Towards improving diabetes care among Arabic-speaking background immigrant population: examining cultural and health beliefs

A thesis submitted for the degree of
DOCTOR OF PHILOSOPHY

By

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Dedication:

This thesis is dedicated to my family

Declaration

This thesis contains no material which has been accepted for the award of any other degree or diploma in any university or other institution and affirms that to the best of the candidate's knowledge the thesis contains no material previously published or written by another person, except where due reference is made in the text of the thesis.

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Glossary of Abbreviations

ASB	Arabic-speaking background
BMQ	The Beliefs about Medicine Questionnaire
BMI	Body Mass Index
CSM	The Common Sense Model
DDS-17	Diabetes Distress Scale
DM	Diabetes Mellitus
DSM	Diabetes Self-Management
DSME	Diabetes Self-management Education
EMG	Ethnic Minority Group
ESB	English-speaking background
FHL	Functional Health Literacy
GPs	General Practitioners
OHAs	Oral Hypoglycaemic Agents
SDSCA	Summary of diabetes Self-care Activities
T2DM	Type 2 Diabetes Mellitus
EM	Explanatory Model
HbA_{1c}	Glycated haemoglobin
HBM	Health Belief Model

Abstract

Type 2 Diabetes Mellitus (T2DM) is currently recognised as a major health issue. Individuals with T2DM are at higher risk of developing a number of microvascular, macrovascular and neuropathic complications. Globally, the prevalence of T2DM is increasing at epidemic rates and it is reaching alarming levels worldwide.

Published data confirms that management of diabetes is more challenging among minority ethnic groups, compared to the general population, for several reasons: higher diabetes-related morbidity and mortality rates, worse glycaemic control, underutilisation of medical services, lower adherence rates, cultural and communication barriers.

Understanding the relationship between patients' cultural and health beliefs and diabetes self-care practices such as dietary behaviours, exercise, self-monitoring of blood glucose and medication-taking has been shown to provide an opportunity to inform development of culturally appropriate diabetes education. Drawing on substantial evidence documenting its effect on clinical outcome measures, the provision of culturally appropriate diabetes self-management education is widely acknowledged as an integral component of diabetes care among ethnic minority groups. Currently, there is a large body of research on cultural beliefs and diabetes experiences that have been conducted among ethnic minority groups such as Latinos/Hispanics, African Americans, Asians, Pacific Islanders and others. Anecdotally, it is known that ASB immigrants have a strong sense of cultural identity, adherence to their traditional and cultural norms and do not assimilate easily into western host society. There is, however, little research conducted among Arabic-speaking background (ASB) immigrants. Diabetes experiences from the perspective of ASB immigrants in Australia were needed to be explored to identify difficulties in performing self-management activities and to recognise modifiable health beliefs that are associated with non-adherence behaviours.

This research, through the two stages reported herein, has investigated ASB immigrants' views and beliefs about diabetes, identified issues in quality use of medicines, explored factors that influenced health care seeking behaviours, assessed diabetes learning needs and preferences, and measured the relationship between health beliefs, adherence and glycaemic control.

Prior to this study, little was known about the diabetes profile, cultural and health beliefs and barriers to diabetes care among ASB immigrants in Australia. The results obtained highlighted poorer knowledge about diabetes and its management among ASB immigrants, compared to their English-speaking background (ESB) counterparts. Arabic-speaking background immigrants intentionally delayed accessing medical services when they experienced classical signs of diabetes, so diabetes complications were already developed at the time of diagnosis for the vast majority of them. Diabetes control of ASB immigrants was suboptimal and they were significantly less adherent to all aspects of diabetes self-care activities (dietary behaviours, exercise and physical activity, foot care, SMBG and medication-taking) than the ESB group. The negative health beliefs held by ASB immigrants were associated with non-adherence behaviours and with worse glycaemic control.

This research has made a significant contribution to diabetes treatment adherence research in an ASB immigrant population. Findings of this research provide detailed information about the interplay between an individual's cultural and health beliefs, adherence behaviour and glycaemic control. Such understanding, which has previously been lacking, may assist diabetes health professionals in planning culturally appropriate diabetes interventions and establishing best practice for this ethnic minority group.

Communications arising from this research

Journal Publications (In preparation)

1. **Alzubaidy H,** Marriott J, Stevenson V, Steele C, Chapman C. Factors learning needs and preferences of Arabic-speaking background patients with diabetes. (for *Diabetes Educator*)
2. **Alzubaidy H,** Marriott J, Chapman C. Illness and treatment perceptions, adherence, and glycaemic control: a comparison between Arabic-speaking and English-speaking patients (for *Diabetes Care*)
3. **Alzubaidy H,** Marriott J, Stevenson V, Steele C, Chapman C. Issues in Quality Use of Medicine amongst Arabic-Speaking Patients with Type 2 Diabetes Mellitus. Diabetic Medicine (for *Diabetic Medicine*)
4. **Alzubaidy H,** Marriott J, Stevenson V, Steele C, Chapman C. Unveiling cultural barriers influencing diabetes self-care activities: the perspective of Arabic-speaking patients. Diabetes Care (for *Diabetes Educator*)

Conference presentations

1. **Alzubaidy H,** Marriott J, Stevenson V, Steele C, Chapman C. Understanding diabetes medications from the perspective of Arabic-speaking background patients with type 2 diabetes. Pharmacy Australia Congress (PAC 2011). Melbourne, Australia

2. **Alzubaidy H,** Marriott J, Stevenson V, Steele C, Chapman C. Patients' delay in seeking medical help: the perspective of Arabic-speaking background patients with type 2 diabetes. Annual scientific meeting of Australian Diabetes Society and Australian Diabetes Educators Association (ADS-ADEA 2011). Perth, Australia.

3. **Alzubaidy H,** Marriott J, Stevenson V, Steele C, Chapman C. Factors Influencing Delay in Seeking Treatment among Diabetic Patients: the Perspective of Australian Arabic-speaking Patients. The 16th International Social Pharmacy Workshop (2010). Lisbon, Portugal
4. **Alzubaidy H,** Marriott J, Stevenson V, Steele C, Chapman C. Unveiling cultural barriers influencing diabetes self-care activities: the perspective of Arabic-speaking patients.

Annual scientific meeting of Australian Diabetes Society and Australian Diabetes Educators Association (ADS-ADEA 2010). Sydney, Australia.

5. **Alzubaidy H,** Marriott J, Stevenson V, Steele C, Chapman C. Issues in Quality Use of Medicine amongst Arabic-Speaking Patients with Type 2 Diabetes Mellitus. National Prescribing Symposium (2010). Melbourne, Australia

CHAPTER ONE: INTRODUCTION

1 Introduction

1.1 DEFINITION OF DIABETES MELLITUS

Diabetes mellitus (DM) is a common and progressive chronic condition that is associated with reduced life expectancy and diminished quality of life.[1] It is a metabolic disorder characterised by a defect in insulin secretion, insulin action, or both.[2-4] A common effect of uncontrolled diabetes is hyperglycaemia, a condition where the blood glucose level is raised and over time leads to serious damage to many of the body's organs, especially the nerves and blood vessels, causing significant morbidity and mortality due to microvascular and macrovascular complications such as ischaemic heart disease, stroke and peripheral vascular disease.[1, 5, 6] There are a number of specific causes of DM. The majority of clinical cases, however, fall into two classes, currently termed type 1 (resulting from β-cell destruction, usually leading to absolute insulin deficiency) and type 2 (resulting from a progressive insulin secretory defect on the background of insulin resistance).[3] Around 90% of people with diabetes in the world have type 2 diabetes (T2DM), largely as a result of excess body weight and physical inactivity.[7, 8]

1.2 PREVALENCE AND BURDEN OF TYPE 2 DIABETES MELLITUS

1.2.1 Global snapshot

There are several studies on future projections of the prevalence of diabetes globally.[9-12] Data for trends in diabetes prevalence is showing rapid rising of diabetes worldwide.[13] Currently, the total number of people with diabetes is estimated to be 366 million and this is expected to rise to 552 million by 2030.[14] According to the International Diabetes Federation (IDF), approximately three more people are being diagnosed with diabetes every 10 seconds.[15] Shaw et al, projected that by 2030 there will be a 69% increase in numbers of adults with diabetes in developing countries and a 20% increase in developed countries.[16] This group also mentioned a major concern regarding the expected increase in prevalence of diabetes in developing countries in that it will affect mostly those in the middle, productive years of their lives - between 35 and 64 - while in developed countries, most people with diabetes are close to, or above, the age of retirement.[16] Boyle *et al,* forecast that the number of adults with diabetes in the United States (USA) is projected to increase 165% by 2050; with the fastest increases occurring in ethnic minority groups and elderly subpopulations.[12] A study conducted in 2010 projected that the prevalence of total diabetes (diagnosed and undiagnosed) in the USA , over the next 40 years, will increase from its current level of about 1 in 10 adults to 1 in 3 adults in 2050.[17]

Diabetes is currently recognised as one of the most challenging health problems, often resulting in substantial morbidity and mortality; diabetes was estimated to be the fifth leading cause of death, and in 2011 it was reported that diabetes caused 4.6 million deaths.[9, 18-20] A recent study by Emerging Risk Factors Collaboration calculated hazard ratios for cause-specific death, according to baseline diabetes status among 820,900 people in 97 prospective studies.[21] Results showed that after adjustment for age, sex, smoking status, and body-mass index, hazard ratios among people with diabetes as compared to those without, death from any cause was 1.80 times higher (95% confidence interval [CI], 1.71 to 1.90), while death from vascular-related causes 2.32 higher (95% CI, 2.11 to 2.56).[21]

Diabetes is known to place heavy economic burdens on health care systems worldwide; some studies have estimated that the health care expenditures are as much as five times higher for patients with diabetes compared to those without diabetes.[22, 23] According to the American Diabetes Association (ADA), health care costs of an individual with diabetes in USA were estimated to be approximately 2.3 times higher than that of an individual without.[24, 25] In 2010, according to data from the United Nations (UN) and the World Health Organization (WHO), for 193 countries, at least 12% of global health expenditures were spent on diabetes care – approximately $376 billion United States Dollars (USD) or $418 billion International Dollars (ID).[26] In the USA, national diabetes costs in 2007 were in excess of USD 174 billion (per year), and it is expected to be USD 336 billion billion by 2034.[24, 27] The results of the Costs of Diabetes Mellitus (CoDiM) study in Germany showed that direct costs of patients with diabetes were estimated to account for 14.2% of total health care costs.[28] In China, at least 23.46 million people currently have diabetes and this number is projected to increase to 42.30 million by 2030.[29] The direct medical cost of T2DM in China was estimated to be USD 26.0 billion in 2007 and were projected to rise to USD 47.2 billion by 2030.[31] Based on enormous economic burden of diabetes it is recognised as an important clinical and public health challenge.[32]

1.2.2 Australian snapshot

Diabetes is the fastest growing chronic disease in Australia where it is estimated to affect in excess of 1.5 million people; it is projected that one Australian is diagnosed with diabetes every five minutes.[33, 34] Currently, more than 3.6 million Australians have diabetes or pre-diabetes.[33, 35] The prevalence of diabetes in the Australian population more than doubled from 1.5% to 4.1% over the 20 years to 2007–08 (**Figure 1**). Approximately 7.4% of the adult population in Australia is affected with diabetes; and almost 1 in 4 Australians over 25 years old has either diabetes or a condition of impaired glucose metabolism.[37, 38] It is predicted that diabetes will be the major cause of morbidity and mortality in the Australian community by 2016.[34, 39] The pandemic of diabetes and the associated economic burden to the Australian healthcare system is no longer in dispute.[40] The estimated total economic burden of the T2DM is estimated to be AUD 6.57 - 10.3 billion annually depending on how and when the estimates were derived.[41, 42]

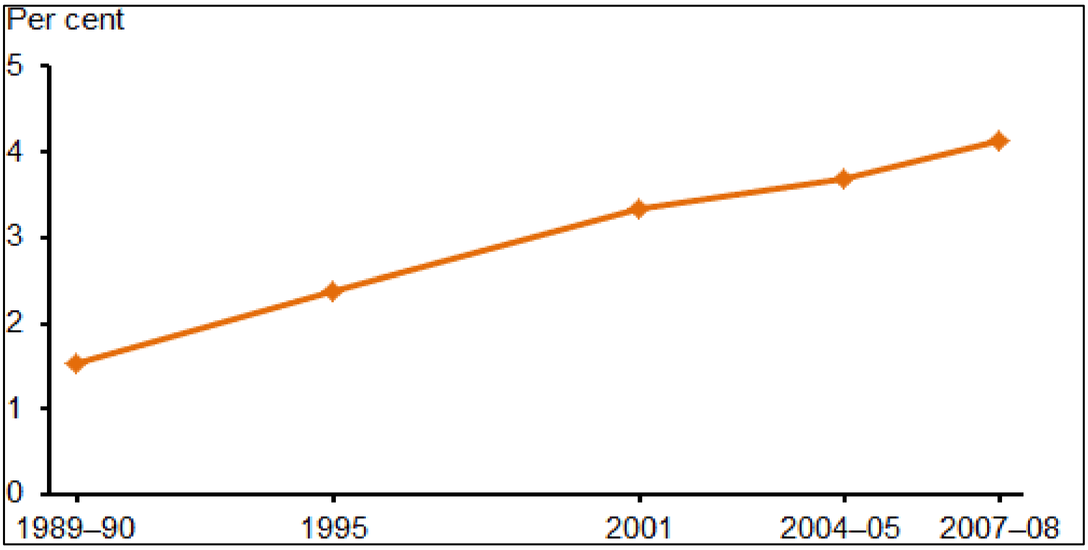


Figure 1: Trend of diabetes prevalence in the Australian population, 1989–90 to 2007–08.[43]

1.2.2.1 A snapshot of diabetes in culturally and linguistically diverse (CALD) groups in Australia

It is well known that Australia is a nation of immigrants, which is defined as people born overseas who have settled permanently.[44] The Australian society is known to be a multicultural, and that it has one of the most diverse immigrant populations in the world; 48 % of Australian population have either been born overseas or have at least one parent born overseas.[45, 46] Compared to the Australian-born population, it is well established that certain culturally and linguistically diverse (CALD) groups, including ASB communities, have higher prevalence rates of diabetes. Arabic-speaking background immigrants make up a significant minority group of the Australian population; in 2011, Arabic was third most common language spoken at home (other than English). In Figure 2 it is shown that men of ASB born in the Middle East and North Africa reported 3.6 times more diabetes compared to Australian-born men.[48]

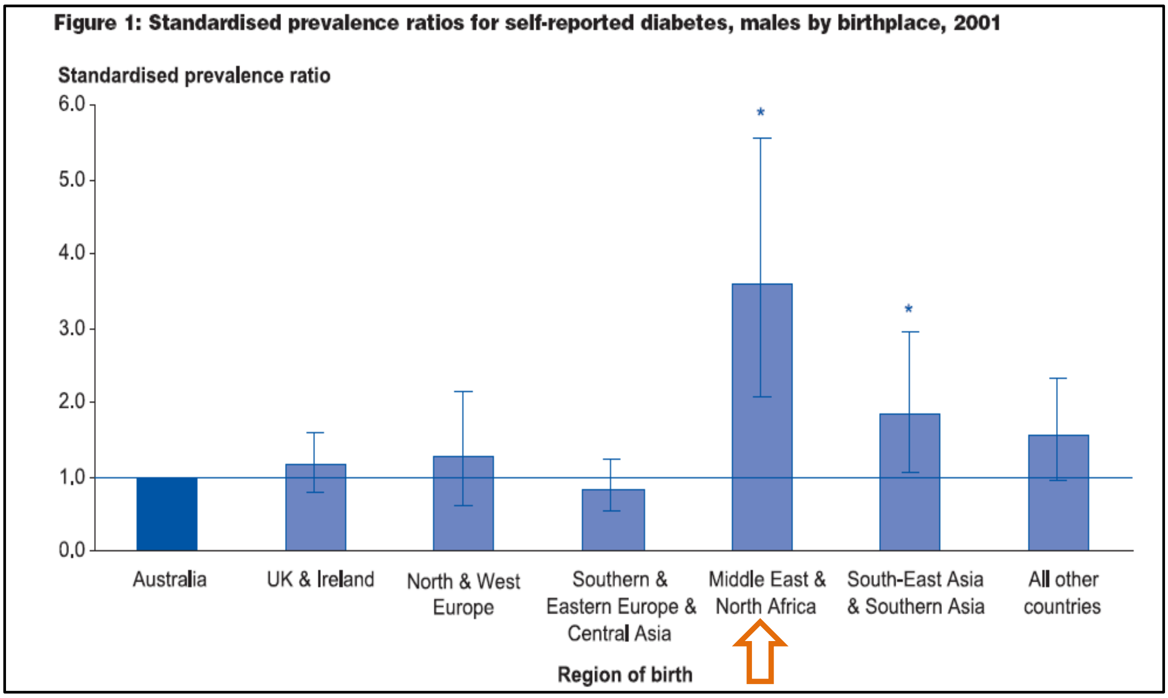


Figure 2: Standardised prevalence ratios for self-reported diabetes, males by birthplace, 2001.[48]

The NSW Chief Health Officer reported that the prevalence of diabetes or high blood sugar was statistically significantly higher among people born in Middle East (8.1%); compared to Australian-born people (3.8%).[49] The high prevalence rates of diabetes among the ASB communities living in Australia were supported by findings of a study conducted in an ASB general medical practitioner's office in Sydney where results showed that 13% of ASB males and 5% of Arabic-speaking females surveyed had diabetes.[50] Differences in the prevalence of diabetes between Australian and overseas born people are attributed to a combination of genetic, biological, behavioural and environmental risk factors.[38, 51, 52]

1.2.3 A snapshot of diabetes in Arabic-speaking countries

In the Arabic-speaking countries, usually taken to mean the 22 member countries of the Arab League where Arabic is either an official language or it is spoken by a significant portion of the population; the prevalence of diabetes has increased alarming over the last three decades.[53, 54] In terms of T2DM prevalence, six of those Arabic-speaking countries are among highest in the world: Kuwait, Lebanon, Qatar, Saudi Arabia, Bahrain and United Arab Emirates (UAE).[55, 56] In 2011, it is estimated that 32.8 million (9.1%) of the populations from the Middle Eastern/North Africa (MENA) region have T2DM, and this number is projected to rise to 60 million by 2030.[57]

Modifiable risk factors that play a key role in the current increase of T2DM in the Arabic-speaking countries include physical inactivity and sedentary life styles, especially after rapid economic growth generated by oil-rich resources in Arabian Gulf countries, changes in dietary behaviours with a proliferation of fast food, due to increased exposure to western lifestyle, and consequential increased rates of obesity, which is known to be a major risk factor for the development of T2DM.[58-60] The obesity rates in the adult population of the MENA region are amongst highest in the world (up to 55% of females and 30% of males are obese).[57, 61, 62] Another important factor that is contributing to the increased prevalence of T2DM in some Arabic-speaking countries is consanguinity in marriage.[63] In a study in Saudi Arabia, results showed positive correlation between consanguinity in marriage and incidence of diabetes; 80% of related marriages had a positive family history of T2DM compared to 20% in non-related marriages.[64] High diabetes-related mortality rates are common in Arabic-speaking countries: in 2011, annual T2DM-related mortality rate was estimated to be around 280,000.[15] High diabetes-related morbidities are also common in Arabic-speaking countries: results of a study in Saudi Arabia have shown that 82% of patients had neuropathy (one of the highest in the world).[65] In the late 1990s, 40% of patients on renal replacement therapy were diabetic (diabetic nephropathy), whereas only 4% of patients entering renal replacement therapy were diabetic in 1980s.[66, 67] Results of studies in Saudi Arabia have shown that about 37% - 41% of patients with diabetes develop a stroke.[68, 69] In Egypt, a cross-sectional study has shown that 42% of patient with diabetes had generalised nephropathy, 22% had peripheral neuropathy and around 5% were blind.[70] In Yemen, the prevalence of retinopathy in diabetic patients was found to be 55%, while in Oman it was 14.4%.[70, 71]

Type 2 diabetes mellitus is affecting a large proportion of populations in the Arabic-speaking countries with high morbidity and mortality rates. Arabic cultural norms appear to have a negative impact on healthy practices needed for diabetes management. Increased food intake at social gatherings is fostered by a cultural norm of ‘generosity’. For the host, offering guests large food portions is a gesture of care and welcoming and the habits of over-eating by guests is a demonstration of respect and appreciation.[72, 73] All these factors, in addition to inadequate public awareness about diabetes management draw attention to the need for determining best practice in diabetes care for ASB patients that do not conflict with cultural norms and address their specific barriers to self-management.

1.3 MANAGEMENT OF TYPE 2 DIABETES

The approach to diabetes management is multifactorial, focussed on optimisation of blood glucose level, reducing risk factors for cardiovascular diseases, and motivational counselling to encourage patients to adopt healthier lifestyles, in addition to regular screening and monitoring for diabetes-related complications.[74-76] The burden of diabetes self-management (DSM) falls largely on patients and involves dietary modifications, taking medications as prescribed, engaging in regular physical activity and appropriate exercise, self-monitoring of blood glucose, and foot care.[77] Effective DSM is required for achieving and maintaining optimal glycaemic control.[78-80] There is now irrefutable evidence supporting the benefits of adequate glycaemic control to delay and prevent the devastating and disabling long-term diabetes complications.[81-83] Nevertheless, adequate glycaemic control has proved to be difficult to achieve and maintain at a practical level, and a significant proportion of patients with T2DM do not meet targets for glycaemic control, blood pressure, and lipids, exposing them to a higher risk for developing complications.[84]

In DSM, patients themselves are given the responsibility of more than 95% of diabetes care, and healthcare professionals have very little control over how patients manage their diabetes in their daily lives.[77] This realisation that diabetes is largely a self-managed condition has stimulated new treatment frameworks and models of care to focus on strategies that promote the achieving and maintaining effective DSM, mainly through providing appropriate and tailored information about DSM and available health services to increase each patient's use of, and access to, healthcare services.[85, 86] A recent position statement of the American Diabetes Association (ADA) and the European Association for the Study of Diabetes (EASD) has emphasised the importance of patient-centred care, which is defined as an approach to "providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions".[87] Patient-centred care is currently recommended as the organising principle underlying healthcare for all individuals with any chronic disease, and is particularly appropriate in T2DM.[88, 89] Supporting patients with appropriate education to enable them making informed decisions regarding lifestyle choices and, to some degree, the medications they use is an integral part of patient-centred approach.[88, 90] On the importance of patients education in the management of T2DM, the Royal Colleges of Physicians and General Practitioners in the UK and the British Diabetic Association have reported that, in the treatment of T2DM, the twin cornerstones are patient education and lifestyle modification. Many factors at patient, healthcare provider, and health system, levels can either directly or indirectly influence a patient's self-management behaviours and metabolic control.[92] At the patient level and in addition to internal physical (biological) factors, there are the psychosocial factors such as family demand, lack of family and social support, lack of cultural support, lack of community and psychological factors. In addition, health beliefs, poor motivation and emotional issues have been shown to profoundly affect the DSM of diabetic patients.[93, 94]

1.3.1 Plasma haemoglobin A1c (HbA1c)

Plasma haemoglobin A1c (HbA1c) is a useful test to characterise dysglycemia in people with diabetes.[95] HbA1c test measures average blood glucose control for the past 2 to 3 months and has a strong predictive value for diabetes complications.[96] Elevated levels of HbA1c (>7%) In people with DM are known to be associated with a higher incidence of microvascular and macrovascular complications.[97, 98] Currently, it is widely acknowledged that HbA1C testing should be performed routinely in all patients. The frequency of HbA1c testing for any individual patient, however, depends on the clinical situation, the treatment regimen used, and the judgment of the clinician.[3]

1.3.2 Non-adherence among people with diabetes

“In literature, terms ‘Adherence’ and ‘compliance’ have been used interchangeably referring to patients’ efforts to follow healthcare advice. The term compliance was defined as “the extent to which a person’s behavior (in terms of taking medications, following diets, or executing lifestyle changes) coincides with the clinical advice”.[99] (‘Non-adherence’ is defined as patients not following treatment recommendations that are mutually agreed upon with healthcare professionals”.[100] Through several well-designed clinical trials, the benefits of medications in terms of improving glycaemic control, micro-vascular complications, cardiovascular risk, mortality, and a patient’s quality of life have been well established.104, 105 In medical practice, however, the non-adherence of patients to prescribed medications, across chronic diseases including diabetes, is recognised as a significant problem.107 Poor adherence rates have been well documented among people with diabetes for whom medications are prescribed.108-111 Results of studies that examined the extent of adherence to diabetes medicines, however, have indicated wide variation in the percentage of non-adherent patients. Some studies reported non-adherence by patients using oral hypoglycaemic agents (OHAs) from 13% to 64%,[112, 113] whereas, in a systematic review of medication adherence among patients with diabetes by

Cramer in 2004, it was reported that adherence rates for OHAs among 11 retrospective studies in which large databases were used ranged from only 35% - 93%.[114]

A significant association has been demonstrated between adherence to diabetic medication and improved glycaemic control in diabetic patients using a number of measures of adherence.[115] Patients with better adherence had reductions of up to 10% in HbA_{1c} level, while poor adherence was associated with elevated HbA_{1c} levels.[116, 117]

1.3.3 Adherence and health care services utilisation

Using hospitalisation rates as an endpoint, the results of five studies show a statistically significant association between higher adherence levels and decreased hospitalisation rates.[118-122] After adjusting for demographic factors, disease severity, and comorbid conditions, patients with medication adherence below 80% had more than double the risk of having diabetes, or cardiovascular disease-related hospitalisation. By contrast, patients with adherence ratios greater than 80% had a 29% decreased risk of hospitalisation for any cause.[119, 123] Balkrishnan *et al* reported the association between poor adherence and hospitalization rates. Their results showed, after controlling for demographic factors and disease severity, each 10% of increase in adherence was associated with a mean decrease of 6.6% in hospitalisation rates for any cause ($P < 0.05$).[124] Two studies evaluated emergency department visits as an endpoint and reported results showing a statistically significant association between higher levels of adherence and decreased visits to emergency department; each 10% increase in adherence was associated with a 3.6% decrease in the mean number of emergency department visits ($P < 0.05$), whilst patients with high adherence levels (ranged between 80% and 99%) were very unlikely to have a visit to emergency department (88%) compared to non-adherent patients (P value or confidence interval was not reported).[115, 125] Moreover, adherence to diabetes medications has been reported to be associated with a reduction in total diabetes-related medical costs, as well as in total medical costs.[126, 127]

1.3.4 Adherence and glycaemic control

Asche *et al* in 2011 provided a comprehensive summary of empirical studies that examined the association between adherence and glycaemic control, and reported the findings of 13 studies. They drew the conclusion that a significant association existed between improved adherence and better glycaemic control.[115] In 2004, Krapek *et al* conducted a study among 301 patients with T2DM to assess the relationship between medication adherence and HbA_{1c}, and found that patients with better adherence had 10% lower associated HbA_{1c} measurements.[116] Similarly, a study by Pladevall *et al* also conducted in 2004, showed that non-adherence was statistically associated with elevated HbA_{1c} in 677 randomly-selected adult patients with diabetes, even after adjusting for demographic and clinical characteristics; a 10% increase in non-adherence was associated with an increase of 0.14% in HbA_{1c}.[117]

1.3.5 Challenges in diabetes care among ethnic minority groups

1.3.5.1 Higher prevalence rates

Previous research has shown that in western countries diabetes prevalence is higher among ethnic minority groups (EMGs) compared to their counterparts in the non-immigrant Caucasian/white population.[128, 129] In the USA, data from the National Health Interview Survey indicated that 6.6% of non-Hispanic whites, 7.5% of Asian Americans, 10.4% of Hispanics, and 11.8% of non-Hispanic blacks had been diagnosed with diabetes.[130] McBean et al also reported that the prevalence of T2DM was the highest among Hispanic patients and the lowest among white patients in a random sample of Medicare fee-for-service beneficiaries.[131] Similar results have been reported from the Netherlands: a recent study by Ujcic-Voortman et al, in Amsterdam showed that the prevalence of diabetes was significantly higher in Turkish (5.6%) and Moroccan (8.0%) people, compared to the Dutch (3.1%).[132] Similarly, in the UK diabetes prevalence is reported to be significantly higher (up to five times) among certain ethnic groups compared with the white population.[133] In the UK the prevalence of T2DM was reported to be 4.3% in the white population, but diabetes prevalence among certain EMG was as high as 11.2%.[134] Epidemiological data from the UK have shown that by the age of 55 years, 1 in 5 South Asians and 1 in 7 African-Caribbean men and women would have diabetes compared to a national rate of 1 in 20.[135] A range of factors are likely to account for the increased prevalence of T2DM among EMGs including genetics, history of gestational diabetes, physical inactivity, excessive food consumption and socio-economic factors.[136, 137]

1.3.5.2 Higher risk of developing diabetes

Although the prevalence of diabetes can provide information on the burden of diabetes in certain populations, it does not capture the individual's risk of developing diabetes, and EMGs are known to have higher risks to develop diabetes compared with white populations.[134, 138, 139] Narayan et al, estimated the age, sex, and ethnicity-specific lifetime risk of diabetes for a population in the USA and showed that, compared to a white population, Hispanics had the highest lifetime risks for diabetes.[140] Likewise, the results of a recent prospective cohort study that included 78,419 women showed that diabetes was significantly higher among Asian, Hispanic and black people than among whites, even after differences in Body Mass Index (BMI) were taken into account.[141] It is known that the presence of pre-diabetes increases the risk of developing T2DM and includes a 1.5 times increased risk for cardiovascular disease, compared with people who have normal glucose levels.[142] Data from the USA showed that compared with a white population, Hispanics are also much more predisposed to develop pre-diabetes.[142] According to the National Health and Nutrition Examination Survey data showed that for Hispanics the lifetime risk of developing T2DM in 2000 was 45.4% for men and 52.5% for women.[143] Given the documented higher risk of pre-diabetes and the development of T2DM among Hispanic/Latino, it is therefore not surprising that the American Association of Clinical Endocrinologists and the ADA supported priority screening among these populations.[144, 145]

1.3.5.3 Higher diabetes-related complications

Ethnic minority groups are known to have worse glycaemic control compared with white population as shown in a recent study by Adams et al.[146, 147] Poorer glycaemic control among EMGs, as well as increased cardiovascular risk factors such as high blood pressure and lipid disorders, has been recognised as a key factor placing these groups at a higher risk of developing serious diabetes-related complications.[148, 149] EMGs are also known to have significantly higher diabetes-related morbidity and mortality.[150] The American Public Health Association reported that amongst EMGs the diabetes-related mortality is around 2.7 times higher than white population, and when underreporting is taken into account then the rate is estimated to be as high as 4.3 times compared to Caucasians.[151] Ethnic minorities residing in western countries have worse glycaemic control , even after adjusting for factors that are known to affect glycaemia and they also have higher rates of diabetes associated complications that are only partially explained by poorer diabetes control and associated cardiovascular risk factors.[149 152-154]

1.3.5.4 Underutilisation of health services

Lower rates of access to, and use of, health and preventative services are well documented among EMGs residing in western countries compared with their non-immigrant counterparts.[86, 155-160] Research on disparities of health care access among EMGs showed that these EMGs are at higher risk of missing the benefits of health care.[161, 162] Many barriers to the use of health services among these groups have been identified, with most of the attention directed towards language problems and cultural differences.[163] It has been reported that patients from EMGs may respond differently when they experience disease-related symptoms compared to white population, because of their particular health beliefs, cultural perception and understanding.[164] Smith et al. reported that the cultural perceptions of EMG patients regarding experienced symptoms may be different from the medical paradigm.[161, 162] In some cases, patients from EMGs consumed time in the process of symptoms appraisal, which is commonly mentioned as a barrier to medical services access. Thus, such occurrences may result in missed opportunities for timely diagnoses.[160, 165]

One of the major factors that inhibits the use of available health services is the lack of local language skill, which acts as barrier to effective communication between patients and healthcare professionals.[166, 167] In 2003, Manderson and Allotey reported that culturally and linguistically diverse groups (CALD) in Australia are less engaged with the health system because of these factors.[168] Henderson and Kendall showed that four prominent CALD communities in Logan, Queensland (Sudanese, Afghani, Pacific Islander and Burmese), experienced difficulties in accessing appropriate health care mainly due to language difficulties and cultural differences.[169] Similarly, Hoang in a qualitative study among Asian migrants in Tasmania showed that participants faced language and cultural barriers when dealing with the healthcare system.[170] In the international literature there are reports of language problems having detrimental effects on health care access among Latino patients in the USA.[171-173] Language problems and patients' cultural beliefs are, however, not the only factors known to obstruct access and use of health services among ethnic groups: lack of family and social support has also been reported as a barrier to health care in an unconstructive way, especially when collective family burdens and responsibilities take precedence over an individual's need.[174, 175]

In some cases EMGs may experience delay and inequalities in accessing to health care services due to health care professional-related and system-related factors: lack of cultural awareness by health professionals about patients from EMGs has been mentioned as a barrier to access, and can also generate resentment in patients. In a study by Adamson et al that included 2500 individuals aged between 18 and 75 years in the South West of England, patients responded to a questionnaire that contained two short vignettes describing scenarios related to cardiovascular disease and cancer. Results indicated that Black respondents, lower socio-economic groups and women were at least as likely to report immediate health care seeking in response to the clinical vignettes compared to White respondents, higher socio-economic groups or men. The authors concluded that inequalities in accessing health care by ethnicity, socio-economic position and gender are not necessarily related to patients in these groups failing to self-refer to primary or accident and emergency care, but rather many delays and inequalities in access to medical services occur at the level of healthcare provision.[176]

Of particular significance is the impact of underutilisation of available medical services on health outcomes for EMGs. It has been reported that limitations in accessing health care services are linked to poor health outcomes especially for those patients with chronic diseases.[177-179] Within this context, the link between a patient's utilisation of diabetes-related medical services and poor glycaemic control was examined in a study by Rhee et al.[180] Results of adjusted analysis of 605 African-Americans with diabetes have shown that HbA_{1c} levels were higher among patients who reported a history of trouble in obtaining medical care, and in patients who reported not having a usual source of care.[180]

1.3.6 Challenges to diabetes self-management among ethnic minority groups

Literature on DSM among EMGs suggests that a patient's socio-cultural environment influences self-management practices.[181-183] Within the dimension of cultural influence on self-management, there are several key phenomena of interest that have been studied to identify culturally-relevant issues and challenges in DSM.[184] The vast majority of studies have been conducted among the following ethnic groups residing in western countries: Black (African-Americans, people of Caribbean decedent), Asians, Hispanics/Latinos and Pacific Islanders.[185-190] Amongst key cultural phenomena identified were: each patient's knowledge about, and experience of, illness (explanatory models), fatalism and religious beliefs, and social support and influence of family and significant 'others'.[191-194] These cultural constructs appeared to largely act as barriers, and in certain cases increased complexity of diabetes management. However, some of these constructs have also been reported as facilitators, depending on culture being studied.[195] Very little has been published on the perspective of ASB immigrants with T2DM.[196, 197]

1.3.6.1 Knowledge and experience of diabetes

Research has shown that a patient's cultural background shapes attitudes and beliefs, understanding and knowledge of, and response to illness.[30, 198-200] Patients of different cultural backgrounds may have different understanding and experience of diabetes.[201-203] From a clinical practice point of view, understanding of the concerns, experiences and knowledge of individuals of EMGs about diabetes is warranted to identify barriers and facilitators of adherence to diabetes self-management, thus enabling development of appropriate health promotion interventions that are compatible with cultural norms and beliefs of target group.[204, 205]

Although it is known that there are differences between newly diagnosed people and those who had diabetes for some time regarding diabetes knowledge, however, this section is focusing on inadequate knowledge or different understanding among EMGs about diabetes and its management.[206] A patient's' diabetes-related knowledge is recognised as a key factor in determining strategies used to manage diabetes. Studies on diabetes-related knowledge, using both qualitative and quantitative approaches, have produced a rich empirical literature about perspectives of non-Arabic-speaking EMGs. Quantitative approach used in these studies was mainly to evaluate patients' knowledge about diabetes compared to 'correct' biomedical views.[189, 207, 208] Although, such an approach allowing health professionals to determine how each patient's knowledge about diabetes relates to their demographic and clinical characteristics it is, however, limited. Quantitative research designs do not usually enable in-depth understanding of participants' perspectives and meanings..

Qualitative-based approaches generate an in-depth understanding of each participant's perspectives about diabetes and their health beliefs in various cultural groups.[209-214] Some studies use a mixed approach, such as the research conducted by Chesla and colleagues that explored differences in diabetes experiences among European and Latino background patients in USA. [215] In this study a mix of open-ended and fixed-choice questions was used that addressed five aspects of personal models: cause, nature, seriousness, and effects of and future concerns about the disease.(adapted from the work of Kleinman and the Personal Models of Diabetes Interview).[216] The authors reported that disease descriptions about the nature of diabetes were categorized as experiential, biomedical, or psychosocial. Disease descriptions varied significantly by ethnicity, with more Latinos using an experiential model and more Europeans using a biomedical model.[215] Those patients who described a more biomedical model of diabetes focussed more on lifestyle changes, while those who described a more experiential model placed greater emphasis on managing fatigue and mood symptoms.

It has been observed that a patient's belief about causes of their disease are an important factor in determining their behaviours.[217] Results of studies that examined causal beliefs among ethnic minority patients with diabetes have shown that patients attributed the development of their diabetes largely to external factors such as intense emotions generated by death of family members or loss of loved ones, physical trauma by the way of car accidents or physical violence, punishment for previous self-indulgence.[209, 218, 219] Others connected their development of diabetes to their own past behaviours, such as substance abuse, consumption of alcohol and smoking.[193, 209, 220, 221] Results of these studies indicated more active treatment behaviours in those who took personal responsibility for their diabetes, compared to those who attributed onset of their diabetes to external factors.[209]

In summary, diabetes-related knowledge and experience among EMGs appears be shaped in part by culture, and these determine approaches to self-management. A patient's knowledge about diabetes is a complex cultural domain that entails understanding about causes, course of illness, complications in addition to treatment strategies of diabetes. As yet, little is known about the perspective of ASB immigrants with T2DM.

In Australia, one study explored the perceptions of people with type 2 diabetes about their self-management strategies and relationships with health professionals using four focus groups, one of which was among ASB patients. The small sample size of ASB participants, use of an interpreter, and cultural differences between researcher and participants may limit interpretations of the findings.[196]

1.3.6.2 Social support of family and significant 'other'

At a broad social level, the role of family and significant 'others' (defined as partner/family member/friend/peer within ASB communities) as a vital factor in diabetes management, which has positive and negative aspects, has long been recognised.[222-226] Researchers have reported on how family dynamics, cohesion, interdependence, interference, co-operation and contextual issues can make a difference in diabetes outcomes and influence self-care activities.[227-229] While some researchers proposed the family role to have a positive impact on diabetes management,[230, 231] others have reported negative influences.[232-236] On the negative influence of family on DSM among EMGs, Samuel-Hodge et al, showed that putting family's needs first, difficulty saying 'no' to family members, and the large number of adults living in one household were identified as barriers to diabetes self-care, and were negatively associated with quality of life, and positively with stress.[232] Also, studies have found that those patients who experience high levels of family conflict displayed poorer adherence or poorer metabolic control.[237, 238] Unresolved family conflicts about diabetes have been related to significantly more depressive symptoms and lower quality of life with diabetes.[239] Family members (immediate or extended) are reported to serve as considerable sources of misinformation.[240] Likewise, care-giving responsibilities to multiple family members are reported as a significant barrier to self-management and potential stressor.[234, 235, 241]

On the positive role of family providing important support to patients with diabetes, Wen et al showed that Mexican Americans with T2DM who reported higher levels of family support and greater self-efficacy, had higher levels of adherence to diet and exercise.[242] Similarly, Epple et al, examined whether active family support for nutritional changes was associated with improved metabolic outcomes for Dine´ (Navajo) individuals living with T2DM.[231] Results have shown that active family nutritional support was significantly associated with control of triglyceride, cholesterol, and HbA1c levels. The authors concluded that family-based intervention is a more useful compared to individual-based educational intervention for Dine´ individuals. Results reported by Carter-Edwards et al, showed that African-American women drew important support from their families.[153]

In summary, social support, family involvement and significant ‘others’ are sociocultural factors influencing diabetes self-management, and these factors appeared to be different across various cultures.[211] Such factors do not appear to have been investigated thoroughly among ASB immigrants with T2DM.

1.3.6.3 Fatalism and religious beliefs

The perspectives of fatalism and religious beliefs and their association with patients’ health behaviours have been studied extensively among EMGs.[243-246] Findings are inconsistent and vary across studied groups, and both positive and negative aspects have been identified.[247-251] Those who viewed God as a healer and believed that the outcomes are in God’s hand tended to be passive in relation to self-care. This was supported by findings of Lawton et al among Muslim Indian and Pakistani patients with T2DM who reported that they believed that God is the healer and everything is controlled by Him.[252] Others perceived God to have more of a supportive role whereby the individual’s religious beliefs play a prominent and positive role by way of providing patients with the strength needed to deal with diabetes-related challenges.[240, 253] Different cultural interpretations and understandings of religious beliefs appeared to be associated with different approaches to illness management among EMGs.[254] Although ASB immigrants are known to hold strong religious beliefs, yet little is known about how these religious beliefs influence DSM practices.[255, 256]

1.4 SUMMARY OF THE LITERATURE REVIEW

Adherence to diabetes treatment recommendations is crucial for optimal outcomes. It is a multifactorial issue, especially for EMGs that can be understood only through the eyes of the 'target groups' of patients, taking into consideration their cultural and health beliefs. A thorough understanding of the patient's perspective on issues related to DSM, particularly non-adherence to medication instructions, provides an opportunity for improving diabetes care through development of interventional strategies and models that promote adherence behaviours and patient-centeredness while recognising each patient's unique cultural perspective.

1.4.1 Gaps identified

Arabic-speaking background groups appeared to be the one of the least-studied ethnic groups: there is a dearth of information about how cultural and health beliefs of ASB immigrants with T2DM, living in Australia or anywhere else in the world, are affecting adherence to DSM practices and glycaemic control.

1.5 SCOPE, AIMS AND OUTLINE OF THE PROJECT

The focus of the research reported in thesis was on exploring psychosocial and psychological factors that are known to influence patients' DSM behaviours, but have not yet been completely investigated among ASB immigrants with T2DM.

1.5.1 Theoretical Framework

In the field of health psychology variables such as beliefs, expectations, anxiety, and health-related behaviours are regarded as separate facets of individuals. It examines complex interrelationships among these factors. For example, patient's beliefs are considered to create changes in behaviour, behaviour interaction This study is guided by the self-regulation model of illness representation developed by Leventhal et al, also known as the "common sense model" (CSM).[257]

1.5.1.1 Description of the Common Sense Model (CSM)

The CSM postulates that when a health threat is confronted, people start to construct a mental scheme of perceptions and beliefs about that threat, termed "illness representation".[258] This representation has two dimensions, cognitive and emotional, both of which drive the individual's selection of the coping strategies they use in response to the perceived health threat.[198, 259-261] Within this model, developing a disease like T2DM is considered as a 'health threat', thus the use of the CSM illness representation provides an opportunity to understand people's coping behaviours, that is, health-related behaviours that individuals adopt in response to their illness.[193, 262]

1.5.1.2 Theoretical underpinnings and utility

The CSM of illness representation has been widely and successfully used to explain how individual's cognitive and emotional processes influence the way in which people perceive, organise, interpret, represent, and make inferences about their somatic experiences, and the way with which they choose to deal with these symptoms.[263-265] According to this model, people are perceived active problem-solvers who seek to be engaged in activities with the intention of either maintaining or enhancing their health status. The CSM has been successfully adapted to examine patient's self-management behaviours for a wide range of illnesses and in various populations.[266-270] Leventhal's CSM suggests that patients' health-related behaviours are heavily influenced by patient's own beliefs and illness representations (Figure 3). To gain a better understanding of study participants' health-related behaviours requires a thorough understanding of participants' beliefs and illness representation. In first phase of this research participants' cultural and religious beliefs are explored in depth using two qualitative methods described in detail in Chapter two (section 2.2). In the second phase, associations between participants' health beliefs, health-related behaviours and outcomes are assessed using quantitative approach (cross-sectional multi-centre survey, explained in detail in Chapter seven (section 7.2). Data collection tools, used in this research, were designed to enable assessment of variables of interest and were informed by CSM of Leventhal.

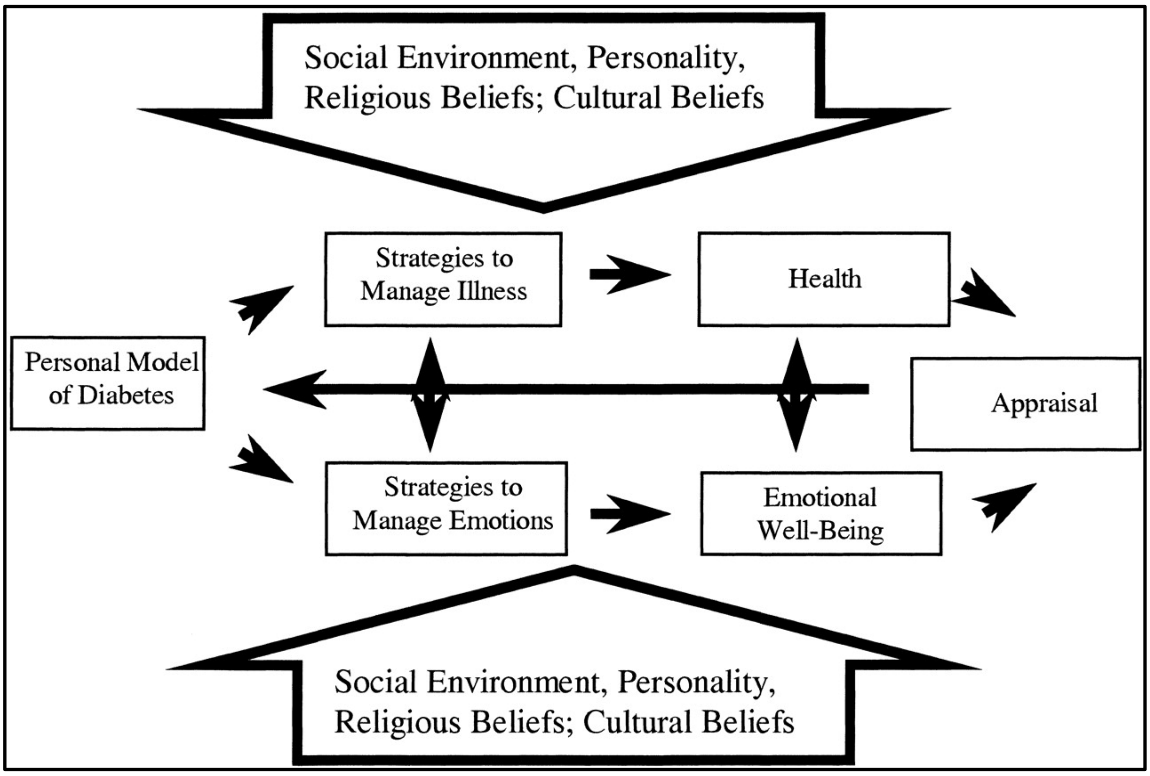


Figure 3: Representation of the Self-Regulation Model.[264]

The CSM framework acknowledges socio-cultural, environmental and religious beliefs as contextual factors that influence patient's illness representation.[271, 272] According to the cultural consensus theory, illness and treatment representations can be viewed as culturally shared schema, and reflect a form of collective memory, such as information obtained through family members, friends and community and healthcare providers.[273-275] These factors have been shown to have an impact on a patient's adherence behaviours, especially among EMGs with diabetes.[276, 277] Using CSM as a research framework allows cultural differences in patients' health behaviour (e.g. adherence) to be investigated by eliciting patients' thoughts about their health and illness.[275]

Research in the field of adherence to medical treatment has demonstrated the usefulness of the CSM in understanding factors that influence patients' adherence to medical regimen or health-related behaviours that patients' engage in to manage their illness.[278, 279] Literature reports that the CSM has a considerable strength as a predictive model of patients' adherence behaviours.[280, 281] Understanding of such factors enables development of more appropriate patient-centred education.[282] The CSM is, therefore, particularly useful in pharmacy research to gain a better understanding about patients' disease experiences, which in the context of this research are diabetes self-management practices.

1.5.2 Aims of this Research

The overall aims of this research are:

1- To explore cultural factors influencing adherence to diabetes management among (Arabic-speaking background (ASB) immigrants with T2DM residing in Australia, using a comparative approach whereby Caucasian English-speaking background (ESB) patients with T2DM are used as the comparable group.

2- To explore factors influencing healthcare seeking behaviours and utilisation of available diabetes health services.

3- To explore learning needs and preferences of ASB immigrants with T2DM.

4- To assess patients' treatment and illness perception about diabetes, adherence behaviours and glycaemic control among ESB and ASB groups.

5- To investigate the relationship between patients' beliefs, adherence behaviours (self-care activities and medication taking) and treatment outcomes measured by glycaemic control (HBA_{1c}) among ESB and ASB groups.

THE THESIS IS STRUCTURED AS FOLLOWS:

Chapters 2, 3, 4, 5 and 6 describe results of the qualitative phase of the research (two studies: 28 semi-structured individual interviews and 10 focus group sessions). Chapter 7 describes the results of the quantitative phase of the research (multi-centre cross-sectional survey) conducted in the Melbourne metropolitan area and a rural region of Victoria. Chapter 8 provides a summary of the results obtained from the two phases, conclusion and recommendation for future directions.

CHAPTER ONE: INTRODUCTION

This chapter describes background and contextual information. It also provides a summary of previous research findings including a critical appraisal of literature. It concludes with identified gaps in the literature, and the scope and aims of this PhD Project.

CHAPTER TWO: PATIENTS' UNDERSTANDING ABOUT DIABETES AND ITS TREATMENT

This chapter describes patients' understanding of diabetes and its treatment, using Kleinman's Explanatory Model (EM) as a framework. The qualitative methods, individual semi-structured interviews and focus group sessions, are described in detail in this chapter.

CHAPTER THREE: HEALTHCARE-SEEKING BEHAVIOURS

This chapter describes participants' healthcare-seeking behaviours with a specific focus on barriers to, and factors associated with, access and utilisation of currently available diabetes health services.

CHAPTER FOUR: ISSUES IN QUALITY USE OF MEDICINES

This chapter describes issues in quality use of medicines, with a specific focus on patient's knowledge about their prescribed medications, views and beliefs about their medications, and medication-taking behaviours.

CHAPTER FIVE: BARRIERS TO DIABETES SELF-CARE ACTIVITIES

This chapter describes difficulties patients encounter in performing diabetes self-care activities within their own social environments.

CHAPTER SIX: LEARNING NEEDS AND PREFERENCES OF ASB PARTICIPNTS

This chapter describes learning needs and preferences from the perspective of ASB immigrants with T2DM, with a specific focus on educational topics, preferred learning materials and preferred mode of delivery for diabetes education.

CHAPTER SEVEN: PATIENTS' BELIEFS ABOUT DIABETES AND ITS MANAGEMENT

This chapter reports phase two of the research and describes patients' beliefs about diabetes, adherence to diabetes self-management and medications, diabetes-related distress, involvement in medical treatment decision-making, perceived health status and acculturation levels. It also investigates the relationship between patients' beliefs, adherence behaviours (self-care activities and medication taking) and treatment outcome.

CHAPTER EIGHT: DISCUSSION AND CONCLUSION

This chapter summarises the PhD studies and suggests future directions for research

CHAPTER TWO: PARTICIPANTS’ PERCEPTIONS AND UNDERSTANDING OF DIABETES

KEY POINTS ABOUT THIS CHAPTER

This chapter describes:

- Participants’ perceptions and knowledge about diabetes using the constructs of Kleinman’s Explanatory Model (EM).

Summary of findings:

- Results indicated large differences in knowledge and perception of diabetes and its treatment between English speaking background (ESB) and Arabic speaking background (ASB) participants.
- The views of ESB participants’ regarding diabetes and its treatment were generally consistent with orthodox medical knowledge. In contrast, the views of ASB participants were drawn mainly on cultural belief systems.

2 Participants' perceptions and understanding of diabetes

2.1 BACKGROUND

Research to improve diabetes care has examined modifiable patient-related factors such as knowledge, views and attitudes, and perceptions; these factors are known to be important in determining successful self-care practices.[4, 216, 283-288] There has been a growing interest in investigating participants' perceptions and knowledge as part of the recent shift in medical sector towards a patient-centred approach, particularly in diabetes care. Understanding the patients' perspective has been shown to provide a vital opportunity to design and develop effective participant-centred behavioural interventions.[289]

Over the past decades, a growing body of research has shown that people with diabetes who are members of ethnic minority groups (EMGs), may experience, understand and perceive disease differently from mainstream population in western countries.[290] For those minority groups, culturally appropriate diabetes education has generally been developed so that it is oriented towards their beliefs, attitudes and behaviours.[291] This has been done by ensuring there is a thorough understanding of their perceptions, cultural norms and health beliefs, customs, food patterns and health practices.[91] Research to gain this understanding typically preceded the process of developing culturally appropriate health education.[292] These culturally appropriate diabetes educational interventions have demonstrated significant improvement in clinical outcomes among EMGs, however, up until now no such interventions are available to ASB communities.[293]

There are several theoretical models and frameworks that have been used to guide researchers in assessing the way patients perceive diabetes and the role of patients' beliefs, views, knowledge and attitudes in determining health behaviours.[216, 257, 271, 286, 294] There may be some conceptual overlapping between some of these models but they differ in their theoretical grounding and focus.[216] One of the most widely used models is Kleinman's Explanatory Model (EM) of illness, which refers to stories that people construct to make sense of an illness within the context of their culture. These stories are drawn from patients' beliefs, knowledge, views, perceptions, experiences and emotions, and they are translated into patients' behavioural responses to their illness.[286, 295] Explanatory models have five components: aetiology, time, onset of symptoms, pathophysiology, course of sickness and treatment.[296] Klienman's EM has proved to be a powerful device to examine patients' perspectives and has stimulated a large body of research among people with a wide range of conditions including depression,[297] cancer,[298] heart disease,[299], irritable bowel syndrome,[300] asthma,[301], hypertension,[302] obesity,[303] tuberculosis,[304] autism,[305] and diabetes.[296, 306, 307]

Kleinman's EM constructs include both cultural and biomedical perspectives. Thus, the notion of disease versus illness is typically inherent in studies examining EMs. The biomedical view of patients' complaints when conceptualised within the medical framework is referred to as 'disease', whereas the notion of illness includes social, cultural, as well as personal components of sickness.[295] Within this context, Cohen *et al.,* clearly articulated the importance of exploring differences in explanatory models between patients and healthcare practitioners, and these differences have been suggested as one reason for non-adherence in several disorders.[308] Kleinman and his associates described the importance of their explanatory model as follows:

> "Eliciting the participant's (explanatory) model gives the physician knowledge of the beliefs the participant holds about his illness, the personal and social meaning he attaches to his disorder, his expectations about what will happen to him and what the doctor will do, and his own therapeutic goals. Comparison of the participant model with the doctor's model enables the physician to identify major discrepancies that may cause problems for clinical management. Such comparisons also help the physician

> know which aspects of his explanatory model need clearer exposition to participants (and families), and what sort of participant education is most appropriate."

The usefulness of using EMs as a framework among patients with diabetes is in two main areas. Firstly, knowledge of EMs may inform the design of more effective behavioural interventions and, secondly, for healthcare providers (HCPs), assessing EMs related to diabetes can provide a rapid assessment of the patient's perspective. Research has shown that there are differences between patients and healthcare providers EMs. Loewe and colleague compared diabetes models between Hispanic patients and physicians. The physicians believed that the onset of diabetes is a long and slow process. By comparison, patients attributed the onset of diabetes to events or triggers (external factors) such as domestic violence, intense emotions like anger resulting from the act of betrayal, trauma due to the breakup of partners, or stress of migration to the USA.[310] Such differences may contribute to patients' non-adherence to medical instructions.[308, 311] Larme and Pugh reported in 1998 that when HCPs do not understand patients' perceptions of diabetes, their communication with these patients is impaired.[312]

Arcury *et al*, in 2004, conducted in-depth interviews in the USA among rural-dwelling Latino immigrants who were not diagnosed with diabetes.[313] Diabetes was viewed as a serious disease that is based on heredity, it can result from several factors such as strong emotions and lifestyle-related factors (an unhealthy diet, not taking care of oneself), and participants believed that a major and undesirable outcome of diabetes was weight loss. The findings of this study provided valuable insights into beliefs of undiagnosed Latinos to inform community-based interventions for diabetes prevention.[313] A further study in 2005 by Arcury *et al*, also described diabetes EMs in low-income white women and men, aged 18 to 54 years, living in a rural Southern US town. Findings demonstrated that participants had a vague and incomplete understanding of diabetes.[314]

A 2011 study on EMs of diabetes among participants in a Mexican Oaxacan community showed differences between participants' and healthcare providers' views on diabetes causes.[315] The Mexican participants placed emphasis on strong emotions and traumatic events as causal factors for the development of diabetes, while healthcare professionals emphasised diet and lifestyle factors. Jezewski *et al.*, in research among Mexican Americans with diabetes also demonstrated that each of the five components of their EMs of diabetes included elements of both the cultural and the biomedical perspective.[306] The authors concluded that, in clinical practice, when diabetes healthcare professionals assess participants' EMs, it can provide insights into participants' perspectives and describe what is important for those living with diabetes.[306]

Health professionals, including pharmacists, have sought to gain a better understanding about how people's cultural beliefs affect their experiences with diabetes.[316] Such endeavours are driven by the realisation that a patient is more likely to assimilate new medical information about diabetes when it fits within their pre-formed ideas or when it is perceived to be more helpful and valuable than previous ideas.[317] Howard *et al,* argued that the healthcare providers' educational message on benefits of optimal glycaemic control should be framed by reference to participant's perspectives.[318]

There is a paucity of research that describes how ASB immigrants with T2DM about perceive and understand diabetes and its management within their own socio-cultural environment. Such information will help guide health practitioner interaction and future development of culturally appropriate diabetes education that addresses specific cultural characteristics of ASB participants.[187, 319-321]

The aim of this chapter was to explore ASB participants' understanding of diabetes and its treatment using Kleinman's EM of illness as the research framework.

2.2 METHOD

Two qualitative methods were used for this exploratory study: semi-structured individual interviews and focus groups conducted in Victoria, Australia. Results of the individual interviews and focus groups are reported in this chapter and in Chapters 3-6.

2.2.1 Setting

The research was conducted in diverse localities of the Melbourne metropolitan area in Victoria, Australia. Various primary and secondary healthcare settings, both community- and hospital-based locations, were purposefully selected to obtain a diverse group of participants with a wide range of socio-demographic and clinical characteristics as well as broad experiences with diabetes. All interviews in this study were conducted in private rooms at the various sites: two major hospitals (diabetes out-patient clinics), six general medical practices, four community centres (at times, used for diabetes support groups), and the Faculty of Pharmacy and Pharmaceutical Sciences at Monash University.

2.2.2 Recruitment

To avoid the possibility of neglecting significant 'lay' viewpoints, recruitment strategies used in this study aimed at enrolling participants with maximum variation. A purposive sampling procedure was used to ensure the inclusion of people with diverse socio-demographic characteristics, different diabetic control (measured by HbA_{1c} values), and a wide range of diabetes experiences (measured by duration of diabetes). Participants were eligible to be included in the study if they met the following inclusion and exclusion criteria:

- **Inclusion criteria**

1. Arabic-speaking background (ASB) participants:

  - Diagnosed with Type 2 diabetes mellitus

- Self-identified as ASB, which was defined as someone whose first language is Arabic, born in any of the following countries: Iraq, Kuwait, Bahrain, Oman, Qatar, Saudi Arabia, United Arab Emirates, Yemen, Jordan, Lebanon, Syria or Egypt

2. English-speaking background (ESB) participants:

- Diagnosed with Type 2 diabetes mellitus
- Self-identified as "Western" which was defined as someone of Anglo or Caucasian identity born in North America, Australia or United Kingdom, New Zealand and whose first language is English.

- **Exclusion criteria (for both groups)**
  - Participants diagnosed with Type 1 diabetes mellitus
  - Participants older than 75 years
  - Participants with any form of malignancy (cancer). This was because it may affect general disease perceptions
  - Newly diagnosed participants (less than 6 months) with Type 2 diabetes. This was because it was felt that participants needed time to gain the necessary experience of diabetes self-management.

2.2.3 Ethical considerations

The study protocol was approved by the Monash University Human Research Ethics Committee, the Austin Health Human Research Ethics Committee and the Western Health Human Research Ethics Review Panel (Appendix 1, Appendix 2 and Appendix 3). Assistance was also provided by the Victorian Arab Social Services (Appendix 4). Written informed consent was obtained from each participant prior to commencement of the study; patient information sheets were given to participants providing full description about research and involved procedures (there were available either in Arabic and English). Consented participants were reminded that taking-part in this research is voluntary, and if they decided to withdraw from the project they can at any stage prior to beginning of the interview/focus group or in case they become distressed during the conduct of the focus group. Prior beginning of interviews all participants were reminded that any information obtained in connection with this research project that can identify them will remain confidential and will only be used for the purpose of this research project. Obtained information was securely stored in de-identified form at Monash University.

2.2.4 Data collection and analysis

Demographic information was gathered from eligible participants prior to the interviews and/or focus group sessions using a self-completed questionnaire whereas contact details for their doctor and permission to obtain clinical data was obtained afterwards (Appendix 7; Face and content validities of the questionnaire were established following review by two university academics, and five patients). All interviews and focus group sessions with ASB participants were conducted in Arabic without an interpreter, because one of the researchers spoke Arabic fluently. The choice of research questions was guided by Kleinmans' EM.

Interviews and focus groups with ESB participants were conducted in English. All focus groups and interviews were audio-recorded and transcribed verbatim. Arabic transcripts were translated into English by an independent translator and by the Arabic speaking researcher, and the two versions were compared for any discrepancies. Differences were resolved by discussion between the two parties. The transcripts were entered into NVivo (QSR NUD Vivo: version 8.0) software for thematic analysis. After each interview, new data were analysed and new codes and themes were developed that were used to probe for information in subsequent interviews. Data collection continued until data saturation was reached, when no new and relevant information arose.

The multistage process of thematic analysis began with a line-by-line reading of the text to identify the range of responses to the research questions. Data were coded and organised into themes that described the perceptions and views of participants. The author carried out initial analysis, while two members of the research team separately analysed 30% of the transcripts to compare coding and emerging themes. Discrepancies were resolved through discussion.

2.2.5 The Research focus of this chapter

The results reported in this chapter address the following questions posed to the sample of participants with diabetes: both ASB participants and ESB participants:

1. What do you think has caused your diabetes?
2. When someone says 'diabetes', what comes to your mind? What image you have for a person with diabetes?
3. What do you think diabetes does to you? How does it affect your body?
4. How severe is your diabetes? Will it have a short or long course?
5. How do you perceive the effectiveness of prescribed diabetes treatment?
6. What is/are the treatment for diabetes? What kind of treatment do you think you should receive; please reflect back to the time of diabetes diagnosis?

Overall this chapter addresses two specific research questions: What is the EM of diabetes from the perspective of ASB participants? And how do the diabetes EM of ASB participants' compare with the EM of ESB participants?

2.2.6 Limitations

Although recruitment strategies used in this study aimed at enrolling ASB immigrants with maximum variation, however, purposive and non-probabilistic sampling process may preclude any generalisation or extrapolation of findings without further research. Absence of cultural difference between the author and ASB interviewees has helped in obtaining participants' perceptions in a permissive, non-threatening environment and delivering questions in a very clear and cultural-appropriate language. Given the very strong preference of most ASB participants for discussing diabetes and its treatment in a gender-separated session, for all female focus groups a Muslim female research assistant was present helping not only in taking flied notes during the interviews but also in making sure that female participants are comfortable.

2.3 RESULTS

2.3.1 Study participants

A purposive sample of 100 participants with diabetes was recruited in the two groups: 60 ASB participants and 40 ESB. Recruitment continued until data saturation was achieved. Twenty-eight individual interviews and 14 focus group sessions involving a further 72 participants were conducted.

2.3.2 Participants' characteristics

The socio-demographic and clinical characteristics of the 100 participants are shown in Table 1. The two groups of participants were of a similar age, had a similar gender representation (male to female ratio) and range of co-morbidities. More participants in the ESB group compared to those participants in the ASB group had well-controlled diabetes. Use of insulin to control diabetes was higher among the ESB group. Compared to the ASB group, more of the ESB participants were working, either part-time or full-time.

Participants described their perceptions and viewpoints of their diabetes using each of the five constructs of Kleinman's EMs. Resultant themes, sub-themes, and categories related to each construct are reported in Table 3.

Table 1: Participants' socio-demographic and clinical characteristics

Characteristic	Percentage or mean (number or range)	
	ASB (n=60)	ESB (n =40)
Gender		
- Female	63% (38)	60% (24)
- Male	37% (22)	40% (16)
Mean age, years (range)	57 (35-68)	60 (54-69)
Mean years since diabetes diagnosed (range)	9 (1-17)	7 (3-14)
Mean years in Australia (range)	8 (3-18)	NA
Diabetes status (HbA1c)*		
- Excellent control (6–6.9%)	5% (3)	17.5% (7)
- Good control (7–7.9%)	46% (28)	47.5% (19)
- Indifferent control (8–8.9)	20% (12)	22.5% (9)
- Poor control (9–9.9%)	22% (13)	40% (1)
- Exceptionally poor control (>10%)	7% (4)	2.5% (1)
Co-morbidity		
- Hypertension	27% (16)	45% (18)
- Dyslipidemia	37% (22)	22.5% (9)
- Retinopathy	15% (9)	12.5% (5)
- Other cardiovascular disorder	21% (13)	20% (8)
Medication (n, %)		
- None	2 (3%)	3 (7.5%)
- Oral hypoglycaemic medications	48 (80%)	22 (55%)
- Insulin	6 (10%)	7 (17.5%)
- Both, oral and insulin	4 (7%)	8 (20%)
Family history of diabetes mellitus	35% (21)	32.5% (13)
Workforce participation		
- Working part-time	32% (19)	45% (18)
- Working full-time	15% (9)	27.5% (11)
- Housewife	37% (22)	12.5% (5)
- Pensioner	5% (3)	12.5% (5)
- Unemployed	11% (7)	2.5% (1)
Living arrangement		
- Married and living with spouse and/or children	97% (58)	67.5% (27)
- Living alone	3% (2)	32.5% (13)
Proficiency with English (self-rated)		
- Little or none	35% (21)	NA
- Moderate	47% (28)	
- Excellent	18% (11)	
Country of birth		
- Lebanon	38% (23)	NA
- Jordan	7% (40)	
- Iraq	18% (11)	
- Syria	5% (3)	
- Egypt	32% (19)	

ASB= Arabic-speaking background patients; ESB= English-speaking background patients

Table 2: Participants' characteristics

Participants	Age	Gender	Type of interview		Glycaemic control (HBA$_{1c}$ level)
			Focus group session	Semi-structured individual interview	
1. ASB-1	60	Male	✓		9.4
2. ASB-2	64	Male	✓		9.2
3. ASB-3	38	Male	✓		6.8
4. ASB-4	66	Male	✓		9.4
5. ASB-5	52	Male	✓		7.8
6. ASB-6	48	Male	✓		7.4
7. ASB-7	61	Male	✓		7.6
8. ASB-8	58	Male			7.4
9. ASB-9	64	Female		✓	8.4
10. ASB-10	58	Female		✓	7.2
11. ASB-11	56	Female		✓	7.8
12. ASB-12	64	Female	✓		7.6
13. ASB-13	61	Female	✓		7.8
14. ASB-14	59	Female	✓		8.4
15. ASB-15	60	Female	✓		8.7
16. ASB-16	46	Female	✓		7.6
17. ASB-17	62	Female	✓		10.6
18. ASB-18	60	Female	✓		7.4
19. ASB-19	63	Female	✓		7.2
20. ASB-20	56	Female	✓		9.6
21. ASB-21	51	Female	✓		7.6
22. ASB-22	58	Female	✓		8.7
23. ASB-23	48	Female	✓		6.9
24. ASB-24	70	Female	✓		9.4
25. ASB-25	54	Female	✓		7.4
26. ASB-26	63	Female	✓		7.6
27. ASB-27	66	Female		✓	9.3
28. ASB-28	59	Female		✓	7.2
29. ASB-29	68	Male		✓	8.7
30. ASB-30	38	Male		✓	7.2
31. ASB-31	47	Female		✓	6.9
32. ASB-32	52	Male		✓	9.4
33. ASB-33	51	Female		✓	8.2
34. ASB-34	60	Female		✓	7.4
35. ASB-35	52	Male		✓	9.2
36. ASB-36	53	Male		✓	8.4
37. ASB-37	64	Male		✓	9.2
38. ASB-38	44	Male	✓		7.0
39. ASB-39	60	Female	✓		9.6
40. ASB-40	59	Female	✓		7.8
41. ASB-41	61	Female	✓		8.3
42. ASB-42	57	Female	✓		8.2
43. ASB-43	64	Female	✓		10.2

44. ASB-44	53	Female	✓		7.2
45. ASB-45	64	Male	✓		9.4
46. ASB-46	56	Female	✓		7.0
47. ASB-47	57	Female	✓		8.2
48. ASB-48	68	Female	✓		9.4
49. ASB-49	63	Male	✓		9.6
50. ASB-50	35	Male	✓		7.3
51. ASB-51	62	Male	✓		10.4
52. ASB-52	67	Male	✓		7.4
53. ASB-53	59	Male	✓		7.8
54. ASB-54	49	Male	✓		7.0
55. ASB-55	61	Female	✓		8.2
56. ASB-56	64	Female	✓		10.4
57. ASB-57	59	Female	✓		7.2
58. ASB-58	62	Female	✓		8.2
59. ASB-59	67	Female	✓		7.6
60. ASB-60	62	Female	✓		7.8
61. ESB-61	56	Female	✓		6.5
62. ESB-62	63	Female	✓		8.4
63. ESB-63	68	Male		✓	7.4
64. ESB-64	64	Male		✓	7.2
65. ESB-65	59	Male		✓	7.6
66. ESB-66	58	Male		✓	7.8
67. ESB-67	64	Female	✓		8.4
68. ESB-68	61	Female	✓		6.5
69. ESB-69	59	Male	✓		6.4
70. ESB-70	62	Female	✓		7.4
71. ESB-71	60	Female	✓		7.2
72. ESB-72	57	Female	✓		10.8
73. ESB-73	66	Male	✓		8.2
74. ESB-74	67	Male	✓		8.2
75. ESB-75	68	Male	✓		7.6
76. ESB-76	58	Male	✓		7.2
77. ESB-77	66	Female	✓		7.4
78. ESB-78	69	Male	✓		9.6
79. ESB-79	57	Female	✓		7.8
80. ESB-80	56	Male		✓	7.4
81. ESB-81	60	Male		✓	9.2
82. ESB-82	54	Female	✓		6.8
83. ESB-83	59	Female	✓		6.4
84. ESB-84	62	Female	✓		7.6
85. ESB-85	67	Female	✓		8.4
86. ESB-86	68	Female	✓		7.6
87. ESB-87	57	Male	✓		6.8
88. ESB-88	67	Male	✓		7.6
89. ESB-89	62	Female		✓	9.4
90. ESB-90	64	Female		✓	7.2

91. ESB-91	64	Female		✓	8.2
92. ESB-92	58	Female		✓	7.8
93. ESB-93	59	Female		✓	9.2
94. ESB-94	63	Female	✓		8.4
95. ESB-95	58	Female	✓		7.9
96. ESB-96	62	Female	✓		8.4
97. ESB-97	55	Female	✓		7.2
98. ESB-98	58	Female	✓		6.4
99. ESB-99	66	Female	✓		7.2
100. ESB-100	64	Female	✓		8.4

Table 3: Participants' understanding of diabetes and its treatment

Constructs of Kleinman's Explanatory Model of illness*	Themes	Sub-themes	Categories
1. Aetiology	Beliefs about causes of diabetes	Cultural factors	Intense emotional traumas - death of a close family member - fears post physical traumas i.e. car accident
			Cumulative stresses - strong bonding between family members was viewed to be a source of chronic stress
			Migration - separation from home ties - re-location in a strange country with different language and different cultural norms
		Religious factors	Fatalistic views about health and illness
		Biomedical factors	Hereditary factors
			Lifestyle-related factors - inappropriate dietary behaviors - lack of exercise and physical activity - Obesity
2. Time of onset	Beliefs about symptoms of diabetes	Symptoms of diabetes	Hypoglycaemia and hyperglycaemia
	Meaning of the diagnosis of diabetes		

3. Pathophysiology	Beliefs about pathophysiology of diabetes i.e. mechanisms of disease		
4. Course of illness	Beliefs about course of diabetes		
5. Treatment	Beliefs about treatment of diabetes		

*Constructs of Kleinman’s Explanatory Model of illness.[308]

2.3.3 Aetiology: participants' beliefs about the causes of diabetes

Based on participants' responses, the causes of diabetes could be grouped into three categories: cultural, religious, and biomedical factors. The majority of participants in the ASB group believed that cultural and religious factors predisposed them to develop diabetes. In contrast, the majority of ESB participants believed that biomedical factors were the cause.

2.3.3.1 Cultural and religious causes

Within the ASB group, both emotional and physical traumas were cited as the causes for developing diabetes. The participants described emotional trauma as immensely stressful events that generated intense emotions such as severe distress, anxiety, and fretfulness. They believed that these intense emotions affected their bodies and caused diabetes.

> *"… I got diabetes because I was saddened very much after the death of my younger sister. I loved her very much, and she was like my daughter. I got diabetes right after her death." ASB-17*
>
> *"… My son is very special. I loved him more than life itself … he broke my heart* **[when he died]** *… my body couldn't deal with this shock, so I got diabetes. Strong shock can cause diabetes." ASB-42*
>
> *"… I got diabetes because of too much stress in my life. I lived most of my life in Iraq and we had wars for the last 25 years. I think all that accumulative stress and suffering made me have diabetes." ASB-26*

Arabic-speaking background participants also attributed the development of their diabetes to migration. They talked about difficulties encountered in adjusting to their new lifestyle in Australia, including not being able to speak English and fears about raising children in a country with different cultural traditions. When they were probed about what effect migration had had on their health and why they linked the development of diabetes with migration, they talked about experiencing depression and anxiety due to loss of their homeland.

> *"It's not easy to be displaced from your homeland. I felt I lost my world when I left Iraq. Yes, life was difficult there, but I still feel depressed knowing that I can't go back. It's very sad to lose 'home'… all these sad emotions have effects on my body. Sometimes, I think I'm lucky that I ended up with diabetes. It's still better than other diseases." ASB-5*

Some participants also presented a different view, believing that migration was a reason for attaining better health.

> *"I think now I have better health compared with when I was back in Jordan. Here* **[Australia]** *they have a very good health care system. Doctors actually care about people. We can access medical services without big concerns about costs. Now I have started to take better care of myself." ASB-38*

Physical trauma was also blamed as a cause by ASB participants.

> *"… I got diabetes 15 years ago. I had a car accident. I was very much afraid, and around 10 months after that* **[accident]** *I learnt that I have diabetes." ASB-7*

Contrary to the ESB participants, where religion seemed not to play a significant role in their EM of diabetes, all the participants in the ASB group expressed very strong religious beliefs. They believed that they have little say about the events of their lives, that God (Allah) has the ultimate power and that His will determines the course of their life, and therefore that diabetes was meant to happen. Fatalistic thoughts about health and illness were frequently cited as a factor for the development of diabetes. Participants believed Allah's (God) will determines the individual's '*razzaq',* a term referring to financial status, health status, and achievements that are preordained events of life. In gauging ASB participants' religious views, two distinct thought patterns were expressed. Some ASB participants seemed to be indifferent about their health status, as they believed that diabetes was meant to happen, whereas others viewed Allah's will as a support structure, in which they can make amends with having diabetes.

> *"I don't think too much about why and what caused my diabetes. In this life, Allah knows everything, He is almighty. When I was born I had my 'razzaq' predetermined for me. This*

> *'razzaq' includes prosperity, health status; whether or not one I would have children, finances, etc. The way I see it, is that I was destined to have diabetes. So I accepted it as is." ASB-59*

2.3.3.2 Biomedical causes

Biomedical causes of diabetes cited by participants in both groups included: inappropriate eating patterns (including high sugar intake), sedentary lifestyle (minimal engagement in exercise), heredity, consuming too much alcohol, being overweight, and not taking care of oneself. English-speaking background participants, however, had a better understanding about the causes of diabetes, regularly attributing the development of their diabetes to lifestyle-related factors, heredity and the body's deteriorating functioning with age.

> *"My eating habits used to be very bad. After so many years, my pancreas couldn't handle it anymore and I got diabetes" ESB-100*
>
> *"It's not one thing that caused me to have diabetes. It's my wrong eating patterns, incorrect lifestyle… I also used to drink too much, and I got it when I turned 61 years, so I guess ageing counts." ESB-98*
>
> *"I used to eat lots of sugar and fatty foods for so many years, plus I had a family history of diabetes, so when I was told that I have diabetes I wasn't shocked!"ESB-67*

In comparison, ASB participants more frequently cited cultural and religious causes, with only a few citing inappropriate eating patterns: eating too much sugar, high carbohydrate and fat content in traditional Middle Eastern food, large portion sizes, being over-eaters.

> *"You know we typically eat large portions of food at lunch and dinner and there are lots of fats in our foods. We tend to eat very big lunches and go to sleep for two hours after that. No exercise whatsoever, and when we drink tea we load it with sugar. I can't believe that I used to drink 5 to 6 cups of tea a day, each cup with lots of sugar…. Of course I ended up with diabetes!" ASB-19*

Although ASB participants reported heredity as one cause of diabetes, their responses reflected a misunderstanding of the level of influence this risk factor had on the development of diabetes.

ASB participants' indicated that they felt that diabetes was inherited, due to the large number of family members, friends, and peers who had diabetes.

> *"If diabetes runs in your family, you will have it. Nothing can be done about it." ASB-37*

2.3.4 Time of onset: Participants' beliefs about the onset of the symptoms of diabetes

When asked about their knowledge of symptoms of diabetes, participants' responses fell into three categories: knowledge of diabetes symptoms at diagnosis, current physical symptoms associated with diabetes, and hypoglycaemia and hyperglycaemia.

Before diabetes was medically diagnosed, ASB participants had a poor understanding about typical diabetes symptoms, although they were already experiencing them. They struggled to understand what they were experiencing at the time of diagnosis.

> *"I knew something was wrong. I had some symptoms, but I didn't know that they were of diabetes. If I knew that, I probably would have taken it more seriously and gone to a doctor sooner." ASB-19*

> *"I had no idea about diabetes symptoms. I heard about it* [diabetes] *and I knew it was a pretty serious disease. But as for the symptoms that come with this horrible disease, I had no idea." ASB-40*

A few ASB participants stated that they knew diabetes symptoms, yet when they were asked to list them, they could not. Even though ASB participants recognised symptoms as 'abnormal', they seemed not to seek immediate medical attention; rather, they decided to ignore them. They took time to observe and evaluate these 'abnormal' symptoms, mainly to see whether they worsened, persisted or resolved. On a few occasions, ASB participants declared that they suspected their symptoms could be diabetes-related.

> *"I felt something was wrong. I had some symptoms for quite some time, but I didn't go to doctor to have a check." ASB-15*

> *"If there was a severe pain, one would go to see a doctor immediately, but in my case I was just feeling tired and exhausted most of the time. Later, I started to realise that I was thirsty and went to the toilet many times. A long time after that I decided to go and see a doctor and I was told I had diabetes." ASB-7*

It was only after symptoms persisted or worsened that participants decided to access medical services. They feared a medical diagnosis of diabetes, preferring not to know that they had diabetes.

> *"I knew about diabetes symptoms; my mother had diabetes, and my best friend had it too. I suspected that I had diabetes based on the symptoms I had, but I just preferred not to follow up on it. I didn't want to be 'officially' told that I had diabetes. It is a very difficult disease and hard to manage. I preferred not to find out more, so I postponed a check-up for a while." ASB-4*

Compared with ESB participants, ASB participants more frequently reported experiencing symptoms of diabetes that included sadness and depression, tiredness and fatigue, being overwhelmed, blurred vision, and headaches.

> *"Diabetes affects my life immensely. I feel overwhelmed and tired most of the time. I have no energy to do anything. I feel sad most of the time." ASB-32*

Participants in the ESB group appeared to have a better understanding of diabetes symptoms, compared with ASB participants. They knew the most common symptoms associated with diabetes including: blurred vision, fatigue and tiredness, dry mouth and feelings of thirst, and frequent urination.

> *"I knew I had diabetes I started to feel tired, thirsty and went to toilet. All the classical symptoms" ESB-74*
>
> *"I had lots of symptoms for months, but I did not know they were related to diabetes" ASB-3*

Participants in both groups viewed hypoglycaemia as a major concern. They were able to describe symptoms associated with hypoglycaemia including feeling faint, muscle shaking, dizziness and palpitations. Participants in both groups reported great fear of hypoglycaemic attacks.

> *"Hypoglycaemia is pretty bad. Once I felt I was going to die! I pray that you won't ever experience such feelings." ASB-28*
>
> *"I feel like all my energy is drained out of me. My body becomes so weak and I start shaking. Sometimes, my heart beats fast. It may sound like it is not serious but it feels really bad." ASB-29*
>
> *"I believe that every patient with diabetes can describe hypoglycaemia very well! It's really scary, but we all have lollies and we knew how to deal with it" ESB-89*

Responses from ASB participants suggested that hyperglycaemia was perceived to be less serious, compared to hypoglycaemia:

> *"I'm much more afraid of low sugar in my blood. It feels really bad. If I had to choose, I would rather have it* **[blood sugar]** *too high than have it too low." ASB-36*

2.3.5 Meaning of the diagnosis

Participants spoke about what it means to have diabetes. Although participants in both groups reported emotional reactions such as fear, anxiety, worry and nervousness that were coupled with their diagnosis, the intensity of these emotions varied between the two groups. More negative emotions were reported by ASB participants, compared with their ESB counterparts.

> *"Surely diagnosis with diabetes is very unpleasant for many people. But for me it was traumatic. I saw images in my head of very ill, amputated, depressed men. I wasn't imagining or anything, I just saw myself becoming like my father who also had diabetes. He had very poor health and was ill most of the time. Diabetes brought so many other diseases along with it." ASB-33*

The way in which the doctor informed the participants about their diagnosis seemed to have an impact on participants' reactions. For the ASB group it generated negative emotions.

> *"… I remember how little the doctor told me about diabetes. I felt I was all alone with this awful disease. I knew nothing and I was overwhelmed." ASB-51*

There was a trend in the relationship between the place of diagnosis and intensity of negative emotions associated with the diagnosis. It appears that ASB participants who were diagnosed in the Middle East had more negative reactions regarding their diagnosis than those diagnosed in Australia.

> *"I was terrified when the doctor said I had diabetes. I remembered that he spent most of the 5-minute consultation writing my prescription. He told me how to use these pills and a couple of other instructions about diet, and that was pretty much it. I had lots of questions, concerns, and fears that I never had the chance to discuss. I learnt over the years from peers and friends with diabetes how to manage this disease. There is no support whatsoever back there* **[in the Middle East]***." ASB-19*

In contrast, those diagnosed in Australia felt more positive regarding their future with diabetes.

> *"I was very nervous when I was told that I had diabetes. I felt my life was almost ended. I wouldn't be able to eat the same food I used to, I would have other diseases, I might have my legs amputated or my eyes would be affected. But after a while, the doctor told me that nowadays diabetes can be looked after, it could be managed, and I took comfort from his continual support. I'm lucky I'm here in Australia. I wouldn't get the same care back there* **[in the Middle East]***." ASB-47*

Negative connotations and labels associated with diabetes were reported by ASB participants, but not by participants in the ESB group. Arabic-speaking background participants reported that in the Middle East, diabetes is generally associated in people's minds with poor health status, therefore diabetic males were perceived as 'weaker'.

> *"Diabetes is perceived as a serious disease. When a male is diagnosed with it at a young age, people may look at him as a 'sick person' or 'weak'. This illness doesn't come alone, many other illnesses accompany it." ASB-44*

English-speaking participants had very little to say about perceived images of an adult with diabetes compared with ASB participants. When ASB participants reflected on perceived images of a person with diabetes, both males and females talked about the social stigmatisation associated with diabetes. Females spoke of a female with diabetes being a 'less desirable bride' because of the fear of passing diabetes onto children:

> *"Having diabetes is a terrible thing… You know how things are back in the Middle East. If a girl is known to be sick, she would end up with fewer opportunities to get married. I wouldn't allow my son to marry a girl who has diabetes. I would just be concerned about his future kids; they might have it* **[diabetes]** *if their mother has it." ASB-46*

Male participants' perspectives on the public image of an adult with diabetes were mainly concerned with potential sexual dysfunction, especially when diagnosed with diabetes at a young age.

> *"I heard that diabetes has an impact on sexual performance. In TV shows back in the Middle East* **[educational shows about marriage relationships]**, *the first question that the experts or the doctors ask any caller is if he has diabetes. So people assume that diabetes inevitably affects sexual function. It is not good to be known among your peers to have diabetes." ASB-35*

2.3.6 Beliefs about the pathophysiology of diabetes

Arabic-speaking background participants did not appear to have a basic understanding about the pathophysiology of diabetes. In contrast, ESB participants had a better understanding; they talked about the relationship between insulin and sugar in the blood. Some described the failure of the pancreas to produce enough insulin in people with diabetes. Within the ESB group, participants also talked about the development of diabetes complications as a result of elevated glucose levels in the blood.

2.3.7 Beliefs about the course of diabetes

Participants with a relatively longer history of diabetes and those who had developed diabetes-related complications considered diabetes as a more serious illness than those who were recently diagnosed. At the time of diabetes diagnosis, ASB participants reflected that they did not understand that diabetes is a chronic disease, which often requires life-long lifestyle modification and management.

> *“When I was told that I had diabetes, I had no idea about the illness. I learnt about it over the years. I wasn’t informed much at all. I learnt about diabetes mainly by trial and error and from my peers.” ASB-11*

English-speaking background participants were more knowledgeable about the seriousness of diabetes, compared with ASB participants. They talked about diabetes-related complications and they were aware of the importance of diabetes self-management practices, especially in terms of delaying onset or preventing these complications.

2.3.8 Beliefs about the treatment of diabetes

The two groups of participants had different approaches to treating diabetes as well as different attitudes toward ‘conventional’ or ‘western’ treatment modalities. English-speaking background participants reported greater belief in the effectiveness of diabetes treatments than ASB participants, generally acknowledging that oral medications, modification of dietary habits, engagement in physical activity and the use of insulin are the main treatment options for people with diabetes.

In comparison, ASB participants were somewhat sceptical about the use of western medicine. All ASB participants, however, believed that alternative therapies (herbal products) are safe and effective treatments for diabetes and had used them for management of their diabetes.

> *"These herbal medicines are safe. They come from nature, so there are no chemicals, no poisons." ASB-33*

Arabic-speaking background participants talked at length about their use of traditional treatments, either in conjunction with prescribed treatment or instead of their prescribed treatment. Within ASB communities, the advice of peers about the effectiveness of alternative treatments seemed to provide validation for the uptake and use of these treatments.

> *"When someone you know and trust says that these herbs work, you believe him/her don't you?" ASB-40*

Some participants changed their views and attitudes towards herbal treatments. They became more sceptical and developed more negative attitudes towards the use of herbal treatments when these treatments failed or when participants experienced an exacerbation of their disease. Only after ASB participants came to their own decision that these herbal treatments were not improving their diabetes symptoms were they willing to stop using such treatments and resume their prescribed (Western) diabetes treatment.

> *"I started using herbs, special tea; made of seven tree leaves boiled in hot water I was told it is very good for diabetes. I tried it for six months. I could feel that I wasn't ok, but I kept using it! Meanwhile, I stopped my diabetes pills. I was very ill, they took me to a hospital and they gave me insulin as my blood sugar level was very high. They* **[the healthcare providers]** *told me that my kidneys were affected. After that, I stopped the herbs and used the prescribed pills* [OHAs] *only. It was a bit late though." ASB-23*

It appears that participants often did not inform their GPs about use of herbal treatments.

> *"I did not tell my doctor, and he did not ask me." ASB-37*

More ESB participants were prescribed insulin compared to ASB participants (Table 1). Both groups viewed insulin use as a sign of diabetes becoming more serious. Arabic-speaking background participants, however, reported active resistance to using insulin when it was proposed by their treating doctor. They expressed fear of the use of insulin, recalling people who had died shortly after insulin was initiated, thereby associating the use of insulin with death.

> *"I heard that insulin had lots of side effects. My doctor discussed with me the possibility of starting insulin, but I refused it completely. I was terrified!" ASB-30*
>
> *"I don't want to use insulin. It's very bad. Once people start using it, it means they might die soon. My grandmother died pretty soon after she started to use insulin." ASB-14*

Participants raised concerns about the difficulty associated with insulin use. One ESB participant described his concerns about the use of insulin in public. Injecting insulin was sometimes mistakenly perceived as something akin to 'drug use'.

> *"What most concerned me with insulin is whether or not I could learn how to use it properly. I think it is not an easy task at all to administer insulin. I prefer to use pills." ASB-38*
>
> *"I'm a truck driver. Sometimes I inject insulin in public toilets. It hurts to see some people think that I'm using a* **[illicit]** *drug or something. I can tell from the looks in their eyes." ASB-36*

2.3.9 Relationship between EMs and glycaemic control

This study also explored the relationships between EMs, self-care and diabetes control. Results indicated that EMs of diabetes relate to diabetes control (measured by glycated haemoglobin [HbA_{1c}] value). Arabic-speaking background participants, who mainly reported the cultural belief model, seemed to have worse glycaemic control compared with their ESB counterparts who reported biomedical models. In this study, only 20% of ASB participants attained glycaemic control of <7%, compared with 47% of ESB participants (Table 1 and Table 2).

2.4 DISCUSSION

This research investigated challenges in diabetes care in ASB immigrants in Victoria, Australia, a previously underexplored subject in this ethnic minority group. It is known that participants' beliefs about causes of diabetes have an important role in shaping self-care behaviours.[322] This chapter explored Kleinman's EM of diabetes among ASB and ESB participant groups and corroborated the findings of a limited number of previous investigations conducted among other ethnic minority groups.[306, 307, 317, 323]

The results showed that EMs of diabetes differed between the two participant groups. All five constructs of Kleinman's EM showed elements of difference between the views of ASB and ESB participants. Furthermore, two of the constructs, beliefs about the causes of diabetes, and beliefs about the treatment of diabetes, showed important differences related to the cultural belief and biomedical interpretation of diabetes that have the potential to impact the self-management and outcomes and these will be the focus of discussion.

Arabic-speaking background participants reported reliance on cultural belief models whereas ESB participants predominantly used a biomedical model of diabetes, similar to results of Luyas et al and Jezewski et al where Mexican-American participants also reported elements of cultural belief models of diabetes.[306, 317]

2.4.1 Beliefs about the causes of diabetes

The focus of ASB participants on intense emotions as a central explanation for their diabetes is consistent with findings of research conducted among other ethnic groups with diabetes such as Mexican Americans, where they reported strong emotions (*susto*; a word used to describe a very frightening experience) as the cause for the development of their diabetes.[290, 306, 324]

In this study, religious factors formed part of the ASB participants' causal explanations for the development of diabetes. Arabic-speaking background participants are known to hold strong religious beliefs.[325] In 2000, Al-Krenawi and Graham reported the influential role of religion in Arab societies, finding it to be an important context wherein problems are constructed and resolved.[198] Hjelm et al. investigated beliefs about health and diabetes among men from different cultural backgrounds living in Sweden and concluded that, similar to results obtained from ASB participants in this study, religion was considered to be of great importance for the Arabic group in understanding their medical conditions.[197]

Participants' ideas about the cause of their diabetes have been proposed to be associated with self-care behaviours.[194, 326] Results of the current study suggest a relationship between causal factors described by participants and self-care practices that is consistent with research reported by Hunt *et al*. in a Mexican population.[209] English-speaking background participants who cited their own past behaviours as the contributory factors for the development of their diabetes seemed to be more actively involved in self-management behaviours as evidenced by seeking medical advice sooner after the development of symptoms. In contrast, ASB participants who cited cultural and religious factors, with far less emphasis on their own behaviours as triggering factors for development of diabetes, delayed their diagnosis until symptoms were severe and also had poorer self-management practices.

Participants' perspectives about causes of diabetes have also been reported for other ethnic minority groups with diabetes, such as the Dakota Indians. Participants' interpretations and narratives indicated that diabetes was integrated with their cultural history and identity, similar to the ASB participants.[327] Research among Canadian Anishinaabe (Ojibway) communities, however, reported that these communities seemed to link diabetes to their individual choices more like the ESB participants.[328, 329]

2.4.2 Beliefs about the treatment of diabetes

Arabic-speaking background participants' beliefs about diabetes treatment gave high priority to the use of herbal treatments before considering Western medicine. Especially at the early stage following diagnosis, minimal discussion with healthcare provider, lack of knowledge about diabetes treatment, fears and concerns about 'Western medicines', and beliefs that herbal treatments are safe and effective led them to rely heavily on herbal medicines. Arabic-speaking background participants are known to use alternative treatments, often without the knowledge of their healthcare professionals.[325, 330, 331] Use of alternative treatments among ASB group did not appear to be influenced by religious beliefs, most seemed to use alternative remedies as a consequence of the recommendations made by their peers within ASB communities.[307]

2.5 CONCLUSION

Participants in both groups had specific views on what triggered the development of their diabetes. Arabic-speaking background participants felt that external factors, rather than their own health-related behaviours, were the cause of their diabetes (e.g. Allah's will, fate, trauma, cumulative stress, heredity), while ESB participants were more likely to blame personal lifestyle behaviours (e.g. inappropriate eating habits, lack of exercise and obesity) as causal factors for developing diabetes. These results contribute to existing body of literature on diabetes health education by way of exploring ASB immigrants' knowledge and perceptions about diabetes and its management using constructs of Kleinman's EM. Findings reported in this chapter have implications for the delivery of healthcare and education, especially for the ASB population with diabetes.

CHAPTER THREE: HEALTHCARE SEEKING BEHAVIOURS IN PATIENTS WITH DIABETES

KEY POINTS ABOUT THIS CHAPTER

This chapter describes:

- Factors influencing the access to, and the use of, healthcare services among two groups of participants: those of Arabic-speaking and English-speaking background.

Summary of findings:

- Multiple factors that influenced healthcare seeking behaviours were identified.

3 Healthcare seeking behaviours in patients with diabetes

3.1 BACKGROUND

Populations in upper-middle and high income western countries are becoming increasingly multi-ethnic as a result of a rise in migration.[332] Many studies have looked at the healthcare seeking behaviours and utilisation of health services by ethnic groups. Results showed that ethnic minority groups underutilised and delayed access to health care services, when compared with their non-immigrant counterparts.[158, 333-336]

Andersen and Newman discussed determinants of patients' healthcare seeking behaviours and accessing of medical services at two levels - societal and individual.[337] In Australia, with other publicly funded health care systems, access and utilisation of healthcare services are primarily dependent on each patient's decisions.[338] Findings of previous research suggest that patients' delay in seeking medical help is one of the key factors that determine outcomes of health care,[339, 340] resulting in late treatment, and leading to missed opportunities to impact fast response with consequent increase in the probability of severe morbidity.[341-343] The focus of this research, therefore, was to examine individual determinants of healthcare seeking behaviours.

Numerous studies have been conducted within various social and cultural settings and across a wide range of diseases to gain an in-depth understanding of the patient's decision-making process through which they judge their need to use and access available medical services.[176, 344-346] Delay in, and barriers to, accessing healthcare services is recognised as a major concern and has been investigated among ethnic minorities at three levels; patients, health care providers, and systems.[163] Amongst identified barriers to the use of healthcare services among these groups are: patients' appraisal and knowledge of the symptoms, anxiety and depression, health and cultural beliefs, language problems, low level of acculturation, perceptions about health care providers, and lack of private health insurance and high medical costs.[347-349] In Australia, lack of health insurance is not necessarily a barrier, especially since the extent of financial hardship resulting from out-of-pocket medical expenditures is reduced by the Australian government's Medicare system.

Limited information is available about health care seeking behaviours in patients with T2DM.[350 197] It is important to understand factors associated with patients' delay in seeking medical care especially in diabetes where timely diagnosis and treatment limit the chances of developing serious complications and ameliorates the burden of disease.[351-353] Within this context, only a single study, which was conducted among Yugoslavians and Arab men in Sweden, could be found.[197] The study focused on how health health beliefs affected patients' care-seeking behaviour. The author concluded that Arabs showing an active information-seeking behaviour had sought help from health care professionals to a greater extent compared with Swedes and former Yugoslavians.[352] Information about health care seeking behaviours specific to Arabic-speaking background (ASB) immigrants with diabetes is lacking, as is information about this population in Australia.[197]

Without greater understanding of why people delay accessing treatment, current interventions that aim at improving timely access to services may be less effective.[354] The current study aimed to explore how ASB immigrants with T2DM in Victoria, Australia made their decision to seek medical care at the time of development of diabetes symptoms and factors that influenced their decision.

3.2 METHODS

This study used two qualitative methods; semi-structured interviews and focus groups to capture culturally-relevant information about variables of interest (Chapter 2, section 2.2).

3.3 RESULTS

3.3.1 Participant characteristics

The description of study participants, a total of 100 participants in the two groups, is reported in chapter 2, section 2.3.1.

Six main themes emerged from the interviews and focus groups that seemed to influence participants’ healthcare seeking behaviours. Access to, and use of, currently available health services varied between the two groups of participants. Arabic-speaking background participants intentionally delayed accessing medical services when signs of ill-health appeared, resulting in a late diagnosis of T2DM. When participants in both groups were asked about their health care behaviours after receiving the medical diagnosis of T2DM, participants’ responses in the ASB group were different to those of ESB group. Overall, ASB participants reported using herbal products while discontinuing, or not commencing, their prescribed diabetes treatment. Use of these alternative treatments was without knowledge of their healthcare providers and appeared to continue until participants recognised that such treatment modalities were not effective in attaining adequate glycaemic control. By contrast, ESB participants reported following prescribed diabetes treatment and appeared doubtful about use of herbal treatment (Chapter 2.3.8) Unique socio-cultural and religious beliefs that hindered ASB participants’ access to diabetes health services were reported. More negative views and beliefs about healthcare providers were expressed by ASB participants compared to the ESB group.

The findings reported in this chapter are focused on describing the six main themes that influenced participants’ healthcare seeking behaviours (below).

3.3.2 Making sense of symptoms

Recognising and identifying symptoms marked the beginning of the decision-making process to seek healthcare for participants in both groups. The majority of ASB participants, however, struggled to understand what they were experiencing at the time of onset of diabetes. In cases where symptoms were perceived as ‘less dramatic’, ASB participants reported observing these symptoms and adopting a ‘wait and see’ culture. During this waiting period, which varied among participants and ranged from four weeks to more than a year, the experienced symptoms were observed to see whether or not they worsened, resolved, or persisted. More participants in the ASB group than in the ESB group reported disregarding their symptoms and thought that the most appropriate course of action was to allow time to recover. Contrary to the ESB group, ASB participants reported not seeking medical attention for symptoms commonly suggestive of diabetes. Many ASB participants attributed initial symptoms to a range of non-diabetes related factors mainly cumulative stress. In contrast, many ESB participants reported suspecting that their experienced symptoms could be diabetes-related.

> *“We are* **[ASB people]** *are known to have the ‘wait and see’ mentality. I knew something was wrong with me. But I did nothing about it. I was feeling a bit of blurry eyes when I woke up in the morning and sometimes I was feeling thirsty. It didn’t occur to me that I might be diabetic” ASB-31*
>
> *“I felt tired and thirsty most of the time. I suspected having diabetes. So I went for a check-up and I was told that I have diabetes.” ESB-78*
>
> *“I recognised that I wasn’t quite myself, I mean I was generally tired and fatigued. Initially I didn’t pay much attention, but after a few days I decided to go and see a doctor.” ESB-65*

Male participants in both groups reported a tendency to ignore their symptoms and had a reluctance to have further medical check-ups especially when they had no pain and they were able to function relatively normally. They described a ‘personal threshold of being sick’, which is when it would be appropriate for a man to seek medical help.

> *“I felt tired and my muscles hurt especially my calf muscles, but I ignored these symptoms for a long time. One must not run to see a doctor unless he is very sick. You*

> *know it's quite different for men; we have not to appear very cautious about screening and check-ups. To do so it's not very manly." ASB-44*

> *"I had some mild symptoms, nothing too serious. I did not want to go to see a doctor for just having mild symptoms. But now I think I should have. I would have been diagnosed much earlier." ESB-69*

3.3.3 Presence and influence of another person:

Healthcare-seeking behaviours of ESB patients seemed not to be affected much by significant 'others'; they seemed to be more autonomous when it came to health-related decisions compared with the ASB group. Many of the ASB participants however, elaborated on how the presence of another person influenced their healthcare-seeking decision. For ASB participants, significant 'others' seemed to play important roles, mainly in interpreting experienced symptoms and providing information about what could be the best course of action. The influence of significant 'others' in the ASB group contributed to a further delay in accessing needed medical services. Several participants reported being less independent when it came to health-related decisions.

> *"There are lots of differences between our culture and here* **[western society]***, see for example, I remembered when I realised having certain symptoms e.g. feeling tired, lack of energy, and losing weight my mother in law advised me that all these symptoms are because of stress and I shouldn't be worry. She even advised me to use certain herbal treatment to boost my energy levels and increase immunity." ASB-13*

Arabic-speaking background participants were, however, reluctant to discuss their symptoms with their partners. They were gender-specific as they sought information, advice, help or reassurance about experienced symptoms. Female respondents discussed their symptoms with other female family members or with their female friends; male participants discussed their symptoms with male friends. However, gender differences in accepting and believing advice of significant others was apparent. Female participants' decision-making relied heavily on the other person's recommendations; whereas, male participants did not always take offered advice or believe the other person, especially when the advice was to access medical services.

> *"I knew I need to go to a doctor for a check-up but I didn't want to burden my only son. He has two jobs and takes his father for kidney wash three times a week, so I felt I shouldn't trouble him." ASB-48*
>
> *"I think that's very common in our culture that most people are not accustomed to go to see a doctor for check-ups! It would be unusual for people like me to go to a doctor unless there is something very wrong or I'm in severe pain! If a person can tolerate whatever symptoms he/she might have, then it's more likely that they won't go to see a doctor! Going just for a regular check-ups, is very rare, especially for men! If a man start to be worried or concerned about his health, then he will be perceived as being 'soft' or 'feminine'. I can't imagine myself saying to my wife, for example, that tonight I'm going to see a doctor for a check-up as I'm feeling tired and generally unwell!! She would laugh at me!" ASB-16*

3.3.4 Perception of healthcare providers and perceived accessibility to medical services

Decisions of the ASB group to seek medical care seemed to be influenced by participants' perception of the knowledge, expertise and attitudes of healthcare providers as well as the perceived accessibility to medical services. They reported mainly negative beliefs and stereotypes about healthcare providers as well as a general distrust in the healthcare system. Almost all ASB participants who were diagnosed in the Middle East believed that medical services should only be accessed for medical emergencies, severe pain and serious illness, and should be reserved for life-threatening situations. At times, participants' description of not seeking medical help unless severe pain or loss of ability to function was experienced was reinforced by their experience of healthcare professionals' reactions.

> *"We* **[ASB patients]** *are not used to go to a doctor unless we are in a severe pain or in case of emergencies. I don't know if that's right or wrong! But it's how it is! I still remember that once I went to see a doctor in Jordan just for a check-up, he looked at me*

> *with a funny look, and said that I shouldn't be worried that much about my health especially if all was well with me. That encounter made me sort of reluctant to go to a doctor for just having screening tests or check-ups." ASB-37*

For those ASB participants who were diagnosed in Australia, different views about healthcare providers were voiced. They were less reluctant, embarrassed, or concerned about going to doctors and they had more trust in the healthcare system.

> *"I'm very grateful for healthcare system here* **[Australia]***, I can go and see my GP at any time. There is a follow-up system and everything is computerised. I wouldn't imagine myself going for follow-up appointments and keep a record for my health check-up tests as I do now, if I was still back in Egypt. GPs here* **[Australia]** *are in general more trustworthy than back home." ASB-9*

All ASB participants irrespective of whether they were diagnosed in Australia or in Middle East, reported a preference to access general practitioners (GPs) of Arabic-speaking background. Participants reported that it was more likely for ASB GPs to properly understand their experienced difficulties and concerns, compared with non-Arabic-speaking background GPs, because of shared cultural and linguistic background. Participants in the ASB group were willing to delay their access to medical services if Arabic-speaking GPs were not available. In such situations, this appeared to contribute to further delay in getting needed medical assistance.

> *"I like* **[Dr-XY an ASB GP]***, he really understands me. I can talk to him about my 'real' concerns and problems. I never felt that he judged me. I feel safe with him, maybe because he speaks the same language and have the same cultural background. When he goes overseas, I don't see any other doctor, even if I needed to!" ASB-15*

Compared to the ESB group, there appeared to be a reluctance and fear among ASB participants when they are referred to hospital-based diabetes services, mainly consultations with specialists or endocrinologists. Some ASB participants attributed their unwillingness and fear of accessing such services to the fact that diabetes health professionals at such secondary medical services are more likely to be of non-Arabic-speaking background. ASB participants reported difficulties in relating to hospital consultants. When they were probed to elaborate more on their fear of referral, they spoke of two main issues: the fear of being blamed and accused of not being adherent enough and the fear of treatment intensification such as increasing prescribed doses of OHAs, adding another type of OHAs or introducing insulin. Participants reported having further discussions with ASB GPs about treatment plans suggested by specialists, if treatment intensification was suggested. Some participants reported attempting to convince their ASB GPs not to act on these suggestions by promising the ASB GP to adopt healthier lifestyles.

"I don't like to come here **[diabetes outpatient clinic]***, doctors here are strict. I usually feel anxious prior seeing specialists. They demand more things to do, and sometimes suggest increasing doses of my diabetes pills" ASB-17*

The ESB group not only reported strong trust in the advice of diabetes healthcare professionals at secondary care settings; there was much praise for the approach of diabetes healthcare providers at these settings.

> *"I trust specialists here* **[diabetes outpatient clinic]***, they are very knowledgeable…I have received really good care. I have a great respect for them." ESB-80*

In comparison, ASB participants were less inclined to trust such advice.

> *"I trust my GP more* **[compared with specialist]***, I can talk to* **[Dr-XY ASB GP]** *without the need for an interpreter, she gets me. I came here just because I had to" ASB-59*

3.3.5 Socio-cultural and psychological factors

Only in the ASB group, were unique cultural beliefs and psychological factors cited and appeared to influence decisions to seek medical care services. ASB participants reported being anxious, pessimistic and held negative views about their health status at the time symptoms were experienced. When participants talked about context of their formal lives in the Middle East; some reported fear of bearing responsibility for one's own health status, amongst factors that contributed to delay in consulting with healthcare providers."

> *"I knew I had some symptoms, and I should have gone to see a doctor. But, I preferred not to. I was afraid of being 'officially' told I have diabetes, because then I would be responsible for my own health. I preferred not to know, and hoped that these symptoms to go away" ASB-6*

Other ASB participants talked about social labelling, stigma and discrimination for people with diabetes as factors for delaying access to medical services.

> *"For us* **[ASB patients]** *diabetes is such a big thing that sometimes one would prefer to suffer rather than being told to have diabetes. People in our community consider diabetes to bring lots of other diseases with it and it severely diminishes one's health status. I suspected that I have diabetes, but I just delayed going to doctor! I basically I was just buying more time! … Now I knew better, I wish time goes back and acted more quickly" ASB-38*

Participants reflected on how fear and embarrassment of the possibility of being diagnosed with diabetes and general state of anxiety contributed to further delays in accessing medical services. Cumulative stress, feelings of powerlessness and being overwhelmed were reported by participants in the ASB group. These feelings impacted negatively on participants' healthcare seeking behaviour.

> *"We* **[ASB people]** *in general have a shared sense of stress and unease. Noticing mild symptoms like being thirsty or generally tired won't necessarily mean that we go and actively find out what's wrong with us" ASB-33*

3.3.6 Religious beliefs and fatalistic views

As reported previously, ASB participants held strong religious beliefs (Chapter 2.3.3). Participants spoke of the notion that 'everything is predetermined' and fatalistic beliefs were frequently reported such as: 'human life is transient', and 'one should not be consumed in doing things to extend one's life such screening behaviours and accessing to medical services'. A few ASB participants favoured having illnesses; it was perceived as a sign of being close to Allah. These beliefs appeared to act, more often than not, as a barrier to seeking medical care.

> *"I had symptoms for quite some time, and I ignored them. I don't see the point of running to see a doctor and get examined. In this life time, Allah [God] determines everything … I was meant to have diabetes. So what is the big fuss about going for check-ups or have blood tests we will die when we suppose to not earlier and not before!"ASB-3*

> *"I have diabetes now for many years. My health is generally weak! I'm happy to put up with physical suffering by being ill. The closer the person to Allah* **[God]** *the more challenges he experience. Suffering through illness is a way of living in a state of remembrance to Allah." ASB-5*

3.3.7 Lack of knowledge of services

There was poorer understanding among the ASB group about available healthcare services for people with diabetes. The majority were not aware of currently available diabetes-health professionals and facilities. There appeared to be a lack of engagement of ASB participants in community-based support groups. Limited access to diabetes educational sessions was also reported. They attributed their limited knowledge of available healthcare services to their poor reading skills and lack of proficiency, not only in English, but in the Arabic language as well. The majority of ASB participants reported their inability to access internet-based educational materials.

> *"When sometimes I hear people talk about diabetes care services, I have no idea what do they mean? I just go to see my ASB GP. Are there other medical services?" ASB-8*

3.4 DISCUSSION

Participants in the ASB group intentionally delayed access to, and seeking of, professional healthcare services even when alarming signs of diabetes were experienced. This is contrary to the findings of Hjelm et al, who reported that Arab men with diabetes had accessed and used professional health care services to a greater extent compared with Swedes and former Yugoslavians in Sweden.[197] This divergence in health care seeking behaviour of the ASB immigrants could be explained by differences in migratory experiences, integration levels and adaptation to the new host society, in addition to the differences in lifestyle and living conditions. In Sweden, the vast majority of ASB residents are refugees who fled from war and persecution.[355]

The findings of this study identified six factors affected healthcare seeking behaviours in ASB immigrants with T2DM. Four of these factors matched what is already known from previous international and Australian studies about factors and barriers to healthcare seeking conducted among other minority groups: patients' knowledge, perception of healthcare providers, language problems, and lack of knowledge about available services.[174, 356-360]

Although patients' religious and cultural beliefs have been previously identified as a key factor influencing health care seeking behaviours,[155, 361-363] ASB immigrants in this study reported unique socio-cultural, psychological and religious beliefs that hindered access to available diabetes health services, such as collective cultural views, and the lack of accountability and fear of being responsible for one's own health. Anxiety, negative views and indifferent attitudes about a person's own health status at the time symptoms were experienced are amongst reported factors.

In line with previous investigations,[364, 365] ASB participants used alternative treatments, herbs predominantly, without informing their healthcare providers. Many described their use of herbal treatments not to be complementary to prescribed diabetes treatment, but rather as an alternative. Within this context, the study Singh *et al.* conducted in South Africa reported different findings; participants informed their doctors about their use of alternative treatment, unlike participants in the research reported here.[366] A shared cultural and linguistic background between the researcher and participants in addition to the safe and comfortable environment of interviews may have contributed to ASB participants being more willing to share their 'real' experiences with diabetes.

3.5 CONCLUSION

Arabic-speaking background immigrants in this study intentionally delayed access to medical services. They reported unique socio-cultural, psychological and religious beliefs that hindered access to available diabetes health services. These findings have the potential to improve current educational interventions that are aimed at facilitating timely diagnosis of diabetes, reduce delay in accessing medical services and impact fast response to diabetes symptom especially in this understudied ethnic minority communities. Providing patients with general information on symptoms of diabetes, and what to do in the event of experiencing these symptoms, however, may not necessarily be sufficient to promote prompt access to professional healthcare services.

CHAPTER FOUR: ISSUES RELATED TO USE OF MEDICINES

KEY POINTS ABOUT THIS CHAPTER

This chapter describes:

- Issues patients encountered that affect quality use of medicines, grouped in three major areas:
  - Patient knowledge about diabetes medications
  - Patient views and beliefs about their diabetes medications
  - Patient medication-taking experiences

Summary of findings:

- Both patient groups had obvious knowledge deficits about their prescribed OHAs, but the Arabic-speaking background (ASB) patients appeared to have a poorer understanding of their diabetes treatment compared with English-speaking background (ESB) participants.
- Arabic-speaking background participants displayed strongly negative views and orientations toward medicines; they believed that continuous use of prescribed diabetes medicines could be harmful in various ways.

4 Issues related to use of medicines

4.1 BACKGROUND

In diabetes management, medications are recognised as one of the main treatment options.[3, 367] The value of pharmacological therapies in achieving and maintaining adequate diabetes control is widely recognised.[367-369] Several well-designed trials have demonstrated the benefits of medications in improving clinical outcomes and avoiding costly diabetes microvascular and macrovascular complications.[97, 370, 371] Traditionally, pharmacological therapies are initiated only when lifestyle modifications, including dietary behaviours and physical activity, fail to adequately lower HbA_{1c} levels.[372] The American Diabetic Association, however recently made a recommendation to initiate pharmacological therapy at diabetes diagnosis, together with appropriate lifestyle modification for all patients, provided there are no contraindications.[88]

The last three decades have witnessed an expansion in the number and type of diabetes medications available, increasing the likelihood of attaining adequate glycaemic control.[373] Diabetes control, however, often remains suboptimal, possibly related to patients' inappropriate medication-taking behaviour.[374-376] It is widely recognised that after prescribing appropriate diabetes medication regimens, the next step to improve clinical outcomes of individuals with diabetes relies largely on patients' medication adherence.[377] Poor adherence rates to OHAs are well recognised.[114, 378] Patients' low adherence levels are one of biggest challenges in medical practice. In the realm of medication-taking behaviours, it is known that around 50% of patients with chronic diseases are not-adherent.[379] Attaining adequate glycaemic control and optimal outcomes not only requires patients to use prescribed medications effectively, but also requires engagement in a range of self-care activities.[380]

The first step toward helping patients to successfully adhere to their prescribed diabetes treatment is to identify barriers to medication-taking from their perspective.[378] Many previous studies have focused on why patients do not adhere to prescribed treatments and factors associated with this challenge have been identified.[381-385] For patients with diabetes frequently cited barriers to medication-taking are grouped into patient, medication, and healthcare provider-related factors.[378, 386] Patient’s beliefs and views about medicines and the meaning they attach to medication-taking are associated with their medication-taking behaviour.[387] Previous research has also shown how patients react to, think about, and experience medication-taking, within their own social and cultural context, helps GPs understand the challenges in medication-taking.[388-390]

To competently meet patient’s medication-related needs, understanding medication-taking from the patients’ perspective is required.[388, 391, 392] Previous studies have explored the meaning attached to, and the subjective experience of, medication-taking in patients with a variety of chronic illnesses.[388, 393-395] The findings of these studies suggest patients’ experiences of medication-taking transcend specific diseases and medications. Patients with chronic diseases are known to hold wide range of beliefs about their prescribed medications.[396]

Results of limited studies on patients’ knowledge about prescribed diabetes medications, reported that most patients with diabetes had deficits in their knowledge about these medicines, and their importance to improving health outcomes.[397, 398]

There is a paucity of data on barriers to medication taking in ethnic minority groups (EMGs) with T2DM. These groups tend to have higher non-adherence rates, worse glycaemic control and poorer outcomes compared to Caucasians population.[91] There is also little information about ASB diabetic patients’ knowledge and attitudes toward diabetes medications.

The objective of this part of the study was to explore ASB patients’ medication knowledge, views and beliefs, and behaviours to identify issues in quality use of diabetes medicines.

4.2 METHODS

Methods used to obtain the results reported in this chapter are presented in detail in Chapter 2, section 2.2.

4.2.1 Focus of this chapter

Reported results are based on participants' responses to three key areas:

- What do they know about their prescribed diabetes medications?
- What are their perceptions, beliefs, and attitudes toward their diabetes medication?
- How do they experience medication-taking on daily basis.

All questions, key and probing, are listed in the moderator guide (Appendix 7). Participants were asked questions to determine their knowledge about their prescribed diabetes medicines, specifically in relation to food, dosing intervals, mechanism of action and side effects.

Firstly, participants were asked, *"Do you know when to take your diabetes tablets?"* In the case of receiving closed-ended responses, participants were then asked to elaborate further on how they administered each of their OHAs, such as, before, during or after meals. Participants were also asked about dosing schedules - *'How many times do you take your diabetes medicines each day?'* ASB participant responses were compared with their medication list obtained from their GP records to elicit the accuracy of their medication taking.

For those who were using more than one type of OHA, the question was asked, *"Do you know why you are currently using different types of diabetes tablets?"* Participants were also asked about side effects of prescribed diabetes medicines, *"Do you know what side effects your diabetes tablets can cause?"*

Participants were asked about their medication experiences and how they manage their medications. There was no underlying assumption that people were, or were not, taking their medications simply because they were prescribed. Rather, participants were encouraged to reflect on whatever their daily medication taking practices were, with regards to their diabetes treatment, and comment on that. The HbA_{1c} values were obtained from medical records to establish the relationship between knowledge and outcome.

4.3 RESULTS

The themes, sub-themes and categories resulting from the responses to the questions on page 81 are summarised in Table 4.

Table 4: Summary of themes, sub-themes and categories

Themes	Sub-themes	Categories
1. Participants' knowledge about Oral Hypoglycaemic Agents (OHAs)	1.1 Participants' Perception of Information provided	• Mechanism of action • Correct administration • Side-effects
2. Participants' beliefs and attitudes about medicines	2.1 Social aspects of medicine self-management	
3. Participants' medication experiences	3.1 Appraisal of medication-taking	
	3.2 Medication-taking behaviour	
	3.3 Self-evaluation of medicines taking	
4. Communication between participants and healthcare professionals about medicines		

4.3.1 Participants' knowledge about oral hypoglycaemic agents (OHAs)

Both patient groups had obvious knowledge deficits about their prescribed OHAs, but the ASB participants appeared to have a poorer understanding of their diabetes treatment compared with ESB participants.

All participants perceived OHAs only as 'diabetes tablets'. Arabic-speaking background participants were unable to differentiate between the different classes of OHAs (sulphonylureas, biguanides, alpha-glucosidase inhibitors, etc) and were unable to explain why they were using medication from different classes. The ESB participants, even if they could not name which class their medication belonged to, understood that the medication worked in different ways to control their diabetes. By way of comparison, ASB participants did not understand why they were using more than one type of OHA.

> *"Currently, I'm on these three types of diabetes tablets. But I have no clue why I was put on the different types" ASB-18*
>
> "I'm using two different types of diabetes pills; they work in different ways to help my body cope with diabetes" ESB-91

Participants in the ESB group seemed to have basic understanding about actual action of their prescribed medicines. Participants in the ASB group, however, repeatedly spoke about their lack of understanding about mechanism of action of their prescribed OHAs.

> *"I have no idea how these pills work* **[OHAs]**. *I just take them"* ASB-27
>
> *"I really don't know when it is best for me to take my diabetes pills" ASB-25*
>
> *"I know that there is not enough insulin in my body, so these tablets* **[OHAs]** *help in lowering sugar levels in my blood" ESB-76*

Compared to ESB participants, participants in the ASB group had a poorer understanding about administration of their diabetes medicines in relation to food and correct dosing intervals.

> *"… I know how many times I should use my diabetes pills, but I don't know whether it is best to use them with, before or after food. Does it make a difference?" ASB-19*
>
> *"I know exactly when I suppose to take my diabetes medicines. To avoid forgetting to take these tablets; I established a daily routine for myself" ESB-78*

Participants from both groups had poor understanding of OHAs side effects: most participants failed to describe any of the possible side effects of their prescribed treatment.

> *"I know that these pills* **[OHAs]** *cause side effects, but I can't tell you what these side effects are, simply because I don't know. I'm very convinced that they do cause lots of problems in our bodies. But what can I do?" ASB-36*

> *"All medicines have side effects. They* **[medicines]** *fix something in our bodies and they damage another. I'm always worried about side effects of these Western medicines" ASB-46*

> *"I don't know much about side effects of my diabetes pills" ESB-96*

4.3.1.1 Participants' Perception of Information provided

Patients from both groups reported receiving brief information from their GPs about their prescribed OHAs, mostly during the medication initiation period. This information centred on how these diabetes medications should be used. Differences were reported between the groups regarding other information resources accessed about OHAs. Despite the ASB patients acknowledging the need to have more information on their prescribed diabetes treatment, none of the participants reported taking steps themselves to obtain more information by asking pharmacists or by accessing the Internet. Most ASB patients reported asking peers within their own community about prescribed diabetes treatment. Arabic-speaking background participants did not report obtaining any information from pharmacists about their OHAs and do not discuss their diabetes medications when having a prescription refilled.

> *"The doctor prescribed the medications in two minutes and told us how they should be used. That's it really! It's like I was hit between the eyes when I was told I had diabetes. And then I was left on my own. I felt powerless and overwhelmed! I had no idea what diabetes was or how it was managed. Actually, many of us feel unsure and have lots of unvoiced concerns! … I can't use the Internet or read the information sheets that were given to us, so reaching out to friends and relatives for information about what to do is what most of us used to do* **[on diagnosis]**" *ASB-22*

> *"… Haven't you heard the saying, 'Asking a person with a similar disease is better than asking a doctor'? I usually check with my friends* **[about diabetes medications]**. *We meet*

> *twice a week, and we chat about many things. Many of my friends have diabetes, so we exchange ideas and information" ASB-51*

English-speaking background participants reported quite a different experience. Most ESB participants were satisfied with the information they had received. Contrary to the ASB participant experiences, nearly all the ESB participants reported that their GP was the main source of information regarding OHAs. Some also reported pharmacists being their source of information on how to use OHAs.

> *"…When I was prescribed diabetes tablets, the doctor talked to me about them. I was told how to use them and that they would help in controlling my diabetes… Also when I went to pick up the prescription from our local pharmacy, the pharmacist there told me how to use these* **[OHAs]** *tablets. When I want to know more about my medicines I usually use the Internet, read the enclosed information sheet, or I ring my doctor." ASB-36*

> *"If I forget what the doctor told me about the diabetes pills, the pharmacist usually talks to me about them anyway. And If I'm still unsure, I call my GP and ask."* ASB-8

> *"My GP always talks to me about my medicines, and if I don't know what to do or needed more information I usually ask. I also received lots of information about diabetes from diabetes educator… I certainly can claim that I'm adequately informed about basic self-management issues" ESB-87*

Participants with better understanding of their OHAs appeared to have better glycaemic control (Table 2).

4.3.2 Participants' beliefs and attitudes about medicines

Arabic-speaking background participants displayed strongly negative orientations toward medicines in general. They preferred not to take any medicines and to spare their use only for exceptional circumstances. Those who held a more positive attitude toward medication were more likely to be young and diagnosed with T2DM in Australia.

> *"Medicines are made to help us treat diseases; they are safe. Yes, they may cause some side effects, but in my experience I have used them and I haven't experienced any side effects." ASB-32*

> *"Before medicines are available to the public, many trials have been conducted. Their safety is proven, if you like." ASB-16*

Participants in the ASB group seemed to believe that taking diabetes medicines was not necessarily the best course of action. Many participants questioned the validity of their prescribed OHAs. There was a dislike of diabetes medicines among ASB participants, after being diagnosed with diabetes and initiating OHAs, they described their predominant emotions as feeling overwhelmed, distressed, powerless and uncomfortable. These strong emotions, generated by the diabetes diagnosis, seemed to impact on participant approaches to medicines use.

> *"I really hate medicines; I wish I could stop using them. I feel sad when I put them in my mouth." ASB-36*

> *"… I cannot absolutely know that taking diabetes medicines are really helpful" ASB-54*

Participants in the ASB group expressed a lack of conviction about the efficacy of their prescribed medications. They perceived that OHAs were not imperative to attain adequate glycaemic control. Participants associated the persistence of diabetes-related complications with medicines inefficacy. Such beliefs seemed to stem from the perceived association between an absence of immediate diabetes complications and not taking medications as prescribed and lacked awareness that inappropriate prescribed medication use could lead to serious consequences. Such experiences seemed to generate a belief that diabetes medications are of low importance and they failed to perceive their prescribed medications as "life-saving".

> *"I don't know why they* **[healthcare professionals]** *make such a big fuss about diabetes medications. Sometimes I don't take my medicines, and here I am... nothing wrong has happened!" ASB-9*

> *"I still got most of diabetes complications. My eyes were affected, my kidneys are damaged, I have high blood pressure, I have lipid problems and I have my foot problem. So what is the use of these medicines? I'm not sure why everyone makes such a fuss about using them. They are not that helpful, at least in my experience, you know!" ASB-60*

Arabic-speaking background participants expressed misgivings about use of Western medicines (prescribed medicines). They expressed not only their lack of trust in Western medicines but also the belief that such medicines could be harmful in various ways. Medicines were described as 'unnatural' and 'toxic'.

> *"I don't like medicines; they are all made of chemicals." Male, FG, aged 60*

> *"These pills are toxic; I don't like using medicines at all. I only use them when needed. We have a saying, 'Drop the medicine and breathe fresh air'. What this means is that one should stop using these chemicals and try natural things. They are much safer." Male, FG, aged 64 years*

This mistrust of western medicine appeared to be a phase participants went through in the early stages following diagnosis before ultimately came to accept them as beneficial.

> *"We* **[participants with diabetes]** *all passed through this 'phase' of distrusting Western medicines. For example, in my case I stopped using my diabetes pills and tried various things – mainly herbs – for a long time. Only when I got very sick and my diabetes didn't get better, I realised that I should be using the pills." ASB-8*

> *"I used lots of herbal treatments when I first found out that I had diabetes. I guess I didn't like to take diabetes pills and I thought they do more harm than good. But now I know better. But I have to admit that I came to this conclusion belatedly." ASB-9*

4.3.2.1 Social aspects of medicines-taking

Arabic-speaking background participants talked about the social labelling that occurred for people with diabetes, and the association between taking OHAs and being socially disadvantaged. These cultural beliefs translated into a reluctance to use OHAs. Negative social labelling associated with medicine-taking; signified illness and made participants feel as though they were older than they really were - no longer fit and worn-out. ASB participants acknowledged that part of their initial negative reaction towards their diabetes medication was attributed to the popularly held views of diabetes as an illness. It was evident that ASB participant reluctance to use diabetes medications was a response to the perceived stigma of having diabetes in their socio-cultural context. Amongst described collective social labelling for people with diabetes was the perception of dependency, where those who had diabetes were perceived as poorer in health and needed lots of care and support.

> *"… A person with diabetes is perceived as weak, a very ill person who needs lots of care. People* **[in ASB communities]** *would think that this person is no longer 'normal', or if you like, no longer 'healthy'." ASB-31*
>
> *"People think that diabetes is a troublesome disease with no cure and nothing can be done about it, apart from using diabetes pills and trying to manage the diet – which is a very difficult thing to do. If a person is to be jinxed he/she would have diabetes. It is a disaster! One would end up with lots of complications e.g. leg amputations and such horrible stuff. Sometimes people think it would be easier not to even think or admit to having this horrible." ASB-24*

Use of diabetes medicines, for some ASB participants, was even equated with shame attached to diabetes being a disease. They also reported their reluctance to take their diabetes medicines when in public. English-speaking background participants did not raise these views.

> *"Taking medicines is not very acceptable in our society. You know people try their best not to use medicines in front of others as people start to think you are sicker than you are, or even that you may have more conditions than you actually suffer from. They read too much into it... you might be labelled as 'old', 'sick', 'weak': all sorts of things. Because of this I sometimes skip my doses when I'm outside and around people that I don't know very well." ASB-30*

Arabic-speaking background males spoke about the social stigma of having diabetes. They had specific concerns about sexual functioning for a male with diabetes and indicated that in people's minds, for a young male, a diagnosis of diabetes is perceived as a 'disaster'. Participants talked about the widespread understanding that existed in their communities about the link between diabetes and sexual dysfunction. They were therefore troubled about their social image and their peers' opinion. Accordingly, they tried to deny having diabetes.

> *"If you are not lucky in life, you will have diabetes. It is like a jinx! You end up with lots of other diseases and complications. I don't want to use my diabetes pills around my friends – I don't want them to know that I have diabetes. They will make jokes about me. In our society, a male should try his best not to take medicines. It signifies him getting older, becoming ill and weak. And if you have diabetes at my age, people would start thinking that I will have sexual problems by the age of 44. That is a disaster!" ASB-3*

Arabic-speaking background participants felt it would be worse if a person was diagnosed with diabetes prior to getting married. Males would be perceived as a less desirable potential 'groom', as people would be concerned about his sexual health. Female participants also spoke about the drawbacks of females having diabetes and cited problems such as being perceived as less desirable "brides" due to the perceived possibility of passing diabetes to their children.

> *"If people knew that a woman had diabetes, she wouldn't have many people proposing. She would be in trouble! People would be fearful of proposing to her because she might give birth to children with diabetes." ASB-15*

> *"...a woman with diabetes would not only be a less desirable bride, rather her sisters might be also affected! Some traditional men would prefer to get married to a healthy girl from a healthy family." ASB-29*

4.3.3 Participants' medication experiences

Participants provided what seemed to be honest insights about their medication experiences and how they managed their diabetes medicines in particular.

> *"I don't know... it may be because of our similar cultural background or because you asked me simple questions… I don't know! Or it could be because you are not my doctor*

> *or pharmacist, I feel more relaxed to share my true experience. I hope it will help other people with diabetes!" ASB-6*

Participant experiences associated with medication-taking included:

- appraisal of medication-taking
- medication taking behaviours
- self-evaluation of medication-taking

4.3.3.1 Appraisal of medication-taking

Participants reported going through a lay evaluation process i.e. an appraisal phase; during which they attempted to make sense of their medications within their socio-cultural environment. This phase typically began at the time of diabetes diagnosis, after the doctor had initiated diabetes treatment. Frequently ASB participants spoke of an overwhelming sense of burden coupled with the diabetes diagnosis and the many uncertainties about their condition and its treatment. Arabic-speaking participants were always gender specific when seeking information.

> *'When I was first told to use diabetes tablets, I knew nothing about diabetes or its treatment … I was left alone. I didn't know what should be done! I had lots of questions. I asked my female friends for advice. They told me many things; some were right and some were wrong, but I felt more confident in talking with my group of female friends than asking the doctor any questions related to diabetes." ASB-24*

Most ASB participants reported that the appraisal phase was an on-going process whereby they evaluated diabetes medication taking by seeking information and external validation about their condition and prescribed treatment from a 'significant' other. They then integrated the latest information with their prior knowledge, views and beliefs on diabetes and its treatment, in an attempt to better understand their condition and prescribed medications, judging taking diabetes medication as either making sense or as not making sense.

> *"First you* **[a participant with diabetes]** *don't know or are unsure about your diabetes pills. You are told to use them and that's it! So you try your best to get your head around what should be done, and you seek a network of people you trust to get more information from. I guess this phase of wanting to know more and seek validation from people you trust is a common thing for all Arabs with diabetes. We don't use the Internet to get more information – we like to talk with our friends." ASB-7*

Arabic-speaking background participants reported that taking diabetes medicines as prescribed by the doctor was not necessarily perceived as the best course of action, especially during the early stage of diagnosis.

> *"At first* **[right after the diagnosis of diabetes]** *I was thinking about whether I should use diabetes tablets or not. I don't know but I didn't accept the use of medicines easily at first. It is not as if I can use these pills for only three days or a week. I was told that I should use them for a lifetime! I wasn't happy about that" ASB-31*

Arabic-speaking background participants who were diagnosed in the Middle East talked about a feeling of being on their own without adequate support after the initial diabetes diagnosis.

> *"The doctor* **[in the Middle East**] *told me that I had diabetes, and it wasn't good. So I was told to start taking diabetes pills. He told me how to use them and wrote me a prescription. That consultation lasted for a few minutes! I felt very sad about the diagnosis. I had no one to talk about it to, I was pretty much left on my own … I had no idea about diabetes or what I should be doing. I was very distressed!" ASB-17*

4.3.3.2 Medication taking behaviours

After going through the appraisal phase, participants described adapting different approaches to the use of diabetes medicines– acceptance, rejection or sceptical. These approaches appeared to impact and shape participants' medication taking acts. Participants who adapted 'acceptance' approach reported that taking diabetes medicines as prescribed by GPs was the best course of action. Compared to the ESB group, only a few participants in the ASB group reported adapting acceptance approach.

> *"I don't think too much about it* **[diabetes]**. *I take my tablets as the doctor tells me to. He knows what he is doing and I trust him. Ultimately, what the patient should do is to follow the doctor's orders" ASB-59*

Participants in the ASB group who were accepting of medicine use were more likely to be diagnosed in Australia. They expressed their trust in their doctors and felt that they should follow the prescribed treatment regimen. These participants accepted the idea of needing to take chronic medications.

> *"Doctors here [in Australia] are good. I mean I can trust them, they know what they are doing. So if they say I should take these tablets, I do." ASB-24*
>
> *'I didn't think much about it* **[diabetes]** *once the doctor told me I needed to use the pills. Probably, it is just me, I'm like that, if a doctor says something, I do it; I don't complicate things for myself. He* **[the doctor]** *knows what is best for me. So taking medicines is not a big deal for me … I don't mind using medicines if they are prescribed by a doctor" ASB-50*

Participants who rejected the idea of taking diabetes medicines reported stopping the use of their medicines altogether. Such approach was reported largely among the ASB group compared to the ESB group. Participants who adapted 'rejection' approach described a significant emotional burden associated with their diabetes diagnosis. They were greatly troubled with their initial diagnosis and reported a wide range of feelings about taking medication, particularly uncertainty, anxiety and stress.

> *"I refused to take any tablets for so long. I did not know how serious diabetes could be. I thought if I just make a few changes in my food, I will be fine. I was mistaken! When I was prescribed these tablets, I thought I shouldn't use them. Using pills means you are a weak person or ill, and I hated medicines in general. I was always like that; even if I have a severe headache I don't use paracetamol" ASB-10*
>
> *"I still remember very well when the doctor first prescribed me the medicines for diabetes. He was calm and smiling, and I was wallowing in pain and stress about the fact that I was now doomed for life to use these pills," ASB-13*

Arabic-speaking background participants, who rejected use of diabetes medicines as a treatment strategy, went as far as expressing their reliance on their faith, rather than medicines, with one participant declaring that he prayed to God **[Allah]** to cure him. He decided not to take his medicines but rather reduce sugar in his diet.

> *"Initially, I kept praying to Allah* **[God]** *to cure me from diabetes. I did cut sugar from my diet and that was it. I did nothing about it* **[the diabetes]** *for a while, until I got really sick. Then I went to the doctor again and I ended up with more medicines." Participant-60*

Some participants revealed a willingness to endure diabetes-related symptoms just to escape taking OHAs.

> *"At the beginning there weren't many symptoms, so I put up with them so that I didn't have to use the diabetes tablets." ASB-25*

Between these two opposite medication taking behaviours, there were people who appeared to be sceptical about use of diabetes medicines. They played down diabetes as a medical condition and failed to recognise the need for the use of diabetes medicines as prescribed by GPs. Participants who adapted 'sceptical' approach reported developing their own medication taking practices, where they actively altered prescribed regime to supposedly suit their lifestyle or diet.

> *"… I don't necessarily use diabetes pills as prescribed. Sometimes I take extra pills, especially if I am invited for a social event. It is hard to control myself in such situations and I end up eating lots of food. So I usually go home and have an extra pill." ASB-11*

Various ways were reported of participants actively engaging in modifying their prescribed diabetes medication regimen. They described three different approaches to altering their prescribed treatment regime: decreasing prescribed doses, increasing prescribed doses, and replacing or supplementing diabetes medicines with alternative treatments.

> *"After I was prescribed diabetes medications, I decided to use half the prescribed dose. I thought that since diabetes would be there with me for the rest of my life, I should try to*

> *use smaller doses and save them for later. But my situation got worse –, I had eye problems –, so now I follow whatever the doctor tells me. I paid a high price for these trials* **[modifying the prescribed treatments]"** *ASB-2*

> *"Even until today my doctor thinks that I'm using all the three different types of diabetes tablets* **[OHAs]***, but I'm not! I use only two types and in fewer doses. I hate using diabetes medicines! What is the use of them anyway? Everyone with diabetes will end up with lots of complications anyway, so why should I keep taking these chemicals into my body? But I wouldn't say this in front of my doctor though." ASB-6*

More participants in the ASB group compared to the ESB group reported sceptical approach toward use of prescribed diabetes medicines. Arabic-speaking background participants described having a need for more discussion with their peers and people with diabetes who share a similar cultural background. They seemed to actively seek 'trusted' people's opinions about what to do in regard to their diabetes.

> *"I was not sure about use of diabetes medicines. I just wanted 'validation' from my friends! I asked ASB people with diabetes about what should be done to manage diabetes; I got all sort of advice. I tended to use less doses of my prescribed diabetes treatment." ASB-16*

Overall, ASB participants consistently reported failing to conform to their prescribed diabetes treatment regimen. The vast majority reported developing their own medication taking practices.

4.3.3.3 Self-evaluation of medicines taking

Participants pointed out that the diabetes medication experience is not a static event; rather they referred to it as a dynamic process that varied over time. They seemed inclined to test their diabetes medicines themselves to establish whether the medicines worked for them or not. Participants talked about their self-evaluation of diabetes medication taking including two components: the assessment of treatment value or effectiveness, as well as the assessment of medication side effects. The participant below described herbal treatment that she used; it was ‘special tree leaves'. She described adding boiling water to the 7 leaves and left them to brew for 30 minutes before drinking the herbal tea.

> *“I was told to try some herbs. My friend said it was very good for diabetes. I didn't want to use medicines; they are made of unsafe chemicals. So I thought I should try these herbs. I continued using them for a long time. My diabetes got much worse. I didn’t know that then. I was hospitalised and my kidneys appeared to be damaged. I later came to realise that the herbs actually don’t work. I now use my medicines and medicines only…” ASB-1*

4.3.4 Communication between participants and healthcare professionals about medicines

Participants reported relying on their peers and family members for advice about prescribed treatment and to a lesser extent on their ASB GPs as information resources. Participants in the ASB group spoke of being unaccustomed to seeking advice from pharmacists to answer questions about their prescribed treatment.

> *“I usually ask my friend. Consultations with doctors are short, and usually after consultations I still have some questions, so I ask my friend who are like me* **[in having diabetes]**. *Only if I have a major issue or concern would I call the doctor. I’m not used to asking pharmacists; just the whole idea* **[of asking a pharmacist]** *is not much to my liking. But to be honest, I never tried doing that before, so I can’t really assess such an experience.” ASB-7*

4.4 DISCUSSION

This is the first study conducted among an ASB group residing in a developed Western country with a publicly funded health care system, using a qualitative approach and with a comparable group (ESB) representing mainstream society to explore the knowledge, views and beliefs, and medications experience of ASB participants with T2DM. Results revealed that participants in both groups had an incomplete understanding about their oral hypoglycaemic agents; which is consistent with the findings of previous research by Browne et al.[397]

Arabic-speaking background participants had more knowledge deficits about their prescribed diabetes treatment compared to ESB participants. Generally, they were unable to name their OHAs, recount their mechanism of action, describe their common side effects and were oblivious to the rationale for being prescribed more than one OHA type. On the contrary, ESB participants had a better understanding about tablet administration in relation to food, they could list commonly seen side effects, and in some instances knew correct actions of their medications. Although, participants in both groups admitted failing to conform to prescribed treatment regimens, which concurs with results obtained from previous studies,[114, 378, 399] ASB participants admitted lower adherence rates to their prescribed diabetes treatment and evolving their own medication taking practices, typically, using lower doses than prescribed mainly due to fear of long-term side effects and mistrust in western medicine. This mistrust, however, does not necessarily apply to all western medicines, as previous research showed overuse of certain medicines such as antibiotics and antidiarrhoeals among patients in the Middle East.[400, 401] Mistrust about use of OHAs (western medicine) appeared to be related with the need for its chronic use, compared to short term use of other western medicines such as antibiotics. Research among this ethnic group, had previously identified issues in quality use of medicines.[53] Clearly, effective use of medicines is imperative for both groups in attaining adequate glycaemic control; however, it is of special importance for ASB participants who are reported to have higher morbidity and mortality rates.[402]

Differences between the two groups emerged about the sources used to obtain information about their prescribed diabetes treatment. For the ASB participants, information on diabetes and its treatment was predominantly gathered from ‘significant’ close contacts: mainly friends, relatives, or other senior citizens with diabetes within the Arabic-speaking community. English-speaking background participants appeared to obtain their information on OHAs from their GPs and used the Internet to search for information on their diabetes and its treatment. This apparent difference in information seeking may be explained partially by language difficulties and technical problems encountered by ASB participants.

This study adds to existing literature that adherence is not only related to the participant's experience with current medications, but also to experiences with the disease itself, with medication use in the past, and experiences of people with a close relationship to the participant. These experiences influence the participant's attitude towards diabetes medicines, as well as the opinion of the treating physician. [116]

4.5 CONCLUSION

Arabic-speaking background participants with T2DM had significant gaps in their knowledge about their prescribed treatments. The majority of ASB participants were unable to list the names of their prescribed medications, their purpose, and the rationale behind using more than one type of OHA or their major side effects. There was pattern an association between participant knowledge, adherence rates and glycaemic control measured by recent HbA_{1c} values.

To counsel ASB patients with diabetes more effectively during medical encounters with the intention to promote better medications adherence, diabetes healthcare professionals need to acknowledge and understand that ASB patients may have significant deficits in their knowledge about medicines. They may also hold different beliefs and views about medicines and these may impact negatively on their medicine self-management behaviours.

CHAPTER FIVE: BARRIERS TO DIABETES SELF-MANAGEMENT

KEY POINTS ABOUT THIS CHAPTER

This chapter describes:

- Perceived barriers to diabetes self-management among ASB and ESB participants.

Summary of findings:

- Four main themes emerged from participants’ responses as barriers to diabetes-self management: cultural beliefs and social networks, poor knowledge and language problems, religious beliefs, and lack of motivation and emotional distress.

5 Barriers to diabetes self-management

5.1 BACKGROUND

Effective diabetes self-management (DSM) activities by patients, such as adhering to diet and exercise recommendations and monitoring blood glucose levels, foot care and smoking cessation are considered as key factors in attaining adequate glycaemic control, as well as delaying diabetes-related complications.[3, 97, 133, 403, 404] Evidence suggests that 95% of the daily DSM routine required for maintaining adequate glycaemic control is provided by the patient.[191, 405, 406] The daily routine, however, is complex, time-consuming and often requires the changing of long-held habits.[254] Therefore, from the patient's standpoint, these self-care activities have been perceived as difficult, demanding, challenging and frustrating.[407]

Patient-related barriers to self-care have been defined as the "patient's own perception of how challenging are the social, personal, environmental and economic obstacles to achieving or maintaining a specific behavior".[408] Against this background, previous research conducted among certain ethnic minority groups has identified several barriers to DSM including: cultural beliefs and attitudes, fatalism, lack of knowledge, lack of social support, language problems and cost-related factors.[396, 409-414]

Ethnic minority groups with T2DM were found to be less likely than the mainstream population to be engaged in diabetes self-care activities.[415] When compared to that of educated English-speaking populations, ethnic minority groups are known to suffer more from the burden of diabetes, have higher rates of diabetes-related complications, have poorer glycaemic control and worse health status on a number of indicators.[149, 415-418, 420]

Identifying key barriers to self-care from the patient's perspective has been recognised as a crucial step in the process of helping patients to be effectively engaged in DSM behaviors. Such understanding about the barriers to DSM enables the development of appropriate diabetes education that has been shown to reinforce adherence behaviors and improve important outcomes among certain ethnic minority groups.[203]

Hitherto, there has been little research conducted with ASB communities with T2DM leading to a paucity of information about barriers to DSM behaviors among this ethnic group. The research reported in this chapter was undertaken to address this knowledge gap.

5.2 METHODS

Qualitative methods used to obtain the results described in this chapter are presented in detail in Chapter 2, section 2.2.

Results reported in this chapter focus on the response of participants' to the questions listed in section D of moderator guide (Appendix 7), specifically responses to the question - "What makes it hard for you to manage diabetes in your daily lives?"

5.3 FINDINGS

Five main themes emerged from participants' responses about barriers to diabetes-self management: cultural beliefs and social networks, poor knowledge and language problem, religious beliefs, lack of motivation and emotional distress.

5.3.1 Participant characteristics

Characteristics of participants whose responses are reported in this chapter are described in detail in section 2.3.2.

5.3.2 Cultural beliefs and social networks

The role of cultural beliefs and social networks emerged only from responses from participants in the ASB group, not the ESB participants. The ASB participants spoke of cultural norms such as 'hospitality' and 'generosity' that seemed to foster overeating at social ceremonies. Such cultural norms and traditions appeared to cause challenges to ASB participants in managing their diabetes. These participants talked about temptations and tendencies to overeat, and that food has a significant role and meaning in their social lives, to the extent that was perceived to transcend being a necessity for survival.

> *"In our culture* **[ASB communities]** *one has no choice but to overeat when he/she is invited because hosting people keep serving food. In many instances I know that I shouldn't have kept eating and instead said something like 'Thanks, but NO, I had enough'. I'm afraid that if I say something along those lines people would think of me as rude." ASB-41*

> *"Food is very important thing in our culture. We gather around food. We talk about it a lot. We have lots of traditional dishes, they are very yummy, and ASB communities are 'foodie'. If we are happy we eat, if we are sad we eat, if we want to show our respect to certain people we invite them over and cook lots of stuff. Food is a way of communication in our culture." ASB-44*

Health-related decisions of ASB participants were reported to be taken at a collective level with participants reporting that they seek external validation from significant 'other', particularly family members, peers and friends. The involvement of significant 'others' in the form of advice appeared to hinder self-care activities.

> *"We are not accustomed to make health-related decisions on our own. We need to consult and talk to friends, peers or family members prior to any action" ASB-28*

> *"My best friend told me that it would be great for me if I start using herbal tea. She told me that diabetes pills are good but they cause lots of problems on long term, and I should try not to use them. I did use herbal tea that she recommends and reduced sugar in my food and stopped using diabetes pill simultaneously…I now know that was a stupid decision." ASB-60*

Some of the female participants thought that within ASB communities a man with diabetes is more likely to receive more support from his wife than what diabetic woman gets from her husband.

> *"I used to have diabetes for a long time, but I don't remember that my husband gave me a support or engaged me to take better care of myself. Ironically, he was told that he has diabetes 9 months ago. Now I try my best to help him to adapt to this disease. I stopped buying baklava because I know he likes it very much and he would be tempted to eat it if it is at home. I also modified my cooking style to more healthy ones. Whereas before he got diabetes I never changed a thing because I wanted him to enjoy and not to suffer because of my diabetes" ASB-56*

Many participants in the ASB group reported cultural beliefs prevented them from undertaking physical exercises. These beliefs included negative views of society about engagement in any structured physical activities, senior status and feelings of being unsafe. Exercise was viewed as an activity in which only young people might be interested. Older adults, in comparison, are more likely to withdraw from exercise as a result of their perceived senior status.

> *"In our society, a man like me can't be seen jogging around parks. People* **[ASB]** *will disrespect that. When one's head is filled with gray hair, he should not care that much about exercising" ASB-20*

Within this context, ASB female participants spoke of negative perceptions held by ASB communities about female participation in sport, especially for those who have children and those who exercise in public places. Such perceptions seemed to negatively impact on women's involvement in exercise in general.

> *"I can't go for exercising on my own, doing so is not wrong but it's just not quite appropriate either, especially for ASB people" ASB-30*
>
> *"Women like me are better off with not exercising! I have two small children, and I should be spending all my time taking care of them … if my mother-in-law happened to know that I left house to exercise even for 30 minutes, I would be perceived as less of a mother" ASB-26*

5.3.3 Poor knowledge and language problems

Participants' knowledge about diabetes and its management was reported in Chapter 2 and described poor knowledge as a barrier to DSM. Overall, ASB participants had poorer knowledge about all aspects of DSM compared with the ESB group. Poor knowledge as a barrier to DSM behaviors is shown using self-monitoring of blood glucose (SMBG) as an example. Participants in both groups reported integrating SMBG as a part of their daily lives to a varying extent, but participants in the ASB were less regularly engaged in SMBG compared with the ESB group.

> *"I regularly check my blood sugar, and I keep a record of the readings."ESB-82*
>
> *"I rarely check my blood sugar" ASB-5*

ASB participants' poor knowledge about how to interpret results of SMBG and the confusion about what to do if the readings were high seemed to represent a challenge.

> *"I don't check my blood sugar levels as much anymore. I just don't understand what these numbers mean. I don't know what to do when the readings are so high, other than feeling guilty and blaming myself! To be honest, it seems pointless* **[testing blood glucose]***" ASB-8*

By contrast, the ESB group seemed better able to deal with abnormal readings.

> *"If I measure my blood sugar and found that it is high, I usually go for a 30-45 minute walk…come back home rest for a while and repeat the measurement" ESB-85*

Furthermore, language problems limiting the interaction with healthcare professionals were reported by ASB participants as a potential barrier to learning about DSM practices.

> *"There is one pharmacist; she is very nice she always try her best to give me information on how to manage diabetes. I usually smile at her and pretend that I understand but I don't"ASB-17*

5.3.4 Religious beliefs and fatalistic attitudes

While the role of religion on diabetes management was explored in both groups, this dimension seemed not to affect ESB participants' self-care activity in any significant way. Conversely, ASB held strong religious beliefs as reported in Chapter 2.3.3 and their religious and fatalistic beliefs appeared to negatively impact on diabetes self-management. For example, ASB participants who attributed development of their diabetes to Allah (God) and those who believed that everything in one's life is pre-destined were less likely to conform to DSM recommendations.

> *"Whatever meant to happen will happen, so I don't think exercise 20 minutes more or reducing sugar in my tea will have a great impact on my health or the course of my life! Sometimes they* **[healthcare providers]** *make a fuss for no good reason!" ASB-27*

> *"They* [diabetes health professionals] *told me to do many things to help with my diabetes, but, what I know for sure is that 'Allah' is my healer." ASB-58*

> *"Illness and health are already predetermined 'KUL INSAN W NASEEBH'* **[everyone has his own fate]**. *Allah is the most merciful, and everything happen in our lives, happens for a reason." ASB-1*

5.3.5 Lack of motivation and emotional distress

Lack of motivation as a barrier to DSM was reported by participants in the two groups.

> *"I don't have the interest in exercising or eating healthier! To be honest, it's* **[diabetes]** *a life time thing, if it was short-term things would be different…it's just boring if one does everything he/she should be doing to manage diabetes, it become too much!" ASB-11*

> *"Testing blood glucose is just not interesting! I just can't be bothered" ESB-77*

Interference of emotional context in self-management was stronger amongst ASB participants compared to their ESB counterparts. In the discussion about living with diabetes, negative emotional responses, indicating high levels of distress, were more prominent among the ASB group compared to the ESB group. Participants in the ASB reported being subject to stress most of the time; which appeared to contribute to participants' decreased interest in learning or performing diabetes-self management (DSM) activities. Amongst the reported stresses in the ASB group were: leaving their home country and breaking ties, settling down in a new country with different traditions, cumulative stress due to worrying about family members or relatives back in the Middle East, as well as the frustrations with, and negative social stereotyping about, having diabetes.

> *"Stress is a part of our lifestyle, there are so many things to worry about … one has to priorities, ok so in my case I worry about how the rest of my family can join me, I worry about not being able to raise my kids in a balanced way. I want them to be part of the Australian society but at the same time I want them to retain our cultural habits and traditions. I don't have the right mind set to learn more about diabetes management! Or go out and do some exercise … it's really hard to do right health actions in such lifestyle!" ASB-4*

5.4 DISCUSSION

The findings about barriers to DSM reported in this chapter fell into four themes, the first three of which were only reported by ASB participants. Only lack of motivation was reported by both groups. Many of these barriers have been reported in other EMGs and the results reported here demonstrate that ASB people with diabetes have similar barriers to DSM activities to other EMGs, but provide a depth of understanding not reported in other studies.[421-424] A relationship was established between participants' knowledge and diabetes control, measured by recent HbA_{1c} values. Participants with more knowledge tended to have better glycaemic control. Previous studies have documented the notion that improved knowledge results in improved control.[425-427] The results in the current research indicated that ASB participants had a lower level of knowledge and poorer medicine-use practices and this group also had poorer diabetes control judged by the increased percentage of participants who had HbA_{1c} values >7%.

A successful patient-centered approach requires diabetes health professionals to increase their understanding about patients' ongoing barriers to DSM. Such understanding has the potential to help healthcare providers overcoming these barriers, thus increasing patients' participation in self-care activities and improve outcomes.[428-430]

A study, conducted among foreign-born Chinese Americans by Chesla et al in 2009, highlighted how cultural and social aspects were barriers to diabetes management in that group.[233] Arabic-speaking background participants in the study reported here also reported unique cultural norms that appeared to negatively impact on DSM behaviours, such as cultural social behaviours related to food.

The ASB participants reported strong religious beliefs that included fatalistic views about the development of disease that negatively impacted on engagement in DSM practices. These findings are consistent with findings of Egede and Bonadonna in 2003, on the role of religious beliefs and fatalism on diabetes management in African Americans.[191] Walker et al, in a qualitative study that was conducted in Melbourne, Australia in 2005 among Chinese, Vietnamese, Greek, and Italian people reported that fatalism was not a central issue in these peoples' responses to health.[431] It therefore appears that ASB diabetic patients may have unique cultural aspects, which must be considered when devising DSM activities. It seems that ESB group, as cultural the dominant culture in Australia, takes their values for granted and do not necessarily regard them as cultural. The ASB group on the other hand, as immigrants whose culture differs from that of the dominant group, is more likely to identify their values as cultural.

Participants in both groups reported lack of motivation as a barrier to DSM. This is consistent with findings of a qualitative study by Brown et al (2002), in which a total of 36 family physicians participated in focus groups; they also perceived patients' lack of motivation as a key barrier to DSM.[432] The often onerous nature of DSM activities combined with a lack of understanding of their purpose is likely causes of decreased motivation. Emotional stress as a de-motivation factor negatively influencing adherence to DSM has previously been reported.[433-436]

5.5 CONCLUSION

Cultural and religious beliefs, poor knowledge and emotional distress appeared to adversely affect ASB participants' DSM. Knowledge of these barriers will enable healthcare providers to tailor education programs for ASB diabetic patients to improve adherence to DSM and improve long-term treatment outcomes.

CHAPTER SIX: LEARNING PREFERENCES AND NEEDS OF ARABIC-SPEAKING BACKGROUND PATIENTS WITH TYPE 2 DIABETES

KEY POINTS ABOUT THIS CHAPTER

This chapter describes:

- Learning needs and preferences of Arabic-speaking background participants with type 2 diabetes.

Summary of findings:

- Arabic-speaking background participants identified topics that were missing in current diabetes self-management education, such as eating in social ceremonies, modifying traditional meals and ways to exercise in culturally acceptable ways.
- Some education delivery modes that work well with other ethnic minority groups were also highly regarded by Arabic-speaking background participants, including the oral delivery of information, small group educational sessions and a peer support model of diabetes education.

6 Learning preferences and needs of Arabic-speaking background patients with type 2 diabetes

6.1 BACKGROUND

To achieve best clinical outcomes for people with diabetes, , modern treatment strategies highlight the need for teaching and supporting patient's self-management practices.[437] This shift toward a patient-centred approach has been in the vanguard of the change in diabetes management over the last decades.[438] However, patients with diabetes may not have the necessary knowledge or skill needed to successfully manage their diabetes.[439]

Providing information to patients with diabetes does not necessarily ensure accurate application of knowledge principles.[192] Within this context, Duchin and Brown in 1990 reported the absence of the individualisation of content to patient needs, identification of what patients want to know and assessment of patient readiness for learning as central issues.[440]

In diabetes care, deficits in patient education have been identified including inaccurate assumptions of learning needs, inappropriate teaching strategies, oversimplification of behavioural goals, and improper outcome evaluation. To improve quality of diabetes patient education and to facilitate improvement in health care outcomes, the National Diabetes Advisory Board (NDAB) in the USA has developed national standards for diabetes patient education programs, which are updated regularly.[443, 444] Currently, international and national guidelines for diabetes education are available. A large body of research has demonstrated positive effects of educational intervention on diabetic patient's knowledge, self-care behaviours and glycaemic control.[123, 445-447]

The uptake of diabetes education for ethnic minority groups (EMGs) is strongly affected by cultural beliefs.[188] Therefore, it has been recognised that in providing diabetes education for these groups is not merely a matter of providing general information, but rather that the education must focus on specific learning needs and cultural experiences and norms of these groups. A crucial stage in the process of developing and providing patient-centred and culturally appropriate diabetes education involves exploring of patients' views, attitudes and beliefs, along with identifying patients' incorrect health behaviours and determining knowledge deficiencies and assessing of learning needs.[449] Such a process enables accurate identification of both opportunities and barriers for the implementation of health promotion program.[450-453]

The effectiveness of culturally appropriate diabetes education in terms of improving patients' glycaemic control, knowledge, and healthy lifestyles has been demonstrated through several well-designed randomised trials conducted in ethnic minority groups, but not including Arabic-speaking groups.[123, 253, 454-456]

Currently there are culturally appropriate diabetes education programs only for some EMGs.[91] Greenhalgh *et al,* in their work with British Bangladeshi patients with diabetes proposed that culturally appropriate diabetes health education that concords with patients' views and beliefs is more likely to achieve desirable behavioural changes than one that does not.[284]

There is a paucity of information about learning needs and preferences of Arabic-speaking background (ASB) immigrants with T2DM. The aim of the research reported in this chapter was to address this knowledge gap by providing insights about learning needs and preferences from the perspective of ASB immigrants with T2DM living in Victoria, Australia.

6.2 METHOD

The qualitative methods used to obtain the results described in this chapter are presented in detail in Chapter 2.2. Results reported in this chapter are based on responses to the questions asked of ASB participants about two specific areas: what they would like to be taught about diabetes and how they like would to receive such information.

6.3 RESULTS

Two main themes emerged from the responses of ASB participants with T2DM about their learning preferences and needs for diabetes self-management education: preferred education topics and preferred delivery mode. Participants also spoke about current major sources of information and education, and these responses are also reported.

6.3.1 Participants

The characteristics of the ASB participants' whose responses are reported in this chapter are described in detail in section 2.3.1.

6.3.2 Preferences for educational topics and current sources of education

6.3.2.1 Social group meetings as a source of information

Arabic-speaking background participants spoke of having discussions about their diabetes-related issues, concerns and uncertainties with peers and friends within ASB communities. They preferred social group meetings as a way of voicing their diabetes-related concerns, which are not typically expressed during medical consultations. They also reported accessing a healthcare professional (their GPs – who were exclusively ASB) to obtain information only if they perceived their questions to be valid enough to warrant the discussion.

> *"When I talk with my friends, I feel relieved. We understand each other very well. We don't need to be wise or to plan what we have to say! We get to talk about all our real concerns. Even when we all don't have an answer for a question about our diabetes, at least we get to feel we are all in the same boat! We support each other, and we get to learn from one another!" ASB-58*
>
> *"I only go to see* **[GP.65]** *she is of Arabic-speaking background. I feel we have lots in common, things like language, religion and culture…I feel less judged and more understood"ASB-33*

6.3.2.2 Diabetes-related topics preferred by ASB participants

Participants said that they needed to be better educated about how to manage diabetes. Six main topics emerged from the inquiry into what ASB patients would like to be taught about diabetes self-management: dietary behaviours, physical activity and exercise levels, self-monitoring of blood glucose, meaning and importance of laboratory tests, prescribed diabetes medicines and stress management. The lack of understanding of ASB participants about this range of topics was compounded by their reluctance to ask questions of diabetes health professionals, predominantly due to embarrassment, the perceived need to maintain personal dignity and the fear of appearing ignorant.

> *"I was embarrassed to ask what she meant; I didn't want to look stupid. I think for us* **[ASB patients]***, it's really hard to admit that we don't know. So, if we are asked a question like 'Do you know what I mean?' or 'Did you understand?' the answer would always be 'Yes'." ASB-3*

- **Information about diet**

The cultural and social norms that added to participants' difficulty with managing diabetes on a daily basis is presented in Chapter 5: they preferred receiving a dietary management educational program that would teach them specifically about: appropriate modification of traditional Arabic food, diabetes-friendly food choices, appropriate daily portions of food and fruit for patients with diabetes, and how to eat in social ceremonies.

> "*In our culture … if you are invited you have to eat to demonstrate your appreciation for your hosts … if you are the one who hosts the social event you should keep eating mainly to encourage others to keep eating, in either case, one is pressured to keep eating. We should learn more about how to eat and what to do in such event! Especially as social events happen very frequently, and they are centred on food" ASB-6*

Those ASB participants who had access to diabetes education reported that the focus of current 'conventional' diabetes education seemed to be on what an individual with T2DM should avoid rather on what patients want to know. Perceived lack of consideration of patients' life situations and cultural norms was reported a contributing factors in ASB participants current avoidance of attending diabetes education sessions.

> *"They* **[diabetes health professionals]** *talked about a meal plan that I should follow. But they did not ask me if I can follow it or not. Even more than that, all the food I like was not on this plan. They* **[give]** *general advice, but it doesn't work that way!" ASB-10*

> *"She* **[the diabetes educator]** *once gave me advice on foods suitable for a person with diabetes. During the entire session she kept repeating 'should' and 'should not' in reference to food choices. I didn't pay much attention to what she said, simply because I felt that she should ask me about my eating patterns first. After establishing what my eating patterns are, she could then give me some suggestions about it. But no! It was like a one-way discussion, where she told me what she knew rather than what I needed" ASB-45*

Most ASB participants displayed significant knowledge gaps concerning numbers and sizes of food servings that are appropriate for patients with diabetes. Participants expressed their desire to learn about what appropriate amount of food per day for a patient with diabetes. Most participants were oblivious to the concept of food portions. ASB participants did not know what one 'serve' or one 'portion' of food meant.

> *"I would prefer if I was told specifically how much a 'portion' is. She* **[diabetes educator]** *talked about eating one or two portions of a fruit. The problem for me was that I didn't know how much the 'portion' is. I think many of us don't understand how much a serve or portion is!" ASB-59*

- **Information on exercise**

While participants seemed to recognise the general benefits of exercise they were unaware of the required amount of physical activity per week for a person with T2DM. Participants voiced frustration about continually receiving *abstract* advice about the importance of exercise in achieving adequate glycaemic control. Conversely, they expressed their desire to receive *precise* advice on how much exercise is required per week. They wanted to learn more about range of specific exercise activities that would help in controlling diabetes, yet consider health limitations of some participants.

> *"We will all receive health messages in a better way if it is delivered with a context for our own life i.e. is tailored to our needs. Unfortunately, this is not the case. They* **[healthcare professionals]** *talk about what 'should' be done, with no focus on what we are, and aren't, able to do" ASB-13*
>
> *"My doctor keeps reminding me to exercise. He often suggests walking, but it would be great if he tells me how much i.e. what the minimum and the maximum amount of exercise are required from me." ASB-17*

There was a widespread misunderstanding among ASB participants about the difference between 'physical activity' and 'exercise'. The majority of female participants consistently reported household chores as their main form of exercise.

> *"I don't exercise at all; it is not to my liking, but I do all the household chores e.g. vacuuming, dish washing, sweeping, .etc. I think this is more than enough!" ASB-1*

Participants, especially females, appeared to be reluctant to engage in any 'structured' exercise activities, especially in public places.

> *"Nowadays there are gyms for females only, yet they are not available everywhere, and I don't drive so it is a bit difficult* **[to get to them]**. *But to be honest with you, even if there was such a gym next to my house, I wouldn't go. The idea of exercising in a public place–even if it was for females only–it is not to my liking. … It may be because of how we were brought up back in the Middle East with a general dislike to the notion of exercising, especially for females" ASB-44*

- **Information about results of medical tests (including Self-monitoring of blood glucose)**

Participants expressed clear desire to be better educated about how to interpret medical test results. Participants performed blood glucose self-monitoring to a varying extent (Chapter 5.3). Those who reported using blood glucose meters expressed a need for education on how to use the resulting data to achieve better glycaemic control. Participants wanted to be taught what to do when their blood glucose levels are high.

> *"I use the machine* **[blood glucose meter]** *two times a day, and the problem for me is that I don't know what to do when the readings are too high – which happens many times" ASB-40*

Participants also linked their dislike of, or their resistance to, performing self-monitoring of blood glucose (SMBG) to their lack of understanding of what to do if they had a high reading.

> *"I used to measure my blood glucose levels, but not anymore. I stopped because I didn't know what to do when it* **[blood glucose level]** *was high. They* [diabetes professionals] *taught me how to measure my glucose levels very well and I was advised to keep a record of the reading. But I still don't know what exactly to do when these readings are high. It is quite stressful to record true readings when sugar levels are high" ASB-19*

Lack of knowledge among ASB participants about the meaning of test results extended beyond SMBG to other laboratory tests. Participants favoured receiving more information on ideal or required targets and goals, to help them make sense of their current health status. They wanted more details from their GPs about their laboratory test results, specifically when readings are high, what should be done to attain the required levels.

> *"When the doctor talks to me about test results he usually says, "Good", "Not so good", or "It is bad". It would be great if I could have a more solid discussion on lab results. I mean, if he could show me the papers and tell me what these numbers mean, and what they should be, it would be great and clearer for me" ASB-2*

- **Information about diabetes medicines**

The ASB participants expressed a desire to receive more information on how diabetes medicines work and how they affect the body and why more than one type of OHA may be needed.

> *"I don't know how these medicines* **[OHAs]** *work! Nor do I know how they may help me with my diabetes" ASB-33*

> *"I'm using all these diabetes medicines* [OHAs] *but I don't know why! I'm not sure if they are all the same or if they are different" ASB-52*

Arabic-speaking background participants reported a lack of knowledge about side effects of their prescribed medicines (Chapter 4.3). They preferred receiving more information about possible side effects of their prescribed OHAs; to be assured that diabetes prescribed medicines are safe and effective. Participants' preferred clearer explanation about OHAs during medical consultations; they spoke of information being provided is not enough. Some attributed minimal information during medical consultation to GPs' fears that such discussions may lead to patients' withholding their prescribed treatment.

> *"We* **[ASB patients]** *fear using medicines. But if I, however, had more knowledge about side effects of my diabetes pills, I might use them as prescribed without this fear that comes from not knowing what harms can these pills can cause" ASB-13*

> *"… I think that she* **[GP]** *worried that if she tells me more about side effects of my diabetes pills, I would stop using them! But, it is the opposite! When first I started using them, I hold lots of negative thoughts about these pills and I imagined them causing more harm than good! So I used them less than what I was told for years! But, now I have a better understanding about them* **[OHAs]***! If I knew what I know now I would have used these pills as the doctor told me!" ASB-42*

- **Information about stress management**

The ASB participants expressed a desire to learn more about stress management. There was a high level of diabetes-related stress reported by participants. They spoke of several cultural, religious, and political factors that foster their feelings of stress and anxiety.

> *"We* **[ASB]** *are stressed people ... It is just part of our lives. We grow-up with cumulative stress! It is part of our culture! It is the way of life back there* **[Middle East]***!" ASB-30*

> *"They* **[health care provider]** *don't teach us how to cope with stress or how to manage the burden of diabetes. It is very important for all of us to learn about stress management. Our life is full with stress. I'll be happy if I knew how, and my diabetes will be just ok" ASB-1*

The ASB participants who were diagnosed in the Middle East described feeling stressed and overwhelmed especially after being diagnosed with diabetes. They expressed feelings of 'being left alone' without any form of support after the initial medical diagnosis with diabetes.

> *"After the doctor told me that I have diabetes, I was so afraid. I was left alone with this horrible disease. I knew nothing about it. All what was in my mind were images of me as a sick lady who will have lots of complications in the future. I was alone facing this ugly disease" ASB-41*

6.3.3 Preferences for the delivery of diabetes education

Three main categories emerged about participants' preferred modalities for receiving diabetes education: oral versus written materials, small group versus individual education and preferred personnel to deliver educational interventions.

Participants overwhelmingly preferred the oral mode of information delivery rather than reading written information. They spoke of their dislike for reading written information, even when in Arabic.

> *"I don't like reading in general, even in Arabic language, and I don't think that I'm the exception to this 'rule'. I think most of Arabic-speaking background patients are just like me" ASB-57*
>
> *"I think we* **[ASB patients]** *understand better verbally, honestly I never read any of those materials, which I was given. And if I have a question I usually ask my friends but if it was something serious then I ask my doctor or pharmacist" ASB-18*
>
> *"… it doesn't matter even if the reading materials were in Arabic, I still prefer for someone to demonstrate things in front of me rather than looking at pictures in the pamphlets" ASB-6*

Some suggested live demonstrations for learning about self-management practices especially for food preparation.

> *"It would be of great help if they* **[diabetes health professionals]** *can teach us self-practices in a more interesting ways, like do a live class where a group of us come and learn. Food preparation class with live demonstration would be of great help and fun at the same time" ASB-19*

Small group, gender-specific, educational sessions appeared to be the preferred medium to obtain information on diabetes and its management compared to individual information sessions. Participants acknowledged forgetting information on diabetes management and small group meetings could be helpful as they can remind each other of what they have learned. They also reported that group meetings could be an opportunity to meet with other ASB patients with diabetes. In this format those who learned how to keep their diabetes under control could help other members to learn/acquire recommended self-practices.

> *"You know, I forget many of the stuff they* **[diabetes professionals]** *tell me, usually they* **[diabetes professionals]** *throw lots of information at me at once. So if I was told similar information with a group of friends, like in this group, we can remind each other" ASB-31*

The peer support model of diabetes education delivery was highly regarded by ASB patients. Participants wanted to share both negative and positive experiences with diabetes, wanting other members of their community with T2DM to benefit from such experiences.

> *"In a group setting, when some really get it, I mean really learned how to better manage their diabetes. … We would have a real example of the change we need" ASB-28*

> *"… I succeeded you see! My recent blood sugar levels are down. The GP was happy. I would like to share my story with my community: I might help someone" ASB-39*

6.4 DISCUSSION

The exploration of learning needs and preferences of ASB participants with T2DM revealed an expectation of culturally appropriate diabetes self-management education, filling a gap that has now been identified in current knowledge in this area. They provided insights into, and suggestions for, culturally appropriate diabetes self-management education for ASB communities, filling a gap that has now been identified in current knowledge in this area.

Results showed that current diabetes education programs are perceived to neglect ASB patients' life situation and cultural norms. There was an apparent mismatch between currently provided diabetes education and participants' learning needs and preferences. Results of previous research, conducted among Puerto Rican immigrants in the US with T2DM, showed that many of the study participants shunned receiving further education when they perceived the offered advice as neglecting their cultural traditions.[457]

Arabic-speaking background participants' educational needs and preferences were, in many areas, similar to other EMGs that have been studied both in Australia and internationally.[242, 450, 458, 459] Arab-speaking background participants in this study, as with these other EMGs, wanted more tailored information than what they have received about dietary management, exercise, interpretation of test results, stress management and the use of diabetes medicines. Patients' desire for more information than what they receive has been reported previously.[460-462]

Lack of knowledge of how to modify traditional food, numbers and sizes of food servings or eating correctly reported by ASB participants in this study, is consistent with the reported findings of studies conducted among other ethnic minority groups.[326, 463 84]

The study participants desire for more information about their medicines, to learn more about stress management and for emotional support, while not previously been reported for ASB patients with diabetes, is consistent with Kokanovic and Manderson's results on Chinese, Greek, Indian and Pacific Islander immigrants with T2DM in Australia,[211] and to the findings of other EMGs elsewhere.[446, 464]

Arabic-speaking background participants preferred peer-lead delivery of diabetes education. This is consistent with previous findings and the literature reports that diabetes peer support model has been used successful among other EMGs and shown to improve glycaemic control.[465, 466, 469-472] Arabic-speaking background participants disliked reading educational materials, even those translated to Arabic and produced at a low reading level, consistent with findings of previous research in other ethnic groups.[450, 473] Participants in the ASB group reported their preference for small interactive gender-separated diabetes education sessions. Stone et al, in research with South Asian patients with diabetes, also reported a preference for gender-separated diabetes education sessions.[190] The potential for learning via oral/verbal sources was highly regarded by ASB participants. Greenhalgh also reported a preference for oral education sessions in research conducted among British Bangladeshis with diabetes.[284]

Finally, poor understanding by ASB participants about a range of diabetes topics as described in chapter 2, and poor health knowledge are consistent with findings of previous research conducted among other minority groups.[210] However, ASB participants' poor knowledge was further compounded by reluctance to ask questions and cultural norms of agreeing to avoid embarrassment. This finding has not previously been reported, but provides insight into why patients understanding of disease-related issues may be poor in other ethnic groups as well as ASB communities.

6.5 CONCLUSION

The learning needs and preferences for diabetes education in ASB groups have not been identified previously. The ASB participants expressed a clear desire for more tailored information and different delivery modalities for diabetes education. They identified topics that were missing in current 'conventional' diabetes self-management education: modifying traditional meals, eating in social situations/ceremonies and ways to exercise in culturally acceptable ways. Preferred diabetes education delivery modalities were also identified, particularly peer-led, small, interactive, gender-separated education sessions and receiving information verbally. Healthcare providers who are involved in diabetes education will continue to see a number of

ASB patients, including those with limited health literacy. It is crucial to recognise that this ethnic minority group might differ from the mainstream population for which most currently diabetes educational materials have been developed.

CHAPTER SEVEN: ILLNESS AND TREATMENT PERCEPTIONS, ADHERENCE TO DIABETES SELF-CARE AND DIABETES OUTCOMES

KEY POINTS ABOUT THIS CHAPTER

This chapter describes:

- Participants' perceptions of health beliefs, their adherence to self-care activities, their adherence to medication instructions, and diabetes-related distresses.
- Relationships between participants' perception, self-care activities, medication adherence and diabetes control.

Summary of findings:

- Arabic speaking background (ASB) participants were significantly less-adherent to their prescribed OHAs than English-speaking participants (ESB).
- Diabetes control was suboptimal among the ASB participants (mean HbA_{1c} 8.03 ± 1.22); only 16.5% of the ASB participants met target glycaemic control of ≤ 7%.
- Arabic speaking participants' beliefs about medicines differed significantly from ESB: the ASB group reported significantly lower belief in the need and safety of their OHA; most were more concerned about long-term effects and harm of OHAs than the ESB participants.
- Participants' beliefs about medicines correlated with medication adherence: those who viewed diabetes medicines as necessary to control their diabetes, and were less concerned about long-term side effects and harmfulness of these medications, reported better adherence levels.
- There were strong and statistically significant correlations between participants' illness perceptions, self-management activities, and glycaemic control.
- Negative illness perceptions amongst ASB participants were strongly and significantly associated with decreased adherence to all aspects of self-care activities including dietary behaviour, exercise and physical activity, foot care, self-monitoring of blood glucose, which were in turn associated with poorer glycaemic control.

7 Illness and treatment perceptions, adherence to diabetes self-care and diabetes outcomes

7.1 BACKGROUND

Prescribing of medicines is known to be the most common treatment intervention in the medical encounter, irrespective of the disease state,[358] however, about 50% of prescribed medicines are subsequently not taken as directed by healthcare providers.[349, 474] Optimal benefits of prescribed treatment can only be realised if patients are adherent to instructions. Notably, low adherence levels can lead to poorer health outcomes, lower quality of life, increased healthcare costs, and can bias assessment of the effectiveness of treatments.[340, 345, 441, 442] Patients' non-adherence to prescribed medicines remains a significant challenge for health professionals.[344, 475]

To tackle the problem of non-adherence, numerous studies have been performed to understand the underlying causes,[476-479] and two categories of non-adherence – intentional and non-intentional – have been identified.[480] Gadkari and McHorney reported that unintentional non-adherence is characterised as passively inconsistent medication-taking behaviour by patients mainly due to forgetfulness.[481] Whereas intentional non-adherence is seen as a cognitive decision that is influenced by a range of factors related to the patient, the disease, and the treatment.[482, 483] Previous research on adherence-related factors showed that these could be either modifiable or non-modifiable. Socio-demographic, age, ethnicity and environmental factors are amongst unmodifiable factors which inconsistently predict non-adherence to medication when compared with modifiable factors.[482] The key modifiable factors include patient beliefs about medicines, their perceptions about illness, their knowledge levels, and the perceived impact of their health-related decision on daily lives.[480, 481]

To understanding adherence behaviours of patients, newer approaches have focused on assessing two dimensions: the beliefs patients have about treatment; and the their illnesses perceptions.[479] In relation to the first dimension, the Necessity–Concerns Framework has been suggested as a way to develop a clear understanding about key patients' medicine-related beliefs that influence their adherence behaviours.[484-486] According to this framework, beliefs about medications are categorised into two types: adherence-increasing beliefs that are the perceived necessity and advantages of prescribed treatment, and adherence-reducing beliefs that are concerned with perceived harmfulness, risks, and barriers to treatment.[487] Several studies have reported significant association between patients' belief about medicines and their adherence levels.[485, 488, 489] The Necessity-Concern framework can be quantified using the Belief about Medicines Questionnaire (BMQ), which has been found to predict patients' adherence, not only among those with diabetes,[487] but also in other several disease states such as asthma,[490] renal disease,[491] and arthritis.[492]

In relation to the second dimension, patients' illness perceptions, several studies have demonstrated that relationships exist between the beliefs patients have about illness and their self-care behaviours across a wide range of disease states, including, asthma, haemophilia and heart disease.[267, 268, 493] In diabetes, studies have investigated relationships between patients' illness beliefs, adherence to self-care activities and glycaemic control.[216, 286, 381, 468, 494, 495] Results indicated that patients who believed that diabetes was controllable, reported better self-care behaviour by way of diet, exercise and glucose testing, than those who did not.

Most of the research on treatment and illness perceptions in diabetes has been conducted among predominately Caucasian populations. Only two studies examined the role of illness perceptions in diabetes self-care among multi-cultural patient populations (non-ASB EMGs), and results showed different patterns of correlation in different groups.[144, 496] In addition, EMGs are known to have different illness perceptions,[269] therefore findings from the largely European-origin patient population are unlikely to be applicable to those diabetic patient from ethnic minority groups, including ASB patients.

No previous studies have examined relationships between treatment and illness perceptions, adherence or glycaemic control in ASB immigrant populations with diabetes. Research to investigate such relationships among this ethnic minority group is therefore important. The aim of the research reported in this thesis was to identify cultural differences in diabetes illness perceptions and medication beliefs among ESB and immigrant ASB people with diabetes, and to examine the relationships between these beliefs and adherence to diabetes self-care regimens and the impact of these factors on glycaemic control.

7.2 METHOD

The study described in this Chapter was designed as a multi-centre, cross-sectional survey conducted at various settings in the Melbourne metropolitan area and in rural Victoria, Australia. This phase (phase II) of the research started months after completion of phase I. Approval for this study was obtained from Monash University Human Research Ethics Committee (MUHREC), the Human Research Ethics Committee at Austin Health (The Non-Drug Scientific Review Committee), the Human Research Ethics Committee at Melbourne Health (covering Royal Melbourne Hospital and Western Health) and The Goulburn Valley Health Ethics and Research committee (covering rural sites) (Appendix 8, Appendix 9, Appendix 12 and Appendix 13).

Participants in the Melbourne metropolitan area were recruited through diabetes outpatient clinics at three major hospitals, ten general medical practices and five community support groups. For the rural arm of the study, participants were recruited in Shepparton, Victoria through diabetes outpatient clinics at a major rural hospital and its affiliated satellite clinics, three general medical practices and various community support groups. This geographic location was chosen as the rural centre because of its relatively large population of the target participant group for the study - Arabic-speaking people (ASB) who had recently migrated from countries in the Middle-East.

Throughout the twelve month recruitment period, all patients attending diabetes outpatients' clinics were approached and invited to participate in the study while waiting for clinic appointments. Patients themselves determined their eligibility to take part in the study by answering a screening question that was listed on a separate card attached to the front page of the questionnaire (Appendix 14).

Eligible, consenting patients completed a questionnaire (Appendix 15) that included validated measures of each patient's diabetes-related beliefs, their perceptions, behaviours and outcomes (details below). Participants were classified as having an ASB or English-speaking background (ESB) using similar criteria reported in Phase I (Chapter 2, section2.2.2). An Arabic version of the questionnaire, translated by a professional and independent translation service, was available for those who required it. Research assistants helped participants in completing the questionnaire when requested by the participant (Appendix 16 Questionnaire (Arabic Version).

7.2.1 Development of Questionnaire

The 10-page questionnaire comprised 98 items in thirteen sections (Appendix 15), and used self-reported data, except for clinical measures of diabetes control that were obtained, by consent, from each patient's medical records. Eleven of the twelve sections used in this questionnaire were validated tools. The twelfth comprised demographic information and health-related measures. Face and content validities of the questionnaire were established following review by three university academics, two diabetes educators, and nine patients who pilot-tested the questionnaire. Each of the twelve sections is elaborated in more detail below.

7.2.2 Socio-demographic and clinical data

This section of the questionnaire included a total of 13 questions relating to socio-demographic and health-related data. Socio-demographic data included age, gender, birth place, occupation, marital status and educational status. Health-related data included co-morbidity, duration of diabetes and perceived health status. Three questions assessed each patient's preferred sources of information about diabetes and their history of diabetes education.

7.2.2.1 Patient-pharmacist relationship

This section had four questions that were used to assess patient's relationships with community pharmacists. These questions were originally used to determine the trust patient's had in community pharmacists (TRUST-Ph).[497]

7.2.2.2 Patients' beliefs about diabetes medicines

The Beliefs about Medicines Questionnaire (BMQ) is a validated tool that has been widely used in patients with chronic illness, including diabetes.[492, 498, 499] It was used to assess each patient's beliefs about diabetes treatment, and has been shown to predict adherence to treatment.[485] The BMQ consists of ten items measuring two subscales: necessity and concern. Each participant's perceptions on each of the two sub-scales were scored on a five-point Likert scale, ranging from strongly agree with a score of '1' to strongly disagree with a score of '5'.

Mean scores were calculated for the necessity and concerns subscales. For the necessity sub-scale lower scores indicated a stronger belief in the necessity of diabetes medicines. For the concerns sub-scale lower scores indicated greater concerns about use of diabetes medication.

Based upon the empirical and theoretical framework of Aikens *et al,*[500] and to identify participants with high versus low perceived need and concerns about diabetes treatment, the necessity scores were split at a pre-determined value of two, whereas concerns scores were spilt at pre-determined value of three. A similar approach of splitting BMQ scores among patients with diabetes has been reported by Mann *et al*,[501] Clifford *et al* [486] and Tibaldi et al.[502] Using a combination of the spit scores, participants were categorised into one of four subgroups according to their attitudes towards medications: skeptical (low necessity, high concerns);

ambivalent (high necessity, high concerns); indifferent (low necessity, low concerns) and accepting (high necessity, low concerns).

7.2.2.3 Patients' beliefs about diabetes

Participants' beliefs about diabetes were assessed using the validated Brief Illness Perception Questionnaire (BIPQ).[503] The BIPQ has 9 items measuring cognitive illness representation, affective responses to illness (emotional representations) and overall understanding (illness coherence). There are five cognitive illness representations: cause (perceived cause); consequences (patients' beliefs about effects and impact); control (divided into personal control and treatment control); identity (patients beliefs about symptoms attributed to illness) and timeline (patients' beliefs about course and duration of disease), and each is measured using a single item. The BIPQ provides a rapid assessment, and it has been widely used. [503] High scores on the consequences, identity, and timeline items represent more negative beliefs about their prognosis with respect to these domains. Conversely, high scores on the coherence, personal control and treatment control dimensions represent more positive beliefs.

7.2.2.4 Diabetes self-care activities

Self-care in this context is defined as the daily regimen tasks that the individual performs to manage diabetes. A recently revised version of the Summary of Diabetes Self-Care Activities (SDSCA) was used to assess each patient's diabetes self-management behaviour: diet, exercise, blood glucose testing, foot care and smoking status.[504] The SDSCA has 11 items, and it is a brief, reliable and valid measure of diabetes self-management behaviours that has been widely used. The first 10 items of this scale, measure how many days in the previous week patients have been engaged in a certain activities, on a scale of 0–7.

Diabetes self-care activities data is reported in two ways: as mean days of activity in the prior week; and by splitting each aspect of self-care into a binary category, into adherent, if patients have been engaged in self-care behaviours for more than three days of the last seven days, and non-adherent if patient performed specific self-care for less than three days of the past week.

7.2.2.5 Medication Adherence

Each participant's medication adherence was measured using the modified version of the Morisky scale.[505] This scale consists of four items to assess medication-taking behaviour. Reponses for each item were scored 0 for 'Yes' and 1 for 'No', except that the score for item 2 was reversed to score 1 for 'Yes' and 0 for 'No'. Poor adherence was defined as a Morisky score of less than four. Based on total score of the four items, patients were grouped into either adherent (if the total score was four) or non-adherent (if the total score was less than 4).

7.2.2.6 Medication underuse

This section had two items measuring cost and non-cost related underuse of medication over the past 12 months. These items have been used in previous studies.[487]

7.2.2.7 Functional health literacy

Three previously validated items that measured difficulties in reading medical forms or learning about medical conditions were used to measure Functional Health Literacy (FHL). Inadequate FHL was indicated if the total score of the three items was ≤ 10 out of a possible total of 15.[506]

7.2.2.8 Treatment decision making

In this section, each patient's involvement in treatment decision-making was assessed using a modified version of the Control Preferences Scale. This scale comprises five statements that describe different roles for doctors and patients in treatment decision-making. Participants were asked to select only one statement out of five that best described their participation in treatment decision-making.[507-509]

7.2.2.9 Diabetes-related distress

Diabetes-related distress was assessed by the Diabetes Distress Scale - The DDS17. It is a new, brief, validated and reliable instrument.[510] The scale has a total of 17 items representing potential problems that people with diabetes may experience. The DDS17 has four subscales: emotional burden, physician-related distress, regimen-related distress and interpersonal distress. Participants were asked to indicate the degree to which each 'issue' might have distressed them in their daily lives on a scale of 0 to 5, in which '0' represented that the item was perceived as 'not a problem' and '5' where the item was perceived as a 'very serious problem'. As per the scoring instructions, a mean item score of two or higher indicted a level of distress worthy of clinical attention and was labelled as (moderate distress), whereas a mean item score of less than 2 was labelled as (low distress).

7.2.2.10 Patients satisfaction with healthcare decisions

In this section, each participant's satisfaction with healthcare decision was assessed, using modified Satisfaction with Decision scale.[511, 512] The modified scale measures satisfaction with decision independently of their prognosis, and it comprises six statements to which participants indicate their level of agreement on a five-point scale. The possible range of scores is 6 to 30, with higher scores indicating greater satisfaction.

7.2.2.11 Self-efficacy

In this study self-efficacy was defined as the confidence a participant feels about adhering to diabetes medications.[513] To measure medication-specific self-efficacy, a single item – "How confident are you in your ability to take your diabetes medications exactly as directed by your doctor"– was used. Each participant's response to this item was recorded on a 5-point Likert scale ranging from 1, "not at all confident," to 5, "extremely confident." This item has been validated in prior studies among patients with diabetes.[261, 514]

7.2.2.12 Adherence to traditional values and attitudes (acculturation levels)

Acculturation of ASB participants, the level to which they have integrated into the Australian society, was assessed using two subscales. In the first , three questions adapted from the General Acculturation Index were used that have been validated in Mexican Americans.[515] The second subscale was a six item scale, used to assess adherence to traditional values and attitudes among Arabic-speaking patients with diabetes.[516] Five items of the original six were used in this study.

7.2.2.13 Diabetes outcome measures

The most recent glycated haemoglobin value (HbA_{1c}), along with other measures of disease control (BP and lipids), were obtained from each participant's medical records with their written consent. There could be wide variation among participants when 'the most recent' HbA1c was performed, which could be a confounding variable.

7.2.3 Sample Size Estimation

The sample size was determined based on minimum correlation (r) strength of 0.20, α-level of 5% and a power of 80%. The sample size required for the survey was estimated using an online version of correlation coefficient calculator. A total of 360 participants were needed to complete the survey (180 in each arm).

7.2.4 Data analysis

All data were analysed using SPSS version 20.0. Data are summarised as percentages, mean ± standard deviation (SD), and mean differences [95% confidence interval (CI)]. The Chi-square test was used for categorical parameters, while Gamma test was used for ordinal parameters. Descriptive statistics were used for participants' characteristics. Univariate comparisons of categorical date between the two ethnic groups were conducted using chi-square test for equal proportion (or Fisher's exact tests where numbers are small), while Gamma test was used when the parameter was ordinal, and results were reported as numbers and percentages. Univariate comparison of continuous normally distributed variables was tested using the independent-samples Student's t-test, and results were reported as means (± standard deviation) whereas non-parametric data was compared using Wilcoxon rank-sum tests and reported as medians (interquartile range). A two-tailed significance level of 0.05 was used in all analyses. Bivariate associations for continuous normally distributed variables were tested with Pearson's Correlation (r), whereas non-parametric data was tested using Spearman's rank correlation coefficient.

7.3 RESULTS

Results are presented in this chapter both as descriptive statistics and as correlations between diabetes illness and treatment perceptions, self-care activities, adherence to medication and clinical outcomes.

7.3.1 Patients' characteristics

The study population included a total of 701 adult participants classified into; 392 participants in the ASB group and 309 in the ESB group.

Table 5 and Table 6 summarise demographic and clinical characteristics. All ASB participants were born in the Middle East; their mean age was 58 years, whereas 76.7% of the ESB group were born in Australia; their mean age was 60 years. Male to female ratio (gender representation) was approximately equal within both groups. About 84% of ASB participants reported low functional health literacy. Arabic-speaking background participants had inadequate glycaemic control (mean HbA_{1c} = 8.03%) and inadequate blood pressure control (mean SBP/DBP = 134/80 mmHg). The majority of participants were prescribed OHAs (91.5% of ASB and 81.4% of ESB participants).

Table 5: Socio-demographic characteristics

Participants' characteristics		Patients' ethnic background		
		ASB % (n)	ESB % (n)	Total % (n)
Gender	Male	50.1 (197)	53.9 (166)	51.8 (363)
Patient's age (yrs)	mean ± SD	58.04 ± 8.00	60.41 ± 9.54	59.09 ± 8.78
Country of birth	Australia	0.0 (0)	76.7 (234)	33.5 (234)
	Other	100.0 (393)	23.3 (71)	66.5 (464)
Country of birth ASB	Iraq	18.3 (72)		15.5 (72)
	Egypt	24.7 (97)		20.9 (97)
	UAE	0.8 (3)		0.6 (3)
	Lebanon	32.6 (128)		27.6 (128)
	Syria	3.6 (14)		3.0 (14)
	Somalia	12.0 (47)		10.1 (47)
	Jordan	3.1 (12)		2.6 (12)
	Kuwait	1.3 (5)		1.1 (5)
	Palestine	1.8 (7)		1.5 (7)
	Sudan	2.0 (8)		1.7 (8)
Country of birth ESB	UK		2.8 (2)	0.4 (2)
	Ireland		4.2 (3)	0.6 (3)
	USA		0.0 (0)	0.0 (0)
	New Zealand		7.0 (5)	1.1 (5)
	W. Europe		85.9 (61)	13.1 (61)
Level of education	≤12th grade	45.5 (176)	36.3 (109)	41.5 (285)
	High school	31.5 (122)	30.3 (91)	31.0 (213)
	≥university	23.0 (89)	33.3 (100)	27.5 (189)
Functional health literacy	Low	83.9 (329)	33.2 (100)	61.9 (429)
	Moderate	16.1 (63)	66.8 (201)	38.1 (264)
Employment Status	Part-time	19.1 (74)	22.5 (69)	20.6 (143)
	Full time	20.4 (79)	21.9 (67)	21.1 (146)
	Unemployed	10.3 (40)	4.6 (14)	7.8 (54)
	Retiree	16.5 (64)	38.5 (118)	26.2 (182)
	Housewife	33.6 (130)	12.4 (38)	24.2 (168)
Marital Status	Married	69.3 (266)	57.5 (177)	64.0 (443)
	Widowed	16.1 (62)	8.8 (27)	12.9 (89)
	De-facto	0.3 (1)	6.2 (19)	2.9 (20)
	Single	1.6 (6)	15.6 (48)	7.8 (54)
	Divorced	12.8 (49)	12.0 (37)	12.4 (86)
Acculturation levels -Integration to Australia -Adherence to Arabic tradition	mean ± SD	1.97 .± 0.57 2.35 ± 0.69	**NA**	

Table 6: Clinical and health-related characteristics

Patients’ characteristics	Patients' ethnic background		
	ASB % (n)	ESB % (n)	Total % (n)
History of diabetes (years)	7.18 ±4.63 (363)	10.51 ±8.39 (293)	8.67 ±6.78 (675)
Use of oral hypoglycaemic agents (OHAs)	91.5 (354)	81.4 (250)	87.0 (604)
Insulin use	27.9 (101)	48.7 (146)	37.3 (247)
Diabetes co-morbidities	81.9 (321)	78.6 (242)	80.4 (563)
High blood pressure	50.5 (198)	51.6 (159)	51.0 (357)
High cholesterol	51.8 (203)	33.4 (103)	43.7 (306)
Kidney problem	11.0 (43)	13.3 (41)	12.0 (84)
Heart condition	16.3 (64)	22.4 (69)	19.0 (133)
Eye disease	21.9 (86)	12.7 (39)	17.9 (125)
Cancer	1.0 (4)	5.5 (17)	3.0 (21)
Stomach ulcer	10.7 (42)	5.8 (18)	8.6 (60)
Arthritis	28.8 (113)	20.5 (63)	25.1 (176)
Others	2.3 (9)	14.0 (43)	7.4 (52)
Self-reported health status			
- very poor	3.3 (13)	3.6 (11)	3.4 (24)
- poor	22.6 (88)	8.4 (26)	16.3 (114)
- fair	34.1 (133)	26.6 (82)	30.8 (215)
- good	19.7 (77)	37.3 (115)	27.5 (192)
- very good	19.7 (77)	19.5 (60)	19.6 (137)
- excellent	0.5 (2)	4.5 (14)	2.3 (16)
HbA_{1c} value	8.03 ± 1.22 (296)	7.88 ± 1.46 (286)	7.96 ± 1.36 (582)
- ≤ 7 [% (n)]	16.5 (65)	27.9 (82)	21.5 (151)
- >7 [% (n)]	58.8 (231)	64.9 (200)	61.5 (431)
BP Systolic	134.90 ± 12.19 (195)	133.07 ± 16.42 (217)	133.94 ± 14.58 (412)
BP Diastolic	80.40 ± 27.41 (195)	76.55 ± 11.20 (216)	78.38 ± 9.77 (411)
Total Cholesterol	4.87 ± 1.15 (199)	4.31 ± 1.11 (200)	4.59 ± 1.16 (399)
LDL	2.38 ± 0.74 (199)	2.27 ± 0.89 (193)	2.32 ± 0.82 (392)
HDL	1.51 ± 0.95 (196)	1.24 ± 0.58 (198)	1.37 ± 0.80 (394)
Triglyceride	2.02 ± 0.81 (198)	1.95 ± 1.36 (197)	1.98 ± 1.11 (395)

7.3.2 Patient-pharmacist communication

Table 7 shows different relationships between study participants and community pharmacists. Significantly more participants in the ESB group than ASB reported having thought of a pharmacist when they had health problems (*P* = 0.002). Participants in both groups reported accessing community pharmacies only to obtain information about prescribed medicines; 52.4% and 47.6% in the ASB and ESB groups respectively. Overall, only 19% of study participants in both groups reported always following pharmacist recommendations with significantly fewer participants in the ASB group than ESB (7% versus 32.9% respectively).

Table 7: Relationships between patients and pharmacists

Patient–pharmacist relationship	Patients' ethnic background			*P* value
	ASB% (n)	ESB% (n)	Total (n)	
Whether patients had thought of the pharmacist when they had health problems	46.7 (98)	53.3 (112)	210	**0.002***
Whether participants visited a pharmacist only to get more information about prescribed medicines	52.4 (132)	47.6 (120)	252	0.234
Whether patients had discussed their prescribed medications with their pharmacist	64 (246)	71 (218)	464	0.061
How often patients followed pharmacist recommendations:				**0.01***
- sometimes	36.4 (88)	39.5 (83)	37.8 (171)	
- often	56.6 (137)	27.6 (58)	43.1 (195)	
- always	7.0 (17)	32.9 (69)	19.0 (86)	

*****P values for the first three questions were calculated with χ-test (categorical data). Gamma test used to calculate *P* value of last question (ordinal data).

7.3.3 Adherence to Diabetes self-care activities

As reported in section 7.2.2.4, results of adherence to self-care activities are reported in two ways – summary results are presented as means and medians; a pre-defined cut-point is used for a data-oriented approach, where non-adherence is categorised as fewer than 3 of the previous 7 days self-reported as adherent. Frequency histograms (

Figure **4**) show data distributions of diabetes self-care activities of the two groups as measured by the SDSCA scale. Mean and median scores of participants' self-care activities, as per healthcare providers' recommendations, during the past seven days are shown in Table 8. ASB participants were significantly less adherent to all aspects of diabetes self-care compared with ESB participants: dietary behaviours (*P* = <0.01; 95% Confidence Interval = -1.17, -0.84), exercise and physical activity (*P* = <0.001, 95% Confidence Interval -1.14, -0.61), blood glucose testing (*P* = <0.001) and foot-care (*P* = <0.001).

Table 8: Summary of diabetes self-care activities

SDSCA	**Patients' ethnic background**		***P* value**	**95% Confidence Interval**
	ASB Mean ± SD	**ESB Mean ± SD**		
Diet (Total)	3.93 ± 0.93	4.94 ± 1.26	**<0.001***	(-1.17, -0.84)
Diet – General	3.56 ± 1.34	4.98 ± 1.57	**<0.001***	
Diet – Specific	4.31 ± 0.97	4.90 ± 1.42	**<0.001***	
Exercise	2.77 ± 1.40	3.65 ± 2.13	**<0.001***	(-1.14, -0.61)
SDSCA	**Patients' ethnic background** **ASB Median (interquartile range)**	**ESB Median (interquartile range)**	***P* value**	
Blood sugar testing	4 (2 – 5)	1 (0 – 3.5)	**<0.001†**	
Foot care	5 (4 – 7)	2.5 (1.5 – 4)	**<0.001†**	

SDSCA = Summary of diabetes self-care activities; **P* calculated with independent t-test. †*P* calculated with Wilcoxon rank-sum tests. Differences is significant at the 0.01 level (2-tailed)

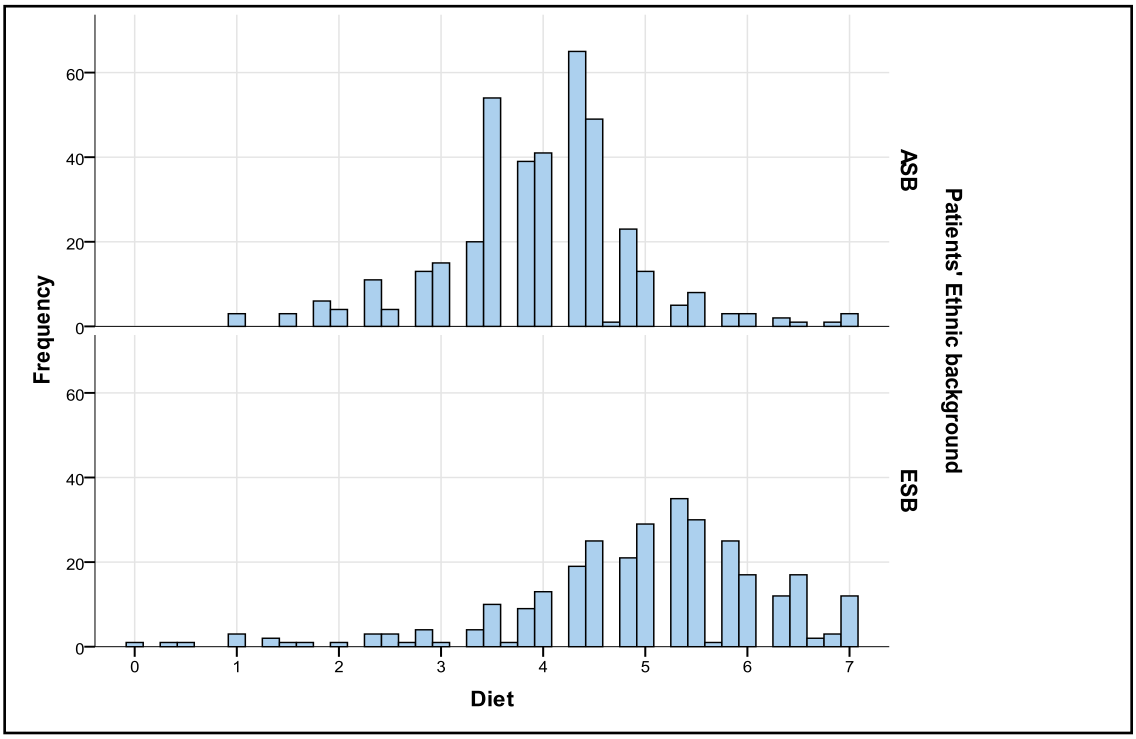


Figure 4: Frequency of Dietary self-care behaviours during past 7 days by the two groups (ASB and ESB), assessed using SDSCA scale.

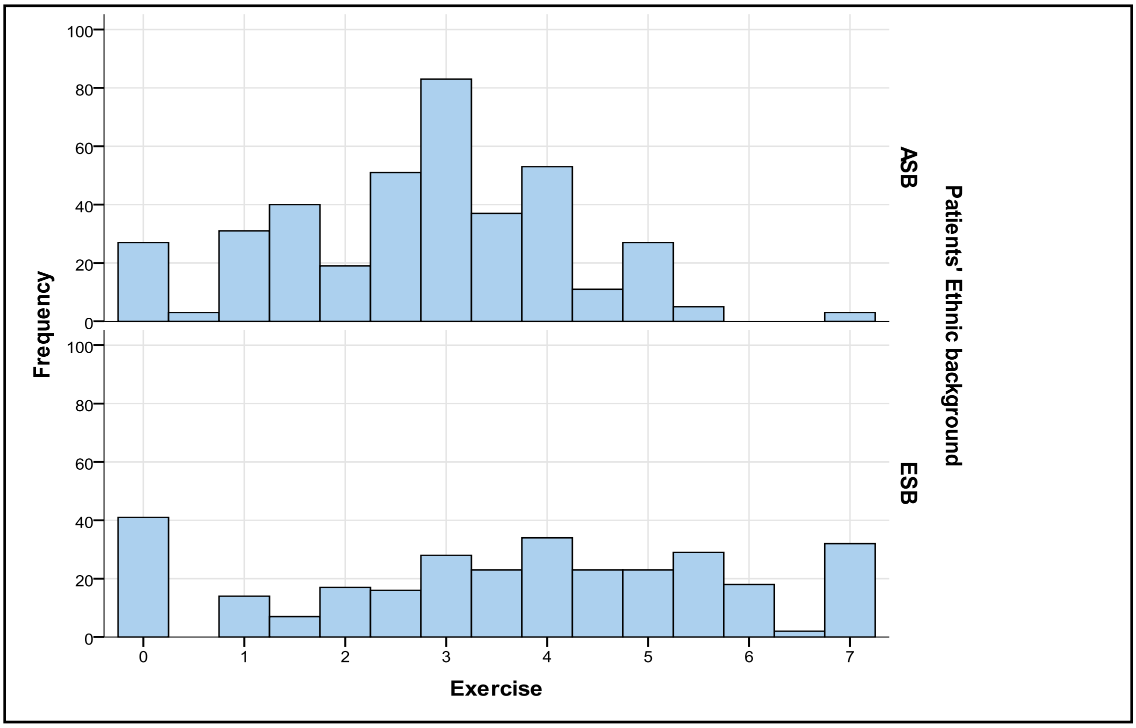


Figure 5: Frequency of Exercise behaviours during past 7 days by the two groups (ASB and ESB), assessed using SDSCA scale.

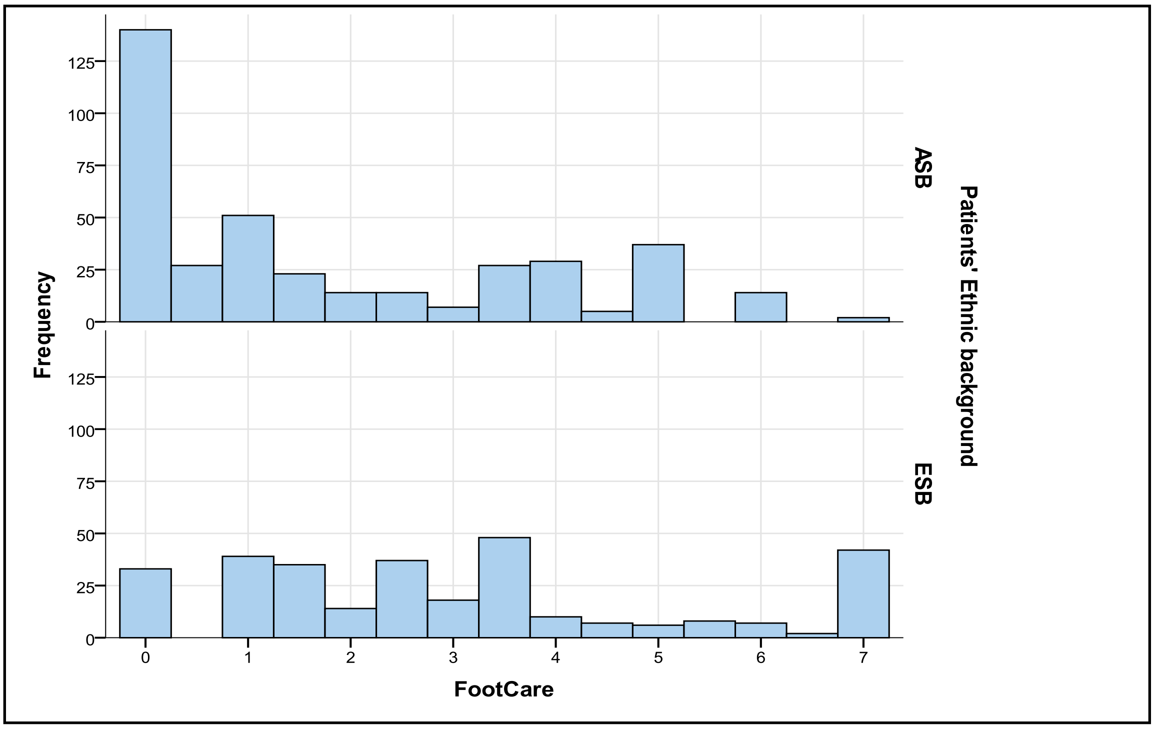


Figure 6: Frequency of Foot-care behaviours during past 7 days by the two groups (ASB and ESB), assessed using SDSCA scale.

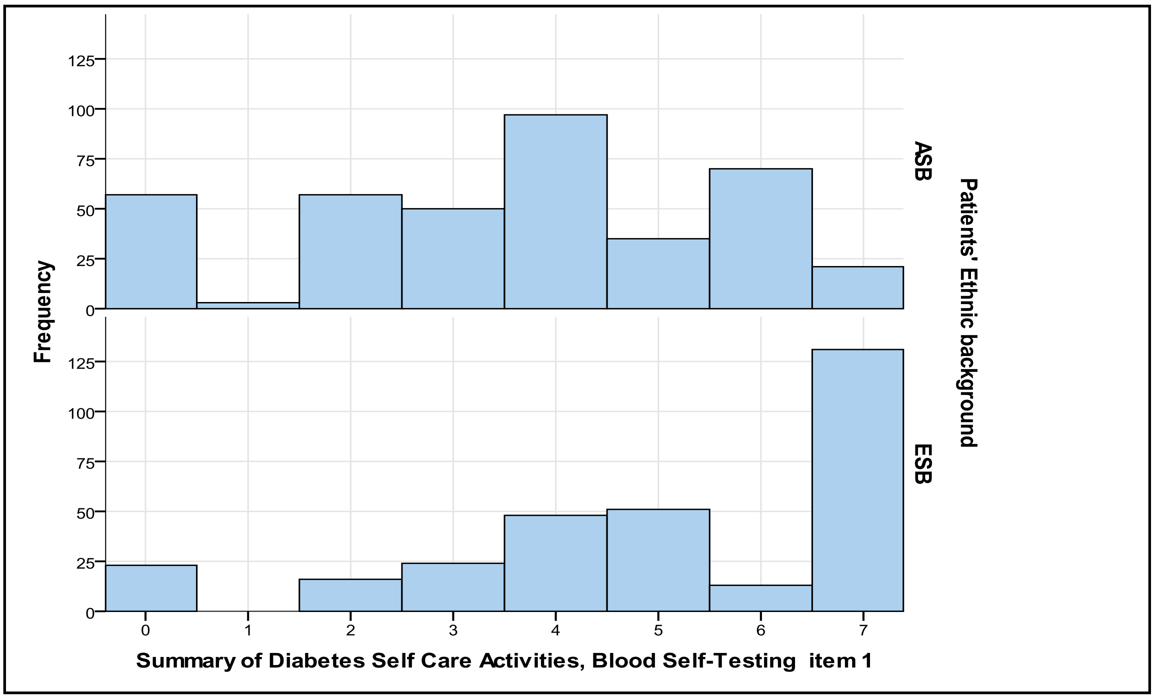


Figure 7: Frequency of Exercise behaviours during past 7 days by the two groups (ASB and ESB), assessed using SDSCA scale.

Table 9 shows a data-oriented approach that dichotomised each aspect of diabetes self-care into binary categories: adherent, when patients have been engaged in the self-care behaviour for more than three days of the last seven days, and non-adherent if patient performed specific self-care for less than three days of the past week. Participants in the ASB group were statistically less adherent. On adherence to dietary recommendations, there was a statistically significant difference between the two groups, with ASB participants being less adherent (P = 0.002). Low levels of adherence to physical activity and exercise were reported by more than half of study participants in the two groups (54.1%). Compared with the ESB group, significantly lower levels of adherence to blood glucose monitoring were reported by ASB participants (*P* = <0.001). A significant difference was also found in the number of smokers within each group; 26.7% of ASB participants compared to only 13% in the ESB group.

Table 9: Summary of diabetes self-care activities (binary)

The SDSCA	Patients' ethnic background			P value for difference*
	ASB% (n)	ESB% (n)	Total% (n)	
Diet				
- Non adherent	15.1 (59)	7.5 (23)	11.7 (82)	
- Adherent	84.9 (331)	92.5 (285)	88.3 (616)	<0.01*
Exercise				
- Non adherent	65.1 (254)	40.1 (123)	54.1(377)	
- Adherent	34.9 (136)	59.9 (184)	45.9 (320)	<0.001*
Blood glucose testing				
- Non adherent	42.8 (167)	20.6 (63)	33.0 (230)	
- Adherent	57.2 (223)	79.4 (243)	67.0 (466)	<0.001*
Foot care				
- Non adherent	70.8 (276)	57.5 (176)	64.9 (452)	
- Adherent	29.2 (114)	42.5 (130)	35.1 (244)	<0.001*
Smoking				
- No	73.3 (277)	87.0 (267)	79.4 (544)	
- Yes	26.7 (101)	13.0 (40)	20.6 (141)	<0.001*

SDSCA = Summary of diabetes self-care activities. **P* calculated with χ-test (categorical data).

7.3.4 Diabetes-related distress

Diabetes distress refers to worries and emotional burdens that patients' experience when they manage a demanding disease like diabetes; diabetes distress was measured using the DSS-17 (section 1.2.1.10). The frequency histogram (Figure 8) shows data distributions of diabetes distress by the two the groups. Overall, ASB participants displayed higher levels of diabetes-related distress compared with their counterparts in the ESB group (*P* = 0.04). Statistically significant higher levels of distress were experienced by ASB participants across the three sub-scales, emotional burden, regimen-related distress and diabetes-related interpersonal distress (*P* = < 0.001). There was no significant difference between the two groups on the fourth subscale physician-related distress.

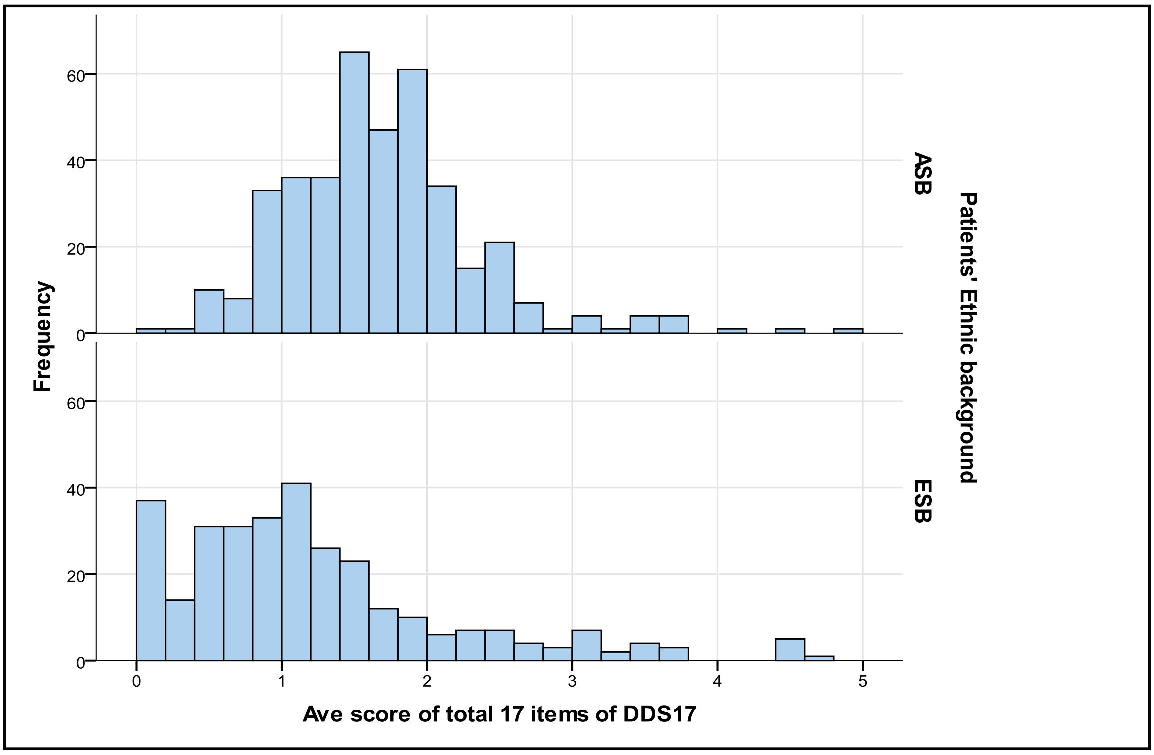


Figure 8: Frequency of diabetes-relates distress by the two groups (ESB and ASB) assessed using the DDS-17.

Table 10: Diabetes-related distress

The DDS-17	Patients' ethnic background			*P* value for difference*
	ASB% (n)	ESB% (n)	Total% (n)	
Emotional burden				
Low	30.6 (120)	63.2 (194)	44.9 (314)	
High	69.4 (272)	36.8 (113)	55.1 (385)	**<0.001***
Physician-related distress				
Low	91.1 (357)	87.2 (266)	89.4 (623)	
High	8.9 (35)	12.8 (39)	10.6 (74)	.108
Regimen-related distress				
Low	50.0 (196)	75.5 (231)	61.2 (427)	
High	50.0 (196)	24.5 (75)	38.8 (271)	**<0.001***
Diabetes-related Interpersonal Distress				
Low	52.3 (205)	84.3 (257) 15.7	66.3 (462)	
High	47.7 (187)	(48)	33.7 (235)	**<0.001***
Total				
Low	76.0 (298)	84.0 (258) 16.0	79.5 (556)	
High	24.0 (94)	(49)	20.5 (143)	**<0.04***

DSS = Diabetes distress scale. **P* calculated with χ-test (categorical data).

7.3.5 Patients' beliefs about diabetes treatment (treatment perception)

With regards to participants' beliefs about diabetes medicines, Table 11 shows that ASB participants exhibited higher concerns about the use and the effects of diabetes medicines compared with their counterparts in the ESB group, based on average mean score of the five items of BMQ-Concern sub-scale (mean ± SD of BMQ-Concern; 2.60 ± .86, and 3.41 ± .76 respectively). ASB participants were less likely to see the need for diabetes medicines than ESB participants (*P* = <0.001, 95% Confidence Interval = -0.93, -0.68).

Table 11: Participants' beliefs about diabetes medicines

The BMQ	Patients' ethnic background		*P* value	95% Confidence Interval
	ASB Mean ± SD	ESB Mean ± SD		
Need	2.35 ± .51	1.86 ± .82	**<0.001***	(0.38 to 0.58)
Concern	2.60 ± .86	3.41 ± .76	**<0.001***	(-0.93 to -0.68)

BMQ = the Beliefs about medicines questionnaire; *Correlation is significant at the 0.05 level

Boxplots have been used to graphically depict participants' beliefs about diabetes medicines

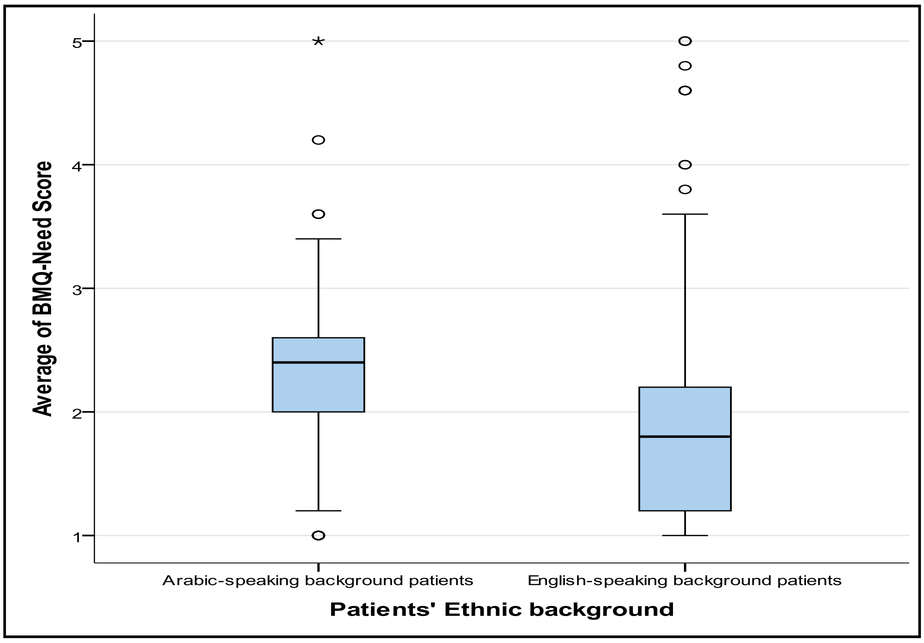
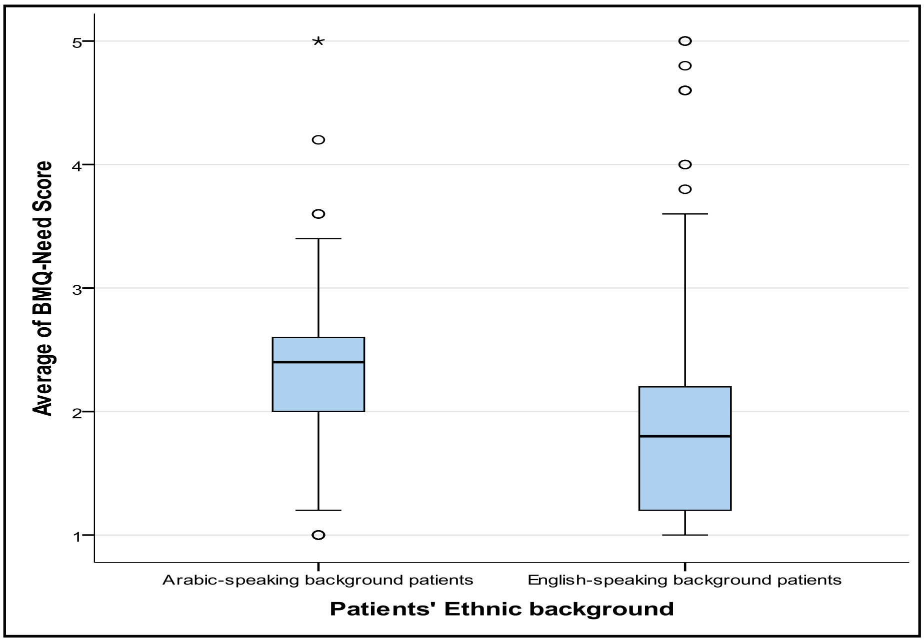


Figure 9 and **Figure 10**). Average mean scores of ASB participants were higher on BMQ- need, and lower on BMQ-concern subscales compared to ESB participants.



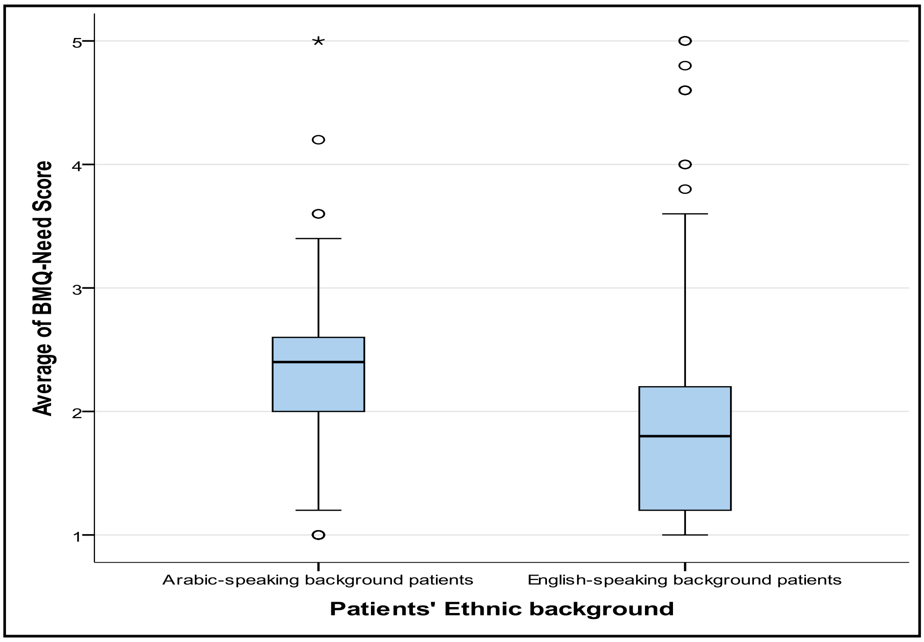


Figure 9: Boxplot of BMQ-need subscale scores by the two groups

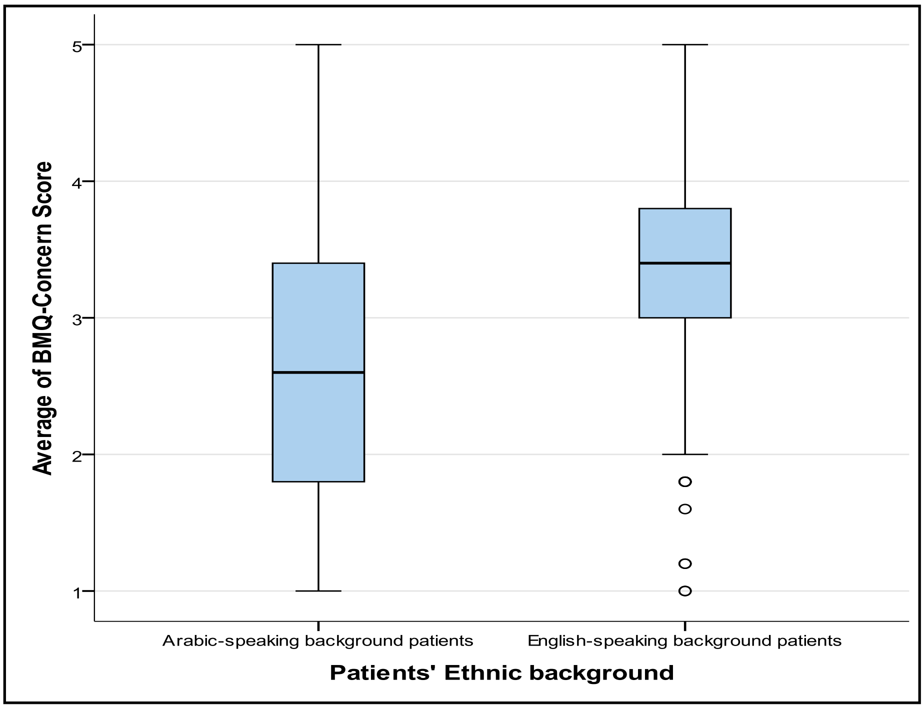


Figure 10: Boxplot of BMQ-need subscale scores by the two groups

When examining patients’ beliefs about diabetes medicines using a data-oriented approach (section 7.2.2.4), a mid-point split was conducted on the Necessity and Concerns scales of the BMQ. Accordingly, participants in both groups were assigned to one of following four groups: Accepting (high Necessity, low Concerns), Ambivalent (high Necessity, high Concerns), Indifferent (low Necessity, low Concerns) or Sceptical (low Necessity, high Concerns). Figure 11 shows the distribution of participants across the four attitudinal groups. More than half of the ASB participants were sceptical about the use of OHAs, by contrast only about 11% of the ESB participants were sceptical. Similarly, more than half of ESB participants accepted the idea of using OHAs to manage their diabetes, by contrast only about 14% of the ASB participnts were accepting.

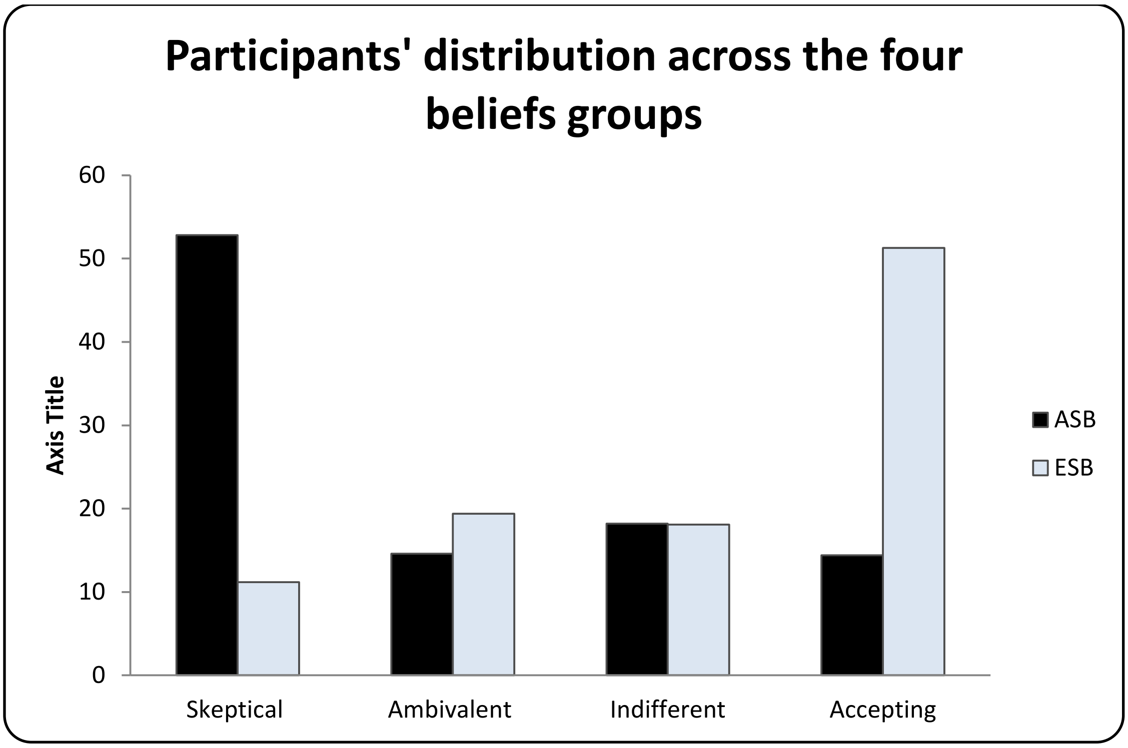


Figure 11: Participants' distribution across the four beliefs groups

7.3.6 Patients’ beliefs about diabetes (illness perception)

Significant differences were found between the ASB and ESB groups across all items of the Brief Illness Perception BIPQ. English-speaking background participants reported more positive beliefs about diabetes than the ASB group. For example, ESB participants reported higher beliefs in their personal ability to control diabetes, they also reported higher beliefs in the ability of their prescribed treatment to control diabetes, and they reported a better overall understanding about diabetes (Personal control, treatment control, and coherence perception, *P* values for the item <0.001). More negative beliefs about diabetes were reported by the ASB group in comparison with their counterparts in the ESB group. For example, more somatic complaints due to diabetes were reported by ASB participants (identity perception, *P* values <0.001). They also believed that their diabetes had a considerable negative impact on their personal lives (consequences, *P* values <0.001). Regarding timeline dimension, ESB participants reported more chronic perception of their diabetes nature compared with ASB group (*P* = <0.001) (Table 12).

Table 12: Comparison between the two groups of illness perception

BIPQ	Patients' ethnic background		*P* value	95% Confidence Interval
	ASB Mean ± SD	ESB Mean ± SD		
Consequences	6.28 ± 1.92	4.71 ± 2.61	**<0.001***	(1.21 , 1.89)
Timeline	7.86 ± 1.76	8.90 ± 1.77	**<0.001***	(-1.30 , -0.78)
Personal control	5.76 ± 1.49	6.57 ± 2.10	**<0.001***	(-1.08 , -.54)
Treatment control	6.28 ± 1.49	7.90 ± 1.82	**<0.001***	(-1.85 , -1.36)
Identity	5.73 ± 1.92	4.29 ± 2.37	**<0.001***	(1.12 , 1.76)
Concern	6.59 ±2 .27	6.21 ± 2.76	**.054**	(-0.01 , 0.74)
Coherence	5.46 ± 1.97	7.23 ± 2.02	**<0.001***	(-2.06 ,-1.46)

BIPQ = Brief Illness Perception Questionnaire; *Differences is significant at the 0.01 level (2-tailed); †*P* calculated with independent sample t-test.

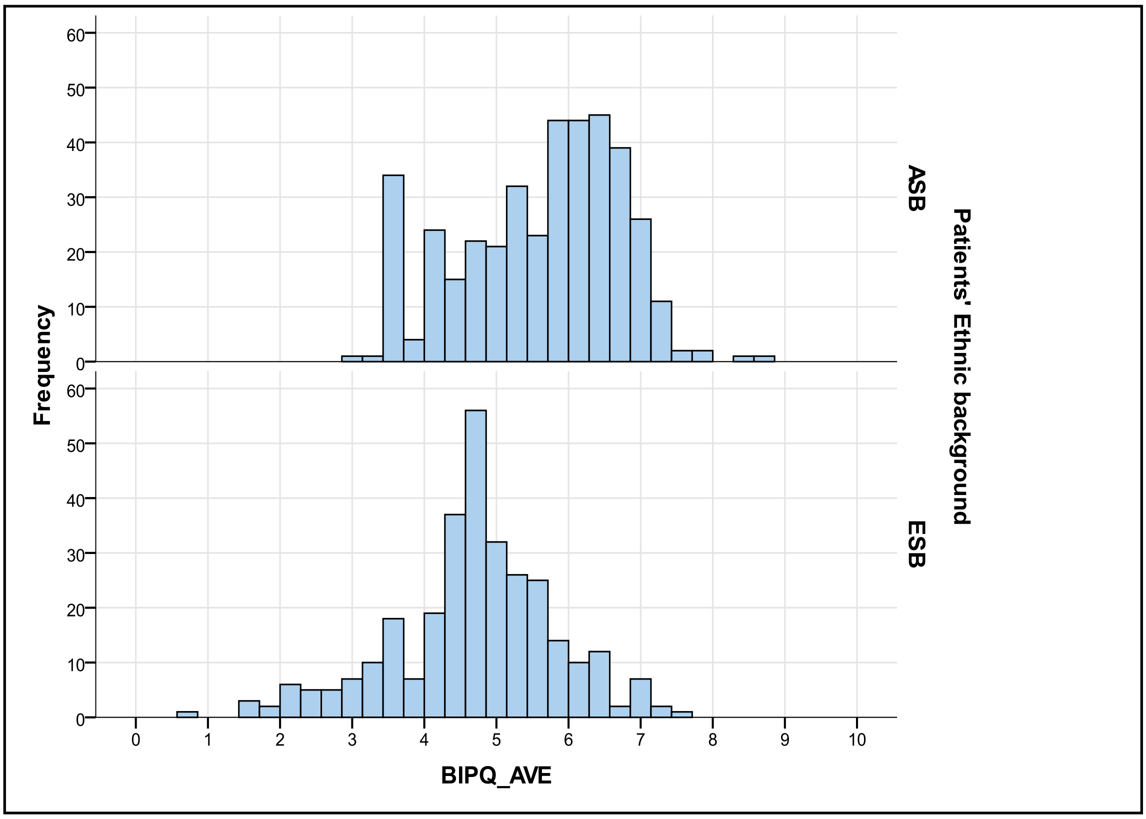


Figure 12: Frequency of illness perception (diabetes) by the two groups (ESB and ASB), assessed using the BIPQ.

7.3.7 Patients' involvement in treatment decision-making

Participants' responses on the modified Control Preference Scale were classified into three distinct categories: active, collaborative or passive roles in treatment decision-making. There were significant differences in the distribution of the three roles across the two groups (*P* = 0.002). Overall, more than half of ASB participants reported passive roles. Of the ESB group, 13.6% chose the 'active' role statement, whereas among ASB group only 2.6% of participants reported playing active roles (Table 13).

Table 13: Patients' involvement in treatment decision making

Patients' ethnic background	Patients' roles in treatment decision-making			P value for the difference*
	Active% (n)	Collaborative% (n)	Passive% (n)	
ASB	2.6% (10)	40.5% 1(58)	56.9% (222)	0.002
ESB	13.6% (41)	37.4% (113)	49.0% (148)	
Total	7.4% (51)	39.2% (271)	53.5% (370)	

*Differences are significant at the 0.01 level (2-tailed); † P value was calculated using Gamma test to (ordinal data).

7.3.8 Patients satisfaction with healthcare decision

Reported satisfaction with healthcare decisions was generally higher among the ASB group compared to the ESB group (*P* <0.001), as shown in Table 14.

Table 14: Patients' reported satisfaction with the decision.

The Satisfaction with decision scale	**Patients' ethnic background**		***P* value**	**95% Confidence Interval**
	ASB Mean ± SD	**ESB Mean ± SD**		
Average total of the six statements	2.85 ± .57	1.89 ± .71	**<0.001***	(0.87 to 1.06)

**P* calculated with independent sample t-test.

7.3.9 Patients' self-efficacy

Self-efficacy in taking OAHs as prescribed by healthcare providers was significantly higher among participants in the ESB group compared with ASB group (*P* <0.001) (Table **15**).

Table 15: Participants reported self-efficacy in taking diabetes medication

Patients' Ethnic Background	**Patient's self-efficacy in taking diabetes medication exactly as prescribed**					**Total**	**P value for the difference***
	Not at all confident	Not confident	Unsure	Confident	Extremely confident		
ASB	7	17	59	283	8	374	<0.001
ESB	4	1	12	176	104	297	

******P* value was calculated using Gamma test (ordinal data)

7.3.9.1 The correlations between illness perceptions and adherence to diabetes self-management

There were significant relationships between participants' illness perceptions and self-reported adherence to diabetes self-care activities (Table 16). For the ASB group, negative beliefs about diabetes were strongly and significantly correlated with poorer adherence to diet recommendations, exercise, blood glucose testing and foot care. Identity perceptions (reflect more somatic symptoms linked to diabetes) were strongly and significantly associated with poor adherence to dietary behaviours, exercise, blood glucose testing and foot-care (Spearman's rank correlation coefficients: -.228†; -.503†; -.481†-.494 respectively; P values <0.001 for four aspects of diabetes self-management). Positive perceptions were also significantly and positively associated with better adherence to DSM. ASB participants' perceptions about their ability to control diabetes (personal control) were strongly associated with better adherence behaviours to exercise = (rs=.286); blood glucose testing (rs = .274); and foot care (rs = .242).

Table 16: The correlations between illness perceptions, adherence to diabetes self-care activities, and glycaemic control by the two ethnic groups (ASB and ESB)

BIPQ ASB group	Adherence to Diabetes self-care activities			
	Dietary behaviours	Exercise	Blood glucose testing	Foot-care
Consequences	-.124*	-.485†	-.435†	-.516†
Timeline	.106	-.241†	-.160†	-.284†
Personal control	.181†	.286†	.274†	.242†
Treatment control	.213†	.260†	.321†	.258†
Identity	-.228†	-.503†	-.481†	-.494†
Concern	-.132†	-.401†	-.414†	-.489†
Coherence	-.263†	.335†	.312†	.284†
Total score of BIPQ	-.210†	-.604†	-.580†	-.629†

BIPQ ESB group	Adherence to Diabetes self-care activities			
	Dietary behaviours	Exercise	Blood glucose testing	Foot-care
Consequences	-.137	.037	-.137*	-.163†
Timeline	.010	-.039	.123*	.029
Personal control	.310†	.115*	.120*	.133*
Treatment control	.065	.052	.215†	.168†
Identity	-.035	-.013	.001	-.044
Concern	-.052	-.025	.010	.103
Coherence	.325†	.051	.112	.112*
Total score of BIPQ	-.217†	-.045	-.128*	-.128*

BIPQ = Brief Illness Perception Questionnaire; *Correlation is significant at the 0.05 level (2-tailed); †Correlation is significant at the 0.01 level (2-tailed); ‡Spearman's rank correlation coefficient (*P* Value).

7.3.9.2 The correlations between illness perceptions and treatment perceptions and glycaemic control

Correlations between participants' illness perception, treatment perceptions and glycaemic control (HbA_{1c}), are presented in Table 17. For the ASB group, positive beliefs about medicines (low scores on the BMQ-Need subscale indicating strong beliefs in need for diabetes medicines) were strongly and positively correlated with better glycaemic control (rs. = 320†, *P* <0.001). Participants who had higher concerns about diabetes medicines had worse glycaemic control. Negative beliefs about medicines were significantly correlated with worse glycaemic control in both ASB and ESB groups (rs. = -.355†, P <0.001); rs. = -.216†, *P* <0.001 respectively). Overall, the perception that diabetes is a threating illness (assessed by computing an overall score of BIPQ) was significantly correlated with better glycaemic control; stronger associations were observed in the ASB group compared with ESB (rs. = -.406†, P <0.001); rs. = -.266†, *P* <0.001). Participants in both groups who reported high belief in their personal ability to control diabetes had a better glycaemic control (rs. = .244†, P <0.001); rs. = -.251†, P <0.001 for ASB and ESB groups respectively). For the ASB group, illness coherence (overall understanding about diabetes) was significantly correlated with HbA_{1c}; participants who reported better understanding about diabetes had better glycaemic control (rs.375†, P <0.001).

Table 17: The correlations between treatment and illness perceptions and glycaemic control by the two ethnic groups (ASB and ESB)

Treatment and illness perceptions	Glycaemic control (HbA_{1c})	
	ASB group (*P* value)	ESB group (*P* value)
The BMQ Need	.320† (<0.001)	.020 (.734)
Concern	-.355† (<0.001)	-.216† (<0.001)
The BIPQ Consequences	.212† (<0.001)	.150 (.012)
Timeline	-.118 (.043)	.089 (0.134)
Personal control	.244†(<0.001)	.251† (<0.001)
Treatment control	.239† (<0.001)	-.014 (.810)
Identity	.306† (<0.001)	.128* (.003)
Concern	.202† (<0.001)	.107 (.071)
Coherence	.375† (<0.001)	.084 (.159)
Total score of BIPQ	.406† (<0.001)	.266† (<0.001)

BMQ = the Beliefs about medicines questionnaire; *Correlation is significant at the 0.05 level (2-tailed); †Correlation is significant at the 0.01 level (2-tailed); ‡Spearman's rank correlation coefficient (*P* Value).

7.3.10 Relationship between treatment perception and adherence to medicines

ANOVA was used to examine the relationship between treatment perceptions and self-reported adherence to medicines and Ethnicity (Table 18); there were significant differences between adherent and non-adherent participants. Interaction between ethnicity and self-reported adherence to diabetes medication was tested and there was no significant effect (P= 0.3), therefore it was removed from analysis. Adherent participants in both ethnic groups displayed more positive beliefs about need for, and use of, diabetes medicines (measured by lower scores on the BMQ-Need compared with non-adherent (1.88 versus 2.18 respectively).

Table 18: ANOVA testing of ethnicity, treatment perception and medication adherence

Tests of Between-Subjects Effects					
Dependent Variable: Participants beliefs about medicines (assessed by mean score of BMQ-Need subscale)					
Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	58.275[a]	3	19.425	51.441	.000
Intercept	1610.671	1	1610.671	4265.381	.000
Ethnicity	14.172	1	14.172	37.530	.000
MS_BI	9.916	1	9.916	26.259	.000

Ethnicity * MS_BI	**.403**	**1**	**.403**	**1.067**	**.302**
Error	257.533	682	.378		
Total	3383.073	686			
Corrected Total	315.808	685			
a. R Squared = .185 (Adjusted R Squared = .181					

Remove interaction
Dependent Variable: Participants beliefs about medicines (assessed by mean score of BMQ-Need subscale)

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Intercept	2328.337	1	2328.337	6165.301	.000
Ethnicity	22.117	1	22.117	58.564	.000
MS_BI	9.697	1	9.697	25.678	.000
Error	257.936	683	.378		
Corrected Total	315.808	685			
a. R Squared = .183 (Adjusted R Squared = .181)					

2. Patients' ethnic background

Dependent Variable: Participants beliefs about medicines (assessed by mean score of BMQ-Need subscale)

			95% Confidence Interval	
Patients' Ethnic background	Mean	Std. Error	Lower Bound	Upper Bound
Arabic-speaking background patients	2.232	.039	2.156	2.308
English-speaking background patients	1.823	.036	1.753	1.893

3. Medication adherence

Participants beliefs about medicines (assessed by mean score of BMQ-Need subscale)

			95% Confidence Interval	
MS_BI	Mean	Std. Error	Lower Bound	Upper Bound
adherent	1.881	.046	1.790	1.971
non-adherent	2.175	.030	2.116	2.234

7.3.11 Acculturation levels and glycaemic control

Glycaemic control was negatively associated with ASB participants' acculturation levels - the more acculturated the participant into Australian society the lower the HbA_{1c} value, thus better glycaemic control. Less integrated ASB participants (lower scores on General Acculturation Index) had worse glycaemic control [P <0.001, person's (r) correlation = -0.321]. The more adherent ASB participants to Arabic tradition and values (lower scores on five-item scale for assessing adherence to traditional values and attitudes), had worse glycaemic control [P <0.001, person's (r) correlation = -0.325].

7.3.11.1 Multivariable predictors of glycaemic control

Stepwise multiple linear regressions by the ASB and ESB groups were performed separately to predict glycaemic control (Dependent Variable was HbA_{1c}). Four variables significantly predicted HbA_{1c} value in the ASB group: positive beliefs about diabetes medicines were positively associated with HbA_{1c} i.e. the stronger the belief in the need for diabetes medicine the better the glycaemic control (Unstandardised B Coefficient = .447, $P < 0.001$). While negative beliefs about treatment (assessed by the BMQ-Concern subscale) were negatively associated with HbA_{1c} (Unstandardised B Coefficient = -.187, $P < 0.001$), the lower patients concerns about diabetes medicines were, the better glycaemic control. Exercise was negatively associated with HbA_{1c} - the more exercise participants reported, the lower their HbA_{1c} (Unstandardised B Coefficient = -.207, P = 0.001). Finally, overall understanding about diabetes (assessed by coherence perception) was positively associated with HbA_{1c} (Unstandardised B Coefficient =.088, $P = 0.009$). A total of 25 variables have been entered into the model, 19 variables have been excluded from ESB group, and 18 from the ASB. For the ASB group, the overall model explained 24% of variance in HbA_{1c} (R Square = 0.24) (Table 19). Amongst excluded variables were diabetes-related distress (assessed by DDS17 scores) there was no improvement in the ASB ($P = 0.32$) however, a slight improvement in the ESB group ($P = 0.051$). The relationship overall was positive; with those reported higher diabetes-related depressive symptoms had a worse glycaemic control (HbA_{1c} value). In the ESB group the co-efficient was 0.19, whereas in the ASB group it was 0.09.

Table 19: Stepwise multiple linear regression model summary

Model Summary					
Patients' Ethnic background	Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
Arabic-speaking background patients	1	.376[a]	.141	.138	1.12110
	2	.451[b]	.204	.198	1.08173
	3	.477[c]	.228	.219	1.06743
	4	.490[d]	.240	.228	1.06081
English-speaking background patients	1	.274[e]	.075	.071	1.34840
	2	.320[f]	.102	.095	1.33095
	3	.344[g]	.118	.107	1.32179

a. Predictors: (Constant), Exercise

b. Predictors: (Constant), Exercise, BMQ_Need_Ave_Orig

c. Predictors: (Constant), Exercise, BMQ_Need_Ave_Orig, Brief Illness Perception questionnaire item 7(coherence)_ R

d. Predictors: (Constant), Exercise, BMQ_Need_Ave_Orig, Brief Illness Perception questionnaire item 7(coherence)_ R, BMQ_Concern_Ave_Orig

e. Predictors: (Constant), Brief Illness Perception questionnaire item 3 (personal control) _ R

f. Predictors: (Constant), Brief Illness Perception questionnaire item 3 (personal control) _ R, BMQ_Concern_Ave_Orig

g. Predictors: (Constant), Brief Illness Perception questionnaire item 3 (personal control) _ R, BMQ_Concern_Ave_Orig, History of diabetes (years)

7.4 DISCUSSION

This multi-centre cross-section large Australian study is the first to investigate relationships between patients' illness and treatment beliefs, adherence behaviours and glycaemic control in ASB immigrants with T2DM.

Of particular significance was the finding that compared to the ESB group, ASB participants had significantly poorer adherence levels to all aspects of diabetes self-management including: diet, exercise, blood glucose testing and foot-care. This is consistent with findings of research among other ethnic groups. Given the importance of diabetes self-management in achieving optimal glycaemic control, these poor adherence levels among ASB immigrants are noteworthy; highlighting need for effective clinical intervention.

Evidence suggests that diabetic patients' self-care practices may be driven by their illness and treatment perceptions. Exploring illness and treatment beliefs may be one way of addressing the challenge of poor diabetes adherence and sub-optimal glycaemic control (high HbA_{1c} levels) among this ethnic group, especially since research has shown a correlation between patients' illness perceptions and their HbA_{1c}.[144]

In this study, perceptions and beliefs about diabetes differed significantly between the ASB and ESB groups. Significantly more negative illness and treatment perceptions were reported by the ASB participants and they were associated with significantly lower DSM adherence rates and poorer medication adherence. Negative illness and treatment perceptions reported by the ASB participants were also significantly associated with poor glycaemic control. Arabic-speaking background participants perceived their diabetes to have greater serious effects (higher consequence scores), more somatic complaints due to diabetes (higher identity score), and higher concerns about diabetes (higher concern score). These findings are similar to findings of a recent systematic review and meta-analysis showing the correlation between illness perceptions and glycaemic control in diabetes.[517] This review included results for 2006 patients recruited from a range of countries and settings, but did not include Arabic-speaking patients.

The research reported in this thesis is the first to identify the association between illness perception and glycaemic control in ASB immigrants with T2DM. Predictors of HbA_{1c} were investigated in this study given its importance as an indicator of diabetes control. The final regression model to predict HbA_{1c} among ASB group showed that positive treatment perceptions (stronger beliefs about need for using medicines and lesser concerns about use of these medicines) and understanding about diabetes were associated with better glycaemic control and that ASB patients had more negative perceptions and poorer understanding that were associated with poorer outcomes.

Arabic-speaking background participants saw less of necessity for diabetes medicines compared to ESB participants and reported higher concerns. These beliefs were associated with poorer adherence to diabetes medicines. Similarly, Barnes et al reported that Tongan patients with diabetes had less belief in the necessity of diabetes medicines and those beliefs were associated with poor adherence compared to European patients.[496] The results of this study, therefore, suggest that patients' adherence may improve by addressing modifiable negative illness and treatment perceptions. Interventions based on changing illness perceptions have been shown to improve outcomes among patients with heart attack.[493, 518, 519] Very little is known about such interventions for poorly controlled diabetic patients.[468]

Those in the ASB group in this study who had lower levels of acculturation into the Australian society had worse glycaemic control. Lack of acculturation was also reported as an important risk factor for dysglycemia among Arab immigrants in USA.[516] Research has shown that Hispanic patients with diabetes who have been able to integrate into European-American culture appeared to have a lower prevalence of T2DM, whereas those who were less acculturated had dysregulation of glucose metabolism and more pronounced patterns of insulin resistance.[520, 521] Cairampona reported that acculturation levels of Mexican Americans with diabetes were significantly related to their diabetes knowledge and had the potential to impact on how patients manage their disease.[522] Added to the lack of acculturation of first generation Arab immigrants with T2DM in Australia are strong social kinships and ties within ASB communities and the difficulty caused by the lack of diabetes education back in the Middle East where the lack of public awareness about the healthy lifestyle required for diabetes management is pervasive.[55] These 'closed' social networks and dynamics are known to impose a strong negative effect on diabetes self-management.[523, 524]

7.5 CONCLUSION

This study showed that ASB immigrants’ illness and treatment perceptions about diabetes health were significantly different from their counterparts in the ESB group. Participants in the ASB group were less-adherent to all aspects of diabetes self-management. Non-adherent patients to diabetes medicines reported significantly less belief in the need for diabetes medicines and more concern about their use. Negative illness perceptions, of ASB participants, were strongly and significantly associated with lower adherence to all aspects of self-care activities, including dietary behaviour, exercise and physical activity, foot care, self-monitoring of blood glucose and were also associated with worse glycaemic control. Understanding patients’ perceptions may provide opportunities for improving adherence to medication and self-care activities. Importantly, poorer adherence to all aspects of DSM in the ASB participants correlated with poorer diabetes outcomes, according to HbA_{1c} levels

CHAPTER EIGHT: CONCLUSIONS AND RECOMMENDATIONS

8 Conclusions and Recommendations

8.1 SUMMARY AND CONCLUSION

Type 2 diabetes (T2DM) worldwide is rising to epidemic levels, placing an enormous financial burden on health care systems. Epidemiological data has shown that T2DM affects large numbers Arabic-speaking background (ASB) patients throughout the world.[55]

In Western countries, T2DM management among ethnic minority groups (EMGs) is known to be more challenging when compared to the ESB population.[91] Manifestation of challenges include: higher prevalence rates, higher risk factors, poorer treatment adherence rates, worse glycaemic control, higher diabetes-related morbidity and mortality rates, higher hospitalisation rates and underutilisation of available health services.[416, 525-528] Several randomized clinical trials confirmed that lifestyle modification, particularly diet and exercise, can decrease the incidence of T2DM and improve outcomes; however, the uptake of such modifications is known to be poor among EMGs.[529-533]

To successfully manage EMGs with T2DM, research has shown that a thorough understanding of the illness experiences within the patients' socio-cultural environment is required[293] and that culture affects adherence to disease management.[233, 250, 276, 534, 535] There is a large body of literature that has identified culturally relevant issues in T2DM management across several EMGs including Hispanics/Latino, Asian, African-Americans and black populations living in western societies.[185, 186, 277, 284, 326] Till now, very little is known about how ASB immigrants experience and manage their T2DM.[38, 196, 197] Research suggests that health beliefs of EMGs may differ between cultures and these beliefs are known to influence self-management practices and healthcare seeking behaviours.[536] It is important to know more about the ASB diabetic population, as the findings of previous research has demonstrated that EMGs have more deficits in their knowledge about diabetes, experience more potential barriers to the use and access of available health services and self-management, and they also exhibit worse diabetes-related outcomes compared to white populations.[147, 537] It is not known whether these barriers to care extend to the ASB group. A comprehensive study was needed to determine the cultural and health beliefs among the ASB population with T2DM. Studies among non-ASB EMGs have shown that culturally appropriate interventions improved HbA_{1c} levels, knowledge and adoption of a healthy lifestyle.[91, 293] A thorough understanding of ASB patients' cultural and health beliefs is needed before similar interventions can be developed for this ethnic minority community with diabetes.

Phase I of this research was designed as a qualitative exploration of cultural issues associated with, and knowledge about, diabetes management among 60 ASB patients with T2DM using a comparative approach with a group of 40 ESB diabetic patients representing western culture. Results are reported in Chapters 2-6 of this thesis.

The key findings were that ASB participants differed from the ESB participants in their knowledge, healthcare-seeking and medication-taking behaviours. Arabic-speaking participants believed external factors, rather than their own health-related behaviours, were the cause of their diabetes (e.g. Allah's will). They intentionally delayed accessing medical services when they experienced classical signs of diabetes, therefore diabetes complications were already developed at the time of diagnosis for the vast majority of ASB participants. The denial and downplaying of diabetes symptoms by ASB participants emanated mainly from fear of having to bear the responsibility and accountability for their own health, coupled with the collective negative views about poor diabetes prognosis and its associated poor quality of life. Arabic-speaking background participants developed their own medication-taking practices that varied from what was prescribed, without the benefit of input from health professionals. This research has identified several issues with the quality use of diabetes medicines, including poor knowledge (e.g. when to take them, how often, with or without food, common side effects, why different types of OHAs are prescribed), collective negative views about regular use and side effects OHAs, social networks within ASB communities that seemed to have a strong negative effect on medication-taking behaviours. Conflicting treatment advice from family members, peers and friends within ASB communities appeared to foster use of herbal medicines instead of prescribed treatment. Learning needs, preferences and barriers to diabetes education of ASB immigrants have not been identified previously. Arabic-speaking background participants expressed a clear desire for more tailored information and they identified topics that are missing in current 'conventional' diabetes self-management education. They also identified their preferred modalities for the delivery of diabetes education. It is essential to recognise that the education needs of this EMG may differ from the rest of the population, for which current diabetes educational materials have been developed.

After qualitatively exploring cultural issues in management of T2DM among ASB immigrants in Phase I, and to triangulate these findings, a quantitative approach was used in Phase II. The second phase was designed as a multicentre, cross-sectional survey using a number of pre-validated questions to quantify diabetes profile, adherence levels to self-management, and examine predictors of diabetes control among ASB immigrants. Individual patient glycaemic control measures were used to identify outcomes of treatment for each participant.

Phase II findings described adherence behaviours, diabetes-related distress and glycaemic control among 392 ASB immigrants with T2DM compared to 309 ESB participants. Health beliefs, treatment and illness perceptions were found to be associated with poor adherence and with poor glycaemic control, thereby linking beliefs, behaviours and outcomes. These associations have not been investigated previously in this ethnic group. Compared to the ESB group, ASB immigrants were significantly less adherent to their prescribed OHAs. Participants' beliefs about medicines in both groups significantly correlated with medication adherence. Those who viewed diabetes medicines as necessary to control their diabetes and were less concerned about long-term side effects and harmfulness of these medications reported better adherence. Health beliefs and perceptions about diabetes were significantly different between the ASB and the ESB groups. Negative perceptions of diabetes that characterised ASB participants were strongly and significantly associated with lower adherence levels in all aspects of self-care activities including diet, exercise, foot-care and self-monitoring of blood glucose. These negative perceptions were also significantly associated with worse glycaemic control. Results showed suboptimal control of diabetes among the ASB participants, highlighting the need for an appropriate and effective intervention.

8.2 WHAT THIS THESIS ADDS

The Leventhal Common Sense Model of health behaviour postulated a connection between health beliefs, behaviours and outcomes. This model was explored in an Arabic-speaking population with diabetes and is the first research to demonstrate how sub-optimal health beliefs in ASB patients are associated with poor self-management behaviours leading to poor treatment outcomes.

8.2.1 Knowledge

Compared to their ESB counterparts, ASB Immigrants had major deficits in their knowledge about diabetes and its management.

8.2.2 Beliefs

Arabic-speaking background immigrants held significantly more negative beliefs about diabetes, perceived significantly less necessity for, and higher concerns about, diabetes medicines and exhibited significantly higher diabetes-related emotional distress compared with the ESB group.

8.2.3 Behaviours

Arabic-speaking background immigrants were significantly less adherent to all aspects of diabetes self-care including: diet, exercise, foot-care, and self-monitoring of blood glucose compared with ESB participants. They also had significantly poorer adherence to diabetes medicines taking.

8.2.4 Outcomes

Arabic-speaking background immigrants had suboptimal diabetes control, with only 16% attaining adequate glycaemic control. Poorer adherence was significantly associated with poorer glycaemic control.

8.3 CONCLUSION

This work has made a significant contribution to diabetes treatment adherence research in ASB patients. Findings of this research provide detailed information about the interplay between individual's cultural and health beliefs, adherence behaviour and glycaemic control. Such understanding may assist in planning of culturally appropriate diabetes interventions for this ethnic minority group, which is currently lacking. Finally, lessons learned from the ASB immigrant communities in Victoria may also apply to other ASB communities in Australia and elsewhere, contributing to improving health outcomes and quality of life, both within Australia and internationally.

8.3.1 Recommendation for future research

Future research in diabetes care for ASB communities might build on the findings of this research to formulate successful, culturally appropriate health education for these communities. It is suggested, for future diabetes interventions for ASB communities, to incorporate learning needs and preferences identified in this research to rectify those negative beliefs, attitudes, and behaviours that already exist in Arabic culture, and which hinder attaining adequate control. Research should also address the practical barriers to patients' adopting positive health behaviours. Development of intervention models specifically addressing identified barriers to ASB patients adherence is the next step. If future research interventions focused on patient-level determinants of adherence behaviours, and limit clinical interventions to what is feasible aiming at achieving ‘realistic’ health targets, then significant improvements to diabetes care in ASB communities are possible.

8.3.2 Recommendations to healthcare professionals

Based on key results identified in this study healthcare professionals need to acknowledge that ASB immigrants require clearer and more culturally tailored diabetes education. Specific recommendations for diabetes health professionals working with ASB immigrants include the following:

(1) acknowledgement of the importance of cultural mores in diabetes self-management ;

(2) encouragement of patients to voice their questions and uncertainties in part by providing a safe environment in which they can share stories about their diabetes challenges;

(3) provision of orally and delivered by peer-led modalities in small interactive and gender-separated educational sessions about self-care activities and alternative therapies is highly regarded by this ethnic group; and

(4) addressing the importance of food within Arabic-culture and help patients to control their eating habits during social ceremonies.

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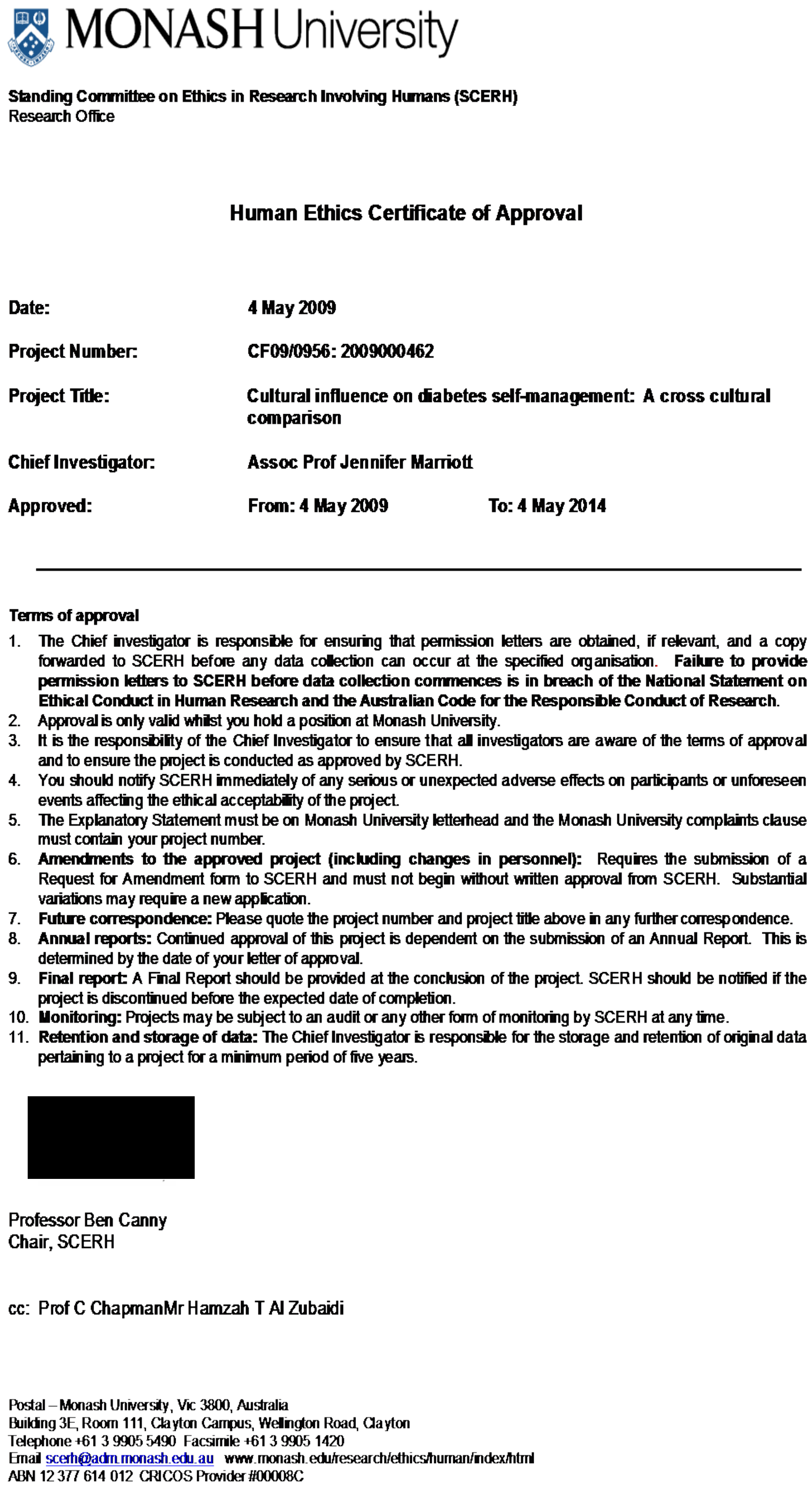
10 Appendices

Appendix 1 Monash Ethics Approval letter (study one)



MONASH University

Standing Committee on Ethics in Research Involving Humans (SCERH)
Research Office

Human Ethics Certificate of Approval

Date: **4 May 2009**

Project Number: **CF09/0956: 2009000462**

Project Title: **Cultural influence on diabetes self-management: A cross cultural comparison**

Chief Investigator: **Assoc Prof Jennifer Marriott**

Approved: **From: 4 May 2009** **To: 4 May 2014**

Terms of approval

1. The Chief investigator is responsible for ensuring that permission letters are obtained, if relevant, and a copy forwarded to SCERH before any data collection can occur at the specified organisation. **Failure to provide permission letters to SCERH before data collection commences is in breach of the National Statement on Ethical Conduct in Human Research and the Australian Code for the Responsible Conduct of Research.**
2. Approval is only valid whilst you hold a position at Monash University.
3. It is the responsibility of the Chief Investigator to ensure that all investigators are aware of the terms of approval and to ensure the project is conducted as approved by SCERH.
4. You should notify SCERH immediately of any serious or unexpected adverse effects on participants or unforeseen events affecting the ethical acceptability of the project.
5. The Explanatory Statement must be on Monash University letterhead and the Monash University complaints clause must contain your project number.
6. **Amendments to the approved project (including changes in personnel):** Requires the submission of a Request for Amendment form to SCERH and must not begin without written approval from SCERH. Substantial variations may require a new application.
7. **Future correspondence:** Please quote the project number and project title above in any further correspondence.
8. **Annual reports:** Continued approval of this project is dependent on the submission of an Annual Report. This is determined by the date of your letter of approval.
9. **Final report:** A Final Report should be provided at the conclusion of the project. SCERH should be notified if the project is discontinued before the expected date of completion.
10. **Monitoring:** Projects may be subject to an audit or any other form of monitoring by SCERH at any time.
11. **Retention and storage of data:** The Chief Investigator is responsible for the storage and retention of original data pertaining to a project for a minimum period of five years.

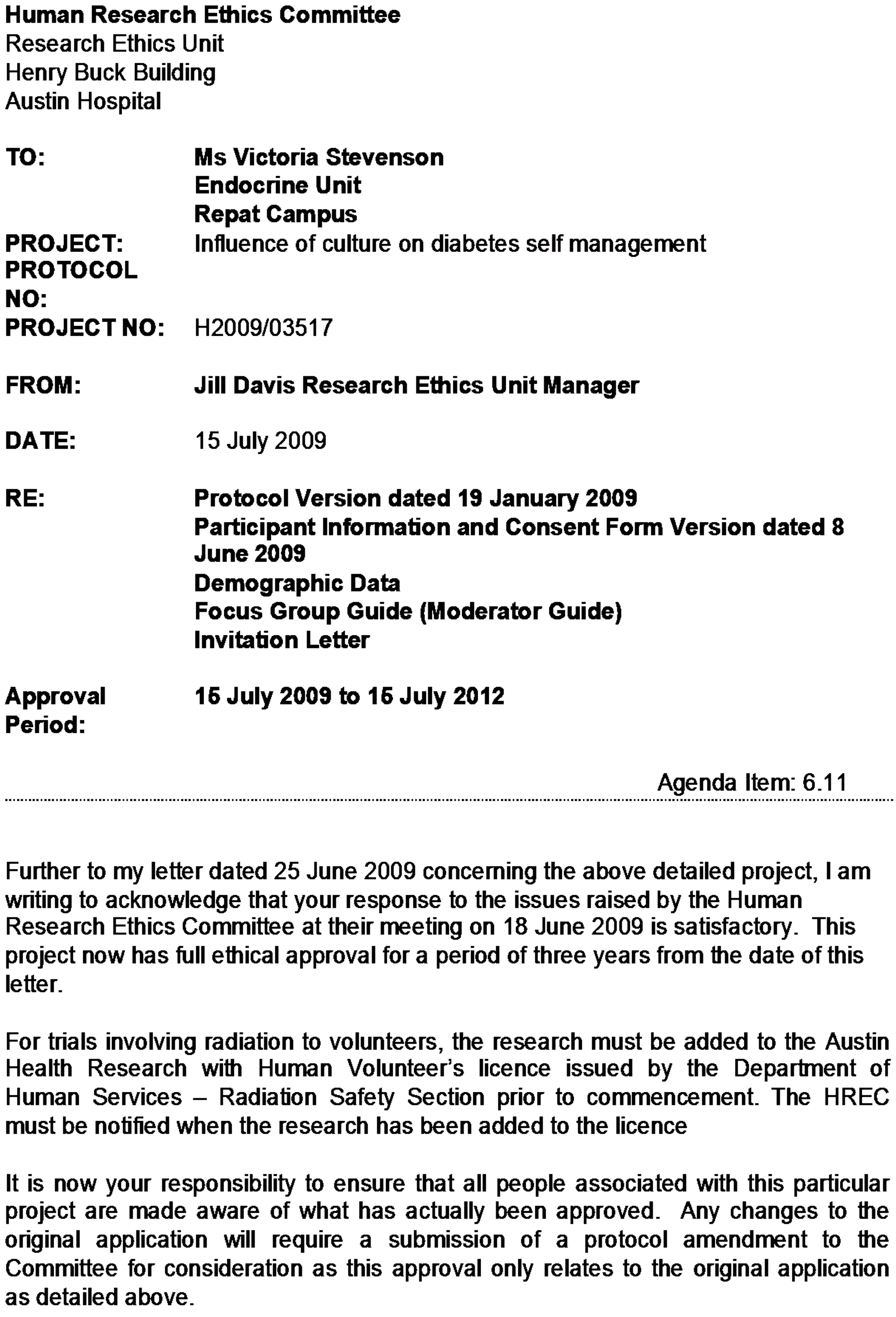
[redacted]

Professor Ben Canny
Chair, SCERH

cc: Prof C ChapmanMr Hamzah T Al Zubaidi

Postal – Monash University, Vic 3800, Australia
Building 3E, Room 111, Clayton Campus, Wellington Road, Clayton
Telephone +61 3 9905 5490 Facsimile +61 3 9905 1420
Email scerh@adm.monash.edu.au www.monash.edu/research/ethics/human/index/html
ABN 12 377 614 012 CRICOS Provider #00008C

Appendix 2 Ethics Approval letter from Austin Health



Human Research Ethics Committee
Research Ethics Unit
Henry Buck Building
Austin Hospital

TO: **Ms Victoria Stevenson**
Endocrine Unit
Repat Campus
PROJECT: Influence of culture on diabetes self management
PROTOCOL NO:
PROJECT NO: H2009/03517

FROM: **Jill Davis Research Ethics Unit Manager**

DATE: 15 July 2009

RE: **Protocol Version dated 19 January 2009**
Participant Information and Consent Form Version dated 8 June 2009
Demographic Data
Focus Group Guide (Moderator Guide)
Invitation Letter

Approval Period: **15 July 2009 to 15 July 2012**

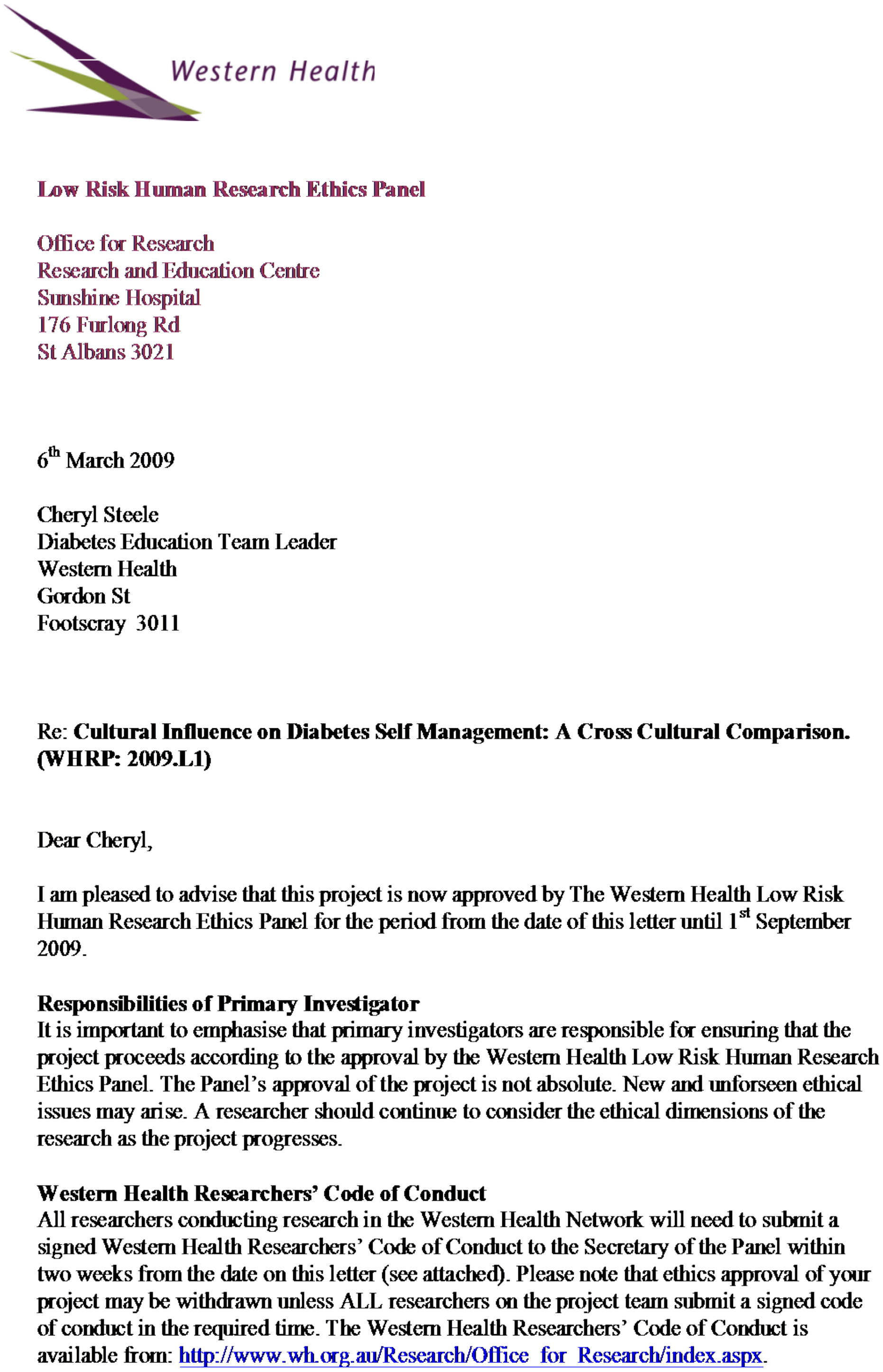
Agenda Item: 6.11

Further to my letter dated 25 June 2009 concerning the above detailed project, I am writing to acknowledge that your response to the issues raised by the Human Research Ethics Committee at their meeting on 18 June 2009 is satisfactory. This project now has full ethical approval for a period of three years from the date of this letter.

For trials involving radiation to volunteers, the research must be added to the Austin Health Research with Human Volunteer's licence issued by the Department of Human Services – Radiation Safety Section prior to commencement. The HREC must be notified when the research has been added to the licence

It is now your responsibility to ensure that all people associated with this particular project are made aware of what has actually been approved. Any changes to the original application will require a submission of a protocol amendment to the Committee for consideration as this approval only relates to the original application as detailed above.

Appendix 3 Western Health Ethics approval



Western Health

Low Risk Human Research Ethics Panel

Office for Research
Research and Education Centre
Sunshine Hospital
176 Furlong Rd
St Albans 3021

6th March 2009

Cheryl Steele
Diabetes Education Team Leader
Western Health
Gordon St
Footscray 3011

Re: **Cultural Influence on Diabetes Self Management: A Cross Cultural Comparison. (WHRP: 2009.L1)**

Dear Cheryl,

I am pleased to advise that this project is now approved by The Western Health Low Risk Human Research Ethics Panel for the period from the date of this letter until 1st September 2009.

Responsibilities of Primary Investigator
It is important to emphasise that primary investigators are responsible for ensuring that the project proceeds according to the approval by the Western Health Low Risk Human Research Ethics Panel. The Panel's approval of the project is not absolute. New and unforseen ethical issues may arise. A researcher should continue to consider the ethical dimensions of the research as the project progresses.

Western Health Researchers' Code of Conduct
All researchers conducting research in the Western Health Network will need to submit a signed Western Health Researchers' Code of Conduct to the Secretary of the Panel within two weeks from the date on this letter (see attached). Please note that ethics approval of your project may be withdrawn unless ALL researchers on the project team submit a signed code of conduct in the required time. The Western Health Researchers' Code of Conduct is available from: http://www.wh.org.au/Research/Office_for_Research/index.aspx.

Adverse Events or Unexpected Outcomes
As the primary investigator you have a significant responsibility to monitor the research and to take prompt steps to deal with any unexpected outcomes. You must notify the Panel immediately of any serious or unexpected adverse effects on participants, or unforseen events, which may affect the ethical acceptability of your project. Any complaints about the project received by the researcher must be referred immediately to the Secretary of the Panel (see attached template).

Reporting
Approval to continue a project is conditional on the submission of bi-annual research reports. A final report should also be provided at the conclusion of the project (see attached templates). If your work is completed within 6 months a final report only is required. All reporting timeframes begin from the date on this letter. Report forms are available from The Western Health Low Risk Human Research Panel website: http://www.wh.org.au/Research/Ethics/index.aspx. Please note that failure to submit reports will mean that a project is no longer approved, and/or that approval will be withheld from future projects.

Conditions of Approval
The Panel may apply additional conditions of approval beyond the submission of bi-annual/final reports.

Conflicts of Interest
When reporting the research, the researcher should again disclose any actual or potential conflicts of interest, including any financial or other interest or affiliation that bears on the research. Conflicts of interest can arise after a project has been approved, and where they do they must be reported as soon as possible.

Amendments
If, as you proceed with your investigation you find reason to amend your research method, you should advise the Panel and seek approval for the proposed changes. If you decide to discontinue your research before its planned completion you must also advise the Panel of this and of the circumstances. Depending on the type of amendment – whether it is minor or major – will determine how long the review process for an amendment will take (see attached template).

Storage of Data
All data should *normally* be stored on Western Health Network systems. These systems provide high levels of manageable security and data integrity, can provide secure remote access, are backed on a regular basis and can provide Disaster Recovery processes should a large scale incident occur. The use of portable devices such as CDs and memory sticks is valid for archiving, data transport where necessary and some works in progress. The authoritative copy of all current data should reside on appropriate network systems; and the principal investigator is responsible for the retention and storage of the original data pertaining to the project for a minimum period of five years.

If you anticipate any problems meeting this requirement please contact me to discuss an alternative secure data storage arrangements.

All reports or communication regarding this project is to be forwarded to the Secretary of the Panel.

On behalf of The Western Health Low Risk Human Research Ethics Panel I wish you well with your research.

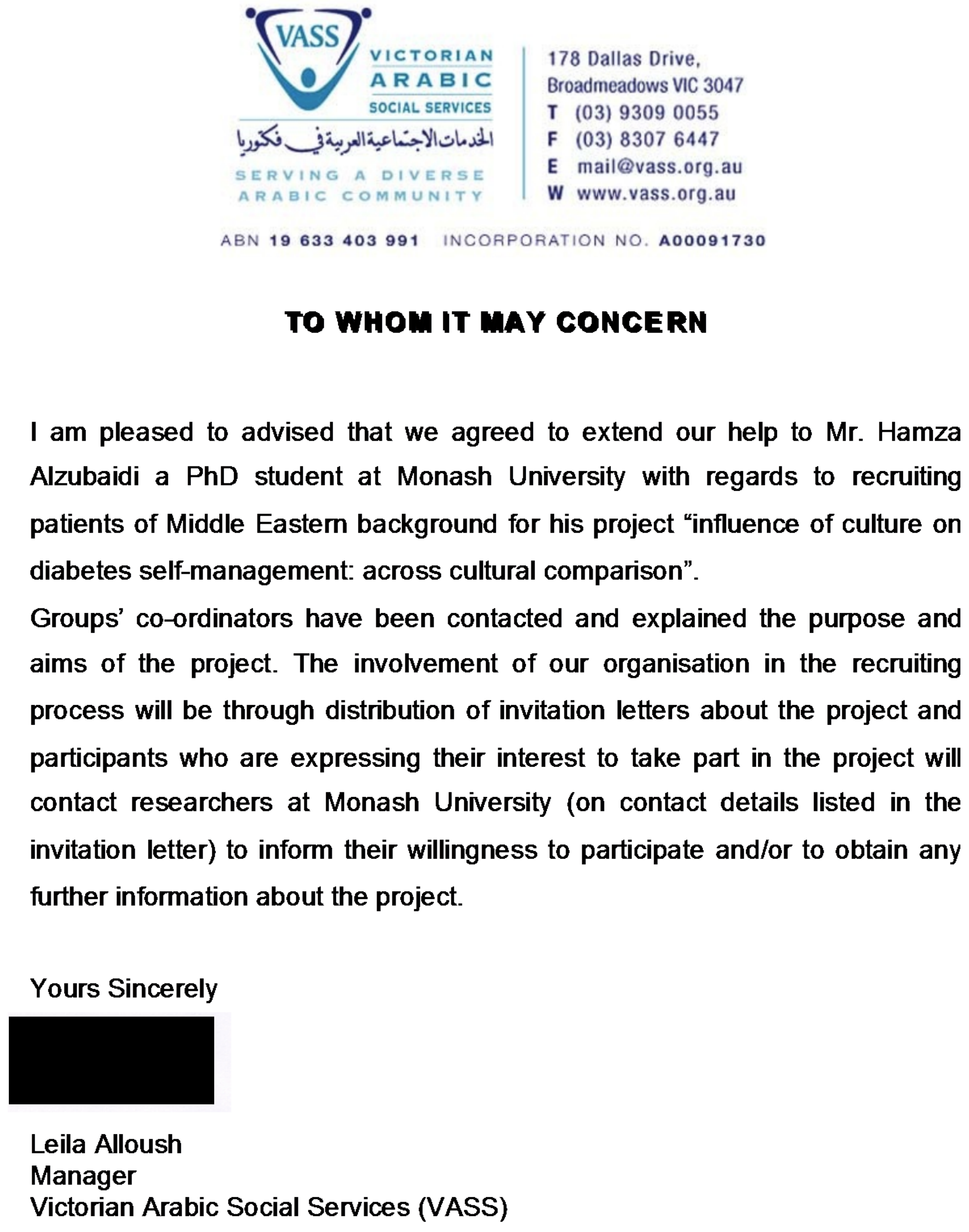
Regards

Louise Sillar
Secretary

On behalf of

David Newman
Panel Chairperson
Western Health Low Risk Human Research Ethics Panel

Appendix 4 Letter of Approval from Victorian Arab Social Services (VASS)



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TO WHOM IT MAY CONCERN

I am pleased to advised that we agreed to extend our help to Mr. Hamza Alzubaidi a PhD student at Monash University with regards to recruiting patients of Middle Eastern background for his project “influence of culture on diabetes self-management: across cultural comparison”.

Groups’ co-ordinators have been contacted and explained the purpose and aims of the project. The involvement of our organisation in the recruiting process will be through distribution of invitation letters about the project and participants who are expressing their interest to take part in the project will contact researchers at Monash University (on contact details listed in the invitation letter) to inform their willingness to participate and/or to obtain any further information about the project.

Yours Sincerely

[redacted]

Leila Alloush
Manager
Victorian Arabic Social Services (VASS)

Appendix 5 Patients' Explanatory Statement and Consent form (English version)

PARTICIPANT INFORMATION AND CONSENT FORM (PICF)

Site: Austin Health

Full Project Title: Cultural influences on diabetes self management: A cross cultural comparison

Principal Researcher: Victoria Stevenson, Cheryl Steele

Associate Researcher(s): Associate Professor Jennifer Marriott
Professor Colin Chapman
Mr. Hamzah Alzubaidi

1. Introduction

i. You are invited to take part in this research project. The research project aim is to explore cultural issues which may affect how you manage your Type 2 Diabetes. This Participant Information and Consent Form tells you about the research project. It explains what is involved to help you decide if you want to take part.

ii. Please read this information carefully. Ask questions about anything that you don't understand or want to know more about before deciding whether or not to take part. You might want to talk about it with a relative, friend or your local health worker.

iii. Participation in this research is voluntary. If you don't wish to take part, you do not have to.

iv. If you decide you want to take part in the research project, you may be asked to sign the consent section. By signing it you are telling us that you:

- Understand what you have read;
- Consent to take part in the research project;
- Consent to be involved in the procedures described;
- Consent to the use of your personal and health information as described. You will be given a copy of this Participant Information and Consent Form to keep

2. What is the purpose of this research project?

The purpose of this project is to explore:

Appendix 6 Patients’ Explanatory Statement (Arabic version)

Pacific International Translations (Australia) Pty Ltd
Trading as
The International Language Company
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www.intlangco.com.au

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نموذج الموافقة ومعلومات المشترك

MONASH University
Pharmacy and Pharmaceutical Sciences
Austin Health

الموقع: أوستين للصحة

عنوان المشروع الكامل: التأثيرات الثقافية على تدبير العلاج الذاتي لمرض السكري: مقارنة ثقافية متبادلة

الباحث الرئيسي: فيكتوريا ستيفينسون

الباحثون المساعدون: الأستاذ المساعد/ جينيفر ماريوت
الأستاذ كولين شابمان
السيد حمزة الزبيدي

1 المقدمة

i ندعوك للاشتراك في مشروع هذا البحث. ويهدف مشروع البحث إلى استكشاف العوامل الثقافية التي قد تؤثر على كيفية تعاملك مع مرض السكري من النوع الثاني. ويخبرك نموذج الموافقة ومعلومات المشترك هذا عن مشروع البحث. ويشرح ما ستشترك فيه ليساعدك على أن تقرر إذا أردت الاشتراك.

ii نرجو قراءة هذه المعلومات بحرص. واطرح الأسئلة عن أي شيء لا تفهمه أو ترغب في معرفته أكثر قبل أن تقرر ما إذا كنت ستشارك أم لا. وربما ترغب في أن تتحدث عن الأمر مع قريب لك، أو صديق أو طبيبك المحلي.

iii الاشتراك في هذا البحث عمل تطوعي. وإذا كنت لا ترغب في الاشتراك فليس عليك ذلك.

iv إذا قررت أن تشارك في مشروع البحث، فربما يطلب منك توقيع جزء الموافقة. وبالتوقيع عليه فأنت تخبرنا أنك:

- تفهم ما قد قرأته؛
- توافق على الاشتراك في مشروع البحث
- توافق على الاشتراك في الإجراءات التي تم وصفها
- توافق على استخدام بياناتك الشخصية والصحية كما هو موصوف. وسوف تحصل على نسخة من نموذج الموافقة ومعلومات المشارك هذا لتحتفظ به.

Certified as a true translation, completed by an accredited Arabic translator on our behalf, of the document/s supplied by the Department of Pharmacy Practice of Monash University.

Signed: [redacted]
Dated: 08 July 2009 Job No: M09070045

Appendix 7 Self-reported questionnaire and Moderator Guide

MONASH University
Pharmacy and Pharmaceutical Sciences

PART A: Demographic and clinical data

Q1. Sex

- ☐ Male
- ☐ Female

Q2. Age: ___________ years

Q3. Level of education

- ☐ Less than high school
- ☐ High school
- ☐ College or University graduate
- ☐ Post graduate

Q4 From the following choices, please choose what describes best your living arrangement?

- ☐ Married and living with spouse and/or children
- ☐ Living alone

Q5. Have you ever attended a diabetes education class?

- ☐ Yes , if yes how many?.........................
- ☐ No

Q6. How long have you been diagnosed as diabetic? (Duration of diabetes)

……………… years and ……… months

Q7. Country of origin

- ☐ Australia
- ☐ Overseas

Q9. if you were born overseas how long have you been in Australia?

………….. Years

Q10. Are you taking any oral hypoglycaemic medicine (diabetes pills)?

- ☐ Yes, please specify how many oral medications you are using …………………
- ☐ No

Q11. Are you using insulin?

- ☐ Yes

☐ No

Q12. From the following choices, please choose what describes best your employment status?

☐ Employed
☐ Unemployed
☐ Pensioner
☐ Housewife
☐ Others, please specify ……………..

Q13. From the following choices, please choose what describes best your marital status?

☐ Married
☐ Widowed
☐ Single
☐ Divorced

Q14. HbA1c .... (from medical record)

Q15. do you have any other illnesses beside diabetes?

☐ Yes
☐ No

If yes, do you have any of the following?

☐ Blood pressure
☐ Lipid problem
☐ Retinopathy
☐ Heart problems
☐ Others, please specify …………………….

Q16. Do you have family history of diabetes mellitus?

☐ Yes
☐ No

Q17. How do you rate your proficiency in English language (for Arabic-speaking background patients ONLY)

☐ Little or none
☐ Moderate

☐ Excellent

PART B: focus group guide (Moderator Guide)

AECTION A: CULTURE AND CONCEPTUALISATION OF DIABETES

When someone says ‘diabetes’, what comes to your mind? What image you have for a person with diabetes?

Probes;

- ⇒ Definition of diabetes
- ⇒ Symptoms of diabetes
- ⇒ Complications of diabetes
- ⇒ How diabetes affects the body
- ⇒

What do you think diabetes does to you? How does it affect your body?

How severe is your diabetes? Will it have a short or long course?

How do you perceive the effectiveness of prescribed diabetes treatment?

What is/are the treatment for diabetes? What kind of treatment do you think you
How did you know that you have diabetes?

When do you seek health care or access medical services?

Probes;

- ⇒ On regular bases
- ⇒ When you feel something is going wrong (feeling unwell)
- ⇒ Experiencing troublesome symptoms
- ⇒ When you need medication
- ⇒ Is there any fear or reluctance to seek health care unless necessary?

What do you know about the cause of your diabetes?

Probes;

- ⇒ hereditary or genetics
- ⇒ life style; eating excess sweets, alcohol consumption,
- ⇒ stress such as death of family members

SECTION B: PATIENT-PROVIDER COMMUNICATIONS

Is there any information that you wanted to have from your doctor? Or wanted to say but couldn’t it, during your consultation?

Do you have any issues with expressing your concerns to your doctor during consultation?

How do you perceive your involvement in making decisions regarding your prescribed regimen?

SECTION C: USE OF PRESCRIBED MEDICINES

What do you know about their prescribed diabetes medications?

How do you feel about use of diabetes medicines?

Can you describe your experience with medication-taking on daily basis?

How many times do you take your diabetes medicines each day?

SECTION D: SELF-MANAGEMENT OF DIABETES

What makes it hard for you to manage diabetes in your daily lives?

In your point of view how culture affects your food intake?

Probes;

⇒ What does your daily meal compose of, mainly?
⇒ What food do you classify as “popular” in your culture?

Can you describe the challenges of modifying the traditional diet?

Can you describe the role of food in social ceremonies?

Being Middle Easterner / westerner diagnosed with diabetes; how do you perceive God’s involvement in having the disease?

Probes;

⇒ God’s will or is it a punishment?, Caused and controlled by God?

How do you feel about the control of your diabetes?

What do you think of herbal products/remedies in the management of diabetes?

Probes;

⇒ Would you use alternative (unconventional) treatments for diabetes, if they were recommended by people you trust?
⇒ Have you ever/sometimes substitute your prescribed medication with alternative treatments? And if you use these products would you discuss their use with your GPs.
⇒ Do you have any concerns or doubts about the use of herbs in the treatment of diabetes?

How you perceive the involvement of your family in the management of your diabetes?

Probes;

SECTION F: CULTURE AND EDUCATION PROGRAM INFORMATION

Have you ever accessed information about diabetes?

Probes;

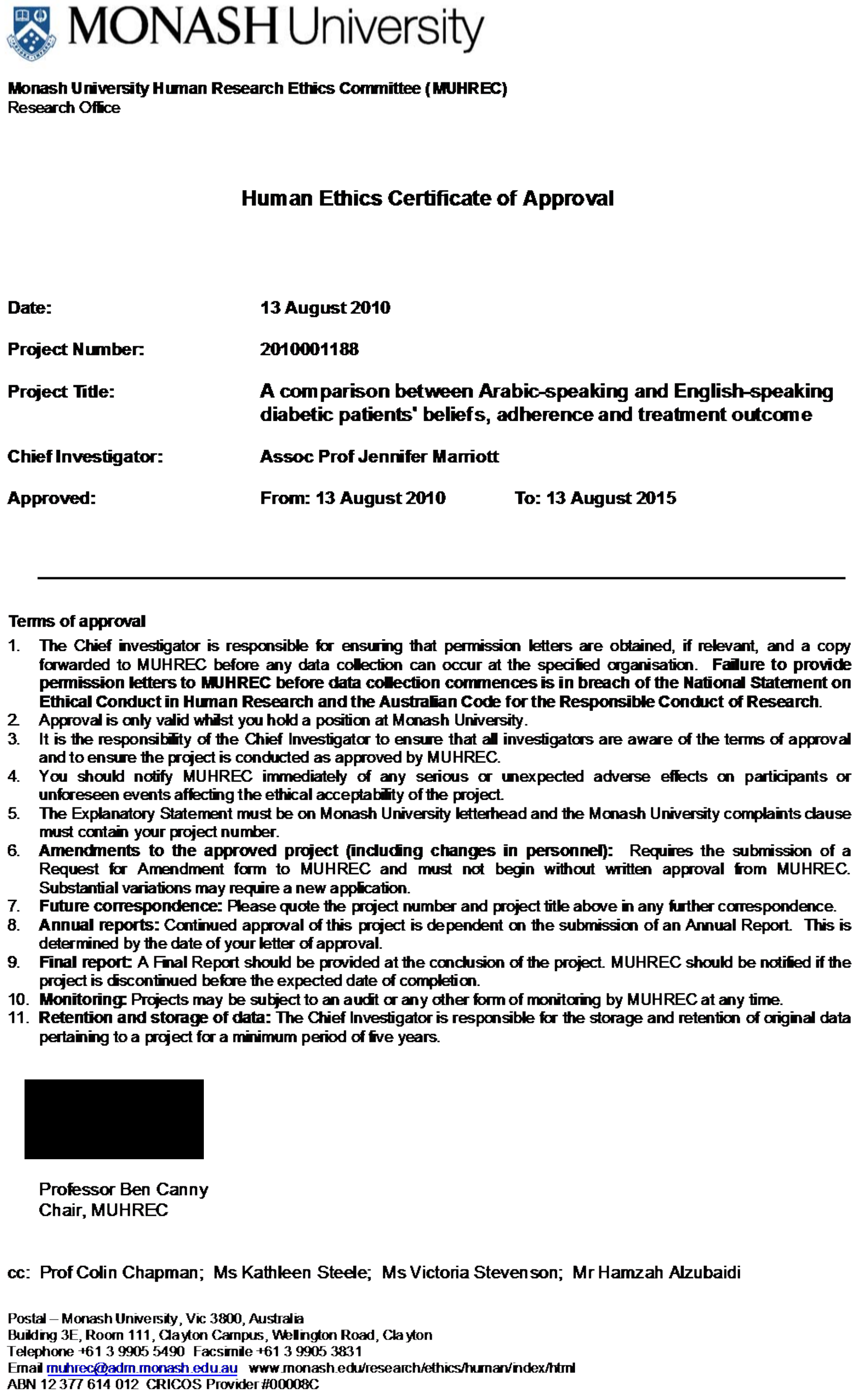
⇒ How do you perceive accessing to information when needed?
⇒ Do you face understanding and interpreting self-management information?

What diabetes-related topics would you like to know more about?

What are the preferred ways for you to receive diabetes education?

What are your suggestions for the development/design an educational program especially for Middle Eastern patients with type 2 diabetes?

Appendix 8 Monash University Ethics Approval



MONASH University

Monash University Human Research Ethics Committee (MUHREC)
Research Office

Human Ethics Certificate of Approval

Date: **13 August 2010**

Project Number: **2010001188**

Project Title: **A comparison between Arabic-speaking and English-speaking diabetic patients' beliefs, adherence and treatment outcome**

Chief Investigator: **Assoc Prof Jennifer Marriott**

Approved: **From: 13 August 2010** **To: 13 August 2015**

Terms of approval

1. The Chief investigator is responsible for ensuring that permission letters are obtained, if relevant, and a copy forwarded to MUHREC before any data collection can occur at the specified organisation. **Failure to provide permission letters to MUHREC before data collection commences is in breach of the National Statement on Ethical Conduct in Human Research and the Australian Code for the Responsible Conduct of Research.**
2. Approval is only valid whilst you hold a position at Monash University.
3. It is the responsibility of the Chief Investigator to ensure that all investigators are aware of the terms of approval and to ensure the project is conducted as approved by MUHREC.
4. You should notify MUHREC immediately of any serious or unexpected adverse effects on participants or unforeseen events affecting the ethical acceptability of the project.
5. The Explanatory Statement must be on Monash University letterhead and the Monash University complaints clause must contain your project number.
6. **Amendments to the approved project (including changes in personnel):** Requires the submission of a Request for Amendment form to MUHREC and must not begin without written approval from MUHREC. Substantial variations may require a new application.
7. **Future correspondence:** Please quote the project number and project title above in any further correspondence.
8. **Annual reports:** Continued approval of this project is dependent on the submission of an Annual Report. This is determined by the date of your letter of approval.
9. **Final report:** A Final Report should be provided at the conclusion of the project. MUHREC should be notified if the project is discontinued before the expected date of completion.
10. **Monitoring:** Projects may be subject to an audit or any other form of monitoring by MUHREC at any time.
11. **Retention and storage of data:** The Chief Investigator is responsible for the storage and retention of original data pertaining to a project for a minimum period of five years.

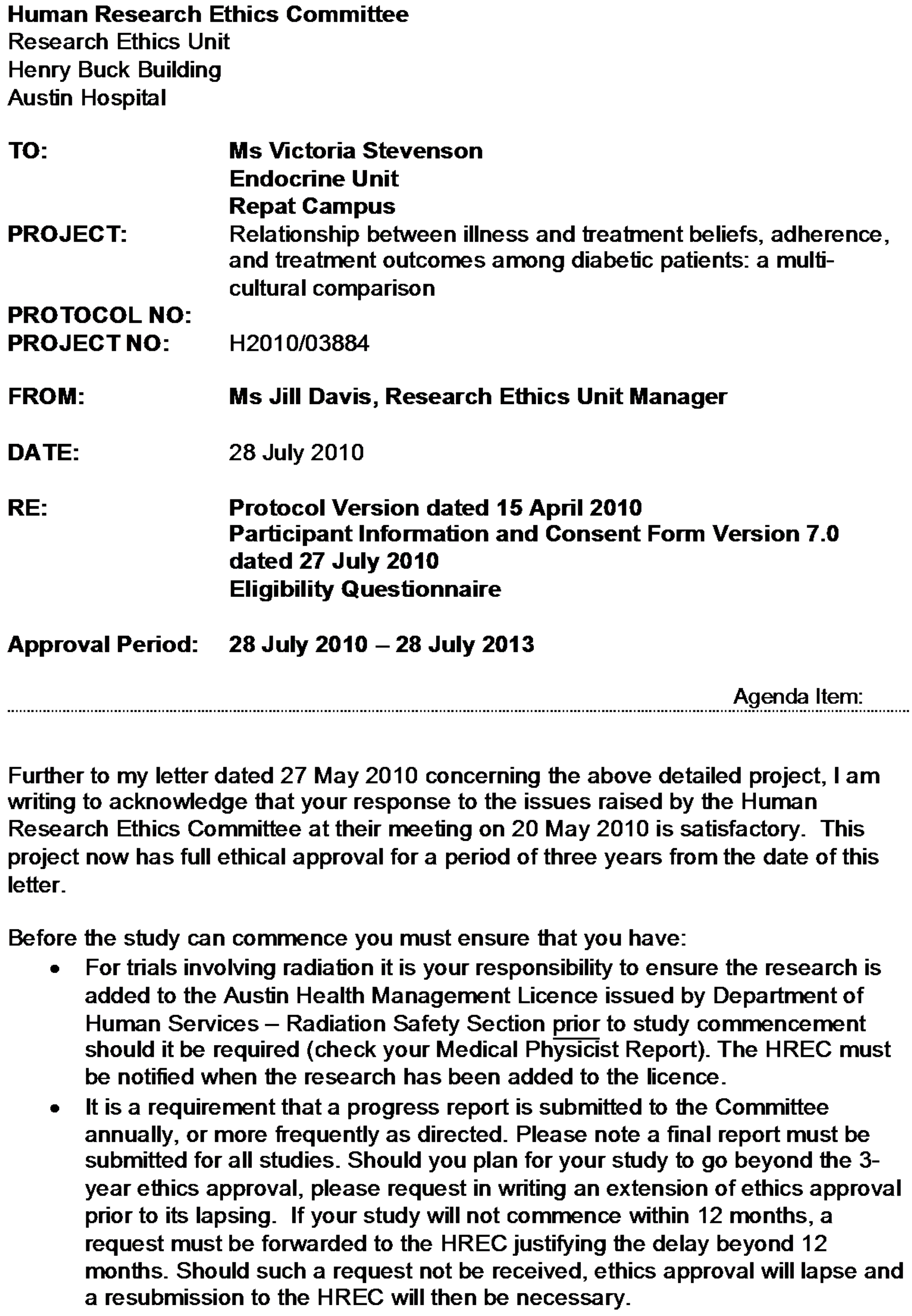
[redacted]

Professor Ben Canny
Chair, MUHREC

cc: Prof Colin Chapman; Ms Kathleen Steele; Ms Victoria Stevenson; Mr Hamzah Alzubaidi

Postal – Monash University, Vic 3800, Australia
Building 3E, Room 111, Clayton Campus, Wellington Road, Clayton
Telephone +61 3 9905 5490 Facsimile +61 3 9905 3831
Email muhrec@adm.monash.edu.au www.monash.edu/research/ethics/human/index/html
ABN 12 377 614 012 CRICOS Provider #00008C

Appendix 9 Austin Health Ethics Approval



Human Research Ethics Committee
Research Ethics Unit
Henry Buck Building
Austin Hospital

TO: **Ms Victoria Stevenson**
Endocrine Unit
Repat Campus
PROJECT: Relationship between illness and treatment beliefs, adherence, and treatment outcomes among diabetic patients: a multi-cultural comparison
PROTOCOL NO:
PROJECT NO: H2010/03884

FROM: **Ms Jill Davis, Research Ethics Unit Manager**

DATE: 28 July 2010

RE: **Protocol Version dated 15 April 2010**
Participant Information and Consent Form Version 7.0 dated 27 July 2010
Eligibility Questionnaire

Approval Period: **28 July 2010 – 28 July 2013**

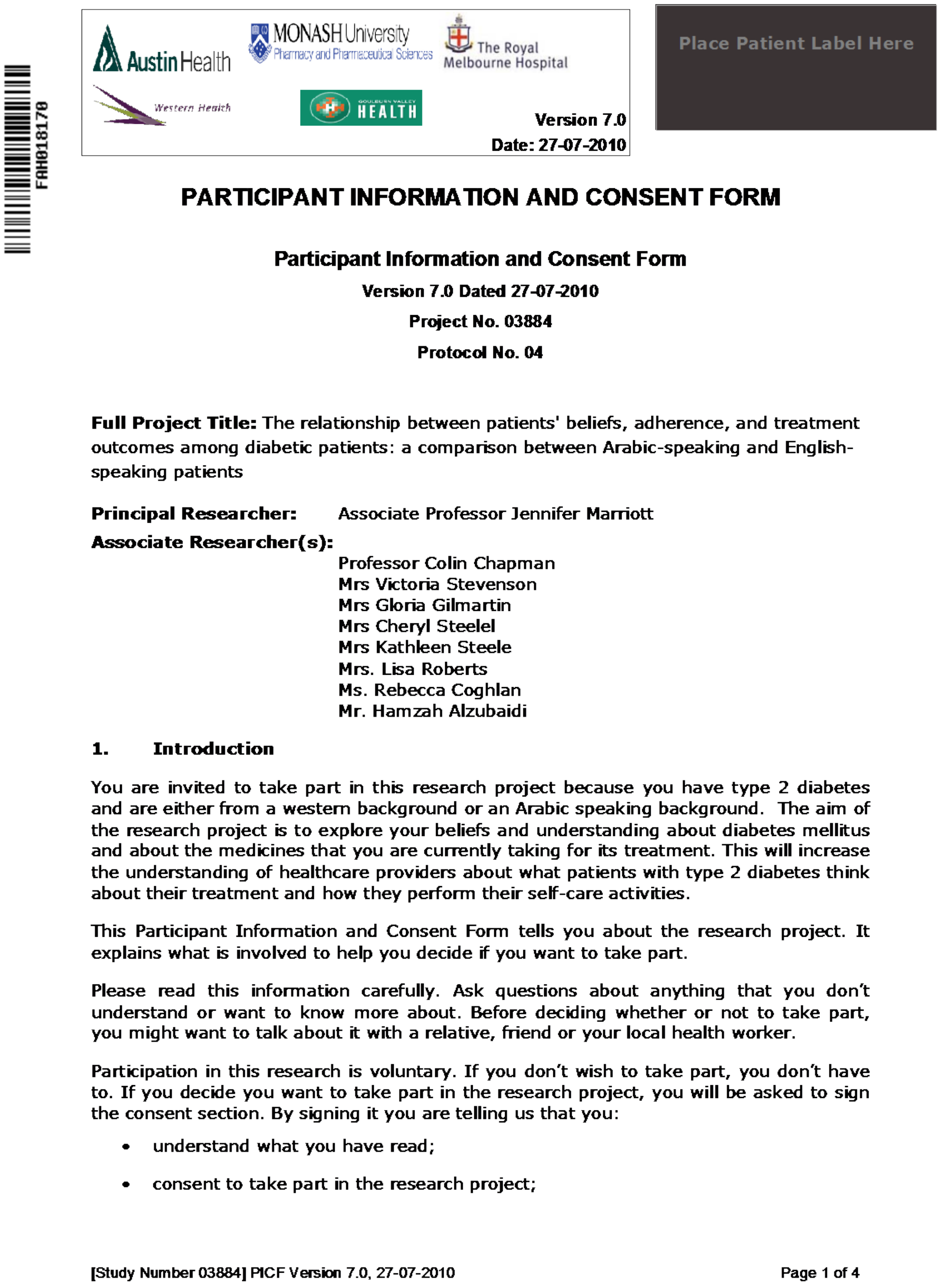
Agenda Item:

Further to my letter dated 27 May 2010 concerning the above detailed project, I am writing to acknowledge that your response to the issues raised by the Human Research Ethics Committee at their meeting on 20 May 2010 is satisfactory. This project now has full ethical approval for a period of three years from the date of this letter.

Before the study can commence you must ensure that you have:

- For trials involving radiation it is your responsibility to ensure the research is added to the Austin Health Management Licence issued by Department of Human Services – Radiation Safety Section prior to study commencement should it be required (check your Medical Physicist Report). The HREC must be notified when the research has been added to the licence.
- It is a requirement that a progress report is submitted to the Committee annually, or more frequently as directed. Please note a final report must be submitted for all studies. Should you plan for your study to go beyond the 3-year ethics approval, please request in writing an extension of ethics approval prior to its lapsing. If your study will not commence within 12 months, a request must be forwarded to the HREC justifying the delay beyond 12 months. Should such a request not be received, ethics approval will lapse and a resubmission to the HREC will then be necessary.

Appendix 10 Patient Information and Consent form (English version)



Version 7.0
Date: 27-07-2010

Place Patient Label Here

PARTICIPANT INFORMATION AND CONSENT FORM

Participant Information and Consent Form

Version 7.0 Dated 27-07-2010

Project No. 03884

Protocol No. 04

Full Project Title: The relationship between patients' beliefs, adherence, and treatment outcomes among diabetic patients: a comparison between Arabic-speaking and English-speaking patients

Principal Researcher: Associate Professor Jennifer Marriott

Associate Researcher(s):
Professor Colin Chapman
Mrs Victoria Stevenson
Mrs Gloria Gilmartin
Mrs Cheryl Steelel
Mrs Kathleen Steele
Mrs. Lisa Roberts
Ms. Rebecca Coghlan
Mr. Hamzah Alzubaidi

1. Introduction

You are invited to take part in this research project because you have type 2 diabetes and are either from a western background or an Arabic speaking background. The aim of the research project is to explore your beliefs and understanding about diabetes mellitus and about the medicines that you are currently taking for its treatment. This will increase the understanding of healthcare providers about what patients with type 2 diabetes think about their treatment and how they perform their self-care activities.

This Participant Information and Consent Form tells you about the research project. It explains what is involved to help you decide if you want to take part.

Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative, friend or your local health worker.

Participation in this research is voluntary. If you don't wish to take part, you don't have to. If you decide you want to take part in the research project, you will be asked to sign the consent section. By signing it you are telling us that you:

- understand what you have read;
- consent to take part in the research project;

- consent to participate in the research processes that are described;
- consent to the use of your personal and health information as described

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

2. What is the purpose of this research project?

The purpose of this research is to compare health beliefs and behaviours among people with type 2 diabetes mellitus from a western background and an Arabic speaking-background. This study aims to increase the current understanding of healthcare providers about how patients with type 2 diabetes perceive their treatment and how they perform their self-care activities.

The information obtained from this study may help us make recommendations to doctors for improving the use of medicines by patients with type 2 diabetes and to help in advising health care providers on which aspects of diabetes and its management they should focus their patient education efforts.

The results of this research will be used by the researcher Hamzah Alzubaidi in the Department of Pharmacy Practice - Monash University, to obtain his Doctor of Philosophy.

3. What does participation in this research project involve?

Participation in this study involves completion of a questionnaire about you in general, your health and your use of medicines. This questionnaire will take about 15 to 20 minutes for you to complete, with help if you require it from a person not involved in the research. You will not be paid for your participation in this research.

4. What are the possible benefits?

There may be no direct benefit to you from your participation in this research. The knowledge gained may assist in the future management of patients with type 2 diabetes mellitus.

5. What are the possible risks?

There are no foreseeable risks other than the inconvenience of your time required to complete the questionnaire. If you become upset or distressed as a result of your participation in the research, the researcher is able to arrange for counselling or other appropriate support. Any counselling or support will be provided by staff who are not members of the research team and without cost to you. In addition, you may prefer to suspend or end your participation in the research if distress occurs.

6. Do I have to take part in this research project?

Participation in any research project is voluntary. If you do not wish to take part you don't have to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your usual care or your relationship with those treating you or with Austin Health.

7. How will I be informed of the results of this research project?

If you would like a copy of the aggregate results to be sent to your home address please provide full postal address on the consent form. Alternatively, you can obtain a copy of the study reports, by contacting Hamzah Alzubaidi on (03) 9903 9057, e-mail;

hamzah.alzubaidi@monah.edu or Associate Professor Jennifer Marriott on (03) 9903 9533, e-mail; jennifer.marriott@monash.edu

8. What will happen to information about me?

All the information collected from individual participants during the course of this study will be kept confidential. Storage of the information will adhere to Austin Health guidelines. Information collected will be kept on Austin Health premises in a locked cabinet or password protected computer for 7 years from the date of completion of the study.

Any information obtained in connection with this research project that can identify you will remain confidential and will only be used for the purpose of this research project. Information about you may be obtained from your health records held at this, and other, health services for the purposes of this research.

In any publication and/or presentation information will be provided in such a way that you cannot be identified.

9. Is this research project approved?

The ethical aspects of this research project have been approved by the Human Research Ethics Committee of Austin Health.

10. Who can I contact?

The person you may need to contact will depend on the nature of your query. Therefore, please note the following:

For further information or appointments:
If you want any further information concerning this project or if you have any problems which may be related to your involvement in the project (for example, feelings of distress), you can contact the principal researcher Ms Victoria Stevenson on Ph: (03) 9496 5000, Pager 2608, (03) 9496 4414 or Hamzah Alzubaidi on (03) 9903 9057.

For complaints:
If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact: Ms Jill Davis, Manager Research Ethics Unit, 9496 4034.

FAH018170

11. Consent

I have read this document, or have had it read to me in a language that I understand, and I understand the purposes, procedures and risks of this research project as described within it.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described.

I understand that I will be given a signed copy of this document to keep.

Participant's name (printed) ………………………………………………………………………………………

Signature Date

Name of witness to participant's signature (printed) ……………………………………………….

Signature Date

If you would like a copy of the aggregate results to be sent to your home address please provide full postal address:

…………………………………………………………….
…………………………………………………………….
…………………………………………………………….
…………………………………………………………….
…………………………………………………………….

Declaration by researcher*: I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Researcher's name (printed) ……………………………………………………………

Signature Date

Appendix 11 Patient Information and Consent form (Arabic version)

PARTICIPANT INFORMATION AND CONSENT FORM (PICF)

MONASH University Pharmacy and Pharmaceutical Sciences · The Royal Melbourne Hospital · Western Health · Austin Health · GOULBURN VALLEY HEALTH

استمارة معلومات وموافقة للمشاركين في هذا البحث

استمارة معلومات وموافقة للمشاركين في هذا البحث
النسخة 7 التاريخ 2010 07 27
المشروع رقم: 03884
بروتوكول رقم: 4

لعنوان الكامل للمشروع: العلاقة بين معتقدات مرضى داء السكري والتزامهم ونتائج علاجهم: مقارنة بين وجهات نظر المرضى لمتحدِّرين من الشرق الأوسط والمرضى القوقازيين

لباحثة الرئيسة: السيدة فكتوريا ستفنسون

لباحثون المساعدون: الأستاذة جنيفر ماريوت، بروفسورة مساعِدة
بروفسور كولين تشابمان
الأستاذ حمزه الزبيدي

1. مقدِّمة

دعوكم للمشاركة في مشروع البحث المذكور أعلاه. والهدف منه استطلاع آرائكم ومعتقداتكم ومفاهيمكم حول السكّري نمط 2 والأدوية التي تتناولونها حاليًا لمعالجتة. ستؤدي هذه الدراسة إلى توسيع معرفة مقدِّمي خدمات الرعاية الصحية حول نظرة مرضى السكري النمط 2 إلى علاجهم والطريقة التي يعتنون بها بأنفسهم وبصحتهم.

يشرح لكم نموذج "معلومات وموافقة المشاركين" هذا مشروع البحث وما ينطوي عليه من أجل مساعدتكم في اتخاذ قراركم بشأن لمشاركة أو عدم المشاركة في هذه الدراسة.

نرجو منكم أن تقرأوا هذه المعلومات بدقة وأن تطرحوا علينا أية أسئلة تراودكم ومهما كانت أو إذا كنتم تودون توضيح أية تفاصيل. بل أن تتخذوا قراركم بالمشاركة ربما كنتم تودون التحدث عن الموضوع مع أحد أقربائكم أو أصدقائكم أو موظفة الصحة المحلية.

بالنسبة للمشاركة في هذا البحث فهي طوعية، وإذا كنتم لا تشاؤون المشاركة فلستم مجبَرين على ذلك، لكن إذا وافقتكم سيُطلب منكم وقيع الجزء الخاص بالموافقة، وبذلك تعتبرون بإنكم تقرّون بما يلي:

- بإنكم تفهمون المعلومات التي قرأتموها؛
- توافقون على المشاركة في مشروع البحث؛
- توافقون على المشاركة في خطوات وإجراءات مشروع البحث التي تمّ وصفها؛
- توافقون على استخدام المعلومات الشخصية والصحية المتعلقة بكم حسبما تمّ وصفه

سوف تعطى نسخة عن "معلومات المشاركين" لكم للإحتفاظ بها.

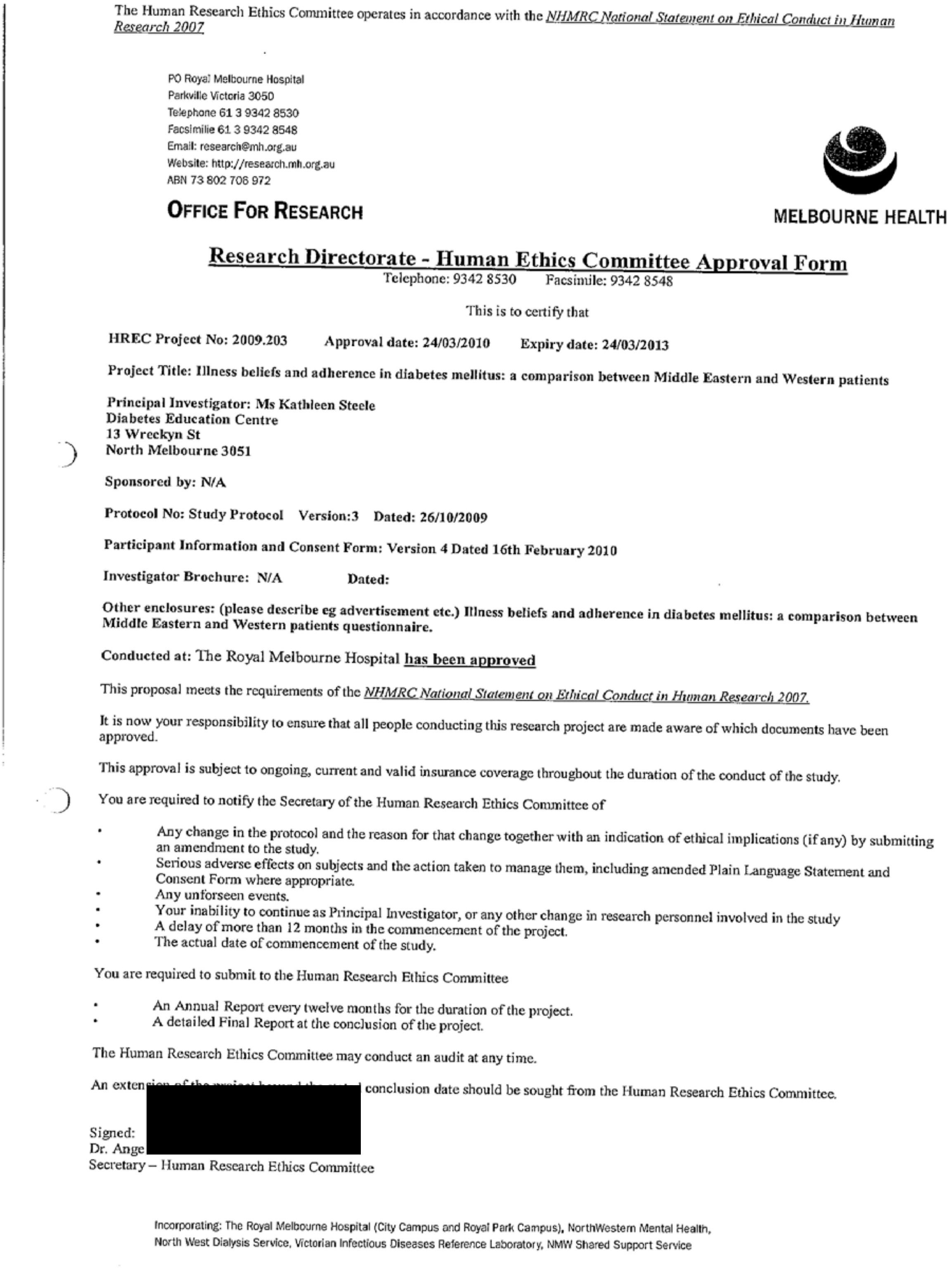
2. ما هو هدف مشروع البحث هذا؟

يهدف هذا البحث إلى توسيع معرفة مقدِّمي خدمات الرعاية الصحية حول نظرة مرضى السكري النمط 2 إلى علاجهم والطريقة التي يعتنون بها بأنفسهم وبصحتهم.

ستساعدنا هذه المعلومات في تقديم توصيات إلى الأطباء لتحسين تناول مرضى السكري النمط 2 للأدوية إضافة إلى إعلام مقدِّمي خدمات الرعاية الصحية بأوجه مرض السكري وتدبيره التي يجب أن يركّزوا جهودهم عليها لتوعية المريض بشأنها.

كذلك، سوف يستخدم نتائج هذا البحث الباحث حمزه الزبيدي، وهو طالب في قسم الصيدلـة في جامعة موناش يحضِّر للحصول على شهادة الدكتوراه.

Appendix 12 Royal Melbourne Health Ethics Approval



The Human Research Ethics Committee operates in accordance with the *NHMRC National Statement on Ethical Conduct in Human Research 2007*

PO Royal Melbourne Hospital
Parkville Victoria 3050
Telephone 61 3 9342 8530
Facsimilie 61 3 9342 8548
Email: research@mh.org.au
Website: http://research.mh.org.au
ABN 73 802 706 972

OFFICE FOR RESEARCH

MELBOURNE HEALTH

Research Directorate - Human Ethics Committee Approval Form

Telephone: 9342 8530 Facsimile: 9342 8548

This is to certify that

HREC Project No: 2009.203 **Approval date: 24/03/2010** **Expiry date: 24/03/2013**

Project Title: Illness beliefs and adherence in diabetes mellitus: a comparison between Middle Eastern and Western patients

Principal Investigator: Ms Kathleen Steele
Diabetes Education Centre
13 Wreckyn St
North Melbourne 3051

Sponsored by: N/A

Protocol No: Study Protocol Version:3 Dated: 26/10/2009

Participant Information and Consent Form: Version 4 Dated 16th February 2010

Investigator Brochure: N/A **Dated:**

Other enclosures: (please describe eg advertisement etc.) Illness beliefs and adherence in diabetes mellitus: a comparison between Middle Eastern and Western patients questionnaire.

Conducted at: The Royal Melbourne Hospital **has been approved**

This proposal meets the requirements of the *NHMRC National Statement on Ethical Conduct in Human Research 2007.*

It is now your responsibility to ensure that all people conducting this research project are made aware of which documents have been approved.

This approval is subject to ongoing, current and valid insurance coverage throughout the duration of the conduct of the study.

You are required to notify the Secretary of the Human Research Ethics Committee of

- Any change in the protocol and the reason for that change together with an indication of ethical implications (if any) by submitting an amendment to the study.
- Serious adverse effects on subjects and the action taken to manage them, including amended Plain Language Statement and Consent Form where appropriate.
- Any unforseen events.
- Your inability to continue as Principal Investigator, or any other change in research personnel involved in the study
- A delay of more than 12 months in the commencement of the project.
- The actual date of commencement of the study.

You are required to submit to the Human Research Ethics Committee

- An Annual Report every twelve months for the duration of the project.
- A detailed Final Report at the conclusion of the project.

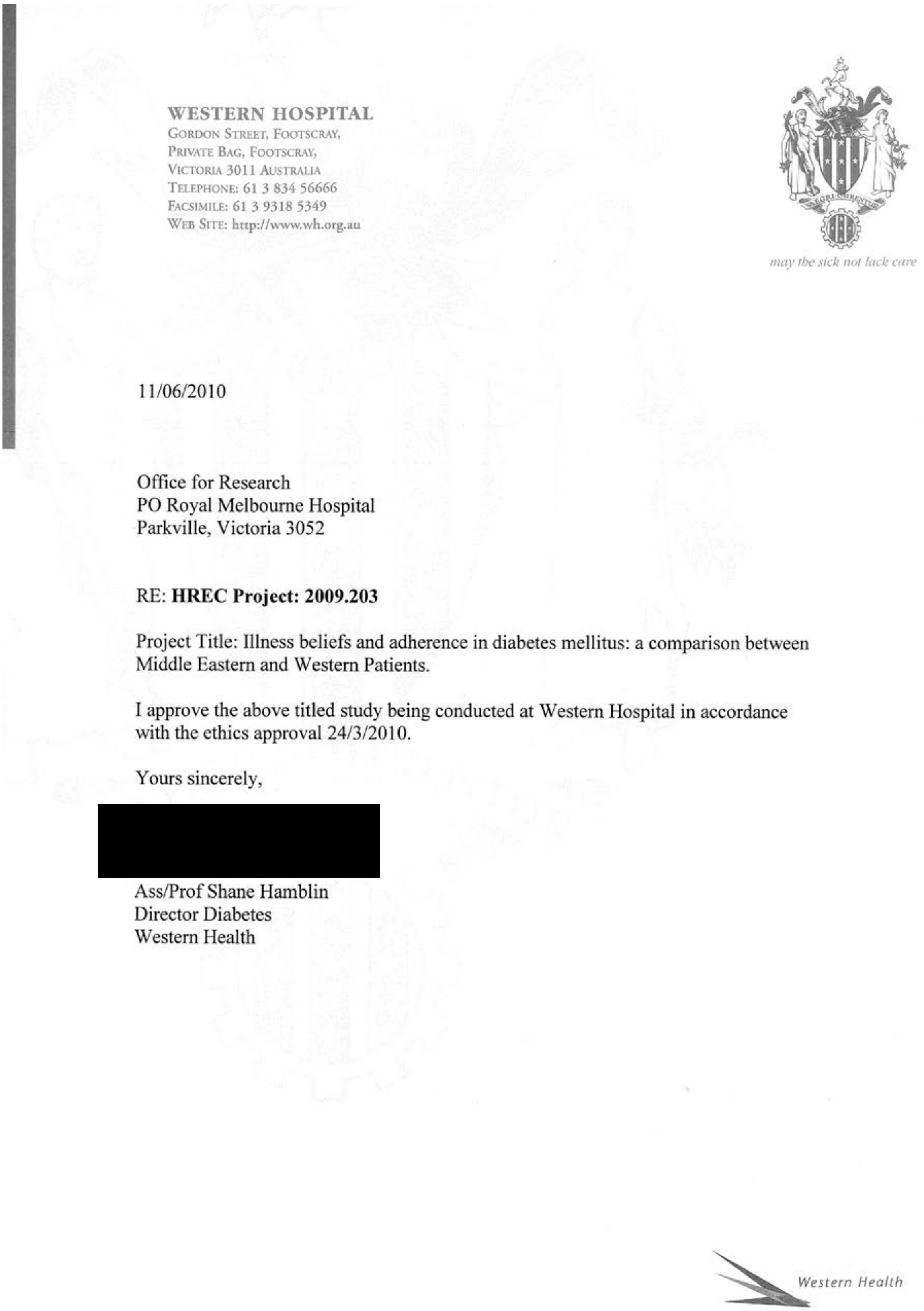
The Human Research Ethics Committee may conduct an audit at any time.

An exten[redacted] conclusion date should be sought from the Human Research Ethics Committee.

Signed:
Dr. Ange
Secretary – Human Research Ethics Committee

Incorporating: The Royal Melbourne Hospital (City Campus and Royal Park Campus), NorthWestern Mental Health, North West Dialysis Service, Victorian Infectious Diseases Reference Laboratory, NMW Shared Support Service

Appendix 13 Western Health Ethics Approval Letter



WESTERN HOSPITAL
GORDON STREET, FOOTSCRAY,
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may the sick not lack care

11/06/2010

Office for Research
PO Royal Melbourne Hospital
Parkville, Victoria 3052

RE: **HREC Project: 2009.203**

Project Title: Illness beliefs and adherence in diabetes mellitus: a comparison between Middle Eastern and Western Patients.

I approve the above titled study being conducted at Western Hospital in accordance with the ethics approval 24/3/2010.

Yours sincerely,

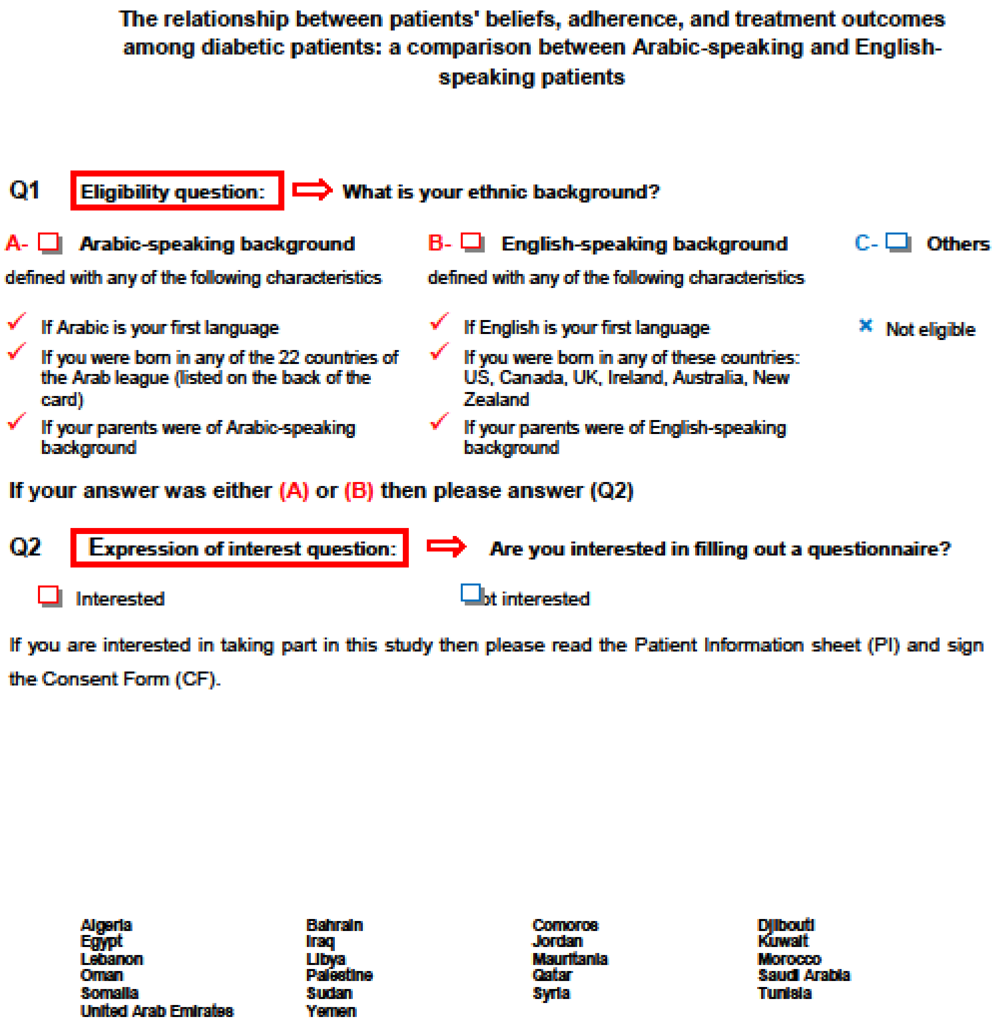
[redacted]

Ass/Prof Shane Hamblin
Director Diabetes
Western Health

Western Health

WESTERN HOSPITAL IS A PROVIDER HOSPITAL OF WESTERN HEALTH

Appendix 14 Eligibility screening question



The relationship between patients' beliefs, adherence, and treatment outcomes among diabetic patients: a comparison between Arabic-speaking and English-speaking patients

Q1 **Eligibility question:** ⇨ **What is your ethnic background?**

A- ☐ **Arabic-speaking background**

defined with any of the following characteristics

- ✓ If Arabic is your first language
- ✓ If you were born in any of the 22 countries of the Arab league (listed on the back of the card)
- ✓ If your parents were of Arabic-speaking background

B- ☐ **English-speaking background**

defined with any of the following characteristics

- ✓ If English is your first language
- ✓ If you were born in any of these countries: US, Canada, UK, Ireland, Australia, New Zealand
- ✓ If your parents were of English-speaking background

C- ☐ **Others**

- ✗ Not eligible

If your answer was either (A) or (B) then please answer (Q2)

Q2 **Expression of interest question:** ⇨ **Are you interested in filling out a questionnaire?**

☐ Interested

☐ ot interested

If you are interested in taking part in this study then please read the Patient Information sheet (PI) and sign the Consent Form (CF).

Algeria
Egypt
Lebanon
Oman
Somalia
United Arab Emirates

Bahrain
Iraq
Libya
Palestine
Sudan
Yemen

Comoros
Jordan
Mauritania
Qatar
Syria

Djibouti
Kuwait
Morocco
Saudi Arabia
Tunisia

Appendix 15 Questionnaire (English Version)

Austin Health The Royal Melbourne Hospital MONASH University Pharmacy and Pharmaceutical Sciences Western Health HEALTH

The relationship between patients' beliefs, adherence, and treatment outcomes among diabetic patients: a comparison between Arabic-speaking and English-speaking patients

Section A: Questions about you

1. Sex: ☐ Male ☐ Female 2. Age: ___________ years

3. In which country were you born? ☐ Australia ☐ Others, please specify……………

If you were born outside Australia, in what year did you first arrive in Australia to live? ……………………

4. What is your level of education?

☐ No formal education ☐ 6th Grade or less ☐ 12th Grade or less
☐ High school graduate ☐ College graduate ☐ Post graduate

5. How long have you been diagnosed as a diabetic patient? ……………years

6. Are you taking any diabetes tablets (diabetes pills)?

☐ Yes, please specify how many oral medications you are using for your diabetes ……………
☐ No

7. Are you using insulin? ☐ Yes ☐ No

8. What is your employment status?

☐ Working part-time ☐ Working full time ☐ Unemployed
☐ Pensioner ☐ Housewife ☐ Self-funded retiree

9. What is your marital status?

☐ Married ☐ Widowed ☐ De-facto
☐ Single ☐ Divorced ☐ Separated but not divorced

10. Do you have any medical conditions, besides diabetes (you can tick more than one)?

☐ High blood pressure ☐ High cholesterol ☐ Kidney problem
☐ Heart condition ☐ Eye disease ☐ Cancer
☐ Stomach ulcer ☐ Arthritis or rheumatism ☐ Others, please specify……………

11. Have you ever attended diabetes education session?

☐ No ☐ Yes, how many sessions have you attended?
☐ 1 session ☐ 2 – 10 sessions ☐ More than 10 sessions

12. If you would like to have more information about diabetes and its treatment, which one of the following resources will be your main source?

☐ Internet ☐ Family and friends ☐ Pharmacists
☐ Doctors ☐ Diabetes educators ☐ Others, please specify……………

13. What would you say about your health at present?

☐ Very poor ☐ Poor ☐ Fair
☐ Good ☐ Very good ☐ Excellent

Section B: Questions about your communication with health professionals

14. Apart from getting a prescription for medicines, when you have an appointment with your doctor, do you discuss all your concerns? ☐ Yes ☐ No

If yes, how often? ☐ Sometimes ☐ Often ☐ Always

15. Have you ever disagreed with pharmacist about your medications?

☐ Yes ☐ No

16. Have you thought of a pharmacist when you have problems with your health or medications?

☐ Yes ☐ No

17. Have you ever visited a pharmacist only to get more information about your prescribed medicines?

☐ Yes ☐ No

18. Have you ever discussed your prescribed medications with your pharmacist? ☐ Yes ☐ No

If yes, how often? ☐ Sometimes ☐ Often ☐ Always

19. Do you prefer a pharmacist who speaks the same language or of the same race as yourself?

☐ Yes ☐ No

20. How often have you followed pharmacists' recommendations?

☐ Sometimes ☐ Often ☐ Always

Section C: Questions about what you think about your diabetes treatment

Please select only <u>ONE</u> rating for each statement, by ticking (✓) the most appropriate response.

A= Strongly agree B= Agree C= Neither agree nor disagree D= Disagree E= Strongly disagree

	A	B	C	D	E
21. My health, at present, depends on diabetes medicines					
22. Without diabetes medicines I would be very ill					
23. My health in the future will depend on diabetes medicines					
24. My diabetes medicine protects me from becoming worse					
25. Missing diabetes medications for a day won't matter in the long run					
26. Diabetes medicines are my best hope for the future					
27. Diabetes medicines keep me alive					
28. Having to take diabetes medicines worries me					
29. I sometimes worry about long-term effects of diabetes medicines					
30. Diabetes medicines are a mystery to me					
31. Diabetes medicines disrupt my life					
32. I sometimes worry about becoming too dependent on diabetes medicines					
33. Diabetes medicines give me unpleasant side effects					

Section D: Questions about your diabetes

For the following questions, please circle the number that best corresponds to your view:

34. How much does your diabetes affect your life?

0	1	2	3	4	5	6	7	8	9	10
no affect at all										severely affects my life

35. How long do you think your diabetes will continue?

0	1	2	3	4	5	6	7	8	9	10
a very short time										forever

36. How much control do you feel you have over your diabetes?

0	1	2	3	4	5	6	7	8	9	10
absolutely no control										extreme amount of control

37. How much do you think your treatment can help your diabetes?

0	1	2	3	4	5	6	7	8	9	10
not at all										extremely helpful

38. How much do you experience symptoms from your diabetes?

0	1	2	3	4	5	6	7	8	9	10
no symptoms at all										many severe symptoms

39. How concerned are you about your Diabetes?

0	1	2	3	4	5	6	7	8	9	10
not at all concerned										extremely concerned

40. How well do you feel you understand your diabetes?

0	1	2	3	4	5	6	7	8	9	10
don't understand at all										understand very clearly

41. Please list in rank-order the three most important factors that you believe caused your Diabetes:

1. ______________________________

2. ______________________________

3. ______________________________

Section E: Questions about self-care activities

The questions below ask you about your diabetes self-care activities during the past 7 days. If you were sick during the past 7 days, please think back to the last 7 days that you were not sick. Please circle the most appropriate response.

42. How many of the last SEVEN DAYS have you followed a healthy eating plan?

0 1 2 3 4 5 6 7

43. On average, over the past month, how many DAYS PER WEEK have you followed your eating plan?

0 1 2 3 4 5 6 7

44. On how many of the last SEVEN DAYS did you eat five or more servings of fruits and vegetables?

0 1 2 3 4 5 6 7

45. On how many of the last SEVEN DAYS did you eat high fat foods such as red meat (which is not the lean meat or game trimmed of all visible fat meat) or full-fat dairy products?

0 1 2 3 4 5 6 7

46. On how many of the last SEVEN DAYS did you participate in at least 30 minutes of physical activity? (Total minutes of continuous activity, including walking).

0 1 2 3 4 5 6 7

47. On how many of the last SEVEN DAYS did you participate in a specific exercise session (such as swimming, walking, cycling) other than what you do around the house?

0 1 2 3 4 5 6 7

48. On how many of the last SEVEN DAYS did you test your blood sugar?

0 1 2 3 4 5 6 7

49. On how many of the last SEVEN DAYS did you test your blood sugar the number of times recommended by your health care provider? ?

0 1 2 3 4 5 6 7

50. On how many of the last SEVEN DAYS did you check your feet?

0 1 2 3 4 5 6 7

51. On how many of the last SEVEN DAYS did you check or inspect the inside of your shoes?

0 1 2 3 4 5 6 7

52. Have you smoked a cigarette—even one puff—during the past SEVEN DAYS?

☐ No
☐ Yes ***If yes***, how many cigarettes did you smoke on an average day? ……………..

Each statement indicates an aspect related to your medicines. Please tick (✓) for the most appropriate response

	YES	NO
53. Do you ever forget to take your diabetes medicines?		
54. Are you always careful in taking your diabetes medicines?		
55. When you feel better, do you sometimes stop taking your diabetes medicines?		
56. Sometimes if you feel worse when you take your diabetes medicines, do you stop taking it?		
57. In the past 12 months, have you ever taken less of your diabetes medications than prescribed by your doctor because of cost?		
58. Many people do not take their prescription medications exactly as prescribed by their doctor. In the past year, have you ever taken less of your diabetes medication than prescribed for any reason other than the cost?		

Section G: Questions about medical information

Please select only ONE rating for each statement, by ticking (✓) the most appropriate response.

A= Strongly agree B= Agree C= Neither agree nor disagree D= Disagree E= Strongly disagree

	A	B	C	D	E
59. I have problems learning about my medical condition because of the difficulty in understanding written information					
60. I'm confident filling out medical forms by myself					
61. I often have someone help me read hospital materials					

Section H: Question about treatment decision-making

62. Each of the following five statements describing different roles for doctors and patients in treatment decision-making. Please select the ONE statement that best describe your preference.

☐ I made the decision

☐ I made the decision after seriously considering the doctor's opinion

☐ The doctor and I made the decision together

☐ The doctor and I made the decision after seriously considering my options

☐ The doctor made the decision

Section I: Questions about the distress caused by diabetes

For the following statements please rate how much of a problem each statement is for you.

If you feel that a particular item is not a bother or a problem for you, you would circle "0". If it is very bothersome to you, you could circle "5", or you may circle any number in between.

Problem	**Ranking seriousness of the problems**					
63. Feeling that diabetes is taking up too much of my mental and physical energy every day.	**0**	**1**	**2**	**3**	**4**	**5**
64. Feeling that my doctor doesn't know enough about diabetes and diabetes care.	**0**	**1**	**2**	**3**	**4**	**5**
65. Feeling angry, scared and/or depressed when I think about living with diabetes.	**0**	**1**	**2**	**3**	**4**	**5**
66.Feeling that my doctor doesn't give me clear enough directions on how to manage my diabetes	**0**	**1**	**2**	**3**	**4**	**5**
67. Feeling that I am not testing my blood sugars frequently enough.	**0**	**1**	**2**	**3**	**4**	**5**
68. Feeling that I am often failing with my diabetes regimen.	**0**	**1**	**2**	**3**	**4**	**5**
69. Feeling that friends or family are not supportive enough of my self-care efforts (eg planning activities that conflict with my schedule, encouraging me to eat the "wrong" foods).	**0**	**1**	**2**	**3**	**4**	**5**
70. Feeling that diabetes controls my life.	**0**	**1**	**2**	**3**	**4**	**5**
71. Feeling that my doctor doesn't take my concerns seriously enough.	**0**	**1**	**2**	**3**	**4**	**5**
72. Not feeling confident in my day-to-day ability to manage diabetes.	**0**	**1**	**2**	**3**	**4**	**5**
72. Feeling that I will end up with serious long-term complications, no matter what I do.	**0**	**1**	**2**	**3**	**4**	**5**
73. Feeling that I am not sticking closely enough to a good meal plan.	**0**	**1**	**2**	**3**	**4**	**5**
74. Feeling that friends or family don't appreciate how difficult living with diabetes can be.	**0**	**1**	**2**	**3**	**4**	**5**
75.Feeling overwhelmed by the demands of living with diabetes	**0**	**1**	**2**	**3**	**4**	**5**
76. Feeling that I don't have a doctor who I can see regularly about my diabetes.	**0**	**1**	**2**	**3**	**4**	**5**
77. Not feeling motivated to keep up my diabetes self-management.	**0**	**1**	**2**	**3**	**4**	**5**
78. Feeling that friends or family don't give me the emotional support that I would like.	**0**	**1**	**2**	**3**	**4**	**5**

Section J: Questions about satisfaction with a health care decision

Please select only <u>ONE</u> rating for each statement, by ticking (✓) the most appropriate response.
A= Strongly agree B= Agree C= Neither agree nor disagree D= Disagree E= Strongly disagree

	A	B	C	D	E
79. I'm adequately informed about the issues important to diabetes treatment decision.					
80. Diabetes treatment decision was the best possible decision for me.					
81. I'm satisfied that the decision was consistent with my personal values.					
82. I expect to successfully continue to carry out the decision.					
83. I'm satisfied that this decision was mine to make					
84. I'm satisfied with the decision					

Section K: Questions about your confidence in following prescribed treatment regimen

For questions 85 and 86 Please select only <u>ONE</u> rating for each statement, by ticking (✓) the most appropriate response.

85. How confident are you in your ability to take your diabetes medications exactly as directed by your doctor?

☐ Not at all confident ☐ Not confident ☐ Unsure ☐ Confident ☐ Extremely confident

86. How confident are you in your ability to carry out all the self-care activities in your daily routine?

☐ Not at all confident ☐ Not confident ☐ Unsure ☐ Confident ☐ Extremely confident

Section L: Questions about adherence to traditional values and attitudes

THIS SECTION IS TO BE COMPLETED <u>ONLY</u> BY PATIENTS OF ARABIC-SPEAKING BACKGROUND.

Please select only <u>ONE</u> rating for each statement, by ticking (✓) the most appropriate response.
A= Strongly agree B= Agree C= Undecided D= Disagree E= strongly disagree

	A	B	C	D	E
87. Duty to one's family comes before personal desires.					
89. Australian of Arabic-background shouldn't disagree among themselves if there are Caucasians around					
90. It would be more comfortable to live within an Arabic-speaking community in Australia.					
91. In the Arabic-speaking community. Human relationships are more warm and comfortable than the outside society					
92. Marrying within the Arabic-speaking community is good					

For questions "93 - 95" Please select only <u>ONE</u> rating for each statement, by ticking (✓) the most appropriate response.

93. I read/speak:

☐ Only Arabic ☐ Arabic better than English ☐ Both equally well ☐ English better than Arabic ☐ Only English

94. Currently my circle of friends are:

☐ Only Arabic ☐ Mainly Arabic ☐ Both Arabic and Australian ☐ Mainly Australian ☐ Only Australian

95. in relation to having an Arabic-background, I feel

☐ Very proud ☐ Proud ☐ Somewhat proud ☐ Little pride ☐ No pride

To be completed by Health Professional

96. Haemoglobin A1C (latest reading) ………………….

97. Blood pressure (latest reading) …………………. Systolic / Diastolic mmHg

98. Lipid profile

- **- Total Cholesterol ………………….**
- **- LDL ………………….**
- **- HDL ………………….**
- **- Triglycerides………………….**

Thank you for your time

Appendix 16 Questionnaire (Arabic Version)

العلاقة بين معتقدات مرضى داء السكري والتزامهم ونتائج علاجهم: مقارنة بين المرضى الناطقين باللغة العربية وأولئك الناطقين بالإنجليزية

الجزء A ـ أسئلة عن نفسك ؟

1 الجنس: ☐ ذكر ☐ أنثى 2 عمرك: .... سنة

3 أين ولدت؟ ☐ أستراليا ☐ غيرها, الرجاء التحديد.......................

إذا ولدت خارج أستراليا, في أي سنة أتيت للعيش في أستراليا؟ ....

4 ما هو مستواك العلمي؟

☐ لا تعليم رسميا ☐ الصف السادس أو أقل ☐ الصف الثاني عشر أو أقل

☐ خريج المرحلة الثانوية ☐ خريج الكلية ☐ دراسات عليا

5 متى تمّ تشخيص مرض السكري لديك؟ منذ .... سنوات

6 هل تتناول أي حبوب لمعالجة السكري (حبوب السكري)؟

☐ نعم، يرجى تحديد عدد الأدوية التي تتناولها بالفم ....

☐ كلا

7 هل تتناول أنسولين؟ ☐ نعم ☐ كلا

8 ما هو وضعك بالنسبة للعمل؟

☐ عامل بدوام جزئي ☐ عامل بدوام كامل ☐ عاطل عن العمل

☐ متقاعد على المعاش ☐ ربّة منزل ☐ متقاعد على أمواله الخاصة

9 ما هو وضعك العائلي؟

☐ متزوّج ☐ أرمل ☐ مرتبط في علاقة شبه الزواج

☐ عازب ☐ مطلّق ☐ منفصل ولكن غير مطلق

10 هل تعاني من أي حالات مَرَضيَّة، عدا مرض السكري (مشكلات صحية إضافة إلى السكري)؟

☐ ارتفاع بالضغط ☐ ارتفاع بمعدلات الكولسترول ☐ عوارض في الكلية

☐ مرض القلب ☐ مرض في العين ☐ سرطان

☐ قُرحة معدية ☐ التهاب المفاصل أو الروماتيزم ☐ غيرها, الرجاء التحديد

11 هل سبق أن حضرت يوما ندوة \ حصة تعليمية عن مرض السكري؟

☐ كلا ☐ نعم, كم دورة حضرت؟

☐ دورة واحدة ☐ 2–10 دورات ☐ أكثر من 10 دورات

12 إذا أردت الحصول على مزيد من المعلومات عن السكري وعلاجه, أي من المصادر التالية تختار ؟

☐ الإنترنت ☐ عائلة والأصدقاء ☐ الصيادلة

☐ الطبيب ☐ مدرسين مختصين بمرض السكري ☐ غيرها, الرجاء التحديد

13 كيف تصنف حالتك الصحية حاليا؟

☐ ضعيفة جدا ☐ ضعيفة ☐ معتدلة

☐ جيدة ☐ جيدة جدا ☐ ممتازة

الجزء B ـ أسئلـة حول تواصلك مع أخصائيي الصحة؟

14 هل تناقش مع طبيبك كل مخاوفك أثناء زيارتك له بغض النظرعن السبب الرئيسي لهذه الزيارة؟ ☐ ☐

إذا أجبت بنعم فكم مرة؟ ☐ أحيانا ☐ غالبا ☐ دائما

15 هل سبق أن اختلفت بالرأي مع الصيدلي حول أدويتك؟

☐ نعم ☐ كلا

16 هل تفكر بالصيدلي عندما تعاني من مشاكل صحية أو مشاكل تتعلق بأدويتك؟

☐ نعم ☐ كلا

17 هل سبق أن ذهبت الى الصيدلي فقط للحصول على معلومات إضافية حول أدويتك الموصوفة؟

☐ نعم ☐ كلا

18 هل سبق أن ناقشت أدويتك الموصوفة مع الصيدلي؟ ☐ نعم ☐ كلا

إذا أجبت بنعم, فكم مرة؟ ☐ أحيانا ☐ غالبا ☐ دائما

19 هل تفضل صيدليا يتحدث لغتك أو من الأصل نفسه الذي تنتمي إليه؟

☐ نعم ☐ كلا

20 كم مرة اتبعت توصيات الصيدلي؟

☐ أحيانا ☐ غالبا ☐ دائما

الجزء C ـ أسئلـة عن معتقداتك المتعلقة بعلاجك لمرض السكّري.

يرجى اختيار فئة واحدة فقط لكل عبارة بواسطة وضع علامة صح (✓) للإجابة الأكثر ملاءمة، حيث تعني الأحرف ما يلي:

A = أوافق بشدة B = أوافق C = لا أوافق ولا أعارض D = أعارض E = أعارض بشدة

E	D	C	B	A	
					21 في الوقت الحاضر، صحتي تعتمد على أدوية السكري
					22 لولا وجود هذه الأدوية كنت سأمرض
					23 في المستقبل، سوف تعتمد صحتي على أدوية السكري
					24 دوائي يحميني ويمنحني ويقي صحتي من أن تصبح أسوأ
					25 إن عدم تناول الدواء ليوم واحد لا أهمية له على المدى البعيد
					26 أدوية السكري هي أفضل أمل لي للمستقبل
					27 أدوية السكري تبقيني على قيد الحياة/تنقذ حياتي
					28 إن وجوب تناولي هذه الأدوية يشعرني بالقلق
					29 أحياناً أقلق بشأن الآثار البعيدة المدى لهذه الأدوية
					30 أدوية السكري هي لغز بالنسبة لي
					31 هذه الأدوية تزعجني وتعترض حياتي
					32 أحياناً أقلق بشأن الإعتماد المفرط على هذه الأدوية
					33 أدوية السكري تسبّب لي آثاراً جانبية

الجزء D - أسئلة عن معتقداتك المتعلقة بمرض السكّري.

بالنسبة للأسئلة التالية، رجاءً ضع دائرة حول الرقم الذي يعبّر عن رأيك أفضل تعبير

34 إلى أي مدى يؤثر مرضك بالسكّري على حياتك؟		
10	1 2 3 4 5 6 7 8 9	صفر
له تأثير شديد في حياتي		لا يؤثر على الإطلاق
35 برأيك كم سيدوم مرضك بالسكّري؟		
10	1 2 3 4 5 6 7 8 9	صفر
إلى الأبد		لفترة قصيرة جدا
36 ما مدى تحكّمك بالسكّري؟		
10	1 2 3 4 5 6 7 8 9	صفر
قدرة كبيرة جداً على التحكم بالمرض		لا تحكم على الإطلاق
37 إلى أيّ مدى تعتقد بأن علاجك للسكّري مفيد لصحتك؟		
10	1 2 3 4 5 6 7 8 9	صفر
مفيد للغاية		مطلقا
38 ما هي نسبة الأعراض التي تشعر بها جرّاء إصابتك بمرض السكّري؟		
10	1 2 3 4 5 6 7 8 9	صفر
أعراض متعدّدة وشديدة جداً		لا أشعر بأية أعراض على الإطلاق
39 ما مدى قلقك ومخاوفك نتيجة إصابتك بمرض السكّري؟		
10	1 2 3 4 5 6 7 8 9	صفر
قلق للغاية		لست قلقا على الإطلاق
40 إلى أيّ مدى تشعر بإنك تستوعب وتفهم مرض السكّري لديك؟		
10	1 2 3 4 5 6 7 8 9	صفر
أفهمه بشكل جيد جداً وبكل وضوح		لا أفهمه على الإطلاق

41 يرجى ذكر العوامل الثلاثة الأكثر أهمية، التي تعتقد بإنها قد سبّبت لك مرض السكري، بشكل متسلسل حسب أهميتها:

1. ....

2. ....

3. ....

الجزء E - أسئلة عن وسائل ونشاطات الإعتناء بنفسك.

الأسئلة أدناه تدور حول النشاطات التي قمتم بها للإعتناء بأنفسكم من مرض السكّري خلال الأيام السبعة (7) الماضية. ، رجاءً ضع دائرة حول الرقم الذي يعبّر عن رأيك أفضل تعبير

42 كم مرة خلال الأيام السبع (7) الماضية قمت باتّباع نظام غذائي أو حمية صحيّة؟

1 2 3 4 5 6 7

43 خلال الشهر الماضي، عموما، كم يوماً في الأسبوع قمت باتباع برنامجك الغذائي؟

1 2 3 4 5 6 7

44 كم مرة خلال الأيام السبع (7) الماضية أكلت خمسة حصص غذائية أو أكثر من الفاكهة والخضار؟

1 2 3 4 5 6 7

45 كم مرة خلال الأيام السبع (7) الماضية أكلت أطعمة كثيرة الدسم والدهون كاللحم الأحمر (غير الهبرا والذي يحتوي على الدهن) أو منتجات الحليب الكاملة الدسم؟

1 2 3 4 5 6 7

46 كم مرة خلال الأيام السبع (7) الماضية قمت بنشاط بدني لمدة 30 دقيقة على الأقل؟ (إجمالي الدقائق للنشاط المتواصل، بما في ذلك المشي).

1 2 3 4 5 6 7

47 كم مرة خلال الأيام السبع (7) الماضية شاركت في حصة تمرين رياضي معيّن (كالسباحة، أو المشي، أو ركوب الدراجة) غير الأمور المنزلية العادية التي تؤديها؟

1 2 3 4 5 6 7

48 كم مرة خلال الأيام السبع (7) الماضية قمت بفحص معدل السكر في دمك؟

1 2 3 4 5 6 7

49 كم مرة خلال الأيام السبع (7) الماضية قمت بفحص معدل السكر في دمك وفق عدد المرات التي نصحك بها اخصائي العناية الصحية الذي يعالجك؟

1 2 3 4 5 6 7

50 كم مرة خلال الأيام السبع (7) الماضية قمت بتفحّص قدميك؟

1 2 3 4 5 6 7

51 كم مرة خلال الأيام السبع (7) الماضية قمت بتفحّص / معاينة أحذيتك من الداخل؟

1 2 3 4 5 6 7

52 هل دخنت سيجارة، حتى لو نفخة واحدة فقط، خلال الأيام السبع (7) الماضية؟

☐ كلا

☐ نعم. إذا أجبت بنعم، كم سيجارة دخّنت في اليوم تقريباً؟..............................

تشير كل عبارة إلى ناحية متعلقة بتناولكم لأدوية السكري. رجاء ضع علامة صحّ (✓) إلى جانب الإجابة الأكثر ملاءمة

الجزء F - أسئلة عن أدويتك.

	نعم	كلا
53 هل سبق وحصل أنك نسيت أن تتناول أدوية السكري؟		
54 هل تنتبه دائماً إلى أخذ دواء السكري بدقة؟		
55 عندما تشعر بتحسُّن، هل تتوقف عن تناول دواء السكري؟		
56 أحياناً، عندما تشعر بأن حالتك أسوأ عندما تتناول دواء السكري، فهل تتوقف عن تناوله؟		
57 خلال السنة الماضية، هل حصل أن تناولت مقداراً من دواء السكري أقلّ من المقدار أوالجرعة التي وصفها طبيبك لك بسبب كلفة الدواء؟		
58 العديد من الناس لا يتناولون الدواء الموصوف لهم من قِبَل الطبيب بدقة وتماماً كما يصفه الطبيب. فخلال السنة الماضية هل حصل وتناولت مقداراً من دواء السكري أقلّ من المقدار أو الجرعة التي وصفها طبيبك لك لأيِّ سبب كان غير الكلفة؟		

الجزء G - أسئلة عن وسائل ونشاطات الإعتناء بنفسك.

يرجى اختيار فئة واحدة فقط لكل عبارة بواسطة وضع علامة صح (✓) للإجابة الأكثر ملاءمة، حيث تعني الأحرف ما يلي:

A = أوافق بشدة B = أوافق C = لا أوافق ولا أعارض D = أعارض E = أعارض بشدة

E	D	C	B	A	
					59 أواجه مشاكل في اكتساب المعرفة حول حالتي الطبية بسبب صعوبة لدي في فهم المعلومات المكتوبة
					60 لدي ثقة بقدرتي على تعبئة الإستمارات الطبية بنفسي دون مساعدة
					61 يساعدني شخصا على قراءة المواد والمعلومات التي أستلمها من المستشفى غالبا

الجزء H - أسئلة حول اتخاذ قرار العلاج

62 تصف كل عبارة من العبارات الخمسة التالية أدوار مختلفة للأطباء والمرضى في اتخاذ قرار العلاج. رجاء إختر العبارة التي تعبر عن رأيك أفضل تعبير

☐ أتخذ القرار بنفسي

☐ أتخذ القرار بنفسي بعد أخذ قرار الطبيب بعين الإعتبار

☐ نتخذ القرار أنا والطبيب سويا

☐ نتخذ القرار أنا والطبيب بعد أخذ اقتراحاتي بعين الإعتبار

☐ يتخذ الطبيب القرار

الجزء I ـ أسئلة عن المضايقة التي يسبّبها لك مرض السكّري.

للعبارات التالية, رجاء حدد درجة المشكلة التي تشكلها كل عبارة بالنسبة إليك. في حال لا تشكل لك العبارة أي مشكلة , ضع دائرة حول الرقم "0". أما إذا كانت مصدرا للإزعاج فضع دائرة حول الرقم "5", أو يمكنك اختيار أي رقم بين هذين الرقمين.

درجة خطورة المشكلة						المشكلة
5	4	3	2	1	0	63 الشعور بأن السكّري يستحوذ مني على طاقة عقلية وبدنية كبيرة جداً بشكل يومي
5	4	3	2	1	0	64 الشعور بأن طبيبي لا يعلم عن موضوع السكّري والعناية بالسكري بقدر كافٍ
5	4	3	2	1	0	65 الشعور بالغضب، الخوف و/أو الإكتئاب عندما أفكّر بوجود السكّري في حياتي ولزوم التعايش معه
5	4	3	2	1	0	66 الشعور بأن طبيبي لا يعطيني توجيهات كافية عن طريقة التعامل مع مرض السكّري
5	4	3	2	1	0	67 الشعور بأنني لا أفحص معدلات السكر في الدم مرات كافية
5	4	3	2	1	0	68 الشعور بأنني غالباً ما أفشل في اتّباع نظامي الخاص بالسكّري
5	4	3	2	1	0	69 الشعور بأن أفراد عائلتي وأصدقائي لا يساندونني بشكل كافٍ في جهودي للإعتناء بنفسي من السكري (مثلاً: ينظمون برنامجاً يتضارب مع برنامجي، يشجعونني على تناول الأطعمة "الغلط" التي تضرّ بي).
5	4	3	2	1	0	70 الشعور بأن السكّري يسيطر على حياتي
5	4	3	2	1	0	71 الشعور بأن طبيبي لا يأخذ مخاوفي على محمل الجدّ كما يجب
5	4	3	2	1	0	72 عدم شعوري بالثقة بقدرتي على تدبير الأمور اليومية
5	4	3	2	1	0	73 الشعور بأنني مهما فعلت، سأصاب في نهاية المطاف بمضاعفات خطيرة طويلة الأمد
5	4	3	2	1	0	74 الشعور بأنني لا ألتزم بدقة كافية بنظام جيّد للوجبات الغذائية.
5	4	3	2	1	0	75 الشعور بأن الأصدقاء أو العائلة لا يقدّرون مدى صعوبة التعايش مع مرض السكّري
5	4	3	2	1	0	76 الشعور بأنني لا أستطيع تحمّل متطلّبات التعايش مع السكّري التي تسيطر عليّ
5	4	3	2	1	0	77 الشعور بأنه لا يوجد لديّ طبيب أستطيع استشارته بشكل دوري بالنسبة للسكري الذي أعاني منه
5	4	3	2	1	0	78عدم شعوري بالحماس لمتابعة تحكّمي الذاتي بمرض السكري والإعتناء بصحتي
5	4	3	2	1	0	79 الشعور بأن الأصدقاء أو العائلة لا يمنحونني الدعم المعنوي الذي أتمناه

للعبارات التالية, رجاء إختر فئة واحدة فقط لكل عبارة بواسطة وضع علامة صحّ (✓) للإجابة الأكثر ملاءمة، حيث تعني الأحرف ما يلي

الجزء J – أسئلة عن قناعتك بقرار الرعاية الصحي

A= أوافق بشدة B = أوافق C = لا أوافق ولا أعارض D = أعارض E = أعارض بشدة

	E	D	C	B	A
80 أنا مطلع بشكل كاف على المسائل المهمة بالنسبة لقرار علاج السكري					
81 إن قرار علاج السكري هو أفضل علاج ممكن بالنسبة لي					
82 أنا راض عن كون القرار يتناسب مع قيمي الشخصية					
83 أنا أتوقع إكمال تطبيق القرار بنجاح					
84 أنا راض عن كوني اتخذت القرار بنفسي					
85 أنا راض عن القرار					

للأسئلة رقم 86 و 87 الرجاء اختيار عبارة واحدة فقط بوضع علامة صح (✓) إلى جانب الإجابة الأكثر ملاءمة

86 ما مدى ثقتك بقدرتك على أخذ أدويتك الخاصة بمرض السكري تماما كما وصفها لك الطبيب؟

☐ غير واثق نهائيا ☐ غير واثق ☐ غير متأكد ☐ واثق ☐ واثق بشدة

87 ما مدى ثقتك بقدرتك على اتباع نشاطات الإعتناء بنفسك في حياتك اليومية؟

☐ غير واثق نهائيا ☐ غير واثق ☐ غير متأكد ☐ واثق ☐ واثق بشدة

الجزء K – أسئلة عن مدى الإلتزام بالقيم والمواقف التقليدية

يرجى إكمال هذا الجزء فقط من قبل المرضى ذووي الأصل الناطق باللغة العربية

يرجى اختيار درجة واحدة فقط لكل عبارة بواسطة وضع علامة صح (✓) للإجابة الأكثر ملاءمة. حيث تعني الأحرف ما يلي:

A = أوافق بشدة B = أوافق C = لا أوافق ولا أعارض D = أعارض E = أعارض بشدة

	E	D	C	B	A
88 واجبات الشخص اتجاه عائلته أهم من رغباته الشخصية87					
89 لا يجب ان يختلف الأستراليون ذووي الأصل الناطق باللغة العربية مع بعضهم أمام القوقازيين					
90 يعتبر العيش ضمن مجتمع ناطق باللغة العربية أكثر راحة في أستراليا					
91 تعتبر العلاقات الإنسانية أكثر طمأنينة و حميمية في المجتمع الناطق باللغة العربية مما هي خارجه					
92 إن الزواج من داخل المجتمع الناطق باللغة العربية هو زواج مناسب					

للأسئلة رقم "93-95" يرجى اختيار درجة واحدة فقط لكل عبارة بواسطة وضع علامة صح (✓) للإجابة الأكثر ملاءمة

93 أنا أقرأ \ أتحدث :

☐ العربية فقط ☐ العربية أفضل من الإنجليزية ☐ اللغتين جيدا ☐ الإنجليزية أفضل من العربية ☐ الإنجليزية فقط

94 حاليا, دائرة أصدقائي هم

☐ عرب فقط ☐ أغلبهم عرب ☐ عرب وأستراليون ☐ أغلبهم أستراليون ☐ أستراليون فقط

95 فيما يتعلق بكوني من أصل عربي, أشعر:

☐ بالفخر الشديد ☐ بالفخر ☐ بالفخر نوعا ما ☐ بالفخر قليلا ☐ لا أشعر بالفخر

شكراً لتعاونكم ووقتكم

To be completed by Health Professional

1- **Haemoglobin A1C (latest reading) ……………………**
2- **Blood pressure (latest reading) …………………… Systolic / Diastolic mmHg**
3- **Lipid profile**
Total Cholesterol ……………………
LDL ……………………
HDL ……………………
Triglycerides……………………