THE SOCIAL DETERMINANTS OF HEALTH OUTCOMES IN TYPE 1 DIABETES MELLITUS

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Candidate statement

'I certify that this thesis does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text'. Kathleen Hill 28.8.17

SUMMARY

BACKGROUND

Type 1 Diabetes Mellitus (T1DM) is a chronic condition that requires a lifetime of diligent self-management to avoid complications. Living with T1DM is a considerable challenge and the inability to follow a prescribed regimen is often termed non-compliance, which fails to acknowledge that the barriers to glycaemic control may be insurmountable. Social determinants of health are aspects of an individual's unique social environment that can affect their capacity for health, decision making and engagement with health care services. Individuals who are burdened by socioeconomic disadvantage may have particular difficulty navigating the health care system and are at risk of disengaging from health care services and the silent development of severe complications.

AIM AND OBJECTIVES

This thesis explores the structural determinants, social context and lived experience of T1DM into adulthood to understand influences on patterns of self-care, engagement with and trust in health care services, and health outcomes.

METHODS

Study one is an examination of the national data on end stage renal disease due to T1DM and study two is a retrospective cohort study of patterns of care and health outcomes of over 1000 individuals with T1DM. Study three is a deep qualitative exploration describing the lived experience of T1DM and barriers preventing access to health care for young people returning to care after developing serious complications.

RESULTS

T1DM prevalence in Australia follows an inverse gradient with higher socioeconomic deciles having an overall lower population prevalence of T1DM (correlation coefficient –.397, $p<.001$). Males with T1DM were more likely to develop end stage renal disease (ESRD) particularly if they are of low socioeconomic status (SES) (RR 1.20, CI 1.002–1.459). Engagement with endocrinology services decreased with increasing age, with high attendance only seen in childhood. Median HbA1c is 8.4%, however almost 40% are in a high-risk category of 9% or above. A recurrent theme in the qualitative data was the tension between

fear of hypoglycaemia and fear of complications, leaving participants debating their options and inducing diabetes distress. Adverse early childhood environments led to subsequent difficulties in establishing close attachment relationships in adulthood and diminished social support. Participants with low social support reported struggling to manage diabetes on their own, combative relationships with health care providers, disengagement from health care for many years and the subsequent silent development of severe complications at a comparatively young age.

CONCLUSION

Several social determinants of health were found to be associated with poorer outcomes in T1DM and an understanding of these 'at risk' groups has the potential to inform clinical practice in relation to increased service provision and a more tailored approach to reduce inequities. These broader structural influences on health are beyond individual control and understanding this will enable tailoring of care to each individual and neutralising the perception of blame. This is vital to building a strong and trusting relationship with young people that will endure over time to ensure surveillance for the presence and progression of diabetes complications.

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TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

GLOSSARY OF TERMS

Atherosclerosis Thickening of arterial walls leading to disrupted blood flow

ATSI Aboriginal and Torres Strait Islander people

Biographical disruption A disturbance in the natural trajectory of a person's life course due to an unforeseen event

DN Diabetic Nephropathy

eGFR Estimated Glomerular Filtration Rate

End stage renal disease (ESRD) Complete renal failure requiring renal replacement therapy

HbA1c A measurement of glycated haemoglobin in the blood that indicates the degree of glycaemic control experienced over the preceding three months

HLA Human Leukocyte Antigen, a genetic variant of the immune system

Hyperglycaemia Blood glucose level above the normal range

Hypoglycaemia A lower than normal blood glucose level

Intensive Treatment Multiple daily injections of insulin or continuous pump therapy accompanied by frequent (>4 times per day) monitoring of blood glucose

Ketoacidosis A metabolic syndrome of elevated blood glucose producing ketosis which if untreated is fatal

Latent Autoimmune Diabetes in Adults (LADA) A form of diabetes with onset in adulthood, which has a similar disease trajectory and requires insulin treatment to T1DM antibody negative which destroys pancreatic islet cells

National Diabetes Services Scheme (NDSS) An organisation through which registered individuals with diabetes can obtain consumables required for diabetes care at reduced cost

Nephropathy Permanent kidney damage with associated reduced renal function

Neuropathy Permanent nerve function loss in the limbs

Renal replacement therapy A treatment option when all kidney function is lost that entails haemodialysis, peritoneal dialysis or renal transplantation

Retinopathy Permanent eye damage with associated vision loss

Socioeconomic Indices for Areas (SEIFA) A proxy measure for SES derived from Australian census data

SMBG Self-monitoring of blood glucose levels

Socioeconomic status (SES) An individual's economic and social position

Social epidemiology A study of the social determinants of health and illness

Standardised mortality risk (SMR) The number of deaths observed in a study population in relation to a matched standard population

Type 1 Diabetes Mellitus (T1DM) An idiopathic autoimmune disorder of the pancreas leading to the absence of insulin and persistent hyperglycaemia which if untreated is fatal

Type 2 Diabetes Mellitus (T2DM) A progressive condition in which the body gradually becomes insulin resistant and/or the pancreas produces insufficient insulin

INTRODUCTION

Type 1 Diabetes Mellitus (T1DM) is a serious chronic disease characterised by the inability of the pancreas to secrete insulin and commonly first diagnosed in childhood. The aetiology of the disease onset remains uncertain, however, there is a general acceptance that some individuals are at risk of the disease due to genetic reasons and there may be an environmental 'trigger' that sets the autoimmune destruction of pancreatic beta cells into motion. The disease onset is rapid occurring over a number of weeks and results in life threatening ketosis, which is the point at which the disease is usually diagnosed. Individuals with T1DM are subsequently dependent on insulin injections for the rest of their lives and require an intensive daily program of dietary management, blood glucose level monitoring and frequently adjusted doses of insulin.

The disease trajectory can lead to a heavy burden of morbidity and mortality. The complications of T1DM can be delayed through good concordance with therapeutic regimens but self-management of T1DM over a lifetime is an enormous challenge even in favourable social and environmental circumstances [1]. The focus of this thesis is an exploration of the social factors that can affect concordance with therapy in T1DM and lead to development of kidney disease at a comparatively young age. Whilst there are other adverse health outcomes in T1DM that relate to damage to the blood vessels of the eyes and heart and to the nerves of the hands and feet, kidney disease is a strong independent predictor of death for people with T1DM [2], reflects a long term outcome and offers a hard end point. Therefore, when examining the impact of social factors that begin in the early childhood environment and have an effect on health outcomes over many decades a long term outcome such as kidney disease can be a strong indicator of disparate outcomes.

Kidney disease progression in T1DM is commonly understood to arise from historical and continued poor glycaemic control yet the factors that promote or inhibit concordance with therapy are multifactorial and not necessarily well understood by health care providers. The prevailing discourse in contemporary diabetes health care is one of individualism and 'responsibility for the self'. This thesis uses a novel combination of epidemiological analysis coupled with a critical evaluation of access to and uptake of the health care service further explored with qualitative analysis to explore the impact of the social environment on disease trajectory in T1DM. A framework of critical social theory has been used to contribute to an understanding of the barriers to concordance with therapy through an examination of the social

determinants of health (SDH). The SDH previously identified as affecting health in large population studies include early childhood environments and educational attainment, socioeconomic status (SES), gender and ethnicity [3]. Critical social theory enables an understanding of the SDH that drive social inequality and result in health disparities [4] that are inequitable.

In this research, a sociological analysis of traditional epidemiology is conducted to explore the socially constructed nature of its findings [5] and to move beyond descriptions of individual behaviour and characteristics as behaviours can be socially patterned and tend to cluster with one another [6, 7]. The thesis is grounded in an extensive review of the current literature pertaining to the social epidemiology of T1DM. Chapter 1 introduces the epidemiological and clinical literature regarding T1DM in relation to the pathogenesis of complications and current evidence regarding known barriers to concordance with therapy. Chapter 2 examines the literature on the social epidemiology of T1DM to determine what is currently known about social factors and outcomes in T1DM. Although many studies have demonstrated that the barriers to concordance with therapy and the influence of the social environment are well defined, they are situated at the level of the individual and have a dominant behavioural paradigm which has limitations. Behavioural models in health care draw on rational choice theory which is underpinned by the notion that informed people will behave in their best interest [8] however the social environment can place constraints on the ability to 'choose'. There has been limited research in T1DM that explores the impact of macro-level determinants on individual disease outcomes and an absence of research that critically examines the role the health care services has in ameliorating disparate outcomes.

The aim of the research was to determine whether SDH result in disparities in health outcomes for people with T1DM in Australia which has not previously been studied, and if so, the mechanisms by which this occurs that will inform future health care service planning. Australia has a well-funded universally available health care service with equal provision of services for all people with T1DM, which could be referred to as horizontal equity, or equal services for a presumed equal need. However if disparate health outcomes in T1DM arise as a result of social factors this argues for a vertical equity approach in health care as some people simply need more input and should therefore be given more [9]. The thesis takes a structured quantitative approach to measure the extent of the problem and a qualitative approach to understand the nature of the problem [10] with a research paradigm that is both positivist and interpretivist [11, 12]. The structural determinants, social context and lived experience of T1DM well into

adulthood is explored to understand how SDH can influence patterns of self-care and negatively affect engagement with and trust in the health care service.

Three studies were undertaken to address the thesis aims and are presented in chapters 3, 4 and 5. Study 1 (Chapter 3) is a quantitative analysis of the prevalence of diabetes in Australia and of national data on the development of ESRD in Australia and New Zealand. This study utilised data on diabetes prevalence in Australia from the National Diabetes Service's Scheme that is a robust source determined to have almost complete coverage. Data on ESRD were drawn from the Australia and New Zealand Dialysis and Transplant Registry, which has complete coverage on the incidence of the hard end point ESRD due to reports from individual renal services in Australia and New Zealand. The rationale for the data sourced for this study was to explore the association between SES and diabetes prevalence and to determine whether SES is a SDH in relation to the development of ESRD. In addition, drawing on the extensive evidence found in the literature regarding inequitable outcomes in T1DM for ethnic minorities in other regions, Study 1 also sought data that could be used to establish whether Aboriginal and Torres Strait Islander (ATSI), Maori, or Pacific Islander ethnicity is a SDH in relation to the development of ESRD.

In Study 2 the antecedents of disparate renal outcomes in T1DM were examined through a retrospective cohort study that examined patterns of care and health outcomes for variations according to SDH for a large group of adults and children with T1DM. This quantitative study whilst fundamentally a retrospective cohort study designed to examine long term health outcomes in relation to the prevalence of early to late stage chronic kidney disease (CKD), also served as an evaluation of uptake of endocrinology services and benchmarks for preventative surveillance. Data were collected, examined and analysed that relate to patterns of health care service usage, and the health service screening for both glycaemic control and for the detection of kidney disease. The data set is large and covers a metropolitan area that includes three hospitals and outpatient clinical care with a range of health care providers for people with T1DM, which is likely to reflect the configuration of health care services for diabetes in other Australian metropolitan areas increasing the studies clinical generalizability.

Quantitative data can clearly demonstrate disparate uptake and utilisation of health care services and differential health outcomes, yet cannot fully explain the mechanisms by which this occurs particularly in how they relate to complex social factors. The intimate facets of social relationships including one that exists between a health care provider and a service user can rarely be understood by quantitative research. Hence, Study 3 involved an in-depth

qualitative exploration of people with T1DM perceptions of the social and environmental factors that may help or hinder diabetes management including reflecting on the health care services as a SDH.

This thesis is concluded in chapter 6 and describes how health is both individually and socially determined [4] through the duality of agency or ‘choice’ in health care behaviours and in the social context of the lived experience which can place constraints on the ability to choose [7, 13-15]. This examination of the SDH outcomes in T1DM seeks to redress the contemporary public health tendency to blame victims in which illness is considered something that individuals are held accountable for [16, 17]. The research intent is to illuminate the structural or ‘macro’ level determinants of health outcomes that relate to disparity according to SES, disparity according to ethnicity, and disparity driven by the health service that holds a duty of care to ensure vertical equity for its more vulnerable populations. An understanding of how social determinants affects health care behaviours and engagement with health care services contributes new knowledge for the development of future strategies to engage disadvantaged young adults with health care services that will ensure surveillance for the presence and progression of T1DM complications.

CHAPTER 1: EPIDEMIOLOGICAL AND CLINICAL LITERATURE ON TYPE 1 DIABETES MELLITUS

1.1 Introduction

The epidemiological and clinical literature on the disease aetiology of type 1 diabetes mellitus (T1DM) and the pathogenesis of complications is introduced in the following chapter. This understanding of the disease aetiology and how complications arise shaped the subsequent direction of the literature search towards a critical review of the current evidence about known barriers to concordance with therapy. This literature review critiques the dominant individual behavioural paradigm which fails to account for the impact of the social determinants of health (SDH) as factors beyond the control of the individual [18]. The search for the literature included in this review was conducted in a systematic way which is described under each sub-heading and further detailed in appendix 1, tables 6-1 to 6-3.

1.2 Type 1 Diabetes Mellitus

T1DM is not a single disease but a group of metabolic disorders that have in common the incapacity of the pancreas to produce sufficient insulin [19] because of pancreatic beta cell destruction or genetic abnormality of these cells. T1DM is generally classified into three distinct types: immune mediated destruction of beta cells, idiopathic diabetes with permanent lack of insulin, and genetic defects of pancreatic beta cells known as maturity onset diabetes of the young (MODY) [20]. The disease aetiology remains largely unknown and it is commonly described as an idiopathic autoimmune disorder. The absence of insulin leads to defective glucose transport and utilisation peripherally, prolonged and persistent elevation of blood glucose levels and ketosis, which if left untreated is fatal [21]. Criteria for the diagnosis of T1DM include symptoms and a random blood glucose level greater than 11.1 mM/L, a fasting blood glucose of greater than 7 mM/L, or a two-hour plasma glucose of greater than 11.1 mM/L after a 75g glucose load [22]. A diagnosis of T1DM is established and Type 2 Diabetes Mellitus (T2DM) excluded by genetic and immunological markers, the absence of C-Peptide and ketosis [21].

Treatment of T1DM aims to reduce elevated blood glucose by frequent daily injections of basal (long acting) and meal dosing (rapid acting) insulin, dietary management and monitoring of blood glucose levels and urine ketones. Persistently elevated blood glucose levels damage the

small and large blood vessels leading to severe complications such as nephropathy, retinopathy, neuropathy and cardiac and peripheral vessel disease. Glycaemic control is assessed by measurement of glycated haemoglobin (HbA1c) in the blood, which is formed by irreversible attachment of glucose to haemoglobin [23]. Glycaemic management in T1DM is considered optimum when HbA1c is maintained at a level below 7% [24]. T1DM makes up approximately 10–15% of diabetes cases worldwide and has an average annual increase of around 3% [25].

1.2.1 Prevalence and geographical distribution of Type 1 Diabetes Mellitus

The research question informing the search is what is currently known about the aetiology of T1DM and is there variation in the distribution of the disease across different countries. Data bases searched were Medline/Ovid, Proquest, Informit, Sage, Web of Science, Scopus and Science direct. The search was limited to 2010-2013 to ensure recent and relevant data. Abstracts were reviewed and papers were included on the basis of incidence, prevalence, epidemiology of T1DM and excluded on the basis of T2DM and duplicates retrieved in subsequent search waves. A total of 247 papers were reviewed, 218 excluded and 29 included in the review. The search strategy is further defined in appendix 1 table 6-1.

The geographical variation in incidence of T1DM is one of the largest observed for any non-communicable disease and this is thought to give some credibility to the notion of an environmental influence on the development of the disease [26]. Incidence varies widely both between and within countries, with some geographical areas being described as T1DM ‘hot spots’. Currently, Finland is estimated to have the highest incidence of childhood onset (age 15 or less) T1DM in the world, with 52.8/100,000 population and Venezuela and China have the lowest incidence with <1/100,000 [27] . This data cited for the European countries comes from multicentre prospective registries stated to have more than 90% case ascertainment in most registries, and the data from other regions is drawn from the World Health Organisations global Diamond study which has undergone rigorous case ascertainment assessment. There has been a considerable increase in incidence in a number of countries recently, including an incidence of 49.9/100,000 in Canada [28], doubling of incidence rates in Rome [29], and a threefold increase in Poland, with the authors suggesting that Eastern Europe has an annual increase almost double that of the traditionally high prevalence countries [30]. There are similar findings in Croatia with an incident trend growth of 10%, [31] and in Auckland the incidence has more than doubled from 10.9/100,000 to 22.5/100,000 [32]. Many studies are

demonstrating these findings in genetically stable homogenous populations [33], a trend that is highly suggestive of a cohort or sinusoidal variation with large peaks in incident rates being reported for similar periods. This raises the possibility that important risk exposures vary over time [34]. This cohort affect can be clearly demonstrated in incidence rates in Czech children with two clear points of change, in 1995 there was an accelerated annual incidence of 15% in children aged 0–4 years but in 2001 the increase slowed significantly, with the authors concluding that changes in trends occur and make long-term predictions of incidence difficult [35]. Epidemics or 'peaks' have been reported in several populations, with one example seen in Western Australia and North East England which simultaneously demonstrated a sinusoidal five year cyclical variation of 14% despite being distinctly different populations in vastly difference geographical locations [36]. Although the incidence of T1DM shows large variance worldwide, environmental or genetic causation has not yet been determined [37]. In Australia between 1999 and 2008 there were 9500 children registered with T1DM and the childhood incidence rate is 23/100,000 which is the seventh highest prevalence globally of thirty countries [38].

1.2.2 Epidemiology of Type 1 Diabetes Mellitus

T1DM used to be described as juvenile onset diabetes. The disease is most often diagnosed in young people aged 10–14 years during puberty [39, 40] but a significant proportion is diagnosed in individuals above 15 years, with up to one-quarter of cases being diagnosed in adulthood [41]. There is wide variance in incidence of T1DM globally and it is generally agreed that the disease arises because of the action of as yet unknown environmental factors in genetically susceptible individuals [42].

It is well established that genetic Human Leukocyte Antigen (HLA) variants account for 50% of T1DM susceptibility and more than 40 other genes account for the remainder [39]. However, genetic susceptibility has been shown not to be sufficient for the development of the disease because not all genetically susceptible individuals progress to clinical disease. Currently, T1DM is being observed increasingly in children with a low genetic susceptibility, which suggests that perhaps environmental factors are escalating and represent a trigger for the development of the disease [30]. In support of this suggestion many studies have revealed an unequivocal temporal variation and seasonal variability of diabetes presentations, and studies of monozygotic twins suggest that only 13–30% are pairwise concordant for T1DM, suggesting

a difference in exposure to an unknown environmental agent [43]. A number of studies have also demonstrated that migrant groups assume the same risk as the host population [21] while being born in a country with high incidence increases the risk for the offspring of parents born in a country with low prevalence [39].

The twentyfold difference in European Caucasian populations is very difficult to explain and while genetic variations and a wide number of hypotheses regarding environmental triggers have been studied, the contribution of any individual factor has yet to be proven [43]. Among the theories suggested are the 'hygiene theory' that reduced contact with early infections compromises the immune system development [44], maternal, foetal and childhood vitamin D deficiency [27, 39], rapid Westernisation, socioeconomic transformation and lifestyle changes [30], factors with a cyclical nature such as exposure to viral illness and bacterial infection in the colder months [36], Enterovirus transmitted through the intestine [45], birth by caesarean section [28], and increasing maternal age [42]. Many of these studies have found correlations between incidence and affluence, supporting the hygiene theory and socioeconomic related lifestyle differences including educational attainment, maternal age and dietary habits, particularly in the Unites States and regardless of ethnicity [46]. This relationship has previously been well demonstrated in Sweden, where the highest incidence occurs in areas with a high proportion of small families and families with high incomes and better education [47], and in Western Australia where the incidence in the highest SES groups is 50% greater than in the lowest [48]. This is in direct contrast to the known association between low SES and the prevalence of T2DM demonstrated in other regions [49] which prompted the exploration of the population prevalence of T1DM and T2DM undertaken in study 1 (chapter 3).

The World Health Organization has recently published data on trends in incidence rates of T1DM and although globally these are relatively stable at 3–4%, many studies have found that there is a marked shift to occurrence in the 0–4 years age group [42, 50-55]. In Sweden, a country with a very high prevalence, a 25-year prospective study demonstrated a clear trend to younger age onset, suggesting exposures affecting young children may be responsible [56]. Thus the impact of prognostic factors that contribute to the chronic complications of T1DM such as disease duration and psychosocial development is now potentially much longer [30] and this has very serious implications for individuals with T1DM.

1.2.3 Pathogenesis of complications in Type 1 Diabetes Mellitus

Microvascular damage in T1DM occurs because hyperglycaemia affects the capillary basement membrane of the retina and glomerulus. In retinopathy, the thickening of the membrane leads to occlusion and ischemia which in turn prompt the development of new vessels which are fragile and prone to haemorrhage and rupture [23]. Diabetic retinopathy remains the commonest cause of blindness in the working population of developed countries [57]. It starts to occur 3–5 years after disease onset and is present in almost all patients after 20 years of diabetes duration. Diabetic nephropathy results from glomerular sclerosis that allows increased passage of albumin into the glomerular filtrate, seen clinically as micro-albuminuria [57]. Neuropathy occurs through pathological distal axonal loss resulting in slowing and eventual loss of nerve conduction [57]. This is experienced as numbness in the feet with gradual extension that reaches the knees with resulting difficulty in walking. The macrovascular complications of T1DM include coronary disease, stroke and peripheral vascular disease leading to lower extremity amputation. This process is thought to occur through accelerated atherosclerosis resulting from a combination of high glucose, altered coagulopathy, high blood pressure and elevated lipids.

1.2.4 Morbidity and mortality in Type 1 Diabetes Mellitus

The research question informing the search is what is currently known about premature mortality and the burden of morbidity for people with T1DM. Data bases searched were Medline/Ovid, Informit, Sage, Web of Science, Scopus and Science direct. The search was limited to the previous ten years to ensure recent and relevant data. Abstracts were reviewed and papers were included on the basis of morbidity and mortality in T1DM and excluded on the basis of T2DM and duplicates retrieved in subsequent search waves. A total of 228 papers were reviewed, 193 excluded and 35 included in the review. The search strategy is further defined in appendix 1 table 6-2.

Even countries with well-developed health care systems have an excess mortality in young people with T1DM [58]. Mortality risk is highest for those in the 0–29 years age group at a time when mortality in this age group in the general population is low [59, 60]. However, the effects of the disease over time makes T1DM a leading cause of chronic health problems including nephropathy, retinopathy, neuropathy and coronary and peripheral vascular disease and present an enormous public health burden [39]. These complications evolve most

commonly after 10–20 years' disease duration [21], which coupled with the young age of onset means that without diligent glycaemic control they affect people in their most productive years. Given the rising incidence trend in children aged 0–4 years complications will potentially occur well before middle age. Life expectancy continues to improve with advances in treatment and whilst there is a substantially reduced cardiac mortality trend evidenced from recent registry based studies [61] large epidemiological studies from Europe have demonstrated that life expectancy for people with T1DM is still 20 years less than for the general population [62].

The incidence and progression of both acute and chronic complications is favourably influenced by strict glycaemic control and intensive therapies [63]. There have been great advancements in the development of intensive treatment regimens with superior insulin replacement therapies. Time trends in mortality for T1DM show that survival has improved over time in the case of early onset (0–14 years) T1DM but has deteriorated since the 1980s in the late onset (15–29 years) age group. In Finland, the country with the highest incidence in the world, drugs and alcohol account for close to 40% of deaths in the late onset group with a large proportion of other deaths being due to acute complications such as diabetic ketoacidosis (DKA) rather than chronic complications [64]. DKA occurs when there is prolonged untreated elevation of blood glucose, which can occur in the setting of acute illness but is more commonly due to failure to inject insulin. Other countries have also recorded an increase in sudden unexpected death outside the hospital setting in the past two decades [65], often referred to as 'death in bed', and a significant excess mortality in childhood before the onset of complications [66]. Similarly a Scottish study demonstrated that recent trends are not showing continued improvement in survival [60] and a striking feature of the data from this study was the very low rates of achievement of glycaemic control targets. The average HbA1c of study participants was 8.5%, and they cited a similar United States of America (USA) study in which the average HbA1c was 10.3%. Globally, most research in T1DM suggests that the ideal of HbA1c below 7% remains an unachievable target for most people with T1DM.

Despite the development of treatment regimens that aim to optimise glucose control, evidence suggests that either these are not being adopted or that they prove impossible for people to manage. In the nine-year Diabetes control and complications trial (DCCT) only 5% of patients who were well supported medically achieved a HbA1c of 6.05% or below [67]. Intensified insulin therapy is highly complex and requires a great deal of diligence and compliance but it has been demonstrated to reduce complications by 50–70% [68]. Maintenance of a near normal

blood glucose level is necessary to reduce complications [69] but recent studies have revealed no novel ideas on how to assist people to achieve this [41]. Recommendations for community management of T1DM can be quite contradictory, with some authors advocating therapeutic regimes that reduce the risk of hypoglycaemia (a sudden and unexpected fall in blood glucose, a distressing occurrence that has a detrimental effect on all aspects of life) [70] and others claiming that insulin restriction because of fear of hypoglycaemia is associated with increased morbidity and mortality [71]. This conflicting advice often confuses patients with T1DM who are simultaneously trying to avoid hypoglycaemia and the associated risk of coma and sudden death while maintaining strict glycaemic control to avoid future complications. This type of pressure induces diabetes-specific distress which itself is associated with a three-fold increased risk of death [71].

Chronic complications commonly occur within 10 years which is likely to affect many young people in their 30s and create a disabling effect on their ability to function normally as young adults. As damage to the kidneys progresses the presence of proteinuria is a powerful predictor of increased mortality [72-74] and individuals with T1DM and proteinuria have a relative mortality rate more than 50 times that of the non-diabetic population, with 25% of this group dying from cardiac disease before reaching end stage renal disease [21]. Diabetic nephropathy is the leading single cause of end stage renal disease (ESRD) and renal replacement therapy haemodialysis is a significant risk factor for death [75].

Poor blood pressure control has been shown to be one of the main determinants of progression to renal disease [76] and median survival has greatly increased with aggressive antihypertensive treatment and glycaemic control. However, studies have shown a median 10-year survival of only 22% [77], threefold rates of death in those with chronic kidney disease (CKD) [74], and at 10-year follow up 40% of patients with nephropathy had either died, or had had a myocardial infarction, stroke, lower limb amputation or peripheral bypass procedure [78]. Hypertension, high LDL cholesterol, low HDL cholesterol, depression and nephropathy are all independent risk factors for coronary artery disease (CAD). Cardiovascular disease is the leading cause of death in T1DM and the lack of a single dominant factor suggests that multidisciplinary and multifactorial research is needed to improve outcomes [79]. Risk factors for the development of complications tend to be interrelated [80] and this clustering effect can also be demonstrated in behaviours such as non-attendance, poor concordance, depression, and smoking. T1DM can be a very labile disease with unexpected swings in glucose stability and

concordance with therapy in the long term is very difficult to maintain. Many longitudinal studies have demonstrated no improvement in HbA1C over time but with concurrent psychiatric disorders and complications increasing by as much as 28–30%, with poor outcomes for young adults in their 20s and 30s [81]. These young people were attending clinics and receiving individual care from the diabetes team but they had no access to formal psychological care. It has been well demonstrated that people with T1DM have significantly higher rates of depression than the general population [64].

A major factor in good diabetes management is a strong and trusting relationship with health care providers who are supportive of the person with T1DM and this is now recognised as an area requiring more research. A study following 2,946 patients with T1DM over 30 months for compliance with medication, appointment attendance and mortality found that 28% of patients missed appointments and this was associated with increased mortality [62]. Clinic non-attendance is a common problem in T1DM and the reasons for it are not well understood, with the largest group of non-attendees being in their 20s. The study found that non-attendees were more likely to have larger body mass index (BMI), increased HbA1c and to be smokers. A causal relationship between clinic non-attendance and BMI or smoking is highly unlikely and it is the underlying social, environmental and psychological circumstances of the person with T1DM that are the reasons for poorer health behaviours. This was not explored in the cited study and these findings highlight the limitations of a biomedical research approach that does not account for social and environmental factors.

In considering the need for research in T1DM that examines the SDH, this review of the literature has revealed some distinctly inequitable outcomes. There is double the risk of death in poorer countries compared with the USA, rates of death are 30% higher for females [82] and there is overall significantly lower mortality for Caucasians [83]. Hamman (2010) surmises that in a generally stable white American population such as that of Allegheny County [84] the poorer outcomes for females are difficult to explain, and yet gender has been well demonstrated as a SDH. Another limitation is the lack of qualitative studies to explore the results found in quantitative data. The causes of the gender inequality may lie outside of biological interpretation and be found in distinctly different psychosocial environments. This idea is explored further in section 2.4, gender as a SDH.

Qualitative research could potentially reveal aspects of the micro-environment that define the behaviours that subsequently contribute to poorer outcomes in different groups, and this will

be undertaken in study 3 (chapter 5). Quantitative studies from the USA have found increasing incidence of DKA and suggest that recurrence of this severe acute complication known to be associated with poor control is more likely to occur in females and in the setting of clinic non-attendance, psychological problems and low SES [85]. These issues will be explored further in study 2 (Chapter 4). Clinic non-attendance is a complicated concept that does not necessarily belong entirely in the domain of patient autonomy. In Finland, geographical variation in standards of care because of a deep economic recession and major reductions in health care services is contributing to morbidity and mortality. Many centres no longer employ specialist diabetes nurses and there have been consequent increased irregularity of attendance and lack of long-term relationships [64]. The benefits of specialist diabetes care have also been demonstrated in a Japanese study that found patients who did not attend a diabetes centre were three times more likely to die and those that did attend were five times less likely to develop ESRD [86]. The authors concluded that education and treatment with an integrated multidisciplinary team, transitional care at the same site and peer support led to better prognosis.

Surprisingly, no qualitative studies were found in this review of the literature on morbidity and mortality in T1DM. In the USA and United Kingdom (UK) significant opportunities for such studies have been missed. In these countries, people who have had T1DM for 50 years and remain well are awarded a medal, and such people are potentially a rich source of information for researchers. The UK cohort was studied for social history but all that was reported was parental longevity. Researchers believed that this together with high levels of protective HDL cholesterol were responsible for outcomes [87]. In the USA, although Joslin medal holders were obviously endowed with protective factors what these actually were remained inconclusive [88]. Both cohorts presented clear yet missed opportunities to examine the psychosocial aspects of long-term survival through qualitative research. The comments of the late Dr Joslin from 40 years ago are also worthy of consideration when examining contemporary outcomes for people with T1DM: “Soon it was learned that those who received this medal were usually those who had ample financial resources for care in the early years of their disease, usually good homes, were intelligent and had the backbone to adhere to the rules of the disease” [89].

In concluding, many authors of the quantitative studies reviewed suggest that while we know conclusively what is needed in T1DM management, a major research priority should be to

understand the barriers to applying what we already know and the psychosocial aspects of care. For this reason, a critical review of the literature on known barriers to concordance was undertaken to develop the rationale for the thesis research and is described in section 1.3.

1.3 Barriers to adaptation to type 1 diabetes mellitus and optimum glycaemic control

The following review of literature seeks to understand what is currently known about barriers to concordance with therapy in T1DM, to critique how barriers to concordance are described at the level of individual behaviours, and to understand which aspects of barriers to concordance with therapy may be acting as SDH. The intent of the review is to examine a broad scope of data pertaining to barriers to concordance with therapy and to thematically group the studies into specific domains. The purpose of the review is also to critically examine different prescribing practices in relation to SDH to demonstrate that health services have a fundamental role to play in the reduction of health inequities in T1DM, a belief that underpins the rationale for the thesis research.

The research questions informing the search strategy are:

1. What are the known barriers to optimum glycaemic control and adaptation to T1DM?
2. To what extent are these barriers related to individual behaviours?
3. To what extent are these barriers related to social determinants of health?

Data bases searched were Medline/Ovid, Proquest, Informit, Sage, Web of Science, Scopus, Science Direct. Abstracts were reviewed and papers were included on the basis of concordance, compliance and adherence to therapy and treatments in T1DM and excluded if they described only the results of clinical trials of treatment interventions Also excluded were duplicates located in subsequent search waves. 1153 papers were reviewed, 1101 excluded and 52 included in the thesis. The search strategy is further defined in appendix 1 table 6-3.

1.3.1 Barriers to concordance with therapy in Type 1 Diabetes Mellitus

A significant amount of literature addresses the concept of T1DM and concordance with therapy. For the review, the literature has been grouped into five broad domains that relate specifically to treatment-associated barriers, family based barriers, developmental and transitional barriers occurring during adolescence and emerging adulthood, socioeconomic and ethnicity related barriers, and finally psychosocial barriers. It is worth noting that there is little mention of the word ‘compliance’ in the literature in relation to treatment goals. The language

has changed significantly with the notion of compliance and adherence being increasingly criticised and reframed as concordance, which should reflect mutually agreed goals [90]. However problematic to this concordance view is the strong evidence drawn from a multicentre study across 13 countries (patient n=5104 provider n=3827) demonstrating that many people with T1DM can see little relationship between their actions and their blood glucose levels yet physicians tend to view poor control as a personal choice [91]. The underlying assumption that poor concordance with prescribed regimens is a rational and deliberate choice reflects a failure to acknowledge that a person may not have the capacity or capability to make rational choices. Despite the change of terminology there is little evidence that there has been any real change in clinical practice. The gap identified in the knowledge is that understanding the social environment and the context in which a person with T1DM is living allows a greater understanding of their *real* alternatives [92], which is the focus of study 3 (chapter 5) in this thesis.

1.3.2 Treatment related barriers to concordance with therapy in Type 1 Diabetes Mellitus

Good glycaemic control is hindered by repeated hypoglycaemia, difficult self-regulation and unrealistic goals [93]. Hypoglycaemia can be a frightening experience with physical symptoms of sweating, confusion, sleepiness and weakness, and at its worst it leads to sudden uncontrollable coma and death. Intensive therapy for T1DM to normalise blood glucose levels carries an inherent risk of hypoglycaemia and this can occur a number of times in a single month precluding optimal control [68]. Hypoglycaemic unawareness occurs after many years of frequent exposure and at least half of the episodes people experience occur at night, which is particularly dangerous [68]. Unfortunately, many young people with T1DM who experience a hypoglycaemic event overcompensate, perhaps because of the understandable feeling of panic, and consume excessive amounts of sugar that serve to not only correct the low blood glucose level (BGL) but also then create a swing of short duration into hyperglycaemia. Health care providers need to question their patients clearly on how they manage low BGL to avoid excessive counteraction [94]. The impact of repeated hypoglycaemic events is well demonstrated in a quantitative survey questionnaire study (n=92) as patients who reported fewer episodes of hypoglycaemia also reported better mental health [95].

Insulin omission is a common occurrence in young people with T1DM and is reported in the context of being busy, not having supplies available and weight loss issues particularly for

young girls. Insulin omission creates an environment of hyperglycaemia which is detrimental and a leading cause of acute hospital admissions. In a study of young adults insulin omission was demonstrated in close to 30% of people studied and this figure was validated by correlation with insulin prescriptions filled in pharmacies [96]. Frequent self-monitoring of blood glucose (SMBG) is recommended in intensive therapy and is associated with better control, with current guidelines recommending a minimum of 4–5 tests per day. Fabrication of results is common in adults and it was demonstrated particularly well in a study of children's recording of blood glucose levels. The patients were not aware that their glucose monitors had a memory function that allowed researchers to corroborate reported results. Researchers found that 40% of children fabricated results [97]. Particularly strong evidenced from a large multicentre cross sectional study (n=1076) of young people with T1DM also demonstrated that 66% did not test daily and 24% tested less than weekly [98]. This study also found that being male, young and newly diagnosed were associated with poorest concordance with frequent SMBG. Several studies discussed SMBG avoidance in relation to denial but did not mention the physically detrimental effects of frequent SMBG. Most health care providers (primarily nurses) responsible for performing this task in clinical care would attest to the extremely poor state of the fingertips of people with T1DM. After several years of frequent needle pricks for SMBG, they are often completely numb and difficult to draw blood from. The visual appearance of multiple small healing wounds is also disturbing. Disease duration is a strong predictor of good diabetes control [19] which perhaps reflects the monotonous and repetitive nature of the large amounts of daily tasks. Given the frequency of these tasks and the amount of time taken each day it is not surprising that poor control occurs in adolescence which is a period of intense socialising and education activities [99].

One aspect that can be overlooked when reviewing barriers to concordance is the reluctance of physicians to adjust treatment regimens. This may relate to lack of knowledge of contemporary insulin therapies and the fear of inducing hypoglycaemia. However, as demonstrated in the Diabetes attitudes, wishes and needs (DAWN) study, physicians reported patient adherence at a much lower level than patients themselves and had a subsequent reluctance to intensify the regime if they believed a patient was already non-compliant [91, 100]. While patient compliance is crucial, what is also required is an aggressive target strategy and physicians' reluctance to work with their patients to intensify the regimen has been described as 'benign neglect' and 'clinical inertia' [101].

1.3.3 Family factors as barriers to concordance with therapy in Type 1 Diabetes Mellitus

T1DM is a disease that affects the whole family and decreased parental involvement and family conflict are associated with poor control [19, 102]. Family structure is a well-documented risk factor for poor control and single parent families have consistently worse outcomes [102]. However, as found in a quite unique study that videotaped mother and child problem solving activities, maternal communication style can be a mediator for better glycaemic control [103] and this is not necessarily diminished in single parent families. Being a single parent does not automatically mean poor parenting and there are wide variations in the stressors and hierarchy of problems to be solved that are dependent upon the socioeconomic situation of single parent families and the number of children. A deeper understanding of the relationship between single parent families and outcomes in T1DM is sought in study 3 (chapter 5).

Currently, quantitative research has demonstrated an association between unmarried caregiver status and higher HbA1c, with a hypothesis that this relationship is the result of fewer parental resources to monitor the child with diabetes [104]. This is a very broad conclusion to draw without deeper investigation particularly given the quantitative questionnaire basis of the study methodology. Social research is more likely to consider the effect of biographical disruption. This is described as a disruption of the whole trajectory of a child's life [105] that could possibly occur as the result of a two parent family becoming a one parent family, but this has not been carefully studied in T1DM. The limited research on the issue demonstrates that maternal communication style is a very important determinant of outcomes because an authoritative style that takes control from the child increases behavioural problems and affects management of the disease [103]. Caring for a child with diabetes can be very stressful, with the diet and treatment regimens difficult to adhere to particularly if the child is fussy about what is eaten [106]. Higher parental knowledge of diabetes and lower perceived burden of the disease on the family were associated with lower HbA1c levels, and youths with high HbA1c levels reported in survey data feeling less supported and encouraged [107]. The intrinsic difficulty these types of studies however is the reliability of the survey response which is not moderated by deeper questioning and the often somewhat leading questions that find their way in surveys. It is important to consider that the quality of family relationships may not be the only variable causally related to treatment adherence [108] and the connection between this and socioeconomic circumstances is an area for further consideration.

1.3.4 Developmental and transitional barriers to concordance with therapy in Type 1 Diabetes Mellitus experienced during adolescence and emerging adulthood

The difficulties of maintaining glycaemic control during puberty and young adulthood are incompletely understood. This group commonly has higher HbA1c levels than the adult population, putting them at greater risk of complications [109]. Negotiating transition to self-care is a difficult challenge particularly through puberty and the process is thought to continue past the age of 18 years [109, 110] with the largest number of high-risk health behaviours seen in the first years of adulthood. There are issues of transition to self-care and reduced parental supervision, changing family roles with increasing autonomy, and intensifying peer relationships [102, 104]. Self-care can decline in adolescence perhaps in part because of perceptions of decreased quality of life which in turn lead to loss of good glycaemic control [104, 110]. Young people with T1DM around the time of transition to adult services have many competing issues in their lives. While negotiating the challenges all young adults face regarding relationships, living arrangements, employment and finances they also have to negotiate with health care providers. Practitioners in T1DM suggest that their focus is on the immediacy of their problems, not the possibility of long-term complications [102, 109]. In a systematic review of medication taking in diabetes, most adolescents with T1DM realised the benefit of following a therapeutic regime and had the intention at least to take their medications [111] but a myriad of events could happen a number of times each day to derail that intention. Poor concordance with therapeutic regimes is not exclusive to adolescents with T1DM, with a number of studies identifying this issue in other chronic diseases such as asthma, Human Immunodeficiency Virus (HIV) and renal transplantation [112]. A systematic review in cancer therapy concluded that around 60% of teenagers and young adults with cancer did not adhere to treatment regimens [113].

During puberty there is commonly a period of biological insulin resistance that makes managing T1DM at this time particularly difficult [102, 114]. There is now increasing evidence that the relationship between poor control and adherence behaviours may in fact be bi-directional. A multicentre longitudinal cohort study concluded that an increase in HbA1c because of the physiological changes of puberty can precede a decline in self-care [114] which can be explained by the frustration of being unable to bring about acceptable blood glucose levels despite the very best of efforts. It is important for health care providers to exercise caution in attributing blame for sub-optimal control in young adults lest this then contributes

to a further decline in self-care and a 'learned helplessness' [114, 115]. Patient education for young adults with T1DM does not always account for the complexities of development and transition [116]. The transition from paediatric to adult health care is a time of increased withdrawal from services and building relationships very early with young adults is essential to successful self-care. Health care providers need to provide positive reinforcement for mastery and acknowledge the impact of devaluing and judgemental approaches that result from unrealistic expectations and 'fear mongering' approaches. These can trigger a sense of failure and drive patients to disengagement [116] and this is further explored in study 3 (chapter 5).

1.3.5 Socioeconomic status and ethnicity as barriers to concordance with therapy in Type 1 Diabetes Mellitus

Socioeconomic status (SES) and ethnicity are two of the most frequently identified causes of inequitable health outcomes [18, 117] and this is particularly true in T1DM. They are identified as macro-level variables but few studies in T1DM have examined the micro-level environment of these health determinants in relation to stress, health beliefs, health literacy and family functioning [102]. A central premise in this thesis is that the relationship between poverty and discrimination is known to contribute to poorer health outcomes [118] and this is particularly pertinent for health care professionals caring form people with T1DM to be aware of. Attitudes and the presentation of information are particularly important when dealing with people from lower socioeconomic backgrounds and diabetes care teams need to match their treatment, language and care to the socioeconomic situation of patients [119]. Being of lower SES can create stressful environments which can only be limited by powerful social support [19]. Being an ethnic minority is often compounded by low SES and two parent white households with higher incomes consistently report better outcomes in T1DM [120]. The complex relationship between SES, ethnicity and outcomes in T1DM is an area that is explored in more depth in chapter 2, which examines the social epidemiology of T1DM and informs the critical social theoretical framework of this thesis.

1.3.6 Psychological barriers to concordance with therapy in Type 1 Diabetes Mellitus

Living with T1DM is a challenge that would tax most people. This raises the question 'is it non-compliance or are the barriers insurmountable?' [121]. The demands of daily treatment and pressure from parents and specialists contribute significantly to psychological distress [95]. The largest study of its kind, the DAWN study across 13 countries, demonstrated that 41% of

people with diabetes reported poor psychological well-being but only 10% were receiving treatment for it, with most care providers reporting they did not have the resources to manage such problems [91]. Depression and anxiety often co-exist [122] and it can be difficult to ascertain whether anxiety leads to depression or *vice versa*. In questionnaire based studies of T1DM, there is plentiful evidence of comorbid depression and there are also suggestions that acute anxiety about hypoglycaemia and long-term health consequences affects metabolic control [123]. There is a large gap between evidence and practice and for many young people poor adherence can be related to depression and low levels of support. Hence a psychologist or psychiatrist should be part of the clinical care team [124] but this rarely happens in clinical practice [95]. Whilst insulin pump therapies have increased HbA1c control they have also increased levels of emotional distress [95] which can in turn affect glycaemic control. It is worth considering whether poor glycaemic control contributes to depression and whether there is a cycle of cause and effect.

Despite having a modern and well-developed health care system, it has been claimed that "the message of adherence to optimal diabetes care is not being heeded by the population" [125]. In critique of this it is worth considering whether the information delivery needs adjustment given the wide social and economic influences in contemporary Australian culture.

1.4 Summary

In summary, although we know a great deal about behavioural and individual barriers to concordance with therapy in T1DM we also know that for many people standards of self-care are still suboptimal. In part this is attributed to biological consequences of treatment, family factors, psychological barriers and age related developmental issues. This review of the literature has critically examined the evidence relating to barriers to optimum glycaemic control to demonstrate the gap in the knowledge that relates to how these barriers considered as individual traits can be strongly associated to social determinants of health. Specifically there has been limited qualitative research into T1DM in Australia that explores the impact of macro-level determinants of health and the role of health care services in disease outcomes. There has also been limited research on the relationship between social support and the social environment [99] and the majority of research in this field is quantitative in methodology. To more fully understand what is currently known regarding T1DM outcomes and the role of the social environment, a systematic search and review of the literature was undertaken and is

described in Chapter 2. This literature review aims to understand what is currently known regarding the social epidemiology of T1DM and to highlight the potential role of this thesis research in demonstrating inequitable health outcomes in T1DM that are the result of SDH.

CHAPTER 2: THE SOCIAL EPIDEMIOLOGY OF TYPE 1 DIABETES MELLITUS

Social epidemiology is the study of the social determinants that influence the nature and prevalence of disease, its social distribution and outcomes [18]. Social determinants of health (SDH) are elements of life circumstances and environments that can affect health and well-being both in an immediate sense and later in life, in a positive or negative way. The most vulnerable groups in a society are those that are most likely to experience negative health effects because of adverse social environments. To gain a full understanding of the differential outcomes in type 1 diabetes mellitus (T1DM) it is necessary to establish what is currently known about SDH and the pathways through which they affect outcomes in T1DM.

Use of the SDH adds criticism to behavioural and lifestyle interpretations that are to a significant extent socially constructed and socially embedded [16]. The SHD that can have a powerful effect on health are ethnicity, poverty, low social status, lack of educational attainment, low social capital, social exclusion and stress in early life [3]. The mechanisms through which SDH affect health relate to resources but these are often psychosocial in nature rather than material resources. SDH often act in combination, and this review of the literature demonstrates that there is considerable overlap of adverse outcomes driven by a combination of SES, family factors and ethnicity. Adverse environments, particularly those that begin in early childhood, can lead to cyclical accumulation of disadvantage throughout the life course. Stress, social relationships, self-esteem, hierarchical position, control and powerlessness all have health implications quite independent of conventional risk factors [126] and this thesis research is intended to demonstrate this. In particular, the role that health care services have as a determinant of health outcomes in T1DM is highlighted.

2.1 Review of the literature on Type 1 Diabetes Mellitus and social determinants of health

An advanced review of the literature is the foundation for original research as it identifies the knowledge gap and allows the researcher to narrow the information to only the data that supports the thesis questions and to create a written argument that establishes a convincing thesis [127]. The nature of the research questions intended by this thesis precluded the use of a fully systematic ‘Cochrane’ style review as the research questions were not related to

treatments and interventions in T1DM which is the premise underlying this type of review often used as the basis for a meta-analysis [128]. Whilst systematic reviews are at the centre of evidence based practice the context of care delivery and patient/carer perspectives are questions often answered in other forms of evidence [129].This review of the literature was intentionally broad and inclusive with the aim of understanding what is known on the subject and in considering if the assumptions drawn are appropriate given the study's methodology. The review has a broader scope and less restrictive inclusion and exclusion criteria [129] and the literature is critically evaluated through an examination of the maid ideas and how these are represented [130]. This review synthesises, analyses and critiques the knowledge gained from the literature and this argument then leads to the thesis 'statement' or research aims [127] which are summarised at the end of this chapter. Broadly, this argument is a critique of the individual approach taken in T1DM health care, a critique of 'victim blaming' and the suggestion that SDH can shape outcomes in T1DM. Highly relevant to this overview of the literature is the inclusion of studies with varied methodologies that oppose this critique by negating or narrowing it [128].

This review was purposeful in searching broadly with the abstract of each paper reviewed for potential inclusion based on the specific contribution that it would add to the review. The search for the literature for this review was however conducted in a systematic way and the strategy for this is detailed under each sub-heading and further described in appendix 2 tables 6.4-6.9. Boolean logic which selected key ideas from the topic statement was used for the search with key words connected by logical operators. The search and critique is conducted in separate waves using key terms from social dimensions that are known to operate as determinants of health; socioeconomic status, family composition, ethnicity and gender. The exclusion of papers from the initial wave for each search (detailed in appendix 2 tables 6.4-6.9) relate purely to the relevance of the paper to the topic, with duplicates added to the exclusion criteria for all subsequent waves.

To further support the thesis statement a review of the qualitative literature on adults with T1DM was undertaken and discussed in 2.6 to identify the knowledge gap relating to qualitative research and adults with T1DM. This deliberately narrow section of the review focussed specifically on searching for papers that sought to understand the disease trajectory into adulthood and how this influences engagement with endocrinology services to demonstrate the gap in the knowledge. The specific search for Australian literature that then

closes this chapter is driven by the fact that there is no current evidence regarding T1DM, social factors and ESRD derived from this region and this is the substantial gap in the knowledge this thesis addresses. The aim of this particular section of the literature review was to set the background for this knowledge gap.

In undertaking this literature review it is acknowledged that reviews of research relating to risk factors are more complex than reviews of treatments and intervention and although a quantitative synthesis of the literature is desirable when a standardised approach to appraisal is taken, a comprehensive and clear summary of relevant studies can be sufficient for synthesis and decision making [131].

2.2 Socioeconomic Status and Type 1 Diabetes Mellitus

The research questions informing this search are:

1. To what extent is SES a factor in inequitable health outcomes for people with T1DM?
2. What is the current understanding of the mechanisms through which this occurs?

Data bases searched were the cumulative index of nursing and allied health literature (CINAHL), Medline/Ovid, Scopus, Proquest, Sage, Web of Science, Science Direct, Informit. The abstracts were reviewed and papers included on the basis of social determinants and SES and excluded on the basis of T2DM and duplicates found in subsequent search waves. This review of the literature was confined to papers from the year 2000 onwards to ensure that the evidence was contemporary as there has been substantial changes to economic growth and associated wealth in the past century. Included in the review are studies that have specifically sought to elucidate the relationship between SES and health and excluded were studies solely of T2DM which has a strikingly different disease trajectory to T1DM. In total, 545 papers were reviewed, 493 excluded and 52 included in this review. The search strategy is further defined in appendix 2 table 6-4.

The literature reviewed demonstrated an inverse relationship between SES and morbidity and mortality in T1DM [132-136] and this is most pronounced in young adults where the mortality ratio widens by more than 40% [132]. This evidence is particularly compelling when arising from high scientific quality evidenced derived from population based cohort studies [132] and large cohorts of people with T1DM (n=3674) reassessed after ten years [134]. The disparity in mortality related to SES is described as more pronounced in T1DM than in T2DM by the

authors of a comprehensive population registry study in Finland, a country with a very high prevalence of T1DM [137]. However, the studies that have examined this relationship are quantitative in research methodology and have resulting *speculations* that the reasons for this disparity are low health literacy, poor health behaviours and inability to afford healthy food or equipment to manage diabetes. Specifically, it has been demonstrated in large epidemiological studies that complications occur at rates 2–3 times higher in patients with low SES, and that HbA1c, blood pressure and albumin excretion all decrease as income increases. This has been attributed unequivocally to poorer self-management in patients with lower SES, yet there is evidence within the Pittsburgh epidemiology of diabetes complications study that people of low SES receive different diabetes treatments compared with people of higher SES [138]. Similar findings in other studies show variations in prescribing practice that are not in the realm of self-management and will be discussed in more detail in 2.3.2.

Both the Pittsburgh epidemiology of diabetes complications study and a population based cross sectional registry study with linked hospital data have demonstrated that the substantially higher mortality in individuals with T1DM and low SES is known to be partially mediated by better control of glucose, lipids and blood pressure [139, 140]. However, it has also been demonstrated that effective disease management varies with SES and ethnicity [141] and access to health services and quality of health services for vulnerable populations must be taken into account. The World Health Organization's global study of complications in T1DM found that health system performance, gross national investment and purchasing power, all of which demonstrate the social distribution of wealth, were clearly linked to the incidence of complications [142]. In developed countries such as the USA and Australia the commodification of health care has increased exclusion [132, 143] and a cross sectional questionnaire study demonstrated that individuals with lower SES were referred for specialist care and training courses less often [144]. The authors of this study suggested that social inequalities could disappear after compensation with treatment and education at a tertiary care centre, and this is described as an example of the inverse care law [145, 146] where those in greatest need are least likely to receive care [147]. The strength of the study is the authors reporting that the patients who participated were 'consecutive' arrivals at the clinic suggesting a lack of selection bias. People with T1DM in more affluent areas received more frequent monitoring and preventative health care and a number of other studies also have identified that individuals from low SES groups were less likely to be offered intensified treatment regimens,

suggesting disparities in the treatment being given [148, 149]. Families struggling with basic management were not likely to be offered pump therapy even though it improves control [135, 139, 149] and a small body of literature from studies that explicitly aimed to measure depression in T1DM suggests that although psychosocial factors led to poor control in lower SES patients, the relationship was bidirectional with poor control also leading to depression [148, 150]. This is an important finding which hints at the complexity of causal factors for poorer outcomes in low SES.

A systematic review conducted to explore the relationship between low SES and increased risk of severe hypoglycaemic events found an association in eight of the nine studies reviewed [151]. This may in part explain the reluctance of physicians to prescribe an intensive regimen, and it has been demonstrated that people with higher education qualifications and higher income were more likely to be prescribed intensified therapy [138]. The authors of the systematic review stated that neighbourhood SES was an independent predictor of health outcomes and the relationship between SES and poorer outcomes in T1DM was at the individual level with increased stress and negativity leading to poor behaviours [151]. It is difficult to fully accept this conclusion drawn from a systematic review of nine quantitative studies that has not explored the voice of the person with T1DM that can be gained from qualitative enquiry.

There is also evidence that food insecurity may be partly responsible for the increased risk of hypoglycaemia. A Canadian study of the risk of severe hypoglycaemia in patients with T1DM and low SES found that 60% of Canadians receiving government income support reported moderate or severe food insecurity [152]. Another interview based Canadian study of 183 young children with T1DM found that 21.9% reported food insecurity and this was associated with higher HbA1c, more frequent hospitalisations and living in families with low incomes and a high proportion of single parents [153]. Similar findings have been demonstrated in the general South Australian population, with a deep qualitative exploration revealing that single parent families experience higher levels of food insecurity leading to poorer choices in food quality [154].

Of particular interest to this research is the identification of which elements of SES influence metabolic control and through which pathways. Current evidence does not provide definitive proof that this is occurring at the individual level and there are suggestions that the macro-environment is at least partly responsible. It is known that individuals with low SES are more

likely to smoke and this has been cited in a number of studies as an explanation for poorer outcomes [140, 155, 156]. These large observational studies use registry data and have no participant input and yet the conclusion is that poor outcomes are the result of poor health behaviours, with commentary that people of higher SES are more receptive of health education and more willing to improve their behaviour. This assertion describing poor behaviours as a conscious choice does not make any allowance for the disadvantaged circumstances of living in relative poverty. Only one study in the review which reassessed more than 2000 participants from a five day teaching and treatment program adjusted for known risk factors such as smoking and was able to demonstrate that the relationship between poorer outcomes and low SES persisted [134]. It has been well established that negative aspects of the social environment are the cause of higher smoking prevalence in low SES groups [157].

Individuals who experience poverty have a much lower self-reported quality of life and this is also seen in T1DM [158]. If poverty and illiteracy are associated with 'ignorance and incorrect perceptions,' which is a broad conclusion to draw in a study that utilised telephone surveys to determine quality of life [158], the reason may not lie solely in the realm of the individual because it could be argued that health service providers are not communicating effectively with such people. Evidence linking health care practices and SES in T1DM is limited [142], but one Australian prospective longitudinal study with children who have T1DM (n=158) found low household income was associated with lower parental knowledge of diabetes and poorer control *only in patients under specialist care,* while patients of similar background in shared or primary care had knowledge levels equivalent to those of patients with higher SES [143]. This may be due in part to a common belief held by diabetes specialists that their 'personal cognitive and relationship styles are universal' [93]. Studies of medication compliance in other chronic diseases have demonstrated that the person with the disease often cited the gap in competence and power between the patient and the doctor as a barrier to a truly concordant relationship [159]. In their disturbingly titled paper 'Do as I Say or Die: Compliance in Adolescents with Cancer', Windebank and Spinetta (2008) describe a significant element of enabling concordance is improving the doctor–patient relationship by investing time and effort in follow through. The authors stated that "most important of all is to have respect for the adolescents who look to us to help them *find a reason to comply*" [160].

In summary, the evidence demonstrates a clear and strong relationship between low SES and poorer outcomes for people with T1DM which is inequitable. Higher SES is associated with

lower HbA1c, blood pressure, cholesterol, rates of complications and a highly significant reduction in mortality. There is also evidence that insulin doses are smaller in the most disadvantaged groups who are also less likely to have been prescribed intensive therapy. This indicates existence of prescribing practices that disadvantage those who are already disadvantaged and the reasons for this are not clear. Similar disparity in prescribing practice has been demonstrated in individuals with T2DM, where those in disadvantaged areas were less likely to be prescribed insulin [161]. These quantitative studies highlight a significant knowledge gap in that the causal factors for the identified relationships can only be hypothesised or speculative and consequently are often largely based on individualism and blame of the person with the disease. No studies identified in this review asked for the perspective of the person with diabetes and this argues the need for a deeper exploration of factors that go beyond individual control in those with lower SES. Also of interest is the concept that a social gradient in morbidity and mortality can occur through three psychosocial pathways, stress in early childhood, low social support and, importantly, invidious or shaming comparisons [162]. This concept is particularly relevant to study 3 (chapter 5) in the in-depth exploration of the heath care encounter. Many studies cited also found a relationship between ethnicity and outcomes and this was largely attributed to ethnic minorities being of a lower SES. However ethnicity is known to be an independent social determinant of health [117] and this will be discussed in more detail later in this chapter (2.4).

2.3 Family composition and Type 1 Diabetes Mellitus

The quantitative literature on T1DM, particularly large epidemiological studies of complications, has consistently demonstrated a relationship between single parent status and poorer metabolic control. This research methodology lacks in-depth exploration and is generally presented as blame without consideration of the macro-environmental factors that are associated with this relationship. There is, however, a small body of literature in which family composition has been explored in detail in an attempt to define the shared characteristics of single parent families in T1DM.

The research question informing this literature search is if family composition is a factor in concordance with therapy for children with T1DM through what mechanisms does this occur?

Data bases searched were CINAHL, Medline/Ovid, Scopus, Proquest, Sage, Web of Science, Science Direct, Informit. The abstracts were reviewed and papers included on the basis of

family composition and excluded on the basis of studies of family based interventions, T2DM and duplicates found in subsequent search waves. 198 papers were reviewed, 185 excluded and 13 included in this review. In addition 9 other papers found through previous search strategies that specifically added important information about family composition were also included in this section of the review. The search strategy is further defined in appendix 2 table 6-8.

Each study incorporated both an examination of outcomes and of parental demographics through in-depth interviews and questionnaires and demonstrated a strong relationship between single parent status, particularly female head of house, and poorer metabolic control [163, 164] including in Australia [165]. Findings derived from the data collected for a randomised control trial added some depth to this demonstrating that children from single parent homes had poorer self-concept, decreased academic achievement and increased levels of psychopathology [166]. While these findings are not disputed, a limitation of these types of studies is the fixed quantitative nature of the data collection using a series of survey tools, and the discussion again had a sense of individualism and blame with limited consideration of the more practical problems of T1DM such as cost of care that may have contributed to the findings. It has been estimated that families with children who have T1DM had out-of-pocket medical expenses more than 50% higher than other families and they are often forced to make difficult decisions about the use of limited financial resources for health care [167]. The cause of the poorer metabolic control seen in single parent families is most likely to be multifactorial and include SES because higher incomes are known to be associated with more favourable control [165, 168]. Cross-sectional questionnaire based studies have found that single parents were more likely to report increased neighbourhood stressors, unfair treatment and a perceived vulnerability that disappeared in the presence of income as a predictor [169, 170]. Children from single parent families with T1DM were more likely to be admitted to hospital because of missed outpatient appointments that would have delivered preventative control and this is believed to be partly due to the costs associated with appointments [171, 172]. One reason why at risk populations who are referred for additional support do not follow through may be because families at greatest risk of poor outcomes are also those with fewest resources, and small details like expensive medical centre parking may be beyond their means [172]. Importantly for the premise of this thesis clear evidence of the importance of family compositions as a social determinant in diabetes control can be seen in a study of African American children with diabetes living in one parent homes. Patients had HbA1c levels of

14.4% compared with 11.3% for African Americans in two parent homes. By controlling for ethnicity this study rebutted the hypothesis that higher HbA1c levels are biologically determined [166] which is a strong theme in the review of how outcomes are reported in relation to ethnicity.

In summary, no assumption can be made that single parents are 'worse' parents. These studies have demonstrated that SES is the most likely reason for most of the variation in patterns of care and parental psychological distress. There is significant co-variation between SES, ethnicity and single parent families that leads to multifactorial disadvantage [164] and research linking family climate to longitudinal trajectories of glycaemic control is non-existent [173]. Qualitative studies of people with T1DM raised in single parent families would likely elucidate the exact mechanisms within this vulnerable group that contribute to poorer outcomes and this is explored further in study 3 (chapter 5).

2.4 Ethnicity and Type 1 Diabetes Mellitus

The review of the evidence relating to SES and T1DM has given sufficient evidence to warrant exploring whether ethnicity as a social determinant influences outcomes in T1DM or whether certain ethnic minorities are burdened with excess morbidity and mortality because of their low SES. Ethnicity is a social determinant that is quite distinct from race. The term race implies a set of biological characteristics whereas the term ethnicity includes cultural dimensions [117]. Race can determine health outcomes with certain racial groups having disproportionate levels of disease and illness but these are generally patterned evenly throughout a population. While disparities in health status among ethnic minorities may be genetically determined, they are more likely to be the result of SDH. The distinction between race and ethnicity is important for this research to enable differentiation between outcomes that are *claimed* to be related to race (biological) and outcomes that are highly likely to be related to ethnicity as a SDH, a concept argued in section 2.7 in relation to Aboriginal and Torres Strait Islanders (ATSI), Maori and Pacific Islanders.

The research question informing this review:

Is ethnicity a factor in inequitable outcomes for people with T1DM?

Data bases searched were CINAHL, Medline/Ovid, Scopus, Proquest, Sage, Web of Science, Science Direct, Informit. The abstracts were reviewed and papers included on the basis of

ethnicity and race and excluded on the basis of T2DM, if not explicitly defining ethnicity and outcomes, and duplicates found in subsequent search waves. 1166 papers were reviewed, 1139 excluded and 27 included in this review. The search strategy is further defined in appendix 2 table 6-5.

The prolific literature on ethnicity and T1DM demonstrates clear inequitable outcomes for the most vulnerable ethnic minorities. Large epidemiological studies have demonstrated much poorer outcomes in terms of higher prevalence of complications and increased mortality in T1DM for African Americans and Hispanic people in the USA, ethnic minorities in Europe, Asian people in the United Kingdom and Maori and Pacific Islanders in New Zealand. Disparities in outcomes were not confined to complications of T1DM but also to treatments and transplantation, for example with 92% of T1DM simultaneous kidney–pancreas transplant recipients in the USA being White [159].

Many studies claim that it was not possible to demonstrate that ethnicity was the key element of higher mortality because SES is often a confounder, with groups such as African Americans, Hispanic, Maori and Asian people living in countries as ethnic minorities and generally experiencing the lowest SES. Studies in America have shown that nearly all ethnic minorities are in the lowest socioeconomic groups and this can lead to the conclusion that SES is driving poor control [135]. Similarly in the UK, A prospective cohort study with participants followed for 28 years demonstrated that Asians with T1DM suffer exceptionally high mortality rates but could not determine whether the reasons for this are aetiological or health care related [174] raising the possibility of health care access as a determinant of health. A few studies have however been able to show the effect of ethnicity independent of SES. A multi-ethnic retrospective study in America demonstrated that black youth had a higher risk of complications independent of income [175], in New Zealand a data base review utilising multivariate analysis of high HbA1c found the single remaining determinant was ethnicity [112], and in a large prospective clinical assessment cohort study with Maori and Pacific Islanders an excess of diabetic retinopathy remained after adjusting for SES [176]. In contrast other authors of a data base review of multiple paediatric diabetes clinics and a prospective cohort study discuss higher levels of HbA1C in ethnic minorities have situated the relationship at the level of the individual, citing ‘insulin resistance’ as the cause [177, 178]. This type of argument tends to obscure the structural determinants of inequitable outcomes and has led to calls for ‘candid epidemiology research’ [113].

In most studies in this review of ethnicity and T1DM, social patterning is discounted as an explanation in favour of genetic determination or behavioural characteristics that are independent of broader structural influences, particularly that of health care systems. Caution is also needed in evaluating research findings that include ethnic minorities to assess how they are defined and at what percentage they are represented. Some studies claimed 'ethnically diverse groups' yet the majority of participants were White and privately insured [179]. Evidence purporting to be from 'universal' or 'uniform' care from the same provider and used to explain why health care delivery or ethnicity were not determinants of outcomes [149, 180] failed to acknowledge that clinics with a predominantly white workforce may not be able to offer culturally appropriate care to ethnic minorities.

2.4.1 Access to care for ethnic minorities with Type 1 Diabetes Mellitus

Access to health care goes beyond geographical proximity to include factors within an organisation that create sufficient appeal to lead to 'realised access' [9]. There is evidence of poorer quality of care being given to ethnic minorities, particularly if they were also of low SES, and they are known to express a 'fatalistic acceptance' of poor quality care [181]. There is considerable evidence of poorer outcomes for ethnic minorities in the USA, a country with inequitable health care funding arrangements [182]. For example, African Americans had poorer control and a higher burden of complications from T1DM [183] and mean age of death was 40 [184], which was a ninefold greater risk of death. These and other statistics indicate gaps in access to comparable health care [185]. The reasons behind the disparities in outcomes are disputed. Many American studies have concluded that there is greater insulin resistance in 'non-Whites', while also finding that ethnic minorities have dyslipidaemia (treatable) and hypertension (treatable). This raises the question as to whether the outcomes were genetically determined or related to disparities in care [178]. In addition, a study of the impact of a multidisciplinary intervention program over six years showed there were improved outcomes only for White people [177]. The authors again concluded that this was due to insulin resistance but they also acknowledged that none of the staff on the intervention team was African American. Importantly, the authors of this paper followed their discussion by citing Auslander et al. (1997) from a study of T1DM in St Louis, who found that poorer control was associated with a greater perception of racism.

Studies examining the overlap of low income and minority status in T1DM, again utilising quantitative survey research to assess psychological traits, suggest that outcomes are related to decreased personal coping and problem solving, low acceptance of the disease and increased avoidance behaviours [186] all of which are attributed to individual behaviours. However, health services must be held at least partly accountable. Hospital data base audits reveal that non-white and 'poor' children are more likely to use emergency services and be admitted with DKA and it is suggested that this may be because they are not able to afford regular preventative care [183, 187, 188]. This finding is not confined to T1DM and children with other chronic illnesses and without private insurance in the USA are known to receive less preventative care [188]. In addition, length of hospital stay has been shown to be shorter for African American and ethnic minority patients who are discharged prematurely, offered less community care support on discharge, and have a greater chance of readmission [189].

2.4.2 Prescribing practices in ethnic minorities with Type 1 Diabetes Mellitus

In section 2.1, it was shown that physicians' prescribing practices can vary depending on patients' SES. Similar patterns are seen for ethnic minorities, highlighting the commonalties of disadvantage experienced by vulnerable populations. In a comprehensive review of patient perceptions about treatment regimens compared with their physicians' perceptions that involved 178 families and used multiple data collection methods, Valenzuela (2011) was able to demonstrate stark differences in opinions. Families believed the explanation for the disparity in intensive treatment prescriptions was cost of care, while according to physicians it was competence. The rates of intensive treatment prescription were 52.7% for White youth, 29.5% for Hispanic youth and 19.1% for African American youth [190]. In New Zealand, one study showed that SES and ethnicity were both independently associated with HbA1c [191]. Other important findings were that Maori children were more likely to live in the most disadvantaged areas and were more likely to report less frequent injections of insulin but in larger doses, which suggests differential prescribing practices. Regimen disparity in an era that advocates intensive treatment of T1DM leads to disparities in outcomes. It has been shown in the USA that pump therapy was not prescribed based on HbA1c control alone but that prescribing may reflect clinician bias. In multiple quantitative studies although baseline HbA1c levels were the same across ethnic groups, factors associated with receiving pump therapy were being White, having private insurance and an annual income in excess of $100,000 [175, 192, 193]. Disparity in prescribing practice has also been demonstrated in Australia and New Zealand, with a large

clinical cohort study of Maori and Pacific people demonstrating higher HbA1c levels and lower levels of prescribed antihypertensive agents, particularly Angiotensin Converting Enzyme inhibiters which are renal protective [176].

2.4.3 The impact of SES in ethnic minorities with Type 1 Diabetes Mellitus

A significant barrier to implementation of the T1DM regimen is the cost of health care visits and the consumables required to manage the regimen, including a healthy diet. Poorer outcomes may be a reflection of socioeconomic barriers to implementation of the suggested regimes [186, 194]. In the USA, diabetes mortality is substantially elevated in African American and Hispanic youth and intensive glucose control is a costly option for those with no health insurance [185, 195]. The majority of excess deaths in ethnic minorities were totally preventable because 'there is no plausible scientific explanation to support pathophysiological differences' and White young people with diabetes had an 'excellent mortality experience' [185]. Other authors have refined this by examining ethnic differences in levels of engagement with preventative health care, where those of low SES were less able to engage regardless of ethnic group [194]. Authors concluded that poorer outcomes in ethnic minority groups could be explained by lack of resources to implement suggested treatments and more severe disease at presentation. In contrast, when a deep qualitative exploratory method is used rather than survey questionnaires, Hispanic and African American participants cited financial and racial barriers to regimen adherence. They believed that not having health insurance was associated with poorer care, and they also cited food and employment insecurity, stereotyping and class differences [193, 195]. These contrasting findings starkly illuminate the flaw of speculating the reasons for poor outcomes based on quantitative study data and the new insights that can be gained through qualitative enquiry.

In summary, this literature review has revealed a pattern of unequal outcomes. It has been claimed that it is difficult to establish ethnicity as an independent social determinant of health and that it may be a proxy indicator for SES; however, in the social stratification seen in some countries SES could be a proxy for ethnicity. The disparity in intensive regimen prescription is largely presented as clinician bias but this should not necessarily be situated at the level of the prescribing doctor. The reason for prescribing a simpler regimen may be related to fear of the patient experiencing a life threatening hypoglycaemic event if prescribed intensive therapy. Failure to prescribe intensive regimens for disadvantaged children and ethnic minorities may

reflect physicians' doubts about family competence to manage the therapy, but such doubts represent a failure of the educational support that is available [196]. Evidence suggests that youth with low self-management competence benefit most from intensive treatment [190]. However, this cannot be provided by health care practitioners who do not have the resources to support the education required. Without support and education, minority youth who describe perceiving the risk of short term complications as more serious than long term complications [197] will continue to be burdened with high levels of morbidity and mortality.

Despite the strong evidence for inequitable outcomes in relation to ethnicity in T1DM, a comprehensive study of the topic is beyond the scope of this thesis. Ethnicity is poorly recorded in health care settings in Australia, either being not reported at all or not self-defined, both of which make data unreliable for use in study 2 (chapter 4). The recording of Aboriginal and Torres Straits Islander (ATSI), Maori and Pacific Islander ethnicity is accurate in the Australia and New Zealand Dialysis and Transplant Registry (ANZDATA) and this will be used as a data source for an exploration of end stage renal disease (ESRD) that includes ethnicity and SES as SDHs in study 1 (chapter 3). Different outcomes amongst ethnic minorities and those of low SES are one of the most critical public health problems we currently face [198].

2.5 Gender and Type 1 Diabetes Mellitus

The research question informing this review is:

Are there differential outcomes in T1DM according to gender?

Data bases searched were CINAHL, Medline/Ovid, Scopus, Proquest, Sage, Web of Science, Science Direct, Informit. The abstracts were reviewed and papers included on the basis of specifically examining outcomes in relation to gender or sex and excluded on the basis of T2DM and duplicates found in subsequent search waves. 774 papers were reviewed, 747 excluded and 27 included in this review. The search strategy is further defined in appendix 2 table 6-6.

Findings about outcomes in T1DM related to gender can be contradictory and difficult to identify. This may be partly because of differences in baseline characteristics of study populations, particularly age at diagnosis, but may also be because there is plausible evidence for three distinct influences on gendered outcomes. These are sex-specific genetic risk, the

influence of puberty, and differences in adolescent and young adult behaviours relating to gendered norms. The following literature review is grouped by these factors.

2.5.1 Different gendered outcomes in Type 1 diabetes mellitus based on genetic risk and age of diagnosis

Studies have demonstrated that females with T1DM have unfavourable outcomes in relation to mortality risk compared with females in the general population. Women generally tend to live longer than males but this benefit is lost with T1DM, and therefore women have a higher relative risk of death rather than a higher standardised risk [60, 64, 66, 84, 199]. This strong evidence is drawn from large population based epidemiological studies of mortality in T1DM in the UK, Europe, USA, Japan and Finland. This relationship is thought to be due to biological reasons such as higher serum cholesterol and other adverse cardio-metabolic profiles in women [200]. However the evidence can be contradictory, with other studies demonstrating that accelerated atherosclerosis and coronary artery calcification is more often seen in men [201, 202]. However, it can be concluded from large observational studies that both males and females with T1DM experience premature mortality compared with the general population and this is largely attributed to cardiac disease.

Studies attempting to identify gender differences in mortality have tended to examine familial relationships, for example clustering of poor health in families regardless of gender. Some studies of T1DM have demonstrated that the risk of any child developing complications from T1DM was greater if a parent had poor health, particularly T2DM [203]. This is particularly robust evidence drawn from a case control study of n=8114 people with T1DM. Parental longevity was associated with long term survival in T1DM, and males with T1DM were more likely to die if a parent had died before the age of 50 years. Population based registry data has also indicated that siblings of deceased diabetics were also more likely to die [204]. Early mortality does tend to cluster in families in the general population and these studies suggest that complications share an underlying possibly genetic risk factor [203]. In critique of these findings however, the possibility of intergenerational disadvantage and the SDH must be considered alongside genetic risk [204]. While acknowledging that there is familial risk of coronary artery disease, particularly due to hypertension, the familial clustering of smoking behaviours, stress and low SES affects the whole family. The authors of this particular study do conclude that while some risks are under familial control, morbidity and mortality may be a reflection of both genetic predisposition and environmental factors.

Age at diagnosis has a clear effect on the development of future complications, with credible evidence from large epidemiological studies conducted in different regions that diagnosis before puberty is health protective but that diagnosis during puberty leads to demonstrably poorer glycaemic control and the onset of complications [205-210]. There are several possible explanations for this, most of which centre on insulin resistance in puberty, the impact of growth hormone and sex hormones. There is clear acknowledgement also in most of these studies of lifestyle factors, the reduction of parental control and the changing behaviours of the child with diabetes.

While there is compelling evidence that a diagnosis before puberty is health protective and a diagnosis during puberty is not, a diagnosis in adulthood is predictive of future complications in males only, and this is most apparent in relation to kidney damage. The protection against renal disease seen in women in the non-diabetic population is somewhat diminished in T1DM [211], but being male remains a significant independent predictor of the progression to ESRD [207, 212] and this risk appears increased with late onset T1DM [206]. A recent study claimed that the historical higher risk for males found in the Pittsburgh Epidemiology of Complications in Diabetes study conducted twenty years ago [213] no longer existed and that women had effectively caught up and now had the same level of risk of ESRD. However the authors noted that a weakness of the comparison was that the more recent cohort studied were all diagnosed before the age of 17 years [214]. Gendered findings specific to diagnosis in adulthood in males have been confirmed by other authors, who have shown that there was no difference in progression to ESRD in males or females diagnosed before the age of 20, but being male and diagnosed after the age of 20 continued to carry a higher risk of ESRD [215]. This study was a large population-based study in Sweden (n=11,681) that examined risk of progression to ESRD for T1DM by sex and age of diagnosis. It found that males diagnosed between the ages of 20 to 34 had the highest level of risk. The lowest risk was diagnosis before the age of 10 or being female regardless of age of diagnosis. The authors speculated that if diagnosis during puberty increased the risk then diagnosis post-puberty in adulthood should carry the same risk as diagnosis pre-puberty. This was not uniformly the case and there remained a clear disadvantage for males. Furthermore, the researchers suggested that despite the most important risk factors for the development of ESRD being hypertension and a high HbA1c, there is speculation that oestrogen retards and testosterone accelerates progression.

The FinnDane study, a national multicentre study with special emphasis on diabetic nephropathy, demonstrated that there was no difference in progression to proliferative diabetic retinopathy (PDR) and ESRD in patients diagnosed before the age of 10 but a substantial increase in risk for both sexes if diagnosed in puberty, with overall risk doubled for males diagnosed after the age of 15 [206]. The dual roles of oestrogen and testosterone were cited as a possible explanation but other authors in critique of this have suggested that the changes seen in hormone profiles in males with ESRD might be the result of end organ damage and that the male sex risk factor for ESRD remains poorly understood [216]. There is scant evidence for the role of specific genes. Only one study was found in this review of the literature (2005) hypothesising that the two-fold risk of males in the USA developing ESRD could be attributed to an immune related gene which affected progression of diabetic nephropathy in a sex related manner but only in males [217]. In Australia, the increased risk for males of progressive renal disease is apparent from data demonstrating the female to male ratio for ESRD at 1.7 while the T1DM prevalence ratio is 0.9 to 1.2 [218].

The data for Australia T1DM ESRD (Figure 2-1) also show an increasing trend in incidence, and that presentations are relatively low in Aboriginal and Torres Strait Islander populations (ATSI). This group are however burdened with more than double the incidence of ESRD in the setting of T2DM [219].

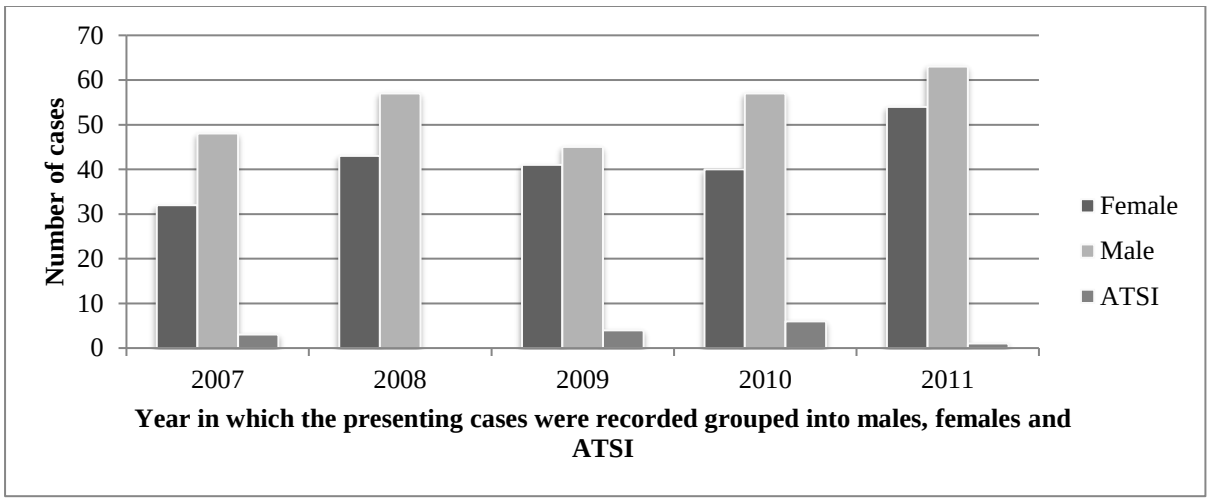


Figure 2-1 ANZDATA Number of cases of T1DM ESRD in Australia by year recorded from 2007–2011

Although data from Australia and New Zealand show a higher number of males than females presenting each year, it is not known whether age at diagnosis affects the development of ESRD

for males or females. This may be a topic for exploration in study 2 (chapter 4) and if a relationship is demonstrated, a larger Australian study is justified.

Other authors have also determined from population data that pre-pubertal T1DM onset delays ESRD [58] and it is tempting to rely on pathophysiological explanations alone. It is worth speculating whether the protection against future development of complications afforded by pre-pubertal diagnosis is a combination of genetic protection and behavioural protection, because younger children may be more accepting of the strict regime and lifestyle modification that are required to manage T1DM. For males diagnosed after the age of 15, apart from the role of sex hormones in relation to the development of ESRD there may also be culturally sanctioned behavioural aspects. Young males diagnosed in adulthood with T1DM described being 'invincible' and 'strong' and spoke of the pressure of conforming to culturally normalised behaviours, leading them knowingly to ignore their diabetes and its management [220]. Social researchers argue that the ideal male body suffers no weakness and when men fall ill it is confronting and causes a sense of loss of control [6]. In the setting of T1DM this could possibly lead to young males challenging themselves to overcome the disease which is, essentially, a form of denial.

In conclusion, a pre-pubertal diagnosis is health protective, females are more prone to albuminuria in puberty because of higher HbA1c but this can be transient, and males are more likely to develop ESRD. At what stage and why the 'male preponderance supervenes' in ESRD has yet to be demonstrated [208].

2.5.2 Different gendered outcomes in Type 1 Diabetes Mellitus based on adolescent behaviours

Despite evidence of the roles of puberty and genetics, there is also credible evidence to suggest that gendered outcomes are driven by different behaviours in males and females. Boys and girls have different approaches to managing difficult situations and this is reflected in 'internalising' and 'externalising' behaviours [221]. Girls tend to adopt internalising behaviours such as anxiety while boys externalise or act out behaviourally, including denial, and this can lead to erratic glycaemic control. Importantly, in trying to understand differential outcomes that may have a common determinant, the externalising types of behaviour are more prevalent in disadvantaged low income youth such as African Americans [221] who previously have been shown to have much poorer outcomes than White Americans.

A comprehensive study of young adults that explored gender and psychological adjustment to T1DM presented a very compelling discussion on why gendered outcomes in adolescents were similar but for different reasons. The study found that coping is generally a stable behavioural trait and that males and females have quite different coping strategies when managing diabetes. The authors found that 24% of young women had depression and anxiety compared with 7.4% of young men, a similar ratio to that in the non-diabetic population, and that depression accounted for lower psychological adjustment to T1DM for females. Young women were more likely to seek social support but males tended to ignore their self-care needs to 'keep the diabetes out of their personal and social identity' [222]. Studies of adolescents have also demonstrated that boys were less likely to seek social support with their diabetes and would commonly report themselves as more self-reliant than their parents did [223]. Other authors found that higher levels of depression and anxiety in females resulted in diabetes mismanagement but agreed that the relationship between health behaviours and outcomes is 'not perfectly aligned' [224, 225]. All of the studies described in the preceding section used quantitative questionnaires with study populations that varied from n=104 to n=280.

Theories such as those discussed above tend to place blame at the level of the individual and there is good reason to criticise how contemporary society, particularly through the media, reinforces gendered stereotypes. A significant issue for teenagers with T1DM that should be openly discussed in the literature and in clinical care is the association between intensive insulin regimes and weight gain. The DCCT (1983–1993) that advocated intensive regimen prescription showed that almost half the participants became overweight [226] and this could lead to an increase in the incidence of eating disorders in females with T1DM who are generally more likely to be unhappy with their weight [227]. Living with diabetes increases mortality risk (2.2 per 1000/person years) as does anorexia (7.3), but living with diabetes and a comorbid eating disorder increases standardised mortality ratio to 34.6 [226]. The authors of this questionnaire-based research found that almost half the teenagers described themselves as overweight and those who skipped insulin to reduce weight had significantly higher HbA1c than compliant teenagers. Researchers also speculated that insulin omission was much higher than reported because teenagers lacked confidence in the confidentiality of self-reporting. Other studies, again questionnaire based, demonstrated that adolescent girls were more likely to omit or restrict insulin to purge calories and to experience ketoacidosis in the setting of eating disorders and dietary mismanagement [71, 85, 228]. Eating disorders are twice as common in

young women with T1DM compared with those without diabetes [227] and this may be directly attributed to the significant weight gain that can be experienced with the intensification of treatment regimens. Purging behaviours in T1DM are now so common they have been classified in the *Diagnostic and Statistical Manual of Mental Disorders*, and this has led to the development of a program to support girls aged 10–12 years with T1DM to address how stereotypical media images of the very lean female body can reinforce negative self-perceptions [227]. Although intensive prescription and the use of pump therapies are recognised as the gold standard treatment for T1DM, putting this into practice is fraught with difficulty when dealing with adolescent mindsets. Older teenage girls were more likely to discontinue pump therapy and cite psychological reasons such as body image and social acceptance [229]. The study's methodology which was medical chart review highlights the limitations of this approach as the reasons for pump discontinuation could be an underlying attempt to avoid weight gain and a qualitative study could have explored this in more depth.

In conclusion, there are a number of gendered behavioural factors that influence metabolic control during adolescence and into adulthood. A dominant social process is the lack of future orientation and young people with T1DM focus on 'now' and not necessarily what is to come. How clinicians can best address this and encourage young adults to consider the future consequences is an area requiring further research.

2.6 Qualitative studies of Type 1 Diabetes Mellitus

A key finding in the review of the literature thus far is that while there is good evidence of inequitable outcomes for people with T1DM in relation to the SDH, the explanations are largely behavioural and situated at the level of the individual. The voice of the person with the disease in largely absent and for this reason a deep qualitative exploration of health outcomes in relation to the SDH is undertaken in study 3 (chapter 5). To inform this study, a critical review of the qualitative literature on T1DM has been undertaken.

The Research questions informing this review are:

1. What are the main findings from the qualitative research with adults who have T1DM to date?

2. What is currently not fully understood that will inform the research in this thesis?

Data bases searched were CINAHL, Medline/Ovid, Scopus, Proquest, Sage, Web of Science, Science Direct, Informit. The abstracts were reviewed and papers included on the basis of being conducted with adults and those that describe SDH. Papers were excluded on the basis of T2DM and duplicates found in subsequent search waves. 404 papers were reviewed, 374 excluded and 30 included in this review. The search strategy is further defined in appendix 2 table 6-9.

There has been a significant amount of qualitative research undertaken in T1DM, most of which is with children and adolescents and centres on concordance with therapies. Qualitative studies included in this review are only those that have explored social determinants of health and that have involved adults including health care providers (HCP). These studies represent the viewpoints of people with T1DM and those of their HCP. Two systematic reviews have also been included and the discussion of this body of literature is grouped under the themes of self-perception, the health care encounter and education.

2.6.1 Self-perception in Type 1 Diabetes Mellitus

Qualitative research helps us to understand people's motivations, perceptions and expectations. These have a profound effect on health seeking behaviours and there is clear need for both qualitative and quantitative evidence to develop the most effective treatments in T1DM [230]. Glycaemic control depends not only individual characteristics but also on cultural and societal influences and qualitative research is needed to explore the lived experience of people with the disease [231]. Much of the qualitative work in T1DM has been with adolescents and parents, and there are few studies with adults with T1DM. there have however been some quality studies of T2DM with adults that explore psychological processes [230]. These studies have been included because it is likely that there are commonalities for adults with T1DM and T2DM in relation to self-perception. One South Australian study of T2DM (n=119 patients and 56 HCP) found that people with diabetes had a 'spoilt identity' and described themselves, each another and their behaviours as being 'in' or 'out' of control [232]. Qualitative research has found that people see themselves as 'good' or 'bad' diabetics and feel that they should have done better [233]. They also experienced chronic sorrow about lost opportunities and poor behaviours in the past [234]. In common with these studies qualitative research that explores life transitions such as completing education and entering the workforce through interviews with young adults with T1DM (n=20) has found that young people regarded depression as 'an almost normal'

consequence of diabetes [235]. Large qualitative studies that used semi-structured interviews with young women and HCP and interpretive phenomenological analyses (n=35 & n=13, n=20) found that the significant and underreported problem of weight-controlling behaviours led to feelings of vulnerability and loss of control [236, 237].

2.6.2 The health care encounter for people with Type 1 Diabetes Mellitus

Health services are very important as a determinant of health because positive experiences with them and HCP are vital to ensure long-term engagement for people with chronic illnesses. There is good evidence that health services are not meeting the needs of people with T1DM. In a Canadian study that used focus groups as the research method of qualitative enquiry, participants expressed their frustration at the lack of access to support, long waiting times at three- to six-monthly appointments, and only the option of the emergency department when things went wrong [238]. The current organisation and delivery of care has proved to be inadequate for chronic diseases, and patients and HCP have called for improved psychosocial care and more education [239]. It is likely that patients' frustration is contributing to disengagement from health services. The consultation experience is central to keeping young adults engaged with services and it can be a highly emotive event, yet a large percentage of HCP have little or no training in communication skills for dealing with young adults [240]. People with T1DM in qualitative interviews (n=30) reported few opportunities to develop relationships with HCP in adult services, and spoke of seeing a different doctor at every visit, leading to conflicting advice [241]. Qualitative interview studies of long-term non-attendees of diabetes clinics have found they had suboptimal management and were likely to return at a later stage with severe complications [242]. A reason for non-attendance at clinic can be the high levels of fear induced by HCP that led to depression and avoidance, and these types of consultations were counterproductive. For 43% of non-attendees in the study cited, their health care provision comprised only the collection of prescriptions. A critique of this research is that although family details, educational attainment and occupation were recorded as demographic data at the start of interviews to establish trust, unfortunately, these data were not analysed, which potentially could have shed some light on the social characteristics of non-attendees.

The most significant finding in almost all qualitative studies with adults is the importance of the nature of their health care encounters. Focus group research has found that diabetes care that focussed on psychosocial needs took second place if mentioned at all [238]. A study of

adults with diabetes conducted in a rigorous way through repeated measuring longitudinally at multiple time points (6 weeks, 6 and 12 months) with a cohort of 40 people reported that the main focus of consultations was clinical management but the need for ongoing responsive support was the most important facet of care sought by patients [243]. In other studies, adults with diabetes reported that the emotional components were the most valued aspects of the health care encounter, with staff who were non-judgemental and showed positive active interest and respect [244]. Patients expressed concern that the computer in the room was the focus of the consultation rather than the patient, and a stated manifest need was for HCP not to focus solely on test results [238]. In paediatric care, a qualitative study that also surveyed over 700 parents found they thought that clinicians affected many of the factors that would impact on whether they raised a resilient child with T1DM. What mattered most to these families was clinicians' understanding of the lived experience [245]. The authors of this complex study that utilised both quantitative and qualitative methods to fully explore the issue also found that when parents brought their children with T1DM to clinics they were often frustrated by condescending attitudes of HCP and reported shame and anger when feeling judged. Another qualitative study that used in-depth interviews (n=17) identified that providers of paediatric services rarely acknowledged the profound impact on parents when a child was diagnosed with T1DM, and that these parents experienced 'chronic sorrow' from the grief of the diagnosis which may never completely resolve [246].

Many parents and adults with diabetes have stressed the importance of clinicians acknowledging their hard work rather than resorting to shocking them with threats and pressure [230]. Scare tactics can result in people distancing themselves, lying or rebelling [238, 247]. This can have severe consequences if communication between HCP and a person with T1DM becomes dishonest. A qualitative study (n=11) of people with T1DM and nephropathy identified that participants had always found their diabetes difficult to control. They spoke of a long history of unhelpful or conflicting advice and no longer felt able to trust HCP, which they found distressing to recall [248]. These participants reported having no frame of reference to understand what was happening to them as their kidney disease progressed, stating that they felt poorly informed.

Patients' experience of failed problem solving in relation to glycaemic control and the treatment regimen over years is a good reason to explore the patient–provider relationship. In contemporary health care, particularly in an acute care model, a compliance paradigm is the

starting point but this immediately creates a 'distant provider dominance' [249]. However, power does not have to be oppressive if HCP use this power to work with their clients in a concordant way rather than 'over' them [249, 250]. A common finding from studies that explored the power dynamic of the clinical encounter was the importance of HCP being aware of their responsibility to maintain the boundaries of the relationship and not use 'blurred sympathy' in attempts to establish false equality when in reality what was needed was the setting of mutually agreed regimens and goals [249]. In practice, however, a mutually reciprocal encounter is extremely difficult to achieve for both the person with T1DM and the HCP.

One factor affecting the quality of the clinical encounter is staff workloads. For example, in-depth interviews with service providers in the UK found that paediatric specialist nurses' caseloads were often above recommended levels, they were allowed only 20 minutes per patient, and in-depth attention was only given in crisis situations [251]. The authors noted that the UK is a country with one of the poorest records in T1DM management. Prescribing a regimen to follow is not sufficient without a discussion of strategies about how the regimen can be successfully integrated into daily life to maintain psychological as well as physical health [233]. Although the literature on barriers to concordance refers to diabetes specific distress and burnout what is often not mentioned is that HCP experience similar distress. It can be very difficult to maintain a harmonious relationship with a patient who has a continual pattern of poor glycaemic control. However, poor glycaemic control is not necessarily a personal choice or a failure of the individual or the HCP. Almost all studies of perceptions of the person with the illness found that the best approach is as an adult/adult partnership that acknowledged the person with the T1DM may be the expert in what is going to work best for them [93].

2.6.3 Education and Type 1 Diabetes Mellitus

There has been little qualitative exploration of the relationship between educational attainment and T1DM outcomes despite the striking finding in the Pittsburgh Epidemiology of Diabetes Complications study that the mortality rate was three times lower for those with a college degree [139]. Social class and education have been consistently associated with knowledge of diabetes [252] and leaving school before the age of 16 is associated with a higher incidence of death, with death rates being twice as high for males [253]. The finding that education is a

predictor of health outcomes in later life has been strongly persistent over time and education is claimed to be the most significant determinant of health [126]. Similarly, adult mortality is inversely related to adult literacy [3, 18, 117]. Quantitative studies of children with T1DM have shown that poor glycaemic control led to more school absence and poorer performance in tests, and hypoglycaemic convulsions were associated with poorer achievement in arithmetic [254]. The authors concluded that any effect of the illness on academic achievement had consequences for success in the future. The importance of the association between health literacy and education in T1DM is likely underestimated, with adults in qualitative research reporting they did not receive or did not retain much information at diagnosis [244] while adults with juvenile onset reported that they were not receptive to education as teenagers, preferring to block it out and now feeling let down by the lack of education in adult services [241, 255].

In summary, there is a large body of qualitative studies in T1DM undertaken with adolescents and parents to explore the lived experience of the disease, while most studies of T1DM in adults used quantitative methods to explore how social relationships affected glycaemic control [256]. The qualitative studies with adults and health care providers explored the nature of the health care relationship and self-perception. The main finding from these studies is that the use of moral language centred on 'good' or 'bad' behaviours was commonplace in the discourses of people with diabetes and their HCP. There is a lack of qualitative research that explores how social determinants can shape health behaviours and the health care encounter. This gap in knowledge was particularly well demonstrated in a systematic review of studies that have included SES, gender and ethnicity. Only one qualitative study was found, which was discounted because of its perceived 'poor quality'. The authors were subsequently able to demonstrate that all quantitative studies reviewed 'controlled' for SES, gender and ethnicity as if they were confounders when in actual fact it is likely that they could be mediators [254]. The authors stated that this is one of the most pressing gaps in the literature and that qualitative research is needed to add to the existing evidence. Understanding these micro-level factors is vitally important to help shape the macro-level factors in health service provision and this is a primary focus of study 3 (chapter 5).

2.7 The social determinants of health outcomes in Type 1 Diabetes Mellitus specific to Australia

The research question informing this review is what is currently known regarding outcomes specific to Australia, is there any evidence regarding inequitable outcomes and what is currently not known about the social distribution of health outcomes in T1DM in this region that will contribute to the research aims of this thesis. Data bases searched were CINAHL, Medline/Ovid, Scopus, Proquest, Sage, Web of Science, Science Direct, Informit. The search was confined to the preceding ten years to ensure recent and relevant data. The abstracts were reviewed and papers included on the basis of being an Australian study. Papers were excluded on the basis of T2DM and duplicates found in subsequent search waves. 533 papers were reviewed, 514 excluded and 19 included in this review. These papers were further reviewed for relevant references to this review which yielded a further 7 papers increasing the review to 26 papers. The search strategy is further defined in appendix 2 table 6-7.

There has been very little published Australian research about how the social environment affects outcomes in T1DM for adults, compared with the literature on the social environment and outcomes for Australian adolescents. Therefore, to inform this thesis, the review of the Australian literature is grouped into the themes of incidence and disease management, the functioning of the Australian health care system in relation to T1DM and a discussion of the social distribution of health outcomes in this region particularly those relating to T2DM and ESRD. The review is supplemented with evidence drawn from overseas to demonstrate the potential relationship between psychosocial factors and poor outcomes that is a focus of this thesis in study 3. It is thought that these themes set the context for the proposed study by demonstrating there is a social distribution of health in Australia and that inequitable access to care exists, thus demonstrating the potential gap in our knowledge regarding the SDH for people with T1DM in Australia.

2.7.1 Incidence and disease management of Type 1 Diabetes Mellitus in Australia

Many studies of adults with diabetes in Australia have included both T1DM and T2DM and while both are important, such research tends to blend the results of the two distinctly different diseases particularly in relation to age and the development of complications. For T1DM there is very little literature on the SDH although some studies of adolescents have discussed SES and family composition in the context of examining factors that influence HbA1c. For example,

an Australian study of adolescents and retinopathy coincidentally associated continuous subcutaneous insulin infusion predominantly with patients who had private health insurance and higher SES [257], mirroring findings in the USA. Additionally, a study with Australian adults to improve well-being demonstrated that mastery of T1DM was not a function of time lived with the disease but rather, was thought to be regulated by social relationships and adequate income [258]. The Hvidoere study of childhood diabetes across 19 countries including Australia found that adolescents whose parents were living together had lower HbA1c as did those who had a working father [165], however again the micro-level mechanisms that drove this is were not explored in any depth.

There is a significant amount of Australian literature on children and adolescents with T1DM. The most recent data on prevalence show that between 1999 and 2005, the number of cases diagnosed in those aged 14 years and under increased from 19.1 to 24.2 per 100,000 population and there was a male excess in diagnosis after the age of 15 [38]. The incidence in those aged 0–14 years was very high compared with many other countries [259], there was a higher prevalence in urban settings, and in one study the incidence in highest socioeconomic groups was thought to be 56% greater than in the lowest socioeconomic group [48]. This isolated finding in Western Australia is explored further in the study of T1DM prevalence in Australia in study 1 (chapter 3). In the Australian setting, T1DM complications have been studied well in children and adolescents and the Standardised Mortality Index in Australia for a child with T1DM is 3.1, reflecting that death in childhood is relatively uncommon. The majority of childhood deaths in T1DM are outside the hospital setting and are due to ketoacidosis and the disturbing phenomenon of 'death in bed' [260]. Australia has a particularly high incidence of 'death in bed' and this accounted for 67% of unexpected deaths of young people (aged under 40 years) with TIDM in New South Wales over a 10-year period while at the same time overdose and suicide accounted for around 80% of the unnatural T1DM deaths (n=400 T1DM deaths, 84 unnatural or unexpected) [261].

Contemporary multicentre cross-sectional studies have demonstrated that the incidence of microvascular complications in adolescence is assessed as quite low [262] although it has previously been demonstrated that this is not the case in children with a HbA1c greater than 8.7%, where microvascular complications are seen at a prevalence of 34% [263].In keeping with evidence from other countries, Australian adolescents have less effective metabolic control than other age groups and parents report that family conflict in these years is often high

[264], however the study was quantitative which has limitations when determining what 'family conflict' means to different people. There have been striking findings in Australia however on the high frequency of hypoglycaemia and the importance of psychological adaptation to the disease. Since the introduction of intensive regimens episodes of hypoglycaemia have become commonplace, particularly those occurring overnight and those resulting in loss of consciousness or seizure, despite patients' mean HbA1c being above 7.5% [263, 265]. This appears to have a significant impact on quality of life, with high rates of depression and one-third of Australian children with T1DM have been diagnosed with a mental disorder [266-268]. In tandem with intensive regimens, 32% of Australian children with T1DM in Western Australia were overweight, which was the highest percentage across this large study conducted in 12 countries, [269] and one-third of adolescents in a Queensland study reported disturbed eating behaviours associated with poorer control [270]. Most Australian studies of T1DM have focused on behavioural and individual characteristics, identifying that predictors of good outcomes in adolescents were increased self-efficacy or ability to self-manage the disease and a conservative risk attitude [271]. There is continued speculation as to the barriers to optimum glycaemic control but a deeper qualitative exploration of the perceptions of adults regarding the lived experience of the disease will add to our knowledge and support the development of patient-centred treatment regimes.

2.7.2 The function of the Australian Health Care System as a determinant of health outcomes in Type 1 Diabetes Mellitus

A recent study in the UK suggested that around 12% of patients with diabetes are 'lost to care', a similar finding to other studies, although the other studies cited were all conducted more than 25 years ago [242]. A recent study in Australia demonstrated marked attrition of young adults with T1DM from health care services, with 50% lost to care after five years [255] and this was significantly higher in regional areas where there were lower rates of surveillance and screening for complications and demonstrated poorer control [272]. The authors called for urgent service redesign to encourage young people to engage with the health care system. Unfortunately, in most health care services outpatient appointment management has become highly inflexible because of increasing demand for services.

The importance of holistic care in T1DM has been emphasised in this literature review, however fewer than 25% of young adults in a New South Wales/Australian Central Territory study were receiving multidisciplinary care and of particular concern was that no psychosocial

care was available for 70% of participants [273]. The young adults in the study reported an under-resourced system and they had difficulty obtaining the recommended three-monthly appointments. The authors speculated that the decline in attendance rates over time in this population reflected dissatisfaction with care rather than increased expertise in diabetes management. A telephone questionnaire study of young Australians with T1DM investigating perceived rural health care service delivery revealed a preference for personal support rather than electronic communication, lack of access to age appropriate care and that adult services were too focused on self-management and adherence [255]. Studies like these show the need for an Australian study of factors that health services need to address to improve retention and engagement with young adults and to ensure a strong relationship that continues over time.

The value of a support program during the transition from juvenile to adult services has been demonstrated. In one such program, HCP managed appointment scheduling and provided additional telephone support to maintain clinic attendance and build strong relationships. Outcomes included significantly improved HbA1c and reduced admissions for ketoacidosis while the cost of the program was offset by the reduced costs associated with hospital admissions [274]. A large national study, the diabetes Management and Impact for Long-term Empowerment and Success (MILES) survey (n=3338) of people with T1DM and T2DM, found that although levels of self-care were reported in similar ways to urban areas, people with diabetes in rural areas lacked access to endocrinologists, were more likely to see community nurses and the years of life lost to diabetes were greater [275]. The authors suggested that a significant contributor to this could be the demonstrated socioeconomic disadvantage found in rural Australia coupled with high costs of accessing care, a barrier reported by respondents.

It has been argued that in Australia the focus of care is on biomedical and technological advances and people with diabetes often feel 'lost, frustrated and a failure due to unrealistic expectations' [276]. It was stated that the behaviours of both the person with diabetes and the clinician were major contributors to outcomes, and that the time had come to 'measure what we value' rather than valuing what we have measured. The diabetes-MILES Australia study is the largest study of its kind in Australia and further results will be disseminated over the next several years. It includes patients' perceptions of the lived experience of T1DM and T2DM, but some of its limitations are that 72% of respondents are aged over 45, most speak English, are married or in a de facto relationship, have at least high school education and are in paid work with an annual household income of $40,000 [277]. These limitations, reported by the

authors, highlight the difficulty of reaching marginalised groups in survey research, particularly disadvantaged young people with T1DM, Indigenous Australians and those from culturally and linguistically diverse (CALD) backgrounds.

2.7.3 Evidence of poor outcomes for young adults with Type 1 Diabetes Mellitus drawn from overseas

There is an absence of epidemiological research in Australia that examines the relationship between psychosocial factors and outcomes for adults with T1DM and yet there is compelling evidence from overseas that some young adults experience very poor outcomes. A UK cohort study of people with T1DM (n=87) aged 17–25 years who were followed prospectively and re-interviewed 11 years later found that 85% reported hypoglycaemia in the previous month, the number of people with serious complications had increased from 3% to 37% while the number with psychiatric disorders increased from 16% to 28%. In addition, 37% (all women) reported weight controlling behaviours such as purging and insulin omission and 14% of these women had attempted to commit suicide or had self-harmed [81]. The authors concluded that the poor outcomes for many young adults with T1DM demonstrated that the effects of psychiatric complications may persist into adulthood and that this had previously been underestimated. The study also assessed potential SDH such as employment status, marital status, and current health care provider that could be considered supportive mediators but the data lacked the deeper analysis that could have been gained from in-depth interviews.

A large cohort study in Sweden (n=4097) of people diagnosed with T1DM after the age of 15 found that the standardised mortality ratio (SMR) was significantly increased in late onset, short duration diabetes (SMR 3.5) and was particularly high for males (78%), with 45% of these being in the oldest subset for age at diagnosis (30–34 years) with a SMR of 4.1 [278]. Examination of death certificates showed that this fourfold higher risk of death could be attributed largely to alcohol and drug abuse, depression and the twofold higher incidence of suicide, which mirrored that found in the US and Norway [278].

Population based cohort evidence suggests that the risk of developing ESRD in short duration disease within 15 years of T1DM diagnosis is minimal with effective early prevention [279]. However, early onset ESRD is seen in clinical practice in Australia and there is good reason to speculate that effective early prevention fails in the absence of engagement with health care services [220]. Additionally, given that there is a significantly higher mortality for males

diagnosed at older ages, the ESRD data may not truly show adverse outcomes for males because they may have died before developing ESRD [279].

2.8 Aboriginal and Torres Strait Islander, Maori and Pacific Islander ethnicity as a social determinant of health outcomes in Australia and New Zealand

There is a very small body of evidence regarding the prevalence of T1DM in the ATSI, Maori and Pacific Islander populations and in relation to disease outcomes. This evidence is scant and inconsistent. There is however a great deal of literature on health outcomes in T2DM and on the incidence of ESRD for Indigenous people in Australia and New Zealand, and it is from this literature that a sense of the social distribution of health and illness is drawn.

Indigenous people in Australia and New Zealand have a much higher prevalence of T2DM [18] and a disproportionate incidence of ESRD due to diabetes. Nation wide registry data for a 14 year period demonstrates that of Indigenous Australians diagnosed with ESRD, 70.9% have T2DM compared with 20.9% of the general population [280]. Maori people with diabetes have a 46-fold greater risk of progression to ESRD than European New Zealanders with diabetes and this is largely attributed to higher rates of obesity, smoking, hypertension and poorer control. There is however also acknowledgement that the faster progression to ESRD experienced by Maori people could be related to differences in the treatment of chronic kidney disease (CKD) [281]. The authors also assert that familial disposition and genetic determination may be causal influences because of the high number of families with multiple members burdened with the disease. This explanation fails to account for the well-demonstrated intergenerational cyclical disadvantage experienced by Maori people as a result of colonisation [282]. Genetic studies of the familial clustering that is purported to contribute to increased rates of ESRD in Indigenous populations are likely to be thwarted by the fact that very few ESRD patients have living parents and the familial clustering may simply reflect shared disadvantage [283]. The disparity is well demonstrated, with registry data indicating the incidence of progression to ESRD from CKD of any cause being more than ten times higher for Indigenous Australians than for non-Indigenous populations [284]. This difference is most striking in cases of ESRD related to diabetic nephropathy (DN) and is not correlated with the increased incidence of the actual disease, which is generally thought to be 2–5 times higher in Indigenous Australians [284]. These outcomes are profoundly inequitable regardless of any discussion of genetics or behaviours. Deterioration to ESRD is not inevitable whether CKD is due to DN or

any other cause, provided that health services conduct adequate early surveillance and provide comprehensive medical care.

The poor outcomes in T2DM for this region's Indigenous peoples have been shown to be worse than those of other vulnerable ethnic groups in the USA and the UK. There is speculation based on the quantitative registry data that they are a result of 'increased susceptibility, harmful lifestyles and maladaptation to westernization, and adverse intrauterine environments' [284]. There is an urgent need for research in Australia that explores how being a vulnerable marginalised population affects access to appropriate health care and effective management of CKD. The type of epidemiological data presented here has not undergone a sociological analysis to investigate the impact of SDH, and in the case of ethnic minorities these are often overlooked or barely mentioned in published reports [6]. For example, it has been demonstrated that urban Indigenous Australians have a 10-fold higher incidence of progression to ESRD but for those living in remote areas there is a 30-fold greater incidence [285] because of inadequate health care provision. National data in Australia show the annual percentage of late referral for ESRD is 22%, but this varies greatly across states, with Tasmania having the lowest rate of 8% and the Northern Territory the highest rate of 40% [286], with 40% of Indigenous Australians referred late for specialist care and commencing dialysis within three months [283]. Indigenous Australians have the worst health, lowest life expectancy and highest child mortality rates for all Australians [287], over half of Indigenous Australians are welfare dependant, most have limited access to culturally appropriate health care services, live in overcrowded housing and have inadequate community infrastructure [288].

Apart from Indigenous people in Australia, the prevalence of diabetes and its known modifiable risk factors is higher in migrants than in those who are Australian born, with rates 6–7 times higher in Pacific Island migrants and five times higher in those from South Asia. An equally a strong area-based social gradient has been demonstrated for these groups in Victoria [289]. CALD Australians with diabetes in qualitative enquiry report difficulties in chronic disease management and in negotiating the health care system and these contribute to an 'unsettled self-identity', feelings of inadequacy and loss of control over everyday life, which leads to inability to control the disease [290]. Any structured intervention tailored to ethnic minorities with diabetes that incorporates culture, language and health literacy skills has a positive outcome, highlighting the need for further research on culturally competent diabetes care [291]. Importantly, studies of diabetes in Australia mirror those in the USA and the UK with a failure

to acknowledge the social processes within institutions that can contribute to differential outcomes, despite there being a significant critique in the South Australian literature linking racism to poorer health outcomes [287, 292, 293]. We will continue to see poorer outcomes in this region's ethnic minorities unless we 'tackle white privilege in Australia and the way it is codified in the structures and institutions of society' [294].

2.8 Summary and thesis aims

Despite strong international evidence suggesting that SES, gender and ethnicity are social determinants of health for people with T1DM, it is not known whether outcomes for people with T1DM in Australia are socially patterned and if so, the mechanisms through which this occurs. These gaps in our knowledge are addressed by the three studies undertaken for this thesis that explore the population prevalence of diabetes and the development of ESRD in relation to SES, health service use and health outcomes in relation to the SDH, and a deep qualitative exploration of the lived experience of the disease and social factors that are health protective or that can hinder optimum glycaemic control and lead to the development of complications.

Most studies that have previously examined differential outcomes in T1DM speculated that they result from increased insulin resistance, genetic susceptibility, low health literacy and poor health behaviours. These explanations used biomedical and/or behavioural models that ignored the social patterning of poor outcomes in marginalised vulnerable populations who often have the lowest SES. This is a primary focus of the three studies that follow. There is good evidence to support such research because despite Australia having comprehensive health services there are still failures that can be seen in the lack of appropriate care for Indigenous Australians and CALD minorities with diabetes and those living in rural areas. There has been little acknowledgement of the SDH that may be driving this, particularly the role of the health care system in inequitable outcomes. The research in this thesis critically examines the role of health services as a determinant of health outcomes for people with T1DM.

Disengagement from care and the subsequent development of complications can be a significant problem for young people with T1DM, particularly around the time of transition to adult services, and this is explored further in study 3 (chapter 5). The levels of disengagement in Australia may reflect dissatisfaction with care and in particular the distinctly different model of care used in adult services, which places full responsibility for retention to care on the person

with diabetes. In addition, individuals burdened by socioeconomic disadvantage have particular difficulty navigating the health care system and notions of compliance and adherence offer justifications for attributing blame which when felt by vulnerable populations contribute to their 'dropping out of care' and the subsequent almost silent development of severe complications.

Australian research is needed that explores the structural determinants, social context and lived experience of T1DM well into adulthood to understand how this influences patterns of self-care and engagement with health care services. Such research must include the perspective of the person with the disease. An understanding is needed of how the social environment affects health care behaviours, how engagement with care contributes to our knowledge and what is needed to develop future strategies to engage disadvantaged young adults with health care services to ensure surveillance for the presence and progression of complications. T1DM will never be 'cured' by attention to psychosocial factors but this does not diminish the important role that they have in the self-management of this chronic disease [233].

The specific research aims derived from the review of the literature this thesis seeks to address are;

Study 1 Chapter 3 seeks to examine the population prevalence of T1DM in Australia for an association with area SES, to determine whether there is any relationship between T1DM ESRD and area SES, and to re-examine DN ESRD for ASTI, Maori and Pacific Islanders.

Study 2 Chapter 4 seeks to explore how gender, the age of disease onset and SES affect glycaemic control, engagement with health services and the development of complications in a cohort of Australian adults and children with T1DM.

Study 3 Chapter 4 seeks to describe the lived experience of the disease, to understand how the psychosocial environment affects the management of T1DM and to gain insight into why certain groups are at risk of disengagement with health care, leading to poor outcomes.

CHAPTER 3: STUDY 1 SOCIAL INEQUITIES IN THE PREVALENCE OF DIABETES AND IN THE DEVELOPMENT OF END STAGE RENAL DISEASE

3.1 Introduction

Over one million Australians are living with diabetes and 10% of these have type 1 diabetes mellitus (T1DM) [24]. Australia has one of the highest incidence rates worldwide of childhood T1DM at 23 cases per 100,000 and while a higher incidence of type 2 diabetes mellitus (T2DM) is known to be associated with low socioeconomic status (SES), this has not been demonstrated for T1DM [38, 49, 295]. In other countries, socioeconomically disadvantaged people have higher rates of morbidity and mortality in T1DM [132-136] but very little is currently known regarding T1DM prevalence and end stage renal disease (ESRD) for people with low socioeconomic status, Aboriginal and Torres Strait Islanders (ATSI), and Maori and Pacific Islanders in Australia and New Zealand. This study of T1DM and ESRD is an exploration of social inequalities in relation to SES, gender and ATSI, Maori and Pacific Islander ethnicity. In reporting the results an explanation is given on how they address the research questions and compare with existing literature, theories and prior explanations [12].

3.2 Background and rationale

Survival in T1DM has greatly increased because of aggressive antihypertensive treatment and glycaemic control, but even so life expectancy remains considerably lower than the national average [62]. The presence of kidney disease is a powerful predictor of increased mortality [72-74] with 25% of people with T1DM and kidney disease dying from cardiac disease before developing ESRD [21]. In addition, although the relative female sex protection against renal disease seen in the non-diabetic population is somewhat diminished in T1DM [211], in other countries males are more likely to develop ESRD because of T1DM and the reasons for this have yet to be fully understood [206, 207, 212]. This study seeks to add to the current evidence in relation to risk factors for the development of ESRD the presence of which increases the risk of death seven fold in comparison to the general population [296].

In 2014, there were 25,626 people in Australia and New Zealand receiving renal replacement therapy (RRT) for ESRD, with 35% of cases attributed to diabetic nephropathy (DN) [297]. In this region, people with low SES are more likely to develop ESRD due to any aetiology, but

the disparity is most pronounced in DN [298, 299] with a relative risk of progression to ESRD for low SES versus high SES of 2.38 [299]. While studies from other countries have found a higher likelihood of ESRD due to T1DM for people with low SES [138, 142] this has not previously been studied separately from T2DM in Australia and New Zealand.

The incidence of T1DM in the ATSI population is estimated to be 11.6 per 100,000 but this may be an underestimate because of probable lower levels of registration with the National Diabetes Services Scheme (NDSS) and underreporting of Indigenous status [38]. Although the incidence of T1DM nephropathy has not previously been explored for ATSI, Maori and Pacific Islanders, the incidence of progression to ESRD from CKD in these populations due to any cause is much higher than the general population [284]. It is also known that ATSI, Maori and Pacific Islanders have a disproportionate burden of ESRD [297] from DN, which is attributed to a higher prevalence of T2DM but also to an increased likelihood of progressive renal disease [284].

3.3 Aims and objectives

The aims of this study were to examine the population prevalence of T1DM for an association with area SES, to determine whether there is any relationship between T1DM ESRD and area SES, and to re-examine DN ESRD for ASTI, Maori and Pacific Islanders.

3.3.1 The role this study has in adding to the current evidence

There have been a number of studies undertaken in Europe using registry data that have measured the prevalence of kidney disease in cohorts of people with T1DM and demographic factors that are associated with poor outcomes. Whilst previously demonstrated in Australia and New Zealand that people with diabetes and low SES have poorer outcomes in relation to kidney disease there have been no Australian studies to date that have used registry data to study T1DM ESRD in isolation from T2DM in relation to outcomes for people with low SES. In addition whilst it is known that there is a higher prevalence of diabetes in low SES populations this study seeks to compare and contrast the population prevalence of T2DM with the population prevalence of T1DM in relation to socioeconomic disadvantage to understand this regions at risk populations for future health service planning.

3.4 Method

Disaggregated de-identified individual level data were sourced for this study and ethical approval was obtained from Southern Adelaide Clinical Human Research Ethics Committee (SACHREC) (reference number 564.13, appendix 4-1).

3.4.1 Quantitative research method

This observational study is a secondary analysis of existing data using an ecological design, a method which can be critiqued for ecological fallacy through the assumptions that are made about individuals based on group data [300]. However, the purpose of this observational ecological study is not to determine causation but to make large scale comparisons between groups [301].

Quantitative research is fundamentally positivist in nature [14] and is intent on finding correlations from observable data. The research measures objective facts independent of context [11, 302]. This phase of the research incorporated collection and coding of data, analysis of frequencies to check trends and distributions, and an examination for correlations between demographic characteristics and outcomes. The characteristics of the data determined the descriptive and inferential statistics used through an examination of normality, distribution, level of measurement and the number of independent and dependent variables [10].

3.4.2 Data collection cases of end stage renal disease

The Australia and New Zealand Dialysis and Transplant Registry (ANZDATA) records the incidence and outcomes of dialysis and transplant treatment for people with ESRD. It is located at The Royal Adelaide Hospital, South Australia. The information collected by the ANZDATA Registry is used for research that is of benefit to the data contributors, a process overseen by a network of nephrologists, surgeons and renal nurses with interest and expertise in using the data [303]. Australian population data and individual-level de-identified data on all cases of ESRD due to T1DM in Australia and New Zealand for the five-year period from 2008–2012 (n=534) were obtained from the ANZDATA Registry. Data were also obtained on the relative risk ratio (RR) for T1DM and T2DM ESRD for ATSI and Maori and Pacific Islanders through an analysis of all data held in the registry.

3.4.3 Data collection socioeconomic status

The Socio-Economic Indexes for Areas (SEIFA) is an index developed by the Australian Bureau of Statistics (ABS) that ranks areas in Australia according to relative socioeconomic advantage based on information from the five-yearly Census [304]. The structure of SEIFA allows measurement of key components of SES such as income, wealth, social class, occupation, education and community cohesion. The combination of these measures allows an integration of the individual, household and community factors that can influence health [305]. Data in SEIFA are ranked in deciles from 1 (lowest SES) to 10 (highest SES). ANZDATA records the residential postcode for each Australian case and the postal areas SEIFA (2011) was used to identify the SES for each postcode of every case.

3.5 Analysis

The analysis of SES excluded ESRD cases from New Zealand because no postcodes were collected (n=77). Invalid postcodes were given for three cases in Australia and these were excluded from analysis.

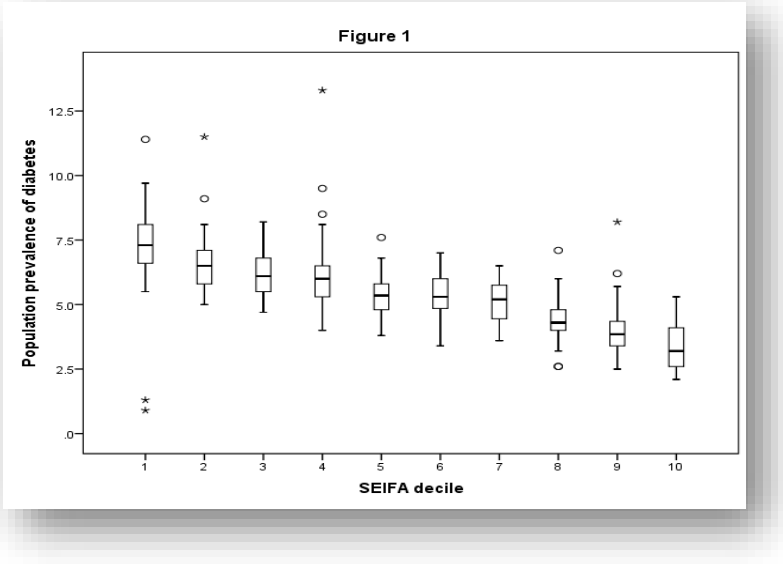
Population size in each postcode with a case of T1DM ESRD and the population prevalence of diabetes in that postcode were drawn from the National Diabetes Service Scheme (NDSS) registrant database and converted into population prevalence in each SEIFA decile using the ABS database which lists the SEIFA decile for each postcode. People with diabetes register with the NDSS to access consumables for diabetes care at reduced cost and the register is thought to have almost complete coverage. The population prevalence of all types of diabetes which includes 85% T2DM serves as a perfect control group to demonstrate the association with SES which is then applied to T1DM in isolation. To calculate the relative risk of T1DM ESRD in relation to SES the 10 SEIFA deciles were collapsed to two categories, low SES (deciles 1–5) and high SES (deciles 6–10). The total size of the population studied for diabetes prevalence was 7,434,492.

Details of every case of T1DM ESRD from 2008 to 2012 were entered into a spreadsheet (SPSS Statistics for Windows, version 21, IBM Corp., Armonk, NY; IBM Corp 2012) for analysis. For the continuous data, Levine's tests of normality were used, which have an assumption that the variance between groups is normally distributed, with a *p* value of >.05 demonstrating that the assumption of normality has not been violated. For normally distributed data, a parametric t-test was used for independent variables (IV) with two categories, and an analysis of variance

(ANOVA) was used for IVs with more than two categories. Where the continuous dependent variable (DV) was not normally distributed and the IV had more than two categories, the non-parametric Kruskal–Wallis tests and Spearman's rank correlation coefficients were used [306, 307]. Relative risk estimates were calculated with a chi-squared analysis.

3.6 Results

3.6.1 Population prevalence of diabetes in Australia



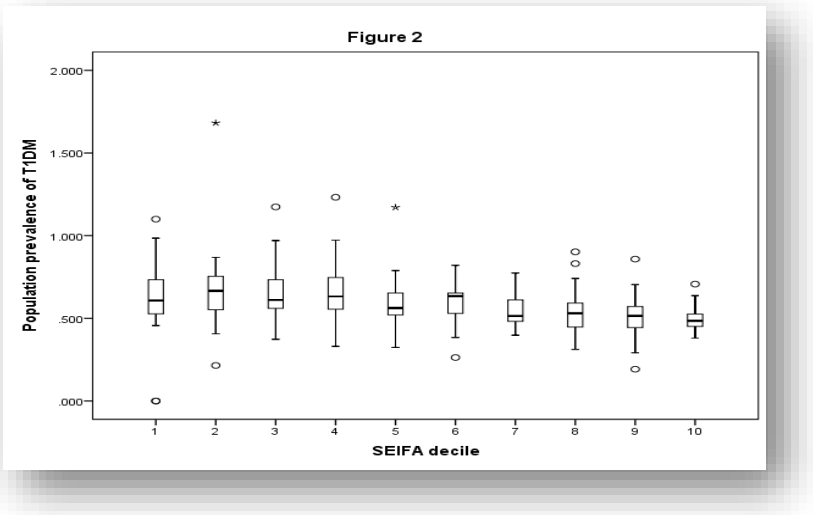
SEIFA decile	Diabetes %
1	**7.34**
2	6.53
3	6.17
4	6.19
5	5.34
6	5.31
7	5.09
8	4.32
9	4.01
10	**3.38**

Figure 3-1 Population prevalence (percentage) of any form of diabetes in Australia by SEIFA decile from 1 (lowest SES) to 10 (highest SES).

Population prevalence for any form of diabetes was plotted against the SEIFA deciles. The mean prevalence was 5.3% (IQR 4.2–6.3, SD 1.63). In Figure 3-1 data are presented in box and whisker plots with outliers (extreme cases in each decile) represented by the symbols ˚* which denote individual postcodes. The prevalence of diabetes in the Australian population varied considerably by SEIFA decile. There was an incremental increase in prevalence as SES decreased, with the lowest SEIFA decile having a prevalence of diabetes more than double that of the highest decile, demonstrating an inverse social gradient (Figure 3-1). The correlation coefficient for association between SEIFA decile and the percentage of the population with diabetes was –.765 (Spearman's p <0.001, appendix 3-1).

The largest proportion of diabetes cases were T2DM (85%) with the remaining 15% being T1DM and gestational diabetes. The outliers seen in Figures 3-1 and 3-2 were included in the analysis. They represent postcodes (communities) with a much higher or much lower prevalence than that seen in the decile overall and may represent familial clustering or a particularly high density of a single minority ethnic group, both of which are known to be associated with diabetes prevalence. The postcode with zero prevalence seen in decile 1 (lowest SES) in Figure 3-2 is a remote area and may represent lack of services and/or registration with the NDSS.

In Figure 3-2, T1DM data are presented in box and whisker plots with outliers indicated by the symbol ˚. The mean prevalence of T1DM was 0.588% of the population (IQR 0.49–0.66, SD 0.161).



SEIFA decile	% diabetes
1	**.624**
2	.637
3	.645
4	.658
5	.597
6	.598
7	.547
8	544
9	.520
10	**.492**

Figure 3-2 Population prevalence (percentage) of T1DM in Australia by SEIFA decile from 1 (lowest SES) to 10 (highest SES)

The national prevalence of T1DM is known to be 0.5% and previously this has been reported as not being associated with SES [308]. The results showed that population prevalence of T1DM in this study followed a small but statistically significant inverse gradient with higher SES deciles having an overall lower population prevalence of T1DM (Figure 3-2). The correlation coefficient for association between SEIFA decile and the percentage of the population with T1DM was –.397 (Spearman's p <0.001, appendix 3-1).

3.6.2 Type 1 Diabetes Mellitus end stage renal disease

Incidence rates (new presentations) of T1DM ESRD in Australia are shown in Table 3-1. Rates have been steadily increasing but there was a much lower incidence for people of ATSI descent.

Table 3-1 T1DM ESRD incidence per million population with the lower and upper bound values for the period 2008–2012

Year	Australia	ATSI	Maori (NZ)
2008	5.90 (4.69–7.34)	0.26 (0.03–0.95)	6.22 (1.69–15.93)
2009	4.86 (3.77–6.16)	0.51 (0.14–1.33)	6.12 (1.66–15.68)
2010	5.43 (4.29–6.79)	0.63 (0.20–1.48)	3.01 (0.36–10.88)
2011	6.50 (5.25–7.96)	0.12 (0.003–0.69)	5.93 (1.61–15.20)
2012	8.27 (6.85–9.89)	0.36 (0.07–1.06)	*n/a

The crude incidence of ESRD due to any cause per million population was 110 [297] with T1DM representing about 7.5% of cases in 2012.

3.6.2.1 Age of presentation with T1DM ESRD

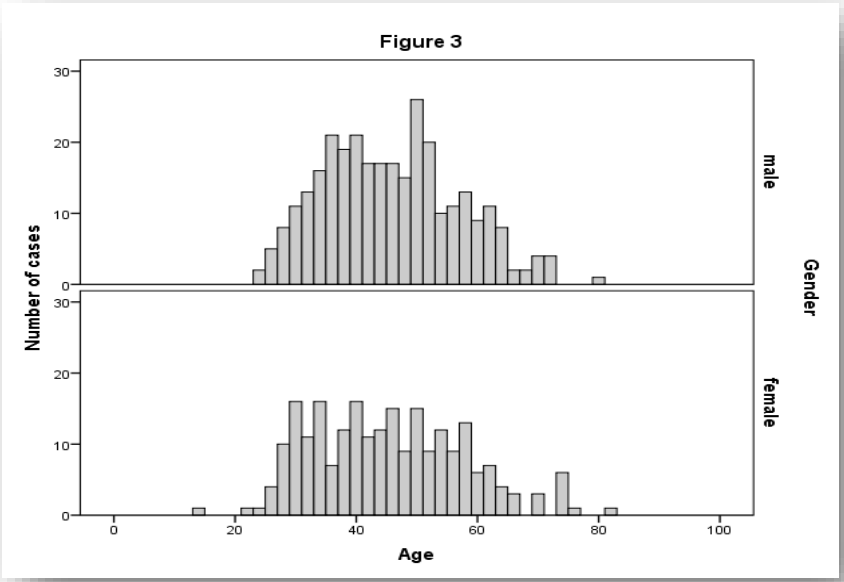


Figure 3-3 Age of presentation with T1DM ESRD by gender

Between 2008 and 2012 the age distribution of incident ESRD cases for males and females was normally distributed (Figure 3-3). The mean age was 45 but with a large variation, and very few cases were diagnosed after the age of 60 years. More males developed ESRD than

females (56.3% versus 43.3%). The youngest person diagnosed with T1DM ESRD in the period was aged 14 years and the oldest was 81 years. Age of onset of ESRD in T1DM did not differ significantly by gender (Table 3-2).

Table 3-2 Mean age of presentation with T1DM ESRD by gender

Gender	n	Mean	SD	C I of the difference
Male	303	**45.30**	11.1	–1.494–2.534
Female	231	**44.78**	12.4	
Levine's *p*=0.76	(skew=0.342, kurtosis= –.374).	*p*=.612		

3.6.2.2 ESRD, SES, age and gender

There were similar numbers of incident cases of T1DM ESRD in each SEIFA decile from the lowest SES (1) through to 9 (range 43–50) with a slightly smaller number (32) in decile 10, the most advantaged SES. There was little difference in age of presentation by SES, with the mean age being almost identical between deciles 1 (47.31) and 10 (47.19).

A multivariate one-way ANOVA demonstrated no significant difference between the age of presentation in relation to SES for males or females (*p*=.766, *p*=.289, appendix 3-2). However, males of low SES were at increased risk of ESRD compared with females of low SES (RR 1.20, CI 1.002–1.459, *p*=.043) (table 3-3, appendix 3-3).

Table 3-3 Percentage of T1DM ESRD cases by gender and SES

	Low SES	High SES
Males	**55.3**	**44.7**
Females	45.7	54.3

These results need to be interpreted with caution because an examination of the population at risk is necessary to understand relative risk fully. No clear relationship was seen between RR of ESRD and SES decile. The range was from 0.88 in decile 6 to 1.33 in decile 3, with the RR being almost identical for deciles 1 and 10 (appendix 3-4). A summary of these findings is given in table 3-4.

Table 3-4 Relative risk of T1DM ESRD with cumulative crude incidence per 100,000 population and comparing low SES and high SES

SES	Number of cases	Total population	Crude incidence	RR
Low	232	3,721,179	6.23	**1.04**
High	222	3,713,313	5.97	

3.6.3 Type 1 Diabetes Mellitus and Type 2 Diabetes Mellitus end stage renal disease in Aboriginal and Torres Strait Islanders, Maori and Pacific Islanders

The number of ATSI and Maori and Pacific Islanders with ESRD from T1DM was very low, while the RR for all other Australians and New Zealanders was 2.99 (CI 2.14–4.18, p <0.001) [309]. For ESRD in the setting of T2DM the RR was 6.57 for Indigenous Australians (CI 6.04–7.14, p<0.001) and 6.48 for Maori and Pacific Islanders (CI 6.02–6.97, p<0.001) [309].

3.7 Discussion

3.7.1 Population prevalence of Diabetes Mellitus

The incidence of diabetes in the Australian population follows a pronounced inverse social gradient, increasing incrementally as SES falls. It was previously reported that the national prevalence of diabetes was 5.4% and that low SES was associated with a threefold higher prevalence of T2DM [310], but the striking and uniform social gradient demonstrated in this study has not been described previously. A recent study in Germany also demonstrated a similar picture of a social gradient in the prevalence of diabetes [311]. Across the population there was also a statistically significant gradient with the highest incidence also seen in areas with lowest SES. Although the incidence of T1DM shows a large variation worldwide, environmental or genetic causation has not yet been determined [37] and this is the first study to describe an inverse relationship between incidence of T1DM and SES.

3.7.2 Type 1 Diabetes Mellitus and end stage renal disease

The mean age of presentation with T1DM ESRD (45 years) is significantly lower than for all aetiology (other than paediatric-specific ESRD) with the national mean age of presentation with ESRD being 60 years [286]. There were few T1DM ESRD cases diagnosed after the age of 60 years, probably because of higher mortality seen in T1DM [312]. There was an excess of ESRD for males with T1DM in Australia and this may be due to several factors. There is an

overall higher incidence of T1DM in males [38], higher cardiac mortality has been demonstrated for females with T1DM [313, 314] resulting in death before the development of ESRD, and a higher risk for males of developing ESRD regardless of disease aetiology [286]. This study has also shown the increased risk of ESRD for males of low SES. There is considerable evidence for poorer outcomes in people of low SES with T1DM [132, 136] and of the higher risk of ESRD for males [207, 215], however no other studies to date have found an increased risk of ESRD only for males of low SES. A recent Swedish study found that being of low SES increased the risk of death two- or three-fold, and that males were more likely to die overall, but this was not explicitly examined in relation to males of low SES [315]. This contradictory evidence may relate to different populations with different baseline risk factors and more Australian research is warranted to explore the higher risk of ESRD for males of low SES to determine if it is an adverse outcome or in fact a survival advantage.

3.7.3 Aboriginal and Torres Strait Islanders, Maori and Pacific Islanders

The very low incidence of T1DM ESRD in the ATSI and Maori and Pacific Islander populations, in the face of their extremely high incidence of T2DM ESRD, is difficult to interpret for a number of reasons. The issue of survival may be an underlying factor because there is a well-demonstrated intergenerational cyclical disadvantage experienced by Indigenous people as a result of colonisation [282]. ATSI people have the worst health, lowest life expectancy and highest child mortality rates of all Australians [18] and death rates due to diabetes, which is generally reported as T2DM in this population, are 30 times higher than in other Australians [316]. In addition, there appears to be nothing in the literature on young adult onset T1DM in the ATSI population despite Australian data demonstrating that almost 50% of cases of T1DM are diagnosed after the age of 15 years [24, 295]. Studies conducted overseas suggest that up to 30% of cases diagnosed as T2DM test positive for autoantibodies and could be due to T1DM or late onset autoimmune diabetes in adults (LADA) [317]. This raises a second possibility, that of misclassification and conflation of T1DM with T2DM, which could lead to incorrect treatment and earlier death. These findings in relation to T1DM suggest a need to investigate diabetes classification in the ATSI population with autoantibody and C-peptide testing. It is also worth noting that in regard to the grossly inflated risk of ESRD due to T2DM in ATSI, Maori and Pacific Islanders, these populations also have the lowest SES, and being an ethnic minority and of low SES are independently associated with poor outcomes in diabetes [191].

3.8 Study strengths and limitations

All new cases of ESRD requiring renal replacement therapy are registered with ANZDATA and the data are therefore considered to be complete. The use of postcodes as a proxy for individual SES does have limitations, because SEIFA data which are disaggregated are then aggregated into a single unit. While this is a common approach in social research, the limitation of this process for accurate determination of an individual's SES and the risk of ecological fallacy is acknowledged. The use of SEIFA categories has repeatedly shown that health status is related to socioeconomic status, but offers little understanding or direction beyond that to identify exactly which facets of socioeconomic disadvantage lead to health disadvantage [318]. The association between SES and ESRD could be a consequence of people moving to an area of low SES after diagnosis because of chronic illness and reduced capacity for income. In addition, there are competing risks for ESRD development in relation to the high cardiac mortality seen in T1DM. The absence of postcodes for New Zealand cases of ESRD also impeded the study of differential outcomes in relation to SES and consequently this part of the study was confined to Australia. With regard to the population prevalence of diabetes Australian residents are required to register with the NDSS to obtain consumables for SMBG and insulin prescriptions at subsidised cost and hence this register provides good data coverage of both T1DM and T2DM. A limitation of this phase of the research was the use of only 454 Australian postcodes to determine diabetes prevalence. While this sample is highly representative and approximately one third of the total Australian population, to gain full understanding of the relationship between diabetes prevalence and SES it would be necessary to examine population prevalence across all Australian postcodes. A diagnosis bias to T2DM for a case of T1DM cannot be excluded when using registry data and there may be inconsistent classification of ethnicity for ATSI, Maori and Pacific Islanders. Data relating to prevalence and renal outcomes of T1DM in the ATSI, Maori and Pacific Islander population is thought to be widely underreported and insufficient for conclusions to be drawn.

This study makes a unique contribution to the evidence in describing the inverse gradient seen for diabetes prevalence and low SES which has implications for practitioners in health promotion and for those responsible for the planning of health services within Australia.

3.9 Conclusion

It has previously been demonstrated using ANZDATA that populations in Australia of low SES carry a heavier burden of ESRD. This study of T1DM ESRD over a five-year period shows that there appears to be an increased risk only for males of low SES. Other countries have reported an inverse relationship between SES and mortality in T1DM [132-136] with a much higher likelihood of death for people who are socioeconomically disadvantaged and this disparity is more pronounced in T1DM than in T2DM [137]. ESRD may not be the most suitable measure of disproportionate outcomes in T1DM in Australia and New Zealand, given that a high mortality from the disease for people of low SES before reaching ESRD is likely. For this reason, it remains uncertain whether this study demonstrates an increased risk for males or a survival advantage. While there are doubts about classification of diabetes in the ATSI population, the grossly inflated risk of DN ESRD for ATSI, Maori and Pacific Islanders over the time period studied is a shared disparate outcome across these three minority populations that has changed little in the past twenty years.

3.10 Acknowledgement

The data reported here have been supplied by the Australia and New Zealand Dialysis and Transplant Registry. The interpretation and reporting of these data are the responsibility of the author and should not be seen as an official policy or interpretation of the Australia and New Zealand Dialysis and Transplant Registry.

CHAPTER 4: STUDY 2 A RETROSPECTIVE COHORT STUDY OF PATTERNS OF CARE AND HEALTH OUTCOMES IN TYPE 1 DIABETES MELLITUS

4.1 Introduction

Treatment of type 1 diabetes mellitus (T1DM) is designed to reduce elevated blood glucose levels, which if persistent cause damage to small and large blood vessels leading to long term severe health problems. Assessment of glycaemic control is through the measurement of glycated haemoglobin (HbA1c) in the blood and glycaemia management in T1DM is considered optimum when HbA1c is maintained at a level of 6.5–7% [24]. The incidence and progression of both acute and chronic complications in T1DM is favourably influenced by tight glycaemic control, achieved through intensive therapies involving frequent blood glucose monitoring and multiple daily injections of insulin [63, 76]. Recent studies have demonstrated persistently low rates of achievement of glycaemic control targets while trends in T1DM do not show continued improvements in survival [60], with average life expectancy for people with T1DM in Australia being 12 years less than for the general population [312]. Although a near normal blood glucose level is needed to reduce the potential of complications [69] it remains an insurmountable challenge for many people with T1DM [41]. Renal complications commonly occur within 10 years of diagnosis and as damage to the kidneys progresses the presence of proteinuria is a powerful predictor of increased mortality [72, 74]. Up to one-quarter of people with T1DM and kidney disease die from cardiac disease before reaching end stage renal disease (ESRD) [21]. The most recent evidence suggests that acute complications of diabetes are more likely to occur in females, in a setting of clinic non-attendance, psychological problems and low socioeconomic status (SES) [85]. The current recommendations for clinic attendance are that people with T1DM be monitored 3-4 times per year and assessed by a multidisciplinary team for glycaemic control and surveillance of complications including kidney disease at minimum once a year [319], and this has been demonstrated to improve outcomes when occurring in an integrated clinical care model at a tertiary health care centre [62, 144, 320, 321]. However, access to and use of health care services can be affected by social determinants of health (SDH), with negative consequences on individual capacity to navigate and engage with health care services. The performance of

services in relation to managing people with chronic illness is a strong determinant of health outcomes.

4.2 Aims and objectives

The aim of this study was to explore how SDH such as gender, the age of disease onset and SES affect glycaemic control, engagement with health services and the development of complications in a cohort of Australian adults and children with T1DM.

The broad objectives were to:

a) Describe a cohort of individuals with T1DM in relation to their baseline characteristics including gender, age, and age of disease onset;
b) Audit the health service usage data to explore patterns of care, glycaemic control, morbidity and mortality with a specific focus on kidney disease;
c) Analyse for correlations between patterns of care and outcomes and gender, age of disease onset and SES.

4.2.1 The specific hypotheses that will be tested are described in full in section 4.3.3The role this study has in adding to the current evidence

This study is a critical examination of an endocrinology service that aims to meet the needs of more than 1000 adults and children with T1DM. This examination includes not only the usual bench marks such as glycaemic control and engagement with the service also includes an examination of the way in which the service conducts standard practices in relation to screening for glycaemic control and the presence of kidney disease. Regular screening for kidney disease is vitally important in T1DM as estimated glomerular filtration rate (eGFR) slopes predict the risk of ESRD better than HbA1c profiles [322]. The health service from which the data to conduct this research is drawn from represents a large geographical area of Australia servicing children and adults with T1DM across three hospitals including outpatient clinical services with multiple health care providers. This is thought to represent the broad configuration of T1DM health care services seen in other Australian cities and the results are likely to be similar if the study were to be conducted elsewhere in a metropolitan region. This increases the generalizability and clinical relevance of the findings and this studies results have the potential given its location and large size to be generalised to other populations of people with T1DM within Australia to identify at risk groups.

4.3 Methods

The research used a retrospective cohort design whereby existing data were collected retrospectively for a cohort of adults and children diagnosed with T1DM and under the care of the endocrinology department of a major metropolitian tertiary care centre. Retrosptective cohort designs allow researchers to study a population that shares a common characteristic to make comparions in specific outcomes [7]. Data (table 4-1) were obtained from the Open Architecture Clinical Information System (OACIS), a software program used by the South Australian Health Department to archive data from all health care encounters within the South Australian public health care system including for pathology and other clinical testing. The endocrinolgy service of this major metropolitican tertiary care centre practices point of care testing for HbA1c.

Table 4-1 Data used on individual patient characteristics and the clinical variables of interest in this study

Variable of interest	Definition of data that describes this variable
Gender	Male or female
Age	Age at the time of the study
Age of onset of T1DM	Age at diagnosis
Measures of glycaemic control	Most recent HbA1c measurement in the preceding twelve months 10-year mean HbA1c calculation
Measures of kidney disease	Screening for kidney function determined as having either a serum creatinine record or a laboratory test of urinary albumin or protein ¶
Patterns of clinic attendance	Current care status defined as: Regular endocrinology care (at least yearly) Erratic endocrinonology care (attending endocrinology clinic but less than yearly) Other care (not attending endocrinology but using other services such as eye, podiatry, cardiology, emergency department in the preceeding twelve months) Out of tertiary care (no recent attendance to the service)
Socieconomic status (SES)	Socio-Economic Index for Areas (SEIFA) using residential postcode as a proxy indicator for SES. SEIFA ranks areas in

	Australia according to relative socioeconomic advantage based on information from the five-yearly Census [304].
Death	Yes or No and age at which death occurred.

¶ The use of reagent strips to test urine to detect kidney disease is inaccurate because reagent strips test predominantly for albumin and do not detect tubular or low molecular weight proteinuria. Only a laboratory assessed urine sample can be understood as a valid measure of kidney function [323]. The use of creatinine to determine eGFR in children has not been validated. Accuracy and sensitivity to small changes are sacrificed when looking at low serum creatinine levels, because creatinine will still be in the normal range with up to half of kidney function lost [323]. Therefore, children aged below 18 have not been included in this analysis (but they have been included in kidney function screening). For consistency in assessment only eGFR recorded after April 2013 are included because at this time the CKD-EPI equation to assess eGFR replaced the MDRD equation and eGFR was then expressed as normal if > 90 [321].

4.3.1 Ethical considerations

4.3.1.1 Confidentiality

Ethical approval for the study was obtained from Southern Adelaide Clinical Human Research Ethics Committee (SACHREC) (reference number 564.13, appendix 4-1). Individual consent was not sought for this phase of the research because, in accordance with the National Statement on Ethical Conduct in Human Research,

a) The study involves negligible risk;
b) It is impracticable to obtain consent from a group of patients this size and there is no known reason as to why consent would not be given if asked;
c) The data once collected are aggregated, de-identified and maintained to ensure confidentaility;
d) There are potential benefits for the organisation to examine the outcomes of service delivery.

4.3.1.2 Data and privacy

The researcher stored all data on password-protected computers and servers. In accordance with the SA *Health Code of Fair Information Practice* the collection of identified information in the initial phase of the research was directly related to the primary purpose of original collection and was intended to evaluate and audit the provision of a service. No new information was collected and only existing data were analysed. Personal health information may be used or disclosed provided the research has been approved by a Departmental or Divisional Research and Ethics Committee in accordance with NHMRC guidelines issued under S.95A of the Commonwealth Privacy Act (SA *Health Code of Fair Information*

Practice).

4.3.2 Sample frame

There were 1,470 people with T1DM registered under the care of the endocrinology service in this geographical catchment area which offers ambulatory care, primary health care and services three hospitals. The range of year of diagnosis was from 1936 to 2013 and the cohort is large enough and diverse enough to be representative making the study findings generalizable.

The medical record numbers were released to the researcher in January 2014 following approval from the SACHREC. All cases were described as T1DM and insulin dependent, however there are many different classifications of diabetes. Antibody testing in diabetes to aid diagnosis is thought to lack specificity and current recommendations are that the diagnosis be made on clinical presentation and progression [324]. A small number of cases in the dataset had records suggestive of latent autoimmune diabetes in adults (LADA), which is more closely related to T1DM than type 2 diabetes mellitus (T2DM) in its characteristics of a diagnosis before age 50 years, the presence of hyperglycaemia and the likelihood of requiring insulin replacement therapy [325]. Given the size and age of this dataset it is probable some cases of LADA had been diagnosed as T1DM but because all LADA cases are insulin dependent and likely to exhibit a similar progression of disease the suspected cases were included in the analysis. There is some potential for error in classification, with patients initially being included in the dataset before diagnostic test results are received and the inadvertent inclusion of cases of T2DM. For this reason, a number of exclusions have been made to ensure the validity of the study and these are detailed in table 4-2.

Table 4-2 Rationale for inclusion or exclusion of cases from the study

Patient type	Action
Age 29 years or below at diagnosis	Accept as T1DM
Age 30–50 years at diagnosis	Confirm diagnosis with one of Evidence of antibody testing; Evidence of absent or extremely low C-Peptide; Documented diagnosis of T1DM on a hospital admission. In the absence of confirmation – case is excluded.

Age 50 years and above at diagnosis	If no documentation in electronic medical records of late onset T1DM, exclude on basis of age at diagnosis.

It is believed that this process has given the strongest likelihood of a homogenous group that is large enough to test the hypothesis and is further detailed in table 4-3.

Table 4-3 Process of case exclusions from the study

Number of cases	Justification for exclusion
1,470 cases in original data set	• 124 duplicate cases • 35 incorrect medical record numbers or implausible patient details
1,311 cases refined data set	• 138 cases of T2DM misclassified as T1DM • 60 cases of mature onset diabetes that were unable to be confirmed as T1DM • 42 cases in which the year of diagnosis was unknown and disease duration could not be established
1,071 cases final data set	• Valid cases retained for analysis

All cases were retained in the original dataset and deleted from the final dataset before analysis. The deleted cases are described in Appendix 4-2. The dataset was built in SPSS (IBM Corp., SPSS Statistics for Windows, Version 21, Armonk, NY: IBM Corp. 2012) with each case being given a unique identifying study code for data collection. The clinical data for each case were drawn retrospectively from OACIS with a census date of 31 January 2014.

4.3.3 Hypotheses

Propositions or statements of a relationship are generated as hypotheses which have at least two variables, can be predictive, are logical, falsifiable and can be empirically tested to give a 95% probability that the results are not due to chance alone [302]. Hypotheses based on the literature review were used to determine the data to be collected and the proposed analysis to meet the aims and objectives of the study and the rationale for each is presented below.

4.3.3.1 Gender as a social determinant of health

Despite evidence of the role of puberty and genetics in T1DM there is credible evidence to suggest that outcomes can be affected by differential behaviours in males and females. For example, being male, young and newly diagnosed is associated with poorest concordance with frequent self-monitoring of blood glucose [98], insulin omission is a common occurrence to induce weight loss particularly for young girls, and HbA1c levels in those who skip insulin to reduce weight are raised sixfold [226]. In addition, being male and diagnosed after the age of 20 requires diligent screening and management because it carries a higher risk of ESRD than for all other ages of male onset and females irrespective of age of onset [215]. The hypothesis that will be tested is gender as a social determinant of health influences health service engagement, glycaemic control and disease outcomes in T1DM. This hypothesis proposes that gender is a SDH and explores whether gender differences can be demonstrated in the uptake of health care services, glycaemic control and disease outcomes.

4.3.3.2 Age of onset of Type 1 Diabetes Mellitus as a social determinant of health

Age of diagnosis is known to affect the development of future complications. Diagnosis before puberty is thought to be associated with a reduced incidence of complications and diagnosis during puberty leads to demonstrably poorer glycaemic control and the subsequent onset of complications [205]. In puberty there is often a period of biological insulin resistance that makes managing T1DM at this time particularly difficult [102] and there are also behavioural changes seen in emerging adulthood that relate to autonomy and self-determination [109, 110]. Diagnosis during this state of flux can impact on the successful self-management of a chronic disease over the life span and there is evidence to suggest that outcomes can be worse in late onset short duration disease [81]. The majority of evidence relating to age of onset suggests that behavioural factors have the most prominence and for this reason age of disease onset is examined in this analysis as a social rather than a biological determinant of health. The hypothesis that will be tested is that age of onset in T1DM influences subsequent health service engagement, glycaemic control and disease outcomes.

4.3.3.3 Socioeconomic status as a social determinant of health

There is a known inverse relationship between SES and morbidity and mortality in T1DM [132-136] but this evidence is drawn from other countries and has not been well studied in Australia, a country stated to have a universal health service that provides comprehensive health care irrespective of income [326]. The hypothesis that will be tested is that SES as a

SDH influences subsequent health service engagement, glycaemic control and disease outcomes in T1DM. This analysis is designed to determine whether SES is a SDH for the cohort, to inform a deeper exploration of this in study 3 (chapter 5).

4.3.3.4 *Use of health care services as a social determinant of health is associated with variation in glycaemic control and disease outcomes in Type 1 Diabetes Mellitus*

Access to health care is a social determinant of health not only in relation to geographical proximity but in 'realised' access [9], which is reflected in sustained engagement with services. Receiving specialist care in a tertiary health care centre is associated with the best outcomes in T1DM [86] and the consultation experience is central to keeping young adults engaged with services [240]. Disengagement with care can have a profound effect on health trajectory in T1DM [242], leading to the absence of surveillance for complications. Studies in Australia have shown marked attrition from health care services of young adults with T1DM, with 50% lost to care after five years [255]. In addition, while studies of T1DM in people of low SES tend to cite poor self-care behaviours, it has also been shown that people who are socially and economically disadvantaged have particular difficulty navigating the health system and building trusting relationships with health care providers [16, 327]. The hypothesis that will be tested is that the use of health care services as a SDH is associated with variation in glycaemic control and disease outcomes in T1DM. This study will undertake an in-depth analysis of health care access for the cohort, seeking to determine variation in the type of care accessed in relation to the SDH.

4.4 Analysis of Data

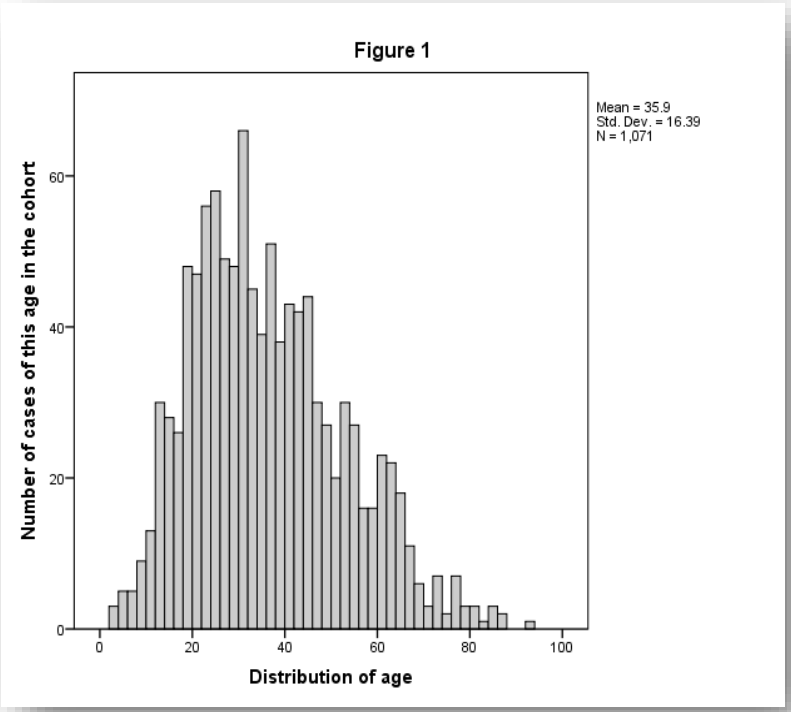
Relationships in the categorical data were tested using chi-squared and Phi for two groups, and Cramer's V for more than two groups. For the continuous data, tests of normality were conducted which have an assumption that the variance between the groups is normally distributed with a p value of <.05 demonstrating that the data has violated the assumption of normality [328]. Where the continuous dependent variable (DV) was not normally distributed and the independent variable (IV) had two categories, the Mann–Whitney U was used, and for more than two categories the non-parametric Kruskal–Wallis test was used [306, 307]. The ten year HbA1c data were examined with the use of a regression equation to determine the impact of disease duration.

Multiple regression analysis was then conducted to examine the relationship between continuous data IV's and the continuous DV's to assess how strong the bivariate relationships found are (significance level < 0.05) and to eliminate the possibility of a type 1 error which occurs when the alternative hypothesis has been accepted when it is in fact it is not true. Multiple regression is a statistical technique that allows the researcher to assess the relationship between one DV and several IV's and the term regression is used when the intention is to assess the best predictor of a DV but not however to determine causation [329].

With regard to the bivariate relationships found logistic regression modelling has been conducted which again allows the researcher to determine the best predictor of a given outcome and to eliminate the possibility of type 1 error. The goal in logistic regression modelling is to find the best combination of IV's to predict the observed outcome using 'goodness of fit' tests to choose the model that does the best job of predicting with the fewest predictors [329]. The IV's that were found in bivariate analysis to have a statistically significant association with the outcome or DV were used in the model and the DV was recoded to become binary for the logistic regression modelling with the discrete outcome of interest being coded '1' and the absence of this outcome being coded as '0'. All predictors were selected on carefully considered theoretical grounds before being used in the model to avoid an over fitted model, and were selected simply because they have the potential to affect the outcome of interest. A risk in the interpretation of results in logistic regression is if the IV's have 'multicollinearity' and have a close relationship with each other. The ideal model has IV's that are not closely related to each other but the capability of having a close relationship with the outcome [330]. The analysis has used a direct logistic regression where all of the predictors are added at the same time to the model which is the method of choice if there is no explicit statement about the order of importance and allows the model to control for the effect of the other predictors [306]. For the remaining analysis relative risk (RR) was calculated in a standard binomial way and confidence intervals generated in SPSS.

4.5 Results

4.5.1 Description of the cohort



There was a wide range of age in the cohort (Figure 4-1) which was not normally distributed (Kolmogorov–Smirnov and Shapiro–Wilk tests of normality $p<.001$).

Figure 4-1 Age distribution within the cohort

Due to the non-normally distributed nature of the data the median age is reported which was 33 years (SD 16.39) and 11% are under the age of 18.

Just over half of the cohort were male (52.1%).

Age of onset of T1DM is shown in Figure 4-2. The youngest age of disease onset was under one year and the oldest was 54 years of age. The commonest age of onset was in puberty and 22.5% of the cohort were diagnosed after the age of 23 years of age (see table 4-4). This is in line with the reported age of onset distribution in Australia [295] making the cohort representative of the broader population.

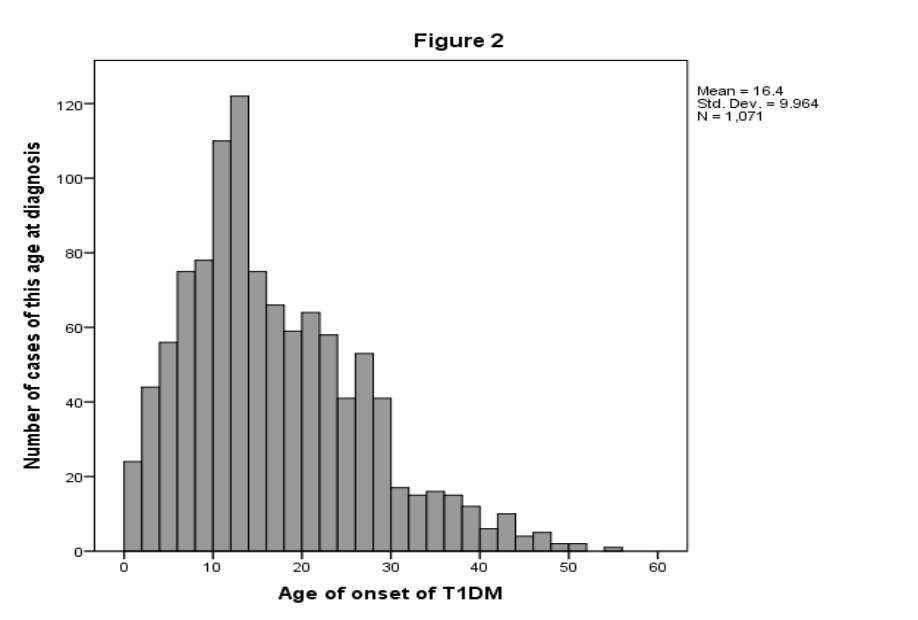


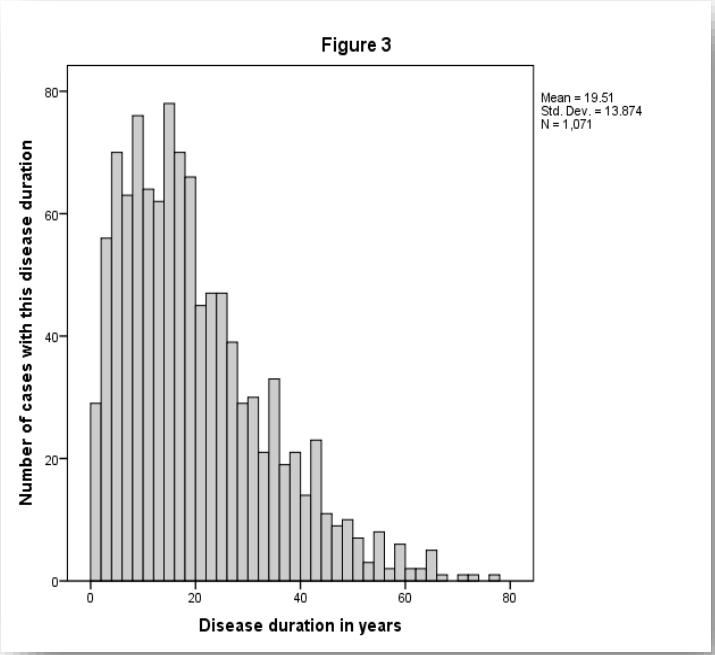
Figure 4-2 Age of onset of T1DM in the cohort

Table 4-4 Age of onset by age categories

Age of onset (years)	Number of cases	%
0–5	124	11.6
6–10	202	18.9
11–16	**297**	**27.7**
17–23	208	19.4
24–30	143	13.4
30+	97	9.1
Total	1071	100.0

The median age of diagnosis for the cohort was 14 years (SD 9.96), and was slightly higher for males (15 years of age versus 13 years of age). There was also a slight excess of male diagnosis after the age of 23 (24% versus 20%), which is in line with the reported sex distribution in Australia [295].

The median disease duration for the cohort at the time of the study was 17 years.



Disease duration ranged from zero to 76 years and was highly skewed, reflecting both the retrospective design of the study and the known reduced life expectancy for people with T1DM.

Figure 4-3 Disease duration in years

4.5.2 Deaths observed in the cohort

There were 66 deaths recorded preceding the census date and 30.9% of these people died before reaching the age of 45 years. More males than females died (39 versus 27) but the difference was not statistically significant (*p*=.241, appendix 4-5). As shown in table 4-5, 56.1% of deaths occurred in people with late onset disease who were aged 17 or over at diagnosis.

Table 4-5 Percentage of deaths by age of onset

Age of onset (years)	Percentage of cohort (%)	Percentage of deaths (%)
0–5	11.6	4.5
6–10	18.9	15.2
11–16	27.7	24.2
17–23	**19.4**	**25.8**
24+	**22.5**	**30.3**

Within the cohort the RR for death in late onset disease compared with onset before the age of 17 was 1.77 (CI 1.108–2.841, *p*=.016).

Given the accumulation of diabetic complications with disease duration it could reasonably be expected that death would be associated with disease duration.

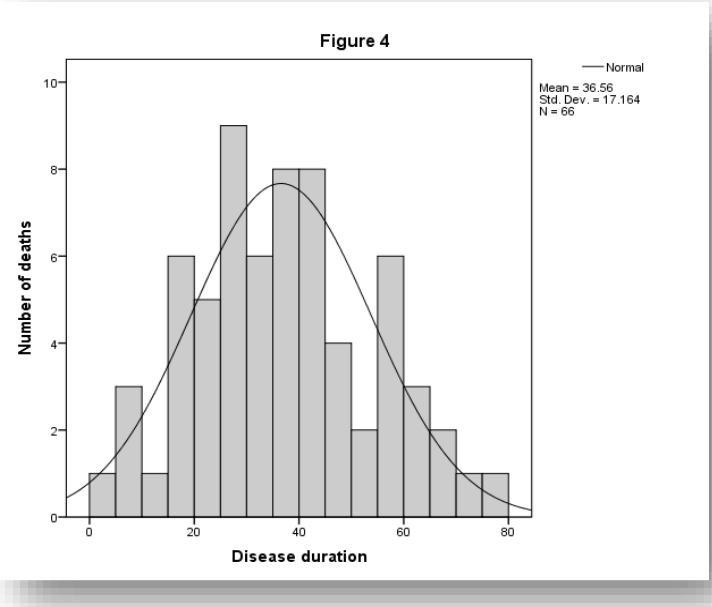


Figure 4-4 shows that there was a close to normal distribution of disease duration in the cases of observed deaths (skew=0.251, kurtosis=0.502) suggesting that death was not associated with long disease duration but with other causes.

Figure 4-4 Deaths observed and disease duration

4.5.3 Use of endocrinology clinics and other services in the preceding twelve months

The cohort was examined for their health care usage patterns and allocated into groups according to their use of services in the preceding year. The data base is comprehensive and captures all encounters with the service including those provided by nursing and allied health practitioners. Therefore a determination can be made that an individual is no longer receiving any care from the service. Accessing an endocrinology clinic on at least one occasion in the preceding year was considered to be the best model of care and first in the hierarchical ranking of service use.

Only 48.5% of the cohort attended endocrinology services in the preceding 12 months. A further 20% received erratic endocrinology care, defined as being seen by endocrinology services but less than the services recommended minimum of annually, with evidence of attendance with endocrinology services at some point in the preceding 24 months.

There were a further 20% who used other hospital services such as the emergency department, eye, cardiology and renal clinics without attendance at an endocrinology clinic in the preceding year (however, they may have accessed care in private clinics).

The remaining 11.5% had no activity at all and were assumed to be disengaged from endocrinology care or no longer residing in South Australia (out of care).

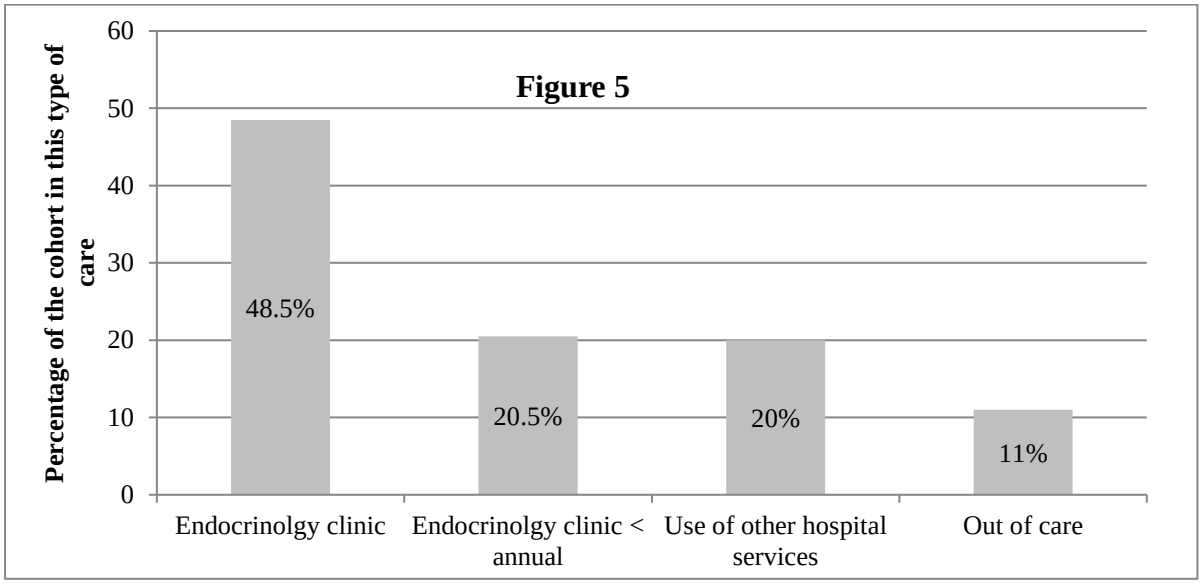


Figure 4-5 Type of care received in last 12 months

The cohort is grouped in figure 4-5 to their current type of care defined as attended an endocrinology clinic in the preceding year, attended an endocrinology clinic not in the preceding year but in the last 24 months, using other hospital services such as the emergency department, eye, cardiology and renal clinics or not accessing any type of care.

There was no statistically significant relationship between gender and type of care (p=.549, appendix 4-3) and hypothesis 4.3.3.1 differential service use according to gender is not supported.

Age however was significantly associated with type of care, with high levels of engagement with endocrinology services for younger people and a continuous downward trend for older age groups (Cramer's V=.283, p<.001; appendix 4-4) (Figure 4-6).

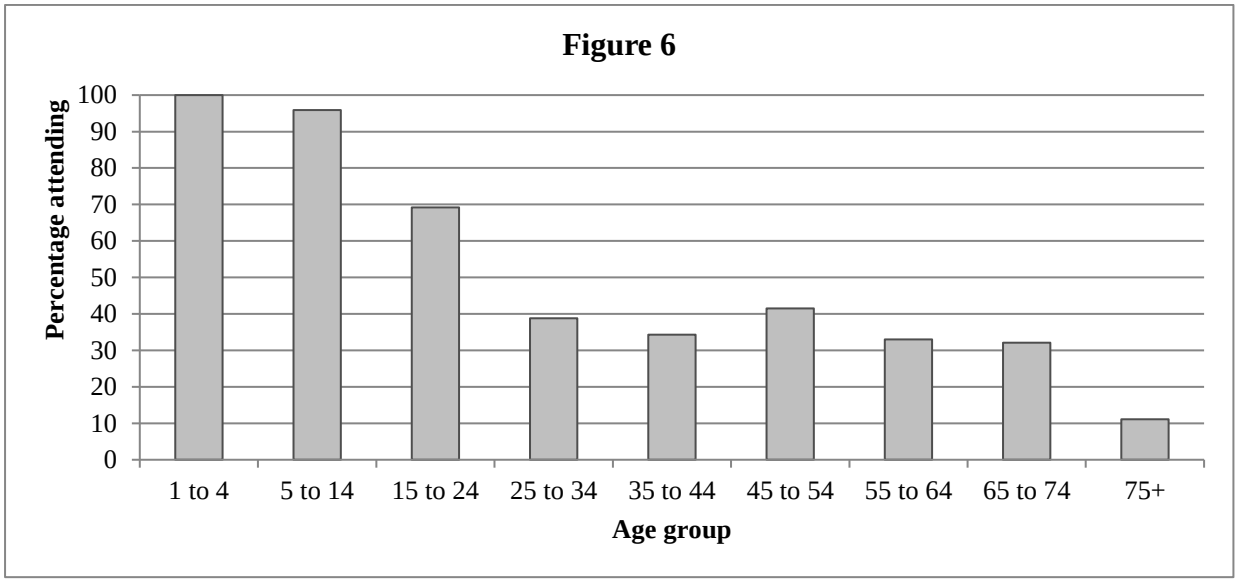
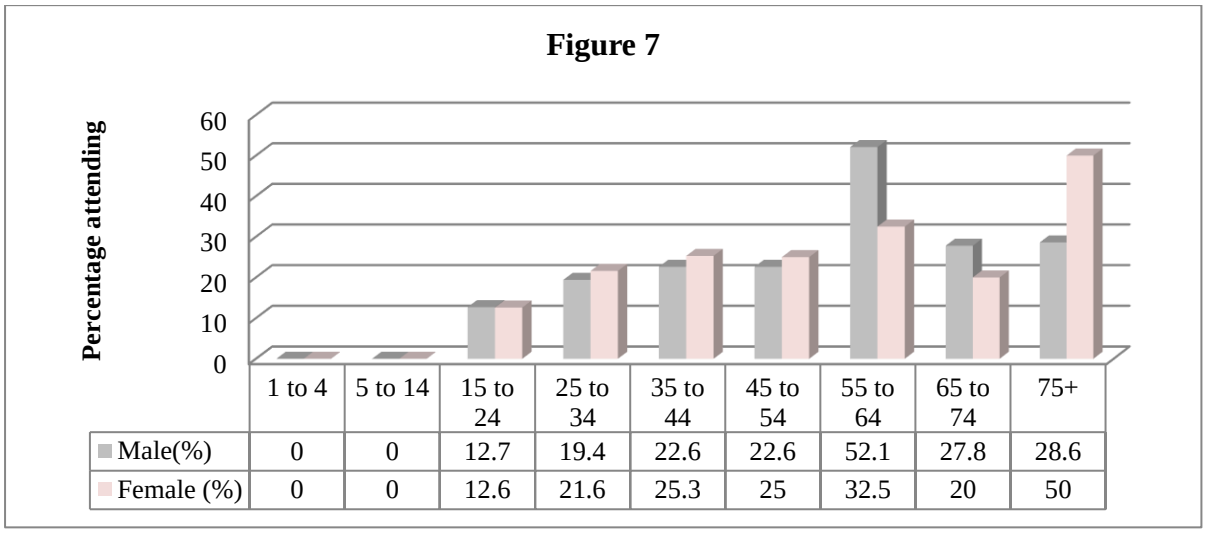


Figure 4-6 Percentage of cohort attending endocrinology clinic by age group

This occurred in tandem with an increase in the use of other services without attendance at an endocrinology clinic with increasing age (Figure 4-7).



	1 to 4	5 to 14	15 to 24	25 to 34	35 to 44	45 to 54	55 to 64	65 to 74	75+
Male(%)	0	0	12.7	19.4	22.6	22.6	52.1	27.8	28.6
Female (%)	0	0	12.6	21.6	25.3	25	32.5	20	50

Figure 4-7 Percentage of cohort using other services without attendance at an endocrinology clinic by age group

Late onset disease is associated with lower use of endocrinology services overall supporting hypothesis 4.3.3.2 that age of disease onset would be associated with differential service usage.

Tables 4-6 and 4-7 demonstrate the percentage of the cohort in each age of onset category by type of service for males and females in the preceding twelve months.

Table 4-6 Males by age of disease onset and type of care accessed in the preceding twelve months

Age of onset (years)	Regular endocrinology care (%)	Erratic endocrinology care (%)	Other services (%)	Out of care (%)
0–5	55.6	22.2	14.3	7.9
6–10	52.2	12.0	15.2	14.1
11–16	41.2	19.6	22.9	9.8
17–23	**38.6**	20.2	17.5	15.8
24–30	**35.0**	23.8	22.5	7.5
30+	42.9	14.3	25.0	**18.9**

Table 4-7 Females by age of disease onset and type of care accessed in the preceding twelve months

Age of onset	Regular endocrinology care	Erratic endocrinology care	Other services	Out of care
0–5	65.6	9.8	13.1	6.6
6–10	59.1	11.8	15.5	10.0
11–16	46.5	21.5	19.4	8.3
17–23	**38.3**	16.0	20.2	17.0
24–30	**38.1**	28.6	15.9	9.5
30+	**31.7**	29.3	34.1	2.4

Males and females diagnosed in adulthood had lower engagement with endocrinology care and this was particularly striking for females diagnosed after the age of 30, with a reduction of over 50% in engagement (p=.001, appendix 4-8). Males diagnosed after the age of 30 comprised the highest proportion of people out of care.

4.5.4 HbA1c

Only 57.4% of the cohort had HbA1c measured in the preceding twelve months (Figure 4-8). Being in regular endocrinology care was associated with higher rates of HbA1c measurement, with 91.58% of those seen in the endocrinology clinic having HbA1c recorded (Phi=.659, *p* <.001, appendix 4-9).

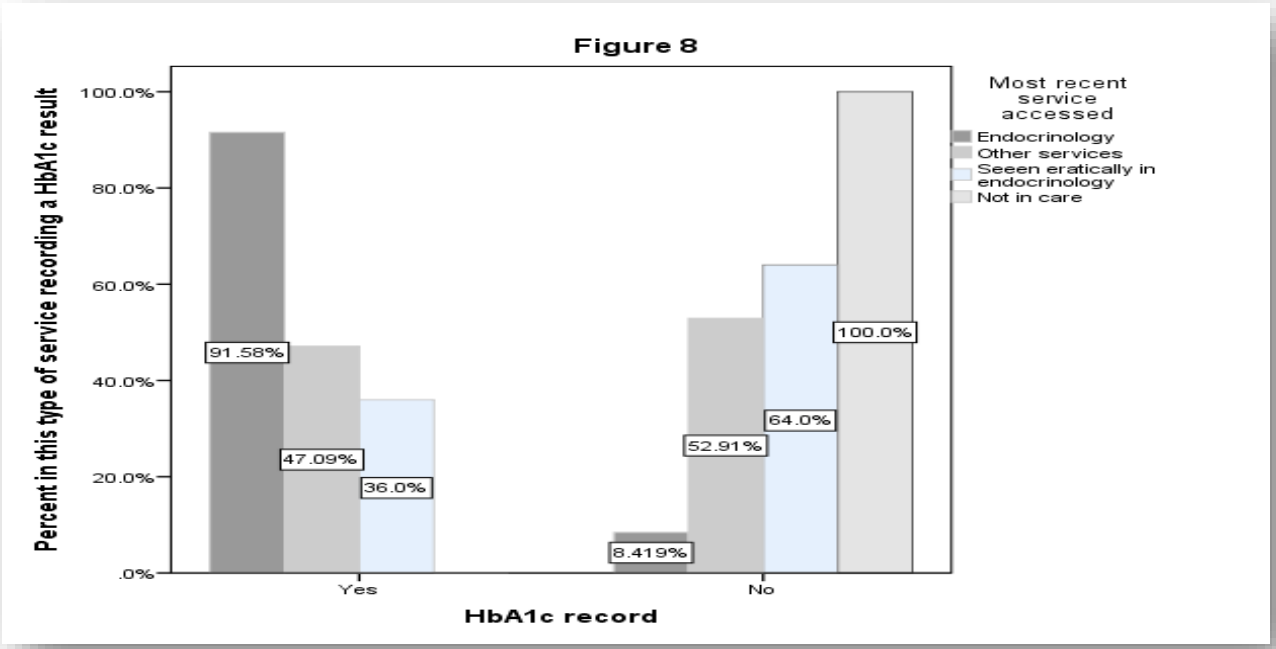


Figure 4-8 The cohort screening for HbA1c grouped by type of service accessed in the preceding twelve months

Of those who attended endocrinology clinics less than yearly, 36% had had HbA1c recorded in the preceding year, while for those using other services, 47% had had HbA1c measured in the preceding year.

Levels of HbA1c were not normally distributed (skew=1.097, kurtosis=1.841, figure 4-8, tests of normality appendix 4-6) therefore median values are reported. The median HbA1c value was 8.4% for all patients, with type of care having little influence on the median HbA1c value (appendix 4-10).

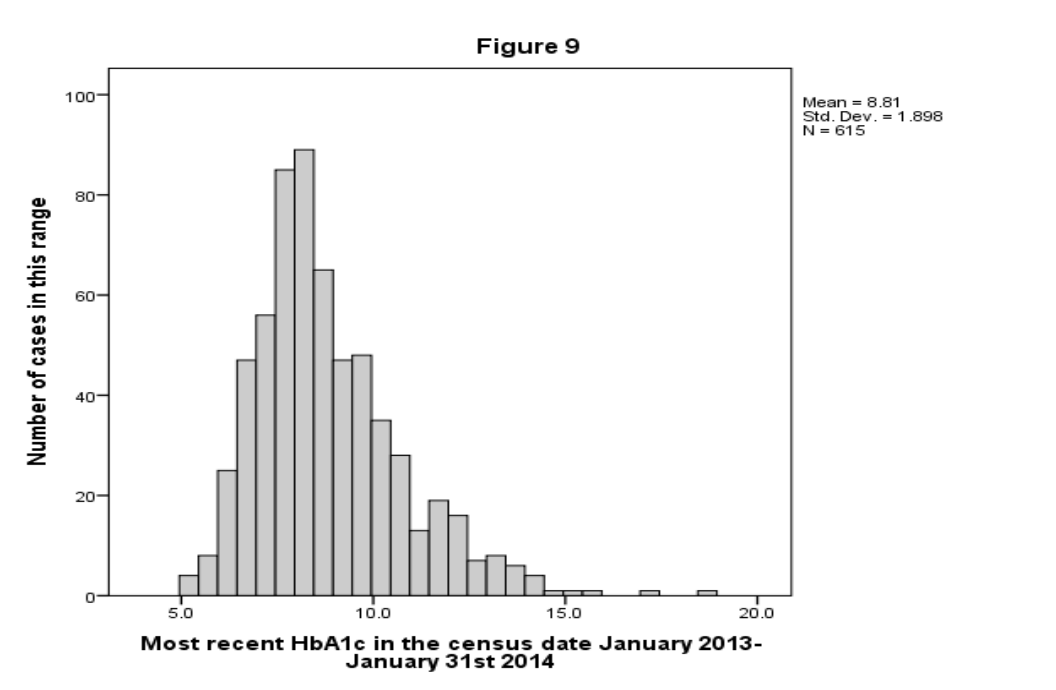


Figure 4-9 Most recent HbA1c level recorded in previous 12 months

The HbA1c in females was slightly higher than for males (8.5% v 8.3%) but this was not statistically significant (Mann–Whitney *p*=.112, appendix 4-7). Only 14.9% of HbA1c levels recorded were at or below the recommended value of 7% while 37.2% of results were in the very high risk group at greater than 9%. The lowest median HbA1c levels were seen in the age groups 1–4 years and 65–74 years (7.8% & 7.6% respectively), and the highest in the age groups 5–14 years and 15–24 years (9.3% & 9.2% respectively).

4.5.5 Kidney function screening

Only half (52.3%) the cohort had the recommended annual kidney screen in the preceding 12 months. Kidney screening was not associated with gender (*p*=.182), age (*p*=.341), length of disease (*p*=.468) or age of onset (*p*=.864). It was associated with being in endocrinology care, where there was the most likelihood of screening occurring (75.3% of cases) compared with 24.6% of cases using other services being screened (Phi=.492, *p* <.001 (appendix 4-11).

4.5.6 Prevalence of kidney disease

An assessment of eGFR was possible in 61% of adult cases (n=652) and is shown in table 4-8. The prevalence of kidney disease in the cohort was estimated at 26.8%. This raises an important issue given the lack of screening for the nearly one-third of the cohort that was not attending care, or those attending services whose kidney function was not assessed.

Table 4-8 Prevalence of kidney disease by stage of CKD as defined by Kidney Health Australia [321]

Stage of CKD	Percentage of cases
1 Normal renal function eGFR > 90	73.2%
2 eGFR >60 <90	12.1%
3 eGFR 30–59	6.1%
4 eGFR 15–29	1.8%
5 eGFR <15	4.0%
6 ESRD with transplant	2.8%
Overall prevalence of CKD	**26.8%**

Males and females were equally likely to develop kidney disease (p=.882). The likelihood of having normal renal function was lowest in people with early childhood onset, and disease duration was moderately correlated with kidney disease (Cramer's V=.547, p<.001).

The likelihood of normal renal function was also low in late onset disease (p=.004 appendix 4-12). For those with early childhood (0–5 years) onset, the percentage of the cohort with kidney disease was higher than those without it, which most likely reflected long disease duration. In late onset disease however, the percentage of the cohort with kidney disease was also higher than those without it (Figure 4-10).

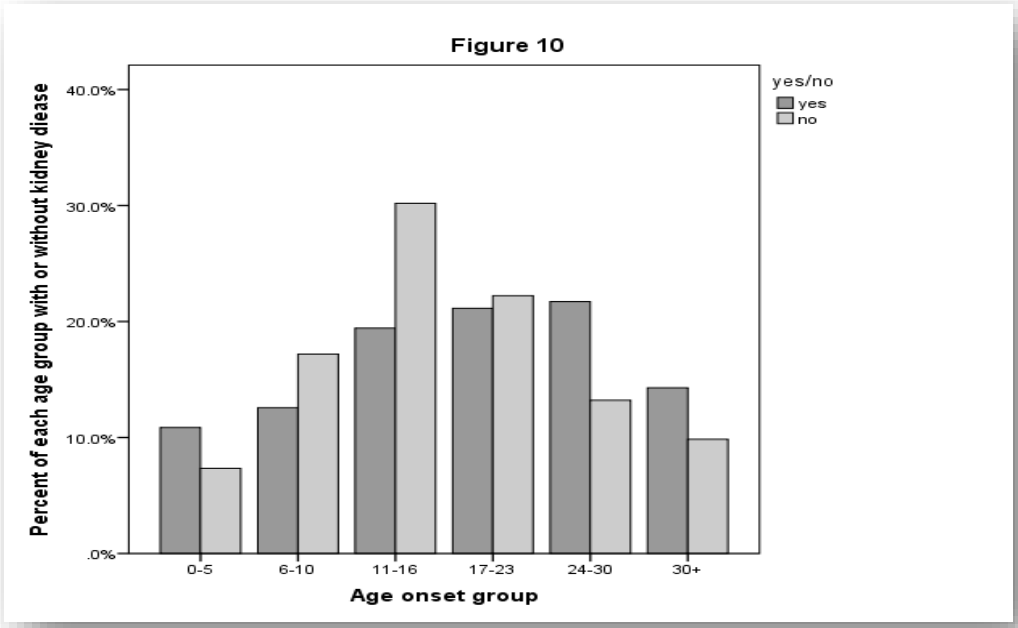


Figure 4-10 Age of disease onset and the prevalence of kidney disease

In figure 4-10 the cohort is grouped into age of onset of T1DM with the bar chart demonstrating the proportion of each age group with (yes) or without (no) kidney disease. The RR for kidney disease in late onset T1DM compared with onset before 17 years of age within this cohort was 1.41 (CI 1.096–1.833, *p*=.007, appendix 4-13) supporting hypothesis 4.3.3.2 that age of disease onset would be associated with differential outcomes in T1DM.

4.5.7 Socioeconomic status

Hypothesis 4.3.3.4 proposed that there would be measurable differences in health care usage, glycaemic control and disease outcomes that varied according to SES.

SES by SEIFA decile for the cohort showed a bimodal distribution which reflected the catchment area (Figure 4-11). There were 24 cases with invalid or missing postcodes excluded from the analysis.

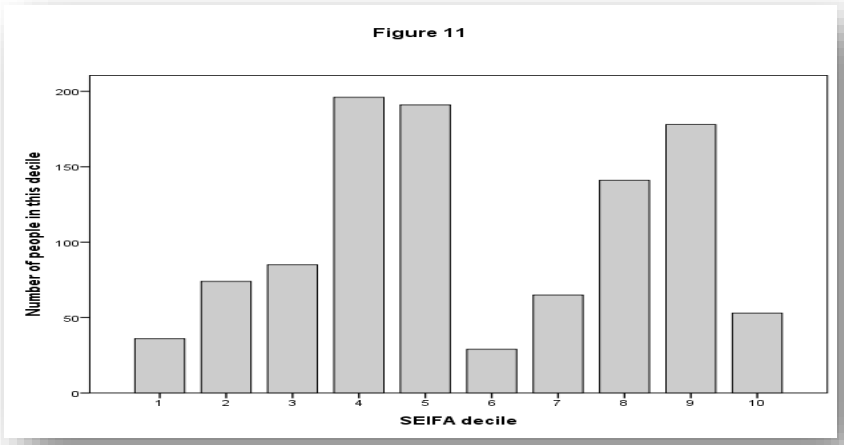


Figure 4-11 The cohort grouped by SEIFA decile

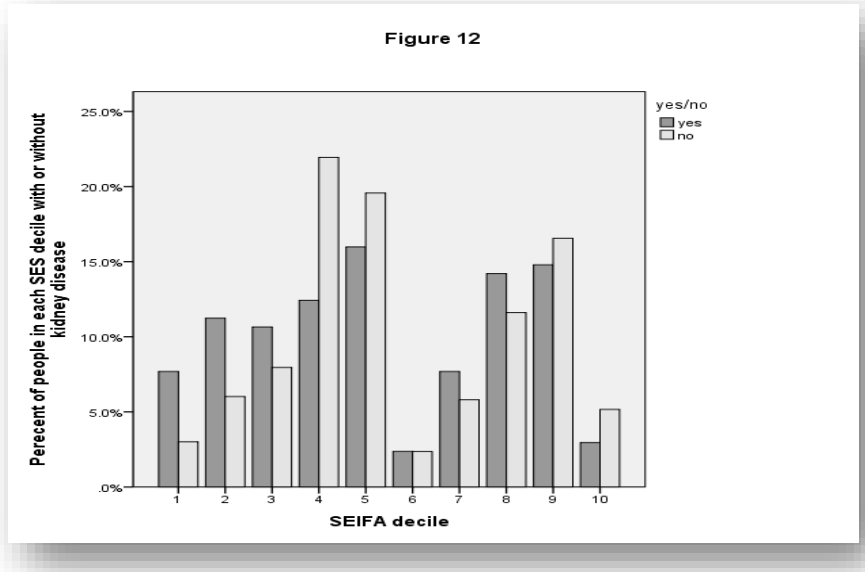


Figure 4-12 The cohort in whom kidney disease could be assessed by eGFR grouped by SEIFA decile

In the 61% of cases for whom kidney function could be determined by eGFR, people with the lowest SES (deciles 1–3) were more likely than not to have kidney disease (*p*=.010 appendix 4-14 Figure 4-12).

More deaths occurred in the lowest SES deciles 1–5 (61.5%, *p*=.049), especially in females (19 versus 10, *p*=.035, appendix 4-15). Although establishing cause of death was not an aim of this study, 61.8% of deaths showed evidence of kidney disease prior to death and half of these had ESRD. Females were more likely to have kidney disease at death (79.3% versus 48.7% for males).

The current type of care showed significant variation by SEIFA decile (*p*=.014) but the bimodal distribution of SEIFA data made interpretation of this relationship difficult because of small numbers in certain care categories. To elucidate the findings, SES was grouped into low SES (deciles 1–3,) medium SES (deciles 4–7) and high SES (deciles 8–10).

Table 4-9 Current type of care by SES

SES	Endocrinology	Other services	Erratic care	out of care
Low	**36.9%**	**24.1%**	17.4%	12.3%
Medium	49.3%	17.0%	18.1%	8.9%
High	45.4%	19.1%	19.6%	11.8%

As shown in Table 4-9, people with low SES were less likely to be engaged with endocrinology care and more likely to be using other services than people with medium and high SES (*p*=.032, appendix 4-16). Hypothesis 4.3.3.3 that access to care and outcomes would show variation with SES is supported.

4.5.8 Mean 10-year HbA1c

All HbA1c records for each person in the cohort over the preceding 10 years were collated and analysed. The limitation of this approach is that some people would have fewer readings than others because of their disease duration and this is particularly true for children. Despite this, average glycaemic control over disease duration to date is still a useful assessment of treatment target outcomes. Mean HbA1c was calculated for 986 people in the cohort (91%) and 85 cases had no HbA1c data.

As seen in the box and whisker plot in figure 4-13 the mean HbA1c value was 8.86% (SD 1.6, CI 8.75–8.95). The range was 5.1% to 14.8% and there were several outliers in the upper range, with 5% of the cohort having readings of 12% and over.

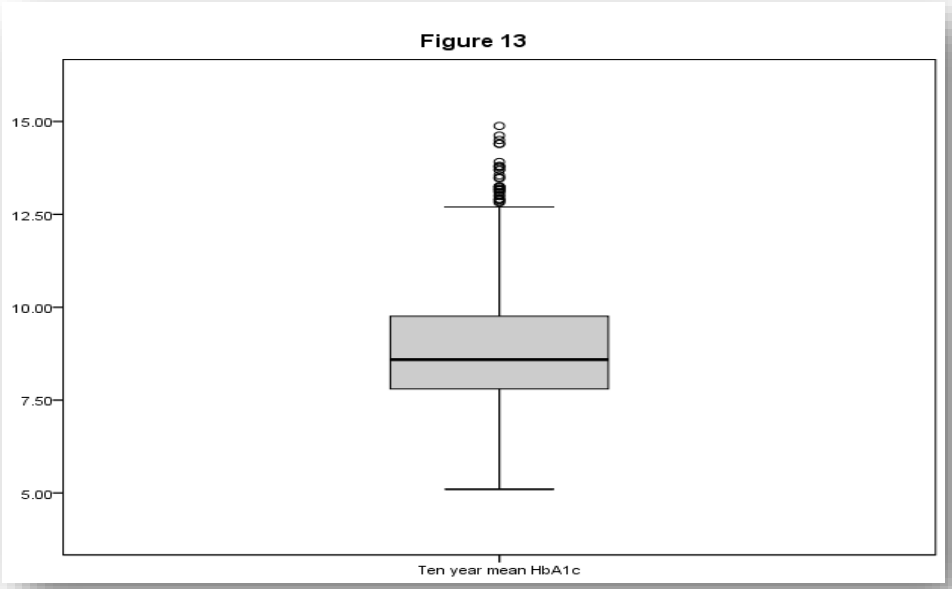


Figure 4-13 Mean 10-year HbA1c for the cohort

Excluding these outliers reduced the median value to 8.58%, similar to the median value seen in the HbA1c records for each case taken in the preceding year (8.4%). From Table 4-10 it can be seen that only 10% of the cohort met treatment targets [24] and that almost 40% of the cohort were at high risk because of their mean HbA1c levels and the potential these have for the development of complications.

Table 4-10 Percentage of cohort in each HbA1c range

Mean HbA1c (%)	Percentage of the cohort in this group
7.00 or below	10%
7.01–8.00	20.3%
8.01–9.00	30.1%
Above 9.00	**39.6%**

The mean 10-year HbA1c values (appendix 17) were not associated with gender (p=.237) or current type of care (p=.353), but were associated with SES (Figure 4-14). Highest mean 10-year values were seen in the lowest SES deciles 1–3, with a mean value of 9%, with the lowest mean values in the highest SES deciles 8–10, with a mean value of 8.6% (p=.013, appendix 4-

17) supporting hypothesis 4.3.3.4 that there would be measurable differences in glycaemic control that varied by SES.

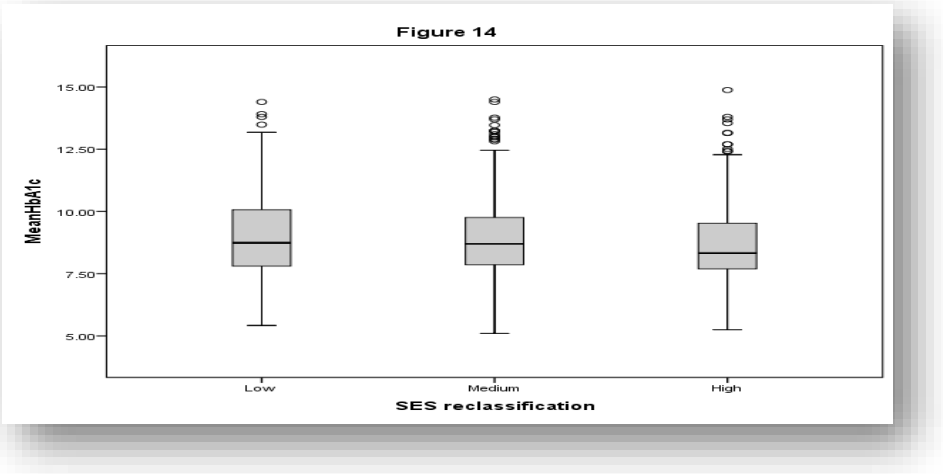


Figure 4-14 Mean 10-year HbA1c by SES

Mean 10-year HbA1c values tended to show improvement with disease duration (p<.001, figure 4-15) with values tending to cluster on the line of best fit with increasing disease duration. The regression equation showed that mean HbA1c (y=9.27) decreased by 0.02% (x) for each additional year of disease duration. This may reflect that mastery of glycaemic control is gained over time, but alternatively it may reflect the small number of cases with long disease duration in the cohort, which may suggest that people with high HbA1c levels do not survive into long disease duration.

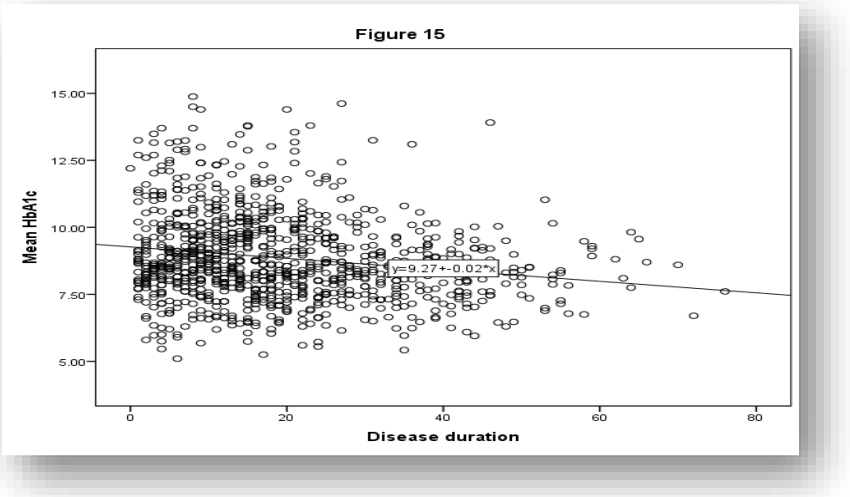


Figure 4-15 Mean 10-year HbA1c values by disease duration

4.5.9 Multiple regression modelling of HbA1c as a dependent variable

Included in the multiple regression model were the continuous IV's age, age of onset and disease duration. The DV of interest was the HbA1c reading for each case in the preceding year (n=615). The results demonstrated that the model was significant (p<0.001) and that all three IV's were correlated with the outcome variable although the correlations were small (appendix 4-18). Short disease duration, younger age and younger age of onset were all negatively correlated with HbA1c (table 4-11) suggesting an inverse relationship meaning that older age, longer disease duration and older age at diagnosis were associated with a reduction in HbA1c.

Table 4-11 Pearson's correlations for HbA1c

Pearson's correlation	HbA1c	Significance
Disease duration	-.173	<0.001
Age of onset	-.134	<0.001
Age	-.226	<0.001

However, the model fault is that duration and age are highly correlated (.797) and age of onset and age are moderately correlated (.542) and there is high multicollinearity (tolerance range 0.002-0.006 acceptable value >0.1). Standard coefficients (Beta) suggests that duration makes the strongest unique contribution (-.605) however this is not statistically significant. In model 2 age is removed and the multicollinearity is reduced to an acceptable range (tolerance .995 VIF <10) and disease duration and age of onset now significantly predict HbA1c. As in the bivariate analysis disease duration is correlated with an improvement in HbA1c however the effect is very small with only 5.2% of variation being explained (r^2 0.052).

Almost identical results were found in the multiple regression modelling for the ten year mean HbA1c (n=986). Pearson's correlations were -.182 for disease duration, -.190 for age, and -0.63 for age of onset. Whilst the model was significant (p <0.001) it explained only 4% of the variation (r^2 0.04), there was a high degree of multicollinearity (tolerance range 0.002-0.006) which improved in model 2 when age was removed making both duration (p <0.01) and age on onset (p 0.015) predictive (appendix 4-19).

4.5.10 Logistic regression modelling with attendance at endocrinology clinic as a predictable outcome

Attendance at the endocrinology clinic in the preceding twelve months was recoded for binary logistic regression as '1' in SPSS to denote a positive attribute or a case that has the 'outcome' of interest and the analysis was possible for 982 cases. The independent variables in the model were the categorical variables gender, SES as low ('1') or high ('0'), age of disease onset as childhood '1' and adulthood '0' with childhood given the positive attribute as the expected predictor of the outcome, and disease duration recoded into categorical data as short duration '1' as the expected predictor of the outcome and long duration as '0'. The categorical nature of these variables was indicated in SPSS. The dichotomous categorical variable gender was recoded appropriately by SPSS as '1' and '0' for the pair. The basic block for the model which included the constant was predictive of 51.4% of cases. The regression model with the inclusion of the IV's increased the predictive potential to 73.1% of non-attendees with a model coefficient (goodness of fit) $p<0.001$. However only short disease duration and late onset disease were predictive of the outcome and included in the final model (appendix 4-19). As the results in table 4-12 indicate short disease duration was highly predictive of attendance at endocrinology clinic (OR 2.53 CI 1.93-3.33 $p<0.001$) and childhood onset disease was highly predictive of attendance (OR 1.81 CI 1.39-2.37 $p<0.001$) supporting the findings of the multivariate analysis.

Table 4-12 details the results of the binary logistic regression.

Table 4-12 Results of the logistic regression for prediction of attendance at endocrinology clinic

	B	S.E.	Wald	df	p	Odds ratio	95% CI lower	95% CI upper
Gender	.155	.132	1.371	1	.242	1.16	.90	1.51
SES	.042	.133	.099	1	.753	.95	.74	1.24
Childhood onset disease	.598	.135	19.516	1	0.000	1.81	1.39	2.37
Short disease duration	.932	.139	45.052	1	0.000	2.53	1.93	3.32

4.5.11 Logistic regression modelling with kidney disease as a predictable outcome

Logistic regression was conducted with kidney disease as the outcome of interest coded as '1' for the presence of kidney disease and was possible for 634 cases. The IV's for the model were gender as categorical data, SES as high or low, late or early onset disease onset which was re-coded in the opposite way to the endocrinology logistic regression to denote late onset disease as '1' as the expected predictor and disease duration as a continuous variable. The model with the IV's was predictive of 79.5% cases and the Cox & Snell R square test and the Nagelkerke R square test determined that the model was a good fit (Chi square 203.203 $p < 0.001$) and explained between 27-40% of the variance. Whilst disease duration was predictive of the presence of kidney disease (OR 1.10 CI 1.08-1.12 $p<0.001$) late onset disease was also associated with a higher risk of kidney disease in comparison to disease onset in childhood (OR 2.65 CI 1.70-4.14 $p<0.001$) (appendix 4-20).

Table 4-13 details the results of the logistic regression

Table 4-13 Results of the logistic regression for the presence of kidney disease

	B	S.E.	Wald	df	p	Odds ratio	95% CI lower	95% CI upper
Gender	.109	.220	.247	1	.619	1.11	.72	1.71
SES	-.067	.225	0.089	1	.766	.93	.60	1.45
Early versus late onset	.977	.227	18.568	1	0.000	2.65	1.70	4.41
Disease duration	.103	0.009	129.216	1	0.000	1.10	1.08	1.12

To add more explanation to the findings with regard to disease duration and the presence of kidney disease which are moderately correlated in the analysis at 4.5.6, disease duration was recoded to a binary value. Whilst binary long disease duration was not a statistically significant predictor of kidney disease short duration disease is significantly predictive of the *absence* of

kidney disease and explains 18.5-26.9% of the variation in the logistic regression model (OR 9.25 CI 6.09-14.08) (Appendix 4-20).

4.5.12 Summary of the hypotheses tested

4.3.3.1 Gender as a social determinant of health influences health service engagement, glycaemic control and disease outcomes in Type 1 Diabetes Mellitus

Overall in the hypothesis testing gender is not supported as a social determinant of outcomes in T1DM as there is insufficient evidence of differential patterns of care and health outcomes in relation to gender. When differential outcomes have been found by gender these are strongly related to age of disease onset.

4.3.3.2 Age of onset of Type 1 Diabetes Mellitus as a social determinant of health influences subsequent health service engagement, glycaemic control and disease outcomes

The hypothesis is supported. Age of disease onset examined as a social determinant not a biological one has been found to be highly predictive as a determinant of health outcomes and is an independent risk factor for low engagement with endocrinology services and the development of kidney disease.

4.3.3.3 Socioeconomic status as a social determinant of health influences subsequent health service engagement, glycaemic control and disease outcomes in Type 1 Diabetes Mellitus

The hypothesis is supported in part. People in this cohort with T1DM and low SES had higher prevalence of kidney disease and death, lower use of endocrinology services, higher use of other services and higher HbA1c levels however this relationship was not strong enough to be demonstrated in the regression modelling as a predictor.

4.3.3.4 Use of health care services as a social determinant of health is associated with variation in glycaemic control and disease outcomes in Type 1 Diabetes Mellitus.

The hypothesis is supported and the health service itself is a social determinant of health in relation to suboptimal screening for glycaemic control and kidney disease. The results in this study have demonstrated low levels of engagement with endocrinology services overall and suboptimal screening for HbA1c and the presence of renal disease without which outcomes could potentially be much worse.

4.6 Summary of the key findings in this study

This cohort was broadly representative of T1DM in Australia given the slight male excess (52.1%), the median age of diagnosis (14 years) and the percentage of the cohort diagnosed in adulthood (22.5%). The median age of the cohort at the time of the study was 33 years with 11% aged less than 18 years, and the median disease duration for the cohort was 17 years.

4.6.1 Mortality

The deaths recorded in this cohort were at a relatively young age, with one-third occurring before the age of 45. The analysis demonstrated that rather than death being associated with disease duration, there was an association with late onset disease (diagnosis after the age of 17 years) where the relative risk of dying increased to 1.77 in comparison to disease onset in childhood. This is in line with findings from other international studies and while the phenomenon of poor outcomes in short duration disease is not well understood, it is most often attributed to psychological factors rather than disease specific factors [81, 278]. This is explored further in 4.7.2, age of onset as a social determinant of health.

4.6.2 Health service use

There was a striking decrease in the use of endocrinology services as people with T1DM grew older, with the attendance rate of 100% for those aged 1–4 years falling to 26% for those aged 55 years and over. Conversely, there was increasing use of other services without endocrinology care with age, from no use by those aged 1–14 years to 40% use by those aged 55 years and over. This could be interpreted in different ways and the qualitative phase of this research will elucidate why this might be the case (study 3 chapter 5). Many people with T1DM in this cohort appeared to have disengaged from endocrinology services over time and this could indicate either that they had the disease under control and had returned to primary care in general practice without the ongoing need for endocrinology care, or that they were dissatisfied with care and withdrew from the service.

Of particular concern were the low levels of attendance in young adulthood seen in this study in the context of poor glycaemic control. Australian research to date has demonstrated that there is marked attrition from health care services of young adults with T1DM [255]. Fewer than 25% of young adults in a New South Wales/Australian Central Territory study were

receiving multidisciplinary care [273] and these young adults reported an under resourced system and difficulty in obtaining the recommended three-monthly appointments. For the cohort examined in Study 2, the reduction in attendance rates over time could potentially reflect dissatisfaction with care rather than increased expertise in diabetes management which is an important theme that will be explored in the qualitative phase of this research. Outpatient appointment management can be highly inflexible because of increasing demand on tertiary services in major metropolitan hospitals, and this is likely to be highly problematic for the cohort. This study has demonstrated that being in regular endocrinology care gave the highest likelihood of being screened for glycaemic control and kidney disease, and this has implications for the detection and management of complications.

4.6.3 HbA1c

The cross-sectional mean HbA1c level in this study was 8.4%, with only 14% of cases achieving the treatment target of 7% and almost 40% at high risk of developing complications [331] with HbA1c levels above 9%. Mean HbA1c levels varied by age with the lowest levels seen those aged 1–4 and 65–74 years, and the highest levels in those aged 5–24 years, which was also a period of decreasing engagement with the endocrinology service. The 10-year mean values showed a similar trend, with a mean value of 8.58%, with only 10% of cases achieving treatment target levels and 40% with levels that placed them into the very high risk group. Regression modelling suggests that little in terms of demographics predicts HbA1c to a great extent suggesting that a near normal HbA1c is an unachievable target for the vast majority of people with T1DM. Similar findings were seen in a study from the UK with a similar population profile, where the mean HbA1c was 8.5% [60]. Most research in T1DM suggests that the ideal HbA1c of below 7% remains an unachievable target for most people with T1DM. Despite the research and development of treatment regimens that aim to optimise glucose control, evidence suggests either that these are not being adopted or that they prove impossible for people to manage. In the nine-year DCCT trial only 5% of patients who were medically well supported achieved HbA1c of 6.05% or below [67]. It is vitally important for clinicians to acknowledge that intensive insulin regiments can be very difficult to maintain and suboptimal glycaemic control is not a personal choice, which is a theme explored in depth in the qualitative phase of this research (study 3 chapter 5).

4.6.4 Screening for kidney disease

Only half of the cohort had been screened for kidney disease at the recommended frequency of at least annually [321]. Diabetic nephropathy develops most commonly after 10–20 years' disease duration [21], which means that without diligent glycaemic control and regular screening it will affect young people in mid-adulthood, their most productive years. As damage to the kidneys progresses, the presence of proteinuria is a powerful predictor of increased mortality [72-74]. Given this strong evidence the low levels of screening seen in the study are of serious concern. Cases with the highest likelihood of being screened were those in regular endocrinology care and there is an urgent need to understand the factors associated with disengagement from specialist services, which are best understood through an in-depth qualitative examination (study 3 chapter 5).

4.6.5 The prevalence of kidney disease

The overall prevalence of kidney disease in this cohort was very high (26%) but this figure is likely to be an underestimate given that almost one-third of the cohort did not attend regular care for screening. The risk factors for the absence of regular clinic attendance included low SES and late onset disease, both of which were also independently demonstrated in this study to be risk factors for kidney disease. Risk factors for the development of complications tend to be interrelated and this clustering effect can be seen in behaviours such as clinic non-attendance, poor concordance and depression [80, 332]. However, the low levels of screening and the high incidence of kidney disease seen in this cohort are multifactorial and health services need to be accountable for delivering care according to recommended guidelines, which includes surveillance for complications at minimum of once per year [24, 321].

4.7 Discussion

4.7.1 Gender as a social determinant of health

Females in this study had slightly higher HbA1c levels and other studies have demonstrated that adolescent girls were more likely to omit or restrict insulin to purge calories and experience ketoacidosis in the setting of eating disorders and dietary mismanagement [71, 85, 228]. This may be directly attributed to the significant weight gain that can be experienced with the intensification of treatment regimens. While females were not more likely to develop kidney

disease overall, they were more likely than males to have existing kidney disease and to die from other causes before the development of ESRD. This supports the assumption from the national T1DM ESRD study (chapter 3) that the male excess of T1DM ESRD is possibly a survival advantage and worthy of further study. The most striking finding in relation to female gender was found in health care attendance and age of disease onset, with females diagnosed in adulthood engaging with endocrinology services at rates 50% lower than females with childhood onset. This may relate to psychological factors such as a degree of maturity and acceptance of the diagnosis leading to high levels of mastery. However it may also relate to the phenomenon of women as carers who are more likely to put family members' needs before their own health care needs [333]. Males also had similar lower levels of attendance at endocrinology clinics with increasing age, and a high proportion of males diagnosed in adulthood were no longer accessing care. With increasing age came higher use of other services, which is suggestive of management of developing complications. Males with late onset T1DM also had a slightly higher relative risk of kidney disease (RR 1.46) than females with late onset disease (RR 1.38) in comparison to those with childhood onset disease.

4.7.2 Age of disease onset as a social determinant of health

In this study, late onset disease was associated with poorer outcomes with an increased relative risk of death and of developing kidney disease. Age of diagnosis is known to influence the development of future complications, with diagnosis before puberty thought to be health protective, and diagnosis during or after puberty leading to demonstrably poorer glycaemic control and the onset of complications [205, 206, 208]. The findings in this study are consistent with other research, particularly a large cohort study in Sweden of T1DM diagnosed after the age of 15 years (n=4097) which found significantly increased mortality in late onset short duration diabetes. The standardised mortality ratio (SMR) was 3.5 and this increased for the oldest subset of age at diagnosis (30–34 years) to 4.1 [278]. Examination of death certificates showed this higher risk of death was attributed largely to alcohol and drug abuse, depression and the twofold higher incidence of suicide, which mirrors findings in the US and Norway [278]. This is strongly suggestive that age of disease onset is a social rather than a biological determinant of health. The findings in this study are also consistent with other evidence that demonstrated that while the female sex protection against renal disease seen in the non-diabetic population is somewhat diminished in T1DM [211], being male remains a significant

independent predictor of the progression to ESRD and this risk appears increased with late onset T1DM [206, 207, 209, 215]. This current study adds to the evidence demonstrating that late onset disease also affects health service usage with much lower use of endocrinology services overall, and this lack of engagement with health care services may be a factor in the increased incidence of kidney disease and death in people with late onset T1DM.

4.7.3 Socioeconomic status as a social determinant of health

This study found that low SES was negatively associated with mortality, health service usage and health outcomes. People in this cohort with T1DM and low SES had higher prevalence of kidney disease and death, lower use of endocrinology services, higher use of other services and higher HbA1c levels. There is a known inverse relationship between socioeconomic status and morbidity and mortality in T1DM [132-136] with the prevalence of complications and death becoming higher as income falls. Reasons suggested for this include low health literacy and poor health care behaviours. However, social inequalities are known to disappear after compensation with treatment and education at a tertiary care centre and unfortunately, in relation to diabetes, this can lead to what is described as the inverse care law [145] [146] where those in greatest need have least access to care [147]. People of higher SES are believed to be more accepting of health education and more ready to improve their behaviour but this is easier to do in a favourable environment. What are viewed as 'poor health care behaviours' are not necessarily conscious choices and it is important to consider the challenges of managing the complexity of T1DM in the less favourable environment of relative poverty [220]. The mechanisms through which low SES mediates poorer outcomes are multifactorial and include determinants other than income. A small body of literature exists that suggests that although psychosocial factors can lead to poor control in a lower SES cohort, the direction of causality can be reversed with poor control leading to depression [148, 150]. The most recent evidence from Western Australia, a study of 93 young adults, found that being employed or a student mediated the impact of low SES and was associated with better glycaemic control [334]. Elucidating the mechanisms through which low SES leads to poor outcomes is a major theme of the qualitative study to add to our understanding of the impact of SES on T1DM management and outcomes (study 3 chapter 5).

4.8 Study strengths and limitations

The use of retrospective data where the information characterising the individual is recorded at some time point in the past is commonplace in studies that seek to determine the antecedents of long term health outcomes in chronic diseases [335]. The strengths of this study lie in the large sample size that covers three hospitals with ambulatory care and available data that details the nature of all encounters with the service. This allows a robust analysis of factors that impact on engagement with care and the study would be generalizable to other metropolitan areas in Australia due to similarities in the configuration of health care services for people with diabetes within Australia. The cohort is highly representative in terms of gender and the distribution of age of disease onset. This study as conducted however has a number of limitations. The use of retrospective data prohibits the collection of additional data that could be of interest to the study which with a cohort of this size would have been beneficial if ethnicity and educational attainment which are key social determinants of health were available for the study. As with study 1 the use of SEIFA to determine individual SES also has limitations which are fully described in chapter 3. In this cohort of people with T1DM there may have been cases of latent autoimmune diabetes in adults, however the disease trajectory would be similar to that in adult onset T1DM and therefore any such cases would be unlikely to affect the study's findings. There is one private endocrinology clinic in the catchment area which is thought to service a small number of patients who may have accessed HbA1c and kidney function screening through private pathology providers for which data are not available. However, whilst not complete the data in this study are representative of the population studied. The number of samples used to calculate 10-year mean HbA1c varied in each case due to variations in disease duration, a small number of these results were obtained during a phase of acute illness and hospital admission, and for these reasons the resulting analysis should be interpreted as a guide to average glycaemic control for the cohort. That said however the standard deviation for the ten year averages in HbA1c was low (1.6) and the short CI is suggestive of an accurate determination (CI 8.75-8.95). For the logistic regression analysis it is acknowledged that binary data can be a rather blunt tool in which a cohort are divided into two groups based on their characteristics however the findings in the analysis do strengthen the argument created in the multivariate analysis and determine the 'at risk' groups for future service planning.

4.9 Conclusion

The findings in this study suggest that glycaemic control was suboptimal in this cohort and a significant proportion of people were at high risk of complications. Kidney disease was the main complication studied and its prevalence was found to be very high. A number of SDH were found to be associated with poorer outcomes and understanding these 'at risk' groups has the potential to inform clinical practice in relation to increased service provision and a more tailored approach to reduce inequities. This issue is likely to be multifactorial and difficult to interpret in a retrospective cohort study and qualitative in depth exploration is warranted to elucidate the psychosocial factors associated with poorer outcomes. This study also found that screening for glycaemic control and kidney disease was suboptimal and this has the potential to delay the detection and appropriate treatment of complications throughout the disease trajectory and the determinant of this is health services themselves.

CHAPTER 5 STUDY 3 A QUALITATIVE EXPLORATION OF THE SOCIAL DETERMINANTS OF HEALTH OUTCOMES IN TYPE 1 DIABETES MELLITUS

5.1 Introduction

The purpose of study 3 is to add a deeper exploration to the findings from studies 1 and 2 to determine the mechanisms through which differential outcomes in type 1 diabetes mellitus (T1DM) occur as described by the *person with the disease*. Qualitative research helps us to understand people's motivations, perceptions and expectations and brings greater insight into the mechanisms by which social determinants of health (SDH) can affect self-management in chronic illness. Both qualitative and quantitative evidence are needed to develop the most effective treatments in T1DM, because glycaemic control is highly dependent not only on individual characteristics but also on the social environment [230, 231]. In the literature review undertaken for this thesis, it was identified that there had been limited research undertaken with adults with T1DM to explore the diagnosis experience and the disease trajectory well into adulthood. This research is vital to understand the environmental and psychosocial factors that develop through the life course and which subsequently act as SDH to affect diabetes management in either a positive or a negative way.

5.1.1 Type 1 diabetes mellitus and socioeconomic status

In the quantitative research undertaken for this thesis, it was shown that low socioeconomic status (SES) was a risk factor for decreased engagement with endocrinology services and the development of kidney disease, particularly for males, and this is one finding that is informing the next phase of the research. This qualitative research with adults aims to explore the important relationship between SES and social support in diabetes care [99] and the role this may have in the subsequent development of severe complications such as end stage renal disease (ESRD), which is a primary focus of this thesis. A theme explored in relation to SES and the health care encounter is that of unequal power during health care encounters that can lead to comparisons between people with T1DM and the provider [90] and the potential this has to lead to disengagement from care for people with low levels of social support and low SES.

5.1.1 Type 1 diabetes mellitus and age of disease onset

In study 2 (chapter 4) it was found that a diagnosis of T1DM in adulthood was associated with poorer outcomes than a diagnosis in childhood. The most plausible explanation for this could be psychosocial reasons, given the lack of a known biological determinant. Similar studies from other countries have also demonstrated increased mortality in adult onset T1DM [81, 261, 278]. These findings could be suggestive of low adaptation to the required significant disease-related behavioural changes which may be less likely to become embedded behaviours in adulthood than when disease onset occurs in childhood. However, it is also important to consider the lower overall engagement with endocrinology services seen in adult onset disease in study 2 that suggests disengagement from health care is also a factor in poor outcomes.

5.1.2 Type 1 diabetes mellitus and the role of the health care service

Concordance with therapy is known to be a key mediator for glycaemic control and for some people with T1DM, difficult glycaemic trajectories and low levels of engagement with health care services lead to the development of complications at a comparatively young age. For both the person with the disease and the health care provider (HCP) this creates the belief that they have not managed their condition as well as they should have done, which is a form of victim blaming [336]. This has been described as a public health morality that licences resentment towards people burdened by the results of their actions [337]. The qualitative literature on type 2 diabetes (T2DM) describes this morality well when defining 'good and bad diabetics' [232] but in this thesis it is purported that this morality is very different for people with T1DM.Although people with diabetes in their discourses are widely reported to view themselves as accountable for their glycaemic control, people with T1DM, which is a very difficult disease to equilibrate, rely heavily on the support of their endocrinology team and an important part of this qualitative exploration is to understand how people with T1DM with difficult glycaemic control trajectories describe their perceptions on the role of the health care service has in supporting them.

5.2 Aims and objectives

The aim of study 3 was to describe the lived experience of the disease, to understand how the psychosocial environment affects the management of T1DM and to gain insight into why certain groups are at risk of disengagement with health care, leading to poor outcomes. The specific objectives were to conduct in-depth qualitative explorations of participants' life

course histories to understand how T1DM has been incorporated, to establish factors associated with optimal diabetes management and factors that precede disengagement from health care services. Themes explored in the qualitative study include the diagnosis experience including when this occurs in adulthood, the highs and lows of the disease management trajectory, and participants' reflections on the impact of a lifetime chronic condition that requires constant daily diligence to manage successfully. The absence of qualitative research with adults who can describe the lived experience of T1DM and give insights into how health care services can better meet the needs of the people most vulnerable to dropping out of care has been one of the most pressing gaps in the literature [254].

5.2.1 The role this study has in adding to the current evidence

There has been a scarcity of literature on the subjective experience of living with T1DM as described by adults. This study explores this issue in depth from the time of diagnosis over many years of the disease trajectory with a diverse group of adults with T1DM. In particular this study adds unique knowledge of how people of low SES experience the health care encounter in comparison to people with high SES. This study, in presenting the view of the participants, has the potential to inform clinical practice guiding clinicians in meaningful ways to connect with their clients ensuring a relationship that is sustained over time.

5.3 Methods

5.3.1 Qualitative research method

Qualitative research is the exploration of a phenomenon achieved through the deep probing of an individual's perceptions of events that encourages participants to define it in their own words and on their own terms. Traditional epidemiology is not subject to critical reflection that exposes embodied structures and processes [338] but this is an integral process in social epidemiology and is the intent of the final deep qualitative explanatory phase of this thesis. Qualitative research is designed to give an idiographic or person-centred thick description [302] of a complex phenomenon; it is interpretive and seeks the meaning and contextualised nature of the experience [338, 339]. The qualitative enquiry method taken in this study is a narrative interview approach with the researchers role being that of a good listener and the participants role as story teller rather than a respondent and the focus of the interview is on concrete events [340]. Sensitively conducted qualitative research enhances participants' self-

awareness, reflexivity and empowerment and can be therapeutic for both participants and the researcher if undertaken with empathetic understanding of the setting from the point of view of the person in that setting [302].

Concepts in qualitative studies are quite different to those in quantitative research, particularly in this research on the SDH, because they are conceptually 'understood' rather than numerically measured. Qualitative data collection is an interactive process with a unique mix of measures and themes that can be difficult to replicate [302]. The central question in this qualitative study and thematic analysis was 'how do structure and context impact on actions?' [341]. The research design was intensive and involved examining a small number of cases in depth [342]. The rich descriptive detail obtained from this enquiry enables examination of the issue from the consequence back to the cause or antecedent [343] by locating common experiences that allow us to understand the context in which decisions about concordance with therapies and lifestyle or health behaviours are made.

Rigour and validity whilst commonly attributed to quantitative research are also central themes in qualitative research. The use of rigorous methods which are described in detail allows the findings of this qualitative study to be applied to similar groups or settings. Criteria have been developed for improving the interpretive, methodological and theoretical rigour of qualitative research, and these include ensuring that the research as reported illuminates the subjective meaning, actions and context of those being researched [344]. The study has theoretical and conceptual rigour because the theory and concepts have been chosen to ensure that the research strategy is consistent with the stated research goals [339]. Validity in qualitative research is found in the degree to which the researcher has measured what they set out to measure and evidence of a logical link that can be seen between the objectives of the study and the questions that were asked [11]. Credibility and authenticity in this research can be found in the fit between what the participants said and the representation of this and in demonstrating that the research findings are clearly linked to the qualitative data. This analysis stays true to participants' recounting of the lived experience and represents them well [343].

In study 3 semi-structured in-depth interviews were used for data collection with open-ended questions to explore the participant's reflections on certain events. For researchers, hearing people share their stories is a privilege and a deeply rewarding experience [339]. In-depth

interviews are issues orientated and seek to explore the complexity of meanings and interpretations in a particular defined situation [339, 341]. Semi-structured interviews allow the researcher to explore a predetermined group of concepts that are related to certain events, but also allow for participants to digress and discuss matters of importance to them on their own terms [345]. The number of participants is considered large enough when the researcher is satisfied that the data collected cover enough dimensions of the study with rich depth [339].

5.3.2 The role of the researcher in the qualitative data collection and interpretation

Qualitative research participants are responding to how they are invited to tell us about their stories and the researcher holds a central role in the quality of the data collection [340]. In social research it is important to be conscious of the 'double hermeneutic' [5]. This is an understanding that while the object of study gives their own interpretation of events, the researcher will then undertake an interpretation of this recounting. People are invariably motivated in discourse to disguise some of their feelings to protect vulnerable aspects of themselves which makes an interpretive approach essential to the process [340]. Therefore, researchers must be reflexive and constantly take stock of their own preconceptions and subject these to the same scrutiny as given to the other data [13, 339]. Researcher subjective knowledge is often described as a barrier to qualitative research as if preconceptions and prior knowledge are always a negative aspect of the interpretive nature of the research method. However researcher knowledge and subjectivity can play a positive role in qualitative research in the social sciences particularly if they have substantial knowledge and interest in the topic. Theories of social class and power can sensitise qualitative researchers to see actions and hear view points and to put their interpretations of them to test [346] which can in fact create a more meaningful interpretations of the data. Underlying attempts to distance the researcher may actually be efforts to adhere to a positivist paradigm and Goldstein (2016) in citing Morrow (2005), states that the value of the reflexivity may be found it what it adds rather than what it takes away [347]. Morrow (2005) takes this debate one step further in saying that intepretivist and ideological theorist embrace the position of the researcher as a co-constructer and as unapologetically political [348]. The researched and the researcher can both take their lead from the other and the intent in this study is participant empowerment and a critique of the power imbalanced nature of the health care encounter. Whilst it is most often said that the researcher holds the power in the relationship, the converse can actually be true with the

researcher feeling compelled to empathise with the participant and feel guilty for causing heartache and distress [349]. Critical to the process of self reflection for a qualitative researcher is the process of journal keeping in which notes are made not just about the participants responses but also their own. The interviews need to be well spaced out to allow for reflection and also to ameliorate the negative effect of distressing interviews needing emotional recovery before attempting to collect and interpret more data [349].

5.3.3 Framework for qualitative interviews

The conceptual framework of critical social theory guides the enquiry. This gives the understanding that while humans are purposive agents with reasons for their actions that involve reflection, rationalisation and motivation, there will also be patterning of social relations and phenomena that is a result of deeply embedded 'structures' or societal norms [15]. This qualitative enquiry is an exploration of these concepts in relation to the self-management of T1DM and will 'step back' from individualism and reflect on the conditions under which people act [350]. The enquiry is centred on SDH which are measured as concepts in the qualitative data. The primary focus is on describing the increased risk or susceptibility to adverse health outcomes that is related to low socioeconomic status (SES) and lack of environmental resources [351], but the supportive elements of a favourable environment in relation to disease outcomes are also considered. The operationalised measures of SES and environmental resources for the qualitative exploration include employment, income, education, housing, and social support including social cohesion, social inclusion and social empowerment [351, 352]. Other important factors are access to and quality of health care including ease of access, retention to care, engagement with services, patterns of attendance, degree of institutional trust and interpersonal trust [353].

5.3.4 Semi-structured interview guide

5.3.4.1 The lived experience of the disease

Baseline information regarding participants' gender, age at time of interview, age at diagnosis with T1DM and disease duration was collected. Participants were then asked to describe their individual diagnosis experience, how their families reacted and how they felt at the time. This

provided important contextual information because the diagnosis of a chronic illness can create 'biographical disruption' where not only is the physical body affected but the whole life trajectory [16]. The day-to-day nature of T1DM was explored, with participants recalling an average diabetes day in depth, knowledge of which is a significant gap in the current understanding of diabetes-specific distress for adults with T1DM as identified in the literature review in chapter 1. Comparison of the experiences of participants who adapted relatively easily to the diagnosis with those of participants for whom the diagnosis was a significant life changing event adds depth to our knowledge, allowing us to see how people with T1DM could fail to gain a sense of mastery. Participants were also asked whether they had any family members with diabetes, which may have given them prior knowledge about the disease, its management and potential for complications. This theme proved particularly useful in determining how prior knowledge translates into a fatalistic sense about diabetes and expected health outcomes.

5.3.4.2 Early childhood environment

Participants' early childhood environment was explored, including details of family composition and parents, because there is a known association between single parent families and poorer disease outcomes. [163-165]. An exploration of the mechanisms that could underlie this, with deep probing of parental accord, roles in diabetes management and relationships with siblings (if any) formed part of the interview process. The socioeconomic circumstances of the family in early childhood and the perceived financial costs associated with diabetes care were also explored. This information described the context in which each participant developed a sense of support that evolved into one of autonomy at the time of transition to self-care. The theme of early childhood environment also included a description of perceived stigma relating to the T1DM diagnosis, which is the process by which the reactions of others 'spoils' normal identity [16]. This was explored through probing the extent of participants' disclosure of diabetes status to others and their perceived reactions. For participants with adult onset T1DM these themes were explored more generally and tailored to a discussion of how their early childhood environment shaped their acceptance and understanding of their illness in adulthood.

5.3.4.3 Educational attainment

Educational attainment is an important determinant of health and lower education achievement is known to be associated with poorer health outcomes [139, 253], hence this theme was of particular importance to those participants who had not fared well and had developed complications. An exploration of each participant's ability to interpret information specific to T1DM was conducted, which included recall of competency in numeracy and literacy in relation to managing the insulin adjustment regimen and the ability to process and understand the health information that was needed to make appropriate decisions [354]. This theme deepens our understanding of the association between education and outcomes in T1DM. This concept was explored through determining years of schooling and highest qualification achieved but also by the participants describing their engagement with and enjoyment of school. Types of learning style were discussed, including the use of written and/or visual information and there was an in-depth exploration of T1DM health education received throughout the disease trajectory and identification of limitations in understanding diabetes education faced by participants. This understanding of education and health was then applied when asking participants to describe their behaviour in health care encounters.

5.3.4.4 Socioeconomic status

The well demonstrated inverse relationship between low SES and morbidity and mortality in T1DM situates the causal mechanisms within an 'individualism' approach, most noticeably one of poor health behaviours [62, 355]. This research used a structural approach but without the arbitrary measure of income commonly seen in quantitative research by exploring the socioeconomic context in which health care decisions were made. Participants were asked to reflect on their parent/s' occupation during their childhood and their sense of economic security derived through housing, employment and income security. Next was a focus on decision making about healthy food choices, managing T1DM and health in the workplace, and the perceived costs of care. Some participants who described a secure environment from an SES perspective offered insights into how health care services may be experienced differently in this context.

5.3.4.5 Social support

Perceived social support can be readily explored in qualitative research because it refers to a person's *belief* in the amount and quality of support that is available from family, friends and

broader social networks [356], which can be understood without being measured. Social support is especially important in adolescence because it promotes the development of trust and a belief that the world is supportive. Negative life experiences at this time are known to affect the perception of social support well into adulthood [356, 357]. Trust is vital for the integrity of the encounter between a person with T1DM and their health care professionals [353] and of particular interest was an exploration of the participants recall of their early childhood environments, perceptions of social support, interpersonal trust and trust in the health care system. While adversity is often cited as an antecedent to negative effects on well-being, moderate exposure to adversity can also prepare us for future adversity by strengthening capacity [358, 359] which in turn increases resilience or the ability to 'bounce back'. This important concept was explored with participants. An understanding of perceived social support was gained through exploring current family composition and relationships, friendship groups, involvement in community groups and sense of autonomy or control in everyday life. All participants were asked the direct question "who do you have in your life that you could go to for everyday help if you needed it?" followed by probing to understand the nature of the relationship and participants' perception of the support that would be available if needed.

5.3.4.6 Access to and use of health care services

This theme involved an in-depth exploration of participants' perceived relationships with the health care system particularly in relation to the management of their diabetes. They described how they accessed services, their perceived barriers to accessing care and their perceptions of the types of care and support that they had received through the years from their diagnosis with T1DM. These data were varied in nature and there followed deep probing of situations in which participants had disengaged from care and the reasons for this. This theme was important particularly for the participants who were purposively sampled to address this research aim. The health service as a 'structure' gives rise to mechanisms that create 'roles' which under certain conditions can direct a course of action [4] and disempowerment leading to disengagement may be one example of this. Access to and quality of health care were explored by asking about glycaemic control, development of complications, difficulties in managing the treatment regimen, particpants' engagement with health care services, their history of practitioner relationships particulary in the event of an inabilty to build strong and trusting relationships over time, any history of poor concordance or risk taking and reasons for this and

any avoidance of health care encounter (and if so, why?). Within this interview theme is a sub-theme of fear of complications and it was important to identify how information about these was relayed and the impact it had on participants' ability to imagine an attractive future, lack of which could reduce their sence of agency and purpose [360].

5.3.5 Ethical considerations

Ethics approval to conduct this research was sought after the findings of the two quantitative studies were known and the interview themes had been developed. Approval was obtained from the Southern Adelaide Clinical Human Research Ethics Committee (SACHREC reference number 501.15 appendix 5-3). The study was advertised in renal and endocrinology clinics (appendix 5-1) and suitable participants were advised that the study was being conducted by clinic staff and identified to the researcher as potentially suitable. Potential participants were given a participant information sheet, a consent form (Patient Information and Consent Form (PICF) appendix 5-2) and with their permission were telephoned one week later to determine whether they would like to participate.

The researcher has a clinical role in the renal service and was well known to several potential participants but no patients in a dependent relationship with the researcher were approached directly. Being in a dependent relationship with a researcher while receiving care and treatment may create a perception of undue coercion or foster an increased willingness to participate to please the clinician, which is an unethical use of power and privilege. For these reasons referral of people receiving renal replacement therapy in the health service was though an introduction to the study from the medical and nursing staff and the subsequent mailing of a letter of introduction and PICF.

Study participants are afforded the right to be fully informed regarding the purpose and intent of the study, the right to privacy and confidentiality and protection from harm [338] through careful explanation, good data management and sensitive interviewing. One challenge in qualitative research is the development of mutual trust and intimacy during the interview process in the absence of an ongoing relationship [339]. In overcoming this, the researcher gave an honest appraisal about what would be gained, fostered a strong sense of empathy and acknowledged that each participant was in control of the process, telling the story on their terms. The researcher actively responded with empathy and avoided criticism when difficult

scenarios and periods of poor glycaemic control were recounted and this resulted in a positive experience in relation to self-disclosure and validation of participants' individual experiences.

Conducting qualitative interviews with people burdened by illness can be emotionally distressing for both researcher and participant but not to respond with understanding and compassion is a deficit on the part of the researcher as a human being [361]. A true test of ethical qualitative research is whether it causes the researcher to suffer with their participants [362]. Deep feeling is unavoidable in any type of qualitative research but especially so when examining people's sense of grief and loss because of their poor health and this had a significant impact on the researcher during this phase of the study. Ethical considerations in undertaking human research focus strongly on participant protections and rarely is the focus on researcher psychological protection. It is therefore vital that researchers undertaking qualitative interviews that may cause emotional distress actively seek and are offered support from their organisations for debriefing opportunities that do not breach the confidentiality agreement between the researcher and the participant.

5.3.6 Theoretical sampling to saturated theory

Qualitative research uses small samples that provide rich detailed data, and data collection is complete when no new concepts emerge from interviews and the question has been answered [341, 345]. Sampling in this phase of the research is purposive, strategic and meaningful [10] to find information rich cases with the aim of describing the process of the phenomenon, not its distribution. Purposive sampling was used to address the research aims, with criterion sampling used in the initial stages to identify participants who met certain criteria [339]. The first people sampled were those with a history of difficult disease management and the development of complications (n=5) who were identified through the promotion of the study in the renal unit. These participants could describe reasons why their kidney disease may have occurred. Stratified sampling was used next to identify participants with contrasting experiences (n=8). These participants were recruited from endocrinology clinics and were identified by attending physicians as having reasonable glycaemic control and, more importantly, a history of regular clinic attendance and a strong concordant relationship with the endocrinology service. While clinician assessment of concordant relationships may be biased, these participants were probed at interview to describe their feelings towards their clinicians and the level of concordance that they felt the relationship entailed. The final participants were

males (n=4) with a difficult disease trajectory that had led to ESRD. They were sampled purposefully through the promotion of the study in renal outpatient clinics. These final participants were sampled to address the study aim of exploring factors that led to disengagement from health care and the experience of returning to care after the development of severe complications. In total, recruitment ended when 17 people had participated in the study because at this point in the data collection no new information was being offered and the interview themes had reached saturation [345]. While the purposive sampling resulted intentionally in more males with ESRD in the study, the participant group retained diversity with different disease experiences, highly varied ages of onset and a wide range of disease duration and these are further described in 5.4 and detailed in table 5-1.

5.3.7 The qualitative interviews

In-depth interviews were conducted with participants and occurred over several months with thematic analysis occurring contemporaneously with recruitment to the study. This approach to qualitative research enables constant comparison between and within cases and allows for early themes from the initial interviews to be explored in more depth in subsequent interviews [363, 364]. Interviews were of one hour duration on average, and occurred in the participant's centre of care. The interviews were audio recorded and professionally transcribed before analysis. The researcher also kept a memo journal throughout the data collection process in which early themes and issues that required follow up in future interviews were documented and these memos formed the early concepts for data analysis [339]. Notes were also taken about non-verbal cues that were observed early in interviews when participants were initially cautious given the researcher's status as a HCP, and again when some participants became emotionally distressed at the recall of events. Notes on non-verbal cues were used by the researcher to reflect on the double hermeneutic and her own role in shaping the qualitative data collection.

5.3.8 Thematic analysis

The first step in analysing the transcribed qualitative data was to become fully familiar with the data through reading and re-reading the transcripts. Data were then coded, which involved labelling passages of text as a construct and grouping these constructs together in a node or theme to explore their meaning [339, 345]. The data were analysed in NVivo (QSR Nvivo10 2014) and first coded into common phrases, expressions or experiences. These codes were then

developed into the themes that were found in the qualitative data. This process is known as open coding. It was followed by axial coding in which the initial labels given to a construct were grouped with similar constructs to form a theme [10]. An example of a group of nodes that formed a theme was participants' descriptions of their relationship with their primary caregiver in childhood. This was coded as parental role model, their relationships with mother coded as maternal attachment, descriptions of leaving home at a young age because of parental conflict was coded as adversity in childhood and their age and recounted experience of becoming responsible for their own diabetes care was coded as transition to self-care. Together these codes formed the theme of 'early childhood environment'. Similarly, the theme of health care access was defined through the participants' data being labelled into the codes of the patient as the expert, negative connections with HCP and positive connections with HCP. Concepts in the data are building blocks, they are abstract but form clusters and interconnect and together form a 'web of meaning' [302]. Persuasive qualitative research involves transcribing, reading, creating memos and a codebook, open coding and labelling, grouping the data into themes, interrelating the themes, presenting the findings, assessing how the research question has been answered and comparing the findings with previous literature [12]. Theoretical saturation of the themes occurs when the data is rich enough to ensure that the themes are well developed and are addressing the research aims. This was achieved by the comparison of individual data case by case to determine both commonality and contrast, data from the same individuals to understand the common threads within the narrative, the empirical evidence derived from the literature discussed in chapters 1 and 2, and the relationships that can be seen between the themes in relation to how one theme is capable of shaping another [363, 364].

5.4 Results

The predominant themes found in the data related to the challenges of living with T1DM and how early childhood environments, particularly positive maternal attachment, fostered a strong sense of self determination and led to the ability to form close attachment relationships in adulthood. These close attachment relationships in adulthood are what provided the participants with the social support that is vitally important to manage T1DM successfully. For some participants, absence of these critical social factors led to diabetes management being especially difficult, without social support and with subsequent combative relationships with

HCP which then further compounded poor diabetes management for the person, who now lacked both social support and health care support.

Participants were asked to describe their own glycaemic control without imposing a numerical value on this. Although many described their current HbA1c result all participants then reflected on what this meant to them in regard to considering their glycaemic control as good, poor or improving with time. Some participants were identified as having gained a sense of mastery over their T1DM by considering their explanations regarding their disease trajectory, self-management and engagement with health care services. Mastery was considered to have been gained when participants described a deep understanding of their individual glycaemic control and factors that affected this and they had an ability to engage with HCP in a proactive way, gaining useful tools and advice from the encounter. Mastery in T1DM was also denoted by having the ability to demonstrate a sense of purpose and optimism regarding the future despite the constant daily problems and challenges associated with diabetes management. This sense of purpose and optimism suggested these participants had strong adaptation to living with this chronic disease and it contrasted with experiences of other participants who appeared to feel defeated by the illness.

In table 5-1 details are given about the demographic characteristics of study participants in relation to the key SDH that have been explored in this research and their clinical trajectories. In particular the participants without a sense of diabetes mastery are highlighted to demonstrate the link between early childhood environments and social support. The heterogeneous group comprised of ten males and seven females with a diverse age range of 23-62 and a diverse range of age of diagnosis from that varied from 1 year of age to 51 years of age. In addition the cohort had a wide range of disease duration from 3 months to 53 years and were able to share a variety of experiences from recent diagnosis to the challenge of dealing with health complications in long duration disease.

The study results are presented with the themes of the lived experience of the disease, early childhood environment as a social determinant of health outcomes, socioeconomic status as a social determinant of health outcomes and access to and use of health care services as a social determinant of health outcomes. Together these themes address the stated aims of the research, which were to describe the lived experience of the disease, to understanding the ways in which the psychosocial environment impacts on the management of T1DM, and to gain insight into

why certain groups are at greater risk of poor outcomes through long term disengagement with the health care service.

Table 5-1 Description of the participants

Gender	Age (years)	Age of onset of T1DM (years)	Disease duration (years)	Early childhood environment	Level of social support	Self-reported glycaemic control	Sense of mastery	History of kidney disease
P1 Male	36	16	20	SP low maternal attachment	Low ##	Poor	No	ESRD¶
P2 Male	42	3	39	SP low maternal attachment	Low ##	Poor	No	ESRD¶
P3 Female	41	8	33*	Positive	High	Good	Yes	ESRD¶
P4 Male	57	21	36	Positive	High	Good	Yes	ESRD¶
P5 Female	62	9	53	Positive	High	Good	Yes	ESRD¶
P6 Female	32	15	17	SP strong maternal attachment	High	Good	Yes	No
P7 Male	55	50	5	Positive	Moderate #	Good	No	No
P8 Female	56	51	5	Positive	Moderate	Good	No	No
P9 Male	26	26	0.3	Positive	High ǂ	Good	Yes	No
P10 Female	58	14	44	Adopted, low maternal attachment	Low ##	Moderate	Moderate	CKD¶¶
P11 Female	23	5	18	SP moderate maternal attachment	Low ##	Improving	No	No
P12 Male	26	25	1	SP Positive paternal attachment	High	Good	Yes	No
P13 Female	29	21	8	Positive	High	Good	Yes	No
P14 Male	27	5	22	Adopted, moderate attachment	Moderate	Poor	No	CKD
P15 Male	32	1	31	Mother T1DM deceased	Moderate	Poor	No	KP Tx¶¶¶
P16 Male	55	7	48	SP positive step father relationship	High	Good	Yes	KP Tx¶¶¶
P17 Male	51	25	26	SP low maternal attachment	Low ##	Poor	No	CKD¶¶

*Disease trajectory complicated by severe and chronic pancreatitis
Early childhood environment SP – single parent
ǂ At least one close attachment relationship who is involved with diabetes care
At least one close attachment relationship but managing diabetes care independently of this person
No close attachment relationship and managing diabetes care independently
¶End stage renal disease (ESRD) ¶¶Chronic kidney disease (CKD) ¶¶¶Dual kidney–pancreas transplant (KP Tx)

5.4.1 The lived experience of type 1 diabetes mellitus

5.4.1.1 Diagnosis experience

To gain a deep understanding of the lived experience of T1DM, participants were asked to reflect on their diagnosis, their experiences of living with T1DM and the challenges that they face. Those with childhood onset had imperfect recollection of the actual illness onset itself but could describe their parents' reactions, which tended to involve a sense of grief and loss. Some described how their parents' reaction to the diagnosis left them as a child supporting the parent and feeling guilty and responsible for upsetting the family. Participants with adult onset also had similar experiences and feelings of responsibility in relation to parental grief:

> *P9 "My mum was heartbroken. My mum was really shocked that I got it. I think she was more upset and worried about it than I was. She just kept crying and saying that if she could take it away she'd have it so I wouldn't have to have it".*

Disease onset in adulthood was described as confronting, with a short period of symptoms that made little sense delaying the diagnosis by several weeks. Common symptoms at onset were thirst, dysuria and lethargy, with adult onset participants commonly describing thinking that they had influenza. The diagnosis, when it came, was a complete shock with the participants describing a sense of disbelief and feeling dazed by the haste with which they found themselves at the hospital being taught how to self-administer insulin:

> *P17 "He opened his drawer, pulled out an insulin pen with a tube of insulin in it, and said 'get used to it'".*

The day of diagnosis and commencement of therapy was recounted as a surreal experience and the blunt nature of this experience was in a way recalled as a terminal event, with life changing dramatically from that moment on:

> *P7 "The first educator said it's not really a life changing disease and a week later I was completely – I completely disagree with her".*

Education at the time of diagnosis was intense and extended over the following days, with information being given about insulin dose adjustment for glycaemic balance and dietary

intake. Participants with long disease duration recounted a set regimen that involved a standardised insulin dose, self-monitoring of blood glucose (SMBG) on average three times daily, and a sense of relief when plastic syringes became available and they no longer had to 'boil' glass syringes to sterilise them. Those diagnosed more recently recalled training for intensive therapy which involved multiple daily injections of insulin with dose adjustments determined by carbohydrate counting and SMBG 6–8 times daily. This theme is of particular importance in relation to withdrawing from care, which often occurred when an endocrinologist attempted to transfer a participant from the childhood regimen to intensive therapy, and this is further described in 5.4.5.1. Of particular interest in this study was the high number of participants (9) who described a family history of diabetes and two of whom had a parent with T1DM. Participants who observed a parent with diabetes from childhood were purposefully probed to explore their parent's disease trajectory, the development of complications and their parent's reaction to their own diagnosis, which has led to insights regarding the development of a fatalistic point of view with regard to diabetes and the potential disease trajectory:

> *P15 "It was a subconscious feeling of that but it wasn't an active feeling fatalistic about it. It was look, just live your life as best you can… that was just the mindset back then, it's going to happen regardless".*

Finding two participants who were diagnosed at the age of 50 was unexpected but offered considerable insight into the shock of receiving a T1DM diagnosis well into adulthood and the challenge of adjusting established lifelong behaviours. Both participants were antibody positive proven cases of T1DM. They both described a sense that living with diabetes was a surreal experience even five years after diagnosis and although both had partners they expressed a very clear sense of being individually responsible for their diabetes management and avoided involving their spouses in their care. They also reported a gradual withdrawal from their former social environment as the rigours of disease management became too difficult to incorporate and both reported increasing social isolation.

5.4.1.2 Education and T1DM

Participants described the education they received around the time of diagnosis while they were experiencing a sense of transformation into a new life with diabetes and which left them feeling overwhelmed. The education was intensive and delivered at a time when participants' minds

were busy processing huge amounts of information. Consequently, participants reported remembering only small amounts of it:

> *P9 "When I left hospital I didn't really know what I was doing. They gave me some needles and said 'you need to inject. There you go'. I was left pretty quickly 'here's a bag. Here's everything in it. Test your blood, take six units with every meal, call us with your readings'. That part was very quick and out the door".*

Fortunately, education in T1DM is evolving and never ending and the participants drawn from the endocrinology clinic described how constant repetition, practice and support led to eventual mastery in diabetes management. Participants described feelings of mastery when they finally gained a complex understanding of their *individual* glycaemic responses to food and insulin administration, which allowed them in most cases to predict what their blood glucose levels were likely to be and how the day looked for them in terms of management. This sense of mastery was achieved by individual endeavour but also through accessing repeated support from the endocrinology service to try different regimens until the right balance had been reached. This has very serious implications for the young, short disease duration participants with diabetes complications drawn from the renal clinics. These participants described a history of low engagement with school because of learning difficulties and subsequently being unable to understand the complicated regimes that they were being asked to undertake. They primarily described their difficulty in absorbing information in the HCP consultation and making little sense of the written information:

> *P 2 "…but for me to read it, to put text to what I'm doing, doesn't work for me very well".*

> *P1 "…being able to see evidence of it rather than just hearing it, so people showing you pictures of things".*

These participants also described negative childhood environments and low levels of social support both of which appear to diminish health literacy in relation to the capacity to be an active participant in the health care encounter, which is a theme explored in more detail in 5.4.5.1.

P15 "At my kidney failure diagnosis they sort of updated my knowledge a bit and said 'look we're counting carbs rather than glucoses'. There was about 15 to 20 years of knowledge advancement that I missed out on".

5.4.1.3 Disclosure and stigma

Findings show that the notion of stigma in diabetes, particularly for T1DM, may be a thing of the past because participants diagnosed in the last 10 years did not express this perception at all, a finding that contrasts with previous studies. Only one participant described a sense of stigma and this occurred more than forty years ago:

P10 "People didn't understand back then about having injections and even the kids at school would keep away from me. It was just a really difficult time when you're 14".

Participants diagnosed more recently reflected on the fact that they were quite open in disclosing the fact that they had diabetes and they were not able to perceive any sense of stigma. They described discussing diabetes care openly with their friends, family and work colleagues, without stigma but with a sense of involvement that sometimes bordered on judgement. This was done in a participatory way, seeking reassurance that the person with diabetes was doing well:

P9 "Like the girls do it at work about testing my blood 'oh is it high? That's high. How are you going to fix that?' Like it's ten; it's not high".

The participants of this research did not use the moral language about themselves and their diabetes that had been found in previous studies in relation to being a 'good' or 'bad' diabetic, or being 'in' or 'out' of control. Instead, they described their diabetes management as being a really difficult challenge and that, irrespective of outcomes and even when control was poor, they were all doing their best:

P9 "(I) Sat and spoke to my mum and she was like 'you're trying to be the perfect diabetic; there isn't one'.

5.4.1.4 Tension between the fear of hypoglycaemia and the fear of complications

The participants in this research described a constant tension between the desire to maintain a normal HbA1c to avoid the known complications of T1DM, and the experiences and fear of hypoglycaemia. When recalling hypoglycaemic events, they were described with a strong sense of horror at what became of them:

> *P15 "I fell on the floor and I'd bitten my lip and my mouth was bleeding and the kids were there and the young one was only young and he was screaming, didn't know what to do".*

These past experiences had created a sense of anticipatory fear and in many cases a reluctance to optimise glycaemic control lest it led to a hypoglycaemic event. However, the fear of complications was also a constant companion and described as potentially a brutal bodily insult resulting in limb amputations and death. This fear drove the desire to optimise glycaemic control despite the risk of hypoglycaemia and this tension left participants debating their options. It is thought to be responsible for the phenomenon described as diabetes distress that is discussed further in 5.4.1.5.

> *P4 "Oh yeah, that's why you have to be -- you've got a line and you can't stray from that line too much because suddenly you think that you're doing all right and you're a bit under that line or you're a bit over that line and you think you're doing all right but if you're not it comes; it'll get you".*

5.4.1.5 Diabetes specific distress

Diabetes specific distress is a phenomenon described in many studies and which is quite distinct from a diagnosis of depression or anxiety. Diabetes specific distress relates to an anxiety or depressive response to the demands of the treatment regimen and the constant pressure that is felt. The participants in this research articulated this distinction very clearly, and although they described psychological distress it was constantly linked back to the relentless nature of daily surveillance in their diabetes management:

P6 "it's almost like you want a holiday from diabetes, like it's almost like you want a psychological break from it, it's like looking after a sick child".

P10 "Can't I just give it to someone else for 24 hours and I'll be normal and then I'll take it back? I'm going to have it tomorrow and next week and next year and forever".

Participants described how this relentless pressure accumulated until they felt overwhelmed and deflated. On reflection, they saw it as a type of depression but without a formal diagnosis:

P4 "It's a circle because you get anxious or you get a bit down in the mouth about it. It gets worse and then it gets worse and then it gets worse. A lot of people, you find before they became a diabetic they probably weren't that depressed".

Participants were asked to describe any offers of psychological support they had received during the course of their illness and almost all confirmed that this had been offered. The great majority, however, declined the offer and expressed a sense of fear and distrust of formalised psychological care:

P2 "You make me go see this person' (psychiatrist) and I will never talk to that man again in my life, you know what I mean? No matter what, you have broken my trust because we were just meant to be talking in a general kind of thing".

It is thought that that the need for psychological support could be more closely related to social support rather than institutional formalised support and this is further described in 5.4.3.

5.4.1.6 Fear of the future

Generally, the participants with T1DM were well informed about the possible complications of their condition and could describe potential problems of the eye, heart, kidney and circulation. The exception were participants who had disengaged from care after a troubled disease trajectory and who subsequently expressed a sense of disbelief when they returned to care with severe complications. This is discussed in more detail at 5.4.5.2. While knowledge of potential complications is vital to ensure that a person with T1DM strives for good glycaemic

control, it is important to note that this knowledge also induces fear and possibly further contributes to diabetes distress:

> *P10 "They sort of try and scare you into doing the best job you can with your diabetes and it's no good scaring people because you don't want to live in fear".*

5.4.2 Early childhood environment as a social determinant of health outcomes in type 1 diabetes mellitus

The idea that early childhood environment is a social determinant of health was explored with all participants being asked to describe with whom they lived when growing up and to discuss in detail their relationships with their parent(s). This was explored through a series of questions about parental involvement and support in childhood irrespective of age of disease onset. Seven participants described living in a single parent childhood environment, which in quantitative studies is often described as being associated with poorer outcomes in T1DM. However, participants in this study showed that growing up in single parent families did not always result in poorer outcomes in T1DM. It appeared that maternal relationship was the critical factor in supporting participants, whether in a one or two parent family. With strong maternal attachment, the child with diabetes felt cared for and supported and the transition to self-care was relatively seamless:

> *P16 "I don't reckon she pushed me. I reckon it was when I was ready to do it. Mum wasn't like that; she'd just go on and on".*

When there was low maternal attachment and involvement, the child with T1DM had to take responsibility immediately and this was often at an age when their cognitive level was below that needed to self-manage this complex chronic illness. Four participants had low maternal attachment and childhood onset T1DM and all four described self-management without parental involvement from as young as six years:

> *P1 "Because I think she didn't understand it she was a bit scared about it because she had no idea how to deal with it or anything like that and she didn't know what it meant, like in the way of what I had to do to look after myself after that, so she was always without realising it, she pushed me away more than helped me accept it".*

This led to incomplete understanding of the impact of diabetes over the lifetime and the importance of maintaining an optimum glucose level to prevent complications. Participants with childhood onset and low maternal attachment in childhood described a lack of knowledge about diabetes complications and a 'set and forget' mentality in relation to standardisation of insulin dose for many years. This led to prolonged hyperglycaemia and the silent progression of complications.

In participants with adult onset disease, maternal relationship was also a striking feature of adaptation to the diagnosis and mastery in relation to intensive therapy:

> *P9 "It was my mum that was going through it and working it out and I would just question her and she'd be like 'well, what do you think? We'll do it this way' and then we'd work it out together and then we'd both agree so then I'd take my insulin".*

Three participants with adult onset T1DM who came from single parent families and who described close parental attachment after family breakdown also described a strong sense of resilience and self-determination when it came to adapting and managing their disease:

> *P6 "People have said I've got an inner strength that I don't know I've got"*

Participants clearly described how the quality of their maternal relationship helped or hindered their diabetes management irrespective of age. However, while maternal relationship was important for a sense of self determination in relation to the management of T1DM, another strong theme independent of age of disease onset was the importance of strong social support, particularly a close person being involved in diabetes care and this is explored further below.

5.4.2.1 The impact of low maternal attachment on adult attachment relationships

There appeared to be a strong relationship between low maternal attachment and an inability in adulthood to form close attachment relationships that could be a source of support in diabetes management. Participants who recalled adverse early childhood environments with low maternal attachment also reported either not being in a relationship at the time of the interview or a history of low quality relationships in adulthood:

P10 "I've had two husbands and I've had three long term relationships, I've always felt that I choose the wrong people because anybody that shows me a bit of love and affection I will just -- I latch on because that's what I'm missing and that's what I'm looking for".

For participants, adverse early childhood environments with low parental attachment affected their life trajectory in a cyclical way by inhibiting the ability to bond closely in adulthood, which led to ongoing low levels of social support. In direct contrast, participants with positive parental attachment also reported strong attachment relationships in adulthood and the presence of a strong support person who helped with diabetes management. In addition, this study has shown that being in a single parent family is not always associated with poorer outcomes, and when parental attachment remained strong participants described a strong sense of social support and, in time, mastery in their disease management.

5.4.3 Social support as a social determinant of health outcomes in type 1 diabetes mellitus

A striking finding in this research was the relationship between high levels of social support and the ability to develop a sense of mastery in relation to diabetes management. Participants who described feeling that their diabetes was under good glycaemic control also spoke of having a strong support person who was closely involved in the day-to-day management of diabetes and their navigation of the health care system. This increased engagement with HCP and promoted an active interaction from which there were significant gains:

P 12 "I just relate it as to like a formula one driver. So I'm like the driver who's doing everything but they're (partner and endocrinology team) the pit crew and they're everyone who does all the maintenance side of things behind the scenes, so you couldn't do it by yourself; you couldn't do it".

Whilst T1DM is often referred to as a self-managed condition, this is simply not the case. A central component of the day-to-day treatment is the presence of a supportive person who understands diabetes and what needs to be done. For participants, this strong social support took the form of practical support such as medication management, dietary support and liaising with HCP but it also involved also psychological support, often described simply as having someone to talk to:

P13 "I think I used to probably complain to [him] a lot about it and I didn't want him to do anything about it, it was just like he was a backboard for me. Sometimes you've just got to let it out and tell someone".

5.4.3.1 The absence of social support

In direct contrast, low levels of social support were described by participants who had struggled with their diabetes management, had a history of poor glycaemic control and the development of complications and, without exception, the absence of specialist care. These factors appear to be interconnected, with low levels of social support leading to erratic and difficult glycaemic management, with no one to turn to for help and a sense of isolation in the health care encounter making it more difficult to navigate

P10 "You're struggling with trying to cope with having the disease but you're also struggling with trying to cope with other people's reactions towards you and you're struggling to sort of cope with how do I fit into society now because I'm this lone figure".

P14 "I think you're a number, you know, number one, number two, number three... this is shit. I'm just wasting my time here. They don't really care".

Managing diabetes alone, with little or no social support and no medical or allied health support, is an insurmountable task which results in suboptimal glycaemic control for long periods of time and the silent undetected advancement of severe complications.

5.4.4 Socioeconomic status as a social determinant of health outcomes in type 1 diabetes mellitus

A central theme explored in this qualitative study is the known inverse relationship between SES and morbidity and mortality found in the review of the literature. Participants were asked to describe their SES in an exploration of their perceptions of their parents' occupations and their economic security in childhood, their schooling and educational achievement and their own work history, particularly if there were periods of unemployment or insecure work tenure that affected their sense of economic security. They were also asked to describe the cost of care to determine whether T1DM placed an additional economic burden on people with low SES. Through this probing, the concept of SES was not measured but rather understood in depth

without quantification. Two opposing patterns emerged from the data. Participants who demonstrated a sense of mastery in diabetes care, a history of strong maternal attachment and high levels of social support also described parents with professional occupations, completing high school and their own employment history as secure in tenure and professional in nature. In contrast, participants who could not achieve mastery in diabetes management gave a history of low maternal attachment, relationships characterised by conflict, leaving the family home at a young age, low levels of social support and the absence of a close interpersonal relationship at the time of the study. Their parents had worked in unskilled labour or retail roles, they had left school early or struggled academically, and their subsequent occupations were similar to those of their parents:

> *P1 "I had lots of short jobs. I was in and out of work all the time…I tried doing a few different jobs. I never really had any goals as to what I really wanted to do; I'd just try and do anything really. There was no real focus on something specific that I wanted to do".*

The use of the term socioeconomic status in the literature in relation to poor outcomes perhaps suggests that the key factor in the relationship is low income. Participants identified this as significant but not in the way that might be expected:

> *P2 "Like for me to give up a working day, you know, to go see a foot person".*

While the cost of care was described in detail by participants it was not a strong theme and they did not consider it a barrier to good glycaemic control, principally because much of the equipment and consumables were heavily subsidised by the National diabetes services scheme (NDSS). Most participants also agreed that having to eat a healthy diet with little daily variation largely resulted in a reduction in food costs and minimal purchase of prepared foods outside the home.

Participants who described their background as low SES explained in much greater detail how the mediators for poorer outcomes were low levels of social support, low health literacy and low self-esteem, and these manifested as an invidious distrust of the endocrinologist and an inability to engage with care:

P17 "That was another part of the problem, I found him (endocrinologist) a bit off putting, he was a bit up himself, I used to walk into his office, a room like this and there would be this big carved wooden table and this big chair and he was in (place) and all that stuff, kind of rubbed me the wrong way, he was a bit elitist you know, and I didn't feel comfortable, I don't know why, looking back".

This is a significant psychosocial factor that led to withdrawal from care and is further described in 5.4.5.1. In relation to the social environment, this research has demonstrated that factors in early childhood with an adverse impact on life chances are low maternal attachment and low social support, which are commonly associated with a family background of low SES. This environment subsequently leads to difficulty engaging with schooling, employment in low-skilled manual occupations, diminished health literacy and the inability to fully engage with HCP. It is thought that self-esteem is a significant component of this and this is explored in more depth in the recounting of the health care experience.

5.4.5 Access to and use of health care services as a social determinant of health outcomes in type 1 diabetes mellitus

The nature of the health care encounter was a central theme in this research and was explored with all participants. Intense and directed questioning encouraged participants to reflect on their health care encounters, their relationships with HCP, and what they perceived as a good relationship with a basis of trust and in which they felt empowered to speak freely about issues that were important to them. A strong theme that emerged was the need to be recognised as someone with the capacity to contribute to the discussion in a meaningful way to ensure that participation in the encounter was active and not passive. There was a striking contrast between the statements of participants who were engaging with endocrinology services and those who failed to do so. The mechanisms implicated in this were multifactorial and included HCP that participants could relate to:

P13" My specialist is amazing too 'cause she probably thinks that I'm a big worry wart so she just goes 'don't even worry about it; you're doing great. Just keep doing what you're doing and just stop worrying'.

Or not:

P5 "They're arrogant shits. They seem to -- because they think they know everything about the disease they can tell you what you should do, what you shouldn't do. What they don't understand is they've got no bloody idea at all".

Participants with high levels of social support and a sense of mastery described interactions with HCP that demonstrated strong capability in health literacy and reciprocal respect:

P6 "He said 'you'll understand this disease better than anyone else, a doctor or whoever' and I think those words stuck with me".

A strong sense of self-esteem gave some participants the confidence to navigate the health care encounter on their own terms and take from the experience the information and tools that they needed to support their diabetes management:

P13" I think that's quite a good relationship and I feel comfortable with her changing anything. I think I put the trust in her for that, things that they adjust and change, they work and you're like 'yeah, that actually worked for me".

Health literacy as a concept in health care is most often thought of as ability in literacy and numeracy but in fact it encompasses much more. A vital aspect of health literacy is the ability to engage in a meaningful way with HCP to develop a concordant relationship that enables joint decision making and common goals. Participants emphasised the importance of this, describing a keen need for HCP to acknowledge their expertise as the person with the disease and to consult them on changes that needed to be made to the treatment regimen. Participants who were having problems managing their diabetes needed help and did not want to be criticised or blamed, but their inability to articulate this resulted in a passive health care encounter from which they received very little:

P2 "I think if you're speaking to a specialist and they're asking you how they're making this work then you're going to feel more open to explain to them exactly what's going on in your life. When you rock up and see a specialist and he's demanding you do this you're not really going to open up and explain to them what's going on in your life

because you're going to tell them what they're telling you because you just want to get out of there".

Diabetes management involves a complex duality between self-responsibility and the health care system's responsibility. This was highlighted by one participant's use of the term 'we' rather than 'I' when describing encounters with HCP following the development of severe complications and the loss of much functioning in their early 30s:

P1 "I think if we focused more on the things that I can do and the benefits that it would give me if we did that, then I probably would have accepted it better".

The negative impact of low maternal attachment, low levels of social support and low health literacy which are social and environmental determinants of health was, surprisingly, best articulated by a participant who described a supportive childhood environment, a loving partner and strong relationships with HCP:

P4 "You see a lot of people that have difficulty in managing their diabetes. I think you need to look at their overall life, you know, where they've come from and the actual environment which they're living in at the moment".

5.4.5.1 Disengagement from health care

Nearly half of the participants (7 of 17) described being disengaged from endocrinology care for many years. Two of these had established good relationships with a general practitioner and while they eventually developed kidney disease, it was known to be occurring and happened after long disease duration. The other five participants had been unable to establish a close relationship with a HCP, and their care consisted of having prescriptions filled with no surveillance for kidney disease until the abrupt and sudden diagnosis that kidney disease was well advanced at a comparatively young age:

P15 "Went into the GP for some antibiotics for a cough that wouldn't go away and they said 'oh we'll just take a blood test, just to check that everything's all right' and that's when the kidney function came back at 19 percent, and that was the first test that was

done with a kidney function test on it, so I went from thinking I was healthy to end stage kidney failure. If it had been tested six months, a year, two years beforehand it probably would have shown up but it just wasn't".

P14 "Nothing could explain the lower back and they were putting it just as 'it's in your head' sort of a psychological thing. It was only until my GP carried out some more tests and talking to him a bit more and carried out blood tests and diabetes sort of thing that it came up 'there's possibly something wrong with your kidneys'".

In each of these five cases disengagement occurred in the setting of difficulty managing the condition very early in the diagnosis or in the immediate period following transition to adult services and to an intensive regimen. Poor glycaemic control and subsequent combative relationships with HCP preceded all cases of disengagement. The downward cycle had multiple elements that started with an inability to master the regimen and achieve glycaemic control, participants' inability to engage with HCP who talked down to them and made them feel that they are wilfully disregarding the advice given and that poor glycaemic control was a personal choice:

P2 "...and I said to him 'well, you're wasting my time and I'm wasting yours. If you can't figure out a system that is going to work for my diabetes we're wasting each other's time' and that's why I never seen a diabetic doctor for eight or nine years".

P14"It was basically 'your thing's high. We've told you what to do but you're not listening so why waste our time?' That's what it felt like".

These participants acknowledged that there were periods when they took their standardised dose of insulin to stay alive, did not SMBG and consequently developed a fatalistic attitude about the potential of the health complications they were now experiencing:

P17 "Kind of gave up on it after a while, became too hard, closed my eyes, didn't want to know about it".

The fact that scenarios like these have been described has important implications for clinical care. This is best demonstrated by participants who returned to endocrinology care after the

development of kidney disease. They carefully and insightfully described their strong need to be judged not by the mistakes they made in the past but by what they needed now:

> *P15 "I imagine that there would have been a little bit of 'come on, what have you done?' as people - it's just how people are but I just said 'yeah, look, this is the current state of play. My goal is to take better care of my sugars so that I avoid any more further damage; how do I do it?' So I've come out and just said straightaway 'look, you specialist, me patient. Let's work together. Let's get it done".*

5.4.5.2 The impact of kidney disease, regret, loss and grief

The catastrophic impact of renal failure on a young person in what should be the prime of life cannot be underestimated. This theme was explored in this research to demonstrate how much is lost when an adverse childhood environment leads to low levels of social support, difficulty achieving glycaemic control and disengagement from care. The need to attend haemodialysis sessions for up to five hours a day, three times a week, has a huge effect on participants' lives:

> *P2 "Put me on sickness benefits and put me on the dole and sit me in a room and I'll smack my head against the wall for the rest of my life".*

Participants who had fared poorly with their diabetes management described their sense of deep regret, loss and grief for the health they could have had:

> *P17 "My life has been ruined by it, I'm 51, I've had my feet amputated, got kidney disease, my eyes are playing up, I can't read without my glasses, it cost me my job, it's cost me a lot".*

Poignantly, participants who had received kidney–pancreas transplants described their hope for the future but not without caution:

> *P16" The most important thing to me was that the pancreas kept working because I didn't want to have diabetes anymore. In my head because I'd had it so long, that's what I wanted to be rid of. Even though I'd hate it if I had to go back on dialysis that was the most important thing in my head".*

5.5 Discussion

The concept of being able to make a rational choice, which arguably underpins contemporary chronic condition self-management, fails to take into account that 'agency' refers not only to intent but also to a person's capability and it is necessary to measure both to understand unintended health consequences [15]. This research has used a critical social theory perspective to explore participants' individual agency and the social structures and mechanisms that shape the experience of living with T1DM, including factors that supported or hindered diabetes management and the importance of engagement with and trust in health care services.

5.5.1 The lived experience of type 1 diabetes mellitus

The majority of literature to date on diabetes shows that when diagnosed with diabetes, people experience a sense of spoilt identity and then describe themselves as good or bad diabetics [232, 233]. Participants in this research identified changing public perceptions of the disease, with no sense of stigma regarding either the diagnosis or the ability to optimise glycaemic control. They often made complete disclosure of the diagnosis to work colleagues and close friends as well as to family. That said, however, the diagnosis of T1DM was clearly a challenging one irrespective of age, and mastery was only achieved with constant support and education over time. People with T1DM often describe receiving little education about diabetes or not really understanding it at the time of diagnosis [241, 244, 255], which makes ongoing engagement with health care services vital so that explanations can be repeated and knowledge embedded.

Participants with a sense of mastery described a repeated and sustained daily endeavour in which glycaemic control could be unpredictable despite their very best efforts. The fear of complications and the fear of hypoglycaemia are competing elements and despite the introduction of intensive therapies and new knowledge this fear has remained unchanged for 25 years, when research found people with T1DM feared hypoglycaemia to the same extent that they feared complications [365]. This constant anxiety is likely responsible for the diabetes distress described by participants. Diabetes specific distress is a phenomenon that is quite distinct from a diagnosis of depression or anxiety, both of which are known to be more common in people who have T1DM [124]. Diabetes specific distress relates to an anxiety or depressive response to the demands of the treatment regimen and the constant pressure that is felt from

family member and clinicians [71, 95]. The phenomenon is known to be widespread and in the latest Diabetes Attitudes, Wishes and Needs study (DAWN2) conducted in 17 countries it was found that diabetes related distress was a factor for 44.6% of respondents while the availability of person-centred chronic illness care and support was rated as low [366]. Participants in this study echoed these findings, saying that they did not want formalised psychological care. There is a clear need for holistic supportive care that is centred not only on diabetes management but also on individual characteristics and needs. This need was most keenly felt by participants with adverse early childhood backgrounds, low levels of social support and an inability to engage with health services.

5.5.2 Early childhood environment as a social determinant of health outcomes in type 1 diabetes mellitus

This study has demonstrated that entering adulthood with a strong sense of self-determination fostered by a positive early childhood environment and high levels of social support led to mastery in T1DM. Maternal attachment was a vital element in the development of self-determination for participants, with those with a history of maternal support describing how they adapted more readily to T1DM diagnosis and treatment regimens. Family breakdown in relation to parental separation has been described previously as a factor in poor glycaemic control [163, 164], but participants reported it as being mediated by strong parental attachment that remained intact during and after the parental split. This finding supports findings of a large Australian study of adolescents and their parents (n=2,062) in which it was shown that although family structure was predictive of metabolic control, of equal importance were family dynamics and communication which were also robust predictors of HbA1c [165]. It is thought that where strong parental attachment is retained following family breakdown it sustains support in adolescence and is a central factor in the development of a sense of self-determination.

A novel finding in this study was the ability of low parental attachment to impair the capacity to develop close attachment relationships in adulthood, resulting in low levels of social support. This has not previously been described in diabetes care. Parental support in emerging adulthood is vital for the development of trusting and intimate relationships in adulthood [356] and parental warmth, particularly maternal, is highly predictive of prosocial behaviour in adulthood and the development of long term relationships [367, 368]. The quality of maternal caregiving

in childhood predicts the extent to which adults are able to feel comfortable relying on partners and peers [369]. This finding has important implications for health care services so that children and adults with T1DM who may be at high risk of poor outcomes in the future can be identified and assisted.

5.5.3 Social support as a social determinant of health outcomes in type 1 diabetes mellitus

Participants described various levels of social support in relation to their diabetes care. Those who had an active support person involved in their diabetes management also described strong adaptation, problem solving and a sense of mastery in their disease trajectory. Participants who had a support person such as a marital partner in their lives who was not involved in the day-to-day care of their diabetes described lower levels of diabetes distress and felt in control of their diabetes to some extent but were not able to express a sense of mastery. Participants who had no support person struggled with glycaemic control, had difficulty engaging with health care services and expressed a sense that management of T1DM was too hard, giving up and with just the very basics of glycaemic care in place. Social support has components of instrumental support, companionship, emotional support, relationships and connections [370]. This research has demonstrated that high levels of social support are also predictive of positive engagement with health care services and that the absence of social support leads to inability to build active partnerships with HCP to support self-care. In diabetes care, having higher resources in relation to social support leads to higher motivation to do well and it is important therefore to consider the economic and social context that makes choices real and available [371]. People that do well are advantaged their resources, which enables them to succeed and to become 'health capable' [92].

5.5.4 Socioeconomic status as a social determinant of health outcomes in type 1 diabetes mellitus

Low SES is known to be detrimental to health [3] and in T1DM this relationship has been well demonstrated [132, 133, 135]. Most often, this is attributed to the 'poor behaviours of the poor' and described in the context of individual and rational choice. However, recent research in T1DM has found that a low SES environment is associated with inequalities in social support and that low SES families may fail to identify a primary care provider as the main point of contact for a diabetes-related problem [372]. This study has compared the experiences of

participants who described a background of unskilled parental occupations, early school leaving and unskilled employment with others who described positive early childhood environments and high health literacy in adulthood. The comparison showed that the two groups of participants experienced the health care encounter very differently. A strong sense of self-determination led to encounters with HCP in which the patient was treated as an equal contributor who could debate and discuss diabetes management and draw from the encounter the tools needed to continue self-managing their condition. Participants with low levels of social support described a passive encounter with a strong sense of blame that led to no resources being taken from the consultation and, eventually, withdrawal from care. SDH are treated as risk factors attributed to the individual but this study has demonstrated that they interrelate and create a network of causal pathways that drive psychosocial and behavioural pathways [373] which manifest as the inability to engage with health care services. What happens in the micro environment (HCP consultation) can be changed to improve outcomes at the macro level because it reflects the structural and cultural context of society and compliance research should not be an opportunity to relocate blame from the HCP to the patient [16].

5.5.5 Health care access as a social determinant of health outcomes in type 1 diabetes mellitus

Australia has a well-developed health care service that offers universal access and it is known that inequalities in diabetes outcomes can disappear after compensation with treatment and education at a tertiary care centre [144]. However, adults who feel poorly equipped to manage T1DM may also experience difficulty navigating the health care system, and in what is described as the inverse care law [145] may be less likely to receive care. Some participants in this research described feeling that health care services had let them down. There was a duality in their discourse between self-blame and system-blame, with the participants who had not fared well with their diabetes management describing their struggles with glycaemic control, difficulty adapting to an intensive regimen, and feeling intimidated and under resourced to manage their encounters with HCP. This in turn led to a passive encounter in which little was gained and eventually resulted in disengagement from care with dire consequences. The participants in this study at times blamed themselves for their inability to manage their diabetes, but they also gave strong accounts of where they thought the system should be blamed for failures in offering sufficient support and in listening to their individual stories and the problems that they have. The accountability for poor outcomes, while most often attributed to

the individual, also lies with health care services that allow people with T1DM to collect insulin prescriptions and consumables over many years without active endeavours to refer them to specialist care and to screen for complications. Previous qualitative research has demonstrated that the fear of being judged for poor glycaemic control results in clinic avoidance [374] and high HbA1c levels may lead to clinic non-attendance and the beginning of a downward spiral. To improve outcomes in T1DM we need to incorporate psychosocial care, listen to young people's views about clinics [375] and consider the important role that a transition clinic could play [376]. Services have failed to meet the needs and preferences of their patients leading to high attrition rates because of the absence of joint consultations and shared decision making [377] and this is particularly true for adults with T1DM and further compounded for those with adverse socioeconomic environments.

5.6 Study strengths and limitations

Qualitative research is not intended to be generalised to the population as a whole because of its unique mix of researcher and participant measures that is difficult to replicate. Findings can however be applied to similar groups to gain insight into the lived experience of T1DM. Sampling bias is a limitation of purposive sampling because the researcher deliberately selects cases that can bring the most illumination to the problem under study. In this study there was a bias towards people with ESRD and this may have limited the data collection to a narrow focus which is often the case when researching a specific phenomenon. The addition of participants with early CKD that was being managed well resulting in contrasting experiences may have improved the study overall. In this study, the selection bias was controlled for to some extent by the semi-structured nature of the interviews which took an evolving path determined by individual participant experiences. No research is truly without researcher bias because we study problems to which we suspect we may know the answer at least in part, but the process of researcher reflexivity allows us to change our preconceived ideas as the research process evolves and we are presented with new learning from unexpected results. The role of the researcher in the qualitative study who has a clinical background in renal replacement therapies and first-hand knowledge about how long periods of disengagement from care in T1DM have a strong association with the development of ESRD and how this may influence the study as it progresses is acknowledged. Research interests often come from problems encountered in the clinical environment which is vitally important however does also mean

that the researcher potentially has preconceptions about the answers to the research questions. Whilst it is acknowledged the researcher has a keen interest in understanding the factors that lead to disengagement with care as a *health care practitioner,* the interview questions were completely open ended and approached with a 'tell me about your health care experiences' rather than specific item questioning and occurred late into the interviews once a rapport and a sense of trust had been established. All interviews were conducted in clinics which afforded the participants a sense of the endeavour being undertaken to hear their views on clinic and to improve the service. This approach aided the sense of neutrality needed to collect reliable qualitative data and to truly represent the participant's views. The qualitative data gained through the interview process with participants who had developed ESRD tells the story of the multiplicity of accountability for health outcomes and is also of grief and loss which is particularly compelling to hear from young people in the prime of their lives burdened by profound illness and reduced quality of life. Qualitative research undertaken by a clinician specialising in the area results in a greatly increased sense of empathy and renewed understanding of how well meaning intentions do not always result in a concordant relationship and improved health outcomes. An additional strength of this study is the diversity of the study participants in relation to a broad range of ages, age of disease onset and the amount of time that the participant had lived with T1DM resulting in particularly strong thematic analysis given the heterogeneous sample. In addition this study is unique in exploring the disease trajectory and lived experience of T1DM well into adulthood which has previously been under researched.

5.7 Conclusion

This qualitative study has explored the lived experience of T1DM and the impact of SDH through in-depth interviews with 17 adult participants with highly varied life circumstances and disease trajectories. The results have demonstrated that a positive early childhood environment, particularly maternal attachment, is a factor in the development of a sense of self-determination and resilience in diabetes care. Participants with low maternal attachment tended to have low levels of social support and were under resourced for the challenges of managing a highly complex disease. HCP may view a pattern of poor glycaemic control as a rational choice when in fact it is no choice at all because the challenge has become insurmountable in the absence of strong external support. Patterns of poor glycaemic control viewed in the health

care encounter without an understanding of the context or life circumstances in which they are occurring lead to an inability to engage with health care services. Disengagement from services and the absence of specialist care further isolates people, leaving them managing their diabetes alone with limited success. The development of severe complications is the unfortunate consequence and understanding this is an opportunity to consider service redesign. Listening to the views of people with T1DM about their clinic experiences allows HCP to learn of the unmet need for a more empathetic encounter that considers individual capacity and capability. A tailored approach to care is vital to delay the onset of complications and would involve increased support for self-management, monitoring for those who withdraw from care, and active endeavours to re-engage with young people.

CHAPTER 6 DISCUSSION AND CONCLUSION

This thesis has sought to explore the complex relationship between social determinants of health (SDH) in type 1 diabetes mellitus (T1DM) through three studies. Study 1 examined the population prevalence of T1DM for an association with area socioeconomic status (SES) and re-examined Diabetic Nephropathy end stage renal disease (ESRD) for Aboriginal and Torres Strait Islanders (ATSI), Maori and Pacific Islanders. Study 2 explored how SDH affect glycaemic control, engagement with health services and the development of complications, and study 3 through a qualitative exploration sought to elucidate some of the mechanisms through which this occurs. For people with T1DM the self-management of this complex life-long disorder is relentless and unpredictable and the presence of comorbid anxiety and depression in T1DM is high [64]. Those who fail to manage T1DM optimally and develop severe complications at a comparatively young age could potentially be viewed as being responsible in some way for their health outcomes because they generally have a history of low concordance with therapies and prolonged poor glycaemic control. It is likely that such a person with diabetes would in part blame him or herself for the inability to adhere to a therapeutic regimen and establish good glycaemic control. However, this research has demonstrated that there are low levels of engagement with the endocrinology service and an expressed dissatisfaction with care, with participants in the qualitative study also blaming health care providers (HCP) and the health care system for their inability to gain a sense of mastery in T1DM. This results in the development of adversarial relationships with HCP, characterised by a lack of trust that stems from the failure of HCP to view the whole person in the context of their life and the challenges they face, rather than just the illness [378].

To date, factors that lead to low concordance with therapy in T1DM, as described in chapters 1 and 2, are not fully understood and are largely perceived as individual behavioural characteristics. Known barriers to concordance with therapy are the fear of hypoglycaemia and psychological distress [68, 95] and reaching adulthood with the transition to adult services [110, 376]. However, social factors are also associated with poor glycaemic control and include ethnic minority status [177, 178], SES and low levels of family cohesion and parental support [132, 133, 379]. The relationship between social factors and poor outcomes in T1DM has previously been defined at the individual level through discussions of inadequate parenting and

individual poor health care behaviours. In the context of T1DM and the development of severe complications this is blaming the victim [6, 336]. A deeper understanding of how the social environment can help or hinder concordance with therapies and engagement with health care services in T1DM was warranted to ameliorate the blame felt by individuals and to understand the roles that health care services can take in reducing health inequities.

In this thesis, there is an exploration of SDH outcomes in T1DM. SDH are elements of a person's unique environment that can affect health positively or negatively and which are best described as the environment wherein a person is born, grows up, lives, works and ages [380]. The SDH that are discussed in this thesis and which are known to influence health both in an immediate sense and later in life are early childhood environments, SES, educational attainment and social support [3, 18]. It is believed that health is negatively affected by social determinants through long-term exposure to adverse environments [3, 381]. Adverse environments tend to cluster together, with poor social and family circumstances leading to lower educational attainment and subsequent lower employment status which in turn generates a cyclical low social status that can be intergenerational.

A critical social theoretical framework was used in this thesis to explicate how unfavourable social circumstances can diminish an individual's capacity for good health [342, 382] and create health inequities. These health inequities go beyond simple measurable differences in health outcomes because they have a moral component and the health disparity is judged to be both unfair [383] and beyond compensation at the level of the individual. When the social environment is unfavourable, health outcomes are worse and this research reveals in great depth how adverse social environments affect the lived experience of a chronic complex disease. This thesis asserts that for people with T1DM health is both individually and socially determined and the concluding discussion is grouped into the key themes that emerged from the three studies within this thesis.

6.1 The key themes that emerged from the three studies in this research

A sequential explanatory approach was adopted with each phase of the research informing the next (figure 6-1), allowing both a measure of the extent of the problem and an explanation of the nature of the problem [12]. Critical social theory is a mix of quantitative positivism, a fixed measurable 'truth', and qualitative interpretivism which accepts that there are multiple 'truths' depending on individual life circumstances [14]. The use of a critical social theory framework

in this thesis has revealed that although humans are free to make their own choices they are also constrained by their histories and social context which can shape beliefs and subsequently limit options [302].

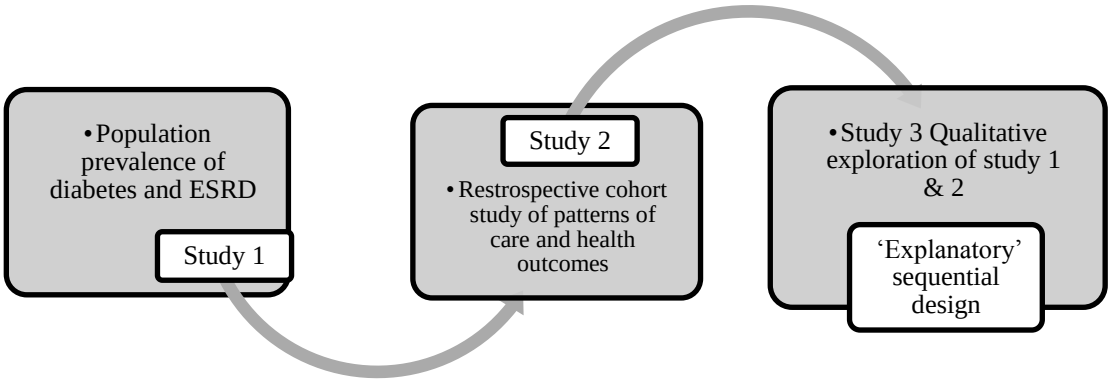


Figure 6-1 Explanatory sequential design

Study 1 was a quantitative exploration of the population prevalence of diabetes using the Socioeconomic Indexes for Areas (SEIFA) as a comparator and the incidence of ESRD in Australia and New Zealand. These are both measured in a robust way through the National Diabetes Services Scheme (NDSS) and the Australia and New Zealand Dialysis and Transplant Registry (ANZDATA). This study demonstrated that low SES was a social determinant of health in relation to both the higher diabetes prevalence and the increased risk of poor renal disease outcomes. It also demonstrated that ATSI, Maori and Pacific Islander ethnicity was a social determinant of inequitable health outcomes. All three populations also live in low SES circumstances and it is likely that while ethnicity can be a strong SDH, SES is also likely to have a substantial role in driving this inequity. This finding reflects those seen in other countries but the gap that persisted in our knowledge was of the components of low SES that drive the inequitable outcomes. This gap informed study 2.

Study 2 was a quantitative retrospective study of health service access and use and health outcomes for a cohort of adults and children with T1DM. The study showed that there was a relationship between poorer outcomes and both disease onset in adulthood and low SES. Additionally, there were measurable differences in patterns of attendance at health care services for people with adult onset T1DM and those with low SES, which was probably contributing to the poorer health outcomes.

The mechanisms that influenced patterns of attendance at health care services were explored in a deep qualitative way in study 3. This brought greater insight into the reasons why certain

groups were more vulnerable to disengaging from care and the subsequent development of severe complications at a comparatively young age.

The conclusions drawn from studies 1, 2 and 3 relate to the lived experience of T1DM, T1DM and kidney disease, age of disease onset as a social determinant of health outcomes, ATSI, Maori and Pacific Islander ethnicity as a social determinant of health outcomes, SES and social support as social determinants of health outcomes and the role of the health service as a social determinant of health outcomes. Each of these is now discussed separately.

6.2 The lived experience of T1DM

The purpose of exploring the lived experience of T1DM in the qualitative phase of this research was twofold; first to address a gap in the literature because most qualitative research in T1DM has been conducted with adolescents and the parents of children with T1DM, and second to demonstrate patients' struggles to achieve optimum management of T1DM. An exploration of the disease trajectory from diagnosis into adulthood allows insights into the barriers to optimal glycaemic control that are not always easily overcome.

The diagnosis of T1DM in a child appeared to induce a sense of grief for parent/s, with childhood onset participants recalling their parent/s being terribly upset and consequently they themselves feeling guilty for upsetting the family. This parental grief with components of both fear and sadness is similar to that seen in other childhood chronic illness including asthma, diabetes and arthritis [384]. Childhood onset participants described their parental support and how, when this was positive, the transition to self-care occurred slowly and in a supported way that fostered a degree of control over T1DM. When parental support was lacking, children with T1DM found themselves managing their own care at a young age with very little insight other than the need for a fixed insulin dose and periodical self monitoring of blood glucose (SMBG). This resulted in an abrupt and overwhelming transition to intensive therapy in adult services and preceded withdrawal from care. The diagnosis of T1DM in adulthood was described by participants as a psychologically traumatic event, creating a sense of shock and a clear divide between life as it was and life as it now will be. The process of adaptation to the diagnosis was long and sustained and required intensive support from the endocrinology service, without which full adaptation failed to occur and living with T1DM became a constant battle to maintain blood glucose levels in a stable range.

The second reason for exploring the lived experience of the disease was to demonstrate patients' struggles to achieve optimum management of T1DM. Even those participants who

described gaining a sense of mastery in their diabetes management spoke of frequent unpredictable high or low swings in glucose levels leading to hyperglycaemia or hypoglycaemia, which left them feeling frustrated and as if they had failed. There was constant tension between the fear of hypoglycaemia and of hyperglycaemia and this led to diabetes specific distress because of the need to consider diabetes management challenges many times a day, which could be a thankless task. Critiques of intensified insulin therapy have highlighted the increased risk of hypoglycaemia and the multiple challenges in achieving a stable blood glucose pattern, and it is accepted that people with T1DM fail to achieve stability because of unpredictable glucose levels and subsequent psychological problems [68, 93]. This research has demonstrated that people with T1DM described the disease itself as highly unpredictable and with a constant tension between the fear of hypoglycaemia and the fear of future complications. A pattern of poor glycaemic control can result in a sense of hopelessness and without sustained support from the endocrinology team there may be many years of persistent hyperglycaemia and the onset of severe complications.

6.2.1 Glycaemic control in type 1 diabetes mellitus

Study 2 demonstrated that glycaemic control in a cohort of individuals with T1DM under the care of a major metropolitan health care service was suboptimal, with only 10% of the cohort reaching target HbA1c and 40% being at high risk for the development of complications. The development of intensive regimes and insulin pump therapy has been lauded as delaying the onset of complications, but the findings from this research mirror those from other countries [385-387] and show that despite advances in treatment and technology optimal glycaemic control remains for many an elusive goal. T1DM will continue to contribute to morbidity and mortality while the focus remains persistently on individual health care behaviours despite the evidence that people with T1DM need broader psychosocial care to support acceptance of the disease despite other life challenges. This is just as important as physical care but it is an aspect that is largely overlooked and considerably under resourced [366].

6.3 Type 1 diabetes mellitus and the development of kidney disease

Study 1 demonstrated that T1DM results in approximately 100 cases of ESRD each year in Australia and New Zealand and this occurs at a younger age than any other chronic kidney disease (CKD) aetiology aside from childhood onset CKD [297]. Although an excess of T1DM males with ESRD has been demonstrated in Europe [209], this study has demonstrated there is

increased risk for males of low SES. However, this result needs to be interpreted with caution given the known increased risk of death for females with T1DM [64] and the association between ischaemic heart disease and deprivation in T1DM seen only for women [388]. This finding may represent a male survival advantage and this merits further study through the NDSS and the national death registry. Study 2 also demonstrated that screening for kidney disease was suboptimal in a large cohort of individuals with T1DM, with only 61% being screened at any time in the preceding 18 months. This is unacceptable practice given the known association between the disease and the greatly increased risk of developing kidney disease [331]. Of equal concern was the high prevalence of existing kidney disease seen in the cohort (26%), and low levels of engagement with endocrinology services coupled with suboptimal screening could mean that the prevalence is likely to be underestimated.

6.3.1 Age of disease onset as a social determinant of health outcomes in type 1 diabetes mellitus

A striking finding in this research was that adult onset disease was associated with poor outcomes. In study 2 this was seen in the higher number of deaths of patients with adult onset T1DM, and in the increased relative risk of developing kidney disease in adult onset T1DM. Similar mortality findings have been found elsewhere, with a large European registry study finding an standardised mortality ratio (SMR) of 4.1 in the first year of diagnosis for adult onset T1DM in patients aged 30–34 years, and while a small number of these deaths was attributed to acute complications such as hypoglycaemia and ketoacidosis, the majority were due to alcohol, drugs and suicide [278]. Similarly, an Australian study of adult deaths in T1DM found that in those aged 40 or under, while some deaths could be attributed to acute causes the majority were due to narcotic overdose or unexplained death in bed [261].

The increased risk of kidney disease found in adult onset T1DM in study 2 has also been demonstrated in Europe in relation to ESRD [215]. A significant limitation of studying this issue in Australia is the lack of a standardised diabetes registry as seen in the United Kingdom and Europe. In study 1 the ages of people with T1DM ESRD were obtained from ANZDATA, but age of disease onset was not recorded and limited further exploration in greater depth. Furthermore, although study 2 demonstrated a higher likelihood of kidney disease in late onset T1DM, a limitation of retrospective studies is the variable availability of clinical outcome data.

To date there has been very little research into the increased risk of poorer outcomes in late onset disease, with most studies concentrating on the profiling of genetic risk and determining

diagnosis criteria for late onset diabetes. Two participants in the qualitative study had late onset adult disease and both described being stunned at the diagnosis, a reluctance to involve their partners in diabetes care and a gradual withdrawal from social participation when they began to feel that the restrictions their diabetes management imposed meant they could no longer participate in social functions.

There has been limited research designed to explicate the mechanisms through which adult onset disease leads to poorer outcomes, with only two studies identified. One was a qualitative study that explored diabetes-related decision making in people with adult onset T1DM (n=8). The author concluded that participants were '*launched'* into diabetes decision making without preamble and that a clear requirement was *reliable* information and the opportunity to *participate* in decision making with HCP [389]. The participants with adult onset in study 3 described in depth the sudden nature of the diagnosis, and the finding of much lower engagement with endocrinology services for adult onset patients in study 2 may relate to the needs that were expressed by participants of the qualitative study. They spoke of their need for their role in the health care encounter to be active not passive, and for them to be seen as experts in their own specific disease management.

A quantitative study of adult onset T1DM specifically examined late onset versus child onset T1DM with a strong focus on gendered differences [390]. Some findings were inconclusive but overall the authors concluded that adult onset T1DM was associated with higher levels of depression and dejection regarding HbA1C results and this was worse for women [391]. In relating this study to the present research, study 2 demonstrated that engagement with endocrinology services in adult onset T1DM was much lower, particularly for females. It remains a perplexing problem why adult onset disease onset T1DM is associated with an increased SMR and increased risk of kidney disease. It is likely that a broad registry-based study that followed participants prospectively and that had a qualitative component could determine the reasons for poorer outcomes in late onset T1DM.

6.3.2 ATSI, Maori and Pacific Islander ethnicity as a social determinant of health outcomes in diabetes

This study has demonstrated that the relative risk of ESRD due to T1DM for the ATSI, Maori and Pacific Islander populations is much lower than in the general population, but that the relative risk of ESRD due to type 2 diabetes mellitus (T2DM) is six times higher for all three populations. The higher relative risk of ESRD due to T2DM relates to an increased incidence

of the disease [310] and a known higher likelihood of progressive CKD [284]. The very low incidence of ESRD due to T1DM for these ethnic minorities is unexpected given what is known regarding the prevalence of T1DM. In Australia, the most common form of diabetes in youth is T1DM with a prevalence that continues to increase each year [392] and the incidence of T1DM in Indigenous people aged under 25 years in the Northern Territory has been estimated to be as high as 1:1000 [393].

The Diabetes and Related Disorders in Urban Indigenous People in the Darwin Region (DRUID) study, the largest study of diabetes in Indigenous Australians that purported to fill 'critical gaps in the knowledge of incidence, aetiology and prevention', did not distinguish between T1DM and T2DM in its discussion [316] and no diagnostic tests were done to establish diabetes disease type [394]. This raises three important questions in relation to T1DM in these minority populations. The first is the issue of survival, because ATSI, Maori and Pacific Islanders are known to have a reduced life expectancy [18], diabetes onset at a much younger age and outcomes that are generally much worse, with higher death rates due to diabetes [191, 316, 395]. Second, there appears to be no literature on adult onset T1DM in these three populations despite Australian data demonstrating that almost 50% of cases of T1DM are diagnosed after the age of 15 [24, 295]. This raises the possibility of misclassification and conflation of T1DM with T2DM, which could lead to incorrect treatment and potentially death. One reason for this could be the strong link between obesity and T2DM [396], given that these Indigenous populations carry a disproportionate burden of obesity largely driven by poor food choices resulting from lack of availability and affordability in the setting of relative poverty [397]. This is a potential combination of ethnicity and low SES driving worse outcomes. Third, access to and uptake of culturally appropriate health care is known to have a positive impact on diabetes outcomes [291] but this is under resourced and inadequate for the ATSI, Maori and Pacific Islander populations [398]. Consequently, those most likely to need care are the least likely to receive it. Although this present study has not demonstrated an unequal incidence of T1DM ESRD for Indigenous populations, inequitable outcomes have been particularly well demonstrated in relation to ESRD due to T2DM.

6.4 Socioeconomic status as a social determinant of health outcomes in type 1 diabetes mellitus

Low SES is a well-documented risk factor for higher morbidity and mortality than in people of high SES [3, 18, 399]. The research in this thesis showed that low SES is a factor in a higher

prevalence of diabetes, higher levels of disengagement from health care and in the development of kidney disease. The reasons for the higher prevalence of T1DM in low SES populations in Australia found in study 1 are entirely unknown and a much larger study is needed to confirm that this relationship exists. This could be done by examining the population prevalence of T1DM in all Australian postcodes and analysing this against SEIFA. The inverse SES gradient in T2DM, however, was very marked, previously unreported, and could possibly be related to the higher rates of obesity seen in Australian populations with low SES, because this is an independent risk factor for T2DM [400]. The most beguiling explanation for higher obesity rates in populations with low SES is one of individual culpability for poor dietary behaviour and a sedentary life style. These factors, however, are a multifaceted phenomenon that aside from individual behaviours includes unhealthy foods being cheaper to buy coupled with low levels of health literacy in relation to the components of a healthy food basket [154], neighbourhood deprivation leading to unsafe neighbourhoods which limit the ability to be active in the community [401], and low family resources which limit the ability of adults and children to participate in structured exercise and sporting programs. In addition it is known that low SES and low levels of social support reduce self-esteem and increase the tendency to discount long-term benefits in favour of short-term rewards [360, 402].

The research showed that that low SES was a risk factor for disengagement from health care and the development of kidney disease. Previous research in T1DM led to the hypothesis that the relationship between low SES and adverse outcomes was due to individual behaviours and specific risk profiles including smoking behaviours and hyperlipidaemia [125, 155, 156]. The findings in this thesis, however, suggested that the determinants of health for people with low SES and T1DM were likely to be multifactorial and comprised of psychosocial factors that were not necessarily income related. The qualitative phase of the research demonstrated that the costs of care in T1DM were not considered a barrier to good glycaemic control because of subsidies under the NDSS and very low consumption of prepared food purchased outside the home because of the unpredictable glycaemic response. In study 2 it was found that people of low SES were less likely to be in endocrinology care and more likely to be using other services, which suggests that there are SES barriers to engaging with certain health care services. Participants in study 3 identified that a key factor in this was the perception of being judged by HCP because of poor glycaemic control. Participants also described feeling as if HCP had little understanding of the context in which they managed T1DM and they had a clear sense that

HCP were detached from the everyday problems that they are experiencing as people living with diabetes.

People generally view income differences within their own societies differently to the way they view differences between one society and another [381]. Participants in this study reported that aside from the lack of material resources, a central factor in being health capable for people with low SES was the effect of perceived unequal power relations, self-perception and sense of control. The gap in SES status between HCP and the people they care for can lead to very different interpretations of the day-to-day management of T1DM. Secure, satisfying employment and adequate finances foster a sense of control [403] and the ability to imagine a bright future [360] while living with low SES and T1DM leads to changes in the hierarchy of need that would not be evident in more favourable circumstances.

Participants in the qualitative study described the tension generated by the competing needs of secure employment tenure and income security and the day-to-day management of T1DM. Income security is first in the hierarchy of need while management of diabetes becomes something that secondary resources may be directed towards. This leads to misunderstanding by HCP, in which the person with diabetes is seen to be wilfully disregarding the advice they are given when in fact they simply lack the material and psychological resources required for what they are being asked to do. In addition, the use by HCP of future-orientated discussions in managing risk has limited salience for people living in low SES environments, and health care in T1DM needs to be oriented to the dynamics of their 'living present' [360]. The social environment has powerful hierarchical structures and mechanisms that act as determinants of health by shaping individual health related behaviours [15]. The problematic nature of good glycaemic control for people with low SES that can be learned from their stories is that they view the nature of the problem as being much deeper than their own individual responsibility.

6.4.1 Social support

In study 3 it was shown that strong social support was the mediator through which people with T1DM gained a sense of mastery in their disease management that enabled them to engage with HCP in an active way during health service consultations. Those participants who described very low levels of social support in adulthood also described adverse early childhood environments. Life course effects begin in early childhood and set individuals onto life trajectories that cannot be changed by individual choice alone [403]. The importance of feeling secure, safe and loved in childhood is a basic need that has strong links to feelings of self-

worth, self-efficacy and subsequent adult well-being [404, 405]. Previous research into T1DM and family factors demonstrated that when positive, the family environment is associated with good glycaemic control and a two parent biological family is often cited as the most favourable environment for a child with diabetes [19, 102]. However, there is evidence emerging that parental levels of diabetes awareness and involvement, particularly in mothers, play a major role in glycaemic control for children with T1DM [406]. This research found that irrespective of the family structure strong parental bonds, particularly maternal, allowed a child to enter adulthood with a strong sense of self-determination.

A positive early childhood environment also appeared to increase the likelihood of having high levels of social support in adulthood which in turn led to the confidence and capability to develop a sense of mastery in T1DM management whether the disease onset occurred in childhood or adulthood. Reduced social support in the context of low SES environments is an additional mechanism underlying poorer outcomes in health [403] because, even in the context of low SES, feeling cared for, valued, belonging and under mutual obligation has a moderating effect on stressful environments [3]. This study has demonstrated that strong social support with a person to turn to when experiencing everyday diabetes problems is an essential component of good glycaemic control, which in turn is known to ameliorate long term negative outcomes in T1DM [372].

Study participants with adverse early childhood environments and low levels of social support exhibited clear distrust of HCP. They spoke of being ‘just a number’ and that the care provided was standardised and not tailed to their specific needs. Importantly, they also described an inability to ‘open up’ and describe their difficulties honestly in encounters with health services. Our world view is developed in childhood and a positive early childhood environment leads to a world view that is characterised by trust in others and the ability to form trusting and intimate adult relationships [356] that foster high levels of social support. A substantial amount of research has demonstrated that feelings of trust are integral not only to the ability to form close attachment relationships in adulthood but also to the ability to develop concordant relationships with HCP particularly in relation to management of life-long chronic disease [353, 407]. The perception of trust can be diminished when the person with chronic disease is also burdened by low SES and diminished social support [408] because these reduce participatory interactions with HCP and hence can reduce the capacity for health which is further discussed in 6.5.

6.5 Health care services as a social determinant of health outcomes in type 1 diabetes mellitus

There were measurable differences in the uptake of health care services with low levels of engagement with endocrinology services overall and this was most apparent in people with late onset disease and for people with low SES. Overall, less than half the cohort had attended an endocrinology clinic at least once in the preceding year. Strong engagement with endocrinology services was seen only in the youngest children with a steady decline in engagement seen as patients grew older. In tandem with this was increased use of other services to meet health care needs, including emergency departments. The lowest proportions of people attending endocrinology care regularly occurred in young adults, those with adult onset disease particularly females, and people with low SES. Health services are designed to provide care and support for people with T1DM, but a health service is also a social structure that can be critically examined through observation of the mechanisms it possesses and the processes within it [4]. Study 2 demonstrated that levels of engagement with endocrinology services were below 50%. This is highly problematic given that T1DM is responsible for a significant burden of renal disease, as shown in studies 1 and 2. Complications in T1DM occur within ten years of diagnosis for approximately 40% of people [81] and any health care service that does not monitor for and act to rectify patients' withdrawal from care is failing to meet the needs of the community that it is serving.

Health care services in Australia operate with both an acute care model and a primary health care model. Currently, people with T1DM in South Australia are managed in the acute care sector through multidisciplinary teams, which is believed to be the most appropriate model of care [86, 144]. This research has demonstrated that engagement with specialist care is essential for the development of a sense of mastery in T1DM, which participants in the qualitative study described as arising from sustained and intensive HCP support. This presents a significant problem for people with T1DM who have described a history of challenging glycaemic control, a consequential sense of being judged as irresponsible and subsequent avoidance of HCP. The study has also demonstrated that being engaged with specialist care also gave the highest likelihood of being screened for glycaemic control and kidney function to determine the potential risk of future complications. In study 2, while low levels of engagement with specialist care were seen across the cohort they were particularly low for people with adult onset disease and low SES, both of which have been associated with higher risk of developing

of kidney disease which occurs in the setting of poorly controlled diabetes and prolonged hyperglycaemia.

Regulation of HbA1c is better managed through a total care package than a single regimen [409] and study 3 participants described that they gained eventual mastery in diabetes management only through sustained support from the endocrinology team and with high levels of social support. Participants spoke at length about reasons for disengagement from care, and these included their inability to adopt an intensive diabetes care regimen and a subsequent sense that HCP believed that poor control was a personal choice. In turn this led to the health care consultation becoming a passive encounter from which little was gained and much was lost. These outcomes were particularly well described by participants when discussing their transition from paediatric to adult services. This transition was marked by a period of treatment intensification in the setting of adult services where there was greatly reduced contact with HCP and long periods between appointments. Participants considered support for treatment intensification to be inadequate, and they described being unable to master the complicated regimen and instead reverting to their standard childhood treatment with reduced self-monitoring of blood glucose (SMBG). Some were subsequently able to master the intensive regimen through strong relationships with general practitioners and through the sustained endeavours of the endocrinology service to increase the frequency of consultations and hence the level of transition support. For some participants, however, abrupt disengagement with care left them acknowledging that their glycaemic control was likely to have been suboptimal with persistent hyperglycaemia that went unrecorded for many years

The delivery of care to most people with T1DM has not changed significantly in the past 40 years despite the introduction of intensive therapies which require a high level of complex health literacy [410]. Appointment scheduling is still subject to long delays and lengthy intervals and offers little in the way of flexibility. This misalignment between health care need and health care service delivery is particularly pertinent during the transition from paediatric to adult services, which is a high risk period for withdrawal from care [109, 116]. Improving the transition from paediatric to adult services in South Australia has been identified as a high priority but staff and patients in adult services report there is still need for significant restructuring and more resources.

Australian clinics are known to have high attrition rates and this is driving urgent calls for reforms to enable people with T1DM to have engagement with health care services that is

prolonged and sustained [255]. High levels of disengagement are thought to reflect dissatisfaction with care rather than diabetes mastery, with person-centred chronic illness care and support being rated as very low [273, 366]. The problematic nature of T1DM management is not the fault of patients or of HCP because services need to be redesigned to be responsible **to** patients rather than **for** them, by the use of proactive contacts, surveillance and reminders with consistent follow-up procedures implemented and planned proactive care interventions [411]. This is necessary to build trusting relationships with people using services rather than assuming a relationship exists simply because a service is providing care.

Disengagement from care is driven by the failure to have mutually beneficial consultations that value the person with diabetes as the expert on their own day-to-day management [377]. Study 3 demonstrated that this may occur because of a perceived power imbalance or perhaps of the mistaken belief of HCP that their personal cognitive and relationship styles are universal [93], which devalues lay knowledge. Diabetes services in South Australia are offered in a uniform way that is considered equal but it is far from equitable. The services being provided are simply not able to generate realised access, which occurs when people of all social and environmental circumstances can navigate through the service and receive what they need to be health capable. Equity in health care is achieved when potential access to health care is transformed into realised access to health care [9]. Public health approaches advocate development of vertical equity and basing service provision on felt need. To address inequities in health, individuals or groups who are different should be treated differently according to their level of health care need, with selective measures for the most disadvantaged [117, 399].

This thesis research has shown that there are certain groups of people with T1DM who are not accessing health care. This may arise from a sense of being blamed and stigmatised as non-compliant. While clinic attendance is clearly a factor in good glycaemic control the fear of being judged for poor control means that high HbA1c levels can lead to clinic avoidance [374] and this demonstrates the inverse care law whereby those with the greatest need are less likely to receive care [145]. To improve care in T1DM we need to incorporate psychological care and to listen to people's views about clinics [375], and help people to find motivation to modify behaviours that have consequences which may not be immediately apparent [412]. Sociologists of chronic illness now recognise that the stigma associated with the management of illness may be internalised with the person accepting the discredited status as valid, and this emphasises the need to examine critically the 'labellers not the labelled' [413].

P17 "That was another part of the problem, I found him (endocrinologist) a bit off putting, he was a bit up himself, I used to walk into his office, a room like this and there would be this big carved wooden table and this big chair and he was in (place) and all that stuff, kind of rubbed me the wrong way, he was a bit elitist you know, and I didn't feel comfortable, I don't know why, looking back".

6.6 The multiplicity of grief, loss and regret

This thesis cannot be concluded without a discussion of what is lost when a person with T1DM disengages from care and tries unsuccessfully to manage their disease on their own. Studies 1 and 2 demonstrated that the prevalence of kidney disease was very high and that when ESRD occurs it happens at a comparatively young age. ESRD requiring renal replacement therapies (RRT) is extremely life limiting, both in relation to significantly reduced quality of life [414] and as an independent predictor of increased mortality [75]. The burden of T1DM ESRD in Australia and New Zealand is large and accounts for approximately $100,000 health care expenditure for one person per year in relation to the delivery of RRT [321]. These costs could potentially be offset by redesigning health care services to manage young people with T1DM proactively and prevent them from dropping out of care. Where disengagement cannot be avoided, limited services should be maintained, particularly screening for complications, and there needs to be ways of welcoming people returning to care. Participants in this study emphasised that they wanted to be judged on what they needed now, not on what they had done in the past. They shared many insights into how disengagement with care occurred, the subsequent inability to establish close relationships with HCP, only having prescriptions filled, no surveillance for kidney disease and the abrupt and sudden diagnosis when kidney disease was well advance at a comparatively young age. Importantly, while these participants discussed their inability to adapt to an intensive insulin regimen they also described their feelings of blame towards HCP with whom they could not engage and their general practitioners who subsequently failed to monitor their diabetes adequately to screen for complications and encourage them to return to specialist services. They spoke of a deep regret and a fervent wish that they had acted differently in the past and prevented the circumstances that they now find themselves in. It is important for us as HCP to consider this when caring for someone returning to care after a difficult disease trajectory and with development of ESRD. We must neutralise

any sense of blame because the grief felt by a young person with a life being eroded by renal failure is profound;

> *P2 "Put me on sickness benefits and put me on the dole and sit me in a room and I'll smack my head against the wall for the rest of my life".*

6.7 Recommendations for clinical practice and future research

This thesis has highlighted the role of SDH in outcomes for people with T1DM. There has been an ever-increasing body of evidence on the influence of SDH following the World Health Organization's Commission on the Social Determinants of Health in 2008 [380]. Translating this evidence into political action in Australia remains an elusive goal and health inequalities are increasing [415]. Successive governments have acknowledged the role of SDH but they continue to privilege medical care and persist in the promotion of behavioural change models [416]. SDH exist outside of the health sector and intervention by public health advocates and practitioners to ameliorate the effects of health inequities resulting from structural determinants will require collaboration with politicians and those working in public administration [417]. In relation to the specific findings in this thesis, social inequalities in T1DM are at least in part psychosocial and derived from people's perception of the social hierarchy and their positon within it [418]. As a social structure the health service has a vital role in reducing health inequities, and it is to this aim that the following recommendations are made.

6.7.1 Increased understandings of health literacy

Health literacy needs to be understood and assessed by HCP in clinical practice as far more than competency in literacy and numeracy. The qualitative phase of this research has demonstrated that health literacy also encompasses the ability to be a meaningful participant in the health care encounter in order for this to be a positive experience. Health education in T1DM needs to also incorporate a focus on skill development and increasing self-confidence to create interactive health literacy for the person with the illness to exert greater control over the issues that are governing their lives [250] and this is achieved through a process of practitioner led client empowerment.

6.7.1.1 Threshold concepts, power and empowerment

The notion of *social* determinants of health is a relatively new introduction into health care discourse and has yet to gain mainstream understanding. The didactic method of teaching in health care relies heavily on natural sciences or 'facts' and to introduce the idea of a somewhat fluid determinant of health with a strong psychological component creates threshold concepts and troublesome knowledge for HCP. Threshold concepts are new ways of thinking about an issue, a transformed understanding which can inherently represent 'troublesome knowledge' [419]. Troublesome knowledge is an uncomfortable feeling that the new idea or way of thinking about an issue is divergent to your core thinking and this can be experienced by HCP when they are faced with an issue that to some extent involves moralising about the 'power' that is held 'over' the client. HCP extend and invest themselves in the provision of good health care and it is confronting to then be described as part of the problem. Clinical practice however needs to more closely align itself with the provision of equitable care and to do this it is essential to work with people to reduce the perception of power that the HCP holds and to empower people with diabetes to enable a productive encounter in which much is gained. Empowering people is a process whereby the focus becomes salutogenic or put simply on the factors that will promote health and wellbeing rather than the factors that reproduce ill health [420]. Empowering people with T1DM in the health care encounter requires a shift from 'power over' to 'power with' that entails relinquishing some of the decision making to the person with the chronic illness and encouraging them to identify their own problems and activate their own solutions [250]. This may involve the insulin adjustment regimen being refined by the person with T1DM based on their own assessment of the risks and benefits in a feedback loop using a regular assessment of HbA1c as an evaluation tool. In the short term this is unlikely to be detrimental and in the longer term has the potential to engage people with both self management of the disease and in attendance at the endocrinology clinic for regular surveillance. In addition there has been consistent evidence from a large synthesis of global systematic reviews that as the provision of diabetes care remains suboptimal role substitution involving a step-down approach that uses local community health workers alongside HCP is vital to delivering person specific care to certain high risk groups including people of low SES [421].

6.7.2 Redesigning the health care service to better meet the needs of people with type 1 diabetes mellitus

6.7.2.1 Transition care

There is a large body of evidence on T1DM relating to the time of transition from childhood services to adult services, discussed in section 1.3.4. This is known to be a time of high risk for withdrawal from care and there have been many suggestions on how to address it. There is strong evidence supporting establishment of step-up clinics designed to meet the needs of young people with T1DM, where there is a blending of paediatric and adult services and a focus on the transition to adult care [422]. Participants in this research supported this idea because they reported that the principal reasons for disengagement from care was the struggle to transfer to an intensive regimen coupled with reduced HCP input and prolonged intervals between appointments. This leads to the belief that health services are adopting too uniform an approach and are failing to meet individual needs. This is particularly pertinent for people who have come from disadvantaged social environments who may have low levels of health literacy requiring frequent and sustained support to transition to an intensive regimen. The significance of this gap in clinical care is increasing and there is a need for targeted intervention by HCP in endocrinology services in South Australia to prevent the development of severe complications in young people with T1DM. The critical features of a 'step-up' clinic that would benefit adolescents in transition may include high flexibility in after-hours appointments that also accommodates a drop in clinic, proactive contact including personalised calls, and the increased use of role substitution or 'step-down' configurations that utilise clinic staff with skills in areas outside of medicine.

6.7.2.2 Increased social support in relation to integrating the diabetes treatment regimen

Adults with T1DM need intensive sustained support to self-manage this lifetime chronic illness and current service provision has several faults. This research has demonstrated that less formalised endocrinologist/patient delivery and more flexible 'person centred' diabetes care is needed. An integral component of diabetes care is social support. Research in diabetes continues to focus on the absence of formalised psychological treatments, which whilst effective in children and adolescents are thought to have no sustained effect in adults with T1DM [423]. A novel concept would be to trial the introduction of components of 'pastoral' care into diabetes care. Pastoral care has undergone significant reform to meet the needs of modern communities, and has evolved into a fundamental component of child education to support healthy emotional, social and personal development with acknowledgement that social isolation can be similar to depression [424]. Components of pastoral care that have been successfully incorporated into diabetes services providing multidisciplinary collaborative

models of care include life coaching, group classes and customised feedback [425]. Endocrinology services need to evolve from the traditional didactic model of care to one that builds patient–provider relationships by incorporating a detailed understanding of the complexity of an individual's social history, because the fear of being judged is a critical concern for people with diabetes and a known barrier to clinic attendance [426].

6.7.2.3 The development of a surveillance system to monitor for disengagement from care

The Juvenile Diabetes Research Federation is conducting high-quality research to find a cure for T1DM, but in the interim Australia has much to learn from European countries about T1DM national registries and the potential these have for large epidemiological studies of T1DM care and outcomes. Such studies would be particularly useful to understand factors associated with poorer outcomes seen in adult onset disease. There are currently in Australia several points at which data are collected on people with diabetes, including the NDSS register for provision of subsidised consumables, the Pharmaceutical Benefits Scheme providing access to insulin prescriptions at reduced cost, and the Medicare database which records all medical consultations. These are all missed opportunities for surveillance of disengagement from care and screening processes for complications of T1DM, especially kidney disease. Whatever the reasons for disengagement from specialist care, there is a duty of care implicit in the health care system to ensure that no matter which health care services are being accessed, whether in a tertiary centre, general practice clinic or pharmacy, that endeavours are made to ensure that the person with chronic illness undergoes screening to facilitate early detection and appropriate management of the almost inevitable complications. Quite aside from the heavy burden that ESRD places on an individual, it is also associated with huge costs to health services for treatment, which could be substantially reduced through rigorous screening processes and comprehensive multidisciplinary management of the onset of complications. This would be particularly pertinent for the high-risk groups identified in this research in relation to low SES and adult onset T1DM, both in the reduced uptake of services and increased risk of adverse outcomes that have been demonstrated.

6.7.3 Type 1 diabetes in Aboriginal and Torres Strait Islanders

In the past decade, the Council of Australian Governments' 'Closing the Gap' campaign has been implemented, a broad and ambitious undertaking designed to reduce inequalities in life expectancy, infant mortality, housing, education and employment for ATSI people. While there

have been some small gains there is much still to do, with the latest report suggesting that most benchmarks have not been achieved and some have shown a negative trend [427]. This ongoing failure to reduce inequities is largely due the lack of a social determinants perspective, particularly actions to increase social inclusion and empowerment [428]. In relation to the much higher prevalence of diabetes seen in this population, the most recent research launched by the South Australian Health and Medical Research Institute is the 2016 Aboriginal Diabetes Study. This is a study without a social determinants framework that aims to measure the prevalence and outcomes of T2DM in ATSI people aged over 15 years and will be excluding those diagnosed with T1DM. There is urgent need for Australian research with the ATSI population to understand the true prevalence of T1DM, how it is treated in the community and what the outcomes are for this vulnerable population.

6.8 Thesis strengths and limitations

This research has a number of strengths which lie in the methodological approach taken to address the research aims. The issue of SDH and the role they have in health outcomes is an emerging area of research that is under researched in relation to chronic disease outcomes within the Australian health care context. Very little published work specifically explores the impact of the social environment on health care behaviours in chronic illness and this thesis makes a unique contribution to the evidence base. The issue of SDH in T1DM has been explored in a novel way utilising both quantitative research and qualitative research and there are a number of new findings that add to our understanding of the complex role that the social environment has in influencing health care behaviours and thus determining outcomes. The study's findings have implications for future diabetes research, for informing clinical practice and in health service planning. The Diabetes MILES study which is a large body of work underway in Australia is evolving our understanding of the lived experience of diabetes and the barriers people with diabetes face in optimising their health [429]. This thesis adds to this emerging evidence through the identification of specific groups that are at greater risk of poor outcomes in an Australian context which could potentially inform future research to further investigate the mechanisms through which this occurs. In addition, there are important recommendations for clinical practice that can guide clinicians in the specific pathways through which concordant relationships that are warm and reciprocal can be developed. Specifically

study 1 has demonstrated an inverse relationship between diabetes prevalence and social disadvantage which is very strong and seen in an incremental way. This striking gradient is first reported in this thesis and has important implications for addressing the increasing incidence of diabetes seen in the developed world and for political action on the social determinants of health. This knowledge also informs public health practitioners that are working in the field of health promotion and those planning future health care services within Australia. Study 2 has highlighted some of the deficits in clinical care that are contributing to poorer outcomes and identified demographic factors that place some groups at higher risk of disengagement from care than others which has particular relevance for clinical practice. The behavioural paradigm that underpins contemporary chronic disease management approaches is critiqued by highlighting the accountability of the health care service towards meeting best practice standards and equitable health care for people with T1DM. Finally, study 3 has explored disengagement from care in great depth and revealed some of the pathways though which this occurs which can guide clinicians to reflect on their practice and understand how combative consultations are counterproductive, can be ameliorated and the principles through which a more concordant relationship is established. The primary aim of the thesis was to advocate on behalf of people with T1DM, particularly those with difficult social environments, to demonstrate that health is achieved not just with individual endeavour, but with concerted effort by the health service as a structure to adapt the principles of equity based care whereby those with the greatest need are given greater resources.

As with all research the study has a number of limitations which are described in detail in the empirical chapters 3-5. In consideration of the thesis limitations as a whole, it is acknowledged that to more fully understand differential outcomes that are the result of complex social factors, a prospective study with a large cohort of people with diabetes would allow more detail to be gathered on specific SDH at baseline and the impact of these could then be assessed longitudinally contributing further to the body of Australian research on T1DM.

6.9 Conclusion

This thesis research has been an examination of the influence of social determinants of health on outcomes for people with T1DM. Findings showed that poorer health outcomes arose in the setting of disease onset in adulthood, low SES, reduced levels of social support and disengagement from health care services. Disengagement leads to long periods of time in which

glycaemic control is poor and damage to the small and large blood vessels occurs silently in the absence of regular screening. This results in the development of kidney disease that is often only discovered when well advanced and ESRD is imminent. Socially derived inequities in health occur because of the lack of an array of resources that include money, prestige, knowledge and beneficial social connections [430]. The intent of this research was not to change the nature of society but to examine critically the role of health care services in reducing socially derived inequities, and to increase our understanding as HCP of the difficult challenges that people with T1DM face. It is hoped that through the sharing of this research the perception of blame is removed for people who have struggled with their diabetes and are subsequently labelled 'non-compliant', particularly those who have then been burdened by the development of life-limiting ESRD. While the social patterning of health outcomes in T1DM offers insights into groups that are vulnerable to adverse outcomes, this knowledge also offers insights into potential points of intervention. Health inequities in chronic self-managed diseases can be viewed as a matter of choice and individual responsibility. However, choices for people with adverse social environments arise out of constrained and unfair circumstances which make these choices contextual rather than rational [383, 403]. It is important that this difference be understood by HCP if we are to improve health outcomes for *all* people with T1DM. Social determinants of health are treated as risk factors that are attributed to the individual, however they create complex causal pathways that are mediated or moderated by psychological and behavioural aspects [373] and health care services have a vital role to play in identifying this risk and compensating with increased selective measures for vulnerable populations.

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Appendices

Appendix 1 – Literature review strategy - Chapter 1

Table A1-6-1 Literature search T1DM incidence and prevalence worldwide January 2013

Included in the review are papers published from 2010 – 2013 only (which have study data from 2000 onwards), excluded are studies with data before 2000, and studies of type 2 diabetes. Column 4 denotes the number of papers included in this review that met the inclusion criteria once the exclusions were applied and duplications from other databases excluded.

Database	Search terms; T1D*, incidence, prevalence, epidemiology in title+ keywords	Excluded T2DM, conference abstracts, Limit 2010–2013 (published data covering the last 10 years), duplicates	Included in review n=29
MEDLINE/OVID	55	37	18
WEB OF SCIENCE	82	80	2
PROQUEST	32	28	4
SCOPUS	60	56	4
DIABETES CARE	1	0	1
SCIENCE DIRECT	14	14	0
INFORMIT	2	2	0
SAGE	1	1	0

29 papers from this search wave are included in the thesis.

Table A1-6-2 Literature search T1DM morbidity and mortality February 2013

Included in this review are papers from the preceding 10 years, papers predating 2003 excluded. Column 4 denotes the number of papers included in the review that met the inclusion criteria once the exclusions were applied and the duplicates found in other databases excluded.

Database	Search terms; T1D*, morbidity, mortality in title + keywords	Excluded T2DM, Limit 2003-2013, duplicates	Included in review (n=35)
MEDLINE/OVID	126	115	11
WEB OF SCIENCE	22	16	6
SCIENCE DIRECT	18	13	5
SAGE	2	1	1
INFORMIT	0	0	0
SCOPUS	60	48	12

35 papers from this search wave are included in the thesis. 10 additional papers were also discussed in this section of the review that were found in literature search 1 – incidence and prevalence

Table A1-6-3 Literature search T1DM barriers to concordance with therapy February 2013

The intent in this search is to gather broad data on known barriers to concordance with therapy the elucidate the role of social factors. Column 4 denotes the number of papers included in the review that met the inclusion criteria when the exclusions were applied and duplicates removed.

Database	T1D* & concordance or compliance, T1D* & therapy and treatment, T1D* and adherence in title + keywords	Included were papers discussing barriers, excluded were studies that were trials of treatment interventions and duplicates	Of the 52 papers those that discuss early childhood environment and socioeconomic status in detail were added to the search yield in A2-4 and A2-8 respectively, (n=35 included in thesis under barriers)
MEDLINE/OVID	46/147/135/145	453	20
PROQUEST	9	8	1
INFORMIT	6	5	1
SAGE	2/2	3	1
WEB OF SCIENCE	7/1	7	1
SCOPUS	5/37/247	274	15
SCIENCE DIRECT	347/17	351	13

52 papers from this search wave are included in the thesis.

Appendix 2 – Literature review strategy - Chapter 2

Table A2-6-4 Literature search T1DM and SES Feb\March 2013

Included in this review are papers from the year 2000 onwards, column 4 denotes the papers that met the inclusion criteria used in this review under SES and those that were a better fit to ethnicity (SES and ethnicity have a number of overlaps in the studies reviewed).

Database	**Search terms; T1D*, social determ*, socioeconomic, low income, poverty in title + keywords**	**Excluded T2DM and duplicates**	**46 papers identified, studies specifically discussing ethnicity reviewed under that heading (n=31 papers included under SES)**
CINAHL	25	15	10
Medline/Ovid	158	153	5
Scopus	306	282	24
Proquest	8	5	3
Sage	0	0	0
Web of Science	16	16	0
Science Direct	26	22	4
Informit	6	6	0

46 papers from this search wave are included in the thesis.

Table A2-6-5 Literature search T1DM and ethnicity March 2013

No date range, column 4 denotes the number of papers that met the inclusion criteria and were included in the review under ethnicity.

Database	Search terms; T1D*, ethnic*, race, Caucasian, non-white	Excluded if not directly reviewing ethnicity and outcomes in T1DM , excluded T2DM, excluded duplicates	(n=27) Papers in this review combined with 15 papers that also specifically discuss ethnicity as well as SES located in the previous searches (n=42)
CINAHl	5	5	0
Medline/Ovid	682	663	19
Scopus	41	38	3
Proquest	17	16	1
Sage	0	0	0
Web of Science	408	404	4
Science Direct	13	13	0
Informit	0	0	0

27 papers from this search wave are included in the thesis.

Table A2-6-6 Literature search T1DM and gender April/May 2013

No date range exclusion, column 4 denotes the number of papers that met the inclusion criteria and were included in the review once the exclusions were applied,

Database	Search terms; T1D*, male, female, gender, sex	Excluded studies that did not specifically look at outcomes in T1DM by gender, T2DM, duplicates	1 paper that detailed morbidity in relation to gender (A1-2) also included in this review (n= 27 +1= 28)
CINAHL	100	96	4
Medline/Ovid	38	31	7
Scopus	144	136	8
Proquest	316	311	5
Sage	0	0	0
Web of Science	58	57	1
Science Direct	22	20	2
Informit	96	96	0

27 papers from this search wave are included in the thesis.

Table A2-6-7 Literature search T1DM in Australia July 2013

Date range 2003-2013 (preceding ten years). Column 4 denotes the number of papers that met the inclusion criteria and were included in the review once the exclusions were applied.

Database	T1D* & Juvenile & Renal & Kidney combined with Australia (4 search streams)	Excluded older than 1993 and not set in Australia or New Zealand, T2DM and duplicates	19 papers plus 7 others found through snowballing effect in the papers citations (n=26 in total included in the review)
CINAHL	10	9	1
Medline/Ovid	158	146	12
Scopus	289	289	0
Proquest	34	33	1
Sage	5	3	2
Web of Science	36	34	2
Science Direct	0	0	0
Informit	1	0	1

Search terms T1DM, Kidney, Renal, Juvenile confined to Australia only which collected some NZ data which is discussed in the thesis, 19 papers from this search wave are included in the review.

Table A2-6-8 Literature search T1DM and family composition July 2013

No date range exclusion. Column 4 denotes the number of papers that met the inclusion criteria and were included in the review once the exclusions were applied.

Database	T1D* and single parent* or parent in abstract, key works and title	Excluded 'family' based interventions in T1DM, T2DM and duplicates	(n=13 papers)
CINAHL	16	14	2
Medline/Ovid	8	2	6
Scopus	3	1	2
Proquest	7	5	2
Sage	0	0	0
Web of Science	151	150	1
Science Direct	13	13	0
Informit	0	0	0

13 papers from this search wave are included in the thesis. Included in the synopsis of the review of family composition and T1DM were 8 papers from prior search waves that added some additional information specifically relating to family composition and 1 further paper found through citations in a paper retrieved in this search wave.

Table A2-6-9 Literature search T1DM & qualitative studies August 2013

No date range exclusions. Column 4 denotes the number of papers included in the review that met the inclusion criterial once the exclusions were applied.

Database	T1D* & Qualitative in key words or title	Included any studies that discuss SDoH or with adults. Excluded clinical interventions and studies with children and adolescents that do not include SDoH, T2DM and duplicates	(n=30 papers)
CINAHL	90	79	11
Medline/Ovid	84	76	8
Scopus	74	71	3
Proquest	129	123	6
Sage	2	1	1
Web of Science	21	20	1
Science Direct	4	4	0
Informit	0	0	0

30 papers from this search wave were included in the thesis

Appendix 3 - Analysis outputs - Chapter 3 Social inequalities in diabetes prevalence and the development of ESRD Appendix 3-1

Correlation between SEIFA decile and the prevalence of T2DM

			T2DM population percent	SES Decile
Spearman's rho	T2DM population percent	Correlation Coefficient	1.000	-.769**
		Sig. (2-tailed)	.	.000
		N	355	355
	SES Decile	Correlation Coefficient	-.769**	1.000
		Sig. (2-tailed)	.000	.
		N	355	454

**. Correlation is significant at the 0.01 level (2-tailed).

Correlation between SEIFA decile and the prevalence of T1DM

			SES Decile	T1DM population percent
Spearman's rho	SES Decile	Correlation Coefficient	1.000	-.397**
		Sig. (2-tailed)	.	.000
		N	454	355
	T1DM population percent	Correlation Coefficient	-.397**	1.000
		Sig. (2-tailed)	.000	.
		N	355	355

**. Correlation is significant at the 0.01 level (2-tailed).

Appendix 3-2

Age of ESRD correlated with SEIFA decile (Anova split file by gender)

Age is the dependent variable

Gender		Sum of Squares	df	Mean Square	F	Sig.
Male	Between Groups	707.874	9	78.653	.624	.776
	Within Groups	31118.569	247	125.986		
	Total	31826.444	256			
Female	Between Groups	1689.667	9	187.741	1.213	.289
	Within Groups	28946.689	187	154.795		
	Total	30636.355	196			

Appendix 3-3

Relative Risk calculation for low SES versus high SES and gender

Chi-squared Tests of gender and low SES yes/no

	Value	df	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	4.085[a]	1	.043		
Continuity Correction[b]	3.711	1	.054		
Likelihood Ratio	4.090	1	.043		
Fisher's Exact Test				.047	.027
Linear-by-Linear Association	4.076	1	.043		
N of Valid Cases	454				

Risk Estimate of low SES by gender

	Value	95% Confidence Interval	
		Lower	Upper
Odds Ratio for Gender (male / female)	1.468	1.011	2.131
For cohort low ses = yes	1.209	1.002	1.459
For cohort low ses = no	.824	.684	.993
N of Valid Cases	454		

Appendix 3-4

Pairwise comparison of SES deciles (baseline comparator is decile 1) for Relative Risk of T1DM

Decile	Cases	Total population	Crude incidence	RR
1	48	798523	0.601	1.0
2	43	637312	0.674	1.12
3	46	574060	0.801	1.33
4	45	826605	0.544	0.90
5	50	884679	0.565	0.94
6	48	897695	0.534	0.88
7	46	675286	0.681	1.13
8	46	723888	0.635	1.05
9	50	874187	0.571	0.95
10	32	542257	0.590	0.98

Appendix 4 – ethical approval & Analysis outputs – Chapter 4 A retrospective cohort study of patterns of care and health outcomes in T1DM

Appendix 4-1 ethical approval

Southern Adelaide Clinical

Human Research Ethics Committee

Government of South Australia
Southern Adelaide Health Service

10 January 2014
Dear Ms Hill

This is a formal correspondence from the Southern Adelaide Clinical Human Research Ethics Committee (SAC HREC EC00188). This committee operates in accordance with the "National Statement on Ethical Conduct in Human Research (2007)." No hard copy correspondence will be issued.

Application Number: 564.13

Title: The Social Determinants of Health Outcomes in Type 1 Diabetes – a Multiple Methods Observational Study - Application for phase one – A retrospective cross- sectional study conducting a secondary analysis of existing data.
Chief investigator: Kathleen Hill

The Issue: The Southern Adelaide Clinical Human Research Ethics Committee (SAC HREC) have reviewed and approved the above application. Your project may now commence. The approval extends to the following documents/changes:

- SA Health low and negligible risk dated 21 November 2013.
- SA Health indemnity approved dated 21 November 2013.
- Letter of support from Head of Endocrinology
- Approval Period: 10 January 2014 to 09 January 2015

Please read the terms and conditions of ethical approval below, as researchers have a significant responsibility to comply with reporting requirements and the other stated conditions.

For example, the implications of not providing annual reports and requesting an extension for research prior to approval expiring could lead to the suspension of the research, and has further serious consequences.

Please retain a copy of this approval for your records.

Appendix 4-2 A summary of the deleted cases listed by study ID

Rationale	Case numbers
Misclassification (138)	12 13 22 41 62 63 67 73 91 94 100 119 123 131 137 145 150 153 162 174 222 237 243 254 259 271 284 297 303 306 308 320 336 343 345 354 360 364 366 372 415 423 429 455 458 475 477 491 504 527 531 550 558 559 587 607 635 646 647 673 694 698 699 703 716 718 729 732 733 745 750 762 781 783 784 795 804 805 819 820 822 823 824 834 842 849 867 872 883 894 895 896 905 938 941 946 952 959 965 974 995 1004 1007 1019 1021 1035 1039 1043 1045 1076 1078 1084 1097 1129 1162 1174 1180 1220 1226 1232 1240 1251 1252 1253 1254 1255 1257 1265 1288 1291 1292 1293 1341 1356 1378 1391 1398 1420
Incorrect URN (27)	19 24 38 53 68 155 288 476 525 536 543 662 731 944 1153 1156 1176 1178 1183 1189 1198 1203 1334 1338 1400 1422 1423
Duplicate cases (124)	43 108 281 292 305 309 368 377 464 465 514 562 575 592 595 619 628 675 692 701 702 706 711 713 741 743 746 753 756 764 767 771 774 786 788 791 801 808 816 817 825 826 841 845 846 886 887 898 903 908 915 926 927 958 969 977 987 988 990 993 1000 1006 1009 1028 1037 1041 1042 1053 1058 1060 1066 1068 1071 1093 1099 1101 1106 1108 1109 1112 1118 1128 1131 1151 1167 1177 1184 1186 1195 1202 1204 1206 1210 1214 1242 1245 1247 1248 1261 1273 1276 1285 1286 1289 1302 1304 1319 1337

	1344 1347 1355 1358 1360 1367 1382 1395 1416 1437 1451 1456 1458 1470
Unconfirmed cases (60)	5 15 21 55 61 69 76 78 79 85 95 142 160 164 168 191 209 214 215 223 232 276 296 319 334 363 373 386 388 391 411 425 434 505 524 533 588 601 604 708 798 874 880 902 920 941 934 936 1008 1011 1072 1073 1094 1095 1123 1239 1260 1364 1372 1454
No URN given (4) or no records found (4)	11 34 83 112 806 881 1166 1168
No year of diagnosis established (42)	651 659 689 693 724 740 755 772 780 793 794 797 813 848 888 910 948 970 1014 1027 1038 1047 1067 1154 1160 1179 1185 1217 1231 1241 1244 1249 1258 1269 1303 1314 1325 1327 1335 1342 1351 1383

Appendix 4-3 cross tabulation of gender and type of care

Gender & type of care		Value	Approx. Sig.
Nominal by Nominal	Phi	.053	.549
	Cramer's V	.053	.549
N of Valid Cases		1071	

Appendix 4-4 cross tabulation of age and type of care

Age and type of care		Value	Approx. Sig.
Nominal by Nominal	Phi	.441	.000
	Cramer's V	.254	.000
N of Valid Cases		1005	

Appendix 4-5

Cross tabulation of gender and death

		Value	Approx. Sig.
Nominal by Nominal	Phi	-.036	.241
	Cramer's V	.036	.241
N of Valid Cases		1071	

Calculation of relative risk ratio for death in late onset disease versus childhood onset disease

*(37/448)/(29/623) value available for all 1071 cases 0.0825892/0.0465489

	death	No death
Late onset	37	411
Childhood onset	29	594

SPPS output of the relative risk of death in late onset versus childhood onset disease

Chi-squared tests death in late onset versus childhood onset

	Value	df	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	5.854[a]	1	.016		
Continuity Correction[b]	5.247	1	.022		
Likelihood Ratio	5.758	1	.016		
Fisher's Exact Test				.020	.011
Linear-by-Linear Association	5.848	1	.016		
N of Valid Cases	1071				

a. 0 cells (0.0%) have expected count less than 5. The minimum expected count is 27.61.

Risk Estimate of death in late onset disease

	Value	95% Confidence Interval	
		Lower	Upper
Odds Ratio for early versus late onset (1.00 / 2.00)	.542	.328	.896
For cohort died = NO	.962	.931	.994
For cohort died = YES	1.774	1.108	2.841
N of Valid Cases	1071		

Appendix 4-6 Tests of normality for the distribution of the HbA1c data

	Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
Most recent HbA1c in the last year census date January 2013-January 31st 2014	.116	615	.000	.937	615	.000

a. Lilliefors Significance Correction

Appendix 4-7 Non-parametric analysis of gender and HbA1c

	Most recent HbA1c in the last year census date January 2013-January 31st 2014
Mann-Whitney U	43773.500
Wilcoxon W	91359.500
Z	-1.591
Asymp. Sig. (2-tailed)	.112

a. Grouping Variable: Gender

Appendix 4-8 cross tabulation of age of disease onset and current type of care split file by gender (female is 2)

Chi-Square Tests

Gender		Value	df	Asymp. Sig. (2-sided)
1	Pearson Chi-Square	26.382[a]	20	.154
	Likelihood Ratio	30.534	20	.062
	Linear-by-Linear Association	1.532	1	.216
	N of Valid Cases	558		
2	Pearson Chi-Square	44.285[b]	20	.001
	Likelihood Ratio	43.292	20	.002
	Linear-by-Linear Association	12.674	1	.000
	N of Valid Cases	513		

Appendix 4-9 Cross tabulation for HbA1c screening record and current type of care

Cross tabulation type of care and HbA1c screen yes/no

		Value	Approx. Sig.
Nominal by Nominal	Phi	.659	.000
	Cramer's V	.659	.000
N of Valid Cases		1005	

Appendix 4-10 A comparison of median HbA1c by type of care

Most recent HbA1c in the last year census date January 2013-January 31st 2014

Encounters	N	Std. Deviation	Median
Endocrinology	446	1.8687	8.500
Other services	97	2.1702	8.600
Seen erratically	72	1.5761	8.000
Total	615	1.8978	8.400

Appendix 4-11 type of care and evidence of kidney screening yes/no

Kidney screen *encounters Cross tabulation

		Encounters			
		Endocrinology	Other services	Seen erratically	Not in care
Kidney screen	Yes	353	138	69	0
		63.0%	24.6%	12.3%	0.0%
	No	134	68	131	112
		30.1%	15.3%	29.4%	25.2%
Total		487	206	200	112
		48.5%	20.5%	19.9%	11.1%

Symmetric Measures

		Value	Approx. Sig.
Nominal by Nominal	Phi	.492	.000
	Cramer's V	.492	.000
N of Valid Cases		1005	

Appendix 4-12 Cross tabulation analyses of gender, age of onset and kidney disease

Cross tabulation gender and kidney disease yes/no

		Value	Approx. Sig.
Nominal by Nominal	Phi	-.006	.882
	Cramer's V	.006	.882
N of Valid Cases		652	

Cross tabulation age of onset group and kidney disease yes/no

		Value	Approx. Sig.
Nominal by Nominal	Phi	.163	.004
	Cramer's V	.163	.004
N of Valid Cases		652	

Cross tabulation age of onset group and kidney disease yes/no

Appendix 4-13

RR kidney disease by age group

(100/316)/(75/336) value available for 652/1071 cases

0.3164556/0.2232142 = 1.41

	Kidney disease	No kidney disease
Late onset	100	216
Child onset	75	261

SPSS output

Chi-squared tests presence of kidney disease in late onset versus childhood onset

	Value	df	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	7.210[a]	1	.007		
Continuity Correction[b]	6.743	1	.009		
Likelihood Ratio	7.222	1	.007		
Fisher's Exact Test				.008	.005
Linear-by-Linear Association	7.199	1	.007		
N of Valid Cases	652				

a. 0 cells (0.0%) have expected count less than 5. The minimum expected count is 84.82.

b. Computed only for a 2x2 table

Risk Estimate for the presence of kidney disease in late onset versus childhood onset

	Value	95% Confidence Interval	
		Lower	Upper
Odds Ratio for early versus late onset (1.00 / 2.00)	1.611	1.136	2.285
For cohort yes/no = yes	1.418	1.096	1.833
For cohort yes/no = no	.880	.801	.967
N of Valid Cases	652		

Appendix 4-14 Analysis of SES and kidney disease and kidney disease at death

SIEFA decile * kidney disease yes/no Cross tabulation

Count

		yes/no		Total
		yes	no	
Decile	1	13	14	27
	2	19	28	47
	3	18	37	55
	4	21	102	123
	5	27	91	118
	6	4	11	15
	7	13	27	40
	8	24	54	78
	9	25	77	102
	10	5	24	29
Total		169	465	634

Symmetric Measures

		Value	Approx. Sig.
Nominal by Nominal	Phi	.184	.010
	Cramer's V	.184	.010
N of Valid Cases		634	

Kidney function at death		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	>90	26	38.2	38.2	38.2
	>60	6	8.8	8.8	47.1
	30-59	10	14.7	14.7	61.8
	15-29	6	8.8	8.8	70.6
	<15	18	26.5	26.5	97.1
	Tx	2	2.9	2.9	100.0
	Total	68	100.0	100.0	

Kidney function at death * Gender Cross tabulation

			Gender		Total
			1	2	
ESRD at death	>90	Count	20	6	26
		% within ESRD at death	76.9%	23.1%	100.0%
	>60	Count	1	5	6
		% within ESRD at death	16.7%	83.3%	100.0%
	30-59	Count	4	6	10
		% within ESRD at death	40.0%	60.0%	100.0%
	15-29	Count	3	3	6
		% within ESRD at death	50.0%	50.0%	100.0%
	<15	Count	9	9	18
		% within ESRD at death	50.0%	50.0%	100.0%
	Tx	Count	2	0	2
		% within ESRD at death	100.0%	0.0%	100.0%
Total		Count	39	29	68
		% within ESRD at death	57.4%	42.6%	100.0%

Appendix 4-15 Deaths by SEIFA decile cross tabulation

Decile * Age died is the date last entry in OACIS Cross tabulation

Count

		Death		
		NO	YES	Total
Decile	1	34	2	36
	2	66	8	74
	3	77	8	85
	4	188	8	196
	5	177	14	191
	6	28	1	29
	7	56	9	65
	8	134	7	141
	9	173	5	178
	10	50	3	53
Total		983	65	1048

Symmetric Measures

		Value	Approx. Sig.
Nominal by Nominal	Phi	.127	.049
	Cramer's V	.127	.049
N of Valid Cases		1048	

Same test using split file by gender

Gender			Value	Approx. Sig.
1	Nominal by Nominal	Phi	.177	.046
		Cramer's V	.177	.046
	N of Valid Cases		546	
2	Nominal by Nominal	Phi	.189	.035
		Cramer's V	.189	.035
	N of Valid Cases		502	

Appendix 4-16 Analysis of type of care by SES reclassified into low (1) medium (2) and high (3)

SES reclassified cross tabulation with type of care

		Value	Approx. Sig.
Nominal by Nominal	Phi	.127	.032
	Cramer's V	.090	.032
N of Valid Cases		1048	

SES reclass * Encounters Cross tabulation

		Endocrinology	Other services	RIP	Seen erratically
SES reclass	1.00	72	47	18	34
		36.9%	24.1%	9.2%	17.4%
	2.00	237	82	32	87
		49.3%	17.0%	6.7%	18.1%
	3.00	169	71	15	73
		45.4%	19.1%	4.0%	19.6%
		478	200	65	194
		45.6%	19.1%	6.2%	18.5%

Appendix 4-17 Analysis of 10-year HbA1c and gender, SES and care status

Mean HbA1c and gender

Test Statistics [a]

	MeanHbA1c
Mann-Whitney U	116021.000
Wilcoxon W	248376.000
Z	-1.183
Asymp. Sig. (2-tailed)	.237

a. Grouping Variable: Gender

Mean HbA1c and reclassified SES

Ranks

	SES reclass	N	Mean Rank
MeanHbA1c	1.00	187	508.43
	2.00	446	498.55
	3.00	331	446.22
	Total	964	

Test Statistics [a,b]

	MeanHbA1c
Chi-Square	8.723
df	2
Asymp. Sig.	.013

a. Kruskal Wallis Test

b. Grouping Variable: SES reclass

Mean HbA1c and encounters (current care status)

Test Statistics [a,b]

	MeanHbA1c
Chi-Square	4.414
df	4
Asymp. Sig.	.353

a. Kruskal Wallis Test

grouping variable; encounters

Appendix 4-18 Multiple regression HbA1c

Regression modelling cross sectional HbA1c taken in the last year

		Most recent HbA1c in the last year census date January 2013-January 31st 2014	Disease duration	Age of disease onset	Age
Pearson Correlation	Most recent HbA1c in the last year census date January 2013-January 31st 2014	1.000	-.173	-.134	-.226
	Disease duration	-.173	1.000	-.074	.797
	Age of disease onset	-.134	-.074	1.000	.542
	Age	-.226	.797	.542	1.000
Sig. (1-tailed)	Most recent HbA1c in the last year census date January 2013-January 31st 2014	.	.000	.000	.000
	Disease duration	.000	.	.008	.000
	Age of disease onset	.000	.008	.	.000
	Age	.000	.000	.000	.
N	Most recent HbA1c in the last year census date January 2013-January 31st 2014	615	615	615	615
	Disease duration	615	1071	1071	1071
	Age of disease onset	615	1071	1071	1071
	Age	615	1071	1071	1071

Model Summary[b]

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.229[a]	.052	.048	1.8521

a. Predictors: (Constant), Age, Age of disease onset, Disease duration

b. Dependent Variable: Most recent HbA1c in the last year census date January 2013-January 31st 2014

Coefficients[a]

Model		Standardized Coefficients		95.0% Confidence Interval for B		Collinearity Statistics	
		Beta	Sig.	Lower Bound	Upper Bound	Tolerance	VIF
1	(Constant)		.000	9.389	10.116		
	Disease duration	-.605	.377	-.267	.101	.003	302.389
	Ageof disease onset	-.450	.361	-.270	.099	.006	156.489
	Age	.500	.538	-.127	.243	.002	425.854

a. Dependent Variable: Most recent HbA1c in the last year census date January 2013-January 31st 2014

Coefficients[a]

Model 2		Standardized Coefficients		95.0% Confidence Interval for B		Collinearity Statistics	
		Beta	Sig.	Lower Bound	Upper Bound	Tolerance	VIF
	(Constant)		.000	9.404	10.126		
	Disease duration	-.184	.000	-.036	-.015	.995	1.005
	Age of disease onset	-.148	.000	-.043	-.013	.995	1.005

a. Dependent Variable: Most recent HbA1c in the last year census date January 2013-January 31st 2014

Regression modelling ten year mean HbA1c

		MeanHbA1c	Disease duration	Age of disease onset	Age
Pearson Correlation	MeanHbA1c	1.000	-.182	-.063	-.190
	Disease duration	-.182	1.000	-.074	.797
	Age of disease onset	-.063	-.074	1.000	.542
	Age	-.190	.797	.542	1.000
Sig. (1-tailed)	MeanHbA1c	.	.000	.024	.000
	Duration	.000	.	.008	.000
	Age of disease onset	.024	.008	.	.000
	Age	.000	.000	.000	.
N	MeanHbA1c	986	986	986	986
	Disease duration	986	1071	1071	1071
	Age of disease onset	986	1071	1071	1071
	Age	986	1071	1071	1071

Model Summary[b]

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.200[a]	.040	.037	1.59743

a. Predictors: (Constant), Age, Age of disease onset, Disease duration

b. Dependent Variable: MeanHbA1c

Coefficients[a]

Model		Standardized Coefficients		95.0% Confidence Interval for B		Collinearity Statistics	
		Beta	Sig.	Lower Bound	Upper Bound	Tolerance	VIF
2	(Constant)		.000	9.251	9.742		
	Disease duration	-.188	.000	-.029	-.015	.995	1.005
	Age of disease onset	-.077	.015	-.023	-.002	.995	1.005

a. Dependent Variable: MeanHbA1c

Appendix 4-19 Binary logistic regression with attendance at endocrinology clinic as the dependent variable

Dependent Variable Encoding (attendance at endocrinology clinic)

Original Value	Internal Value
No	0
Yes	1

Case Processing Summary

Unweighted Cases[a]		N	Percent
Selected Cases	Included in Analysis	982	91.7
	Missing Cases	89	8.3
	Total	1071	100.0
Unselected Cases		0	.0
Total		1071	100.0

Categorical Variables Codings

		Frequency	Parameter coding (1)
Early or late onset	late onset	375	.000
disease	early onset	607	1.000
SES high or low	high	441	.000
	low	541	1.000
Binary disease	20+ years	347	.000
duration	0-20 years	635	1.000
Gender	1	508	.000
	2	474	1.000

Omnibus Tests of Model Coefficients

		Chi-square	df	Sig.
Step 1	Step	62.026	4	.000
	Block	62.026	4	.000
	Model	62.026	4	.000

Model 1

Variables in the Equation

		B	S.E.	Wald	df	Sig.	Exp(B)
Step 1[a]	Gender(1)	.155	.132	1.372	1	.242	1.168
	SES dichotomous(1)	-.042	.133	.099	1	.753	.959
	Binary duration(1)	.915	.140	42.532	1	.000	2.497
	Early versus late onset(1)	.591	.137	18.596	1	.000	1.805
	Constant	-1.074	.177	36.899	1	.000	.342

a. Variable(s) entered on step 1: Gender, SES dichotomous, binary duration, early versus late onset.

Model 2

Variables in the Equation

		B	S.E.	Wald	df	Sig.	Exp(B)
Step 1[a]	Binary duration(1)	.930	.139	45.052	1	.000	2.535
	Early versus late onset(1)	.598	.135	19.516	1	.000	1.818
	Constant	-1.042	.146	50.807	1	.000	.353

a. Variable(s) entered on step 1: binary duration, early versus late onset.

Appendix 4-20 Binary logistic regression with kidney disease as the dependent variable

Case Processing Summary

Unweighted Cases[a]		N	Percent
Selected Cases	Included in Analysis	634	59.2
	Missing Cases	437	40.8
	Total	1071	100.0
Unselected Cases		0	.0
Total		1071	100.0

Dependent Variable Encoding

(presence of kidney disease)

Original Value	Internal Value
No	0
Yes	1

Categorical Variables Codings

		Frequency	Parameter coding (1)
Early versus late onset	child onset	326	.000
	adult onset	308	1.000
SES high or low	high	264	.000
	low	370	1.000
Gender	1	323	.000
	2	311	1.000

Omnibus Tests of Model Coefficients

		Chi-square	df	Sig.
Step 1	Step	203.203	4	.000
	Block	203.203	4	.000
	Model	203.203	4	.000

Model Summary

Step	-2 Log likelihood	Cox & Snell R Square	Nagelkerke R Square
1	531.994[a]	.274	.400

Analysis for binary short disease duration coded as '1' the IV predictor

Model Summary

Step	-2 Log likelihood	Cox & Snell R Square	Nagelkerke R Square
1	624.903[a]	.185	.269

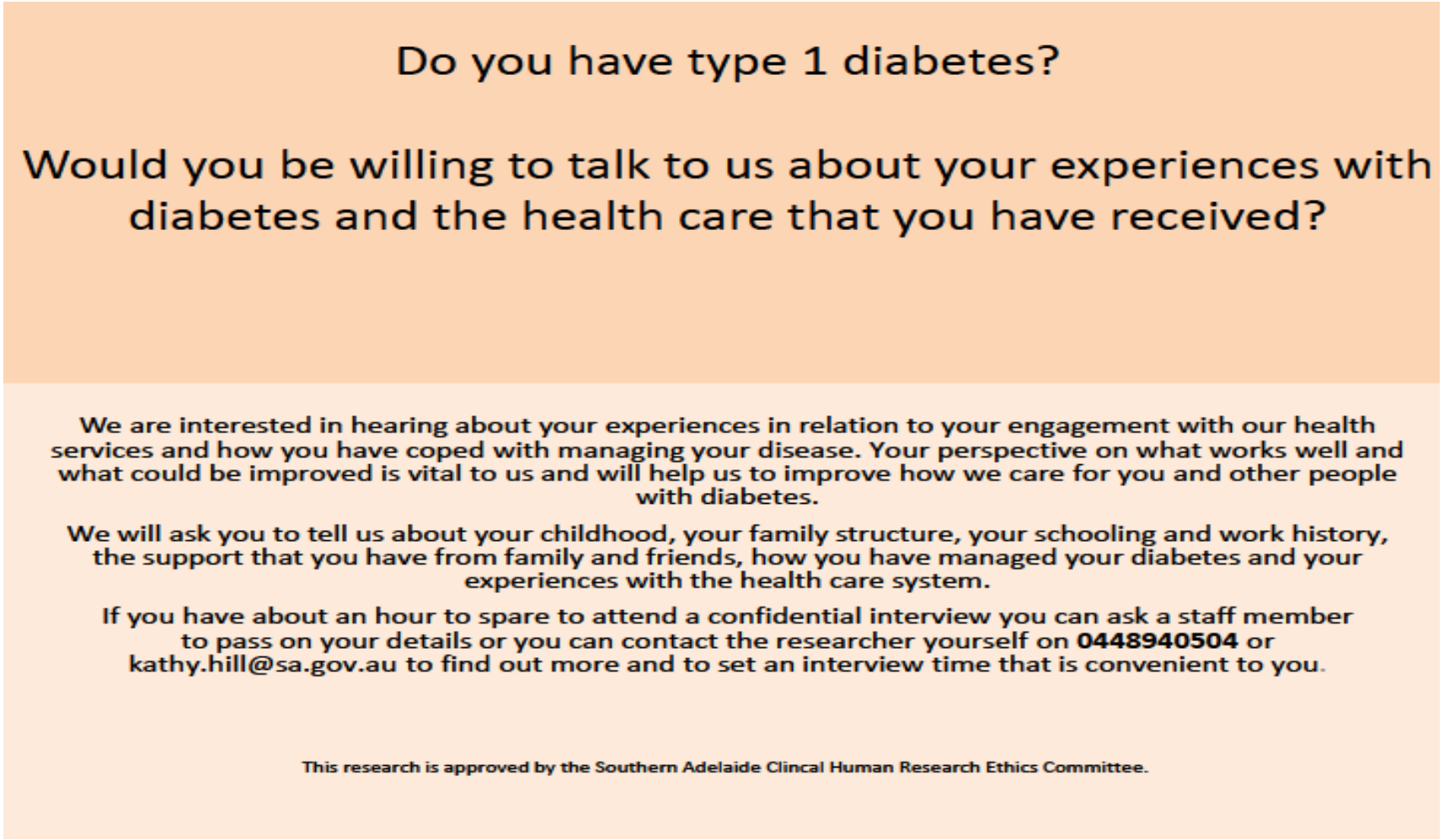
Variables in the Equation

		B	S.E.	Wald	df	Sig.	Exp(B)
Step 1[a]	Binary duration(1)	-2.225	.214	108.383	1	.000	.108
	Constant	-.028	.119	.056	1	.812	.972

The negatively reported Exp B indicates an extremely low risk which when converted into OR is 9.25.

Appendix 5 – Chapter 5- A qualitative exploration of health outcomes in type 1 diabetes mellitus

Appendix 5-1 study recruitment flyer



Appendix 5-2 PICF

Dear (insert name)

Thank you for agreeing to receive some information about participating in a research project titled 'The social determinants of health outcomes in type 1 diabetes mellitus – a qualitative study'. Attached is the participant information sheet and consent form which will explain the purpose of the study and what is involved in more detail.

I will contact you in about a week by phone to ask if you would like to participate. Should you have any questions about this project please contact me on 0448940504.
Thank you,

Kathleen Hill
xxx (Institution name)

PARTICIPANT INFORMATION SHEET

Title; 'The social determinants of health outcomes in type 1 diabetes mellitus – a qualitative study'

Principle Investigator; Kathleen Hill

Location; xxx (name)

1 Introduction

You are invited to take part in this research project because you have type 1 diabetes mellitus and you have given permission for us to contact you. This Participant Information Sheet/Consent Form tells you about the research project. It explains the processes involved with taking part. Knowing what is involved will help you decide if you want to take part in the research. Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative, friend or local health worker. Participation in this research is voluntary. If you don't wish to take part, you don't have to. If you decide you want to take part in the research project, you will be asked to sign the consent section. By signing it you are telling us that you:

• Understand what you have read
• Consent to take part in the research project
• Consent to be involved in the research described
• Consent to the use of your personal and health information as described.

You will be given a copy of this Participant Information and Consent Form to keep.

6 What is the purpose of this research?

The purpose of this research is to understand how different aspects of your social environment may have helped or hindered you in the management of your diabetes. These aspects are known as social determinants and affect your health in a different way to the medical management that you receive. There has been a great deal of research with children who have type 1 diabetes but very little with adults that asks them to describe the lived experience of managing the condition. We hope to understand a little better what some of the main barriers are to managing diabetes and what we can do as a health service to better support people with type 1 diabetes throughout their life not just when they are first diagnosed. The results of this study will be used by the researcher to complete a Doctor of Philosophy.

7 What does participation in this research involve?

If you agree to participate in this research you will be asked to attend a single interview with the researcher which will be timed to your convenience and take place within your centre of clinical care. The interview will be audio recorded so that we can be certain of what you have said. You will be asked in a general way to describe your childhood, your family structure, your schooling and work history, the support that you have from family and friends, how you have managed your diabetes and your experiences with the health care system. You do not have to answer any questions that make you uncomfortable and can end the interview at any time. We will also be asking your permission to view your electronic medical records to understand your blood sugar control, your kidney function, your attendance at clinics and any complications you may have had. There are no costs associated with participating in this research project, nor will you be paid.

8 Other relevant information about the research project

We hope to speak with between 15 and 30 people across these four sites to give us a comprehensive understanding of the issue. This research project has been designed to make sure the researchers interpret the results in a fair and appropriate way and avoids researchers or participants jumping to conclusions. The researcher has previously studied this issue in different ways and will continue to share the results of this research with your clinical care team to help them to understand type 1 diabetes from your perspective.

9 Do I have to take part in this research project?

Participation in any research project is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage. Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your routine care or your relationship with your health care staff.

10 What are the possible benefits of taking part?

We cannot guarantee or promise that you will receive any benefits from this research, however we do hope to better understand the experiences of people with diabetes and to be able to make some recommendations that will help to support people like you in the future.

11 What are the possible risks and disadvantages of taking part?

You may feel that some of the questions we ask are stressful or upsetting. If you do not wish to answer a question, you may skip it and go to the next question, or you may stop the interview immediately. If you think that your distress about your health is an ongoing issue you can let us know and we can discuss arranging some additional support with your clinical care team.

12 What if I withdraw from this research project?

If you do consent to participate, you may withdraw at any time and this will not affect your care. You should be aware that data collected up to the time you withdraw will form part of the research project results. If you no longer want your data to be included please let us know.

13 What happens when the research project ends?

When this research project ends the results will be shared with the clinical staff of your hospital and may published in health journals however you will not be individually identified in any way. Only the researcher will have information about your identity and this will not be shared with anyone else. Your interview recording will be kept in a secure environment within xxx (name) and the audio file will be destroyed when the project has been completed in full and the final results are known. Your interview recording will be transcribed into a written document and you can ask to see this if you wish by contacting the researcher and requesting a copy. We will also be preparing a 'lay' summary of the key findings that can be given to the research participants once the study has finished and before we publish the findings, if you would like to receive a copy of this please let us know at the time of your interview.

14 What will happen to information about me?

By signing the consent form you consent to the research team collecting and using personal information about you for the research project. Any information obtained in connection with this research project that can identify you will remain confidential. Your information will only be used for the purpose of this research project and it will only be disclosed with your permission, except as required by law. Some of what you have said in your interview will be used as quotes to illustrate particular points however this will be presented in such a way that you cannot be identified. In accordance with relevant Australian privacy and other relevant laws, you have the right to request access to the information about you that is collected and stored by the research team. You also have the right to request that any information with which you disagree be corrected. Please inform us if you would like to access your information.

15 Complaints and compensation

If you suffer any distress or psychological injury as a result of this research project, you should contact the research team as soon as possible. You will be assisted with arranging appropriate treatment and support. If you wish to make a complaint about how this research has been conducted you can do so by contacting the research ethics committee on;
(08) 82046453 or Health.SALHNOfficeforResearch@sa.gov.au

14 Who has reviewed the research project?

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC).
The ethical aspects of this research project have been approved by the Southern Adelaide Clinical Human Research Ethics Committee.
This project will be carried out according to the *National Statement on Ethical Conduct in Human Research (2007)*. This statement has been developed to protect the interests of people who agree to participate in human research studies.

15 Further information and who to contact

The person you may need to contact will depend on the nature of your query. If you want any further information concerning this project or if you have any problems which may be related to your involvement in the project, you should contact the researcher first;
Clinical contact person;
Name; Kathleen Hill
Position; Registered Nurse, Renal Unit, xxx (name)
Telephone; xxx
Email; kathy.hill@sa.gov.au
For matters relating to the research at the site at which you are taking part the details of the local site complaints person are;
Local Site Complaints person;
Name; xxx
Position; Manager, Office for research
Telephone; xxx
Email; Health.SALHNOfficeforResearch@sa.gov.au
If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact;
Reviewing HREC approving this research and HREC Executive Officer Details

Reviewing HREC name; Southern Adelaide Clinical

HREC Executive Officer; xxx (name)

Telephone; xxx

Email; Health.SALHNOfficeforResearch@sa.gov.au

Local HREC Office contact

Name; xxx

Position; Research Governance Officer

Telephone; xxx

Consent Form - *Adult providing own consent*

Title 'The social determinants of health outcomes in type 1 diabetes – a qualitative study'

Principle Investigator Kathleen Hill

Location; xxx

Declaration by Participant

I have read the Participant Information Sheet or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research described in the project.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the project without affecting my future care.

I understand that I will be given a signed copy of this document to keep.

Name of Participant (please print) _____

Signature _____ Date _____

Declaration by Researcher

I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Name of Researcher (please print) _____

Signature _____ Date _____

Note: All parties signing the consent section must date their own signature

Appendix 5-3 Ethical approval

Office for Research Government of South Australia

EHealth.SALHNOfficeforResearch@sa.gov .au

Southern Adelaide Local Health Network

Final approval for ethics application

You are reminded that this letter constitutes **ethical** approval only.
Ethics approval is one aspect of the research governance process.
You must not commence this research project at any SA Health sites listed in the application until a Site Specific Assessment (SSA), or Access Request for data or tissue form has been authorised by the Chief Executive or delegate of each site.

Dear Ms Hill

This is a formal correspondence from the Southern Adelaide Clinical Human Research Ethics Committee (SAC HREC EC00188). This committee operates in accordance with the "National Statement on Ethical Conduct in Human Research (2007)." No hard copy correspondence will be issued.

Application Number: 501.15 - HREC/15/SAC/497

Approval Date: 4 January 2016

Title: The social determinants of health outcomes in type 1 diabetes mellitus – a qualitative study.

Chief investigator: Kathleen Hill

Public health sites granted ethical approval:

- xxx (name) Hospital
- xxx (name) Hospital
- xxx (name) Hospital

The Southern Adelaide Clinical Human Research Ethics Committee (SAC HREC) have reviewed and provided ethical approval for the above application. The approval extends to the following documents/changes:

- Qualitative Research Application form vI.1dated December 2015
- Support Letter Head of Department Endocrinology dated 26 November 2015
- Support Letter Head of Department xxx Dialysis dated 9 November 2015
- Support Letter Head of Department Renal Unit dated 4 November 2015
- Appendix 1TlDM flyer dated December 2015
- Appendix 2 Semi-structured interview guide vl dated November 2015
- Appendix 3 Participation agreement letter vl dated 1December 2015
- Kathleen Hill Brief CV

Approval Period: 4 January 2016 to 4 January 2020

Please read the terms and conditions of ethical approval below, as researchers have a significant responsibility to comply with reporting requirements and the other stated conditions.

Please retain a copy of this approval for your records.