).¹¹¹

In-depth interviews are like conversations but have the power to actively encourage the participant to share their experiences and complex topics can be addressed through effective prompting and clarification, leading to new knowledge. Interviews also provide a mechanism for redirecting conversation that digresses¹¹² and enables participants to provide their responses in their own words and way.¹¹¹ For this study, in-depth interviews were selected over focus groups as specific details about personal experiences were encouraged. Moreover, the likelihood of these families meeting in the clinic or at a diabetes-related activity is high, causing the potential for some families to feel uncomfortable.

To ensure the trustworthiness of data obtained from interviews, the relationship between the researcher and the participant must be considered as this may influence how much and what

type of information is shared during the interviews. This relationship should be based on mutual respect and a position of equality as human beings.¹⁰⁸ This will assist to establish confidence in the 'truth of the data' and the truthful interpretation and representation of the participants' views by the researcher, adding credibility to the research.^{90, 113} To further demonstrate credibility, the researcher stated her qualifications, the intention of the research and her place of work at the initial interaction with the participants and reiterated it at the time of the interview.¹¹⁴

Building a positive rapport with participants is beneficial for both the interviewer and interviewee and is achieved through participant engagement. Simply spending time prior to the commencement of the interview to get to know them a little or during the interview, allowing the participants time to answer the question, ensured they felt relaxed and therefore can accurately and comprehensively answer the questions posed to them. Participant engagement is significantly important to the credibility of qualitative research.⁹⁰

When designing this study, the preference was for each parent to be interviewed separately. This strategy allows the participant to freely express their individual views and be open and honest about how they manage T1D in their life. It may also ensure that the participant is not influenced in any way by the presence of their partner and the information they shared.¹¹⁵ The researcher also thought that separate accounts may create the opportunity to identify similarities or differences in each of the parent's perspectives of the same situation, which could be further investigated. However, Taylor & de Vocht (2011), argues that joint interviews can also be valuable as they provide an opportunity for the participants to share their story as they probe, correct and challenge the discussion with each other, potentially providing richer data.¹¹⁵

Following recruitment, all participants provided a signed consent form prior to the commencement of their interview. Informed consent is the principle that individuals should not be coerced or persuaded into research against their will. It endorses that their participation is

voluntary, that they fully understand and comprehend what the research is about, what is being asked from them and the implications of their participation.¹¹⁶ For this study, their signed consent covered both the participation in the study and the audio recording of their interview.

At the commencement of all interviews, individuals were reminded that participation in the research was voluntary and that they could withdraw from it at any time or decline to answer questions. Participants were reminded that if they became upset during the interview, it could be paused or terminated. Participants were also reminded and reassured that their participation or non-participation in this study had no impact on their child's diabetes management or clinical care and that all data collected, both written and recorded, would be de-identified with a unique study identifier.

Ten interviews were completed using the interview guide. Six parents chose to have joint interviews with their partners (three interviews). The reason they cited was convenience; the observation of the researcher, however, was that the parents who completed joint interviews may not have all had equal opportunity to share their own experiences and at times were indeed influenced by their spouse. For example, in one of the joint interviews, one individual seemed more confident and outspoken and tended to dominate the conversation, despite the encouragement of both views.

All interviews were conducted in the participant's home or workplace. Nine of the ten interviews were completed face to face. The tenth interview, a joint interview, was conducted using a voice over internet protocol technologies (VoIP) called Skype, as the family lived over 400 kilometres away from the metropolitan area. These VoIP technologies are becoming more widely used in qualitative research as it provides the opportunity for researchers to interview distant participants, enabling diversity and provides an opportunity for participation of people who would normally not be recruited due to geography. Skype interviews also allow participants flexibility with

regards to the time and place of interviews.¹¹⁷ The Skype interview follows the same procedure as the face-to-face interviews and enables the researcher to make note of body language and facial expressions throughout the interview.

Individual interviews lasted between 33 and 73 minutes with an average of 51 minutes. Joint interviews lasted considerably longer between 65 and 90 minutes, taking an average of 78 minutes. This longer time was expected as extra time is needed to ensure that responses are heard from both participants. All interviews were audio-recorded, with permission, including the Skype interview, to enable continued researcher interaction with the participant/s during the entire interview. Additionally, this ensured accurate transcription of the responses of the participant/s and the ability to review data recorded as required.

3.4.4 Field Journal

Reflections of the interview were compiled into a journal by the researcher immediately following each interview, documenting specific information about it, the process, and the participant/s. This included the environment or room the interview took place, other people who were present in the house or office at the time of the interview, environmental and situation distractions, and the general description of how the interview went. The researcher also recorded facial expressions, emotions shown, and the body language used as these observations are an important factor and add to the overall credibility and completeness of the data collected.

3.5 Data Analysis

Interviews were audio-recorded using two separate Olympus digital voice recorders to ensure the recordings were of high quality and captured accurate information. One recording was kept as a backup, the other used to playback the interview for verbatim transcription. Completing transcription is a lengthy but essential and enlightening process to become familiar with the data.

Listening and re-listening to the audiotape and confirming the accuracy of the transcription contributes to confidence in its overall trustworthiness.¹¹⁸

Confirmability in qualitative research is the ability of the researcher to demonstrate that the data is representative of the participants and not the researcher's viewpoint, bias or prior assumptions.^{90, 108} Therefore, the researcher's supervisors were also engaged to review transcripts to ensure accuracy and discuss the emerging analysis to ensure findings were descriptive of participants' views. Good qualitative data analysis relies on the ability to locate the information and to keep that information in context during analysis.⁹⁶ Therefore, to ensure dependability an audit trail journal was also kept to record all discussions by the research team regarding coding, theme exploration and development as well as the stepwise method of analysis.

Data were analysed thematically. Thematic analysis is a process of identifying, analysing and reporting patterns or themes from within qualitative data that are important or interesting^{109, 119}. These themes may not necessarily be identified across all participants but in the researcher's judgement they are considered important aspects with the view of helping to answer the research question.¹¹⁹ Braun and Clarke (2006) provide a six-phase framework, (see Table 1.) for assisting with thematic analysis however, they state that analysis is not a linear process but rather more a recursive process of moving back and forth between the phases rather than simply moving from one to another¹¹⁹. This framework was used for data analysis for this project.

Phase	Task
Phase 1	Familiarise yourself with your data
Phase 2	Generate initial codes
Phase 3	Search for themes
Phase 4	Review themes
Phase 5	Define and name themes
Phase 6	Produce the report

Table 1. Braun and Clarke's (2006) Six-Phase Framework for Thematic Analysis

Phase one involves becoming familiar with the data. Therefore, the researcher read and reread each separate interview transcription in its entirety, adding handwritten notes of all possible interpretations of it and first impressions down the side. Following this, all transcripts were imported into NVivo 11 (QSR-International), a computer-based data management program to help manage and search data.

The next phase involves the researcher applying an inductive approach to analysing the data. This requires in-depth, line by line reading of the transcript moving within the transcript and between all transcripts to identify what participants were saying.^{109, 120} The aim is to identify patterns and develop descriptive codes that emerge from the data that reflect the research objectives.¹²¹ Maguire & Hennink Glaser (1978, pg. 220) state that “codes must earn their way into the analysis, that is, they must be shown to be valid, robust and useful”.¹²⁰ The development of these codes result from multiple interpretations of the raw data by the researcher and are inevitably shaped by assumptions and experiences of that researcher.¹²¹

To ensure trustworthiness, the researcher’s supervisor similarly read transcripts and created her code list. All codes were jointly discussed and analysed with a final list developed. Following the code development, the researcher began to ascertain the underlying ideas, assumptions, and

conceptualisations; sorting, interpreting and combining codes into broader levels to form overarching themes,^{109, 119}this is the third phase of the framework.

The table below (see Table 2) illustrates this process. The codes of ‘random high BGL’ and ‘thirsty’ are identified with a subtheme of ‘Early Diagnosis’. The codes of ‘grief’, ‘shock’ and ‘heartbroken’ and ‘tears’ created another subtheme of ‘Emotions’. These two subthemes then contribute to a broader overarching theme to create ‘Child’s T1D Diagnosis’. A theme should reflect something important about the data in relation to the research question and the development involves three stages, namely searching, reviewing, and defining. The researcher and supervisor discussed the themes as they were identified and came to an agreement through discussion which was the most representative of the data. The use of investigator triangulation during this phase of reviewing codes and identifying themes enhanced the credibility and helped to minimise potential bias.¹¹⁴

Extract	Coded for	Sub theme
<p>Random finger prick at home came up at <u>13(BGL)</u>, so tested the next day and it was <u>high</u> so took him to the GP (6A-non T1D Mother)</p> <p>Same as what I had, very <u>thirsty</u>, constantly looking for something to drink (1B-T1D Father)</p>	<p>Random high BGL</p> <p>Thirsty</p>	<p><u>Early Diagnosis</u></p>
<p><u>Grief and shock</u>, then the realisation of how this was going to impact us as a family ... I was quite emotional ... felt like I had been hit by something (2A-T1D Mother)</p> <p>When I heard the finger prick was high, I was <u>heartbroken</u>. I went outside and called my parents and just burst into <u>tears</u>. (7A non T1D Father)</p>	<p>Grief, shock</p> <p>Heartbroken tears</p>	<p><u>Emotions</u></p>

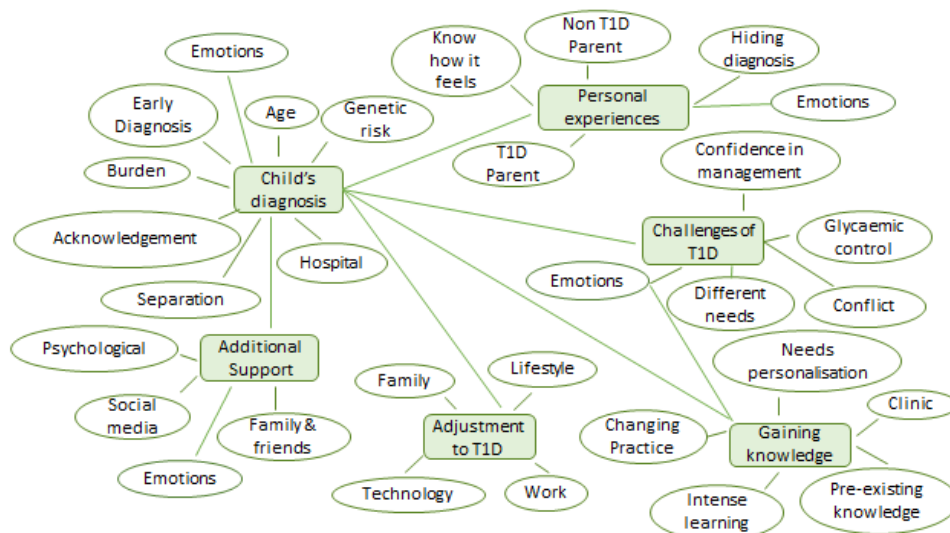
Table 2. Coding Process – Child’s T1D Diagnosis

Phase four involves the continuous reviewing of data and further refining of themes, to ensure the data are representative of those themes and that the data within each of the themes is coherent and distinct from each other. The next step was to determine how these themes sit within the context of the entire data set and identify the story they tell about the data.¹¹⁹

Phase five involves the creation of thematic maps, a visual representation of the identified themes and how they fit together to determine if the themes are reflective of the whole dataset and illustrate the overall story the data is telling in relation to the research question.^{109, 119}

Several thematic maps were created during this phase. These maps helped to refined the number of themes identified and, in order not to make the themes too complex, subthemes were created if needed to demonstrate the hierarchy of meaning within the data.¹¹⁹ Initially, broad themes and subthemes were identified and considered for their validity, (see Figure 4). This map appears congested, however, all initial important categories are identified, for consideration. Through regular meetings with supervisors and continued analysis the themes become stronger and titles were refined. All suggestions and changes were recorded in the audit trail journal which was reviewed as the absolute themes were determined and a final map created. This will be presented and discussed in the following chapter.

Figure 4. Initial Thematic Map



The final phase is producing a report that encompasses the final analysis. The report provides a concise, coherent and logical recount of the story that the data tells, within and across all themes and in relation to the research question.^{117, 119} The use of participant quotes helps to validate the

participants' perspectives and adds transparency and trustworthiness to the findings and subsequent interpretation of the data. The following chapter reports the results.

3.6 Ethical Considerations

Ethical approval was also obtained from the research site, Human Research and Ethic Committee (HREC), to enable participant recruitment, EP2016060 (See Appendix E). Ethical approval for this research was also obtained from the University of Western Australia Human Research Ethic Committee – RA/4/1/8452 (See Appendix F). Documentation applicable to this approval included project research proposal, participant information sheets, recruitment letter, participant demographic questionnaire, interview guide, and a contact card. An amendment for study protocol and recruitment letter was submitted in August 2017 as the inclusion criterion was extended for 12 months to December 2016 (See Appendix G).

Ethical considerations in qualitative research involve several issues, mostly related to dealing directly with the participants, their wellbeing on a sensitive subject matter and being in their environment. As part of the ethical approval process, risk and harm were given due consideration particularly in relation to the potential emotional distress that may result from reliving events and emotions related to the child's diagnosis of T1D or their diagnosis. It was requested by the ethics department that a contact card (See Appendix H) be left with each participant at the completion of their interview, with numbers of support services so that participants could easily access assistance should it be required. No participant required their interview to be terminated.

Respect for the participant's privacy and confidentiality of their information is essential, and this was achieved by using numerical labels to de-identify participant information. Each participant was given a unique identifier, and this was used in the transcription process and in discussion with other project members for analysing and interpreting data and for reporting. The researcher

conducted all interviews and her supervisor had access to de-identified transcripts only. Safety concerns associated with entering the participants' houses were approached with a safety plan which included giving a supervisor, information about the date and time of the interview and the address of the participant. A text message was sent when entering and leaving the house. There were no issues related to safety.

3.7 Data Storage and Access

All data with the participant names are stored separately to de-identified transcripts and recordings. All electronic study information is saved in a password-protected file. The paper copy source data is locked in a secure cupboard, and de-identified and identifiable data are stored separately. Only the researcher and her supervisors involved in this study have access to this information. Audio recording devices with recorded interviews were kept in a locked cupboard, in the researcher's office at the research facility, during the data collection process and until all transcriptions were completed. Recordings were then erased. All data and study information will be kept for five years following publication and will then be destroyed.

3.8 Dissemination of Information

Each participant, including those involved in the trialling of the interview guide, will be given a written report outlining the overall findings of the research. Preliminary information has been shared through a poster presentation at the International Society for Paediatric and Adolescent Diabetes (ISPAD) conference in India and at a Hospital Symposium in 2018. Additionally, an oral presentation was delivered at a national conference, the ENDIA symposium in Adelaide in 2019. Results will be presented to staff from the Diabetes Department with the goal that the outcomes can be translated into the care of these families in the clinical setting. Lastly, a manuscript will be written and published in a health or nursing journal.

3.9 Summary

This chapter describes an overview of the qualitative research approach, the research participants and the setting and the method for data collection and analysis. The next chapter will describe in detail the findings from the interviews and other data collected from the demographic sheets. The use of a thematic map will demonstrate the identified themes and subthemes and participant quotes will assist with explanation of the findings.

Chapter 4 – Results

Chapter three established the methodology, the process for data collection and gave detail regarding the analysis process. The development of the initial thematic map (Figure 4) showed six main themes and many associated subthemes. This chapter will present the overall findings of the study from ten in-depth interviews and the information collected from the demographic sheet. Firstly, an overview of the demographics of the parents and children is presented, followed by an explanation of the findings using a further simplified thematic map which showed five main themes and the integration of some of the smaller subthemes, a detailed explanation of these themes and subthemes will follow.

4.1 Participant Characteristics

The information collected via the participant demographic sheet, included marital status, date of birth, education level, work commitments, and family structure. All parents participating in this study were married and living together in the same house with their child with T1D and his/her siblings. Five families lived in the metropolitan area and two lived regionally. All parents interviewed had completed a high school education with five participants continuing with undergraduate or postgraduate studies. All parents were employed, with five of the seven mothers working part-time or in casual employment and two mothers in fulltime work. Of the seven families who participated in this study only one of the parents with T1D was female.

At the time the interviews were undertaken, the children with T1D were all 16 years of age or younger, with only two of the seven children being female. In this study it was noted that the age of the children at diagnosis was between 2.6 and 12.3 years of age, much younger than the age of the parents at diagnosis, which was between the ages of 16 and 40 years, see Table 3 below. This finding has been identified in other studies investigating parent-offspring groups where there is

male dominance in parent-offspring groups, preferential transmission from father to child and younger age at diagnosis of offspring.^{23, 122}

Participant ID	Gender	Age at time of interview	Level of education	Work	T1D
1A	Female	51	Training College	Full-time	No
1B	Male	54	Training College	Full-time	Yes
2A	Female	37	Undergraduate Degree	Part-time	Yes
2B	Male	45	Training College	Full-time	No
3A	Female	47	Training College	Part-time	No
4A	Female	41	High School	Full-time	No
4B	Male	46	Training College	Full-time	Yes
5A	Female	38	Training College	Casual	No
5B	Male	39	Training College	Casual	Yes
6A	Female	46	Undergraduate Degree	Part-time	No
6B	Male	46	Postgraduate Degree	Full-time	Yes
7A	Female	37	Started Post Grad	Part-time	No
7B	Male	39	Postgraduate Degree	Full-time	Yes

Table 3. Participant Demographics

At the time of the interviews, parents were asked to provide the most recent HbA1C value for their child and themselves (if a parent had T1D). A higher result indicates a higher level of blood glucose in the preceding three months. Table 4 shows that all the children's HbA1C at the time of the interview was higher than that of their T1D parent. Furthermore, it was noted that all T1D children were on the same insulin regimen as their T1D parents, either multiple-dose injection (MDI) or continuous subcutaneous insulin infusion (CDII).

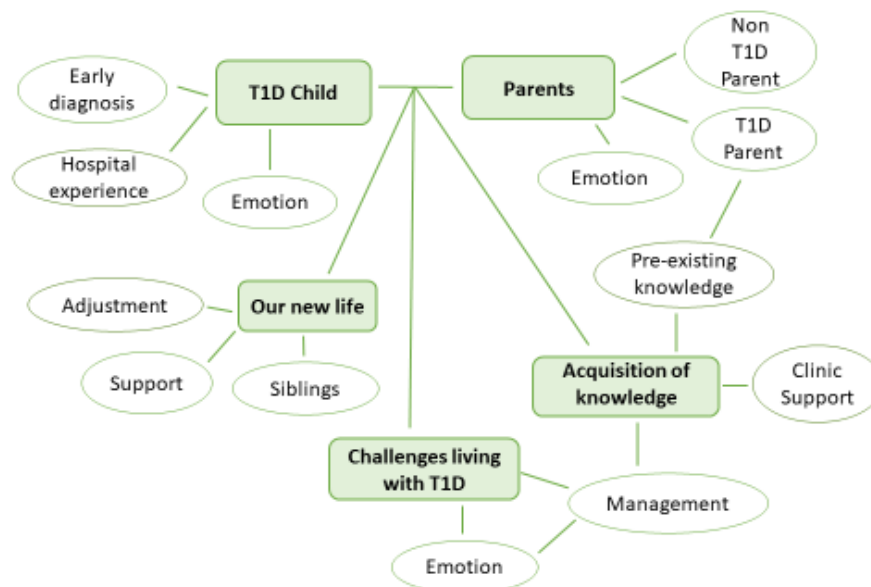
ID	Gender		Age at diagnosis		HbA1C at time of interview		Insulin Regimen	
	Parent	Child	Parent	Child	Parent	Child	Parent	Child
1	Male	Female	11	9.3	*	7.6	CSII	CSII
2	Female	Male	9	2.6	7	8.9	MDI	MDI
3	Male	Male	40+	12.3	*	*	MDI	MDI
4	Male	Male	16	3.9	6.2	7.8	MDI	MDI
5	Male	Male	24	6.1	8.9	9	MDI	MDI
6	Male	Male	37	5.4	5.6	7.4	MDI	MDI
7	Male	Female	21	3.1	8.1	9	CSII	CSII

Unknown value*

Table 4. Age, HbA1c and Insulin Regimen

The thematic map (see Figure 5), displays the five themes that were identified as a result of the data analysis, namely: *'T1D child'*; *'Parents'*; *'Acquisition of knowledge'*; *'Challenges living with T1D'* and *'Our new life'*. The subthemes identified provide further elaboration of the data analysis. Each theme is reported along with its respective subthemes and with participant quotes to substantiate and endorse each.

Figure 5. Final Thematic Map



4.2 T1D Child

This theme outlines the experience parents went through when their child was diagnosed with T1D. It includes the subthemes 'early diagnosis' and 'hospital experience'. It describes the

emotions that were associated with their child's diagnosis. All parents were able to provide a detailed description of their experience associated with their child's diagnosis. Parents who were interviewed separately had very similar recounts of the weeks/days preceding diagnosis. Parents talked in length about their experience when their child was diagnosed, with considerable detail remembered, from those parents whose child was diagnosed nearly three years prior.

Early Diagnosis

The symptoms of T1D in children can be subtle and sometimes overlooked or even confused with other childhood conditions. Parents noted that their child's behaviour had changed in the pre-diagnosis period, with most of the parents noticing recognisable symptoms of T1D. These included increased thirst, lethargy, weight loss (despite an increased appetite) and bedwetting or frequent urination including nocturnal urination.

For about a week she [child with T1D] had been extremely thirsty to the point where she would lose the plot if I was driving and couldn't reach the drink bottle..., she would like guzzle the drink bottle and she was eating like a horse and cranky as... (7A non-T1D Mother)

I guess we really picked it up because [child's name] couldn't go – he couldn't go like 20 minutes without a drink, could he? So even from here to child care at the time, he would scream blue murder if he couldn't get a drink in the car and he obviously, he was going to the toilet a lot then cos he was drinking. (4A non-T1D Mother)

One non-T1D parent stated that on reflection, although she knew what the symptoms of T1D were, she had not even considered it for her daughter despite her constant drinking. This was because there were other issues happening in the household and it was summer.

It was January...everything was up in the air so we weren't really focusing on [child with T1D], not in that way, because she didn't seem sick, it was hot and she was constantly drinking anyway... (1A non-T1D Mother)

Five parents in this study had acted promptly when they did notice symptoms indicative of T1D and had either presented to a hospital emergency department or visited a General Practitioner (GP) within one to four weeks of noticing these symptoms. The outcome of the early recognition of T1D symptoms by the parents and the subsequent speedy presentation to the required medical service resulted in the children being quite well on admission.

"Oh, I think our son might be diabetic" and she [nurse] looked at [T1D child], he was bouncing around like there's no tomorrow and she looked at us... "Oh how come you think that"? And so, we explained... you could tell she had her doubts cos I mean diabetic kids that they see come in are almost in comas... she tested him... "Yep we will take you straight through... [To the emergency room]". (4B T1D Father)

Personal communication with Endocrinologists and Diabetes Nurse Educators, highlighted that parents with T1D often worry about their children developing diabetes associated with genetic susceptibility and will test their children's blood glucose level (BGL) randomly or when unwell just for peace of mind. This concept was considered important to explore, therefore, during the interviews, parents were asked when this occurred. In this study, four parents had recognised specific worrying symptoms and had tested their child prior to presentation to medical services.

And when we came home, he [child with T1D] got a drink and went straight to the toilet, so that was three toilets in 20 minutes...so I said "we're going to test him now...you know we should've done it last week..." (4B T1D Father)

For one family, a random BGL check, resulted in an unexpected result. This T1D father was routinely checking his own BGL before breakfast, when his daughter asked him “Can we all do a blood test?”

Yeah, someone got the sterile wipes out and changed the finger prick needle and everyone had a go and everyone was fairly, you know, in the range that they should be but [child’s name] was at the higher end. (6B T1D Father)

Consequently, the parents of this child rechecked their child’s BGL several times during that day, with each test registering on the high side of normal. The parents made a GP appointment for the next day, not really thinking it would be diabetes as the child did not have obvious symptoms of T1D other than a long-term bedwetting problem that seemed to have been getting worse. A further high reading confirmed by the GP resulted in the child being sent to the hospital.

A non-T1D parent of a teenager in this study recognised the symptoms immediately. Her husband had been diagnosed with T1D just three years prior. Their child had been getting up in the night for a drink and to void. She wanted her child to see a GP, but the child was reluctant. Inadvertently, several days later, this child accompanied an unwell sibling to the GP and the mother took the opportunity to speak with the doctor about her child’s symptoms, initiating the GP to do a urine test. On finding high glucose levels the child was sent to the hospital.

The doctor knew. As soon as I told him what was happening, but I sort of knew as well because my husband was diagnosed in 2010. (3A non-T1D Mother)

In this study, there were two children, subject A and subject B, who had been unwell for a couple of weeks. The parents had noticed a variety of symptoms that had concerned them enough to see a GP on several occasions. The first was a young child who had symptoms of bedwetting, excessive drinking, lack of appetite and poor sleep. The mother attended the GP clinic and was told

that the symptoms could be a behavioural response as the child's dummy had recently been taken away. This child continued to wet the bed during the night for two weeks. One afternoon following an outing to the shops, this T1D mother decided to do a blood glucose test on her child and the test showed 'HI'.

We had a fresh pull-up (disposable underpants) on, and then after the milkshake, it was just drenched straight away. So, I thought that is interesting. So, I said to [husband] "when we get home, I will test him". So, I changed all my stuff on my meter and I did the finger prick.
(2A T1D Mother)

During this interview, where the above quote was taken from, this T1D mother talked more about the emotions around how her child (subject A) had been misdiagnosed and as a result was quite unwell on admission. It was unclear at what point this T1D mother started questioning if these symptoms were related to T1D or if she had thought about T1D at all. The second child (subject B) had visited the family GP two or three times over a two-week period for pains in her stomach. This non-T1D mother had also noticed some weight loss, up to four kilograms over three weeks, despite her huge appetite. When she mentioned this to the GP, she was told that it was not significant. Coincidentally the GP was the treating doctor for her husband's T1D management. The mother became so concerned that their child was becoming more unwell that she presented to the hospital for review. At this point she did not even think it could have been diabetes:

I was more concerned with the fact that she had the pain in her stomach, I thought appendicitis. (1A non-T1D Mother)

On reflection she felt that knowing her husband's condition, the doctor should have been more aware of the possibility of T1D. While the family waited in the emergency room to see the doctor, the T1D father decided to do a BGL check on the young girl and the result showed 'HI'.

[T1D father's name] was with her and he tested her, he showed me the meter that said HI and I just, I just broke down– I had to go outside. (1A non-T1D Mother)

During the interview, the researcher asked why he hadn't tested her earlier, the response was "because we probably didn't want to know if it was". (1B T1D Father)

Hospital Experience

Analysis of the interviews indicated that parents felt that the hospital stay was generally positive. Families were required to stay in hospital between five and eight days and until after all the education sessions had been completed. A frustration voiced by many parents was that they believed the education process could have been completed in a shorter timeframe. Education sessions were only conducted for part of each weekday and there were no education sessions on the weekends. Lengthy stays in the hospital meant family members were separated from each other and parents found this very difficult. Parents commented that this added further stress to an already difficult situation, as they juggled between being with the newly diagnosed child in the hospital and managing the needs of the other siblings, family, and work commitments.

[Father's name] was still working, uhm and then, and I was still working... that we were taking basically nights and days figuring out a roster of who could be there and then sorting out my, uhm, our daughter. (6A non-1D Mother)

Additionally, T1D parents recalled having difficulties with their diabetes management during their child's hospitalisation because of added stress, sleeplessness and a lack of routine.

He [T1D husband] actually had a massive low blood sugar and had had a fit and bit his tongue, and his parents were staying here, looked after him...because of the stress. (5A non-T1D Mother)

Although the hospital stay did present some physical and emotional challenges, some families noted that it helped them to put their situation into perspective. They recognised and acknowledged that other families in the ward were having a more difficult time than they were accepting and managing their child with T1D.

I think we took it pretty well only because of [T1D Father] ...the poor family who were in at the same time They flew in from...had never heard of diabetesand the poor mother, she was hospitalised herself because she was just beside herself, the poor thing, so we were fortunate enough that we knew a little bit... (4A non-T1D Mother)

Emotions Associated with a Child's Diagnosis

On relating their experiences when their child was diagnosed with T1D, parents were asked to recall the emotions they felt relating to the time they realised, or when it was confirmed, that their child had T1D. All parents felt a combination of devastation, shock, grief, fear, and sadness when they were told by the doctors of their child's diagnosis. Additional emotions surfaced after the initial shock associated with the concern and realisation of the overall impact of this chronic condition on their young child and family.

I was shocked – I think because being a health professional knowing the disease – my child has a chronic condition and I know what that means. (6A non-T1D Mother)

...It was grief and shock and then just the realisation of how this was going to impact us as a family ... (2A T1D Mother)

Parents were hopeful in the early stages that the diagnosis of T1D was wrong, questioning doctors regarding the possibility of incorrect results or the chance of it being a different condition.

And then I said to the doctor, “are you sure it’s not a stupid thing, muscular dystrophy or some other genetic thing. I don’t want it to be Type 1”. (2A T1D Mother)

... The first two or three days I hung on every doctor's word and every time they would say something about, so that doesn't mean its diabetes, I was just still waiting for the "yeah it is not".... I was just trying to get the answer I wanted but I never got it. (7A non-T1D Mother)

Strong feelings of fear and worry were identified relating to how the parent felt they would manage a young child with a chronic condition and concern for the child's wellbeing.

That [hypoglycaemia] was always the worry for me because I think when he was diagnosed, my first question was "will he feel his lows overnight?"(2A T1D Mother)

Fear would have been the most prominent one (emotion]). Fear that because we know her character, she is not exactly someone who will be likely to apply to the rules as some others mightthe fear that she would do herself harm by not controlling it. (1B T1D Father)

Parents, particularly non-T1D mothers, felt concerned and worried about describing a sudden loss of confidence and questioning their capabilities as parents of being able to manage a child with T1D.

I felt like I was coming home with a newborn. Doing the carb counting and the insulin, I freaked so my mum is a nurse so I made her come home for the first week and we did it together, so that really helped. (7A non-T1D Mother)

Parents struggled to come to terms with the sudden loss of the child's health and carefree life. T1D parents felt sadness for not being able to keep their child healthy. Parents also acknowledged the struggles associated with having a chronic condition.

Just before his seventh birthday and I think uhm, like my diagnosis eight years ago, hit me fairly hard but you know you're in control of your own health, as a parent of a child you don't want them to have to suffer with anything... (6B T1D Father)

I missed between two and a half and three and a half. I don't remember it. All I remember is the diabetes and that's – I looked at him on his fourth birthday. I've missed you for a whole year. (2A T1D Mother)

In this study, non-T1D parents did not blame their T1D partner for their child's illness. Some of the T1D parents acknowledged the genetic link and although they did not blame themselves directly, some did question their genetic influence.

Well, I guess it was pretty sad that he's got the same as what I have and knowing that he is young and he'd have it for the rest of his life, and you wonder whether it's because of me that he's got it. (4B T1D Father)

A T1D mother was saddened when speaking about the risk of a genetic inheritance of T1D, and although she didn't blame herself directly, she felt some guilt.

"Yeah, I'll feel better, I'll feel less guilty [if there was no genetic link]." (2A T1D Mother).

One T1D parent admitted being worried that others might blame him for his child's diagnosis.

... and then when you're talking to people and you're having to tell friends and family that you know [T1D child] had this diagnosis, you sort of second guess is their initial thought going to be ...dad's got it so that's probably why [T1D child] got it. (6B T1D Father)

One non-T1D mother acknowledged that she had feelings of guilt. These feelings developed following the diagnosis of her son and the subsequent education session they received. Learning about T1D and the difficulties associated with management made her feel guilty that she had not shown enough compassion and understanding to her husband regarding his diagnosis of T1D and management. She had not realised how difficult the condition is to manage until after her son had been diagnosed.

I feel a bit guilty about not fully appreciating what he [husband] was going through. (6A non-T1D Mother)

4.3 Parents

Within this theme, both the T1D parent's experiences of their diagnosis and the non-T1D parent's experience of living with a T1D partner are presented. As with the previous theme, the associated emotions are included.

T1D Parent

The T1D parents were asked about their diagnosis experience to ascertain if their diagnosis and management may have influenced their experiences of their child's diagnosis and subsequent ongoing management. The T1D adults in this study shared some similarities in relation to their diagnosis. They were all diagnosed at an older age than their child and were quite unwell by the time a diagnosis was made.

The symptoms the T1D parents had displayed before diagnosis were predominantly significant weight loss, increased thirst and urination, and lethargy. On reflection, the T1D parents who participated felt their symptoms had been present for up to four months before seeking medical advice. One T1D parent was aged nine at diagnosis and was admitted to the Intensive Care Unit because of being so unwell.

I was quite sick...I lost a massive amount of weight...I think I lost about 10 kilos, but mine was over maybe six weeks from memory... (2A T1D Mother)

Another T1D parent was diagnosed at eleven years of age and recalls being admitted to the hospital for two to three weeks following diagnosis. The other five T1D parents were diagnosed as young adults and were mostly managed and educated by their GP or pharmacist.

And the chemist said 'Go and inject yourself' and I'm looking at the needle and going wow you want me to stab myself with this? (5B T1D Father)

Emotions Related to Diagnosis

All T1D parents recalled a feeling of shock and disbelief when they were diagnosed. One father attended his GP for an issue related to his eye and while there happened to mention his excessive urination and thirst. His GP did a finger prick blood test and he was subsequently given a diagnosis of T1D.

I was absolutely shocked when I first got that [T1D diagnosis] ...yeah when I went up to sort of, uhm, paid the bill at the health centre, she asked me three or four times, "are you okay?" Obviously, I looked pretty white and shocked because I really didn't expect it. (5B T1D Father)

All T1D parents were accepting of their condition. They felt that they had to accept their T1D diagnosis and get on with managing it the best way they could. For these parents there was little to no education about T1D at the time of their diagnosis and no management plan or follow up in place. Most of the education they were given was brief and their spouse or support person was not encouraged to attend or be involved.

I was not involved in any of his [partner's] education. I was not brought in for counselling myself or how to support my partner, and he was very much, "I'm doing this on my own". (6A non-T1D Mother)

This T1D father used his son's diagnosis to assist him in developing a level of acceptance where he was able to discuss his diabetes diagnosis.

"I was heartbroken for him [son with T1D], um, but I think it's actually helped me to be more open about my diagnosis. Before that I, I wouldn't really talk to people about it". (6B T1D Father)

Non-T1D Parent

Although all partners were overtly supportive, they were not actively involved in the day to day management of their partner's T1D management. However, they were available for emergency management such as the treatment of hypoglycaemia or to assist with tasks such as filling insulin scripts, picking up supplies and providing healthy foods.

Early in the relationship, they [partner with T1D] try and hide it, so it is not a problem. They'll do their injections in private... if they are having a low... then they deal with it, they try make it not to be a great issue because they want to fit in with society. After when you're married, ... if you care about the person...you get to know a bit more in depth then you think, "no, they're not doing too well" (2B non-T1D Father).

Only one non-T1D parent had an understanding about T1D prior to meeting their T1D partner; this was because both her sister and mother had T1D. The other adults learned what they needed to know to help their partner when required.

Insufficient education about types of food and long-term complications, coupled with limited medical support meant that some T1D adults struggled for many years to maintain a stable BGL, managing their condition with experimentation or restrictions on certain foods.

Oh, it's horrible. It was horrible for about two or three years until I actually understood what food was doing and how it was doing it like, illness, yeah and what it was working on, yeah. -We just changed everything that we ate, the way we ate and everything. (5B T1D Father)

When T1D parents were asked about management and acceptance of their diagnosis, they commented on their decision early on to manage insulin injections and management changes themselves, with little help from their partner or spouse. Most T1D parents also chose not to share their diagnosis with their friends or colleagues.

He [partner with T1D] didn't tell any of his work colleagues, any of his friends, and only his parents and his brother. He didn't even tell any close friends. It probably took him a year to come out. (6A non-T1D Mother)

One T1D parent felt that she needed to keep her medical condition to herself to avoid being disadvantaged at work.

I want to be considered for the positions that healthy people are considered for, although I had a disability in a sense, because if I had disclosed it way back, I never would have got it. I know there's antidiscrimination laws, but I never would've got that permanent position. (2A T1D Mother)

Additionally, feelings of frustration and resentment were noted, as people assumed, they had T2D because they were an adult. Parents spoke of the difficulty and lack of patience they had when trying to explain the difference, especially to other adults.

And I think getting into my 30's and 40's, it's like you go to a pharmacy, I always go to a pharmacist I know really well cos they know my history, but then you go somewhere to get insulin at a place that don't know you "are you type 2"? Have you just started taking insulin? I've been injecting for 31 yrs... (2A T1D Mother)

Non-T1D Parent

Although all partners were overtly supportive, they were not actively involved in the day to day management of their partner's T1D management. However, they were available for emergency management such as the treatment of hypoglycaemia or to assist with tasks such as filling insulin scripts, picking up supplies and providing healthy foods.

Early in the relationship, they [partner with T1D] try and hide it, so it is not a problem. They'll do their injections in private... if they are having a low... then they deal with it, they try make

it not to be a great issue because they want to fit in with society. After when you're married, ... if you care about the person...you get to know a bit more in depth than you think, "no, they're not doing too well" (2B non-T1D Father).

Only one non-T1D parent had an understanding about T1D prior to meeting their T1D partner; this was because both her sister and mother had T1D. The other adults learned what they needed to know to help their partner when required.

4.4 Acquisition of Knowledge

This theme describes the process of the T1D and non-T1D parents' as they acquired the necessary knowledge when their child was diagnosed and includes the subtheme of pre-existing knowledge and clinic support. Parents commented that the education sessions started immediately, continued over four or five days and were very thorough, covering many aspects of T1D including the physiology of diabetes and management. All the parents who attended the education sessions, acknowledged that the information they received, both verbal and written, was particularly good. Some parents stated that the education would be more effective if individualised and appropriate to the needs of each family. For example, parents of a young child stated,

So, what was I supposed to do with that meal plan? And you're always judged on that, but they don't understand they're lecturing for an eight to 12-year-old age group. The under-fives are a different kettle of fish. (2A T1D Mother)

Pre-existing Knowledge

Some parents, however, felt overwhelmed by the amount of new information received coupled with the unfamiliar terminology they were required to learn and understand. Parents who were already familiar with diabetes terminology even found it difficult at times.

...Even though I was pretty familiar with all the terminology and everything else with it, I think it is expected too much of people to understand straight away all the terminology and what they are dealing with. I found parts of it very confusing even though I knew what they were talking about. (1B T1D Father)

Participants commented that the education sessions thoroughly covered many aspects of diabetes. All parents agreed that this was necessary to ensure that both parents had the same level of understanding, therefore providing reassurance to each other.

It was good to go through the whole process again definitely because when I got diagnosed carb counting wasn't a thing... Yes, it was a long week but I can definitely see the benefit of where that took [Name of Non-T1D Mother] through... After each small session they would ask questions to check retention... and I would always let [Name of Non-T1D Mother] answer. (7B T1D Father)

...for me as a parent I wanted to know from scratch because I knew it was going to be me that was dealing with it... (1A non-T1D Mother)

Both T1D and non-T1D parents who had been living with T1D brought their own level of knowledge and experience about T1D diabetes to their child's diagnosis, including what they had been initially taught and what they had learned in managing their own chronic condition over time. However, all T1D parents noted that they were disappointed during the process of their child's T1D diagnosis and initial education at the lack of acknowledgement they received for their understanding of T1D and how to live with it.

No, they didn't care...no I didn't exist there. I didn't exist... Well, I could've helped but they didn't really want to know I had diabetes. (5B T1D Father)

It was agreed by all T1D parents in this study that the education they had received at their own diagnosis regarding T1D and its management was very limited in comparison to what they learned from their child's diagnosis. Consequently, despite these parents struggling with accepting the diagnosis of their child, they all viewed the situation as an opportunity to learn new knowledge and new ways of managing T1D. They also felt empowered to change and improve their own T1D management to be good role models for their children.

There has been ... times when I wasn't doing blood sugar tests enough, yeah probably even to the point of skipping days and things like that but since [T1D child] has been diagnosed it has really improved my [management]...(7B T1D Father)

Parents felt that they needed to do their own research about current management of T1D, to benefit themselves and their T1D child and to ensure they stayed well informed.

We accepted it [diagnosis of T1D] a bit better because we knew about it...I had done a lot of reading around the area of self-education because ...that's going to be the best way for me to manage it is to get as well informed as possible. (6B T1D Father)

Clinic

Following the initial diagnosis and subsequent discharge from hospital, families at the site of the study are required to attend clinic every three months. This is aimed at assisting parents with the diabetes management specific to their child's needs and provides opportunities for parents to ask questions and to learn new information as required. Parents commented how valuable it was to have the opportunity to ask questions.

The team is brilliant... and I always have lots of questions and I am never made to feel like I am asking dumb questions cos probably am asking dumb questions. (7A non-T1D Mother)

Nearly all parents acknowledged that at times they found clinic to be a little overwhelming given the number of health professionals they saw in one appointment: the endocrinologist, the diabetes educator and often the dietician.

Overall, parents in this study stated that they felt well-supported by clinic staff especially when needing to change insulin levels or deal with days when their child was sick. The convenience of being able to access a diabetes nurse education on the helpline significantly increased the parents' confidence in dealing with daily issues including hyper or hypoglycaemia as well as altering insulin levels.

There was a discrepancy between what staff proposed as treatment options and what the family felt was right for their child was noted by two non-T1D parents regarding continuous subcutaneous insulin infusion (CSII) or pump therapy. The following quotes indicate that, on occasions, clinic staff may not always prioritise individual family needs.

I'm, I'm not keen on him [son with T1D] having the pump and he doesn't want the pump, but ...every time we go [to the clinic] they push; they really want us to go on the pump. (6A non-T1D Mother)

...the pump doesn't suit us... I'm not gonna send him to school with attachment and things could go wrong... they [clinic staff] never discuss the problems. (2B non-T1D Father)

Many parents mentioned the need for education and care to be individualised and that professional staff needed to acknowledge the experiences of families, to ensure a better understand of how to assist them. This needs to go in the acquisition of knowledge section or clinic support.

They just said, "Look at this procedure. We have to go through it anyway". It was frustrating and annoying because I basically was answering the stuff before they were saying it anyway. I already knew what HbA1c was. (5A non-T1D Mother)

I think different people just need different things and I guess for us; we just weren't prepared to be in with newly diagnosed families who... I guess that we felt newly diagnosed families were at a zero and we were probably at a seven out of ten, kind of thing. (4A non-T1D Mother)

Additionally, T1D parents thought that clinic staff needed to broaden their understanding of alternative approaches to T1D management in the community to really appreciate what influences a family's T1D management decisions.

If you are dealing with diabetics, you need to know what's out there. (6A T1D Father)

4.5 Challenges of Living with T1D

This theme describes the challenges parents experienced when managing their child's diabetes, including the roles they each took. Additionally, it highlights the difficulty of having two people with T1D in the family.

Management

All participants commented on the way they managed T1D in the family. Mothers, who in this study were mostly non-T1D, commonly took more of the role of carer and generally attended the clinic appointments due to the fathers' work commitments. All fathers, both T1D and non-T1D, spoke positively of their involvement in the child's T1D management such as, performing blood glucose readings, insulin adjustments and hypoglycaemia management as required. Despite this, T1D children often preferred their mothers to do their insulin injections, pump site changes.

He [son with T1D] likes his mum doing it [needles] more than me cos he gets a bit of a rub on the bottom and all that sort of stuff, whereas I give him a rub, but it's not as good. (4B T1D Father)

[T1D child's name] struggles with daddy doing stuff for her...she will not let him put on the pump or the CGM and cracks it if he does needles. "I want mum to do it. I want mum to do it". (7A non-T1D Mother)

Seemingly, parents within this study worked well together managing their child's T1D. Communication and acknowledging their own personal strengths enabled them to feel supported by each other.

We [parents] even discuss the insulin we're giving him at night time and how much and stuff, so we both sort of know and write it in the book. (5B T1D Father)

Choices of insulin regimen for the T1D child were based on the T1D parent's own previous experiences. Those parents using CSII via an insulin pump believed in its benefit, thereby suggesting it as the treatment of choice for their child.

...my diabetes educator, she's really up to date with a lot of the, I guess psychological effects of pumping, also the management side of those kind of things...It just made sense plus the difference in me where I was not as stable... I guess pre-pump I was basically - I was frying my brain every night between 3am and 6am. (7B T1D Father)

Some non-T1D mothers were happy for their T1D partner to take on the more technical tasks such as changes to pump settings.

I think cos [T1D Father Name] is used to the pump and ... he knows what he is doing... so I tend to take a back seat when it comes to programming it or whatever. (1A non-T1D Mother)

One of the biggest challenges cited by parents in this study was the difficulty in managing their child's glycaemic control, with one day's blood glucose pattern different than the day before. Parents commented that the child wakes up, usually at the same time all week, eats the same kind

of breakfast and generally does the same activities throughout the day, but glycaemic control is not the same from day to day.

You think you have nailed it then she is low for a week and then she is in the 20's for a week, every day is different. (7A non-T1D Mother)

Added to this, parents spoke of frustration when comparing the glycaemic management of the T1D child and T1D parent as they were completely different.

They're both so different in what sends them high and low, so chalk and cheese these two. (7A non-T1D Mother)

...I think about exercise and I drop, [child] does exercise and she skyrockets. (7B T1D Father)

The quote below highlights the realities of managing such a complex condition as T1D and the impact it has on a family. Managing two people with T1D has its obvious challenges, but more so when both are having a medical emergency.

... I have literally had in the supermarket both of them go low at the same time and here's me in the chocolate aisle going "you eat this and you eat this" and people just walking past going "Oh my God". (4A non-T1D Mother) "They're stealing chocolate". (4B T1D Father)

One non-T1D mother commented that her son had been concerned about a planned outing that the T1D parent and the T1D child were attending. His concern was related to his own fear of hypoglycaemia with the addition of having to also look after his father if he too was to have a hypoglycaemic episode.

"Well dad and I can't go, we're both diabetics. We can't, what happens if we have a hypo?" (4A non-T1D Mother)

One T1D mother highlighted the extreme difficulties of trying to manage her own T1D while also caring for a young child with T1D.

Trying to keep my own diabetes – impact of looking after a child with T1D and unable to get the same level of control that I had now there is two of us. One of us has to give and that's gonna be me. It shouldn't be me but it has to be... (2A T1D Mother)

Emotions

Parents spoke openly of emotions associated with the constant awareness required in relation to the day to day management of the T1D child. Despite being vigilant with their child's T1D care, mothers particularly felt directly responsible, especially when there was a problem.

One night I slept in and he [son with T1D] was low by the time I woke up. And I couldn't rouse him. So, after that night, I've been vigilant with finger pricking...it was awful. I felt guilty...how could I sleep and not check? (2A T1D Mother)

Parents spoke about feeling out of control or overwhelmed at times, especially when trying to maintain good glycaemic control. This caused some emotional distress for parents, particularly mothers as they were with the child for longer periods of the day. Additionally, parents acknowledged the difficulties they may face as their child gets older and hormones complicate their management.

At times, there was conflict between parents related to the management decisions made for their T1D child.

We have clashed a couple of times on like, okay, so if we go out to the beach and he has ice-cream. I'm a bit more strict on what that will be like... "You can have that one but you can't have these ones". (6B T1D Father)

Both T1D and non-T1D parents had different ideas as to what BGL level they were comfortable with for their child, especially during the night. One of the T1D fathers in the study, although aware of the potential for hypoglycaemia with a lower BGL had more concerns regarding long-term complications related to high BGL. He preferred his child to have a lower BGL while the child's mother, concerned more with short-term consequences, was not comfortable with this.

I like her [T1D child] above 6. I feel more comfortable with her at 6, I don't like her sitting at 5 or 4 at night (as other parent wants). (7A non-T1D Mother)

One non-T1D mother felt responsible for her child's high blood sugar reading and would withhold information to prevent conflict with her husband and the T1D child.

I used to lie to him [husband] because [Name of T1D child] overall (HbA1c) readings were in the 'nine mark' and that was because I was working... (3A non-T1D Mother)

Some of this conflict surfaced when returning from clinic with the T1D parent challenging what had been suggested by staff for their child.

I did find that what they were telling me now and what [T1D Father] had known all his life conflicting cos he would say "no, no you don't do that" and I would say "that is not what I have been told".(1A non-T1D Mother)

4.6 Our New Life

This final theme describes how parents in this study have adjusted to accommodate their child's diagnosis and worked together as a family to create what is now 'Our new life'. This was shaped by various levels of support from family, this theme also presents the impact of their 'new life' on siblings.

During the interview parents were asked to reflect on the day of diagnosis, with parents commenting that they had not anticipated the enormity and speed of the changes that occurred and were not prepared for it, despite having some insight in to diabetes, given one parent had T1D.

Literally our world was changing completely I mean, yer, its one thing to deal with an adult who has lived with it most of their lives but umm, but to deal with a child. I had never dealt with a child with diabetes before and found it quite scary not only for me but for her (1A non-T1D Mother)

But when it [diagnosis] happened to [T1D child], it was a whole different story, because he was then reliant on us, and our whole life changed, in that instant, that evening. (2A T1D Mother)

One change that most parent found difficult to accept was the perceived loss of the spontaneity in life. Since their child's diagnosis they had to plan everywhere they went.

You have to plan everything out, you can't just "okay we are going overseas at this point, were going on a holiday, we're going to do overnights"...you have to say "what food are we taking? What insulin (are) we taking? Is there a chemist nearby?" (2B non-T1D Father)

Support

In this current study parents were asked about the level of support since the diagnosis of their child. Most parents reported limited support from their own parents and extended family members. Most family members either lived in another town, state or country. Only one family in the study used a grandparent regularly for the care of their T1D child.

My Mother has [T1D child] twice a week. She picks him up from school because I'm at work...I mean it took a little while to get used to it (managing a child with T1D) again because obviously things have changed... but yer, she's totally fine with that. (5A non-T1D Mother)

Another family, who did have their parents living in close proximity, chose not to rely on them. They felt that the grandparents did not manage their child's diabetes as they wanted and did not fully understand the potential harm they could be causing him.

...my wife's parents...we said to them, "do you understand about type 1?" "yes, yes, yes" but they believe running at 15 or higher is good because then they don't have to treat it and they don't realise it, it does internal organ damage and different things so they don't understand the dynamics of how the disease affects the child... they only understand how it affects them.
(2B non-T1D Father)

External support from friends was not always forth-coming. Friends did visit and try to help where they could. However, most parents commented on how friends and parents from school were not keen to take their T1D child on outings or playdates and were especially reluctant for their child to 'sleep over' because of the concerns around T1D management.

There were a lot of people who didn't want to take [T1D child] for a sleep over and that kind of upset her world. (1A non-T1D Mother)

He [son with T1D] used to be (a) really popular little kid at school. He got diagnosed as diabetic and coeliac, and he used to get invited to parties all the time, and then now, he gets to none...but he wants to be with the other kids, you know, and it's really hard because I can't make them invite him. (5A non-T1D Mother)

Moreover, some parents lacked confidence in other parents looking after their child, and if they did allow it, they spent considerable time giving a detailed explanation of what to look out for and how to manage an emergency.

So, it is really sending her [daughter with T1D] with written instructions so I always don't feel safe to do that overnighter or all day. (7A non-T1D Mother)

It got to the stage where I just said "I can't be bothered" ... I got sick of talking about it that way to someone who knew nothing... I found that very frustrating because... you're saying the same story over and over when she wants to play with someone new. (1A non-T1D Mother)

Parents were asked in the interview if they had been offered or had initiated psychological support at the time of diagnosis or the adjustment period following. Some parents did recall being asked at clinic if they "needed to see someone", however they felt the clinic appointment was not the right time.

I think they always say like when you go "who do you want to speak to?" Uhm, and for me if someone just pushed it, I probably would've gone "yes" so that would be good but because of time and things like that, it's not kind of (timely)... (6A non-T1D Mother)

Parents believed a less formal visit from someone would have been more beneficial.

...From my point of view, I would have liked someone to knock on the door and say "how are you going, how are you finding things"? Rather than having to go into [Name of service], it's stressful ... stressful getting there, stressful getting parking, it's a nightmare...if there was something community based (it would be better). (1A non-T1D Mother)

Some mothers mentioned that, on reflection, they would have adjusted more easily if they had some sort of counselling or support group available to them 6 - 12 months following their child's diagnosis. This mother's experience supports this:

...They assigned [name] as my mentor around the six-month mark. She rang up at one point and I think I spoke for a good three or four hours and that was probably my breakthrough moment of ... "I am not alone; my thoughts are normal". That was probably my moment of "yep it is all good". (7A non-T1D Mother)

Two mothers recalled getting to the point where they did feel they needed some professional help, but life got busy and they never initiated it.

I did at one stage think “oh should I go and get some counselling” and kind of feel “oh I just don’t have time”. (6A non-T1D Mother)

A non-T1D father commented that there was no support for fathers as he would have liked. Because he does not generally attend clinic appointments on a regular basis, he had little opportunity to engage with other fathers with T1D children.

...there’s nothing for dads at all so it tends to be like the mums can form group in information circles and that, but dads should have something. (2B non-T1D Father)

Adjustment

This subtheme highlights some of the ideas that parents shared regarding their perception of how the different family members adjusted to their new life. Most parents felt that their child had adjusted to having diabetes well, relevant to their age and cognitive development and that they as parents had worked very hard at helping their child adjust.

...One way that really helped her adjust was before we ate, I would get her to do my insulin ... she was doing my finger pricks and my testing and so that kind of took the edge off her having to do it. It was like “OK me first then you” and that was quite successful. (7B T1D Father)

Parents provided their perspective on how their child adjusted to having T1D. They considered that the young age at which the child was diagnosed had been a benefit to their adjustment as they had forgotten what life was like before.

...I asked him the other day. I said, “do you remember before you were diabetic?” and he said “not really”. So, you forget like... seven years old. (6B T1D Father)

Additionally, T1D parents appeared to develop a unique and special bond with their child; they developed a level of trust and understanding of what it is like to have diabetes.

*She [daughter with T1D] sees herself as him, I think at times [yer mini me – 1B-T1D Father]
... yer she's even a David Bowie (fan)...and she's only eleven...she kinds of tends to follow his
every move. (1A non-T1D Mother)*

*And [T1D Father] was a lot better at it [doing needles] than me and [T1D child] trusted him a
lot more than me. (1A non-T1D Mother)*

Mothers did mention that at times some of the T1D children had voiced a dislike at having diabetes. This was mostly related to painful procedures and general diabetes management such as insertion of pump sets, insulin injections, finger pricks, and food restrictions. Below are some of the comments that T1D children had said to their parents.

"Why am I cursed with this" [Child 1-aged 9yrs]

"How long am I going to be a diabetic and coeliac for" [Child 5-aged 6yrs]

"I hate diabetes and I don't want injections" [Child 6-aged 5yrs]

"I wish I didn't have it" [Child 7-aged 3yrs]

Despite this, some children continued to have concerns, which benefited from continual reassurance.

*She [daughter with T1D] probably, every second or third day she always comes up and says
thank you for keeping me alive mummy. (7A non-T1D Mother)*

*I always say to him at night time "don't worry, I'll check on you in the night. You don't have
to worry". And that way he [child with T1D] can sleep. He's actually started sleeping better
since I've started saying that. (2A T1D Mother)*

Parents stated that it was helpful for all family members to try and keep a positive spin on diabetes through a range of strategies, including reminding their child that other children had severe medical conditions such as asthma or anaphylaxis. Additionally, when it came to speaking with their T1D child about potential short-term dangers and the long-term effects of diabetes, the age of the child determined how much the parents chose to say.

...We haven't gone all doom and gloom, it's just, let's do this so you stay healthy. (7A non-T1D Mother)

We just essentially wanted him, you know, to experience a carefree childhood and not have to worry about, you know, what he needs to eat and exercise and parties... (6B T1D Father)

Non-T1D parents felt that having an adult T1D in the family helped them and all family members adjust to the child's diagnosis more easily by normalising it and seeing that they can confidently live a full, happy and healthy life with this chronic condition.

In some ways having a father or having a parent [with T1D] has been extremely helpful, because it's normal and its part of our... we are family now. (6A non-T1D Mother)

Siblings

The parents in this study reported that siblings showed some concern and were worried and saddened by the diagnosis of their brother or sister.

When [sibling] came back from camp and found that [T1D child] had been diagnosed, he was devastated..." why can't it just be me and not him, he's too little...?" (4A non-T1D Mother)

Most parents felt that generally, siblings coped quite well with the diagnosis of the T1D child. A variety of emotions resurfaced at different times and needed to be considered and addressed. These emotions were primarily associated with the adjustment and changes in family dynamics such

as the restrictions or changes placed on food and the different routine. Additionally, extra attention given to the child with T1D was noted by the sibling as having less time with their parent.

I mean she [sibling] has been great but, uhm we did a little while ago have a thing when she wanted diabetes because, uhm... she thought I didn't love her as much as I love [child with T1D] because I spend so much time... (6A non-T1D Mother)

Talking about a sibling feeling a bit left out and jealous - [T1D child] has to go (into town) a fair bit with Grandma - she's really noticing that he is different and now he has got stuff going on... a lot more aware of it...she turned around the other night saying "can I have an injection?" (5A T1D Father)

All parents found that giving each sibling enough attention was by far the most challenging aspect of having a T1D child, as T1D diabetes management was very time-consuming. They mentioned diabetes-related activities or emergencies often took priority and sometimes interrupted family activities. All parents, particularly mothers, had acknowledged that they needed to adopt new routines with the non-T1D siblings which included special outings or food treats.

Sometimes I think she [sibling] does feel like she misses out and that's why we try and go to special time where she's allowed to have things that [T1D child] is not allowed to have ...but we also try not to spoil her either because we want them to feel like they have the same treatment. (5A non-T1D Mother)

Some parents commented that the older siblings seemed to take on the responsibility of looking after or protecting their younger T1D sibling. In one family, the T1D mother mentioned that the sibling had a very caring nature but her concern was that the child was picking up on her concerns as he had said to her that if he took care of his brother that would help his mother feel less worried.

Well he's [sibling] told me already when they go to out of school hour care next week, he's going to stand by [T1D Child name]... he said to me, "I know a lot of the brothers and sisters play separately, but I'm going to be with [T1D Child] to make sure he's getting the care he needs". (2A T1D Mother)

T1D parents felt reassured that their child would live a healthy life despite having a chronic condition, as they had done to date.

I guess when [T1D child] was diagnosed the whole thing...in my mind is "she is going to be OK. God's got me this far then she is going to be fine". (7B T1D Father)

4.7 Summary

This chapter has presented the findings of the study as five main themes and associated subthemes that emerged from the ten interviews. The thematic map demonstrates how each of these themes is connected and follow a chronological journey from early diagnosis and hospitalisation, to gaining knowledge about how to manage a child T1D and the family adjustment to a new life. The explanations and quotes provide insight into the unique experience of parents when their child is diagnosed with T1D and a parent also had T1D. The following chapter will provide a discussion of these findings using an overarching socioecological model. This framework will illustrate the interplay between the individual level, the interpersonal and the organisational level. The strength and limitations of this study will also be considered, and recommendations discussed.

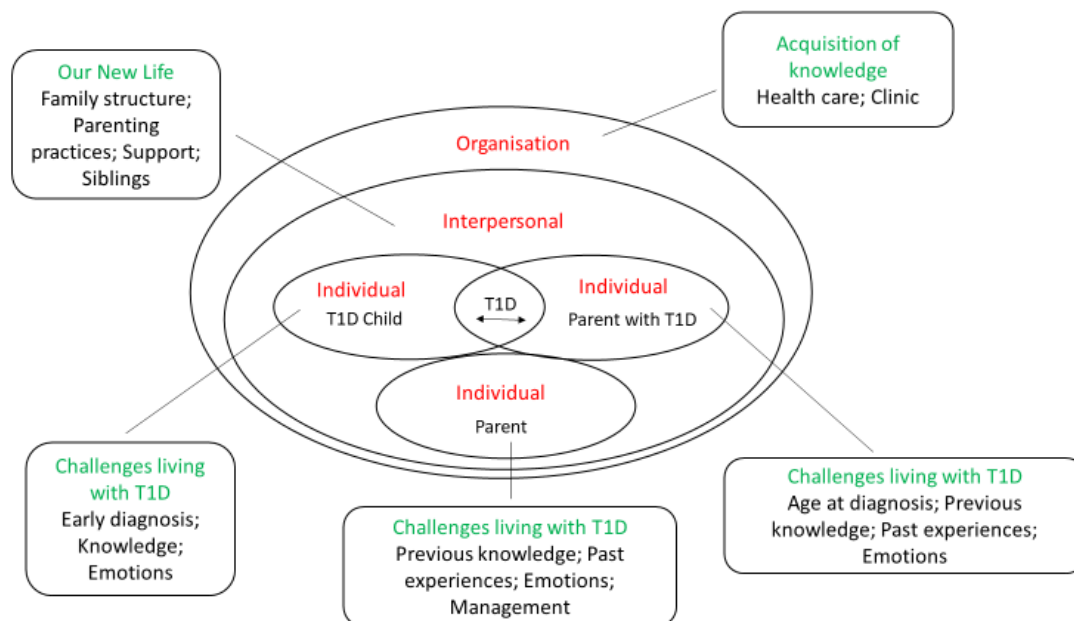
Chapter 5 – Discussion

The need for this study was identified by the paucity of literature that explores the experience of parents when their child is diagnosed with T1D and one parent also has T1D diabetes. The previous chapter presented the findings from the rich data obtained from the face to face interviews, and using the thematic map, the themes and subthemes were outlined. This chapter will discuss the findings in relation to current literature using a socioecological model. Ecological framework was first introduced in the 1970's by Bronfenbrenner who believed that in order to understand human development the whole ecological system needed to be considered.¹⁰⁰ The ecological system comprised of multi-level framework which demonstrated that human development takes place through a complex, progressive and reciprocal interaction between individuals, objects and the environment. And secondly that both the individuals and the environment are continually changing.^{99, 100}

Socioecological models have been used widely in nursing research and health promotion to describe the interactive characteristics of individuals and environments and as a way of demonstrating that no single factor can describe or predict a particular phenomenon or behaviour, but are a result of a dynamic interplay of elements or layers such as personal, situational and environmental which have an influence on the wellbeing, health and illness outcomes.^{101, 123}

The modified socioecological model (see Figure 6) has been informed by the information received from the parent interviews and has been constructed to show the interrelationship between the different layers. The three layers identified in this model are individual, interpersonal, and organisational, attached to each layer are the previously identified themes from the findings to add relevance and depth to the discussion.

Figure 6. Modified Socioecological Model



Individual layer

The individual layer includes the child with T1D, the parent with T1D and the parent without T1D. Each of these elements are connected, affecting the way each experiences the child's T1D diagnosis. Furthermore, the child with T1D and parent with T1D are interconnected. The findings from this study indicate they not only share the commonality of T1D, but they also share a unique relationship. Within this layer, the results from the themes '*Challenges living with T1D*', '*T1D Child*' and '*Parents*' will be discussed.

Results indicated that the children in this study all showed the commonly known symptoms of marked hyperglycaemia, including polyuria, polydipsia, weight loss and polyphagia,¹²⁴ prior to their diagnosis. One significance of this study is the early recognition of these symptoms by parents that determined their decision to do a blood glucose check on their child. Anecdotally, health professionals recognise that T1D parents on occasion perform random blood glucose checks on their children when their child is unwell, to exclude T1D. In this study, five of the seven children had blood glucose checks performed by parents, which led to prompt presentation at a medical facility and subsequent diagnosis. Early symptom recognition has also been noted in other studies where

parents who are health professionals or have a diagnosis of T1D themselves avert DKA by the early presentation of their child for testing.^{125, 126}

DKA is a sign of evolving diabetes, a decrease in circulating insulin associated with an increase in counter-regulatory hormones and is a result of diagnostic delay.⁶ Age has been described as the most common factor for this, with younger children being more at risk,^{6, 126} mostly due to the difficulty of obtaining a conclusive history of symptoms. In this study, no child presented with DKA on diagnosis. Despite T1D symptoms being noticed by most of the parents at some stage, there was a delay by some to do a blood glucose check. Parental responses indicate this may have been related to fear of knowing or denial. A comment such as “we should have done this last week” or not performing a blood glucose check until sitting in the emergency room may be indicators of this.

In this study, two parents sought medical advice for their child on multiple occasions and reported a misdiagnosis by their GP which resulted in delayed T1D diagnoses.¹²⁵ Parents in this situation can feel frustrated at not being taken seriously by the GP or feel blame for their lack of parental experience or parenting behaviours.⁵⁴ Studies have found that following the T1D diagnosis of a child, parents have described feelings of deep guilt, sadness, and self-blame when symptoms were overlooked or there was a delay in diagnosis leaving them questioning whether they could have done more to keep their child safe.^{56, 125, 127} This was not apparent in our study, most likely due to the children’s early presentation and diagnosis. It does; however, raise the question could these feelings be heightened in parents with T1D as they may feel they ‘should’ have known.

It has been well-documented that following a diagnosis of T1D in a child, parents experience reactions similar to those of bereavement. Feelings of shock, fear, anger, anxiety, guilt, blame, frustration, helplessness, hopelessness, sorrow, despair and even profound grief can be experienced at this time.^{52, 62, 63} In the current study, parents described these same feelings at diagnosis and reported that many of these emotions continually resurfaced at different times and

in different situations.⁵⁵ Parents in this study also described feelings related to loss, as has been described in other studies exploring the impact of a diabetes diagnosis on parents and family. These include loss of their child's health, loss of spontaneity, loss of freedom, or flexibility, loss of a certain lifestyle, loss of independence, loss of trustworthiness, loss of favourite foods, loss of social acceptance and loss of future career aspirations.^{43, 62, 87}

Recurring emotions such as sadness, frustration, anger, fear, anxiety and perceived loss of control were described by most parents relating to the management of their T1D child as erratic and uncontrollable blood sugar levels in the child created ongoing challenges of maintaining good glycaemic control to prevent short and long term complications.⁵⁵ These emotions are not uncommon and have been noted in other studies related to the burden of T1D management.⁵⁵

Additionally, feelings of guilt as parents struggle to meet the demands of the treatment regime and required outcomes¹²⁸ and fear of judgement from their partners or health professionals increases their levels of stress.⁶⁷ Stress related to their partner's judgement was evident in this study with one parent commenting that when her child's HbA1c was high, she would hide the result from her T1D husband for fear of being reprimanded. She felt guilty and blamed herself for the high result because she was working instead of being home to remind her adolescent child to administer the insulin injection.

Despite the age of their child, parents still have a responsibility to oversee their child's diabetes management and continue to feel responsible for the overall wellbeing of their child.⁵⁵ It is believed that continued involvement by parents, in the care of children's diabetes management is essential for effective glycaemic control and prevention of long term complications including psychological wellbeing.⁴⁹

This study identified differences in the T1D parent's diagnosis and their child's diagnosis. Firstly, all T1D parents were diagnosed at an older age than their child, with three parents being

diagnosed between 9 - 11 years of age, with two of these parents being admitted to hospital. The other T1D parents were managed as outpatients by their GP or Pharmacist. All T1D parents described a longer duration of symptoms which went unrecognised for some months until they became particularly unwell and presented to medical services.¹²⁶ Only one of the six T1D parents interviewed had some knowledge of T1D prior to their diagnosis.

T1D has usually been regarded as a disease of childhood, however, more than half of the diagnoses occur in adulthood, with no upper age limit.¹²⁹ Being diagnosed as an adult means sudden changes to an already well-established lifestyle, resulting in rapid and significant adaptation.¹³⁰ Feelings of shock and sadness at the loss of the life they knew were emotions described by the T1D parents in this study, and have been noted in other studies.^{129, 131}

T1D parents in this study, reported the feeling of fear and concern around managing hypoglycaemia to prevent loss of work. Other studies have established that young adults are fearful of acute complications such as hypoglycaemia and require positive, constructive assistance from diabetes specialists to successfully manage this, particularly through stages of transition.^{130, 132} T1D in young adults is recognised as challenging as life transitions and stresses can result in a greater risk of developing diabetes-related complications and psychological problems.¹³⁰ Late adolescent-onset has not widely been studied, however, it is acknowledged that young adults find the diagnosis of T1D was stressful and an interruption, but they were able to take care of themselves and gained a better understanding of their condition as they grew older.^{129, 130}

As adults, T1D parents in the current study realised early following their diagnosis that they 'just had to get on with it' and accept that nothing would be the same as it was before, preferring to downplay the attention given to their condition. This has also been noted in other studies where adolescents and adults choose to conceal their diabetes management from family and friends.¹³⁰⁻
¹³² In this study, the reason for understating their condition was not explored, however may have

been related to the age at diagnosis of the parents and /or due to the T1D parent receiving limited engagement from their partner and other family members in the management of their diabetes. The three T1D parents who were diagnosed before the age of 16, spoke about the expectation from their parents to manage their diabetes care independently, with minimal assistance.

In this study, we asked T1D parents about the feelings of guilt related to their child's diagnosis. We also asked the non-T1D parent about feelings of blame. None of the non-T1D parents in this study blamed their partner for their genetic contribution to their child's diagnosis. Two T1D parents acknowledged the possible genetic link, however, did not express excessive guilt. Although studies associated with genetic disorders have found that parents can have feelings of guilt and blame associated with a diagnosis, at different times and in different situations,¹⁹ this was not identified as a theme in this present study.

Interpersonal layer

The interpersonal layer includes the important relationships in an individual's daily life, and in the context of this study includes family structure, parenting practices, and siblings, combining in the theme '*Our new life*'. Within the sociological framework, the interpersonal layer is expected to have an influence on the previous individual layer to influence the participant's experience regarding acceptance and adaption to their child's T1D diagnosis.

Parents spoke openly about the known practical difficulties of managing their child's T1D and maintaining good glycaemic control. The demanding regimen of frequent blood glucose monitoring, insulin adjustment, attention to carbohydrate intake, erratic eating patterns and changing activity levels, coupled with behavioural issues and rapid growth, all resulted in major challenges for parents.¹³³ For the T1D adult, there was less difficulty in maintaining their own glycaemic stability, however, it was noted that the T1D child and T1D parent were very different in what caused them to go high or low, creating challenges for family activities such as dining out.

It was also noted in this study that both mothers and fathers perceived that they were equally involved in their T1D child's management, providing support and reassurance for each other. In recent research, it has been conveyed that fathers have had a greater influence than mothers on their child's adjustment to having diabetes and its management which may be related to the increased level of involvement.^{79, 80} In this study all T1D fathers mentioned having a positive relationship with their T1D child and developed a unique emotional bond as they could understand how they felt and what they were going through. All T1D parents in the study felt that this relationship influenced both their management and adjustment to their child's chronic condition. The more knowledge each acquired the more assistance they could provide for each other. This trusting relationship also influenced both the T1D child and T1D parents' adaption to managing diabetes and being open with the diagnosis.

One of the challenging aspects of managing T1D within a family is the impact it has on non-T1D siblings. Parents in this study spoke positively about how they felt the sibling was adjusting. Other than some intermittent attention-seeking behaviour, most were concerned about the T1D child and took on a caring or protective role depending on the age of the sibling. Derouin (1996)¹³⁴ believes that parents may be unaware of the true nature and extent of their child's feelings, concerns and behaviours, both positive and negative, as most data collected about the coping ability of siblings of children with a chronic condition are obtained from parents' perception.¹³⁴

An increasing body of research indicates long-term childhood conditions can impact negatively on siblings resulting in an increased number of psychological and behavioural difficulties.^{135, 136} In this study, parents commented that the siblings did not openly admit to having fears related to being diagnosed themselves. All parents in the current study commented on the lack of time they felt they had to share with their non-T1D siblings and were very aware of the lifestyle and food restrictions that impacted them directly. Parents in this study spoke about working

at maintaining healthy sibling relationships within the family environment and providing a 'special time' to develop a healthy relationship with them.

Although the parents in this study recognised the difficulties of having a child diagnosed with T1D, one positive aspect that was highlighted by at least three of the non-T1D parents was a sense of comfort and hope they received from having a partner with the same condition. This feeling was associated with knowing that their T1D partner had managed their condition well, did not display complications associated with the disease, and was living a 'good life'. Parents felt that this may have had a positive influence on how they adapted to their child's diagnosis and how the T1D child accepted their diagnosis. However, the families in this study stated that it took them approximately six to 12 months before they felt they had some level of adaption. This is consistent with other studies which show that adjustment to a T1D diagnosis can take between six to nine months.

In this study, all parents felt unsupported by family and friends following the diagnosis of their child. Unfortunately for most families, their parents lived interstate or overseas and for the two families that could rely on grandparents to ease some of the burdens of care, only one family chose to engage their support. The reluctance of parents to accept family support was centred on the grandparent's lack of understanding related to the importance of glycaemic control and the parents' fear of the child becoming unwell in their care.

No parents in this study received any type of psychological support, although two mothers, one T1D and one non-T1D acknowledged they needed some help but "never quite got around to organising it". These parents discussed feelings of being overwhelmed with the constant diabetes care routine and this was compounded by the lack of support from friends and family members. Additionally, the other non-T1D mothers commented on the lack of psychological support available to them and strongly believed that if they had received some type of counselling approximately six months post their child's diagnosis they would have fared better. It has been shown that parents

need more emotional and practical advice in the early stages following a diagnosis of T1D in order for them to adjust well, with most parents unlikely to ask for help.¹³⁷

It is well recognised that parents, particularly mothers, of children with T1D have an increased risk of developing symptoms of anxiety and depression associated with the demands of this chronic condition.^{81, 138} Acknowledgement of psychosocial and family variables by health professionals is essential to be able to deliver effective and proficient care to these families, particularly as psychosocial factors are known to have a direct link with individual health care outcomes.⁸¹ Acknowledging the extra demands that T1D parents can place on themselves, as evidenced in this study, may also be important.

Organisational layer

The third layer is the organisational layer and includes the external elements that influence the other layers such as the health care system including clinics, health professionals and education.

The major difference cited by T1D parents between their diagnosis and that of their child was the limited education and support they received regarding diabetes management at the time of their diagnosis. Most of the T1D parents had their diabetes managed by their GP, with some parents remaining on the same regime for many years, not knowing any different. One parent admits to 'just managing my diabetes but not understanding it'. Reflecting on their pre-existing knowledge, parents felt that their initial education had been limited, as some T1D parents had not engaged in regular diabetes reviews and were not up to date on current diabetes management and technology.

Following their child's diagnosis and subsequent education sessions, T1D parents admitted that this acquisition of diabetes knowledge had affected them positively. The T1D parents felt motivated to improve the management of their diabetes, not only for better health outcomes but

also to be a good role model for their T1D child and family. Changes they made to their management included increased blood glucose monitoring and insulin adjustments as well as increased engagement with doctors and diabetes specialists. Despite being overwhelmed at times by the amount of new information and terminology, they felt they could help their T1D child more effectively. Together with the non-T1D parent, this meant learning together and supporting one another.

The current national and international guidelines regarding education for children, adolescents and adults with diabetes specifies that individuals have the right to accessible diabetes education with a skilled multidisciplinary team and this is essential to promote behaviour change and self-management.^{2,35} It has been shown that people who receive care from specialised diabetes clinics that provide continual and effective education and support have improved diabetes management and fewer complications, thereby increasing their survival rate.^{139, 140}

In this study, health professionals were considered by all parents to be a valuable part of the diagnosis journey and follow up education and management of their child's T1D. One issue that was highlighted was the lack of acknowledgment by health professionals towards the T1D parent having the condition and their level of knowledge. All T1D parents felt that as part of understanding the child's diagnosis and how it would affect the family, the health professionals should have spent some time finding out more about the family situation. The T1D parents felt that they could have contributed some practical advice as to how the diagnosis and insulin regimen of the child would fit into the family. However, all parents, particularly the non-T1D parents valued the benefit of starting the education at the beginning, despite each parent having a different level of prior knowledge.

One family mentioned that they had been hard on themselves, initially, with a perceived expectation that they should be able to cope better than others because they were already living with diabetes and therefore did not want to be treated as a newly diagnosed family. This resulted

in the child missing the opportunity to attend camp and interact with other newly diagnosed children. This family admitted to feeling as though they were in control, having a good understanding of T1D management and did not need any assistance. However, after six months they realised that they were not coping and that there was much more to diabetes than just knowledge. This event highlights the imperative responsibility of all health professionals, particularly diabetes health educators to acknowledge and understand the diversity in family dynamics at diagnosis.

This study and others have recognised that there is a continued need for psychological support focusing on individualised care.^{53, 137} Health professionals need to work closely with families to ascertain if and when psychological care should be offered and in what capacity. A mentoring program should be considered as a support for families who have a child diagnosed with T1D and has a parent with the same diagnosis. Health professionals need to acknowledge parents who have pre-existing knowledge and have a lived experience of T1D to be able to provide effective care.

The socioecological model was used to demonstrate that a chronic condition such as T1D not only impacts the individual that has the condition but has a direct impact on those around them, particularly parents and siblings. Additionally, the external factors such as education and health professional's impact directly. In this study the individual layer included the child with T1D, the parent with T1D, and the parent and showed that there was a certain interconnection between the child T1D and parent with T1D and this directly influenced the management of their diabetes including the insulin regime and also impacted on the choice food and range of activities that the family could partake in to accommodate the different requirements of the T1D child and T1D parent in. This was related to the results from this study that created the theme 'Challenges living with T1D. Additionally this direct interaction of the T1D Child and T1D parent had an added benefit of creating a unique relationship.

The interpersonal layer involves the environment, particularly family. The individual layer directly impacted on this, not only the diagnosis of the child but the way the T1D child and family adjust and adapt to their 'New life'. Parenting practices, family structure and cohesiveness are essential for psychological stability and will have an overall impact on each family member, including the siblings. The final layer is the organisational layer and is directly involved in the 'Acquisition of knowledge'. This knowledge is gained from past and present experiences as well as from Health Professionals and formal education sessions. Parents in this study also chose to acquire their own knowledge from web-based forums and social media. This acquisition of know also has an influence on the previous layers. The social ecological model demonstrates the dynamic relationship between the layers with each layer influencing another at different times and over time.

5.1 Strengths and Limitations

The strength of this study includes the qualitative study design, using semi-structured face to face interviews, where parents were provided an opportunity to tell their story in detail. They were able to describe what it is like to live within this unique situation and provide insight into an area of study that has not yet been investigated. Many parents spoke of the therapeutic benefit of being interviewed as some had not spoken in detail about their child's diagnosis since 'that day'. Additionally, the ability to use VoIP technology enabled participants living outside the metropolitan area to be interviewed, thus increasing the diversity of participant characteristics and experiences.

Limitations of this study included: The sample of parents was selected from the same diabetes facility. As these participants were purposefully chosen and wanted to share their story, this could potentially lead toward participant bias and limited perspectives.¹¹¹ Another limitation was that there was only one female T1D parent in the study. This meant that there was a limited perspective of T1D mothers caring for their T1D children. Additionally, participants were only interviewed once, although this was sufficient to be able to identify common themes across the

sample, a second interview may have enabled deeper exploration into aspects of interest. Finally, the data collection process relied on the participants' recollection of events and emotions. Although participants were given ample time to consider answers thoroughly and questions were clarified as needed to ensure participants had an understanding of what was being asked, their recall may be influenced by previous experiences and their emotional state at the time of interview.¹¹¹

5.2 Recommendation for further study

This study is believed to be the first to explore the experiences of parent's when their child is diagnosed with T1D and one parent also has T1D. This enables further research to be undertaken to explore the experience of the T1D parent at diagnosis and their psychological health related to living with a chronic condition. Additionally, information obtained from siblings within these families would be beneficial to better understand the family cohesion and dynamics, however consideration would be needed due to the age of the siblings.

5.3 Clinical Implications

Psychological outcomes were highlighted in this study and most parents admitted that they would have benefited from having some psychological or mentoring support in the first six months following their child's diagnosis. It is well established that good glycaemic and health outcomes for children are associated with good mental health of their caregivers.^{45, 53} Therefore it is recommended that health professionals assess parents mental health not only at the time of diagnosis but at occasional intervals throughout the first year post diagnosis. Additionally, parents should attend a mandatory counselling session, to enable the experience of diagnosis to be discussed in relation to their own family.

In this study, these families all lacked the support of friends and grandparents who were not confident in taking the T1D child for sleepovers or play dates, resulting in these families getting very little respite from constant diabetes demands. Education for the parents is very comprehensive at

the time of diagnosis with parents receiving verbal and written information about diabetes care and management. Despite this, the information has not been disseminated to extended family and friends. Therefore, some degree of education sessions should be made available to siblings, extended family, and friends to ensure that parents have a well-informed support network available, to relieve some of their burden.

This current study has highlighted the need for individualised patient and family centred, targeted care. This not only includes focusing on the child's diabetes management but also understanding the family dynamics, and experiences of parents. These families who were living with diabetes prior to the diagnosis of their child, had already established habits and preconceived ideas about diabetes management. Additionally, these parents also had both positive and negative experiences related to T1D. This study did not explore the T1D parents' experiences thoroughly but did recognise that their diagnosis and management had a direct influence on their child's diabetes management. Therefore, it is recommended that health professionals firstly acknowledge that these families already live with diabetes and have some pre-existing knowledge and explore more about their experiences. Understanding these experiences will enable effective management plans to be put in place and empower these parents to work with the diabetes team.

5.4 Summary

This chapter has discussed the results from participant interviews and used a modified socioecological model to group previously identified themes into the three layers of the model. Strengths and limitations of the study have been identified and recommendation for further research and clinical implications have been presented. The final chapter will summarise the important findings from the study and address the research questions.

Chapter Six – Conclusion

This study used a qualitative approach to explore parent's perspective of their experience and needs when their child is diagnosed with T1D and to determine if also having a parent with T1D has an influence on their acceptance, adaption and management of their child's condition. Qualitative research focuses on the way people make sense of their experiences and the world in which they live.⁹¹ In the context of the constructivist paradigm, previous experiences are influenced by the interaction of individuals and the environment and this changes over time. This study has allowed the interaction of the researcher and participants to create new knowledge from lived experiences.

Results from this study, found that parents, both with T1D and non-T1D were similar to other parents who have a child diagnosed with T1D with the initial feelings of shock and bereavement at the time of diagnosis. Parents described a period of transition and adjustment with emotions resurfacing in relation to the daily challenges associated with management of their T1D child. Parents felt overwhelmed with the amount of new information and the responsibility of keeping their child safe with little support from external family and friends. Family cohesion and siblings' adjustment adding an extra challenge to the adaption to a new life.

In addition to what is currently known about the difficulties of parents managing children with T1D within families, this study adds new findings and some unique aspects associated with also having a parent with T1D. These will be discussed in the context of addressing the research questions.

1. What are the experiences of parents when their child is diagnosed with T1D and one parent also has T1D?

Children in this study were all diagnosed early before becoming unwell with DKA as parents recognised the symptoms of T1D and presented to medical facilities promptly. Most parents had performed a BGL checks prior to presentation, so had some insight in what to expect from the doctors. This, however, did not prevent the parents from feeling sadness and disappointment or from questioning the possibility that the diagnosis could be incorrect.

Anecdotally, the feelings related to guilt and blame had been discussed by health professionals associated with passing on this genetic condition and was presumed to be a finding in this study. However, we found the all non-T1D parents did not have any feelings of blame towards their partner, associated with their child T1D diagnosis and T1D parents did not express feelings of guilt associated with passing the condition on, however two parents did acknowledged the genetic link.

An interesting finding in this study was the unique bond between the T1D child and T1D parent that had been developed. This was associated with them both understanding what they were going through and impacted on their management and choice of insulin regimen. The diagnosis of the child had also had a positive effect on the adult in the way they viewed and managed their condition and in the acceptance of it. In this study the T1D parent had previously kept their own diagnosis to themselves and managed it alone, however since their child's diagnosis they were now able to share their management and challenges with their family and be more open about their diagnosis with friend.

The acquisition of knowledge was the most positive aspect of this study as T1D parents used this new information, they learned as a result of their child diagnosis, to empowered themselves to improve their diabetes management, to improve their own health outcomes and to be a good role model for their T1D child, and family.

2. How does pre-existing knowledge affect the experience of parents when their child is diagnosed with T1D and one parent also has T1D?

In this study the T1D parents were diagnosed at an older age than their child and consequently had received limited education associated with their diagnosis. Additionally, these parents had not received much support with their diabetes management from their own parents and had chosen to keep their diagnosis mostly to themselves, including requesting little involvement from their partner. Emotions such as shock, sadness and disbelief were identified by the T1D parent in relation to their own diagnosis. Both parents had a level of pre-existing knowledge about T1D when their child was diagnosis and relived positive and negative experiences and emotions related to the spouse's T1D management.

Some parents had mixed feelings about being treated as newly diagnosed initially as they believed they had enough experience from already managing T1D. They felt there was little benefit to be gained from mixing with newly diagnosed families, later realising that a having a child with T1D was very challenging and difficult to manage. Additionally, they felt the child needed to mix with these families to help with their adjustment and gained support from families who understood what they were going through.

3. What support and services parent felt they required when their child is diagnosed with T1D and one parent also has T1D?

Parent in this study, both T1D and non-T1D did not receive any psychological services as part of their diagnosis or their child's diagnosis. Some mothers admitted to needing psychological help in the first year post their child's diagnosis but never got around to organising it. All mothers in this study commented that either psychological help or a mentoring support person would have been beneficial for them particularly in the first six months, to assist them with the acceptance and adaption to the constant responsibility of diabetes management for their child.

This study highlighted that health professionals have a direct influence on individuals T1D experience, both positive and negative and the knowledge they gain and how they manage T1D. Understanding the parents, child and family and the knowledge and experiences they bring are pivotal in developing a supportive trusting relationship. Health professionals are perfectly placed to assess the family's needs on a regular basis and initiate services as required. An important point, echoed by the parents in this study, is for health professionals to listen to what the T1D individuals have to say, as 'there is lot can be learned from people who live with the condition daily'.

The aim of this study was to provide some preliminary descriptive information regarding parents' experiences when their child is diagnosed with T1D and one parent also has T1D. Information obtained from this study has been analysed and summarised in relationship to answering the research questions. This study has highlighted a need for further exploration of the whole family and their needs related to living with a chronic illness.

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Appendices

Appendix A	Recruitment letter
Appendix B	Participant information sheet and consent
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Appendix A



Government of **Western Australia**
Department of **Health**
Child and Adolescent Health Service



THE UNIVERSITY OF
WESTERN
AUSTRALIA

Date:

Dear

I am writing to inform you of a new study being conducted by a research student, Alison Roberts, through the Diabetes Department at Princess Margaret Hospital, together with the University of Western Australia.

The study's short title is GO FWD (**G**athering **O**pinions from **F**amilies **W**ith **D**iabetes) and we are interested in gaining information about how parents with type 1 diabetes and their partners coped and adapted when their child was diagnosed with type 1 diabetes (T1D). Currently there is limited information available about families who have a parent with T1D when their child is subsequently diagnosed with T1D and what resources and support these families require at diagnosis and over time.

Through the study we hope to gain valuable knowledge that may help determine the impact, support and resources required by families who are already living with type 1 diabetes when their child is diagnosed with the same.

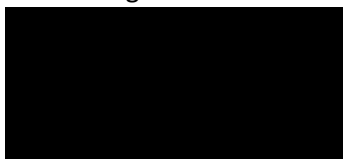
We are inviting both parents of children diagnosed with Type 1 diabetes between 2013 and 2015 to participate in the study. The study involves an interview that can be conducted in your home, in clinic or via skype or telephone, whichever is most convenient for you and should take about 45mins – 60mins to complete. All information collected is analysed anonymously.

You will find an information sheet attached to this letter, explaining the study further. Please take your time to read the information and consider participating in the study. If you have any questions please contact Alison Roberts, the research coordinator for GO FWD, on **9340 8486** or alison.roberts@health.wa.gov.au.

At the end of this letter is a portion to be returned in the prepaid envelop attached, indicating your preference to participate and a preferred contact number.

Your child's future care at this hospital will not be affected in any way by your participation or your decision not to participate in this study and the confidentiality of all participants will be maintained. This study has been approved by Princess Margaret Hospital Human Research Ethics Committee and the University of Western Australia Human Research Ethics Committee.

Kind regards



Associate Professor Liz Davis
Paediatric Endocrinologist
Head of Diabetes and Obesity
Princess Margaret Hospital

Recruitment letter - GO FWD Study – V3: 7th June 2016 (Page 1 of 2)

GO FWD study Team

Alison Roberts; Associate Professor Elizabeth Davis; Dr Ashleigh Lin; Dr Leanne Fried and Professor Colleen Fisher

Name: _____

Childs Name: _____

- I would **like** to participate in the GO FWD study, please contact me on this contact number: _____ to organize an interview.

- I would **not like** to participate in the GO FWD study

Appendix B



Government of **Western Australia**
Department of **Health**
Child and Adolescent Health Service



PARTICIPANT INFORMATION SHEET

Title	A qualitative exploration of the experiences and needs of parents of a child diagnosed with Type 1 diabetes when one parent has Type 1 diabetes.
Short Title	Gathering Opinions from Families With Diabetes: GO FWD
Protocol Number	Version 1, 22 March 2016
Principal Investigator	Alison Roberts
Associate Investigator(s)	Associate Professor Elizabeth Davis, Dr Ashleigh Lin, Dr Leanne Fried and Professor Colleen Fisher
Location	Princess Margaret Hospital and University of Western Australia

Why are we doing the study?

A significant amount of research is available regarding the ongoing challenges parents of children diagnosed with Type 1 diabetes (T1D) face with coping and adapting to their child's illness. There is little information available about how parents who have a diagnosis of T1D themselves, adapt and cope when their child is diagnosed with T1D and what information, support and services these parents require at time of diagnosis and over time.

The aim of the project is to explore parents' perspective of their experiences managing their child's T1D and what factors might influence their coping, adaptation and optimising of their child's diabetes management. This information will be extremely valuable in understanding families living with T1D and will assist in

reviewing the current model of care to ensure delivery of adequate education and support services to these families.

Who is carrying out the study?

The study is a collaboration between the Princess Margaret Hospital for Children and Population Health at the University of Western Australia. The research team comprises Alison Roberts who is a student researcher and this project will form part of her Master of Philosophy by Research degree. Associate Professor Elizabeth Davis, Dr Ashleigh Lin, Dr Leanne Fried and Professor Colleen Fisher are supervisors who will oversee and assist with all aspects of the research project

What will the study tell us?

The study will give us information on the personal experiences of parents with T1D and their partners, when their child is diagnosed with T1D and how they cope and adapt to their child's diagnosis.

This information will contribute to the information already known about the challenges parents encounter and how they cope and adapt to T1D in their families.

Do I have to take part?

Participation in this research is voluntary and you are not under any obligation to participate. Your decision whether or not to participate will not affect your child's future treatment at PMH in any way.

What will you be asked to do if you decide to take part in this study?

If you agree to participate, you will be asked to complete the Consent Form. Following this, arrangements will be made with you, to complete a face to face interview, this can be done while attending clinic with your child or at a place that is convenient to you, including your home.

Both parents will be asked to complete the same interview. With your consent the interview will be recorded on an approved recording device and transcribed in full, following the interview, by the Principal Investigator.

The questions are designed to explore your experiences when your child was diagnosed with Type 1 diabetes and explain what impact this has had on you and your family and what support and services you used or felt you required when your child was diagnosed with T1D.

What are the benefits of the study?

Although we cannot promise the study will help you directly, the information we get from this study may help other families who have a parent and child with T1D. The information we get from this study will help us better understand, families who have both a parent and child with T1D and may assist in reviewing the services and support we provide to families.

What are the possible risks and/or side effects?

We do not expect that any part of this study poses any risk or will cause harm to anyone taking part in it.

What are the possible discomforts and/or inconveniences?

Some parents may find discussing these issues difficult and you do not have to answer any questions that you are not comfortable with, the interview can be stopped at any time and will be, if you become too distressed.

At the completion of the interview, you will be given a list of contact numbers for community based support groups should you feel you need to discuss any issues that arise from this interview. Additionally you can contact the study coordinator and a referral to psychological services can be organised if deemed necessary.

Where is GO FWD study information kept?

All paper information collected as part of this research will be securely lock in a filing cabinet and all electronic data will be stored on a password protected storage device, Audio recordings will be stored on the device until transcribed in full and then erased from the device. Recording device will be kept in a locked drawer. Only researcher working on this project will have access to information.

What about my privacy?

To ensure anonymity an individualized code is assigned to each participant, and all information from your interview and about your family, will be stored using this code, not your names. All information will be kept confidential, meaning we will not share it with anyone without your permission.

Who has approved the study?

Princess Margaret Hospital Human Research Ethics Committee, Research Governance and the University of Western Australia Human Research Ethics Committee have approved this study.

Whom to contact if you have any concerns about the organisation or running of the study?

If you have any concerns or complaints regarding this study, you can contact the Director of Medical Services at PMH (Telephone No: (08) 9340 8222). Your concerns will be brought to the attention of the Ethics Committee who is monitoring the study.

What to do next if you would like to take part in this research or require more information

If you would like any more information about the study or would like to participate, please contact the study coordinator, Alison Roberts, to organise an appointment. She will be very happy to answer your questions.

Alison Roberts Study Coordinator (08) 9340 8486 alison.roberts@health.wa.gov.au.

THANK YOU FOR YOUR TIME



FORM OF CONSENT
(For Parent)

Please note that participation in research studies is voluntary and participants can withdraw at any time with no impact on current or future care.

I have read the

Given Names

Surname

information explaining the study entitled: **A qualitative exploration of the experiences and needs of parents of a child diagnosed with Type 1 diabetes when one parent has Type 1 diabetes.**

Short title: Gathering Opinions from Families With Type 1 Diabetes

I have read and understood the information given to me. Any questions I have asked have been answered to my satisfaction.

I understand I may withdraw from the study at any stage and withdrawal will not interfere with my child's routine care.

I agree that research data gathered from the results of this study may be published, provided that names are not used.

SignatureDate:.....

I, have explained the above to the

(Researcher's full name)

signatory who stated that he/she understood the same.

SignatureDate:.....

Appendix C

Interview guide

Objective 1 - To explore the thoughts and experiences of both parents, when one parent has type 1 diabetes and their child is subsequently diagnosed with type 1 diabetes

Thinking back to the day (your child) was diagnosed with Type 1 diabetes, can you describe what events were happening on or around that day?

Prompts

- Describe events - such as holidays, new siblings
- How long was XXX unwell
- What made you decide to get help
- What was the first thing you did – see GP / go to emergency department
- Who was around to help you
- Tell me about the Drs, nurses and other staff at the hospital you met
- Tell me what it was like when XXX was in hospital

Can you describe to me some of your feelings you experienced when you found out that your child had diabetes?

Prompts

- Describe behaviour, emotional changes
- What were you thinking?
- What were you feeling?
- What transition did you feel you went through from diagnosis to discharge?
- Describe your feelings about your child's diagnosis
- Describe your feelings changes
- Describe your feelings about partner and other children

Objective 2 – To investigate how both parents reflect on their pre-existing knowledge and experiences of managing type 1 diabetes, upon their child being diagnosed with type 1 diabetes

Thinking about your previous knowledge of T1D, can you explain if you think your / partners diagnosis of T1D has had an influenced on how you have coped or managed with the diagnosis of XXX?

Prompts

- Describe your feelings
- Describe your fears
- Help with understanding some terminology / medical procedures/ clinic environment
- Has there been any conflict with management decisions or choice of treatment regime?
- Did you relive the experiences and feelings associated with your diagnosis?
- Who makes management decisions – has that changed?

Can you explain what you think the impact is of having a child dx with T1D as well as a parent has on all family members?

Prompts

- Describe behaviour, emotional changes with sibling, extended family
- Describe any changes in parenting styles such as protective behaviour
- Describe any changes in parents' relationship
- Describe family dynamics / functioning

Objective 3 – To identify the unique support and services both parents received or felt they require when their child is subsequently diagnosed with Type 1 diabetes

Can you describe what supports you had prior to (your child's) diagnosis?

- Psychological
- Emotional
- Physical
- Financial

- Education and resource
- Social such as family, friend, social support groups, online social media

Can you describe what help you felt you needed after your child's diagnosis?

- Psychological
- Emotional
- Physical
- Financial
- Education and resources
- Social such as family, friend, social support groups, online social media

Please describe what professional services or resources you have used to help manage or adapt to (your child's) diagnosis?

Prompts

- Professional services for yourself / child / partner /siblings
- What was helpful Initially
- Over the last few years
- Was this recommended by health professionals
- Was this sought yourself

Describe how you feel today?

How do you think your partner is coping?

How do you think the other family members are coping?

If you had only 10 minutes to talk with a parent you met with a child newly diagnosed with T1D, describe what you would say and why.

Thank you for time and honesty in participating in this interview

If you feel upset following this interview, please ensure you discuss your concerns with your support group or you may wish to contact a professional service – some numbers have been included on this contact card.

Appendix D



Government of **Western Australia**
Department of **Health**
Child and Adolescent Health Service



THE UNIVERSITY OF
WESTERN
AUSTRALIA

Date ___ / ___ / _____

ID _____

Demographics

Parent/ caregiver

First Name: _____

Last Name: _____

Address: _____

_____ Postcode: _____

Gender: _____

Date of Birth: Date ___ / ___ / _____

Marital Status:

- Single
- Married
- Separated / divorced
- De Facto
- Other _____

What is your highest school education level achieved?

- Finished year 10
- Finished year 11
- Finished year 12

Other _____

Have you attended TAFE, training school or college or university?

- No
- Started TAFE/college course but didn't finish
- Completed a TAFE/college course
- Started university undergraduate degree but didn't finish
- Completed a university undergraduate degree
- Started university postgraduate degree but didn't finish
- Completed a university postgraduate degree

Occupation: _____

Employment

- Full-time
- Part-time
- Unemployed
- Casual
- Other _____

Relationship to child: _____

Amount of contact with your child:

- Daily
- Fortnightly
- Weekly
- Monthly
- Specific days, specify _____
- Other, _____

Number of siblings: _____

Number of children living in your house: _____

Number of adults living in your house: _____

Medical conditions, please specify condition and date of diagnosis

Parent with T1D

Date of T1D diagnosis: ___ / ___ / _____

Most recent HbA1c (if known): HbA1c% _____ % Date ___ / ___ / _____

Insulin regime (please tick): MDI/BD – No. of injections/ day _____

CSI

Length of time on current regime: _____

How frequently do you do blood glucose monitoring/ day: _____

Child with Type 1 diabetes

First Name: _____

Last Name: _____

Gender: _____

Date of Birth: Date ___ / ___ / _____

Date of diagnosis: Date ___ / ___ / _____

Most recent HbA1c (if applicable): HbA1c% _____ % Date ___ / ___ / _____

Insulin regime (please tick): MDI/BD – No. of injections/ day _____

CSI

Length of time on current regime: _____

How frequently does your child do blood glucose monitoring/ day: _____

Other medical conditions, please specify **condition and date of diagnosis**

Thank you

Appendix E



Government of **Western Australia**
Department of **Health**
Child and Adolescent Health Service

Our Ref: 2016060EP

A/Professor Elizabeth Davis Endocrinology and Diabetes Princess Margaret Hospital Roberts Road

Subiaco WA 6008

Dear A/Professor Davis

HUMAN RESEARCH ETHICS COMMITTEE (HREC)

HRECREF 2016060EP

STUDY TITLE: A qualitative exploration of the experiences and needs of parents of a child diagnosed with Type 1 diabetes when one parent has Type 1 diabetes

The ethics application for the project referenced above was reviewed by the PMH Human Research Ethics Committee (HREC) at its meeting on 19/05/2016. It has been approved and the following documents have been approved for use in this project.

- Protocol Form 4B
- Research Protocol Version 1 dated 22 March 2016
- Recruitment Letter Version 3 dated 07 June 2016
- Participant Information Sheet Version 3 dated 07 June 2016 Interview Guide Version dated 22 March 2016
- Contact Card Version dated 22 March 2016 Demographic Sheet Version 1 dated 22 March 2016
- Form of Consent for Parents Version 1 dated 22 March 2016
- Form of Withdrawal of Participation Version 1 dated 22 March 2016

Approval of this project from PMH HREC is valid to 17/06/2019 and on the basis of compliance with the 'Conditions of HREC Approval for a Research Project' (attached).

Note: If additional sites are recruited prior to the commencement of, or during the research project, the Coordinating Principal Investigator is required to notify the HREC. Notification of withdrawn sites should also be provided to the HREC in a timely fashion.

A copy of this ethical approval letter must be submitted by all site Principal Investigators to the Research Governance Office or equivalent body or individual at each participating institution in a timely manner to enable the institution to authorise the commencement of the project at its site/s.

This letter constitutes ethical approval only.

This project cannot proceed at any site until separate site authorisation has been obtained from the CE, or delegate, of the site under whose auspices the research will be conducted at that site.

The PMH HREC is registered with the Australian Health Ethics Committee and operates according to the NHMRC National Statement on Ethical Conduct in Human Research and International Conference on Harmonisation - Good Clinical Practice.

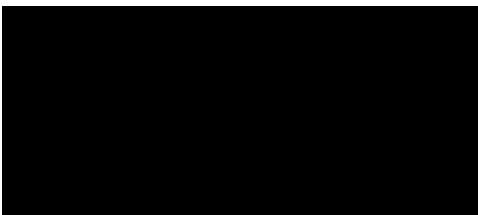
The *HREC's* Terms of Reference, Standard Operating Procedures, membership and standard forms are available from

<http://www.pmh.health.wa.gov.au/development/resources/ethics.htm> or from the Ethics Office. Should you have any queries about the HREC's consideration of your project, please contact Ethics Office.

Please quote the above trial number 2016060EP on all correspondence associated with this trial. Yours sincerely

Dr Mark Salmon Director Clinical Services

21/06/2016



* The Ethics Committee is constituted, and operates in accordance with the National Health and Medical Research Council's National Statement on Ethical Conduct in Research Involving Humans



Human Ethics Office of Research Enterprise

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E: humanethics@uwa.edu.au
CRICOS Provider Code:
001266

Our Ref: RA/4/1/845252

05 August 2016

Dr Elizabeth Davis

School of Paediatrics and Child Health

MBDP: M560

Dear Doctor Davis

Human research ethics office – notification of ethics approval from another ethics committee

Project: A Qualitative Exploration of the Experiences and Needs of Parents of a Child Diagnosed with Type 1 Diabetes when One Parent has Type 1 Diabetes – Recognition Princess Margaret Hospital HREC Approval 2016060EP

Thank you for your correspondence notifying this office of your project's review and approval by a non-UWA Research Ethics Committee. It is noted that you have ethics approval from Princess Margaret Hospital, approval number 2016060EP.

The students and researchers identified as working on this project are:

Name	Faculty / School	Role
Dr Elizabeth Davis	School of Paediatrics and Child Health	Chief Investigator
Professor Colleen Fisher	School of Population Health	Co-Investigator
Alison Roberts	WA Department of Health	Co-Investigator
Dr Ashleigh Lin	UWA Centre for Child Health Research	Co-Investigator
Dr Leanne Fried	Telethon Kids Institute	Co-Investigator

Student(s): Alison Roberts

Although The University of Western Australia reserves the right to subject any research involving its staff and students to its own ethics

review process, in this case, the UWA Human Ethics Office recognizes the existing approval of the non-UWA ethics committee.

1. Approving HREC to receive annual reports, amendments and notification of adverse events

You are reminded that the approving ethics committee remains the monitoring committee for this project. You must correspond with them for matters regarding amendments, adverse events, annual and final reporting.

If you have any queries, please contact the HEO at humanethics@uwa.edu.au.

Please ensure that you quote the file reference – RA/4/1/8452 – and the associated project title in all future correspondence.

Yours sincerely,



Dr Caixia Li

Manager, Human Ethics

Appendix G



Government of Western Australia
Child and Adolescent Health Service

Our Ref: 4813/2016060EP

A/Professor Elizabeth Davis
Endocrinology and Diabetes
Princess Margaret Hospital
Roberts Road
Subiaco WA 6008

Dear A/Professor Davis

**RE: 2016060EP - AMENDMENT OF TRIAL APPROVAL
HUMAN RESEARCH ETHICS COMMITTEE (HREC)**

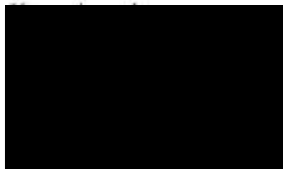
HREC Ref	2016060EP
Study Expiry Date	17/06/2019
Study Title	A qualitative exploration of the experiences and needs of parents of a child diagnosed with Type 1 diabetes when one parent has Type 1 diabetes

The review of the administrative amendment for the above project has been completed and it is now approved. This amendment was for :

Recruitment letter Version 4 dated 29 May 2017

The responsibility for the conduct of this project remains with you as the Principal Investigator at the site/s.

I have been designated the authority to approve administrative amendments on behalf of the Child and Adolescent Health Service HREC in accordance with the Standard Operating Procedures.



Committee

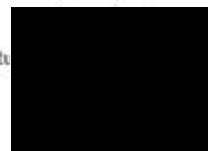
21/07/2017

I have reviewed this administrative amendment and there are no governance implications for CAHS.

I have reviewed this administrative amendment and the governance implications have been addressed by the investigator to the satisfaction of the CAHS Research Governance Office.

Lesley Banfield/Helen Hughes/J Westgarth-Taylor Signatu

te: 21/7/17





Date:

Dear

I am writing to inform you of a new study being conducted by a research student, Alison Roberts, through the Diabetes Department at Princess Margaret Hospital, together with the University of Western Australia.

The study's short title is GO FWD (**G**athering **O**pinions from **F**amilies **W**ith **D**iabetes) and we are interested in gaining information about how parents with type 1 diabetes and their partners coped and adapted when their child was diagnosed with type 1 diabetes (T1D). Currently there is limited information available about families who have a parent with T1D when their child is subsequently diagnosed with T1D and what resources and support these families require at diagnosis and over time.

Through the study we hope to gain valuable knowledge that may help determine the impact, support and resources required by families who are already living with type 1 diabetes when their child is diagnosed with the same.

We are inviting both parents of children diagnosed with Type 1 diabetes between 2013 and 2016 to participate in the study. The study involves an interview that can be conducted in your home, in clinic or via skype or telephone, whichever is most convenient for you and should take about 45mins – 60mins to complete. All information collected is analysed anonymously.

You will find an information sheet attached to this letter, explaining the study further. Please take your time to read the information and consider participating in the study. If you have any questions please contact Alison Roberts, the research coordinator for GO FWD, on **9340 8486** or alison.roberts@health.wa.gov.au.

At the end of this letter is a portion to be returned in the prepaid envelop attached, indicating your preference to participate and a preferred contact number.

Your child's future care at this hospital will not be affected in any way by your participation or your decision not to participate in this study and the confidentiality of all participants will be maintained. This study has been approved by Princess Margaret Hospital Human Research Ethics Committee and the University of Western Australia Human Research Ethics Committee.

Kind regards



Associate Professor Liz Davis

Paediatric Endocrinologist

Head of Diabetes and Obesity

Princess Margaret Hospital

GO FWD study Team

Alison Roberts; Associate Professor Elizabeth Davis; Dr Ashleigh Lin; Dr Leanne Fried and Professor Colleen Fisher

Name: _____

Childs Name: _____

I would **like** to participate in the GO FWD study, please contact me on this contact number: _____ to organize an interview.

I would **not like** to participate in the GO FWD study

Appendix H

CONTACT CARD – To be given to participants following interview

Contact card

GO FWD >> Gathering Opinions from Families With Diabetes

Life line – 13 11 14

Beyond blue – 1300 224 636

Black dog institute – 9382 4530

Study Co-ordinator – Alison Roberts

Ph: 9340 8486

Email: alison.roberts@health.wa.gov.au