The Lived Experiences of Diabetes Healthcare for South Asian Muslims in New Zealand

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Bismillahirrahmanirrahim

I begin this thesis with the recognition of God, the most gracious and the most merciful.

All the goodness and success of this work is attributable to God, and any and all shortcomings are attributable to myself.

Abstract

Diabetes is a disease with a high prevalence and societal burden that disproportionately impacts those of South Asian ancestry. Diabetes can involve demanding and complex self-management dynamics and is associated with significant complications and psychosocial factors. Despite its disproportionate impact upon South Asians, they are under-researched as a minority group, so less is known about their experiences and needs, which can compromise quality of care. In this paper I interviewed 10 South Asian Muslims with Type 2 Diabetes in New Zealand to explore their lived experiences of diabetes healthcare, how they made sense of their diabetes in relational and cultural contexts, and the various healthcare barriers and facilitators they experienced. I analysed these interviews using Reflexive Thematic Analysis. Findings were considered through the theoretical frameworks of healthism, relational healthism and Foucaultian theories of power and discourse. I identified several themes that related to participants' dynamics of worry regarding diagnosis, of complications, and of navigating food choices, as well as participants' dislike and distrust of medication approaches. Participants stories further highlighted the significance of family, and the various ways that theyfelt that their cultural needs were not being met. Participants frequently reported experiences demonstrating breakdowns in shared-decision making processes, which provide significant opportunities for improvement, for a more culturally competent and equitable Aotearoa.

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This thesis is dedicated to my family and my Kashmiri and New Zealand South Asian Muslim community. I hope that we might have a more equitable future, less impacted by the struggles and suffering of diabetes.

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Chapter 1: Literature Review

Diabetes is now one of the most prevalent chronic diseases in the world. Type 2 Diabetes worldwide prevalence in 2017 was found to be 462 million (Khan et al., 2020). This is 6.28% of the world's population. Over 1 million deaths per year can further be attributed to diabetes alone, making it the ninth leading cause of mortality. Diabetes has been found to have significant psychosocial factors associated, as well as a variety of intimidating complications (Harris, 2003). The treatment of diabetes involves a complex self management process, which is unique in how it places the burden of invasive blood glucose monitoring, diet and exercise regimentation, and often multiple daily insulin injections into the hands of the individual (Harris, 2003). Hence there is an importance and complexity in exploring diabetes experiences.

In this research, I sought to explore this complex health experience through the lens of being a South Asian Muslim in New Zealand. This is significant as South Asian Muslims are an under-researched population group who have different conceptualisations of health, and different responses and engagement to mainstream treatment approaches. Because of this, I explored these experiences using a critical realist epistemological approach. This involves an ontological position of realism, assuming that there is a particular reality of culturally competent healthcare that can exist. The critical realist approach then allows me to take positions of considering diverse conceptualisations and ways of being of diabetes healthcare experiences, and contrasting this in relationship with the traditional, mainstream biomedical perspectives. In this chapter I will be providing an overview of the literature about diabetes: its prevalence, biomedical perspectives, psychosocial experiences, intersectional dynamics, cross-cultural perspectives, and barriers to care.

A biomedical perspective of diabetes

Diabetes mellitus (diabetes) is a group of metabolic diseases. It is characterised by hyperglycemia, which results from either a defect in insulin secretion, insulin action, or both

(American Diabetes Association, 2005). The development of diabetes can be linked to several processes. In particular, the destruction of the β-cells of the pancreas can lead to insulin deficiency, which results in resistance to insulin action (Gujral et al., 2013). There is also a deficient insulin action response which can result from inadequate insulin secretion and a level of diminished tissue response to insulin. The vast majority of diabetes cases fall into two broad etiopathogenic categories; type 1 diabetes (T1D) and type 2 diabetes (T2D) (American Diabetes Association, 2005). T1D involves an insulin secretion deficiency. This can be linked to autoimmune processes impacting the pancreas, and genetic factors. T2D relates to a combination of resistance to insulin action, and an insulin secretion response inadequate to compensate (Gujral et al., 2013). This insulin is required for the pathologic process of the uptake of glycogen. The resulting chronic hyperglycemia is associated with long term complications which can include loss of vision, renal failure, peripheral neuropathy, amputations (Gujral et al., 2013), Charcot (degenerating) joints and autonomic neuropathy which can cause gastrointestinal, genitourinary and cardiovascular symptoms and sexual dysfunction. People with diabetes also have increased risks of atherosclerotic, cardiovascular, peripheral arterial and cerebrovascular diseases (American Diabetes Association, 2005). Hence diabetes is classed a significant lifestyle disease and understandably difficult psychological experience

Psychosocial experiences of diabetes

With its complexity, demanding self-care dynamics, and lifestyle challenges, diabetes can be a difficult disease to live with that can be associated with challenging feelings and experiences. Chronic disease is often associated with increased prevalence of mood disorders; however, diabetes is unique in how it places the burden of invasive blood glucose monitoring, diet and exercise regimentation, and often multiple daily insulin injections into the hands of the individual (Harris, 2003). The associated psychosocial attributes such as diabetes-related emotional distress have been found to have practice implications in its contribution to difficulty with diabetes self-management, and worsening diabetes status over time. Hence, in practice it becomes essential for interventions supporting self management to target and address psychosocial attributes such as disease-related emotional distress (Zulman et al., 2012). Moreover, depression may be three times more prevalent in the diabetic population when compared with non-diabetic individuals (Harris, 2003). Multiple studies suggest that prevalence of depression in individuals with diabetes ranges from 15% to 40% (Egede et al., 2003; Egede & Zheng, 2003; Egede et al., 2002; Marcus et al., 1992; Popkin et al., 1998). Diabetes is also a significant cause for disability in the US among people above 45 years of age and its impacts include sexual problems, visual impairments, peripheral vascular disease, neuropathy, coronary artery disease and kidney insufficiency (Rubin & Peyrot, 1992). Issues such as impotence and sexual dysfunction can be three times more likely in men with diabetes than non-diabetic men (Jackson, 2004). These sexual dysfunctions in particular have significant emotional overlays with depression, anxiety, fear and stress.

Many people with diabetes live in fear and anticipation of the development of complications of the disease (Harris, 2003). With more advanced screening technologies, indications of these often occur in asymptomatic individuals. Early detection itself can challenge a person, impacting sense of self, feelings of fragility, and can increase feelings of uncertainty (Reventlow, Hvas & Malterud, 2006). Moreover, complications associated with diabetes can bring up anger, depression and frustration, especially in people who have been striving to maintain their glycemic control (Harris, 2003). This can reinforce a sense of vulnerability, a lack of control, and hopelessness. For those people who have not been able to maintain their glycemic control, complications can bring up feelings of intense guilt (Harris, 2003). The occurrence of complications also impacts the attempted defense mechanism of denial in some, which can result in emotional distress, depression, and anger (Harris, 2003). These dynamics can then feedback and impact motivation for self care (Polonsky et al., 2005). For example, one of the most feared complications of diabetes is blindness. Blindness can result in major lifestyle alterations seen to impact loss of independence, finances, and job security. Hence even the diagnosis of minor background retinopathy can result in overwhelming fear and anxiety, and has been associated with decreased self-esteem, hopelessness and depression (Harris, 2003). These can influence the development of diabetes-related conflict with loved ones, as well as health care providers, straining relationships. This makes engaging with psychosocial dynamics essential for ensuring the health and wellbeing of people with diabetes.

Although diabetes does come with psychosocial challenges, there are fortunately ways of helping people through these challenges. Psychotherapy has been found to be useful in treating the depression associated with diabetes (Simson et al., 2008). Cognitive behavioural therapy has also been shown to have positive impacts on quality of life, mood, and coping for people with diabetes (Gonzalez et al., 2010; Safren et al., 2014; Uchendu & Blake, 2017; Yang et al., 2020). Behavioural and relaxation therapies have also been found to have positive impacts (Ebrahem & Masry, 2017; Khoshkhou et al, 2010). These referenced studies were carried out in the US, Europe, China, Egypt and Iran. This provides healthcare professionals with numerous options to cater to individual people's specific contexts and needs. This is important in the providing of culturally-appropriate support, as one size does not fit all. Therefore it can be helpful to track and measure factors such as diabetes distress in order to monitor efficacy.

A number of self-report instruments have been developed to investigate and monitor these dynamics of distress in diabetes for screening clinically and in research. These instruments include: ATT39, Questionnaire on Stress in Patients with Diabetes-Revised (QSD-R), and Problem Areas in Diabetes scale (PAID) (Polonsky et al., 2005). The PAID is the most widely used and has been associated with diabetes self-care behaviours, glycemic control, general emotional distress, perceived burden of diabetes, diabetes-related health beliefs, diabetes coping, and marital adjustment (Polonsky et al., 2005). The instrument is responsive to change and is a useful measure of several aspects of diabetes-related quality of life. However, instruments such as these have limitations in their capacity to explore the significance of factors within individuals' experiences. For instance, in the PAID only one item addresses how the patient feels about their healthcare provider. Depending on the person's experience, this could be a very significant factor to them which might require further exploring. Diabetes being a chronic lifestyle disease means that individualised, sensitive approaches are important, even as services scale as the prevalence of diabetes continue to increase.

Diabetes Prevalence

As aforementioned, diabetes is highly prevalent worldwide, with a high burden of disease, and significant mortality (Khan et al., 2020). The International Diabetes Federation had estimated the prevalence of diabetes in 2011 to be 366 million worldwide, predicted to rise to 552 million by 2030 (Alam et al., 2014). This burden of diabetes is rising globally, and at faster rates in developed regions. The gender distribution is equal, and the disease peak incidence is at 55 years of age (Khan et al., 2020). However although diabetes has a high prevalence, it is not distributed equally throughout the population.

Comparative studies in Western countries found that the South Asian diaspora have over a fivefold higher risk for diabetes as compared to the majority populations (Parackal et al., 2021). The Adult Nutrition Survey in New Zealand found for South Asians 23% of males and 21% of females reported being diagnosed with diabetes. This compares to 5% European males, 3% European females and less than 1% for other Asian subgroups (Parackal et al., 2015). This pattern is similar in the USA, where a cross-sectional study of US Indians found 29% had diabetes, and a further 37% were prediabetic (Kanaya et al., 2010). Similar patterns have also been found in Canada (Creatore et al., 2010), the UK (Gholap et al., 2011) and Norway (Jenum et al., 2012).

In New Zealand, the overall prevalence of diabetes is 7.0%, and the prevalence of prediabetes is 25.5% (Coppell et al., 2013). It was found diabetes prevalence was slightly higher in males than females: 8.3% and 5.8% respectively. Diabetes was higher among the people classified as having an obese BMI in comparison to those classified as having a ‘normal’ weight BMI; 14.2% compared to 2.5% respectively (Coppell et al., 2013). The New Zealand Health Survey considered this by ethnic breakdown and found the diabetes prevalence in New Zealand to be 10.1% for Pasifika, 8.4% Asian, 8% Māori, 2.9% European (Joshy & Simmons, 2006). However it is unfortunate that these statistics group all Asians into one category as this can hide the drastic intra-group prevalence variations between groups. For instance, there are differences amongst South Asian and East Asian populations, and some groups within these wider categories may have much lower prevalence of diabetes. This includes Chinese people, among whom their prevalence of diabetes in New Zealand was only 0.5%, collected from data between 1990-2004 (Joshy & Simmons, 2006). These differences are important to acknowledge as they reveal the importance of having culturally sensitive approaches to diabetes care. It is also important to note that these statistics have not been stable over time.

Studies in India have found diabetes prevalence rates have increased steadily over the past 40 years. In the 1970’s diabetes rates were 2% in urban areas, and 1% in rural areas (Ahuja, 1979). By 2006 this had risen to nearly 20% in urban areas and 10% in rural areas (Anjana et al., 2011). India now has one of the largest diabetes burdens globally (Anjana et al., 2011). Li et al. (2012) found an increasing dynamic in Chinese as well, with an increase of diabetes prevalence from 2.6% in 2000 to 9.7% in 2010 observed. This prevalence data is unfortunately limited by its age, as the prevalence is changing rapidly over time. This highlights that just because diabetes is now so prevalent in South Asia in areas such as India, does not mean that it has always been that way, or that it must be that way in the future. To understand this drastic change we can consider the causal factors, many of which have changed over time.

Biomedical perspectives of diabetes causal factors

Diabetes is a complex disease with a number of risk factors (Gujral et al., 2013). Where South Asians experience a disproportionately high burden of T2D compared with members of other ethnic groups, numerous environmental and biological factors can contribute to this outcome (Gujral & Kanaya, 2021). Insulin resistance is a precursor for T2D in all populations. However South Asians have been found to be more insulin resistant than Caucasian populations at lower levels of BMI (Gujral et al., 2013). Declines in pancreatic beta cell function are another key pathophysiological factor in diabetes pathogenesis. South Asians can have earlier impairments of beta cell function, which requires further investigation (Gujral et al., 2013). Around 60 genes have been associated with T2D development. However as most of this research has been conducted in European populations, there may still be further genetic differences to uncover (Gujral et al., 2013), as well as various other wider environmental risk factors.

Older age is also associated with T2D risk in all populations. However South Asians have been found to develop diabetes at younger ages. Researchers in Canada found the associated average ages of T2D diabetes for South Asians, Chinese, Blacks and Whites to be 49, 55, 57, and 58 respectively (Chiu et al., 2011). Various biomarkers are also associated with differential risks of diabetes, including reactive oxygen species, leptin and C-reactive protein, leptin and adiponectin (Chambers et al., 2001; Chauhan et al., 2011; Evans et al., 2003; Indulekha et al., 2011; Maritim et al., 2003). Reduced physical activity is also associated with increased diabetes across ethnicities. South Asians tend to have physical activity levels 50-75% lower than Caucasians (Williams et al., 2011). Diet is additionally a very important factor in diabetes. Refined carbohydrates, saturated fats, and trans fats in higher intakes are shown to increase diabetes risk in all populations (Hu et al., 2001). Foods that are high in dietary fiber and low glycemic index foods are associated with a decreased diabetes risk (Hu et al., 2001; Mohan et al., 2009). South Asian meals have been generally found to be of higher caloric values and to have higher percentage carbohydrate than European meals (Burden et al., 1994). The migration of South Asians to Western countries is associated with a change in food consumption patterns. These acculturated diets often involve increased consumption of high carbohydrate foods such as potatoes, biscuits and cakes, and a reduced consumption of fiber, which can have substantial health implications, especially on diabetes (Garduño-Diaz & Khokhar, 2012; Wandel et al., 2008). Cigarette smoking has also been shown to predict glucose intolerance progression, acutely increasing diabetes development risk (Śliwińska-Mossoń & Milnerowicz, 2017). Smoking is additionally associated with microvascular complications which influence diabetes pathogenesis. Short sleep durations and sleep disruptions are also associated with an increased prevalence and incidence of T2D shown to increase risk of diabetes, with numerous mediating mechanisms (Gottlieb et al., 2005; Knutson & Van Cauter 2008; Larcher et al., 2015). Finally, persistent organic pollutants have also been found to have an association with an increased risk of diabetes (Carpenter, 2008). This complex variety of causal factors makes determining diabetes causation multifaceted and complex. However the one particular factor of weight and body fat dynamics has gained particular, controversial attention.

Anthropometry in higher BMI, overweight, obesity and waist circumference are also associated with increased diabetes risk for all ethnicities (Gujral et al., 2013). South Asians have been found to have more levels of abdominal and visceral fat to Caucasians, even at similar BMI. This difference is prevalent even in childhood and adolescence (Gujral et al., 2013). However BMI and obesity considerations can be controversial due to the interacting factors of data integrity and weight stigma. An analysis of the Global BMI Mortality Collaboration has found that the way data has been excluded in weight-health research, informing data selection, analysis and interpretation, elicits major flaws and conclusions should be viewed sceptically (Flegal et al., 2019). Moreover BMI and weight considerations as metrics are deficient in how they do not reflect some changes, such as those which occur with age. This includes how proportion of body fat increases, muscle mass decreases, and these proportions can further differ significantly between and within groups (Rothman, 2008). This can introduce misclassification issues which can lead to biases in considering effects related to obesity. Furthermore it can invite weight stigmatising dynamics which have been shown to be harmful to health, and related to heightened mortality and other chronic disease issues (Tomiyama et al., 2018). This weight stigma, particularly in healthcare settings, can lead to people classified as obese receiving poor care and having worse outcomes. Weight stigma can trigger physiological and behaviour changes which perpetuate weight gain, and dynamics such as the avoidance of exercise (Logel et al., 2015; Major et al., 2016; Puhl & Heuer, 2009; Puhl & Suh, 2015; Vartanian & Shaprow, 2008). Individuals with T2D have been found to report higher rates of weight stigma than the general population, and internalisation of these stigmas (Himmelstein & Puhl, 2021). This weight stigma may lead to a greater risk for obesity, diabetes risk, cortisol level, oxidative stress, eating disturbances, depression, anxiety, body image dis-satisfaction and lower self esteem (Wu & Berry, 2018). This is significant and concerning, as up to 60% of people with T2D reported weight stigma in healthcare contexts (Himmelstein & Puhl, 2021). This weight and obesity stigma can also act as a barrier to the ongoing management of the conditions (Teixeira & Budd, 2010). Hence these dynamics make BMI-weight dynamics sensitive and delicate factors that likely should not be the primary focus due to the complex and interacting causal factors of diabetes. Indeed there is likely variance in the main causal factors of diabetes between different groups of people

The under-research of South Asian minority groups

In countries such as the United Kingdom, British South Asians are the largest minority ethnic group, where they are over-represented in the incidence of certain conditions, such as Type 2 Diabetes, but under-represented in health research (Prinjha et al., 2020). South Asian minority groups in literature are often described as ‘hard to reach’ as well as ‘seldom heard’ (Bhopal & Sheikh, 2009; Prinjha et al., 2020). Reasons for this underrepresentation are numerous and include study design, researcher assumptions, ethical procedures (Beadle-Brown et al., 2012) and language barriers (Bhopal & Sheikh, 2009; Manikam et al., 2017). However Visram et al. (2013) clarified that it is very possible to engage hard to reach groups by considering the individual, cultural and practical barriers to participation. Facilitation centered on whether the research participation could be considered as ‘appropriate’. This can be linked to how South Asian focus groups identify stigma and fear of gossip as strong disincentives to program participation, in the perception of culturally inappropriate services (Bradby et al., 2007). Moreover, in practice, South Asian people have not been found to demonstrate behaviour that ‘hard to reach’ implies, including being difficult, obstructive or indifferent. Hence, the critique has been raised whether it is the South Asian populations who are hard to reach, or the institutions and research practices which might be inhibiting accessibility for certain groups of people, particularly due to culturally inflexible environments (Crozier & Davies, 2007). This is essential to address as insufficient South Asian research representation affects validity and generalisability of findings (Oakley et al., 2003), capacity to develop effective services and interventions to meet minority group needs (Hussain-Gambles et al., 2004), resource allocation and access (McLean & Campbell, 2003), and can perpetuate health inequities (Redwood, Gale, & Greenfield, 2012). Hence, in seeking to address this under-representation of South Asians in health research, it can be useful to investigate South Asian people’s considerations of research involvement, and factors that can influence its accessibility.

Hussain-Gambles et al. (2004) sought to clarify how South Asian people perceived trial involvement and its risks and benefits. They found that motivations to participate in trials included: to help society, to improve their own health and that of family and friends, obligation to the doctor, and to increase scientific knowledge. One of the most common factors South Asians reported that hindered their participation in trials was a lack of being approached. Other factors reported also included feelings of not belonging, mistrust, gender issues, community gossip, religious modesty, and halal-religious incongruence. Hussain-Gambles et al. found that South Asian trial participation was more likely to be from those family members fluent in English, and who were younger. ‘Approachable’ patients of a relatable gender, social class, and English fluency were often cherry picked, whereas older South Asians, from working class backgrounds were found to be more mistrustful. Strategies for effective South Asian clinical trial recruitment were recommended, including: using multirecruitment strategies, consulting community members for study assistance, defining demographic and social profiles to be included to ensure appropriate applicability and eligibility criterion (Hussain-Gambles et al., 2004). Moreover, most literature focuses on first generation migrants and often the difference between generations such as second generation migrants and later is not made explicit. It is important to note the generation of migration of the participants, as this distinction is an essential intra-group difference which impacts many factors including beliefs, social relations, culture and diet (Hussain-Gambles et al., 2004; Muttarak, 2014; Sarfraz, 2015). These factors, and key psychographic differences, can also inform the usage of more effective research approaches.

In researching and recruiting South Asian population groups, non-traditional research approaches have been found to be significantly more effective (Hussain-Gambles et al., 2004). For South Asian groups, responses to written invitations have been found to be lower than reported than other general populations. Alternatively, community-oriented, personal approaches for recruitment have been found to be much more effective (Douglas et al., 2011). This involves recruitment being carried out within the community, with the involvement of both the research team, and with partnerships with local South Asian groups. Participants can also be encouraged to refer friends and family throughout recruitment. Project Dil is an example in the UK that demonstrated this using a peer education session model with the Asian community. Within 6 months Project Dil was able to conduct 54 peer sessions, accessed by over 2000 people from the Asian community. This demonstrates that South Asians are not ‘hard to reach’, but more that they have different approaches that are more culturally appropriate and effective. The incorporation of these more compatible tactics into study methodology is essential particularly for facilitating research into South Asian populations.

New Zealand Muslim intersectional dynamics and conceptualisations

Muslims in New Zealand are a diverse and growing population. The first Muslims in New Zealand were 15 Chinese Muslim golddiggers, reported in the 1874 census. The

Muslim community in New Zealand now consists of more than 40 different ethnicities and well over 60,000 people (Shepherd, 2006). In some literature Muslims are described as identifying and relating as Muslim rather than based on their individual identities (Shah & Culbertson, 2011; Shepherd, 2006). However it is important to take care not to mis-conceptualise culture as a neat, distinct, homogenous entity. In reality, cultures have historical provenance, change significantly over time, and involve individualised cultural-relationships (Narayan, 2000). Narayan (2000) describes that there is significant intra-group variation and individualisation within this cultural distinction. Muslims are not a homogenous group, and individual ethno-cultural norms shape their behaviours in significant ways that sometimes even contrast with religious perspectives (Attum et al., 2021). It is essential to recognize and consider these intra-group differences. This enables people's individual personal cultural perspectives to be accessed, rather than a generalised cultural label (Davies, Elkington, & Winslade, 1993). This is essential to consider as Muslims experience intersectional societal dynamics.

In New Zealand, Muslims have been found to face numerous intersectional barriers including institutional and racial barriers in society, the workplace, and the healthcare systems (Amjad, 2019; Shah & McGuinness, 2011). For example, in the New Zealand healthcare system, when people receive medical advice that they find culturally inappropriate and struggle to implement they are then described as ‘non-compliant’ (Penney, Barnes, & McCreanor, 2011). This blaming-compliance discourse, can contribute to mask the factors that can contribute to non-compliance such as a need to improve medical practitioners cultural competence in working with Muslim populations. Moreover, this facilitates other key barriers, such as that Muslim people in New Zealand lack knowledge about their available health services (Shah & Culbertson, 2011). Other barriers can include language barriers and a lack of finances, which might also be linked to not knowing what services are public health funded, and if there is any way translators may be accessible. To prevent a blaming approach that can be further marginalising it is important to recognise and unpack these intersectional barriers. Furthermore, exploring Muslim perspectives and paradigms can also make alternative approaches to healthcare which can be more effective accessible.

Engaging with Muslim conceptualisations in health promotion when working with Muslim populations has been shown to be highly effective. Religiously tailored workshops and messaging addressing health attitudes have been found to have “overwhelmingly positive responses” (Pratt et al., 2017, p. 1) and facilitated changes in health beliefs in Muslim samples (Pratt et al., 2020). Messages were developed in conjunction with Imams that addressed concerns around modesty, faith before physical concerns, predestination and fatalism. The Imams clarified that receiving healthcare in the right context is not immodest, that mind, body and soul must be kept in balance and all cared for, and that predestination does not preclude prescreening and striving to ward off harm. That Islamic values promote living a healthy, balanced lifestyle, and that prevention is better than cures. Research such as this highlights the power and efficacy of engaging with cultural conceptualisations in order to impact beliefs and actions.

The lack of understanding of religious influences on health and sickness behaviours affects health care practice and can lead to practice problems, ethical dilemmas and communication issues (Rassool, 2015). Rassool & Gemaey (2014) clarify that when assessing a Muslim patient it is important to examine cultural and religious identity, the patient’s explanatory model of their problem or illness, and their cultural factors that relate to the psychosocial environment, therapeutic relationship, and treatment interventions. Muslim communities require culturally sensitive healthcare approaches, and unfortunately less research has been done on Muslim community needs and culturally appropriate services (Ahmed & Reddy, 2007; Hussain, 2009). Important cultural differences include diet, alcohol and drug intake restriction, ideas of modesty, privacy and touch restriction between men and women (Attum et al, 2018). These factors are important to consider as when healthcare conflicts with culture and religion, the therapeutic alliance suffers (Khalifa & Hardie, 2005).

Furthermore, there are strong associations between religious belief and improved health outcomes, especially in contexts such as depression, anxiety, suicide risk and traumatic event recovery (Trenerry & Webster, 2011). In Trenerry & Webster's work, religious belief was also found to be associated with a reduced likelihood to engage in risky health behaviours including cigarette smoking, alcohol and drug abuse. There were however some negative effects found in two groups: those who were attracted to religion for reasons other than creed including for status, security and social opportunities; and those who used negative religious coping strategies such as interpreting negative situations as punishment from God (Trenerry & Webster, 2011). However, survey research has identified that 98% of Muslim respondents perceived life stressors as a test of one's faith (Abu-Ras & Abu-Bader, 2009). This means that psychologically, religious perspectives have a strong impact on health and illness, which should be considered in research.

There are a number of ways that have been proposed through which religion can have an impact on health (Trenerry & Webster, 2011). Religious practices such as praying may help to reduce stress. Being part of an organised religion can provide formal and informal social connection, opportunities and support, which is associated with improved health (Thoits, 2011). Religion may be associated with positive cognitions such as a sense of meaning, purpose, and optimism, which can be linked to cardiovascular, immune and endocrine function (Thoits, 2011; Trenerry & Webster, 2011). Religious belief may support healthier coping strategies, and act as an alternative to less healthy coping strategies such as alcohol consumption and smoking. Forms of religious involvement and attendance can also help to keep people physically active, reducing the risk of diabetes (Singh, Cinnirella & Bradley, 2012; Trenerry & Webster, 2011). This is especially considered by Muslims when practicing their prayer practice, which incorporates a series of movements for around 5 sessions per day (Singh, Cinnirella & Bradley, 2012). These religious factors can facilitate protective health benefits. However, practicing religion can also come with experiences of stigma and discrimination which can have negative health outcomes too.

There are a number of pathways through which religious discrimination can impact health (Trenerry & Webster, 2011). It can limit access to resources that determine the basis of health, such as housing, employment, and education (Trenerry & Webster, 2011). Furthermore, religious discrimination can influence people to internalise negative perceptions and stereotypes of themselves and their ‘groups’, impacting psychological well-being, self-esteem, and negatively impactful conditions such as stress and fear (Trenerry & Webster, 2011). These can have significantly negative physiological effects, particularly over the long term, on immune, endocrine, and cardiovascular systems, contributing to inequities. These factors can also influence people to engage in behaviours that have negative health impacts such as alcohol, drug and cigarette consumption, as well as manifesting in anti-social, aggressive behavior which is associated with negative physical and mental health outcomes (Trenerry & Webster, 2011). Hence there are many influencing factors that interplay in working with Muslim populations; it is essential to be aware of these in order to support people more effectively.

Eating behaviour and the social context of eating

South Asian eating behaviours tend not to fit well into mainstream Western conceptualisations of nutrition. Two ways of conceptualising this mismatch, is in considering the post-swallowing world, and the pre-swallowing world (Crotty, 1993), and sociological perspectives on eating (Delormier et al., 2009). The post-swallowing world encompasses biology, biochemistry and physiology, whereas the pre-swallowing world includes behaviour, culture, society and experience (Crotty, 1993). Traditionally, mainstream nutrition education approaches have focussed more on the post-swallowing world, with an emphasis on preventing obesity (Nestle & Jacobson, 2000). This perspective usually uses Social Cognitive Theory (Bandura 1986), which notes that behavioural change approaches impact individual behaviours by affecting knowledge, self efficacy and attitudes (Contento 2007). However, eating can also be explored as a social practice, where sociological perspectives can support the interpretation of social relations impacting eating patterns (Delormier et al., 2009). An overemphasis on individualistic behaviour change ignores the significant role of social context in shaping behaviour, and disembodies eating and food from the social contexts which individuals live their lives within (Warin et al. 2008). Unpacking and understanding these social contexts is essential for supporting behaviour change intervention (Cockerham 2005, Frohlich et al. 2001, Orleans 2000, Williams 2003). Moreover, it then becomes essential to consider the diversity of social contexts.

When considering eating as a social practice, we can identify significant variance between cultures. Even between subgroups of Asians, significant differences are present between dietary habits, nutrient intakes and blood profiles (Parackal et al., 2015). For example, studies with British Bangladeshi people found within religious and ethnic patterns, foods were not classified in Western food values of carbohydrates, fats and proteins (Chowdhury et al., 2000). Rather food choices were determined by two binary classifications of strong/weak and digestible/indigestible (Chowdhury et al., 2000). In some other parts of Asia classifications of hot/cold are prevalent (Chowdhury et al., 2000). Furthermore, in countries such as India, there can be drastic general inter-group behaviour differences between groups such as Hindus and Muslims in alcohol use, meat consumption, and more (Parackal et al, 2015; Rassool, 2015). These differences can have significant impacts on the ways individuals, and members of cultural groups select the foods they eat and do not eat. This can interact further with social contextual factors such as acculturation.

Upon immigrating to different countries, and becoming minority groups, immigrants' dietary patterns seem to change, also interacting with acculturation dynamics. This is demonstrated in the increased frequent consumption of festival foods by South Asians (Azar et al., 2013). This has been found to be a way of expressing ethnic identity, promoting familial togetherness and supports coping within the stress of adaptation to a new culture (Azar et al., 2013). Unfortunately, this increased consumption of festival foods is also linked as a possible reason for an increase in diet-related disease among migrant populations (Azar et al., 2013). Moreover, this can vary within groups relating to the level of acculturation, as well as vary with the generations. Research on South Asians living in the UK found that time in residence in the host country was associated with reductions in muscle mass, increases in body fat, and metabolic syndrome. When dietary patterns were derived and analysed, it was found this increase in metabolic syndrome was directly correlated with adopting Western diet patterns (Garduño-Diaz & Khokhar, 2013). This highlights the fluid and complex way that socio-cultural norms can interact with social context, through acculturation dynamics, and interplay with health and eating behaviours.

The role of traditional foods in maintaining ethnic cultural identity for South Asians is a key factor in diabetes management. This is exhibited particularly by older generations, and is seen to support cultural and religious values and traditions (Sarfraz, 2015). For example, many Pakistanis continue to consume South Asian foods that they perceive as dangerous or detrimental to diabetes because they considered the foods 'strength-giving' and felt cultural expectations to share food and meals with their family and community members (Lawton et al., 2008). They highlighted the challenge of balancing eating perceived risky South Asian foods with being alienated from their culture and community. To honor your dinner host by eating their food, even if it was high-glycemic, was often reported to prevent offending hosts and their generosity (Imran et al., 2015). They often coped with this by eating South Asian foods in smaller amounts. These socio-cultural norms and the beliefs within can play a significant role in diabetes management and should be considered.

Muslim and South Asian health beliefs

Patient beliefs and practices significantly influence disease treatment and experience, and can be challenging to influence (Brotons et al., 2012; Cummings, 2009; Tomar et al., 2017). Vyas et al. (2003) implemented an intervention for South Asians increasing clinician visits, and found it had no impact on scores of diabetes knowledge or awareness, and did not transfer information effectively. They concluded that different methods of information exchange need to be developed for working with South Asians. Hence it may be more productive to reframe this dynamic away from "compliance" and blame narratives and instead invest time into understanding what it is that people actually believe, and how they interpret and make sense of the situation that they are in (Penney et al., 2011). The management of diabetes in particular is noted to be challenging due to the number and complexity of tasks involved in self-management (Mbaezue et al., 2010).

A key commonly-held South Asian and Muslim belief that impacts diabetes is fatalism, or fatalistic beliefs. South Asians with diabetes interviewed in Lawton et al.'s (2006) research almost universally attributed causes to factors outside of their control, particularly that it is the will of God, a belief commonly expressed by older, first generation migrant South Asians (Lawton et al., 2006; Patel et al., 2015). Other external factors identified include genetics, factors from their migration to the UK, and the associated climate changes. This perspective can also inform a belief that fate and God will look after their diabetes. Contrarily it also can inform future outlooks which tended to be fatalistic, surrounded by a sense of inevitability, expecting that their health would continue to deteriorate and that little could be done to delay or reverse this process (Lawton et al., 2006; Macaden, 2007; Naeem, 2003). These fatalistic beliefs can have an impact on the capability of health practitioners to impact patient beliefs, and can be engaged with to facilitate significant changes (Pratt et al., 2017). Furthermore, these beliefs often do not occur in isolation, and can be informed by familial and community relationships.

Behaviour change models often have an individualistic focus that does not consider relational dynamics which can especially apply in South Asian contexts (Crossley, 2001; Kelly & Barker, 2016; Rhodes et al., 2019). These models might also be considered in relation to healthism - the assumption that health is located in the individual, and is primarily achievable through lifestyle management (Cheek, 2008; Crawford, 1980, 2006; Turrini, 2015). Healthism constructs health as a personal responsibility, requiring individuals to self-manage their risk of illness through self-surveillance and discipline (Cheek, 2008). Relational healthism extends this into interactions in our relationships with concepts such as "we are in it together" (Robson et al., 2021, p. 9). This is particularly relevant in South Asian households as when one member of the family has diabetes, the responsibility of self-management is often shared with family members (Patel et al., 2015). Qualitative studies have described how married men often relied on their wives for managing their diets, cooking and shopping for food for the family (Patel et al., 2015). Family members are often reported as a strong support system for South Asians, with participants sometimes describing that “I would not have been able to manage my sugar levels without family support.” (Singh et al., 2012, p.4). Hence, illness management is a task that is often shared with the South Asian patients' social networks and it is likely that the patients diabetes beliefs are also influenced by this context and traditionally strong family ties (Choudhury et al., 2009; Patel et al., 2015).

British Bangladeshis have been found to hold a high regard for oral explanations from informal sources such as friends, relatives and other patients with diabetes, and much of positive behaviour change was attributed to stories told in informal settings (Greenhalgh et al., 2005; Greenhalgh et al., 1998; Stone et al., 2005). These stories focussed around ‘what to do’ and were observed as ‘chaotically’ communicated in a way that was difficult to facilitate (Greenhalgh 2005). The groups were observed as having a ‘doing’ rather than ‘talking’ orientation, where people attending would often want to check their blood glucose together and compare, and self reflect based on others results. Greenhalgh et al. identified that group-based intervention for minority groups may look and feel very different to traditional diabetes education groups. Greenhalgh et al. (2005) further described that the mechanism through which this group participation might achieve positive outcomes is not through knowledge acquisition as such, but more by providing a forum where participants can negotiate the meaning of knowledge and the prompting of action. Knowledge was repeatedly discussed, reframed, and challenged by the group, whereafter it became meaningful to the participants. This informs why it might be frustrating for medical practitioners acting in formal, traditional settings to give health advice, which then has a minimal impact on behaviour (Vyas et al., 2003). Greenhalgh et al. (2005) further described why narratives apply to health education in how they: are a natural and universal form of communication; create engagement through metaphor, imagery, and suspense; support sense-making and embrace complexity; can be motivating and action focussing; provide lessons; and can occur in formal and informal spaces. This clarifies the importance of incorporating narrative dynamics in the exploration and influence of South Asian belief systems.

Intersectional barriers to treatment for South Asian Muslims with diabetes

Researchers have uncovered numerous barriers to treatment that exist for the South Asian Muslims living with diabetes. Firstly, most South Asians with diabetes have poor knowledge and understanding about the disease and it's related complications (Baradaran & Knill-Jones, 2004; Egede & Dagogo-Jack, 2005; Lawton et al., 2007; Naeem, 2003; Sohal, 2008; Vyas et al., 2003). Some researchers have found that the majority of their South Asian participants did not know what caused diabetes (Choudhury et al., 2009). Knowledge around the management of diabetes was often linked to ideas such as controlling sugar intake, as well as traditional beliefs such as eating bitter foods like bitter gourd to control their diabetes. It was found that when participants did not speak English and did not have a doctor that spoke their language, that there was little access to information (Choudhury et al., 2009; Egede & Dagogo-Jack, 2005; Sohal, 2008). There is a common trend of not being sure of or understanding the root cause of their disease (Lucas et al., 2013). Moreover there was a lack of understanding found of the relationship between lifestyle and disease, and many were often unconvinced that lifestyle choices had an impact on health. Disease risk and causation was instead attributed to external factors including stress, genetics, pollution and the will of God (Lawton et al., 2006) even when participants were able to recall and quote lifestyle advice from health professionals, the relative importance of these risk factors did not result in behaviour change or effective influencing of beliefs. This is then often interpreted as South Asians having poor compliance rates for lifestyle changes including diet and physical activity (Baradaran & Knill-Jones, 2004; Lawton et al., 2006; Macaden, 2007). This, however, does not account for the numerous barriers present for South Asians, or support facilitating through them.

A significant and challenging barrier to diabetes management that South Asians have reported is social stigma. Young South Asians report significant familial cultural pressure to hide their diabetes from others (Singh et al., 2012). This was particularly related to impacting prospects of marriage for those that were younger, and especially women. This applied in how healthy behaviour change could also challenge adherence to traditional social roles, which again was more significant for women (Imran et al., 2015). Diabetes was further perceived as a sign of physical inadequacy, particularly within a social system with family elders arranging the majority of marriages. Other social stigma also included pressures to compromise diet and treatment regimes to meet community social etiquette and to avoid social stigma. This particularly applied to eating traditional foods at social functions, experiencing that having and treating diabetes is shameful and embarrassing, which was contributed to and reinforced by participants' families as well.This can complicate and reduce the effectiveness of diabetes management. Contrarily, this also applies to the dynamic of not eating, and cultural factors such as adherence to fasting during the Muslim holy month of Ramadan also further complicate diabetes care.

Ramadan is a holy month for Muslims, where they fast every day from sunrise to sunset, which can complicate diabetes care (Benaji et al., 2006). Fasting in Ramadan is one of the core five pillars of Islam, and is hence compulsory for all healthy Muslims, and is considered as a deeply spiritual experience (Hassanein et al., 2017). Exemptions are permitted for those with medical conditions, including many with diabetes. However many people with diabetes still choose to fast. Salti et al. (2004) found that 78.7% of patients with T2D fasted at least 15 days of Ramadan, whereas the CREED study (Babineaux et al., 2015) found that 94.2% of those surveyed with T2D fasted for at least 15 days, and 63.6% fasted every day. It is essential for health care professionals and patients to both carefully manage the challenge of navigating Ramadan fasting with diabetes. This is as fasting may lead to a variety of issues including medication non-adherence, dehydration, hyperglycemia and hypoglycemia, and a variety of improvements including in metabolic profile (Gad et al., 2020). Literature illustrates mixed findings in this regard, however Alabbood et al. (2017) conducted a literature review finding improvements or no changes in glycaemic control parameters for all studies, except one, and that the incidence of major complications was negligible. They recommended that patients are empowered with Ramadan-focussed diabetes education to support informed management of their condition during Ramadan. This includes medication adjustments, nutrition and exercise advice, blood glucose monitoring, risk quantification, and knowing when to break the fast to minimise acute complications. This has been shown to be a drastically effective intervention for preventing acute diabetes health issues during Ramadan (Bravis et al., 2010; Gad et al., 2020). Patients who received the diabetes education went from 9 hypoglycaemic events pre-Ramadan, to 5 events during Ramadan, whereas those in the control group went from 9 events pre-Ramadan to 36 events during Ramadan (Bravis et al., 2010). Hence, as with many cultural factors, working with cultural dynamics in an inclusive and competent way facilitated significant benefits.

Physical activity considerations for South Asian Muslims with diabetes

South Asians have significantly lower levels of engagement in physical activity, which is a significant consideration for diabetes management. Lawton et al. (2006) found that for South Asians with diabetes, although people reported an awareness of the need to do physical activity for their diabetes care, few were able to put this into practice. The England Health Survey found that Indian, Pakistani and Bangladeshi men were respectively 14%, 30% and 45% less likely than the general population to meet physical activity guidelines (Fischbacher et al., 2004). Bangladeshi women had particularly low levels of physical activity. They reported only 35% of the level of physical activity as women from the general population, of which only 21% were achieving recommended guidelines for physical activity (Fischbacher et al., 2004). However the number of Bangladeshi women achieving recommended physical activity guidelines has been found to be as low as 7% (Visram et al., 2008). This is a trend mirrored with other South Asian women also, with lowered levels of physical activity being more pronounced in South Asian women than men (Fischbacher et al., 2004). Physical activity has also been noted to be lower in older South Asians. Within the South Asian demographic, Indians tended to have the highest level of physical activity, whereas Bangladeshis tended to have the lowest (Fischbacher et al., 2004). This highlights the significance and variation of intra-group differences, and the importance of exploring South Asian approaches and perspectives on exercise.

Investigation of South Asian peoples' perceptions of physical exercise highlights various barriers, with exercise often described as an additional and sometimes unachievable burden (Morrison et al., 2014). Structured physical activity tended to not be a part of everyday life, particularly for older age groups, and South Asian women (Visram et al., 2008). Hence many had limited knowledge of anatomy and physiology, perceiving the embodied experience of physical exertion such as sweating, breathlessness and increased heart rate as unpleasant, sometimes frightening, and related to illness states and weakness (Lawton et al, 2006). Visram et al (2008) found most of the women in their educational programs had not used much sports equipment before and for example could not pedal the exercise bikes well due to never having ridden a bike. For women there were also barriers relating to the cultural acceptability of exercises within their community, and clothing requirements, such as headscarves which are often desired to not be removed. Other barriers identified by Lawton et al. (2006) included poor climate conditions, which were described as a major barrier, with almost all respondents expressing a strong dislike of going outside in cold, wet, and windy conditions. Another key barrier identified in Lawton et al.'s study was the time barriers in busy lives, particularly of those who worked long hours such as in shops and restaurants and supporting child care. Many South Asians had the notion that family comes first, and that these responsibilities mean taking time out to exercise could be seen as a selfish and culturally inappropriate act. This had an additional gendered dynamic, related to how women described cooking and providing meals at the right times as creating time restrictions too. Some female respondents also described feelings of vulnerability when leaving the home, which were increased for those who had difficulties speaking English. For those willing and able to increase their physical activity, frustration was described for the lack of culturally-sensitive facilities. This included the lack of single-sex facilities and same-gender instructors to mitigate the cultural taboo of exposing their bodies to members of the opposite sex in swimming or gym environments. Furthermore the respondents reported that their health problems made physical activity difficult. This includes comorbidities such as asthma, painful knees and swollen joints which made simple activities such as walking more difficult. Respondents also reported health beliefs around how diabetes would impact and limit their future health. A perception was described that ageing, ill health and bodily decline was coming hand-in-hand, essentially that for many respondents their diabetes was triggering and a sign of irreversible decline, a turning point in their lives that had taken away from their vitality, and this seemed to be demotivating physical activity, and perpetuating a self fulfilling prophecy. This elucidates the complex and significant barriers that South Asians can have in engaging with physical activity. It also highlights the importance of culturally appropriate facilities, activities, environmental dynamics and comfort. However not all respondents reported these perspectives and experiences.

Lawton et al. (2006) found that a minority of South Asian respondents did go on to successfully incorporate and increase physical activity, and sought to clarify why this was. A key theme was a focus on short-term goals, such as the desire to not go on insulin injections. This seemed to relate to factors such as the stigma that could arise from others in the community. These respondents also considered physical activity in conjunction with blood glucose self-monitoring. A sense of gratification and achievement was reported in the experience of exercising and seeing their blood glucose readings going down. This can have a positively reinforcing effect, motivating further physical activity. This informs that physical activity considerations rather than focussing on long term health considerations, should optimally provide gratification, fun, social-engagement, and be able to be smoothly incorporated into people's everyday lives capitalising on what is already close to their current routines and activities (Johnson, 2000; Lawton et al., 2006).

Summary

Diabetes is now one of the most prevalent chronic diseases in the world (Khan et al., 2020). It involves complex, demanding self-care dynamics, and lifestyle challenges that can make it a difficult disease to live with associated with challenging feelings and experiences (Harris, 2003). South Asian Muslims are disproportionately affected (Beadle-Brown et al., 2012; Prinjha et al., 2020), and are an under-researched population group who have different conceptualisations of health, and different responses and engagement to mainstream treatment approaches (Attum et al., 2021; Pratt et al., 2020; Rassool, 2015; Rassool & Gemaey, 2014). Hence this research will seek to explore South Asian Muslims lived experiences of diabetes healthcare in order to facilitate more effective and equitable healthcare.

Chapter 2: Method

Research Design Overview

In this research I focused on exploring the lived experiences of diabetes healthcare for SAMDNZ, understanding how they made sense of their diabetes in relational and cultural contexts, and the various healthcare barriers and facilitators they experienced. In doing so, I explored the challenges and facilitators for SAMDNZ in navigating health advice and in their transition to having diabetes. This can support the development of best-practice healthcare interventions for SAMDNZ and guidelines to support culturally-competent SAMDNZ care (Waitoki et al., 2016). In this chapter, I provide an overview of the qualitative research approach and rationale for the data collection and analysis methodologies chosen for this research.

This research was informed by a critical realist epistemology, and theoretical frameworks of Foucaultian power and discourse theories (Foucault, 1972; Riley, Robson, & Evans,, 2021), healthism (Cheek, 2008; Crawford, 2006; Crawford 1980; Turrini, 2015) and relational healthism (Robson et al., 2022). I approach my research as a Muslim person of mixed South Asian-European ancestry. A group of 10 SAMDNZ were recruited to participate, from Mosques, community groups and online channels. Participants took part in semi-structured interviews and I used Reflexive Thematic Analysis (RTA) to analyse the data (Braun & Clarke, 2021; Braun & Clarke, 2021). Interviews invited participants to share their diabetes journey and what happened at the key transitional points of the healthcare experience. RTA facilitated interactive, interpretative meaning making of the data. A full ethics approval was submitted to the Massey University Human Ethics Committee, including considerations of culturally respectful engagement and confidentiality. Ethical approval was subsequently attained (Appendix 1). The proceeding sections will describe this research process and considerations in more detail.

Participants

Recruitment

Participant recruitment took place from 13th May 2022 till 25th August 2022. In alignment with recommendations on recruiting South Asian participants (Hussain-Gambles et al., 2004), I used a multi-channel approach to recruitment, which encouraged referring participants. Permission to advertise and recruit was discussed and attained with multiple Muslim community organisations. After approval from community organisations was attained, an information flyer (Appendix 2) was prepared for distribution in Mosques and via Whatsapp community group chats. The flyer included information about the study, and how to get in touch with the researcher for more information and/or to participate. Community networks and organisations contacted included the New Zealand Muslim Association

(NZMA), Islamic Women's Council of New Zealand (IWCNZ), local Muslim Whatsapp groups, multiple local Mosques, the Kashmiri Association of New Zealand and the Bangladeshi Association of New Zealand. Recruitment avenues were contacted incrementally given the smaller sample size, in order to manage the inflow and contact of potential participants, and to maintain a consistent and timely interview schedule.

In total, I sought to recruit 8-12 participants. This was informed by the suggested participant numbers for a RTA study at Masters level research, as indicated by Braun & Clarke (2013). This provided a balance of being able to go into sufficient depth of analysis with each individual participant, whilst managing limited research time and resources (O'Reilly & Parker, 2012). This level of participant recruitment sought to enable attention to experiential diversity, as well as sufficient data for the establishment of patterns across the dataset, whilst maintaining a rich, individualised focus on the nuanced individual experience (Braun & Clarke, 2013). As a token of appreciation, participants were respectfully offered a $40 supermarket voucher for their time. A culturally-appropriate gift of nuts was also offered, which was selected as it is also diabetes appropriate.

Inclusion/Exclusion Criteria

Participants were individuals who were of South Asian ancestry, and Muslims, with Type 2 diabetes, who were living in New Zealand. Accordingly,the inclusion criteria included that the participants should be primarily engaged with diabetes healthcare in New Zealand, as opposed to overseas. Participants diagnosed overseas were initially planned to be excluded, as receiving healthcare in a different country and culture for a significant period could influence their initial perceptions and beliefs about the disease, which could influence their experiences of it ongoing. After discussion with my supervisor, we decided to include one participant who immigrated to New Zealand very soon after their diagnosis. This exception was deemed to be appropriate as the participant was the only person using insulin able to be recruited, as well as being a type 2 diabetic with a young baby. Following the research interview, I noted that this participant's particular diagnosis experience overseas seemed to not play a significant factor in their experience, especially as they moved to New Zealand very soon after.

The South Asian population was selected due the group's high rate or susceptibility to diabetes, as well as being an under-researched population. Including participants from an under-researched group supports the reduction of inequity, which is an aim of this research. This lack of research representation is significant as South Asian cultures frequently conceptualise foods differently to Western cultures and follow significantly differing dietary patterns even to other Asian subgroups (Parackal et al., 2015). As RTA recommends homogenous samples (Braun & Clarke, 2021), using one population group is ideal to allow the deeper, focused exploration of particular experiences.

Another key inclusion criteria was being Muslim. This is because there are significant differences in values, and health and illness conceptualisations informed by religious belief differences within the South Asian demographic (Parackal et al., 2015). This also contributes to significant differences in diet and behaviours unique to the Muslim South Asian sub-group. For example, within the Indian subgroup, many Muslims will consume no-alcohol, higher meat diets, compared to Indian Hindus, who often consume lower-meat or vegetarian diets, with alcohol consumption (Parackal et al., 2015). Hence, in order to go deeper into the particular experience of being Muslim South Asian, and to contribute more literature to this under-researched area, this research focussed on the Muslim sub-group.

Exclusion criteria included the potential participant having had their diabetes healthcare primarily overseas and not having had extensive engagement with healthcare in New Zealand. Prospective participants with T1D were also excluded in order to go deep into similar experiences and to understand the specific health advice offered to those with T2D, which may differ from those with T2D. This includes that T1D is often diagnosed at a much younger age, in childhood (Derraik et al., 2012), whereas T2D is on average diagnosed around 46 years of age (Koopman et al, 2005). T2D are much less likely to have insulin injections, and that T2D can be reversible through lifestyle changes, whereas T1D is not (Ang, 2018; Steven et al., 2013; Taylor, 2013; Taylor et al., 2019).

Participant Demographics

Ultimately 10 SAMDNZ were recruited. Demographic information was noted through introductory phone calls in the rapport and relationship building process. This was important and useful in order to contextualise and situate participants' individual experiences where required. The sample was composed entirely of participants of South Asian ancestry, including 4 participants of Fijian-Indian origin, 4 Indian, and 2 Pakistani participants. Six of the participants identified as women and 4 as men. A broad range of occupations were represented in the sample including business owner, engineer, truck driver, seamstress, academic, stay-at-home mother, social worker, and retiree. Participant age was not collected, but rather the time of diabetes diagnosis, and how long they had been living with diabetes. This ranged from 5 to 30 years.

Cultural Responsiveness

This research focussed specifically on South Asian Muslim demographic participants and engaged multiple measures to ensure cultural responsiveness. Cultural consultation was sought through collaboratively discussing the project approach with a Muslim Imam (religious leader), as well as in consultation with a group of Muslim psychologists to ensure social and cultural sensitivity. After an initial introduction and chat, I sent a summary of my research to the Imam and Muslim Psychologists to review. The focus was on whether they had any concerns or considerations they wanted me to further take into account. The Imam had a call with me and we discussed his feedback. The Muslims Psychologists sent me emails with their comments. I discussed these recommendations with my supervisor and then worked to implement them in the research methodology, and to create a semi-structured interview guide (Appendix 3). Where more consultation was required, I went back and discussed these points further. Here, I describe a summary of the recommended implementations.

I was recommended to take extra initial time for rapport building, which was described as essential for when working cross-culturally. Hence, I made efforts to have longer casual discussions when initially meeting prospective participants, and also made time to have longer introductory phone calls. Before beginning interviews, I also emphasised initial connection and rapport building, sharing backgrounds, cultural relationships, family connections, history and upbringing. As a younger, male, Muslim researcher, I was cautioned to ensure sensitivity, comfort and respectful communication in interviewing elders, and Muslim participants who were women. To ensure this, I made time in my initial chats and introductions to understand what mode of interviewing would be most comfortable for the client. Three participants requested me to visit their homes for the interview. One of these participants also wanted their family to be present and involved in the interview. The remaining 7 participants all requested to do phone interviews, and all preferred to do calls with audio only, and no video.

Other key takeaways included to emphasise the confidentiality and privacy of the interview. This was especially noted in that if we met at a community event afterwards, that we did not have to tell anyone how we had known each other, that I would not say anything about the interview, and that they were free to share or keep their participation private. It was also recommended that participants were offered the opportunity to have the interview opened with a Islamic Surah (Qur'an section) or Dua (prayer/supplication). About half of the participants requested this, and all of them requested that the interviewer would do this. I found this helpful for building trust and safety in the relationship. Participants then conducted their interviews in English but were supported in their usage of Urdu and Arabic words and concepts, which were later translated if required in the analysis stage by the researcher. The cultural consultation also recommended clear referral pathways and resources for support as required. This included encouraging the participant to see the GP for further health support if required, referral to Imams, or a Muslim Social Worker organisation if further other culturally appropriate support was required. One participant did request support for a second opinion on their medications, and connected with support services by being directed to a Muslim GP, and another participant was supported with some resources on managing their chronic pain. I was informed of the importance of recognising how diabetes affects a person's whole wellbeing. This particularly included stigmatised dynamics such as the impact on relationships and mental health. Finally, following the interview, when the participants were offered their $40 gift card or small gift, it was recommended to communicate that the gift was from the University. This was in order to ensure that it was not perceived that they had participated motivated by compensation, but rather more respectfully as a token of appreciation on equal footing, with an appreciation of their desire to help their community. Three participants refused the gift card, 2 of them preferred the small gift of nuts, and 1 participant requested for their compensation to be donated to a food bank. Following the interview, participants were offered the opportunity to review their interview transcript or recording. Two of the 10 participants requested to review their transcripts, and 8 of the 10 requested to be sent a summary of the research once it had been completed.

Data Collection

Prospective participants who expressed an interest in participating were contacted for a brief initial call, where the researcher and participants introduced themselves, built rapport, and participant eligibility was ensured. The participant was encouraged and given the opportunity to ask any questions, and any concerns were discussed. If the participant was further interested in the research, the researcher talked through the information and consent forms. These forms were securely stored via the Qualtrics secure survey platform. If the participant was keen to participate, following consent, a time for the interview was arranged in the context that was most comfortable and convenient for the participant.

A semi-structured interview style was selected for this research. This enabled a framework of questions to explore participants' diabetes healthcare experiences, as well as the capacity to adapt in-interview to probe further in exploring and unpacking individualised experiences. This interview style is appropriate to facilitate qualitative depth of information, establishment of rapport, and flexible coverage of topics which may have more or less application to particular individuals (Murray & Chamberlain, 1999; Smith, 1995). Interviews ranged from 45 to 95 minutes due to the varied timeframes in ensuring culturally appropriate, sufficient rapport building time, and succinctness of participant answers. Each interview was audio recorded using either a passcode protected phone or computer. Each interview was then transcribed for analysis, with the support of audio-transcription software. Each transcript was then read through alongside its audio recording to make the necessary corrections to ensure accuracy and data integrity. Participants were offered 10 days to review and edit their transcripts, and 2 participants elected to do so. Of these, 2 participants requested a few minor amendments, which were promptly made. The transcripts were then approved and finalised for analysis.

Theoretical Framework

This research was informed by a critical realist epistemological position. This involved taking an ontological position of realism, which assumes that there can be one particular truth or reality to a situation (Crotty 1998). In this study this was the assumption that there is a particular reality of culturally competent healthcare practice that exists. The epistemological approach of critical realism then allowed me to take positions of considering diverse practices, conceptualisations, and ways of being of diabetes healthcare experiences, and contrasting this in relationship with traditional and mainstream biomedical perspectives. This enabled me to explore different experiences and critically develop themes that could be used to inform a reality of culturally competent practice in our healthcare systems. I used multiple theoretical models to support the conceptualisation of these dynamics.

Theory is the foundation for evidence-based health promotion (Fertman & Grim, 2016). Theory and theoretical frameworks can guide us to the basis of health issues, and help us to interpret the complex nuance of health-related behaviours and practices (Fertman

& Grim, 2016). Well-developed theory helps to explain the factors that influence the phenomena of interest, the relationships between them, and the conditions under which the factors operate and contribute to the phenomena (Nutbeam et al., 2010). This is important as how a phenomenon or health issue is conceptualised, will inform how it is addressed. In this diabetes healthcare research regarding South Asian Muslim experiences, the key theoretical frameworks that will be explicated to facilitate data interpretation and conceptualisation include: power and discourse theories (Foucault, 1972; Riley, Robson, & Evans,, 2021), healthism (Cheek, 2008; Crawford, 2006; Crawford 1980; Turrini, 2015), and relational healthism (Robson et al., 2022).

Discourses are considered to be social practices which contribute to form the objects that they describe, and can play a role in shaping disease experiences (Foucault, 1972). Foucault describes how objects can be constructed through discourses, and then realised through the assemblage of social practices including activities, objects, events and ideas (Prior, 1989). This can influence the development of a discourse of ‘truths’, essentially socially accepted ideas about the world. These discourses can circulate between people and shape inner-most thoughts and feelings, sense-making, self understanding, and ultimately can regulate the conduct of others. Considering discourse can then help us to understand what ideas people are using to make sense of themselves, and interpret the consequences for someone when they say, think, feel or enact these ideas. Foucault took the approach of radically decentering the subject.

Foucault describes this as part of a move away from sovereign power, towards disciplinary power, where people discipline and manage themselves through wilful subjugation to the scrutiny of experts, others, and themselves (Burr, 2015). Foucault particularly described how to this end, surveillance can be used as a form of social control. In this paradigm, the highest level is where this becomes internalised in that people come to monitor and control their own behaviours. This can be done through the consideration of what behaviours are to be ‘normal’. This directs analytical attention to the wider cultural sense-making within which people operate, which are often tied to dynamics of institutional power. In contemporary consumerist societies this is demonstrated in the common discourse of health as an individual responsibility, which is to be managed through individual lifestyle choices. The conceptualisation of power as disciplinary and productive highlights considerations of self-regulation, produced from and through discourse. In the context of health this relates to how discourse influences concepts of self control for lifestyle through being “disciplined.”

Crawford (2006) describes healthist discourses in particular as portraying individuals as self-responsible for their own health. This functions in a way to produce ‘moral’ citizens, who should engage in self-discipline and self-surveillance in order to actively identify and manage potential risks to their health. Health is assumed to be something that must be achieved. Moreover in a ‘health-valuing’ culture, people can self-define in relation to how well they succeed or fail in adopting healthy practices, and by perceptions of character qualities such as “discipline,” believed to support these healthy behaviours. However as in the case of chronic disease, disease or symptoms may develop over decades, hence requiring a vigilant, sustained, medically informed awareness. Crawford describes this as a health consciousness, wherein one considers that their health is in continuous jeopardy. Moreover, in a secular society that does not believe in eternal life or an incarnated one, the one-and-only life becomes everything. Hence health becomes the secular salvation, an attempt to delay the final destination and key to a life free from illness, pain and suffering (Crawford, 2006). This period of increasing medicalisation has been described as the beginning of a trend towards ignoring the socio-political causes of personal suffering (Cushman, 1995 as in Crawford, 2006). This paradigm of individual responsibility for health effectively establishes paradigms of neoliberalism's core tenets. This contrasts an autonomous, prudent and self responsible individual with the image of a careless and foolhardy one, with links made to the burden of social spending, where the virtuous are described as paying taxes to provide medical care for those with unhealthy lifestyles. This eschews the privileges that enable the ability to adopt healthy lifestyles, and seeks to leave behind the concepts of the obligation to care for the sick, to instead moralise health and ascribe personal responsibility. Character traits accounting for health would hence be self-control, self-discipline and will-power, with the contrast being lack of self control, letting go, enjoyment, pleasure and not worrying, often ignoring socio-economic influences.

Relational healthism (Robson et al., 2022) takes the construct of healthism further into considering how relationships also influence constructs of healthism. This construct seeks to address how classic socio-cognitive approaches can be limited in efficacy in practice by being overly individualistic (Hackett et al., 2018; Theis & White, 2021). In practice long term relationships can significantly influence health outcomes with significant variability (Holt-Lunstad & Smith, 2012; Kiecolt-Glaser & Wilson, 2017) attributable to relationship quality, satisfaction (Meyler et al., 2007; Robles et al., 2014), as well as attachment, communication and influence styles (Lewis & Butterfield, 2007; Pietromonaco et al., 2013; Tucker & Anders, 2001).

Data Analysis

I used Reflexive Thematic Analysis (RTA) to analyse the data. RTA is a method for developing, analysing and interpreting patterns across a qualitative dataset, and involves a systematic process of coding the data in order to ultimately develop themes (Braun & Clarke, 2021). These themes are patterns which are anchored by a shared concept, meaning, or idea. RTA has 6 fluid phases which I carried out (Braun & Clarke, 2006), at times moving back and forth between the phases to develop deeper analysis whilst continuously engaging in reflexive thought.

Phase 1 involved familiarising myself with the data. I did this by immersing myself in the data as I transcribed verbatim and read through the data. I also added translations as necessary when the participant incorporated colloquial Arabic or Urdu words. As I went through this process, I took notes in my reflexive journal of my thoughts and comments, and analytic ideas. The essence of phase one involves developing an intimate knowledge of your dataset, and beginning to critically engage with it, using an analytic orientation, and note making. I did this directly on the Microsoft Word program, adding my extra comments using the comments function on the document. As I did this I would often ask myself questions such as how or in what ways is the person making sense of their experience? How socially normative is this depiction? Or what other social conceptualisations does this perspective relate to? How would I feel in this situation, and how does this relate to my experience? What assumptions might be being made here? What kind of ‘world’ is being perceived, revealed or described through this account? How am I reacting to this, and why am I reacting in this way? What ideas are influencing my interpretation? In what varied ways can I make sense of this data? Following familiarisation with all the data, I then moved on to Phase 2, coding.

Phase 2 involved systematically working through the data, ‘coding’ it. Coding means to identify segments of data that appear potentially interesting or relevant for the research questions and applying succinct, analytically-meaningful code labels to describe them. These codes usually should connect to more than one segment of data, as the intention of coding is to begin to capture repetition of meaning within and across the datasets. These code labels are the building blocks of RTA analysis, from which themes will be developed later. I used the software Nvivo to code the data. Nvivo allowed me to automatically group, and then move in and out of viewing the collective codes within a specific code label across all of the transcripts. I considered this to be advantageous over coding on paper and having to manually collate codes. I took the approach of trying to code as many concepts as possible, with the plan to later refine them. Whilst doing this I was mindful to consider both semantic codes, which used explicit participant words, as well as latent codes which involved non-explicit meanings. These were important to consider when moving into Phase 3.

Phase 3 involved generating initial themes. In this phase, clusters of codes were compiled to identify shared patterns of meaning across the dataset. These ‘themes’ are code clusters which share a central, core idea or concept, which provided a meaningful angle towards addressing the research questions. In this phase, I focused on bringing together data in relation to the research questions. As I did this, I needed to be aware of moving beyond a "content analysis" type approach which is more descriptive. However, participants did raise specific suggestions for coping strategies which wove their way through the themes but seemed important in their own right as well. Accordingly, I have also provided a list of these strategies in Appendix 4. This initial theme development then enabled moving into Phases 4 and 5.

Phase 4 and 5 were quite fluid and interchangeable phases. Phase 4 involved further developing and reviewing the themes, particularly in going back to reference them against the full dataset to ensure nuance and precision. In Phase 5 these themes were further refined and consolidated, particularly through selecting data extracts, creating names for the themes, and defining each theme’s central organising concepts. This process involved making significant pivots, particularly in trying to consolidate the themes using common patterns within themes, and in ensuring each theme had clear and distinct boundaries, which some preliminary themes initially did not. This was also facilitated through back and forth discussions and feedback from my supervisor, who provided another perspective to support theme consolidation and refining. These processes enabled moving into Phase 6.

Phase 6 involved writing up the analytic narrative. Writing is a key component of the analytic process for RTA, as components of the analysis are in the writing around the data (Braun & Clarke 2021), and you are producing analysis as you are writing (Trainor & Bundon, 2020 cite from B&C 2021). In this phase I continued to move back to Phase 5, and reconsidering data extracts, theme boundaries, and consolidations. I strived to keep the focus on ensuring accurate telling and unpacking of the participants' experiences, and addressing of the research questions. Throughout the execution of these phases and in their writing, the RTA process was influenced by my positionality and perspectives. I ensured to monitor this impact through the process of reflexivity.

Reflexivity

Reflexivity is an essential part of RTA (Braun & Clarke, 2021). In RTA, the element of reflexivity enables the researcher to also become an instrument of the analysis (Nowell et al. 2017). Reflexivity in RTA involves critically reflecting on our roles as researchers, our research practice and process, and considering how they influence each other (Braun & Clarke, 2021). This challenges the view that knowledge production is independent of the researcher producing it, and is 'objective'. RTA considers that researcher subjectivity is not a problem to be solved or removed. Instead, researcher subjectivity is considered to be a key aspect of qualitative sensibility, and should be understood and managed as a resource for supporting analysis. Braun & Clarke (2021) describe that researchers must strive to understand and own their perspectives. This is important as data analysis and research always is underpinned by theoretical and personal assumptions. Quality RTA involves acknowledging these assumptions and reflecting upon them (Braun & Clarke, 2021). Hence this reflexivity involves the researcher turning their lens back onto themselves and taking responsibility for their own situatedness, and how this might affect the research setting, people participating, questions asked, data collected, and how this data is interpreted. This "locating yourself," essentially involves developing an awareness of your personal positionings in relation to the research and intersectional demographics. Who we are and what we bring to the research shapes and informs the research inevitably through what we notice, or not, and what is taken for granted.

In locating myself I recognise that I am approaching my research as a Muslim person of mixed South Asian-European ancestry, with one South Asian parent, and one European parent. On my South Asian side, all of my family members the generations above me have diabetes. On my European side, none of my family has diabetes. This context has given me certain observations and perspectives on diabetes and culture which it is important for me to be aware of. Hence I am able to be an insider researcher in the elements of being a member of the groups South Asian, Muslim, and a family member of people with diabetes. However I am not an insider researcher in that I myself do not have diabetes. This is important to reflect upon, and I recognise that this has supported me in recruiting participants, developing trust and rapport with my participants, it has supported me in developing questions, and understanding culturally appropriate approaches. In some ways it may have also limited participants' openness, as me and my family are members known within the community and so people may be worried to voice sensitive perspectives.

I am also a male in my late 20’s, able-bodied, cis-gender, hetero-sexual, middle-class, University educated, and born in New Zealand. This means it is important to be considerate of how certain understandings of those of different intersectional experiences, particularly such as of different genders, older ages, education backgrounds, and immigration statuses especially, may be inaccessible for me to fully understand. This also means that I should be sensitive in navigating these differences in ways that are respectful and appropriate. It also means that certain information may be inaccessible to me in general. For example, the literature and cultural consultation raised diabetes’ association with sexual impotence. However, this was a topic that I was not able to sensitively access and explore with participants in this research. To support and maintain this reflexive self awareness and consideration whilst carrying out RTA, keeping a reflexive journal is an important practice (Braun & Clarke, 2021).

A reflexive journal is a tool used to document thoughts and reflections through the RTA process. It can be used to support and clarify meaning making, as well as in interrogation, and critical thinking processes (Gerstl-Pepin & Patrizio, 2009). As I went through the RTA process, I kept a reflexive journal. This included my experiences, and how I reflected and made sense of them during the recruitment process, interview stages, reactions and reflections to participant responses, and thought processes during coding and analyses stages. There are no specific rules on how to structure a reflexive journal, and based on the stage of research I changed between segmenting it by bullet pointed conceptual reflections, segmenting by participant interviews, and then segmenting by date as I moved into the coding processes. I kept my focus on using the journal to support self awareness in my thought processes, unpacking my thinking, and critically reflecting on it. This made it a valuable resource to come back to and reflect upon the deeper assumptions that I was holding, how they could add value to, or constrain the research practice, and considering what I might have had certain responses, and how I might have responded differently.

Chapter 3: Analysis: Results & Discussion

Using reflexive thematic analysis, I developed four key themes from the dataset, as well as several sub-themes. This is displayed in Table 1. Theme one, *worry permeates the experience*, is comprised of the subthemes *diagnosis is often unexpected, shocking and upsetting*, *people worry about complications and their family histories*, and *worry about food*. This theme encompasses how participants worried continuously in their disease management, across the different facets and stages. Theme two, *diabetes is all about self control and discipline*, showcased participants internalising blame and shame dynamics related to sub-optimal disease management, which I related to neoliberal, capitalistic, socio-cultural norms. Theme 3, *we are in it together: diabetes, a family experience*, comprised two subthemes: *family helps* and *sometimes family makes it harder*. In this theme, I explore the dynamics of relational healthism through the lens of SAMDNZ. Family often supported participants in their disease management and lifestyle transition, and could also be the source of tensions and challenges. This was particularly evident in the desire to put family first, and through bringing “tempting” food into the house. Theme 4, *inadequate advice* comprised the subthemes *distrust and dislike of medication-first approaches*, *distrust of ‘big* *pharma' and the politics of diabetes* and *we are different, our needs are not being met*. Theme 4 encompasses the range of participants' unaddressed questions, worries and concerns that could or should have been addressed by sufficient medical advice. Each overall theme highlighted the multifaceted dynamics of the lived experience of diabetes healthcare and will be explored individually. As I explore the themes below, I will also discuss the nuanced interactions between these subthemes.

Theme 1 - Worry permeates the experience

Participants experienced dynamics of worry at multiple points of the diabetes disease experience process. This is demonstrated in the 3 subthemes, in that participants had significant worries at their diagnosis, participants worried about complications and their family histories, and participants worried about their food. Each of these stages had dynamics of worry expressed and embodied in different ways, which will be explored in each corresponding subtheme.

Subtheme - 'Diagnosis is often unexpected, shocking and upsetting'

For almost all participants, the experience of a diabetes diagnosis came unexpectedly. People were often diagnosed during investigation of another issue or a routine check up, and the experience often brought up challenging emotions that were difficult to make sense of. For instance, Samira shared:

> "Yeah, I was scared because it's not just for one or two months disease. It's a whole life disease. So I was very scared about this." [Samira]

For Samira, the duration of the illness in particular was scary. Rather than being a momentary nuisance, diabetes represented a lifelong disease, an ongoing, persistent challenge or difficulty. Her quote resonated with those of others who considered that as diabetes was a lifelong illness, they worried that their bodies were now dysfunctional in a permanent, life disrupting way, as Iqra shared:

> “[It is] just the fear of you know, not getting a long life. Because you are bound to get some failures in your system as well, you know, so that was what scared me.” [Iqra]

For many, their diagnosis was a pivotal point in their life. Participants frequently discussed diagnosis in relation to their life permanently changing, or being deficient in some way, as Iqra describes “having failures in your system.” Participants considered that they had to start worrying about their life, exhibiting a shift in awareness of mortality and wellbeing, and that their life could be shorter than they hoped for. This brought up a range of emotional challenges, as detailed by Noor:

> “The worst thing was being told that yes, definitely you've got diabetes, because you're showing high blood sugars… I knew that my family had it… But I had hoped that it wouldn't happen… I was sad, disappointed and probably angry as well. Because it meant there would be lots of changes that would have to be made about how I was going to deal with this horrible difficulty and yes, they took me some time. Those were the kind of feelings that what now you know, this is just horrible. I don't like it. I don't want it but it was inevitable...On an intellectual level I understood all that. On an emotional level I got upset about it. All these things that you have to live with now when will curve my life. You know all these things.”[Noor]

In this quote, Noor highlighted a range of challenging emotional experiences. Noor felt disappointed to be diagnosed, sad, angry and frustrated. This relates to how she described diabetes as being a “horrible difficulty,” that will “curve” or change her experience of life. Despite saying she understands it intellectually, she indicates that it is still upsetting emotionally. This is a testament to the psychosocial dynamics of a diabetes diagnosis. In a way there can be a mourning or grief experience for the past pre-diabetes life, as participants considered that now life would be different. In trying to find ways of coping with this emotional experience of a diabetes diagnosis, participants took various approaches. The experience of being diagnosed motivated some participants to take significant action to change their lifestyles and behaviours. However, other participants seemed to struggle in making sense of their diagnosis. Some preferred to try and avoid the difficult emotional experiences, or to ignore the idea that they might have diabetes, and what these implications meant. This was highlighted in Yaqub's conflicted experience:

> "It was a general checkup… So this, this time they did the blood test, and then they called me saying that there are some variations in the blood sugar, and then they check the history whether any of my family members had [diabetes]. And I did mention to them that my mother has [diabetes], on a precautionary basis they said that they would put me on Metformin. And I actually didn't feel like any diabetic, even today, I don't feel like being a diabetic patient. But again, because of that, that the numbers input into the bracket of having the medicines… So even if I am taking or not taking, I would not even feel like I'm diabetic, but the numbers are showing that, I'm diabetic.....It is really kind of conflicting, like you are looking at the numbers and saying everyone goes in the same box, but because of the system I am just following the numbers I'm trying to take those kinds of precautions. So I am at the moment probably having diabetes for 15 years but I never felt any kind of issue" [Yaqub]

Yaqub described not "feeling" like a diabetic patient, but because of being in a "numbers bracket" that he needed to take the medicine, which is "conflicting." This demonstrates the challenge some participants had with the traditional mainstream biomedical approach, which uses empirical metrics with categories and thresholds to determine early detection, and diagnosis. Yaqub described an internal conflict about his diagnosis, which fed into the way he engaged with the biomedical approaches, such as the idea of being "precautionarily" put on Metformin. The narrative that one might now be sick, unwell, or deficient in some way is difficult to make sense of without seeing any particular symptoms manifested. The medical discourses indicate that Yaqub should be worrying about diabetes; he did not feel this worry, yet still tries to "follow the numbers" and "take precautions" to respond to these discourses. Hence, although he is not actively worrying, his response is still a reaction located within the discourse of worry. Yaqub's quote also subtly highlighted the conflict of medicalisation and institutional distrust with the individual's experience. He feels a pressure to accept the authority of the medical system deeming him unwell, as this is incongruent with how he feels. This made it difficult to navigate and experience a lifestyle transition without a feeling of "tangibility" of the illness. The conflict of diabetes not feeling real could inform and support a position of ignoring the diabetes diagnosis. This involved essentially carrying on mostly as if it has not happened, and that no change is happening. This experience contrasted with those who did have very real tangible experiences of the impacts of diabetes demonstrated within their families. This highlights the importance of understanding people's embodied experiences of diabetes, as people felt and made sense of the experience differently.

Subtheme - 'People worry about complications and their family histories'

Many participants had family histories and experiences of diabetes, which seemed to inform worry and future concerns. As Fatima shared:

> "No she [mother] don't like changes… She don't like to change food, walk no. Yeah, she have a really bad diabetes. Then she have three times stroke, because she don't want to change anything. I see all this with my mother. That's why I tried to change myself too, to good for me…Diabetes is not good, no good. With diabetes you have to do changes. Otherwise you are going down and down and down and you go a lot higher and higher. And everything is just… you have a stroke… my mom had three times strokes, she die. Yeah, and she have a blood pressure so high. But sometimes she don't want to take the tablet." [Fatima]

Fatima described how her mother had "really bad diabetes" and did not "like to change" her food, engage in physical activity such as walking, or take medications. Fatima described not just her mother's medical history, but also her mother's responses. She described how seeing her mother's health issues and complications, such as having a stroke, influenced her in reflecting on her life and why she might change, rather than going “down and down”. Fatima framed diabetes as “not good, no good” and something she wanted to avoid through making changes. Whilst one way of interpreting this is that she altered her behaviour on the basis of genetic history, Fatima’s linking of her mother’s *personality* and *behaviours,* as well as her medical history invite another perspective that integrates relationality. These relational experiences strongly impacted several participants' experiences of their own diabetes and the worry they felt around it, as further described by Iqra:

“My brother actually passed away, with kidney failure... And I had just picked up now with a borderline case. It really scared me, like, you know, and then the doctor said join the team because my other brother had it, my father died from it. So the doctors was very cautious about it… I've lost two people in the family... And I want to be there for my grandchildren. Yeah, and in Fiji, if you go there, so many people have lost their limbs, and their eyesight, because of diabetes. They haven't been managing well. So I want to manage my diabetes well. So that I am able to you know, be mobile. Inshallah [God willing]…by looking at my family members who had suffered. My father died, he was just [young age], my brother died, he was [young age]. Very young age, they had their whole life in front of them, but they couldn't enjoy. My brother couldn't see his children getting married, my father couldn't see any of us getting married. He didn't see any of his grandchildren. You know, all those things affect us. When we will put that in perspective you know, we don't want to end up like that. It is important to look after yourself. There is a lot to gain by this. By looking after yourself. Because your family is going to enjoy your company, you know, enjoy the quality life that you give to them” [Iqra]

Iqra described seeing her brother pass away from kidney failure, her father dying, and seeing people in Fiji having serious issues from diabetes all “really scaring her.” These experiences inspired her to “want to manage her diabetes well,” because she “does not want to end up like that.” This is of immense importance to Iqra; as she described, her family passing away early meant they missed out on a lot, “they couldn’t enjoy,” “didn’t get to see any of us get married," or "to see any of his grandchildren." For Iqra, Fatima, and many participants, family experiences strongly shaped their worry, concern, and fear around their own diabetes. This tangible first hand knowledge, experience, awareness or understanding of what diabetes, and potential deterioration looked like, appears to be a strong healthcare facilitator. This worry seemed to inspire a strong motivation for change, as participants did not want to replicate the experiences their family members had, and this reality of diabetes was felt more impactful than the medical perspectives communicated. These family experiences can also present challenging psychosocial dynamics, which Samira described:

> "And one common thing in all my family is diabetes. My father and grandfather and me and my sister, they are very slim. They all are very thin. So, my uncle, he was having some bad issues. And my grandfather was also not well, he died. Yeah, he died after five to six years ago…. Sometimes when I get bored of this diabetes… I am taking sugar as if nothing will happen, like my dad, I just want to eat. So because it's not just one or two month disease, its an ongoing disease, I just want to eat, but sometimes it is very much worry for me that my uncle and my father, and my grandfather have, and they're all like, in a very bad condition, like, my father is cholesterol, my uncle has liver, fatty liver. So I don't want to go at that, go there. So sometimes it is worried sometimes it's not worried. Depends on the situation."
> [Samira]

Samira further highlighted how this worry continued to influence her behaviour even when she wanted to ignore the worry or implications of a diabetes diagnosis. Her Uncle and Grandfather both had health issues, but sometimes she gets "bored of this diabetes," and just wants to eat sugar as if nothing will happen. However it still "very much worries" Samira, as she "does not want to go there." This demonstrates how that relationality of seeing health issues in the family had a strong influence, even when participants might be struggling to keep managing their lifestyle changes. Samira also described this experience of diabetes as "a common thing in all her family," while referencing her family's thinness. This is interesting given common discourse which problematises eating practices more by the types of bodies doing the consuming (Trainer, 2017). The assumption is that people with T2D would be in larger bodies, which is not the case for Samira and her family. While many participants with a family history of diabetes were concerned about diabetes, some expressed a perception of the commonality of diabetes, hence making it “nothing new” or not worth worrying about. For instance, Sayid said:

> “A lot of people, about 90% of people have diabetes, so it was nothing new.”[Sayid]

In Sayid’s experience, diabetes is very normalised, common, and prevalent, to the point where it seems “90% of people have diabetes.” This perception of the high prevalence of diabetes, its normality, and Sayid’s experiences of diabetes within his family, has led to him considering that diabetes is “nothing new,” and hence not really something to worry about. Yaqub also described this dynamic in his experiences with his mother:

> “My mom had diabetes, and she was on tablets, and I was only worried about, what about my sugars, chocolates and all those things. But I didn't take much on board as well, I was taking my medicines, but again, I was doing my regular things as well. It wasn't the kind of, sometimes how someone might get shocked to know that they have cancer, I wasn’t, I wasn't in that state…diabetes is not too worrying. I had a little bit of knowledge of diabetes, yeah, you will be having the issues later on with this particular disease, but I wasn't anxious about it… she [my mother] was absolutely fine. I mean, she used to take her medicines on time and used to cut on sugars, but again, no one can resist Indian sweets… I didn't see any kind of worrying thing for her. And yeah, so, we hear that with diabetes, many people have other problems, but Alhamdulillah [praises to God] she didn’t have. She passed away about two years back at about 80 years of age Alhamdulilah. Yeah, so I wasn't that worried about having diabetes.” [Yaqub]

As Yaqub articulated, his mother's lack of diabetes complications taught him that "diabetes is not too worrying," and he "wasn't anxious about it," as his mother "was absolutely fine," and "passed away at 80 years of age." For Yaqub, that familial, experiential knowledge of the experience of diabetes outweighed the strength of influence of medicalised discourses and the communication of groups such as doctors, and influenced the beliefs that "there is not much to worry about." This then contributed to Yaqub "not taking much on board." Increased contacts with diabetes specialists may not significantly influence South Asians beliefs and perceptions of diabetes (O'hare et al., 2004), whereas the influence of peer support diabetes groups were much more resonant and significant (Douglas et al., 2011). These dynamics of worry, familial experiences, and disease awareness interacted in complex, nuanced ways to affect behaviour and experience for participants. For many, the increasing awareness and experience of complications and disease impacts in particular, influenced feelings of distress, concern and worry. Here Ishmael described some of his concerns:

> "Because I was thinking this can affect on my other body parts that came to my mind. Just like eyesight will be weak after some time and your kidney can be affected and those kinds of thinking, then I think it is better to start now. Because automatically it can attack these effects on other body parts. That was why it was in my mind it is better to change now. I think it is awareness, most people don't have that awareness of the side effects. They mostly think it is only one thing. But it's has a lot of side effects on your body." [Ishmael]

Ishmael described his worries that his "eyesight will become weak" and how this motivated him to make lifestyle change as "it is better to start now." When considering how some participants were motivated more than others by this worry of complications, it seemed this variation can be influenced by having an increased emphasis on the value of lived experience. As Ishmael described "most people don't have that awareness of the side effects," that although someone might *theoretically know* about the effects of a disease, but they don’t *really know,* or fully understand diabetes and it’s complications, until you really experience the disease's effects in yourself, or inside your family. Literature supports the complication of diabetes affecting eyesight in particular as being a significant concern and distressor (Coyne et al., 2004; Quandt et al., 2013), as Ishmael articulated. This worry about the future, and potential negative consequences, and suffering from having diabetes complications was highly prevalent. However, worry also permeates into the present moment and everyday behaviours.

Subtheme - ‘Worry about food’ continuously in their disease management.

Food was a particular trigger for worry amongst participants; many described worrying about food ‘all the time’.. For instance, Noor described how worries about food permeated her day-to-day experiences:

> “To be always be thinking about food. What it becomes with this sort of thing, you just become so focused, this is what it was like initially, sort of slow progresses, I can't eat this. I can't do that. Eventually, you sort of think I'm sure I can do this by eating this food, and not including this one here… And I love going to the functions but I just think it's so… you have to be highly motivated not to eat some of those foods, you have to think about what a beautiful biryani [flavoured rice] How do I eat that and what do I miss out in order to eat that so socially it is…. As you know, in our communities, people love you to have more. They insist on you having more. And it is absolutely lovely. You want to eat everything but you just know you can't do it. You have to be a little bit mindful of what you're eating so that you don't get.. and as for desserts well. You just have to sort of have a teaspoon… A few weeks ago I went and just put two tiny spoonfuls of dessert from here. That's all I want. And yet you wanted to eat a whole lot more… Emotionally I just had to think about it all the time. This was my common words I used to use and it's just so silly. Sugar! Now I've got to remember I can't eat that, and you'd go somewhere, like morning tea, people put on

> a morning tea, and you think I can't eat any of these things, or I've got to put a limit to what I eat." [Noor]

Noor described "always thinking about food," and how it intruded into how she really wanted to act and obstructed her. This hints at a series of conflicts. In saying "you want to eat everything, but you just know you can't do it," Noor demonstrated a conflict between desire and action. This conflict is also anchored in cultural dynamics; Noor specifically reflected on how "in our communities, people love you to have more, they insist on you having more," illustrating a conflict between community desires and a person's health needs. Finally, there is a conflict between the "beautiful food" Noor is surrounded by, that she "has to miss out on," and "have only a teaspoon of," and the foods that might be more ideal for managing diabetes. This gives a sense of the numerous tensions and dynamics that participants trying to manage their diabetes must navigate, often without receiving specific advice on how to do so. This demonstrates the wider community, societal, and familial influences that can conflict and inhibit attempts of participants to enact lifestyle change, and follow dietary and lifestyle recommendations. Noor tries to navigate these conflicts by rationalising how she can have what she really wants. She tries to swap foods, have smaller quantities, and find ways to meet her desires in a way that makes it work. Other participants made sense of this tension in different ways. For instance, Fatima described this experience as:

> "Don't eat this. Don't eat that, exercise and all that, you know, life is totally changed. You can't eat what you ate in the past, you can't eat when you have diabetes." [Fatima]

Fatima's expressed her experience of these tensions as a series of imperatives - "don't eat this" and "don't eat that," with having diabetes meaning that you have to "totally change" now, and leave behind the past behaviours. This left Fatima feeling restricted in what she can do and eat. This approach also came with a sense of mourning, for the loss of a person's pre-diabetes life, where the participant did not have to worry. Many participants particularly described strongly changing in their striving to reduce sugar, especially in places where it was easily reducible. Yaqub described this in his attempts to have less sugar in his tea:

> "I cut down the sugars in the tea. That was the first thing I did, because I used to drink lots of tea during that time. Tea and coffee at work and home. But then it was a difficulty…because I wasn't liking it, but I was wanting it…You see sweets and desserts are not a daily thing in our home. So usually it's not a daily thing. It is an occasional thing so if you're having sweets or desserts once a week or once in an occasion that wouldn't mind so I wouldn't cut on that anyway… My regular was at least eight to ten cups of tea at home, for morning and then back from home and then two to three cups of coffee at work. So I used to have about two teaspoons of sugar and then subsequently I cut to one, and then zero… I would rather cut this more and then try to reduce the number of intakes of my deserts. Yes tea was the main thing….My mom used to drink without sugar after she got diabetes. So I had been seeing that work my mom was doing. And then I thought that I would also discuss with other family members, the sugar, what sugar we use this, two sugar basically, because it's a daily routine of having so many cups of tea or coffee can at least reduce that much number of sugar intake. So that's the reason that I had that information on me, and next week seeing my mum, I thought the best and easiest ways to cut the sugar" [Yaqub]

Although having ten cups of tea, two sugars in each is not universal, sugar reduction was popular amongst participants, and seen as a manageable way to reduce sugar intake. Yaqub referenced again that he was influenced in this decision by relational dynamics, through seeing his mother's approach. Before diagnosis, many participants did not worry about sugar. However, the diagnosis of diabetes marked for many a clear borderline whence afterwards they tried to drastically reduce their sugar intake. Given participants' family histories of diabetes, it is perhaps surprising that they did not think about sugar prior to diagnosis. This may indicate that they did not have access to any pre-diabetes familial education or prevention programs. Almost all of the participants described trying to navigate this transition of lifestyle by trying to restrict themselves, yet still having small amounts of what they wanted, as described by Khaled:

> "And that doesn't mean I don't eat everything, I eat everything, but I eat it in a controlled manner… I don't have these sodas and drinks that are there, I don't have the samosas beyond a point if I have a samosa I'd probably have one samosa." [Khaled]

Khaled, in his worry about food, makes attempts to rationalise, trying to categorise foods, surveilling his own behaviour and trying to control it in various ways. He rationalises that some foods that he "would not have," like sodas, but that he "would have a samosa," but "probably only one." This indicates his consideration of a point that one cannot go beyond, where one must exert control, "eating in a controlled manner." This touches upon another strong pattern of trying to "control" oneself, and that these eating and weight surveillance behaviours are often coupled with concepts of discipline, responsibility and moral worth (Trainer et al., 2017).

Theme 2 - 'Diabetes is all about self control and discipline - don't be lazy'

Participants often expressed that the key to diabetes management was in being "controlled" and "disciplined," and that a key issue was being "lazy". This framing suggests an individualistic consideration of disease management, aligned with neoliberal healthism (Cheek, 2008). The inference of this discourse is that one should take personal responsibility to manage one's disease, regardless of the barriers, challenges, or other challenging situational factors. Participants took up this discourse in various ways; for instance, Ishmael explicitly drew on the language of control:

> "Some of them had good control, but some of them was not controlling. So it was making them quite weak to them. I mean, my mom was very, very big. And she was

> a heart patient as well. So that does not make it quite easy, and even it was affecting on the eyesight. Spending normal life, she was getting medicine for a long time. My Uncle was also getting medicine for a long time. Even he was getting so lean as well…But he must be doing that the side he was controlling the other side, he was controlling quite good. “ [Ishmael]

Ishmael and other participants often expressed this discourse of control and discipline as a dichotomy: you were either “controlling” or “not controlling,” disciplined or not disciplined. This dichotomization of control and discipline may make it difficult to see the nuances of the challenges of managing diabetes. Ishmael also referred to his mother as “very big,” and as “not controlling,” and his Uncle as having still requiring medication ‘even though he was “getting lean” and “controlling well”. This indicates the constructs of discipline and self control are also being influenced by weight and size based judgments and discourses. Trainor et al. (2017) has described that public and clinical perceptions of problematised eating are often less focussed on eating practices, but rather on the types of bodies doing the consuming. Moreover, they found that factors such as weight loss did not temper intensity and constancy of surveillance, because of its relationship to ideas of good citizenship and personal responsibility. As Ishmael describes, his Uncle was getting lean, however he still had to keep “controlling.” The ongoing nature and complex management of diabetes may make it especially susceptible to these discourses. This is further expanded upon by Khaled in relation to managing his medications:

> “As a diabetic…you have to discipline yourself… I used to travel… So for example, even if it is one o'clock in the night, and it's 24 hours, since I've had my medicine, I'm in a plane, so I would have my medicine and that really helped me. So having your whatever medication, especially if it is a diabetic and blood pressure medication, as much as possible at the right time, I found extremely helpful, extremely beneficial… It was really hard. Because imagine you're flying and at one o'clock, an alarm to get up you have your medicine and then try to go back to sleep and then you have a

> meeting in the morning. It's really difficult. But I had to adapt… it's a lot of discipline and getting a bit organized. saying, this is what I'm going to do, I have to do it." [Khaled]

Khaled described the disciplinary practices he needed to enact, particularly when encountering the challenge of trying to stick to a medications routine whilst travelling through different time zones. He described the challenge of keeping timings consistent when working all day overseas. This demonstrates that "control," in the context of diabetes, can be really difficult to do "perfectly." In reality, participants were presented with social environments and contexts with no diabetes-friendly options for eating, and difficult scenarios for consistent disease management. Whilst the notion of self responsibility for health is a mainstream contemporary biomedical discourse, that can influence modifying health behaviours (Crawford, 2006), it also does not take into account systemic barriers on the individual, and instead reductionistically focusses on neoliberal ideologies. This is particularly evident in the contexts where it is particularly difficult to stick to the routines, such as those Khaled outlines. These systematic challenges and barriers are important to consider to support participants to avoid feeling like they are failing if they can't follow their plan and control perfectly. When control is seen as dichotomously as done or not done, it does not account for nuanced human experiences. This framing, enabled by individualistic, neoliberal perspectives can be problematised as not enabling flourishing. These neoliberal ideologies frequently underlay a lot of the messages communicated by participants, which Khaled further outlined:

> "If I can share my information and, and something can be done to educate or to have a program, the such people who are not doing the right things…because it's not only they who are causing problems themselves, remember, they are a burden to the country, they are a burden to the health system, they are burden to the family, everything… So the more we can educate people, the more we can bring them to become healthier, prevention is better than cure isn't it." [Khaled]

This narrative describes that one must care to support one’s diabetes so one does not become a “burden.” This view sees people through an economic value of productivity, and disease as a cost, or loss of productivity. As Khaled describes, “a burden to the health system, the family, and causing problems for themselves.” A good neoliberal citizen would be responsible for their own health, and manage their disease to reduce their economic “burden.” This perspective aligns with capitalistic thinking, and can tend to be overly individualistic, not taking into account those systemic barriers, and dynamics of power and privilege. Unfortunately, when participants then struggled to manage their diabetes well, they often attributed internalising blaming and shaming concepts, such as being “lazy.” For instance as Sana described:

> “It's just laziness. pure laziness, that's all… It's more like, I'm just too lazy. Just too lazy on my part…I've got a gym just across the road. But I'm not really too into gyms” [Sana]

Sana sees her lack of action towards healthier behaviours as being “just because of pure laziness” and that she is “too lazy”. Sana allocates blame to herself for her inaction (not going to the gym even though it is across the street), and essentially describes it as a deficiency of self: if she was “better,” she would be doing it, or able to do it. However this does not account for the range of human experiences, variations, likes and dislikes. As Sana later mentions “I’m not really into gyms.” This then raises the question of what physical activity Sana might want to engage with, or what physical activity might be better suited to Sana’s tastes, desires and needs. However rather than addressing these questions, this self-blaming discourse simply ascribes this to a personal deficiency. Participants described these personal deficiencies in various ways. For instance, Yaqub describes how :

> “I controlled my diet at my pace, but you know, as they say that, you have to have this much portions, this many number of times, I really can't do it, is a big discipline… That kind of discipline is in European people more than any other ethnicity. What I mean to say [is that] Pakeha [New Zealand European] people or white people, they

> are more disciplined compared to Indians to have that kind of portions five times a day because I wouldn't have five times a day. Indians usually have three times a day and sometimes I miss them.” [Yaqub]

Sadly, Yaqub demonstrates how this blame and shame of the struggle of implementing significant lifestyle changes can manifest into internalised racism. Yaqub considers that “white people are more disciplined compared to Indians,” and that he “can’t do it.” He also describes how the recommended five portions a day does not work for Indians. This dynamic can stem from the influence of institutional racism, where groups such as Indians are pressured to enact strategies that work for European people and their requirements (Awad, 2013), rather than within frameworks that are well compatible with the individual’s cultural needs. These discourses often portray minority groups as deviant in relation to the dominant, privileged groups, and presents social inclusion as available to “well-adjusted,” assimilating minorites, with a limited scope (Awad, 2013). The resulting dynamic of self blaming and shaming dynamics do not seem to take into account the various institutional and intersectional barriers that can be significantly present. The experience of these discourses and lifestyle changes do not happen in isolation however, and family dynamics were found to play a significant role.

Theme 3 - ‘We are in it together: diabetes, a family experience’

The impact of family on participants' experiences of diabetes encompassed both support and challenges. As discussed in Theme 1, participants oriented to diabetes relationally. In this theme, I will explore other aspects of weaving together of family and diabetes experiences. Rassool (2004), outlined that the family unit is considered the primary social unit in Islamic society rather than the individual, and expressed the importance of this in healthcare. Participants did express a strong family orientation. The diabetes experience was often framed by participants as being “in it together” as a family: diabetes being managed, experienced and accommodated for within the family dynamic – for better or worse.

Subtheme - ‘Family helps’

The experience of the lifestyle transition of diabetes for SAMDNZ is often experienced as a family. Particularly as other family members, present and past, often had diabetes, discourses and practices around diabetes management were sometimes already present in the family. For instance Iqra details:

> “We have a family zoom meetings… On Friday it is about diet. So my brother comes on that and he gives us advice and we take it, some people some take it seriously some do not…every Friday he tells about the research, and what he has found out…. through that we also keep our diabetes in check… because your family has diabetes. It is very very important to keep the family together and talk about it. So everybody benefits from it. So the lifestyle changes everyone's lifestyle changes they do exercises they do they eat properly, they eat proper food and then you know they all concentrate on lots of veggies and fruits … Oh they [family] were very helpful, very encouraging… my husband who doesn't like walking as much used to come along with me to walk. And some days he would just initiate, oh lets go for a walk in the mall… Everybody has been encouraging.” [Iqra]

As Iqra describes “your family has diabetes,” and it is “very important to keep the family together and talk about it, so everybody benefits from it.” Given that in Islam, the family is the primary unit of society (Rassool, 2004), the management of diabetes is not an individual pursuit but a family one. In many participants' families, they were one of several people at various stages of diabetes diagnoses. Accordingly, and as Iqra's quote illustrates, families could thus be supportive of the unit and its management of diabetes by working through dietary and lifestyle changes together. For Iqra, family helped by supporting with understanding diet and lifestyle changes, accompanying her on walks, and encouraging her. Participants put a high value on these shared experiences, learning together, and supporting coping and the lifestyle transitions. In Samira’s instance:

> “So he was doing the work in the home. He was just letting me go outside and go for a walk [while supporting care of the baby]. And sometimes he used to go along with me in the middle of the work when I was really stressed, and I was having some faint issues, also. So at that time also he was supporting me to go out to with him in our daily life. He used to go with me in the night walk, like half an hour, for one hour, sometimes one and a half hour. And for the weekends, we used to go twice a day like for the lunch. We walk for one hour or two hours, and then came back for the lunch. So he was very supportive for this….he's worried about me, he was saying like, you should change your lifestyle, you should change your lifestyle. The main motive in my life has been my husband. So he was on a daily basis giving me a 15 minute lecture, you have to change your life, you have to change your life… He help me inshallah” [Samira]

For Samira, her husband was “the main motive in her life,” supporting her with encouragement, accompanying her on walks, supporting with the baby, and household management. Participants often described, like Samira, that the support was coming from a place of love, and care. This is further demonstrated in Khaled’s experience:

> “I remember coming back home, telling my wife about it [the diagnosis] and hearing nothing, except inshaAllah [God willing] we will take care of you, you take care of yourself, and I'll take care of the food. That's all I heard. But everybody was very quiet about it.” [Khaled]

For Khaled, in his moment of emotional challenge, his wife said nothing worrisome, judgemental, or anything that except how she would help take care of him. Many participants also described the family coming together to support the person diagnosed, as Khaled described, with the commitment to support and care for them. This again demonstrates how diabetes was perceived as a family challenge and an experience where they would work together in taking care of each other. This highlights the crucial importance of family as a significant healthcare facilitator for SAMDNZ. Family should be involved and supported to be on the same understanding as the person with diabetes, and a family-centric approach would be superior for diabetes improvement for SAMDNZ (Rassool, 2004). On the other hand, when family is not in alignment, this can also present certain challenges.

Subtheme - 'Sometimes family makes it harder'

With the closeness and interconnectedness of the South Asian Muslim family units, some participants described challenges that could arise such as Yaqub's experience:

> "You go to the supermarket you see some chocolates... Obviously you pick up chocolates for yourself and your home, and you have it as you have it. But now even then after having diabetes I have to get the chocolates for other people at home… If you are having one or two you are fine. But if you're going beyond because of taste, then someone from the family who are just sitting by you will just say enough, you are having too much. Now that sometimes you know it annoys, but you know then you will be stopped because of the love around you. Yeah I think but still the third one which is stopped, is taking a half rather than the third full one, because the cravings you can't stop it, so you are trying to pick the third one and you're being stopped, as a human you don't feel so bad but because of the concern which is shown to you, you also want to keep your your wish and their wish, and so you take the half of it and then stop basically. So that helps [Yaqub]

Many participants articulated a challenging tension around being diabetic and living with non-diabetic family members still eating sugar. As Yaqub described, even after being diabetic, he still had "to go and get the chocolates for his family," which can be difficult or uncomfortable. For many participants, having sugary foods present in the house made diabetes management difficult as they often struggled not to eat the sugary foods present, particularly when others were eating it. In saying this, Yaqub is demonstrating the relational healthism tension of family - which involves trying to balance being loving and supportive, with being controlling and restrictive out of care and concern (Robson et al., 2022). This is shown in the conflict of bringing contra-indicated foods into the house for the family, who support him lovingly by “saying enough, you are having too much.” This is a pragmatic act of service of love, as participants often considered that family members “need to look after each other,” although when Yaqub is stopped eating, sometimes “it is annoying.” This encourages a nuanced analysis of family dynamics, which at times can present healthcare challenges, such as the dynamic of exposure to sugary foods, as well as a facilitator in supporting lifestyle changes. Sometimes, these challenges are more clear, particularly for SAMDNZ women. For multiple participants who were women, family presented challenges to managing their diabetes through manifesting a pressure to balance family, work, homecare and health. This then culminated in a mindset of the need to put family first before oneself, for instance in Sonia’s experience:

> “I have a lot of responsibilities, looking after kids, and doing my job, running the home, doing everything, I have a lot of responsibilities that I have to do alone by myself. And that's why it's more stressful as well…that's why I'm not looking after myself. I am most looking after others and not looking after myself. There's also one reason. Working for others, doing other responsibilities and other work.” [Sonia]

As Sonia describes “I am looking after others and not looking after myself,” due to all of the responsibilities and duties she has. This presents a challenge to managing diabetes in the time and energy challenge of balancing conflicting obligations with limited time. When Sonia mentions she has “to do this alone by myself,” it highlights this is also likely contributed to by lack of support from her partner. These gendered dynamics can exacerbate existing challenges around managing diabetes for SAMDNZ women. Cultural migration often requires renegotiating familial and gender roles, as immigrants can encounter competing values and demands, such as between health, homecare and work (Spitzer et al., 2003). However South Asian migrants tend to maintain their gender roles (Talbani & Hasanali, 2000; Patel et al., 2012), and this can present some barriers in healthy lifestyle change (Strachan et al., 2015; Patel et al., 2012), and contribute to gender-health disparities (Strachan et al., 2015; Fikree & Pasha, 2004). Asian women in particular are often seen as bonded to the caregiving role ethnoculturally, due to the perception of their importance in transmitting cultural values (Spitzer et al., 2003). These gender roles can result in healthcare providers overestimating the capacity have in working with their health challenges (Gaveras et al., 2014). These gender differences was also raised by other participants, who mentioned an “advantage for men,” as “the female partner was more looking after the male partner.” Unfortunately the healthcare support and advice required to navigate these dynamics and many other challenges was often not available, unaddressed and inadequate.

Theme 4 - ‘Inadequate advice’

Many points arose in the interviews regarding not having sufficient advice to address various challenges, having unheard and unaddressed concerns, and various misinformed perspectives that had been facilitated by medical encounters. Hence this theme has been segmented into numerous subthemes to describe some of the nuances articulated.

Subtheme - Distrust and dislike of medication-first approaches

Participants almost unanimously described their medical encounters as being primarily and sometimes solely focussed on medication prescription. Many felt either totally unsupported with the desire to make lifestyle changes, such as towards healthier eating, or increased physical activity, and often described that they were led to believe it was not even effective, relevant, or had even been deliberately avoided.

> “Nobody says you [to] go down [in sugar, or blood glucose] diet, you do this? No. They just say to me diabetes is up, diabetes is down, diabetes is down or something of this sort. That is all they tell you. No one will tell you about the diet, what you can do to avoid it, only way they think you have to avoid it is to take more tablets. I got a telling off from him [doctor] last time. He said if you don't want to take the tablets you might as well go and see another doctor. His statement. Go and see another doctor if

> you are not happy because I'm not going to deal because I want your diabetes to come down, and the only way it can come down is through medication. That is what he told me." [Iqra]

Iqra described that all she was being told was 'diabetes was up, and diabetes was down', essentially being reported her blood sugar metrics. She thus felt she was receiving inadequate support about what diet to follow or preventative actions she could take. Moreover, her doctor would 'tell her off' for not being keen to continue to increase her medications, and that if she was not going to be compliant, she should go and see another doctor. This approach demonstrates an unproductive power imbalance and lack of shared decision making. Shared decision making (SDM) is considered "the crux of patient centered care," (Godolphin, 2009, p. 1) and has been identified as a key part of healthcare quality and safety. However it rarely happens, and is not often taught (Godolphin, 2009). Many clinicians suffer from a perception-reality gap, where they are practicing SDM, but are not (Stiggelbout et al., 2012). Iqra's experience seems to demonstrate a classic 'compliance' narrative of healthcare. This is where a doctor would tell you what 'you should do', and whether a person is considered a good patient or not is dictated by their following of this advice (Penney et al., 2011). However, improved patient shared decision making can lead to higher quality healthcare outcomes and environments (Elf et al., 2015; Godolphin, 2009). The addition of a dynamic of being or feeling "told off" likely further damages the therapeutic relationship, reducing shared decision making, efficacy of treatment, and increasing marginalisation, indicating a suboptimal dynamic of inadequate advice. Sadly, Iqra is not alone in this experience, and Sonia describes her experience of not feeling adequately supported:

> "Not really [given any advice about what to do]. But I heard some people they said, if the doctor guides you properly, you can have no diabetic too, after that gestational diabetic, if the doctor guide you properly. But my doctor, he didn't guide me properly…. They didn't say anything, they just start giving me medications. Nothing else….Nothing. I search myself, I just changed my diet myself. Because I was quite

> busy, working, studying, and housework. And I do a little exercise, but not very regularly. But if my doctor, he forced me, if you do this, then it will not be happening to you, then it will be more good for me and for my health… Whenever we go to the hospital specialist, they always refer to us to GP whenever we ask anything. They said, Okay, your GP will do it, your GP will do the follow up with these things. And that's the main reason, they should be encouraging us to do the right things, in the right way in the hospital as well... Yeah, my doctor, he didn't support me very well, actually….he should support me and give me more guidelines, how I have to do and how the things are going on. [Sonia]

Sonia raises another issue in the medical system, related to how hospital specialists ask participants to follow up with GPs, who then are not always equipped to provide holistic support and follow up. Hence the consequence of inadequate GP advice and follow up is that Sonia describes how she had to research about diet change, and that “I just changed my diet myself.” She described that the doctor “didn't say anything, they just started giving me medications,” and told her “nothing,” of what she felt should have been done. She articulated that there were clear preventative actions and knowledge that she could have been encouraged with to prevent developing T2D, but felt she was not given. This inadequate advice could be attributed to numerous factors. However ultimately this dynamic further marginalises, and likely influences the development of distrust and disenfranchisement. As this advice is experienced as inadequate, the doctor-patient relationship deteriorates, and when the advice and direction strongly, and even solely emphasises medication, the development of a dislike and distrust of medication was observed in participants.

SAMDNZ participants almost unanimously expressed a distrust and dislike for medications–this is particularly noteworthy in light of how participants described medication as being the primary suggestion they were given by healthcare providers. This seemed to be influenced from the relationship with the doctors, the lack of explanation, choice or options it was communicated with, concerns for side effects or inefficacy, beliefs that being more ‘natural’ was better, and concerns about being ‘reliant’ or being a “pill popper.” As Samira described:

> “Yeah, the medications I was taking. At that time, I was thinking like, I will take for some months, and then I'll stop it. And then, but after the one month, doctors were telling me like, you have to take [the medications] for the whole life. You have to. So I have taken one month, and then I stopped it personally, I did not say to anyone that I had stopped it. So I was not happy with the medications. Because it may have some side effects…. I was worried that it may have some side effects for my brain or for my health. I was worried about that. That's why I stopped it.” [Samira]

After Samira realised “you have to take medications for your whole life,” she stopped taking them due to concerns of side effects. She did not trust that the medications would benefit her overall, and disliked that they would or might have side effects. Samira also mentioned that the doctors were telling her to take the medications, and when she stopped, she did it “personally” and “did not say to anyone that I had stopped it.” This implies that Sonia knew that the doctors were wanting her to take the medications, and she didn’t want to tell them about her concerns. So, she stopped the medications without informing her doctors, likely as she didn’t feel her concerns would be adequately addressed. This demonstrates a lack of shared decision making, and a breakdown in the doctor-patient relationship, ultimately resulting in a suboptimal health outcome (Elf et al., 2015; Godolphin, 2009). These dynamics were further outlined by Ishmael:

> “Most of the time it is even written on the side of the medicine that's okay these are, or might be the side effects the medicine has. Just seeing the people, they are even getting the medicine, but they are not going back to normal life…. it was getting still sick more, getting more weak. Just day by day. So that was another things because if they are getting medicine, they should be getting fine, getting back to normal…If you talk only about diabetes, if somebody is getting medicine, and they can't leave the

> medicine, it's just like, not that they're gonna back to normal without the medicine, they need to go with the medicine. Okay, if I give you an example, if you are taking a Panadol, and then you will be fine. It's not just like that kind of disease to go with the body and you need to take the medicine, otherwise it will be not… going and going. And automatically if you are used to the medicine, and any medicine if you are used to, it is will be not as effective after some time. If you are used to, especially if your body is used to, then you will feel more bad if you're not taking the medicine.”
> [Ishmael]

Ishmael described his concern about the side effects, “on the side of the medicine.” He also raised an important conceptual concern: many participants considered that if they had to take their medications for life, that the medications were not really addressing or helping to resolve their diabetes issues. This concern was evident throughout participants’ accounts, progressed unaddressed, and inhibited participants' buy in to the treatment process and hence effective treatment. This also indicates a lack of shared decision making, influencing suboptimal care and health outcomes (Elf et al., 2015; Godolphin, 2009). Ishmael compared this perception of inefficacy to that of Panadol for a headache. Whereas Panadol aims to address the issue by reducing pain, with diabetes, medication is seen as not enough to allow a patient to return to a “normal life.” This example demonstrates the difference of consideration between medication use in treating acute issues and chronic lifestyle disease. If you have an acute issue, medication might seek to address this issue, and address problematic symptoms. However in the case of chronic disease like diabetes, this demonstrates the importance of the SAMDNZ person having appropriate engagement in the SDM process. This is as ideally they would have strong buy in to the concept of taking the medication, rather than not being willing to, or having significantly unaddressed concerns. Ishmael worried that if he was to keep taking the medicine “you will get used to it,” then “it will not be as effective,” and then “you feel more bad if you are not taking the medicine.” So more than just seeing the medication as ineffective, Ishmael sees that it can be harmful and you can become reliant on it and can make you weaker. However a couple of participants made sense of this in a different way. They seemed to accept the encouraged medical narrative without minding not understanding it, rather considering “if you have to take it (medication), you have to take it.” As Fatima described:

> “Then I thought, oh for the rest of my life I am taking this tablet. No stop. If I got no diabetes, then fine but diabetes, it is that kind of sickness is never go. Doctor told me this never go, once you take tablets the rest of your life you have to take this tablet….yeah, I don't think about I just… before I always think about, oh I have to wake in the morning, take the food then take the tablet, but I don’t think about anymore because this is now part of the life. Yeah. If you're not take it, you'll be going to diabetes high, you'll be sick, you got something else coming in your body. Just take it. That is all. It's not hard. I find before hard, but not that hard. Yeah. But just take it. Just like you are taking food every day….If you don't like to take, I worry it is harming me.” [Fatima]

Fatima described just accepting that she has diabetes “for the rest of her life,” that it is a sickness that will “never go,” and that she will have to consistently take medications now. This influences her perspective that diabetes is “part of her life” now, and that tablet-taking is just a habit in her routine. She considered that if she did not take the medications that she would worry “it is harming me,” and that “she will be sick.” This also relates to Fatima’s experiences of seeing the experiences of her other family members suffering with diabetes. It is also interesting to note that Fatima described herself as struggling with reading (literacy). An implication of this is that she would not be as exposed to other information sources and conflicting points of view online and in other materials. This may influence the tendency to accept what the doctor is saying in a more straightforward way as there may be less other alternative information sources accessible to Fatima. This indicates she may have more barriers to engaging in a SDM process. However despite seeming ‘compliant’, in taking medications, this still does not mean a person is satisfied, happy, or in agreement with their treatment process. These SAMDNZ participant experiences indicate that when prescribing diabetes medications, participants who did not understand their purpose or value, inspired a dislike or distrust of the medication, as the upside benefits were not as clear as the negative side effects. This management of a person’s understanding of the purpose and value of their medications, and their engagement in the SDM process, significantly influenced healthcare efficacy, and dynamics of “compliance.” However if these concerns are not addressed or respected, and still forcefully pushed, this can influence a breakdown of shared decision making, the doctor-patient relationship, and hence influence the development of institutional distrust.

Subtheme - ‘Distrust of ‘big pharma’ and the politics of diabetes’

A handful of participants communicated, in various ways, the belief and feeling that medical institutions seemed to not have their best interests at heart, and were subject to other influences. As Yaqub described:

> “With the numbers I'm finding I'm not able to manage but physically I'm not feeling any diabetes problems for myself… the number of intake of medicines are getting up because of the numbers… maybe 50 or 60 years back, there was no numbers at all. And people were living, but we can't challenge that. I mean, it is something, you know, conspiracy theories or something which we really can't get into or don't want to get into it. We have just followed the medical system. Or follow it or don’t follow it… the numbers have been fluctuating according to the pharmacy, pharmaceutical companies so really, you know, it's a game, or it's not a game, but you know, we are kind of the testing machine for the world… So now there's always a challenge of what new information is coming up, and who is behind it. So, we really don't know what politics is behind these numbers. But you have to follow it.” [Yaqub]

In this quote, Yaqub explored the ways in which being diagnosed with diabetes connects him to a broader system over which he has no control, and struggles to make sense of. Yaqub described how he felt controlled and led by the system, rather than being an active participant in it. He implied a mistrust of the pharmaceutical industry that "you have to follow" even though “the numbers keep changing,” and he can’t observe his symptoms. Yaqub worried that “it is a game,” and that “you can’t help it,” you are “part of the testing machine,” and that “there is always a challenge of what new information is coming up, and who is behind it.” The clear absence, however, is that Yaqub did not feel that he and his best interests were at the core of why they are “‘following the numbers.” In this system, feeling cared for and looked after did not feature significantly. As a result, participants sometimes questioned whose interests were being most served. This perspective may be especially provoked when people feel as though they are being given inadequate advice, in not being given all their options, or in having changes such as lifestyle change inadequately supported, as Iqra described:

> “What I found out was that they don't give you all the other options that you have. Later on, we found that there are so many things you could have done to avoid, I could have done so many things to avoid it, like my diet, dietary requirements, and I could have taken up some exercises and they don't, they just keep giving you tablets, which is not good at all, like he should have said to me, you know, this is these are some of the ways you can maintain your health and you can avoid diabetes, these are some of the things we'll do now straight away, that gave us you know, the diabetes testing kit. And also they put us in the you know pharmac trying to my own profits through these diabetics, what they do is load you with metformin that is so harmful to your body. So he actually later on when my diabetes…what happens with a diabetes, you know, you take Metformin after sometimes the Metformin doesn't.. it is not so effective. So they try that if you take something else with it, and then you try and take something else with it… and the metformin does not control it, you have to have all the other things going with it like the diet and exercise, which they don't advise. And sometimes I've noticed, you know, in among some of our relatives we

> have, we've lost our relatives, not only my father and my brother but on my other side of the the family I have seen my family dying, you know, dying because of kidney failure in other things because they're not taking.. they were not advised well. So what they should be doing that doctors should be trying to try and, you know, advise the patients, what measures they should take so that they're not put on medication, they never talk about it... But medication does not heal diabetes. It does not do much to diabetes. Just put it down for a few years. And then after sometimes it's not effective at all. [Iqra]

Iqra implied being discontent and disappointed that her treatment support was inadequate, and did not provide her with all her options. Rather that “they just keep giving you tablets, which is not good at all.” A strong feeling of institutional distrust was also communicated in the idea that Pharmac (New Zealand Government Pharmaceutical Management Agency) best interests were being put ahead of the diabetic individual and that they “load you with metformin that is so harmful to your body.” Moreover there is a sense of how this mechanism of institutional distrust can be passed on generationally. This is displayed through the strongly influencing and emotive experiences of seeing family members suffering and dying, because “they were not advised well,” and had insufficient support to make the required changes. This can also influence feelings of being a marginalised community.

Subtheme - ‘We are different, our needs are not being met’

The feeling of having your cultural perspectives and needs largely ignored, and at times dismissed, seemed to facilitate a counter response in participant’s of assuring, and asserting one’s difference, their truth. This underlay quite a few participants' experiences, and was communicated strongly and overtly by a few, such as Yaqub:

> “And in the standard six, or whatever is collected in New Zealand as well, even they say Indian, even if it is Pakistani, they put it in the Indian column, Sri Lanka and

> Bangladesh everyone goes in Indian column. How can they put? They should be Indian subcontinent if they're really looked into it. Because they can't generalize Pakistanis to be Indian, because the Pakistanis would hate them if they tell them that they are Indians, but they have that diet program that is Indian program for a Pakistani. What the hell? If we really look into it… The statistics which is collected in the health providers, or any agencies, if a person if they're asking me what ethnicity I'll say, I'm an Indian, but if a Pakistani will not say Indian, but they are put in statistics as an Indian….and the same goes with Bangladeshi. The same goes with Sri Lankan, then they should have an Indian subcontinent rather than Indian because statistics would show wrong information that there are 100,000 or 200,000 or 500,000 Indians but in fact, there are some Pakistanis in it, Bangladeshis in it. Even for political reasons the politicians would say that oh they are Indian so much but they are not, they are Pakistani. That is why there is no representation of Muslims in politics because of this statistics which is collected as Indians and generalized for everyone. Unless and until Pakistanis should be smart enough to say others and put Pakistani rather than an Indian tick on Indian, but are people are always dumb. Hmm. [Yaqub]

Here Yaqub expressed a sense of frustration of people's cultural needs and differences not being addressed. Instead Yaqub has experienced and perceived that "Pakistani, Sri Lankan, Bangladeshi, they put them all in the Indian column," and that this is something that would be "hated." This lumping of all people from South Asia into the category of Indian, unfortunately is a clear example of institutional racism. This is where the narrative is essentially that, "you are all the same," and intra-group differences and individualisation between cultures and people are disregarded (Narayan, 2000). This however is countered by the participant's reality that "we are different, our needs are not being met." Hence it is then unsurprising when interventions and treatment processes then proceed to be less effective with those whose cultural differences have been ignored.

Moreover, Yaqub reflected on how these dynamics of institutional racism also likely influenced having “no representation of Muslims in politics.” These dynamics likely facilitated and relate back to the dynamics of internalised racism Yaqub also expressed - that “Indians are not disciplined enough, that Pakeha are more disciplined,” that Yaqub later articulated. These racist dynamics are expressed and manifested in various ways, including a disrespecting, or marginalising of cultural foods.

One particular area in which participants experienced their cultural practices not being attended to related to food. Most participants expressed experiences, advice, and beliefs that their traditional foods did not fit within the paradigms of having a healthy lifestyle, and in diabetes management. For instance Sayid described:

> [Interviewer] “Do you think the advice is difficult to do or?”
>
> [Sayid] “Yes sometimes. They are going to say eat pasta, eat noodles, I can’t eat all those things.
>
> [Interviewer] “Yes I hear you. What do you like to eat?”
>
> [Sayid] “Roti and curry.”

Tragically, often the advice participants had taken away from the healthcare professionals was not just culturally racist, but blatantly wrong. Sayid has taken away that to manage his diabetes doctors would “say to eat pasta and noodles.” These high carb foods would be sub-optimal for diabetes management (Arora & McFarlane, 2005), and are simply foods from outside Sayid’s culture. Many participants like Sayid, have not been given an opportunity to collaboratively explore how foods like roti and curry might be accommodated to be more diabetes-appropriate. Processes such as SDM could have facilitated the co-development of a healthier diet that would have had improved health outcomes and been easier for the participants to follow. Instead they have come away with a perception that their cultural foods cannot be eaten. This makes advice “difficult to do” as it is less culturally appropriate (Penney et al., 2011), and likely erodes therapeutic relationship, and the trust in it. Although a few participants did mention more appropriate foods such as salads, it was quite surprising to see foods such as pasta, noodles and weetbix listed, and raises questions of what these interactions with medical professionals looked like. Sana details her experience:

> “Well, all my doctor gave me like a sheet, of what I should avoid and stuff. But being an Indian it is really hard. I just visited my doctor not long ago. And he's like, are you eating like a Chinese or an Indian? I'm like, what's the difference? The Indians eat rice and roti, and the Chinese just stirfries. It was hard to change, it is still hard to change my lifestyle. Because how many people want to cook for, my daughter's vegetarian, my son just likes meat and like some sort, and then my husband. But I visited the doctor for something else, for an injury a few weeks ago, and he really sat me down and said, you know, we need to change your lifestyle. And I'm like, I'll try, and he said, that's not good enough. There's no telling me anything. So I have tried to like eat more like stir fries and stuff. And but I do eat wholemeal, whole grain bread. So yeah, I haven't changed that. I still have like two Vogels in the morning, or now we only eat basmati which is good for diabetics. But now I cook brown basmati for myself. So I am trying to make those small, small changes. Yeah, I don't know what more I can do.” [Sana]

Sana’s doctor bluntly asked “are you eating like a Chinese or an Indian,” the implication being that eating like an Indian is bad, and eating like a Chinese person is better. Naturally this advice is not particularly helpful in guiding an Indian person, as Sana describes “it was hard to change, and it is still hard to change my lifestyle.” This demonstrates an underlying notion being communicated that Sana’s traditional foods don’t fit, and that participants are to let go of their inferior culture and foods and practice other superior cultures. This comes across more of a condescending or racist approach to participant’s South Asian cultures, rather than effective healthcare being able to meet participants where they are at in their cultural perspectives and health behaviours, and supporting them to make appropriate changes to improve. Other participants such as Noor also struggled with similar dynamics:

> “The problem was, they could not in those days show you how much of your daily food you could eat. They couldn't tell you how many chapatis you can eat… How do we turn that? Instead of having two scoops of mashed potatoes? Now how do I work the dal out?... it is quite challenging when you're a new diabetic… You just don't know until somebody can actually translate all that English information into your cultural foods….You just want somebody to tell you if you can have two chapati or four. I just wanted someone to actually just break it down for me, what would be easier, then I can learn to work with that… they were helpful in the sense that they could… I got a piece of paper, and they said how many pieces of bread I could have. So it was helpful in the sense of that.. but it was an English, a European diet, do you know what I mean? It was a Kiwi diet. I could have three portions of this and three portions of that. And I could weigh it and I could have so many portions of meat. It was all split up into different categories, which was fine when I did European cooking. Absolutely. I could manage to eat a chop, two roast potatoes, but not when it came to my Indian foods, it was just not nice… How do I eat my food, my cultural food kind of thing... I didn’t cook desi [natural/traditional], cultural foods as much because if I cooked those, I would eat a lot more of it.” [Noor]

Noor described experiencing a lack of support for managing diabetes with Asian foods, and feeling that her traditional foods such as chapatis did not fit into the prescriptive guidelines she had been given. This is important as it made lifestyle changes less accessible to Noor. Noor describes that how the nutrition information was communicated in Western categorisations made it harder to relate these distinctions to Indian foods, like curries. Whereas different South Asian groups traditionally use different food categorisations than carbohydrates, fats, and proteins (Chowdhury et al., 2000). This made it “always a challenge” to make sense of knowing how to eat cultural foods. This demonstrates how lifestyle advice that is not aligned or appropriate to participants' culture is very difficult to enact. Noor tries to navigate this by “not cooking desi [traditional] foods as much.” However this is a poor outcome as there was an important emotional component and connection to eating the desi foods too, which Noor continued to describe.

> “You wanted the taste of your own foods that you been brought up on... I wanted to have more of it, it was the taste, the feeling of fullness…emotionally it makes you feel good. You know, your dal, your rice and your curries…you tasted it and think mmmm it is so tasty and it takes you back to the places, like at this minute just talking about it. I am actually sitting with mom with checking when she's cooking the food and tasting it. Going back to places back when I was young to my grandparents, where we spend a lot of time with my Uncles, and they had us for the holidays, we'd go there and it's all this lovely food appearing.. So at this very moment I'm thinking of that big house with it. Every part of it. I'm thinking of the house, and the food, we would sit on the floor on a mat and that was how it was, sitting on a mat and we all would sit down all around them… And you know, I was like a young girl in those days. And so yes, it brings all those…it kind of connects you to your culture, and all the things that go with it… Yeah, brings you memories of families as well.” [Noor]

Whereas medical systems may try to frame foods in instrumentalist ways (Chowdhury et al., 2010), for SAMDNZ food is an important way of affirming cultural identity (Lawton et al., 2008; Sarfraz, 2015). Noor described wanting “the taste of her own foods” and that “emotionally it makes you feel good.” Noor vividly describes how the desi foods take her back, demonstrating the emotional importance of how they connect her to her culture and childhood, her home and her upbringing. Yet participants were getting the message that these traditional foods did not fit at all into diabetes management. This creates a conflict between the healthcare advice, and participant’s cultural needs, which is difficult for participants to navigate. Hence, finding ways to accommodate traditional foods into appropriate diabetes parameters can facilitate healthcare, and asking participants to shun their traditional foods altogether can creates lifestyle change barriers. Further to foods, participants also encountered challenges in changing physical activity patterns, and in finding appropriate, accessible options, for instance as Sana described:

> “I've got a gym just across the road. But I'm not really too into gyms, but I thought yeah walking is a start, isn't it?... I think it [the walking group] was in on the Facebook or something? One of the women's Muslim women's pages…. Yeah. And NZMA [New Zealand Muslim Association] helped arrange a fitness class too, and I used to attend that. Yes, that got me motivated. I thought if I start the exercise, fitness class, it might motivate me into giving walking and honestly, yeah, yes, thanks to NZMA…. it was a women's only class. And yes, that's what motivated me into going. I thought, okay, small steps, baby steps. So we attended on Tuesdays. And yeah, that was really good because I had hip pains, and in that class... My hip pain went away.” [Sana]

Sana and other participants described having access to options such as gyms. However many described feeling uncomfortable exercising with the other gender and having a preference for same-sex exercise groups. Sana describes only picking up physical activity when she came across a walking group on the “Muslim women’s Facebook pages,” as well as attending a women only “NZMA fitness class” which motivated her on her health journey. Similar to evidence on recruiting South Asian participants (Hussain-Gambles et al., 2004), Sana and other participants valued the social proof of attending exercise options recommended and attended by people they knew. They wanted options they felt would be aligned with their cultural and religious values, such as being same-sex, culturally-aligned, and in more social collectivistic group options, and were less willing and comfortable to access general exercise options. Partly attributable to the lack of available options, participants tended towards accessible physical activity options such as walking, however this presented other common barriers, as Fatima describes:

> “Yeah, just like I'm not doing regular exercise like a walk every half hour or 20 minutes. Yeah, then I have to do that every day. Yeah, in the winter you can’t do it. You have to give up, just do it in a driveway…..With a rainy day. With a winter day. Now I have a surgery but I'm not doing too much walking in wintertime because I just try going in the driveway. Sometimes go up to lights up there. But the summer time I'm doing a lot. Doing a nearby walk, me and my husband were doing a lot, 35 minutes around. Yeah. Every night. Because, summertime we got long day then after work, after dinner, you go to walk 35 minute then come home….. Just walk inside the house, on the driveway when the rain is stopped. Can't go far….I am just thinking myself of other things I can do inside the house to walk around or see the rain stop just in the driveway. Yeah, if it's not stopping the rain, just do it in the house three or four times. Just keep coming and going. After eating, because the Doctor they give the advice to after eating then walk. Don't eat and sleep, it is not good for the body. Diabetes patients it is not good for that. More walk, your blood is going good for walk.” [Fatima]

Many participants listed weather as a barrier to doing physical activity, which was also prevalent in the literature (Patel et al., 2015). However, it was unclear how this was exactly experienced. This is important as many participants had walking as their primary physical activity for diabetes management, Fatima for instance walking every day. Hence many experienced that “in the winter you can’t do it,” and participants resorted to just “walking in their driveway with a rainy day,” or often walking in circles in the house. This is a significant and problematic drop in physical activity, which has serious implications for diabetes healthcare and health outcomes. Fortunately with awareness and understanding of this dynamic, it can actually be easily prevented for great health benefits. For example, one participant reported a solution of walking in malls when it rained. Hence although doctors are giving advice to do physical activity, often the advice is inadequate as it does not account for the accessibility challenges participants faced.

Chapter 4: Conclusion

In this research I explored the lived experience of diabetes healthcare for SAMDNZ. In doing so I explored how SAMDNZ made sense of their diabetes in relational and cultural contexts, and the various healthcare facilitators and barriers they experienced. I used critical realism as an analytic lens, seeking to consider SAMDNZ diverse perspectives, conceptualisations, and experiences and using them to critique and inform what culturally competent healthcare might look like. I used reflexive thematic analysis, informed by theories of power and discourse, healthism and relational healthism to analyse participant responses. In so doing, I identified four key themes of the SAMDNZ lived experience of Type 2 Diabetes, which I have explored above. Throughout, participants spoke about the dynamics of worry they experienced regarding diagnosis, of complications, and of navigating food choices. Participants further highlighted a dislike and distrust of medication approaches, the importance of family-centric approaches, and the various ways they felt that their cultural needs were not being met. This was often associated with breakdowns in shared decision making processes between clinicians and SAMDNZ. The implications of these themes, and opportunities for improvements will be discussed in this section, to provide insights that can support clinicians and healthcare systems, to provide more culturally sensitive lifestyle support to SAMDNZ in their diabetes management.

The impact of the psychosocial dynamics associated with diabetes for SAMDNZ

Dynamics of worry pervaded and shaped participants' experiences of diabetes, and were deeply intertwined with their relationships, family histories and contexts. Participants worried that they had an internal deficiency, and in ways were damaged forever. People with diabetes may feel like their diagnosis is the first step in an irreversible decline, a turning point in life where vitality was being taken away (Lawton et al., 2006). Participants' accounts of their diabetes diagnosis experience reflected this point of no return orientation. More than being simply an individual experience, this experience was also tied to their relational and familial histories - the ways in which they had seen diabetes play out amongst their relatives over the course of their lives. These experiences significantly informed participant’s beliefs and concerns, for some they normalized diabetes and a lack of issues, and for others they enhanced an overall sense of unease, suffering, and inevitable decline. This difference related to the discourses within the family. In interpreting these discourses, Foucaultian theory describes radically decentering the subject, essentially looking past the family, to instead consider the wider sense making within which the family is operating (Riley, Robson, & Evans, 2021). This is because these discourses function to systematically form the object of diabetes within the family, and construct what is considered possible for how participants might be able to live (Foucault, 1978). These discourses then dictate how the idea of diabetes is put into practice, and used to regulate or support the conduct of the SAMDNZ, and what they “have to do.” This was demonstrated in that certain participants considered diabetes not particularly worrying, whereas others considered it a very serious, pivotal change in their lives. However these alternative responses can be still be considered either resistance or reactions to the dominant discourses. There may be several factors informing this dynamic. From a healthcare intervention perspective, these dynamics of familial diabetes discourses support the benefits of healthcare that connects those who have not had tangible personal and familial experiences with diabetes, together with those who have. This is demonstrated in South Asian diabetes peer support groups, which have been quite successful in the UK, where groups share their experiences, stories, and their numbers together, adding an experiential element of tangibility to the diabetes healthcare experience (Greenhalgh, 2005). The role of “numbers” in the diabetes experience had a helpful role for some in how they supported managing their condition, whereas for others they were difficult to reconcile as make sense of, as they portrayed that they were unwell despite people feeling well and asymptomatic. This demonstrated some of the dynamics of surveillance and medicalisation of people who might become unwell, and of healthism in the perceived responsibilities for a “good citizen” to act differently.

The worries participants expressed regarding topics such as future complications, and the impacts of various foods, demonstrated an uptake of healthist discourses. These worries indicated a dynamic of increased health surveillance, and a raised consciousness of concerns of diabetes, and its existential threat. This health consciousness can be understood, in a healthist society, a danger consciousness, where one is aware and sensitive to omnipresent potential harms (Greenhalgh & Wessely, 2004). In the case of diabetes, where there may be minimal symptoms or complications for years, healthism invites a medically informed and sustained vigilance. This constant vigilance worked its way into participants' diabetes experiences; for instance, many seemed to be "always worrying." This interacts with the influence of pharmaceutical industries, who are incentivised in influencing the extension of boundaries of diagnostic criteria for diabetes to expand their consumer markets to make more money (Greenhalgh & Wessely, 2004). This can be demonstrated in the medication first approaches participants experienced, as well as their concerns and feelings that pharmaceutical companies might be pushing diabetics to be taking more medications, with less emphasis on lifestyle changes, and that "the numbers keep changing." Participants also worried about future issues, but some struggled to reconcile this with not experiencing any symptoms or issues at the current time, which could relate to this expansion of diagnostic criteria. Moreover, if the SAMDNZ have familial discourses informing a lack of concern for diabetes and its management, it is also important to address these dynamics as well as other discourses that can impact diabetes management and outcomes, such as blaming and shaming dynamics.

Participants also struggled with dynamics of self-blame and shame associated with the struggle to manage diabetes and lifestyle changes. These discourses resonated with the dynamics of healthism, which consider that health is located in the individual, and is achievable primarily through managing one's lifestyle (Cheek, 2008; Crawford, 2006; Crawford 1980; Turrini, 2015). Healthism constructs health as a personal responsibility, which one must fulfill by self-managing your disease risk through self-surveillance and self-discipline (Cheek, 2008). This is seen as a defining quality of a ”good citizen” and people come to define themselves by how well they succeed or fail in adopting healthier practices (Crawford, 2006). This was demonstrated in how participants described their struggles as “I’m just lazy,” and about how they themselves, or as a group of people were just “not disciplined enough.” These laziness and self blame discourses can mask important cultural needs and intersectional challenges, such as not having culturally-appropriate exercise options available. Participants often mentioned self-discipline, “being a burden,” responsibility, and other related dynamics, and demonstrated internalised self surveillance behaviours. Theories of discourse can consider this a manifestation of power, not used by one group to overtly suppress another, but rather dispersed in a willingness to internalise the gaze of a generalised other who might be watching, and essentially inform the participants feeling like they *should be* eating a certain way (Greenhalgh & Wessely, 2004).

This language of discipline and laziness, and being a burden or not, can be seen as shaming language, designed to promote healthier life choices by communicating health risks and attempting to be a productive way of motivating people to act healthier. However, this kind of language often results in shame and stigma (Spratt, 2021), which has been observed in SAMDNZ in literature as a key healthcare barrier (Bradby et al., 2007; Singh et al., 2012), and was reflexively observed in this research during the recruiting phases. However this overly individualistic focus does not well address the cross-cultural dynamics that can occur in South Asian contexts, and the wider influences of health-enabling or damaging environments. This includes dynamics such as the omnipresence and easy accessibility of high sugar, contra-indicated foods in Western society, which in this research were often found to be being brought into participants' houses. These blaming and shaming individualistic discourses likely contribute to the immense psychosocial impact and challenge of diabetes detailed in the literature, including a depression prevalence of up to 40% (Egede et al., 2003; Egede & Zheng, 2003; Egede et al., 2002). Hence it is essential that unnecessary, burdensome psychosocial stress, such as shaming and blaming for the struggle of lifestyle change, is minimised in practice to improve diabetes management outcomes.

The importance of family-centred healthcare approaches

A key finding of this research was the significance of family in SAMDNZ diabetes healthcare experiences. Family was presented as a key healthcare and lifestyle facilitator. In Islam, family is considered the primary social unit rather than the individual (Rassool, 2004). Family members in South Asian households significantly influence diabetes beliefs, (Choudhury et al., 2009; Patel et al., 2015), often share the responsibility of diabetes self-management (Patel et al., 2015), and are reported as a strong support system for South Asians (Singh et al., 2012). This is associated with the dynamics of relational healthism, which characterises intimate relationships by shared lives and mutual support, and considers health then as a joint endeavor (Robson et al., 2022). Participant's families could be key healthcare facilitators, supporting participants with dietary changes, emotional support, and physical activity. Hence, it is essential to engage with SAMDNZ families. In practice in healthcare this can involve seeking to educate and support the whole family, and building upon the strengths and supports the family unit provides. This can also facilitate valuable work for diabetes prevention for at-risk groups too. However addressing families also highlights the importance of addressing the challenges family can also present.

In this research, family dynamics could also present healthcare challenges in three key areas. Firstly as aforementioned, relational healthism dynamics were demonstrated in how diabetes perspectives of the family were being shared between family members, and were informing their diabetes disease experience and management. Secondly, when family without diabetes brought sugary foods such as chocolates into the home, it made it more difficult for participants to manage their diabetes. Thirdly, particularly for participants who were women, there was a challenge in balancing family care, home care, and work responsibilities, with the pressure to put others first before looking after oneself. This can relate to how South Asian women often present with comparatively lower levels of physical activity relative to South Asian men (Fischbacher et al., 2004). There are a few key implications for this in practice. Practitioners can explore the dynamics of relational healthism for SAMDNZ, and the influence family is having on the capacity for SAMDNZ to manage their diabetes. The practitioner can seek to support coping strategies and plans to deal with the challenges that are presenting for the families in supporting the SAMDNZ, as well as seeking to understand and address how a patient's family histories might be facilitating psychosocial distress and other concerns. Moreover, some participants who were women reported having positive, influential experiences participating in activity programs run by the New Zealand Muslim Association and Islamic Women's Council. Funding and empowering these community organisations with the skills and capability of accessing and supporting provision of culturally appropriate, accessible services to SAMDNZ presented as an effective way that engaged some participants, and made lasting impacts on some participants lifestyles, with the potential to scale to further SAMDNZ.

The many unaddressed challenges and concerns: Chronic lifestyle disease requires culturally sensitive, ongoing, lifestyle support

Throughout the research, participants were identified having many unaddressed questions and concerns about their diabetes and its management. This is a significant healthcare barrier, as it influenced and produced dynamics that led to suboptimal diabetes management. For instance, a key barrier was participants not understanding the purpose of their medications, and having concerns about medication side effects. Due to this, participants often did not take their medications, developed a dislike or distrust of their medications, and an institutional distrust. Participants also did not seem to feel engaged in the process of shared decision making with their medical professional, which has been shown to be important for effective care (Godolphin, 2009). This was reinforced by often not feeling like their needs were being met, and some participants reported people were often being demographically miscategorised as Indian. Participants further reported confusion, questions, challenges with navigating food and incorporating traditional foods, and a lack of knowledge and culturally-appropriate options for physical activity. These unaddressed questions and concerns affected participants to manage their diabetes, their wellbeing and the doctor-patient relationship.

Penney, Barnes, & McCreanor, (2011) found in New Zealand that people categorised as non-compliant by doctors, reported that they were feeling their care was not culturally competent. Combined with participants' experiences as reported in my study, there are many implications here that can inform more effective culturally competent practice. It is essential that SAMDNZ understand the purpose and value of their diabetes medication, and that it is not going to "solve" or "take away" their diabetes. SAMDNZ need to have time to have their questions answered, and when they are trying to navigate the process of lifestyle change, need to have support to help them to answer ongoing questions. These can include how to incorporate certain traditional foods, as well as how to do physical activity when their preferred option of walking is not available, such as if it is raining. Moreover, support is needed for the advocacy and provision of more culturally appropriate exercise options (eg. same-sex exercise classes and facillites). In addressing these needs it seems that health coaches, community support workers, diabetes educators, peer support groups and the like can play a key role in providing ongoing support, and taking the extra time required to address such questions and concerns. Peer support groups for South Asian populations in particular have been demonstrated to be particularly effective (Douglas et al., 2011). These peer support group dynamics support referrals, which is shown to be more optimal for South Asian groups. They also reduce medicalised hierarchies, reducing the impact of institutional distrust, are found to have more of a 'doing' orientation, and are more aligned with narrative and experience sharing, which has all been found to be much more effective for South Asians (Chowdhury et al., 2000; Greenhalgh et al., 2005; Greenhalgh et al., 1998; Stone et al., 2005).

When considering that participants reported that they felt they had not received adequate advice, many participants were using various coping strategies and other techniques to address these needs. Detailing these was not aligned with the reflexive thematic analysis methodology, however this has been collated into a resource detailed in Appendix 4. The facilitation of sharing of these practical experiences could be supportive for SAMDNZ lifestyle changes and diabetes management. Resources like this can also support healthcare professionals with providing tactics for diabetes management to their SAMDNZ patients, as well as allied health professionals such as health coaches, diabetes educators, and peer support workers. These resources essentially include tactics commonly relevant to other SAMDNZ, which the people found worked really well for them, such as reducing sugar in their tea.

Study Limitations

There are a number of important limitations to acknowledge in this research. Firstly I struggled to recruit participants from different South Asian backgrounds. Despite contacting multiple community organisations, I was unable to reach participants from a wider range of cultural backgrounds within South Asia, such as participants with Bangladeshi or Sri Lankan roots. As I had used my personal connections to community organisations to support me in propagating the research recruitment, as well as in forums such as Whatsapp groups and my local community, this meant I was more likely to recruit participants from a similar background to mine. Hence there are likely perspectives of SAMDNZ that I was not able to access and explore, especially for those groups with less connection to the community groups that supported me such as FIANZ, NZMA, and the Islamic Women's Council. However given the small sample, a relative homogeneity of cultural backgrounds can strengthen the findings within this particular cultural context. There also may have been some other categories of participants that were not able to be accessed.

Further, I was only able to recruit one participant with diabetes who was using insulin. I noted in my reflexive journal that during the recruiting process I believe I was able to access people who were diabetic and using insulin, and the few I accessed were not keen to participate. This could be due to numerous important reasons. SAMDNZ who are using insulin may differ from this study's participants in that they likely have not been able to manage their diabetes as well, and so have had to progress to using insulin. They might also tend to have struggled with managing their diabetes more due to factors such as having more significant language barriers, being older, and being more likely to be a first generation migrant (Kim & Keefe, 2010; Sohal et al., 2015). These are all also factors that have been found to increase the challenge of recruiting South Asian research participants (Hussain-Gambles et al., 2004). Insulin-using people might also be more affected by a stigma of injecting medications in their communities (Singh et al., 2012). These stigmas and the shame of not being able to manage their diabetes, the stigma of injecting insulin, and other associated dynamics, likely influenced these people to be less willing to participate in this study. Further research might find ways to better access these insulin-using SAMDNZ.

Numerous participants in this research also mentioned that they had previously been involved in other research as well. This might mean that they could have been more open to participating in research due to their past experiences. It might also mean that this might be a more accessible population subgroup of SAMDNZ, and a sub-group that might be managing their diabetes relatively well, and hence felt good to talk about it, rather than feeling like they were suffering from significant complications, as well as guilt and shame. Hence despite successfully recruiting, this does not mean that all of the diabetes healthcare experience was accessed in interviews with the recruited SAMDNZ.

Another limitation was that in the context of direct interviews, with an unfamiliar interviewer of a younger age, it is likely that certain sensitive aspects of SAMDNZ experiences were not accessible. This may include topics such as sexual impotence, relationship dysfunctions and challenges, and very controversial thoughts and experiences within the community. This was reflexively noted in a few of my interviewing experiences. During cultural consultation, the Imam (religious leader) advised me that a lot of divorces were happening attributable to sexual impotence and dysfunctions associated with diabetes, however no participants opened up regarding these dynamics, and it was not in scope as being appropriate to ask directly. One participant did mention having issues with their partner not supporting them, however did not want to further discuss that topic, and requested that we continue with another topic. Finally, a couple of participants mentioned statements such as ‘oh I shouldn’t say’, and referenced knowing members of my family. Hence this demonstrates that certain sensitive and controversial topics and perspectives may not have been accessed, and this should be taken into consideration while interpreting the finding and implications of this research.

Summary

In this research I explored the lived experiences of diabetes healthcare for SAMDNZ, how they made sense of their diabetes in relational and cultural contexts, and the various healthcare facilitators and barriers experienced. I found a significant impact of psychosocial dynamics such as worry, which is important to acknowledge and address in care. The importance of taking a family-centric approach, building upon the family strengths and supports and to be mindful of the challenges family can present at times, was also highlighted as important. Finally, I also described the need for more collaboration to address SAMDNZ unresolved questions and concerns, and the need for more effective shared decision-making procedures. These findings aim to support better healthcare and diabetes experiences for South Asian Muslims in New Zealand, to support progress towards a more culturally responsive and equitable Aotearoa.

Table 1

Reflexive Thematic Analysis Themes Summary

Theme	**Subthemes**
Worry permeates the experience	Diagnosis often unexpected, shocking and upsetting People worry about complications, and their family histories Worry about food
Diabetes is all about self control and discipline - don't be lazy	
We are in it together: diabetes, a family experience	Family helps Sometimes family makes it harder
Inadequate advice	Distrust and dislike of medication-first approaches Distrust of 'big pharma' and the politics of diabetes We are different, our needs are not being met

Table 2

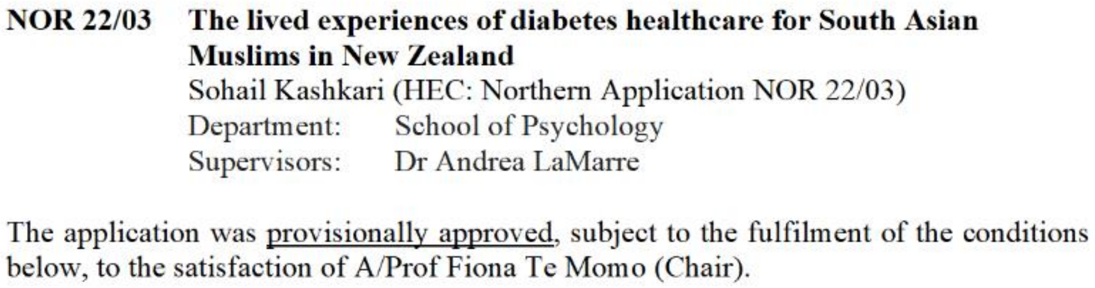
Participant Information Summary

Participant Pseudonym	**Recruitment Pathway**	**Cultural Background**	**Identified Gender**	**Interview Mode**
Sayid	Mosque	Fijian-Indian	Male	Interviewed with family at home
Khaled	Whatsapp group	Indian	Male	Phone interview
Noor	Referral, Whatsapp	Indian diaspora	Female	Phone interview
Ishmael	Mosque	Pakistani	Male	Phone interview
Yaqub	Mosque	Indian	Male	Phone interview
Fatima	Referral from IWC	Fijian-Indian	Female	Interviewed at home
Iqra	Referral from IWC	Fijian-Indian	Female	Interviewed at home

Sana	Referral	Fijian-Indian	Female	Phone interview
Samira	Whatsapp group	Indian	Female	Phone interview
Sonia	Referral, Whatsapp	Pakistani	Female	Phone interview

Appendices

Appendix 1

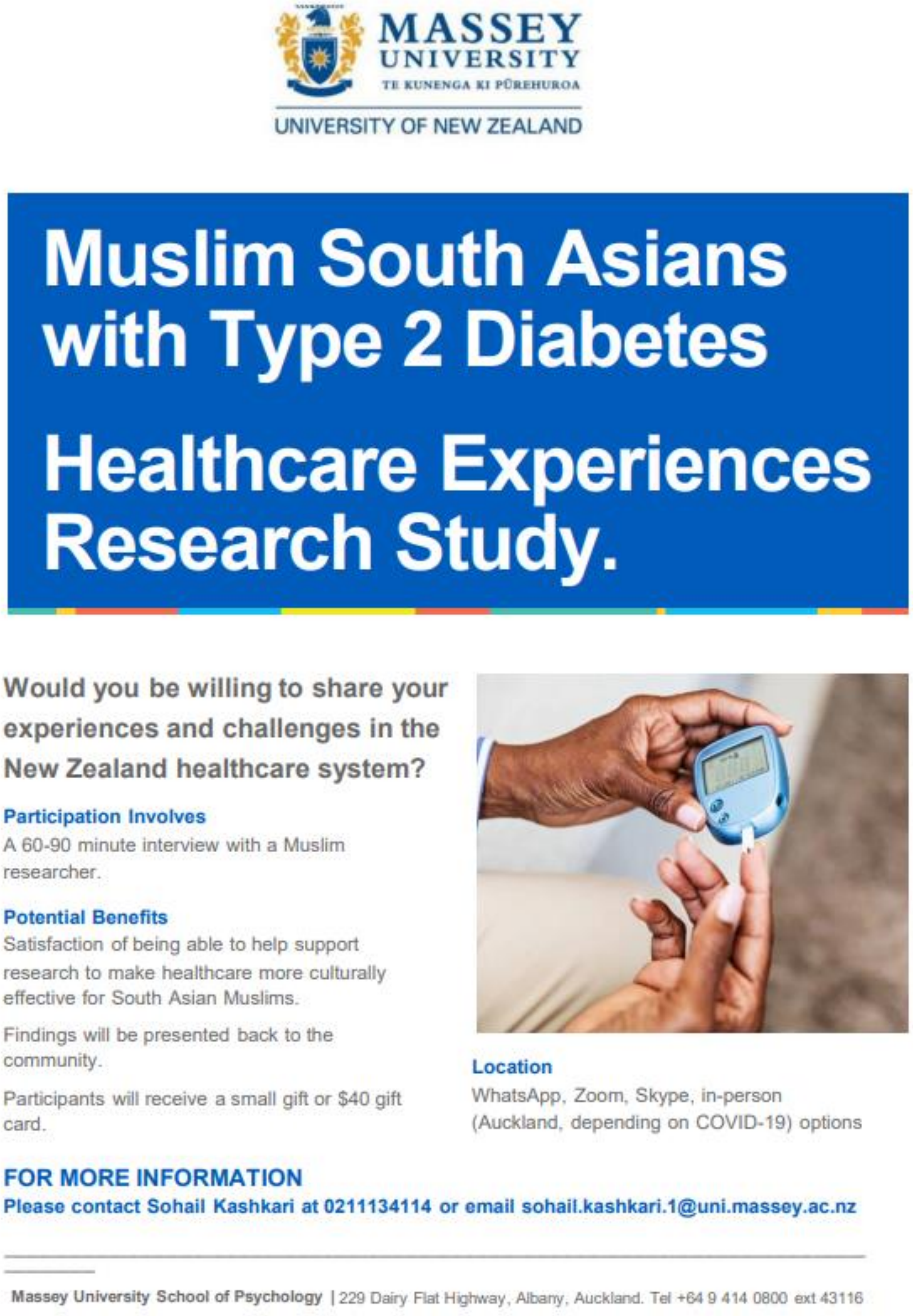


NOR 22/03 **The lived experiences of diabetes healthcare for South Asian Muslims in New Zealand**

Sohail Kashkari (HEC: Northern Application NOR 22/03)
Department: School of Psychology
Supervisors: Dr Andrea LaMarre

The application was provisionally approved, subject to the fulfilment of the conditions below, to the satisfaction of A/Prof Fiona Te Momo (Chair).

Appendix 2



MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

Muslim South Asians with Type 2 Diabetes

Healthcare Experiences Research Study.

Would you be willing to share your experiences and challenges in the New Zealand healthcare system?

Participation Involves

A 60-90 minute interview with a Muslim researcher.

Potential Benefits

Satisfaction of being able to help support research to make healthcare more culturally effective for South Asian Muslims.

Findings will be presented back to the community.

Participants will receive a small gift or $40 gift card.

Location

WhatsApp, Zoom, Skype, in-person (Auckland, depending on COVID-19) options

FOR MORE INFORMATION

Please contact Sohail Kashkari at 0211134114 or email sohail.kashkari.1@uni.massey.ac.nz

Massey University School of Psychology | 229 Dairy Flat Highway, Albany, Auckland. Tel +64 9 414 0800 ext 43116

Appendix 3

Draft Semi-Structured Interview Guide

Qualitative Interview Introduction

Begin with rapport building (whakawhanaungatanga). Can discuss our shared backgrounds, cultural relationships, families, the areas we are from, and where we have grown up.

Ask the participant if there is any particular **Surah or Dua** they would like to start with, or if they would like me to do one?

Goal to explore [can share with participant before beginning]: what your experiences have been with diabetes healthcare in New Zealand.

Explaining interview goal and way the interview will go.

Length 60-90 minutes.

Emphasize confidentiality and privacy. If we meet at a community event afterwards, you don't have to tell anyone about how you know each other. Ensure support person is held to privacy too.

Confirm participant has read and understood the information sheet.

Take time to allow for any questions, and check comfort and that they are happy to proceed.

Research Question: What are South Asian Muslims in New Zealand with Type 2 Diabetes' lived experiences of diabetes healthcare? [Sub research questions below]

- **Sub-question 1**: How do South Asian Muslims experience their diabetes discovery and diagnosis?
    - How did you first find out that you had diabetes?
        - What happened?
        - What were you thinking or feeling at the time?
    - Did your life change after the diabetes diagnosis? If so, how?
    - [If they found out they had diabetes while at the doctor] What happened during your visit to the doctor?
        - Did the doctor give you any advice? What did they say?
        - How did you feel during the experience?
- **Sub-question 2:** How do South Asian Muslims experience the lifestyle transition of having Type 2 Diabetes?
    - What was your experience with implementing the doctor's advice into your life?
    - Was there anything that you changed after your visit to the doctor? [Other areas of life too]
        - [If yes] What influenced you making that change?
        - [If no] Did anything get in the way of making changes?
    - Did anyone or anything make these changes easier? If so, who/what?
        - Prompts: family, broader community, cultural foods?
    - Did anyone or anything make these changes harder? If so, who/what?
    - What was it like going to social and community functions?
        - How did you --- cultural foods?
    - Did the doctor recommend any medications? How did you feel about taking/using them?
        - [Prompt: can check if that has changed over time?]

- **Sub-question 3:** What are the diabetes healthcare barriers and facilitators for South Asian Muslims in New Zealand?
    - What is diabetes to you?
        - How did you come to this understanding?
    - Do you ever struggle to manage your diabetes?
        - [If yes] When you are struggling to manage your diabetes, what is happening?
            - What are you thinking/feeling when you are struggling?
            - What are some of the things that help you when you are experiencing those feelings?
    - When you are managing your diabetes well, what makes that possible?
        - What are you feeling/thinking when you are managing it well?
        - Is there anything you find helps you find helpful in managing?

Scenario: [script: I am now going to share a brief hypothetical scenario with you and ask you a few questions about what would happen next]

[Ali/Yasmin/other pseudonym] goes to a family and community meeting. Everyone is sitting around chatting, and food is being served. Some of the traditional food are fried and some are sugary, but all of them taste a bit like home. [Pseudonym] knew this situation was coming, and their family knew [pseudonym] has diabetes. What happens that night? What is that person thinking? What are they feeling? What happens? What are people around them doing?

Advice for others: [script: to conclude the interview, I was wondering—based on what we've talked about today and your experiences] What advice would you give to a South Asian Muslim who is about to be diagnosed with diabetes?

Check in: If needing any support or resources based on content of interview. If they desire to have more culturally-appropriate resources for diabetes, to share with them.

Interview closing: Thank them for their time. Explain that they will get a chance to review the transcription or recording if they like. Do they desire to, and if so what would they prefer?

Appendix 4

Coping Strategies & Advice from SAMDNZ

- Making a good routine makes it easier to change, doing planning in advance
- Considering: Why can’t I do it? If others can do it, I can
- Taking your medications out with you. Put the tablet on the table during mealtime to try help prevent forgetting
- Using a smaller plate for meals
- It all gets easier adapting changes as time passes
- Get friend to do exercise together with you, and try make it part of a routine
- Going for walks after having sweets to keep blood sugar down
- Takes high fibre bread/naan when going out and at others houses
- Having meat with rice/curry/carbohydrates to slow their breakdown and reduce blood sugar spike
- When feeling that you have to take desert, sharing it with your spouse/family
- Have healthy snacks, like vegetable sticks and dips
- Have curries with salad
- Include more fibre in diet
- Considering glycemic index in foods
- Take food home from events, rather than trying to eat it all there
- Take care from added sugar
- Eat higher fibre bread
- Try to take starch out of the rice, wash it
- Try get as much fiber as you can, eat vegetables.
- Using a diabetes resource book with food pictures with those who struggle with language or literacy
- Seeing TV material about diabetes was helpful and motivating
- Don’t snack while watching TV

- Reading and researching online
- Look at different diabetes websites
- Taking extra time to discuss with relatives who are doctors/health professionals helped people
- Reading books about diabetes
- Sleep is important
- Have a balanced life: sleep, rest, work
- Have programs in the mosques – benefits of talking to others
- Picking up an exercise habit, which makes you then want to eat healthier too
- Taking food home from events to eat next day, instead of feeling the need to eat it all right then
- Considering that looking after your diabetes is also about looking after your internal organs

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