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A Cultural Adaptation of a Diabetes Self-Management Programme for Patients with  
Type 2 Diabetes Attending a Primary Health Care Centre in Saudi Arabia

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A thesis submitted in accordance with the requirements for the Degree of Doctor of  
Philosophy of University of London

**April 2019**

Department of Health, Environments and Society

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Funded by The Saudi Arabian Ministry of Higher Education

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## ABSTRACT

**Background:** Self-management is an integral part of chronic disease management. Diabetes self-management programmes have shown to be effective. However, they are not standard practice in all high prevalence settings. For example, although the prevalence of Type 2 Diabetes in Saudi Arabia is 23%, such programmes have yet to be developed and deployed to serve this population. Self-management programmes are highly culturally and context specific, requiring substantial research and refinement to make them effective.

**Aim:** To culturally adapt the Stanford Diabetes Self-Management Programme to be more relevant to patients with type 2 diabetes attending a primary health care centre in Saudi Arabia.

**Methods:** A total of 39 participants were recruited from clinic settings to attend a six-week programme and their feedback was used to inform the adaptation. A qualitative study of this process and the experiences of diabetes was built into the programme. This consisted of non-participatory observations in a chronic disease clinic, informal meetings with a team of health care professional and a series of focus groups with participating patients to explore perceptions of the programme and barriers to self-management. These were audio-recorded, transcribed verbatim and thematically analysed.

**Results:** Gender and social norms and roles, religion and reliance on Allah were the main themes emerging from the data.



**Conclusion:** Adapting the evidence-based intervention through using a cultural adaptation framework was not fully successful. This is due to complexity of incorporating findings such as gender and gender roles into the adaptation and at the same time maintain fidelity of the original programme. The finding of this study suggests that content and messages of behaviour change intervention may benefit from being gender-specific, especially in Saudi Arabia. The study contributes to more understanding of barriers to self-management among Saudi patients.

## **DEDICATION**

I dedicate this thesis to the woman with the kindest and most beautiful soul

Mama Um Ja'far

May you rest in peace

## ACKNOWLEDGMENTS

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I'd like to sincerely give my deepest thanks and appreciation to my supervisors; Kiran Nanchahal for her patience, encouragement, guidance and support along the way; Claire Thompson who introduced me to the real world of qualitative research. Thank you for your detailed feedbacks and eye-opening conversations. Without both of your input, support and guidance, this work would not have been possible.

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Finally, my husband Kumail- Thank you for believing in me. This would not have been possible without your tireless encouragement and support every single minute of the way.

## LIST OF ABBREVIATIONS

T2DM	Type 2 Diabetes
FGDs	Focus Group Discussions
MOH	Ministry of Health
DM	Diabetes Mellitus
SI	Symbolic Interactionism
GDHA	General Directorate of Health Affairs
IDF	International Diabetes Federation
WHO	World Health Organisation
QoL	Quality of Life
BMI	Body Mass Index
SA	Saudi Arabia
NM	Not mentioned
HbA1C	Glycaemic Control
DSMP	Diabetes Self-Management Program
CDSMP	Chronic Disease Self-Management Program
SMI	Self-Management Intervention
CINAHL	Cumulative Index of Nursing and Allied Health Literature

EVM

Ecological Validity Model

RCT

Randomised Control Trial

ADA

American Diabetes Association

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# Chapter 1: INTRODUCTION

## 1.1 Overview

This chapter provides an overview of the current study. It also provides the outline of this thesis.

## 1.2 The research problem

Diabetes mellitus is a common chronic disease and a major public health concern globally. Although the prevalence of diabetes varies widely among populations, it has increased globally in recent years. The World Health Organisation (WHO) estimates that 422 million people have diabetes worldwide, with type 2 diabetes accounting for 90% of all cases (WHO, 2016). According to the Global Report on Diabetes (WHO, 2016), 1.5 million people died due to diabetes in 2012. Most diabetes attributable deaths occur in middle and low-income countries (WHO, 2016).

Type 2 diabetes is characterised by insulin insensitivity with relative insulin deficiency. It is often attributed to excess body weight and physical inactivity in genetically predisposed individuals. It is a major cause of morbidity and mortality because it considerably increases the risk of stroke, cardiovascular disease, blindness and renal disease. Moreover, it has a significant impact on societies, economies and health systems. Although there is no cure for diabetes, it can be managed by implementing lifestyle changes, and in some cases, using medication. Successfully managing diabetes reduces the likelihood of developing complications.

The tremendous economic and demographic changes in the past few decades in the Middle East region have resulted in significant lifestyle changes. In 2012, the region had the highest prevalence of diabetes in the world (International Diabetes Federation, 2015). Saudi Arabia is among the top 10 highest countries in the world in terms of diabetes prevalence (International Diabetes Federation, 2015).

In order to prevent the development of diabetes complications, patients are required to adopt healthy behaviours in order to change their life-style, such as adhere to their medication regimen, adopt a healthy life style, regularly monitor their blood glucose as well as follow-up with their health care provider. Self-management is an umbrella to all these behaviours. Self-management is considered to be the cornerstone of overall diabetes care (Norris et al., 2002). It is a key determinant of health outcomes and has become a popular term for behavioural interventions and healthy behaviour (Kate R. Lorig & Holman, 2003). self-management was found to be an appropriate approach to the control and management of diabetes (Newman et al., 2009). It was reported to enhance the health and quality of life and reduce the economic burden placed on families as well as healthcare systems (Bodenheimer, Lorig, Holman, & Grumbach, 2002).

Several international organisations, such as the International Diabetes Federation (IDF, 2015), American Diabetes Association (ADA) (2012) and the National Institute for Health and Clinical Excellence (NICE, 2009) highlight the need to emphasise self-care as an important element of diabetes management.

It is important to note that, although the use of the terms self-care and self-management are commonly interchangeable in the literature (Grady & Gough, 2014), some authors attempted to differentiate between them.

Self-care has a wide range of definitions. It has been defined as practices and behaviours undertaken by the individual to maintain their health and wellbeing and prevent disability and pain (Ausili, Masotto, Dall'Ora, Salvini, & Di Mauro, 2014). Self-management on the other hand was defined by Barlow et al (2002) as the ability of an individual to manage the symptoms, treatment and the physical and psychosocial impact, and undertake the lifestyle changes required in living with a chronic illness.

It is suggested that both terms are differentiated in that self-care refers to actions taken by an individual to promote health and prevent illness, whereas self-management is the management of an existing chronic illness (Barlow et al., 2002; Grady & Gough, 2014).

Due to the lack of consensus in literature to distinguish between self-care and self-management (Ausili et al., 2014), both terms will be used interchangeably in this thesis.

Self-management programmes are abundant in developing countries. However, although Saudi Arabia has a very high diabetes prevalence, it has not yet integrated diabetes self-management programmes within the health system. This study will attempt to address this gap.

The Stanford diabetes self-management programme was selected to be adapted to achieve a derivative that is culturally more relevant for Saudi patients with type 2 diabetes in primary care.

### **1.3 Thesis Outline**

This thesis includes ten chapters. This current chapter (chapter 1) provides an overview of the research problem.

**Chapter 2:** provides an introduction to diabetes in Saudi Arabia and describe its epidemiology. It also describes the Saudi health care system and diabetes care. It studies the literature of studies conducted in Saudi that attempted to address diabetes self-management. Moreover, it provides literature about widely used self-management programmes worldwide. Culture and the concept of culture adaptation is provided. The chapter discusses the evidence-based programme that was selected for adaptation. The chapter ends by stating the research question, the main aim and lists the objectives.

**Chapter 3:** provides a systematic review that conceptualises cultural relevance of diabetes self-management programmes using The Ecological Validity Model.

**Chapter 4:** Presents the methodology utilised in this study and describes the data collection process for each of the methods as well as the methods of data analysis used.

**Chapter 5:** This chapter provides a detailed account of the unique context of Saudi Arabia. The chapter ends with a section that describes the context of the primary care centre where the study took place.

**Chapter 6:** This chapter describes the results of the non-participatory observations that took place in the chronic disease clinic.

**Chapter 7:** Provides the main themes that emerged from the Focus group Discussions

**Chapter 8:** The adaptation of the programme is included in this chapter

**Chapter 9:** This chapter discusses the aspects that need to be considered for the programme to be relevant for the Saudi context.

**Chapter 10:** This chapter provides a discussion of the findings of this study

**Chapter 11:** summarises the findings of the study and provides recommendations and implications for practice.

## Chapter 2: **LITERATURE REVIEW**

### **2.1 Saudi Arabia: An Introduction**

This section provides an overview of diabetes in Saudi Arabia and establishes the context for the proposed research project.

Saudi Arabia is the largest country in the Middle East with a land area of two million square kilometres. Its total population is estimated to be 29 million, of which 26% of the population are non-Saudi. More than 85% of the population resides in urban areas. The economy of Saudi Arabia is mainly based on oil production, which yields 80% of the government budget. The current Gross Domestic Product (GDP) per capita is US \$20,328 (Ministry of Health, 2014).

The rapid urbanisation that occurred after the discovery of oil in the 1970s caused socioeconomic and lifestyle changes. The physical inactivity rate is estimated to be 60.7% and 74.9% among men and women, respectively (MOH, 2014). Obesity rates are also rising, leading to an obesity rate of 28.6% in men and 39% in women (World Health Organisation, 2014). In recent years, the improvement in healthcare and lifestyle changes has led to a shift in the patterns of disease from infectious communicable diseases to chronic noncommunicable illnesses. In 2010, cardiovascular disease (42%), hypertension (12%), malignancies (9%) and diabetes (6%) were among the ten leading causes of death in Saudi Arabia, accounting for approximately 71% of the total mortality rate (WHO, 2014)



**Figure 1 Map of Saudi Arabia**

### 2.1.1 *Epidemiology of Diabetes in Saudi Arabia*

According to the Ministry of Health (MOH), the prevalence of diabetes for the total population is 16.4%, and it is 28% for those 30 years of age and older (MOH, 2016). Community-based studies as well as those conducted in health settings have shown a steady increase in the prevalence of diabetes in both men and women from 2.5% in the 1980s (Bacchus, Bell, Madkour, & Kilshaw, 1982) and 10% in the 1990s (El-Hazmi et al., 1996) to 23.7% in 2011 (MOH, 2016). This increase cannot be ignored.

The association between diabetes and macro-vascular and micro-vascular long-term complications, such as cardiovascular disease, renal failure and neuropathy, will cause the prevalence of these conditions to increase as well. Al-Wakeel et al. (2009) noted that diabetic nephropathy is the leading cause of chronic renal failure in Saudi Arabia. An IDF study found that 54% of diabetes patients had renal disease (IDF, 2015). Furthermore, 65% of patients with diabetes attending outpatient clinics experienced peripheral neuropathy complications (Halawa et al., 2010). The prevalence of diabetic retinopathy was found to be 30%, and 6.2% had diabetic foot, of which 1.3% required amputations (Khan et al., 2011).

Along with the increase in the prevalence and complications of diabetes, the diabetes mortality rate has also increased. For example, in 2002, mortality caused by diabetes represented less than 3% of the total rate (WHO, 2014), but by 2010, this figure had doubled to 6% (WHO, 2014). Moreover, cardiovascular diseases are a common complication of diabetes, suggesting that the true mortality rates resulting from diabetes is much higher.

Due to this increasing trend, an inevitable strain has been placed on the healthcare system. The annual cost of diabetes care in Saudi Arabia is estimated to be \$9.6 billion (Alhowaish, 2013). On average, medical healthcare expenditures for those diagnosed with diabetes is estimated to be ten times higher than those without diabetes (\$3,686 vs. \$380 per capita) (Alhowaish, 2013).

Studies have shown that diabetes is poorly controlled (Al-Elq, 2009; Al-Ghamdi, 2004; Al-Hussein, 2008; Eledrisi et al., 2007; Qari, 2005) Overall, less than 50% of



patients have achieved the target glycated haemoglobin (HbA1c). Other clinical parameters, such as blood pressure and lipids, have not been within the optimal range (Al-Elq, 2009; Kharal et al., 2010). Thus, Saudi Arabia must introduce new health services and apply new strategies to address this issue.

### *2.1.2 Healthcare System in Saudi Arabia*

Approximately 60% of healthcare services in Saudi Arabia are provided and financed by the MOH (Walston, Al-Harbi, & Al-Omar, 2008). Other governmental providers, such as the Ministry of Aviation, the Ministry of Interior and the Ministry of Higher Education (which also administers the university hospitals), participate in the delivery of health services; however, these services are usually provided for employees and their dependents. Services have been provided for free to all Saudi citizens as well as expatriates working in the public sector (Almalki, Fitzgerald and Clark, 2011), but recently, the MOH implemented a compulsory employment insurance-based scheme for all expatriates and all those working in the private sector (Saudis and non-Saudis) to minimise the healthcare expenses of the government. There is also a contribution from the private sector, which provides its services for a profit (M. H. Almalki, Hussen, Khan, Almaghamisi, & Alshahrani, 2018).

The healthcare system in Saudi Arabia is semi-decentralised. There are 19 health directorates within the 13 regions of the country supervised by the MOH. Each regional directorate has several hospitals as well as health sectors. All health sectors manage several primary care centres. The directorates are responsible for implementing the MOH's policies, plans and programmes. They have an autonomous

responsibility in terms of management, recruitment, training, supervision and evaluation of services; however, they have a limited spending authority (Almalki, Fitzgerald and Clark, 2011). Lump-sum budgets are provided for each directorate, and all other activity expenditures must be authorised by the MOH (Walston et al., 2008). This can affect the autonomy of the directorates to make decisions when needed.

Public healthcare is financed through government revenues. The annual budget for the MOH was approximately 40 million Saudi riyals (£7 million) in 2011 (MOH, 2014). This accounted for 6.9% of the total annual budget of all government-sector services (MOH, 2014).

The healthcare system is a three-tier system comprised of primary, secondary and tertiary care. Primary care is supplied by primary care centres, which provide curative as well as preventive services. According to the MOH, there are 3,981 primary healthcare centres throughout the country (Ministry of Health, 2011). Primary care serves as a 'gate-keeping' function for referrals to general and specialised hospitals (Walston et al., 2008).. It is responsible for providing services such as provision of child and maternal care, immunisation and provision of drugs and the management of chronic diseases. Advanced cases are referred to general hospitals (secondary level), and more complex cases are then referred to specialist hospitals (tertiary level of care). Unfortunately, the communication and referral processes between these levels are not coordinated. For example, there are no communication channels available to send patients back to primary care after a referral to the secondary or tertiary levels.

### *2.1.3 Diabetes Care in Saudi Arabia*

In response to the growing health problem, several healthcare initiatives have been announced over the past few years to manage diabetes in Saudi Arabia. The most significant initiative was the government's establishment of the Diabetes National Committee. The Committee's mission is to plan, supervise and support activities to manage diabetes at the national level. In addition, it is responsible for the implementation of the Executive Saudi National Plan to Combat Diabetes 2010-2020. The plan was designed by the MOH in 2009 (MOH, 2009). The aim of this plan is to develop a systemic approach to the treatment of the disease at the national level and across different healthcare organisations. The plan's goals are to 1) prevent risk factors, 2) increase screening and prevent complications, 3) improve diabetes health services, 4) invest in health systems and community health research, 5) improve the surveillance and follow-up of patients with diabetes, 6) involve patients and their families in health services development and 7) activate community participation to control diabetes.

Regarding these goals, there is a specific emphasis on screening and awareness-raising campaigns that are conducted in community settings, such as malls and supermarkets (Almalki, Fitzgerald and Clark, 2011). Nonetheless, other improvements that have taken place after designing this plan are inconclusive, and more importantly, the way these goals are to be achieved is unclear.

Moreover, diabetes control is generally suboptimal considering that HbA1c, lipids and blood pressure targets are not met, and the prevalence of diabetes complications is

rising. This could be explained by largely prioritising a reactive approach to disease management, focusing on acute care rather than a proactive approach that emphasises prevention and early treatment. The reactive approach to healthcare is more expensive and often less effective.

The extremely high prevalence of diabetes in Saudi Arabia indicates that a tremendous effort is required to manage the disease in the long-term, including an attempt to decrease further medical complications for affected people. It is therefore imperative that the Saudi government and health authorities engage in efforts to promote healthy diets and exercise regimes for the general population. For those who already have type 2 diabetes, these efforts must include improvements to health education and enhanced patient self-management strategies.

Unfortunately, little action has been taken towards the primary prevention<sup>1</sup> of diabetes, and interventions are limited to annual awareness-raising campaigns organised by the MOH. Hence, there is an urgent need to implement strategies and programmes that aim to influence lifestyle behaviours to reduce the incidence of diabetes. Primary prevention is pivotal to diabetes; however, secondary<sup>2</sup> and tertiary preventions<sup>3</sup> are also crucial to minimising the burden of the disease. In Saudi Arabia, secondary prevention has been given adequate attention, although it is clear that less effort has been devoted to tertiary prevention. The aim of tertiary prevention is to prevent and/or

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<sup>1</sup> Primary prevention aims to prevent the development of the disease before it occurs through measures such as; immunisation, health promotion and health safety practices

<sup>2</sup> Secondary prevention aims detect a disease as soon as it occurs in order to slow its progression. This includes screening for diabetes to identify those with pre-diabetes and recommend exercise and diet to prevent its progression to diabetes.

<sup>3</sup> Tertiary Prevention aims to reduce an impact and complication of an existing illness. For example, regular ophthalmology examination for patients with diabetes to screen for diabetic retinopathy.

reduce diabetes complications. This can be achieved by screening for complications in addition to providing interventions that aim to modify lifestyle and self-care behaviours.

#### *2.1.4 Literature on Diabetes Care Interventions in Saudi Arabia*

I conducted a non-systematic literature search to have an overview of interventions for diabetes care and management in Saudi Arabia to identify any efforts to explore diabetes self-management. Four interventions were found to have been conducted in Saudi Arabia to improve diabetes care and management. Uddin et al., (2001) explored and briefly described a health education intervention for people with type 2 diabetes in primary care centres. 438 participants were recruited to attend 12 patient education sessions for a period of 5 days. Two trained nurses delivered the sessions. The sessions covered the following topics: explanation of diabetes, symptoms and management of hypo and hyperglycaemia, the role of exercise and diet in diabetes, medications, diabetes complications, foot care, diabetes care during special occasions such as Ramadan and Hajj. The sessions also included practical training regarding glucose self-monitoring, insulin injection technique and healthy food preparation. Pamphlets, videos and booklets were used as materials to deliver the intervention. The participants were divided into groups consisting of a maximum of 12 patients with females and males attending alternatively. Outcomes were collected three months before and one year after the intervention. Clinical outcomes collected included: HbA1c weight, blood pressure and lipids. Glycaemic control improved in both groups. It increased from 1.72% pre-intervention to 50% post intervention and from 8.6% to 58.6%. for men and women, respectively. All the metabolic outcomes were significantly improved in

the three follow up periods. However, weight and low-density lipoprotein were not significantly different after three months of the programme. After one year all parameters were significantly improved except for high density lipoprotein. The authors claim that the programme was developed and adapted to local conditions by a team of healthcare professionals. However, it is not clear what aspects were taken into account in the adaptation process. The structure of the sessions was not precisely described in the article. Moreover, a randomised controlled method would have been more robust in programme evaluation.

A study by Al-Khaldi and Khan (2000) examined the impact of the presence of mini clinics within a primary health care centre. This study did not provide any explanation regarding the aim of the mini clinics or how they are conducted. Interestingly the study reported that the increase in pamphlet distribution in primary health care is an indication of improved diabetes outcomes.

In 2011, Alfadda et al.,(2011) aimed to determine whether the use of an assistant would improve physician's behaviour, patient's management and diabetes outcomes. This study utilised a randomised controlled multicentre method. The intervention group consisted of the primary care physician and an assistant. The assistant is a healthcare professional who reviewed patient's file prior to their appointment with the physician. Clinical and biomedical information was entered into a computer program which generated a checklist of the clinical and biomedical screening tests that should be carried out in the current visit. The check list was reviewed by the physician during the patient's visit. The control group did not include an assistant. 679 participants were recruited: 517 and 162 in the intervention and control group, respectively. The authors

claim that the intervention significantly improved the screening for diabetes retinopathy (24.7% to 98.5%) nephropathy (37.8% to 73.3%) and neuropathy (25.9% to 92%). However, no improvements were achieved regarding diabetes biomedical outcomes. Although this was the only study found that attempted to use a randomised controlled study design, it still has limitations. It is not clear what type of diabetes was included in this study. The authors did not mention the inclusion and exclusion criteria of participants. And no justification for the use of this particular intervention (using an assistant to review patient files) was provided in the article.

A more recent study was conducted in a tertiary hospital in Riyadh (Al Hayek et al., 2013). The study explored the impact of an education programme on patients' diabetes control, anxiety, depression and adherence to self-care behaviours such as: adherence to diet, physical exercise, medication and self-monitoring of glucose. This prospective study recruited 104 patients. The programme consisted of twelve sessions conducted within six months. It was delivered by a trained nurse prior to a one to one counselling session with a doctor. The content of the programme was not described in detail in the article only mentioning distributing hand-outs, pamphlets and audio and video tapes to the participants. The study resulted in a reduction of HbA1c among the participants from 8.3% to 7.2% at 6 months. Significant improvement was demonstrated on all outcomes compared to baselines. Outcomes were evaluated through self-reported questionnaires which may have led to recall bias. The study mentioned the absence of a control group as a major limitation to the validity of this study and no data is available about follow-up and adherence once the study ended.

Several authors recommended the application of international diabetes management guidelines to improve diabetes management and outcomes in Saudi Arabia (Al Hayek et al., 2013); (Eledrisi et al., 2007). Saudi researchers have acknowledged the importance of self-management on diabetes control. They have recommended empowering patients and providing knowledge for them to undertake self-management behaviours (Al Hayek et al., 2013). Azab (2001) concluded that a self-management program is needed to improve diabetes control in Saudi Arabia. No self-management programmes are implemented in Saudi Arabia, particularly in primary care.

The MOH recognises the importance of education for patients of diabetes regarding how to manage their condition, hence the availability of a fact sheet on the basics of diabetes care in primary care centres; however, from personal experience, the curriculum is presented in a one-page document consisting of several topics, such as symptoms of hypoglycaemia, the importance of medication, exercise, diet and foot care. The physician is required to check the list and discuss each topic. There are no guidelines or details regarding the content or delivery method of these topics.

Although the MOH recognises the importance of diabetes self-management, it is not being offered as part of routine diabetes care in Saudi Arabia. A national reference for diabetes (a booklet) was published in 2011 (MOH, 2011). The reference explains diabetes and its types, treatment modalities, complications and tips for patients during travelling, fasting and performing Hajj. Although the introduction of this booklet emphasises the need to develop self-management skills, there is no indication of this in the booklet. In addition, this booklet might not be accessible to those with low



literacy skills because only a written version is available online. The contents of this booklet provide general knowledge about diabetes and do not consider the influential socio-cultural aspect. For example, the importance of exercise is emphasised; however, the difficulty for women to perform exercise due to a lack of designated areas and the societal rejection of outdoor sports is not considered, so the means of implementing exercise for women is not mentioned. It is unlikely for an individual to implement behaviour changes if the means for undertaking them is not explained, especially if social and environmental conditions are averse to the behavioural changes.

Several international organisations, such as the International Diabetes Federation (2012), American Diabetes Association (ADA) (ADA, 2012) and the National Institute for Health and Clinical Excellence (NICE) (2009), highlight the need to emphasise self-care as an important element of diabetes management.

Despite increasing research worldwide dedicated to diabetes self-management, to date, there have been minimal efforts to explore self-management implementation in the Saudi Arabian context. As mentioned, some studies have attempted to examine diabetes management in Saudi Arabia; however, the interventions mainly focused on diabetes education rather than self-management. Moreover, none of the interventions involved patients in the development process, and thus it is likely that they were developed by healthcare professionals. Therefore, the content of these interventions may not have addressed the difficulties patients face in managing diabetes. During this study, the need for self-management interventions in Saudi Arabia was examined.

## **2.2 Literature on Diabetes Self-management and Self-management Education**

Self-management of a chronic disease in general refers to the ‘ability of an individual to manage symptoms, treatment, physical, psychosocial consequences and lifestyle changes in living with a chronic disease’ (Barlow et al., 2002). In other words, it is not an alternative to medical care; rather, it aims to help individuals become active participants in their own care and is not adversarial to healthcare providers (Kate R. Lorig & Holman, 2003).

In diabetes care, self-management is considered the cornerstone of effective diabetes care (Norris et al., 2002). It is a key determinant of health outcomes and has become a popular term for behavioural interventions and healthy behaviours (Lorig and Hollman, 2003). self-management was found to be an appropriate approach for the control and management of diabetes (Newman et al., 2009). It was reported to enhance health and quality of life and to reduce the economic burden placed on families as well as healthcare systems (Bodenheimer et al., 2002).

The increase in chronic disease prevalence has led to the development of interventions to enhance patients’ self-management. Diabetes self-management interventions have emerged as resources to assist patients in managing daily diabetes care through the dissemination of information and the facilitation of self-management behaviours. Knowledge about the disease and specific lifestyle guidelines are necessary but not adequate to facilitate the appropriate behavioural changes (Funnell et al., 2011). To improve the control of diabetes, management should include changes in behaviours

and lifestyles, which include weight control, physical activity, blood glucose monitoring and adhering to a treatment plan.

A distinction should be made between self-management education and traditional education. The latter offers information and technical skills, whereas self-management education teaches problem-solving skills, allows patients to determine their problems and helps them make decisions and take the appropriate actions to manage these problems (Lorig et al., 2001). Hence, self-management education is a complement to, rather than a substitute for, traditional education (Bodenheimer et al., 2002).

Diabetes self-care seems to be a challenging task for many patients. It is influenced by psychological, motivational and educational factors (Lorig & Holman, 2003). The ability and willingness of patients to change their behaviours is a basic requirement for self-management; therefore, it has been suggested that the use of approaches based on theories is essential because they are more likely to lead to behaviour change (Elder, Ayala, & Harris, 1999).

### **2.3 Theories of Behaviour Change**

Behaviour change is the central aspect of self-management (Newman et al., 2009). Theories of behaviour change have been used for self-management interventions with the aim to enhance patients' capacities to manage their illnesses. Interventions based on theories have been found to be more effective in inducing behaviour change than those developed on a pragmatic basis (Elder et al., 1999). The use of theories assists in identifying the variables that require modification to facilitate behaviour changes,

and the theories can explain the success or failure of an intervention to elicit behaviour changes by providing an analytical explanation (Bartholomew, Parcel, & Kok, 1998).

Various theoretical approaches have been used in the development of self-management interventions for different diseases; however, the most commonly used theory is the Social Cognitive Theory, which was developed by Bandura (2004). This theory emphasises self-efficacy as an influencing factor on behaviour. Self-efficacy is described as the individual's belief in his or her capability to perform a certain behaviour in a specific situation (Bandura, 2004). Therefore, the stronger the perception of the ability to perform a task, the more likely the person will be to carry out the task. Moreover, the theory incorporates perceived facilitators and barriers that influence behavioural goals.

## **2.4 Widely Used Diabetes Self-Management Interventions**

### **Programmes**

Appendix 10 provides examples of four of the most widely applied intervention programmes: the Stanford Disease self-management Programme, the Flinders Programme, the EXPERT Patient Programme and DESMOND.

A large amount of research in the literature has been dedicated to self-management interventions, especially for patients with type 2 diabetes, and there have been a number of systematic reviews on diabetes self-management interventions. Appendix 11 presents an overview of 12 systematic reviews of type 2 diabetes self-management interventions (Concha et al., 2009; Deakin, McShane, Cade, & Williams, 2005; Duke,

Colagiuri, & Colagiuri, 2009; Eakin, Bull, Glasgow, & Mason, 2002; Egginton et al., 2012; Fan & Sidani, 2009; Foster, Taylor, Eldridge, Ramsay, & Griffiths, 2007; Gary, Genkinger, Guallar, Peyrot, & Brancati, 2003; Glazier, Bajcar, Kennie, & Willson, 2006; Hawthorne, Robles, Cannings-John, & Edwards, 2010; Leeman, 2006; Loveman, Frampton, & Clegg, 2008; Norris et al., 2002; Norris, Engelgau, & Narayan, 2001; Radhakrishnan, 2012; Steed, Cooke, & Newman, 2003; Steinsbekk, Rygg, Lisulo, Rise, & Fretheim, 2012; Warsi, Wang, LaValley, Avorn, & Solomon, 2004).

These reviews show good heterogeneity for all aspects of the interventions reviewed. The type, content, settings, intervention deliverer, participants and outcome measures are also diverse. Most interventions include multiple components and strategies. The content of interventions within each review is also diverse. It ranges from being unspecified to involving nutrition, physical activity, goal setting, problem solving, foot care and psychological strategies. The settings include either a healthcare facility, such as hospitals, out-patient clinics and primary care centres, or community settings. Intervention tutors can be health professionals, lay persons or both. The outcomes vary considerably, and a few reviews only considered clinical parameters, such as glycaemic control (HbA1C), lipids, weight and Body Mass Index (BMI). Other reviews focused on psychological outcomes, such as Quality of Life (QoL), depression and self-efficacy.

The key observations that emerged from the review of systematic reviews are:

- Improvements in clinical parameters, such as HbA1c, lipids, weight, BMI and blood pressure

- Improvements in behaviours, such as dietary behaviours, physical activity, blood glucose monitoring and foot care
- Improvements in psychosocial aspects, such as QoL, self-efficacy and anxiety
- The heterogeneity of interventions hinders the comparability of results
- It is difficult to compare outcomes due to their variability and complexity. There is no consensus, for example, on which component, delivery method or setting constitutes an effective self-management intervention
- There appeared to be inconsistencies between the intention and the content of some interventions. Some interventions were merely didactic and did not aim to enhance self-management skills and/or change behaviours; however, they were described as self-management interventions and vice versa
- Evidence on the effect of the intervention on morbidity and mortality was not strong
- These reviews and meta-analyses showed modest but significant glycaemic control, but the improvements seemed to decrease with time. The evidence for other clinical parameters, such as lipids, blood pressure and weight, was variable

Due to the complexity of these interventions, it is impossible to determine which might be effective if implemented in different settings or for different target groups. According to Newman et al (2009), a delivery approach must include a population-based strategy with a list of patient-centred options that can be tailored to the capacities and circumstances of the clinical or community setting where they are offered as well as to the individual and family's capacities, circumstances and preferences'.

Studies that are successful in Western countries are not inevitably effective for people in different contexts. Consequently, any lessons from the interventions may need to be modified to be more suitable for the Saudi Arabian context.

Previous research has suggested that patient involvement (Loveman et al., 2003) and cultural factors and barriers (Deakin et al., 2005) are important factors in the development of interventions that seek to increase self-management skills among patients with diabetes.

## **2.5 Culture: An Influencing Factor on Self-management**

Culture has a major influence on health. Advances in health promotion interventions have prompted the emergence of the cultural relevance principle (Castro, Barrera, Holleran Steiker, & Steiker, 2010). When an intervention lacks relevance to the needs and preferences of a cultural group (i.e. beliefs, customs, traditions and lifestyle), it would consequently exhibit low levels of effectiveness (Castro et al., 2010).

### *2.5.1 Definition of Culture*

Fiske (2002, p. 83) explored how cultural and psychological anthropologists viewed culture and captured his findings by defining culture as ‘a socially transmitted or socially constructed constellation consisting of such things as practices, competencies, ideas, schemas, symbols, values, norms, institutions, goals, constitutive rules, artefacts, and modifications of the physical environment’.

Culture is a complex construct. It guides the actions and decisions of a particular group. Culture is defined as the set of values and beliefs that defines a national or ethnic group and influences their behaviours (Barrera & Castro, 2006). A group of people can be defined as a ‘cultural group’ when they share the same values, beliefs, social norms and roles (Betancourt & López, 1993).

Culture influences patients’ perceptions of their ability to adapt to lifestyle changes. Therefore, it has an effect on undertaking self-management. Self-management should focus on experiential learning in which the culture of the participants does not conflict with the programme strategies.

To enhance the efficacy of interventions for a specific context, researchers have called for targeting or tailoring self-management intervention to the specific needs of the intended population. A distinction should be made between ‘targeting’ and ‘tailoring’ self-management interventions. ‘Tailoring’ has been defined as ‘any combination of strategies and information intended to reach a specific person, derived from an individual assessment’ (Hawkins, Kreuter, Resnicow, Fishbein, & Dijkstra, 2008). On



the other hand, ‘targeting’ occurs when interventions are implemented for members of a specific subset of the general population who share common demographic characteristics (Kreuter & Wray, 2003). Both approaches are similar in adapting health messages to the characteristics of the participants; however, they differ in segmentation and customisation (Radhakrishnan, 2011). Tailoring interventions is not justified if the needs of the targeted population are similar, which could apply to the Saudi population because they are a homogenous group, especially those who are patients of primary care centres.

Due to the breadth of existing self-management interventions, it is difficult to justify developing an entirely new intervention. Castro et al. (2010) recommended finding a closest-fit intervention for the target group and then adapting it according to patients’ needs and the context.

### *2.5.2 The Saudi Arabian Cultural Context*

Due to the cultural and health system differences, Middle Eastern countries cannot simply implement self-management interventions developed in Europe or North America. For example, the literacy rate of the older populations of Saudi Arabia is relatively low; therefore, printed instructions would not be appropriate. Also, Middle Eastern cultural norms related to male and female behaviours vary considerably from those in the West. For example, in Saudi Arabia, women do not drive or engage in outdoor sports activities. This has ramifications for health-seeking behaviours, consequently effecting self-management behaviours. Therefore, recommendations that emphasise the importance of physical exercise, for example, should also provide

the means of performing exercise in consideration of these obstacles. Moreover, providing transportation services might provide the means for women to access healthcare services when needed.

In addition, traditionally, the Saudi culture is both hierarchical and collectivist. Family members rely on each other for support. A reliance on family for care may cause delays in seeking healthcare, especially preventive care. Therefore, the involvement of family members might enhance the ability of patients to adopt self-management behaviours.

Regarding healthcare providers, Saudis respect and trust doctors. This should be considered when choosing who delivers the intervention. For example, the EXPERT programme that was developed in the UK is delivered by lay people with diabetes. This might not be effective in the Saudi context because patients may not consider lay people to have sufficient experience to give advice. At the healthcare provider level, incentives and support for health professionals to prioritise self-management is lacking in Saudi Arabia.

Self-management interventions developed in individualistic cultures, such as North America or Europe, may not accommodate collectivistic values and behaviours. Implementing these interventions in Saudi Arabia may not lead to behaviour changes and may not yield the desired outcomes. In the absence of evidence-based interventions designed and tested for the target population, adaptation may be a more viable and cost-effective option for systematically integrating patients' cultural perspectives and values into the intervention (Marsiglia & Booth, 2015)

### 2.5.3 Cultural Adaptation of Interventions

Bernal, Jiménez-Chafey and Domenech Rodríguez (2009, p. 362) defined cultural adaptations as *'the systematic modification of evidence-based treatment or intervention protocol to consider language, culture, and context in such a way that it is compatible with the client's cultural patterns, meanings, and values'*.

A culturally adaptive intervention is an intervention in which participant-specific modifications to the intervention are integrated into the intervention protocol based on process, mediator or outcome measures (Castro et al., 2010). Modifications are made in response to the characteristics of the targeted community and their environment to produce optimal outcomes. The primary aim of cultural adaptation is to generate a culturally equivalent version of the intervention. Translation from one language to another is the most obvious form of intervention adaptation (Guillermo Bernal, 2006). Using culturally appropriate material for the intervention, such as culturally specific case studies, role play, hand-outs and exercises, is another way to culturally adapt an intervention (Castro et al., 2010).

In the process of intervention adaptation, it is not sufficient to merely base adaptations on intervention theories or researcher/expert recommendations. It is essential to recognise the differences between the group for whom the original intervention was developed and the group for whom the intervention is being adapted (Chen, Reid, Parker, & Pillemer, 2013). Castro et al., (2010, p. 3) referred to the cultural adaptation (Sun, Tsoh, Saw, Chan, & Cheng, 2012) process as a process that *'involves a planned,*

*organized, iterative, and collaborative process that often includes the participation of persons from the targeted population for whom the adaptation is being developed’.*

Cultural adaptation can sometimes be viewed as a top-down approach if the adaptations are made without the involvement or input from members of the target population (Barrera, Castro, Strycker, Toobert, & Toobert, 2013). On the other hand, Falicov (2009) argued that cultural adaptation lies mid-way between both approaches. For example, a top-down approach is adopted when the original intervention is relevant to all cultural groups and does not require any adaptation, and a bottom-up approach is adopted when an intervention is developed considering the values, traditions and practices of a specific cultural group; however, Barrera et al.,(2013) claimed that both approaches can be integrated by utilising stage models to guide the adaptation process.

#### *2.5.4 Cultural Adaptation Stage Models*

Chen et al., (2013) states that to effectively adapt an intervention using participant feedback, it is necessary to: 1) seek participants’ feedback after they are provided with the intervention and 2) assess participants’ feedback to determine which aspects to adapt. However, researchers have varying opinions about how much of the original unadapted intervention should the participants be exposed to, before soliciting their feedback. For example, Wingood and DiClementes's (2008) ADAPT- ITT framework, developed for culturally adapting evidence-based HIV interventions, includes a phase where the participants’ feedback and reactions are sought after attending one module of the original unadapted intervention through a method termed ‘theatre testing’; a

method usually used to gauge people's reactions to TV advertisements, public posters and announcements. They claim that the advantage of using this method is gathering feedback on the content in a short time frame (Wingood & DiClemente, 2008). On the other hand, Kumpfer et al., (2008), who developed a framework to culturally adapt the Strengthening Families Programme, suggest conducting a pilot of the full original unadapted intervention with participants of the target group, then subsequently elicit feedback from them in order to attempt the cultural adaptation.

Exposing participants to a portion of the intervention only, could merely attain their overall impression of the part they have attended and will not allow to obtain feedback about detailed aspects of the intervention, such as; the total number of sessions delivered, session content and how the intervention is applied in a specific setting (Chen et al., 2013). Lacking detailed feedback will probably not aid the adaptation process (Chen et al., 2013).

### **Why use a cultural adaptation model?**

To aid the implementation of evidence-based interventions in a specific community, cultural adaptation models encourage involving community members and employing qualitative methods to obtain insights into and an understanding of the community's cultural and social norms as well as the local environment (Cabassa & Baumann, 2013). By doing so, the community attributes can be used when adapting the intervention (Damschroder et al., 2009)

Targeted cultural adaptation models integrate culture into the process of implementing interventions by proposing methods and guidelines that aid this process. Models generally recommend that adaptations (Cabassa & Baumann, 2013):

- Involve the developers and users of the intervention as well as other community members to inform the adaptation
- Are preceded by formative research, such as Focus Group Discussions (FGDs), interviews and surveys, to determine the needs of the population
- Include adjustments and the documentation of means of participant engagement and retention as well as the acceptability of the intervention
- Employs an iterative process to test and refine the adaptations to ensure the maintenance of intervention fidelity
- Are tested for their effectiveness through formal evaluations

### **Who should facilitate the adaptation?**

Some cultural adaptation models recommend seeking the aid of a Cultural Adaptation Specialist to assist in making the interventions more relevant to the target group by integrating their knowledge of the culture of the target group into the adapted intervention (Domenech, Rodríguez and Bernal, 2012). Cabassa and Baumann (2013) listed the attributes of a Cultural Adaptation Specialist as follows:

- Is acquainted with the values and practices of the target group
- Speaks the language in a culturally competent manner
- Is self-aware of their values
- Is an active participant in the community
- Informs the adaptations by using conceptual frameworks
- Are familiar with the intervention
- Possess problem-solving skills that will enable them to communicate information between the target group and researchers

Utilising the expertise of only a single person is not recommended, especially a healthcare professional or an expert, during the process of culturally adapting an intervention (Cabassa & Baumann, 2013). It is therefore essential to involve community members in this process and to solicit their perspectives on their needs as well as the barriers and facilitators of an intervention (Jones & Wells, 2007).

To my knowledge, there are no self-management interventions that have been developed for any Arab country. Therefore, an evidence-based intervention that could be the closest fit to the Saudi context was selected.

## **2.6 Intervention selected for adaptation**

The Flinders programme is an on-going programme (Flinders University, 2013) delivered to patients individually at each visit. Therefore, its on-going implementation depends on the individual healthcare provider's engagement availability. The healthcare provider must extend each patient's appointment to conduct an interview prior to delivering the message. This will likely hinder their engagement and participation. It is also likely to be less feasible due to the need to provide training for all healthcare providers.

The EXPERT programme (Kennedy et al., 2007) is designed to be delivered by lay workers. This might affect the acceptability and trust of the patients in the programme. Although it is adapted from the Stanford programme, the evidence of its effectiveness is quite limited.

The DESMOND programme (Khunti et al., 2012) is also delivered by healthcare providers; however, the programme is only provided for one full day or two half-days. The limited contact time is likely to negatively impact the effectiveness of this programme.

The Stanford Diabetes self-management Programme (SDSMP) (Stanford Patient Education Research Centre, 2014; (Lorig et al., 2001) was selected for adaptation for the following reasons:



- It is based on a theory of change. Evidence suggests that interventions based on theories of change lead to more significant outcomes (Newman et al., 2009). The Stanford programme is based on Bandura’s Social Cognitive Theory, which aims to increase patients’ self-efficacy in adopting self-care behaviours. Substantial research has evaluated the theoretical model and supports its efficacy in increasing self-efficacy.
- It is delivered in groups, which could make it more feasible to conduct.
- It may be the closest fit to the Saudi context because it can be delivered by healthcare professionals, which might be more suitable in this context, and/or a lay worker, which may help motivate more interactions compared to delivery by a health professional alone. Utilising expert patients may effectively increase Saudi women’s engagement in the programme as well.
- It is widely used and has resulted in significant positive outcomes in multiple studies (Dongbo, Ding, McGowan, & Fu, 2006; Gitlin et al., 2008; K R Lorig et al., 1999; Swerissen et al., 2006).
- It has been rigorously tested in RCTs (K R Lorig et al., 1999; Swerissen et al., 2006).

The programme aims to improve health behaviours, health status and self-efficacy, therefore reducing emergency visits and healthcare costs. The programme also has the goal to improve HbA1c. The sessions in the programme focus on managing diabetes

as a disease and discussing its treatment approaches, such as blood glucose monitoring and how to use the results to improve control; preventing, detecting and treating acute and chronic complications; goal setting and problem solving; and adjusting psychosocially to living with diabetes. It is delivered within 15 hours (2.5 hours per week for six weeks) in a group setting. An outline of the SDSMP is provided in Appendix 20.

Based on a brief review of culturally adapted self-management interventions, it is unclear how cultural adaptations are undertaken. Therefore, a systematic review was conducted to explore how cultural adaptations are conceptualised. The Ecological Validity Model (EVM) was utilised to synthesise the data and to determine whether using a more systematic adaptation of interventions would have resulted in a successful intervention and significant outcomes. As a result of the systematic review, the SDSMP was selected for adaptation using the EVM. The systematic review follows in the next chapter.

## Chapter 3: **SYSTEMATIC REVIEW**

*Conceptualisation of cultural relevance in diabetes self-management interventions:  
a systematic review*

### **3.1 Introduction**

Advancements in health promotion interventions have prompted the emergence of the cultural relevance principle (Castro et al., 2010). When an intervention lacks relevance to the needs and preferences of a cultural group (i.e. beliefs, customs, traditions and lifestyle), it would consequently exhibit low levels of effectiveness (Castro et al., 2010). To enhance the efficacy of interventions for a specific context, researchers have called for targeting or tailoring self-management interventions to the specific needs of the intended population. Self-management interventions can either be tailored or targeted for a specific population or group. A distinction should be made between targeting and tailoring self-management interventions. ‘Tailoring’ has been defined as ‘any combination of strategies and information intended to reach a specific person, derived from an individual assessment’ (Hawkins et al., 2008). On the other hand, ‘targeting’ occurs when interventions are implemented for members of a specific subset of the general population who share common demographic characteristics (Kreuter and Wray, 2003). Both approaches are similar in adapting health messages to the characteristics of the participants; however, they differ in segmentation and customisation (Radhakrishnan, 2011).

Despite the consensus that cultural context is a key component of behavioural health interventions, especially those supporting self-management, there is an ongoing debate regarding how to design effective, culturally relevant health interventions. To my knowledge, previous systematic reviews that examined culturally relevant interventions for type 2 diabetes only focused on either the assessment of the effectiveness of culturally specific interventions (Hawthorne et al., 2008) and/or only reviewed interventions for a specific target group, such as Latinos and Hispanics (Concha et al., 2009; Whitemore, 2007). The review conducted by Whitemore (2007) included studies that only targeted Hispanics. The study provided a description of the cultural strategies of the interventions and the efficacy of the interventions related to diabetes outcomes; however, frameworks were not considered. The review conducted by Concha et al., (2009) used the cultural sensitivity framework developed by (Resnicow, Baranowski, Ahluwalia, & Braithwaite, 1999) to assess the cultural sensitivity of diabetes management interventions that address the emotional well-being of Latinos.

To my knowledge, none of the existing systematic reviews have examined the principles or components of culturally relevant interventions. In addition, they have not extensively described or empirically examined cultural sensitivity frameworks.

There are two frameworks that aid the development or adaptation of culturally relevant behaviour change interventions. The cultural sensitivity model identifies two distinct content areas: deep culture, which includes aspects of culture, such as beliefs, value systems and norms, and surface culture, which refers to elements such as language, food and customs (Resnicow et al., 1999); however, this model merely focuses on

tailoring the content of the intervention. The Ecological Validity Model (EVM), a more comprehensive model developed by (G Bernal, Bonilla, & Bellido, 1995), has been used to guide the adaptation of mental health interventions for Hispanics. It incorporates eight dimensions: language, persons, metaphors, content, concepts, goals, method and context (see Table 1). This review does not propose that the EVM is the only appropriate model; however, the model emphasises the consideration of the development and the technical and theoretical aspects of the intervention (Guillermo Bernal, 2006) Hence, it considers the cultural relevance of the process, the content and the delivery methods of the intervention. This framework could therefore be used as a systematic approach to intervention development and implementation considering context and culture.

<b>Ecological Validity Model Dimensions</b>	<b>Definition</b>
<b>Language</b>	The use of culturally appropriate and culturally syntonic language that is responsive to the cultural group
<b>Persons</b>	Consideration of the role of cultural similarities and differences between patient and provider
<b>Metaphor</b>	The use of metaphors and/or symbols shared by the target group
<b>Content</b>	Addressing cultural knowledge of values, customs and traditions shared by the target group
<b>Context</b>	The consideration of the targets' group broader social, economic and political context
<b>Concept</b>	The use of a theoretical framework to inform the development of the intervention.
<b>Methods</b>	The use of culturally appropriate methods and strategies to achieve the outcomes of the intervention and the methods used to generate culturally relevant strategies.
<b>Goals</b>	Establishing goals between patients and deliverer of the intervention, taking into consideration the cultural values, customs and traditions of the target group,

**Table 1: The Ecological Validity Model's dimensions and their definitions**

### *3.1.1 Aim*

The aims of this review were to assess the way culturally relevant type 2 diabetes self-management interventions are conceptualised and to evaluate their efficacy on diabetes outcomes.

### *3.1.2 Inclusion and Exclusion Criteria*

Studies were included if they met the following criteria:

1. SMI specific for patients with type 2 diabetes only. Other forms of diabetes will be excluded due to treatment differences.
2. Patients with type 2 diabetes of any age group
3. The intervention does, in fact, address diabetes self-management, per se. Studies will be included if the reported self-management intervention includes at least one of the following:
  - Problem solving
  - Goal setting
  - Behavioural support;
  - communication skills
  - Self-monitoring

- Emotional management
- Treatment action plans

These criteria were considered due to the inconsistency between the intention and the content of some reported interventions. Some interventions are merely didactic and do not aim to enhance self-management skills and/or change behaviours; however, they are described as self-management interventions.

4. Describe a self-management intervention that is culturally tailored or targeted.
5. Studies based on a randomised control trial (RCT) or pre-post comparative study design were included.
6. Studies published from 2000 to the present.
7. Studies published in English.

### *3.1.3 Exclusion Criteria*

1. Studies that involved patients with Type 1 diabetes
2. Studies were excluded if they are Cross-sectional and non-interventional studies will be excluded because they are more likely to provide merely descriptive information and, in some cases, do not provide information regarding the effectiveness of the intervention or its impact on diabetes outcomes.

### 3.2 Methods and Search Strategy

A search strategy was developed to access published articles. A limited search of Medline and CINAHL using the terms 'self-management' and 'diabetes' was performed to identify relevant keywords from titles, abstracts and study descriptions.

The search terms identified were:

- Self-management
  - Self-care
  - Self-help
  - Self-monitoring
  - Self-adj manage\*
  
- Type 2 diabetes
  - Diabet\*
  - NIDDM
  - T2DM
  
- Cultur\* target\*
  - Tailor\*



- Competence/competent /competency/compet\*
- Relevant
- Sensitive
- Social context
  - Cultural context
- Program/programme/program\*
  - Intervention
- Design\*
  - Develop\*
- Adapt\*

The identified terms and their synonyms were used to conduct an extensive literature search. CINAHL, Embase, Medline and Google Scholar were searched. Full copies of articles published in English since the year 2000 that met the inclusion criteria based on their titles, abstracts and subject descriptors were obtained for data synthesis. The search also included screening the references and the bibliographic lists of articles.

An initial search of the databases identified a total of 1701 potentially eligible articles. The titles and abstracts and/or full text (if not clear) were screened for relevance. Duplicate studies were removed. The full texts of 53 studies were retrieved for further screening. Seventeen articles met all inclusion criteria. Of these articles, seven were excluded because they did not report the study outcomes. Thus, ten studies were included for this review. Figure 2 provides a flow chart of the article selection process.

Data were extracted and tabulated for analysis. From each of the included studies, author and year of publication, study design, target group and effects on diabetes outcomes were extracted. The dimensions of the EVM by Bernal et al.,(2006) were used as a framework to extract and analyse the data. It is important to note that none of the studies referred to any of the model dimensions explicitly. The data included in this review were extracted and sorted according to each dimension of the EVM based on the author's interpretation of the reported articles.

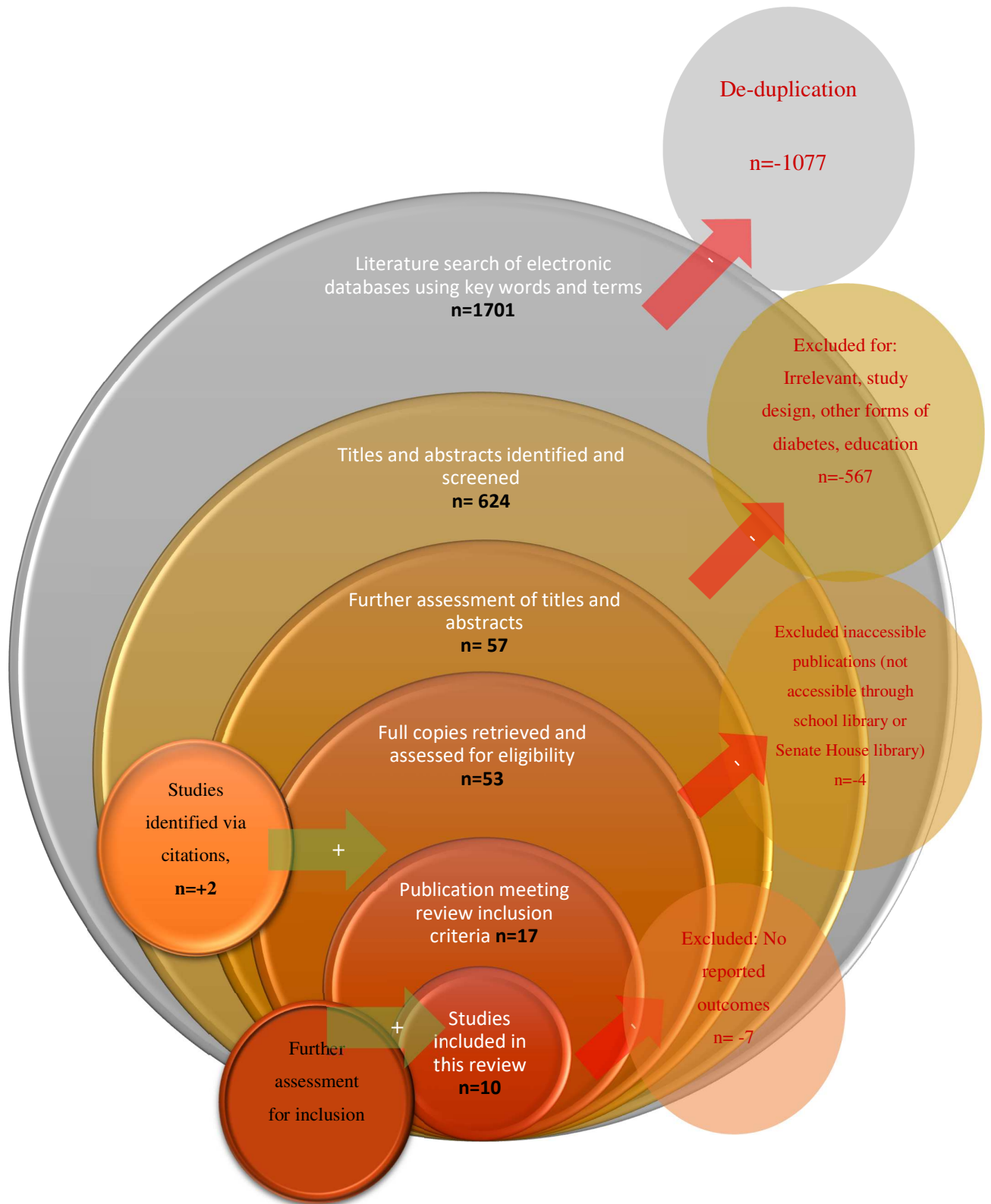


Figure 2: Study Selection Flow Chart ('n' is number of studies at each stage)

### **3.3 Quality assessment**

It can be argued that the effectiveness of an intervention is highly influenced by the quality of the methods used to test the intervention. RCTs are considered the gold standard for evaluating interventions; however, considering that this review examined how cultural adaptations in diabetes self-management interventions are conceptualised, pre- and post-design studies are relevant and should not be overlooked. Existing quality assessment tools involve only individual study designs and therefore could not be utilised for this review. Moreover, the quality of the included studies was not assessed because this review mainly involves an application of the EVM model rather than an evaluation of the effectiveness of the interventions. None of the existing quality assessment tools are related to the assessment of the cultural adaptation of interventions.

### **3.4 Results**

#### *3.4.1 Descriptions of included studies*

Eight studies were RCT, and two used a pre-post design. Nine of the included studies were conducted in the US, and one was conducted in Canada (Gucciardi, Demelo, Lee, & Grace, 2007). Three studies targeted African Americans; one targeted urban African Americans (Anderson et al., 2005), another targeted rural African Americans (Utz et al., 2008) and the third did not specify (C D Samuel-Hodge et al., 2009). The majority of studies targeted Latinos in the US (R. Barbour, 2013; Brown, Garcia, Kouzekanani, & Hanis, 2002; Rosal et al., 2011; Teufel-Shone, Drummond, & Rawiel, 2005;

Vincent, 2009) One study targeted Puerto Ricans, and one study targeted Portuguese Canadians (Gucciardi et al., 2007)

The interventions were varied and complex. Most of the interventions were conducted in community settings, such as churches (Utz et al., 2008), community centres or the participants' homes. Others took place in clinical settings, such as primary care centres or hospitals.

The types of providers varied and included nurses, certified diabetes educators and community health and lay workers. Several interventions were conducted in group settings, and others were provided to participants individually.

#### *3.4.2 Application of the Ecological Validity Model*

Components of the EVM were used to examine the 10 interventions included in this review. Appendix 12 provides a comparison of the studies based on their inclusion, or lack thereof, of the model's dimensions. A brief introduction of the model's components and the findings from the analyses of the interventions are discussed in the subsequent sections.

#### *3.4.3 Language*

According to Bernal et al., (1995), using the appropriate language when delivering interventions indicates that the culture is integrated appropriately. The efficacy of an intervention depends on effective communication. This dimension also considers the participants' literacy skills when conveying information. Therefore, the consideration

of literacy skills and using a ‘culturally syntonic’ language, meaning a language relevant to the target group, were taken into account during the analysis.

Nine of the 10 studies examined literacy levels. Gucciardi et al., (2007) considered literacy and reported using a grade five reading level for their written material. Similarly, Anderson et al., (2005) reported using an appropriate reading level for the culturally tailored materials. Other interventions addressed literacy in other forms, such as minimising written material, using video tapes (Brown et al., 2007; Rosal et al., 2011), pictorial flipcharts, visual aids (Teufel-Shone et al, 2005; Gucciardi *et al.*, 2007; Samuel-Hodge et al., 2009) and game formats (Samuel-Hodge et al., 2009) and reading questions aloud to participants (Brown et al., 2005; Teufel-Shone et al., 2005). Osborn et al., (2010) and Vincent et al., (2008) reported using literacy sensitive materials, but the method used was not discussed.

Utz et al., (2008) and Osborn et al., (2010) used culturally syntonic language. Although the intervention reported by Utz et al., (2008) targeted African Americans, for which English is the dominant language, the language characteristics of the region where the intervention took place were used. Osborn et al., (2010) targeted Puerto Ricans in the US. Although Puerto Ricans speak Spanish, the study explicitly mentioned the use of the Puerto Rican dialect in delivering the intervention.

Whether interventions were translated into and/or from another language was not evaluated in this review.

#### 3.4.4 *Persons*

This dimension refers to the patient-provider match. The cultural similarities and differences between patients and providers should be considered when developing interventions for a target group (Bernal et al., 2006). This dimension was considered in five studies (Brown et al., 2002; Teufel-Shone et al., 2005; Utz et al., 2008; Osborn et al., 2010; Spencer et al., 2011). The most explicit example of this was employing Hispanic lay workers from the participants' community to deliver the intervention (Teufel-Shone et al., 2005). In Spencer et al., (2011), community health workers were ethnically matched to the participants (Latino and African American). In addition, community health workers of Puerto Rican heritage delivered the intervention in Osborn et al.,'s (2010) study, and Mexican American staff were utilised by Brown et al.,(2002).

The other studies did not report the ethnicity and/or ethnic similarities between participants and the delivering staff, but they did report utilising personnel who spoke the language of the intervention target group, such as Portuguese-speaking health professionals (Gucciardi et al., 2007) or health professionals and lay workers who spoke Spanish (Vincent et al., 2008; Rosal et al., 2011).

#### 3.4.5 *Metaphor*

According to Bernal et al., (1995), using metaphors enhances the motivation of the participants and strengthens the cultural environment. Only two studies addressed metaphors in their interventions. Utz et al., (2008) used the metaphor 'sugar' rather

than ‘diabetes’ in the title of the programme because it is commonly used within the target group (African Americans). On the other hand, Osborn et al., (2010) employed ‘the teach-back’ technique in which participants were asked to repeat the given instructions in their own words to confirm their understanding. This was used by the interventionists as feedback to use the words the participants used to improve the intervention.

#### *3.4.6 Content*

This dimension addresses the cultural knowledge of the values, customs and traditions of the target group and its incorporation into the intervention messages. The knowledge of the target groups’ values and traditions is essential for the intervention messages to be more effective, hence motivating behaviour changes (Kreuter et al., 2006). The use of culturally relevant content in the included studies varied. Eight of the 10 studies described intervention content that considered the cultural knowledge of the target group to some extent (Brown et al., 2002; Teufel-Shone et al., 2005; Anderson et al., 2005; Gucciardi et al., 2007; Utz et al., 2008; Vincent et al., 2008; Osborn et al., 2010; Rosal et al., 2011). All eight interventions incorporated the cultural knowledge of the target group in diet-related components of the intervention, such as the modification of traditional foods and recipes to healthier versions and providing cooking demonstrations. Gucciardi et al., (2007), Osborn et al.,(2010) and Rosal et al.,(2011) supported the role of ‘familism’ in the Hispanic culture by incorporating messages regarding how to cope with eating at social and family events and how to manage family expectations.



Osborn *et al.*,(2010) dispelled myths Puerto Ricans have regarding diabetes care in their intervention messages. In addition, although it is somewhat vague, Brown *et al.*,(2002) reported incorporating cultural health beliefs into the intervention messages.

#### 3.4.7 Context

This dimension refers to the broader social, economic and political context of the target group. Six of the 10 studies addressed the context of the target group (Brown *et al.*, 2002; Teufel-Shone *et al.*, 2005; Gucciardi *et al.*, 2007; Utz *et al.*, 2008; Vincent *et al.*, 2008; Samuel-Hodge *et al.*, 2009). Interventions targeting Hispanics and Latinos acknowledged familism through the participation of the family in the intervention (Brown *et al.*, 2002; Gucciardi *et al.*, 2007; Utz *et al.*, 2008; Vincent *et al.*, 2008; Rosal *et al.*, 2011) or conducting family sessions in the homes of the participants to address the family's collective behaviours (Teufel-Shone *et al.*, 2005). Brown *et al.*,(2002) and Utz *et al.*,(2008) both considered the effects of role models within the culture and requested that leaders and role models describe their experience with diabetes.

Due to the value of oral history and teaching in the African American culture, Utz *et al.*,(2008) utilised storytelling as a culturally appropriate approach to deliver the intervention. On the other hand, Samuel-Hodge *et al.*,(2009) considered religion and spirituality as important to the African Americans targeted for the intervention, and thus the sessions were delivered in churches and began with a prayer.

The economic context was considered for the intervention messages developed by Vincent *et al.*,(2008). The messages regarding physical activity suggested low-cost

activities, such as walking inside local malls and using soup cans for strength training, and activities that can be performed at the participants' homes were demonstrated.

#### 3.4.8 *Concept*

This dimension examines whether the intervention is informed by a theoretical model. Nine of the 10 interventions were informed by theoretical frameworks. The Social Cognitive Theory guided the development of four interventions (Utz et al., 2008; Vincent et al., 2008; Samuel-Hodge et al., 2009; Rosal et al., 2011). Anderson et al.,(2005) and Spencer et al.,(2011) used the Empowerment Behaviour Change Model. The Social Learning Theory was used by Teufel-Shone et al., (2005). Gucciardi et al., (2007) used the Theory of Planned Behaviour, and the Information-Motivation-Behavioural Skill Model was used by Osborn et al., (2010).

The concept dimension also includes whether the theoretical framework used to inform the intervention is consistent with the target group's culture. Although it is important to consider this criterion when developing interventions, none of the authors linked the use of theoretical frameworks with the attributes of a specific cultural group.

#### 3.4.9 *Methods*

This dimension involves the methods and strategies used to achieve the outcomes of the intervention. The methods dimension was included in nine of the 10 studies. The importance of family support for diabetes self-management and decision making regarding diabetes management was emphasised by Brown et al., (2002), Teufel-Shone et al., (2005), Gucciardi et al., (2007), Utz et al.,(2008), Vincent et al.,(2008)

and Rosal et al.,(2011). The involvement of family members was more likely to lead to positive outcomes. Methods also included strategies such as offering home visits for personalised counselling to the participants and their family members (Teufel-Shone et al., 2005, Rosal et al., 2011) and providing cooking demonstrations of traditional foods and ethnic recipes (Brown et al., 2002; Teufel-Shone et al., 2005; Gucciardi et al., 2007; Utz et al., 2008; Vincent et al., 2008; Rosal et al., 2011). Other strategies utilised included the use of soap operas, which are popular among Mexican Americans, to convey self-management messages (Rosal et al., 2011). Educational games were also used as a strategy to augment the information provided (Rosal et al., 2011; Teufel-Shone et al., 2005).

This dimension also includes the methods used to generate culturally relevant strategies. Most of the studies used formative methods, either prior to the development of the intervention or to test the appropriateness of the intervention for the target group. Focus groups were utilised prior to the development of the intervention to obtain a better understanding of the target group's culture (Utz et al., 2008). Osborn et al., (2010) used focus groups to assess the barriers and facilitators of self-management behaviours to inform the messages of the intervention. In addition, focus groups were employed to develop recruitment strategies (Samuel-Hodge et al., 2009). Gucciardi et al., (2007) utilised the use of focus groups with participants to assess the cultural appropriateness of the intervention.

Brown et al., (2002) and Rosal et al., (2011) used literature reviews to identify the characteristics and needs of the target group. Teufel-Shone et al., (2005) and Vincent et al., (2008) relied on the knowledge and experience of the study investigators and

lay workers. One study used a community-based participatory approach to develop the intervention (Spencer et al., 2011).

#### 3.4.10 Goals

This dimension refers to the established goals between the patients and the deliverers of the intervention. It is essential that the values, customs and traditions of the target group inform the goals of the intervention (Bernal et al., 1995). Eight of the 10 studies addressed this dimension. For example, due to Teufel-Shone et al.'s (2005) awareness of the value of family in the participants' culture, they conducted their intervention at the participants' homes with the involvement of family members. They linked the goal of improving the participants' self-management behaviours to family cohesion, unity and resilience.

The goals of eight studies were established between the participants and the intervention deliverers (Anderson et al., 2005; Gucciardi et al., 2007; Utz et al., 2008; Osborn et al., 2010; Rosal et al., 2011; Spencer et al., 2011). The intervention deliverers of these interventions worked with participants to set goals and to develop the steps to achieve them. Samuel-Hodge et al., (2009) sent postcards with messages tailored to individual behavioural goals previously set by the participants.

### **3.5 Intervention Effectiveness on Diabetes Outcomes**

Most of the included studies assessed the efficacy of interventions on diabetes outcomes. The effectiveness of interventions was determined by evaluating the reported intervention outcomes. The outcomes varied across the studies; hence, they were categorised into clinical, behavioural and diabetes knowledge.

#### *3.5.1 Clinical Outcomes*

Glycaemic control was evaluated in the majority of the included studies (nine). Five of the nine studies reported a significant improvement in HbA1c (Brown et al., 2002; Gucciardi et al., 2007; Osborn et al., 2010; Rosal et al., 2011; Spencer et al., 2011), while three studies reported modest changes in HbA1c (Anderson et al., 2005; Utz et al., 2008; Samuel-Hodge et al., 2009).

Other clinical outcomes included BMI, blood pressure and lipids. One study reported a significant change in weight and BMI (Vincent et al., 2008). With respect to lipids, Brown et al., (2000) and Rosal et al., (2005) reported significant improvements. Blood pressure was significantly improved in one study (Osborn et al., 2010).

#### *3.5.2 Behavioural Outcomes*

The behavioural outcomes evaluated in the studies included dietary and exercise behaviours and glucose monitoring. The majority of studies evaluated dietary behaviours (six), such as adherence to a healthy diet, food label reading and reduced sweetened drink consumption. Four of these studies reported significant

improvements (Teufel-Shone et al., 2005; Utz et al., 2008; Osborn et al., 2010; Spencer et al., 2011).

Teufel-Shone et al.,(2005), Rosal et al.,(2011) and Spencer et al.,(2011) found a significant improvement in physical activity. Vincent et al.,(2008) reported a significant increase in the number of steps taken each day. Osborn et al.,(2010) found no significant effect on physical activity.

Blood glucose monitoring was evaluated in seven studies (Brown et al., 2000; Teufel-Shone et al., 2005; Utz et al., 2008; Vincent et al., 2008; Osborn et al., 2010; Rosal et al., 2011; Spencer et al., 2011), but only three studies showed a significant effect on blood glucose monitoring.

### 3.5.3 Diabetes-related Knowledge

Diabetes-related knowledge was evaluated in four studies (Teufel-Shone et al., 2005; Vincent et al., 2008; Osborn et al., 2010; Spencer et al., 2011), and all reported a significant increase.

## 3.6 Conclusion

The EVM was used as a framework to analyse culturally relevant diabetes self-management interventions and to report their efficacy on diabetes outcomes. Based on the inclusion criteria, 10 studies were included in this review. Language was the criterion most adhered to in all 10 studies. The ability to communicate with providers enhances patients' understanding and trust (Anderson et al., 2003).

Literacy must be considered as a component of language. Health literacy is defined as ‘the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions’ (Ratzan and Parker, 2000). Therefore, analysing literacy should extend beyond the reading level to the understanding necessary to adopt self-management behaviours.

The consideration of cultural similarities and differences between the participants and the providers was met by nine studies. It is important to involve providers who are familiar with the target group; however, they do not necessarily need to be of the same race or culture as the target group. Providers should understand the barriers patients encounter in adopting self-management behaviours. They should also have worked with patients similar to those targeted and should have an understanding of their cultural backgrounds.

Eight studies included theoretical models, which varied across the studies; however, it is interesting that the studies that addressed the concept dimension included behavioural change theories rather than cultural frameworks. This might be justified by the fact that the interventions were developed with the aim of changing behaviours. Surprisingly, none of the included studies used cultural models or frameworks in the development of the interventions. The use of such models could prevent developing interventions based on the assumptions and perceptions of intervention developers regarding how to make an intervention culturally relevant for the target group; however, the majority of studies (eight) were guided by formative research. The use of formative research has been identified as a fundamental element of intervention design (Needleman & Needleman, 1996; Resnicow et al., 1999)

Eight of the 10 studies incorporated content that reflected a knowledge of the culture and the uniqueness of the target group.

Cultural context was addressed in eight studies. The social, economic and political contexts of the target group should be considered across all phases of the development process, including planning and piloting, translating instruments, collecting data and interpreting the data (Bernal et al., 1995).

Eight studies set relevant intervention goals. This could be achieved either by asking participants at the development stage to state their overall goal for the intervention or by considering participants' goals individually and tailoring the steps to achieve these goals for each individual.

The use of metaphors was the least considered dimension. It was addressed in two of the 10 studies. Metaphors or concepts used by patients could be different from those used by healthcare professionals, which could lead to misunderstandings that affect the outcomes of the interventions. Metaphors may have been used in the interventions but were not explicitly discussed in the study reports.

Two of the 10 studies incorporated all eight dimensions of the EVM (Osborn et al., 2010; Utz et al., 2008) reported modest changes to HbA1c, and (Osborn et al., 2010) found a significant improvement in HbA1c and dietary self-management behaviours but not physical activity. On the other hand, although Brown *et al.*, (2002) and Spencer et al., (2011) reported significant results in all the evaluated outcomes, both studies incorporated five of the eight dimensions of the model. Therefore, it is not possible to



conclude that specific dimensions of the EVM predict the success of the intervention. In addition, the complexity of the interventions does not allow for such an inference.

#### *Efficacy of culturally relevant interventions on diabetes outcomes*

Although six studies showed significant differences in clinical or behavioural and knowledge-based outcomes, the study designs did not allow for determining whether the intervention was successful due to its cultural relevance or other aspects of the intervention. Thus, comparative trials are needed to determine whether culturally adapting an intervention alters diabetes outcomes.

### **3.7 Research Implications and Recommendations**

Based on the analysis of culturally relevant diabetes self-management interventions using the EVM, the following recommendations were developed:

- Published articles describing interventions often lack details regarding the content of the intervention. In this review, additional culturally relevant components and/or strategies might have been included but were not reported. This could be due to the limited manuscript space. Detailed intervention manuals could be provided with published articles as supplementary electronic files.
- This review does not suggest replacing the behavioural change theoretical frameworks with cultural models. They should be used in conjunction to ensure that cultural elements are addressed during intervention

development. The use of cultural models in intervention development may aid in developing interventions in an articulate and systematic way.

- Employing formative research is essential when developing interventions. Focus groups, literature searches and interviews can be used to identify aspects such as beliefs, opinions regarding the intervention and language use among participants, therefore informing intervention development and implementation. In addition, factors that influence the feasibility and efficacy of the intervention can be identified through formative research.

### **3.8 Limitations of this Review**

Studies that may have addressed cultural relevance without explicitly stating it in the study report were likely overlooked and not included in this review. The review did not include non-English studies. None of the studies were related to the Middle East.

### **3.9 Research Question**

*How can an existing self-management intervention be culturally adapted to the Saudi context?*

#### *3.9.1 Key aims and objectives:*

The study aim was to culturally adapt a diabetes self-management intervention for patients with type 2 diabetes treated at primary care centres in Saudi Arabia.

The following objectives allowed for achieving this aim:

1. Explore participants and health care professionals' perceptions and experiences on the cultural relevance of the programme
2. Incorporate participants and health care professionals' perceptions and experiences in the cultural adaptation of the programme

## Chapter 4: **METHODOLOGY**

### *A clinic-based ethnography*

#### **4.1 Overview**

In order to address this research questions, a qualitative approach was utilised and consisted of various qualitative methods. The study was conducted over a period of one year, taking place in the city of Dammam in Saudi Arabia. All data was subjected to a thematic analysis. A total of 39 participants took part in the study and they were recruited through convenience sampling. This chapter will describe the research process in detail in chronological order and reflect on my positionality as a researcher in the field.

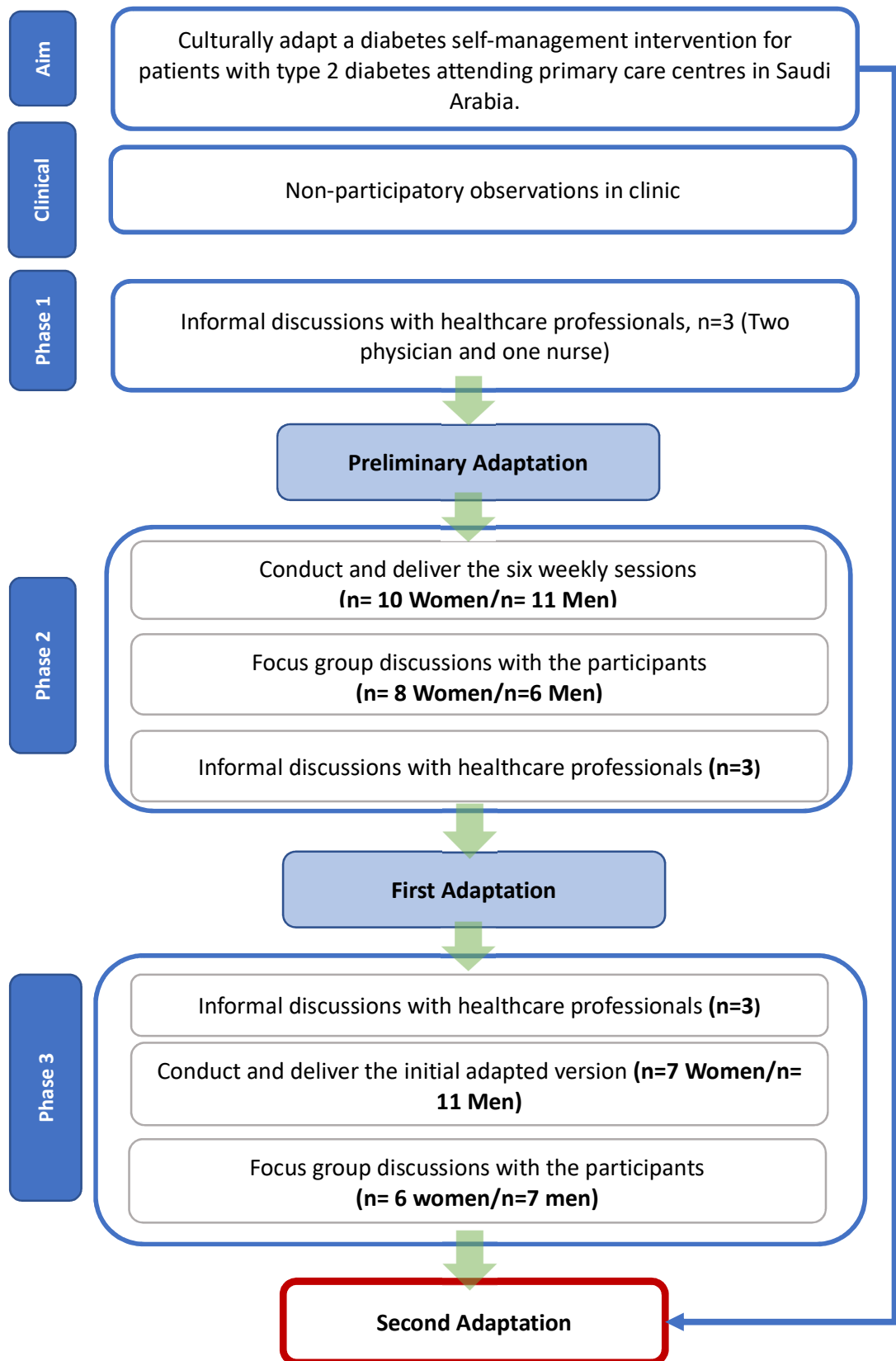


Figure 3 Study Methods Flowchart

## **4.2 Study Design**

The underpinning aim of this study was to culturally adapt a diabetes self-management programme for patients who are treated at primary health care centres in Saudi Arabia. For this reason, exploring participants' daily experiences with diabetes as well as their experiences during the sessions by employing a qualitative design is appropriate for this study. Denzin and Lincoln (2005) referred to a qualitative design as an inquiry that uses various methods to position the researcher in the world, hence making it visible. Qualitative methods consider the meaning of the world from the participants' viewpoints (Creswell, 2013) by exploring the nature of their experiences and what the experiences mean to them (Denzin & Lincoln, 2005). This design is suitable when the aim is to understand an issue within the context in which it occurs (Denzin & Lincoln, 2005). Utilising a qualitative design was suitable because this study aimed to understand the experiences of patients with type 2 diabetes related to self-management behaviours in their daily lives as well as their perspectives regarding the relevance of the programme's session elements. An ethnographic approach was utilised for this study.

Ethnography originated in the writings of anthropologists in the nineteenth century who travelled to observe other cultures (Silverman, 2011). It involves providing a descriptive account of people in their specific social context (Kleinman, 1992). It incorporates various qualitative data collection methods to produce a comprehensive account of people's social lives and cultures (Hammersley & Atkinson, 2010). Brewer (2000) defined ethnography as 'the study of people in naturally occurring setting or

“field” by methods of data collection which capture their social meanings and ordinary activities, involving the researcher participating directly in the setting, if not also the activities, in order to collect data in a systematic manner’. It examines a small number of people intensively rather than investigating a small number of variables with a large number of participants (Hammersley & Atkinson, 2010).

This study employed an iterative inductive deductive approach as well as a deductive approach using the EVM factors as a priori template during the coding process. This hybrid approach allowed for answering the research question by integrating the model factors as a process of the deductive thematic analysis while allowing for themes to emerge from the data using an iterative inductive approach.

An iterative process refers to utilising a ‘systematic, repetitive and recursive’ approach to a qualitative data analysis (Mills, Durepos, & Wiebe, 2010). Utilising an iterative approach implies carrying out tasks repeatedly in a similar manner. Cultural adaptation process frameworks also call for conducting an iteration between methods in order to achieve the adaptation (Castro et al., 2010; Wingood & DiClemente, 2008).

In this study, the elements that were in iterative interplay were; data collection, a preliminary analysis and further data collection (Mills et al., 2010). The iteration was performed by carrying out different data collection methods and analysing the emerging data to inform the adaptation of the programme. The same process was repeated again after delivering the adapted programme for further modifications. The Second Adaptation was not delivered or tested. Figure 3 Study Methods Flowchart) illustrates the sequence of the iterative process.

First the clinic context was explored through non-participatory observations of clinic consultations taking place at Al-Khaleej primary health care centre. The cultural adaptation process consisted of three phases. Phase 1 included informal meetings with a team of health care professionals to achieve a preliminary adaptation of the programme. Phase 2 included three components; delivery of sessions, FGDs and informal meetings with the health care professionals to achieve the first adaptation. Phase 3 involved an iteration of the second phase with different participants to achieve a second adaptation. The informal meetings that took place in this study were conducted with the same team of health care professionals. Participants, however, were different in each phase. Those who attended the sessions were invited to attend the subsequent FGD. Some of the participants who attended the sessions declined the invitation to attend the FGDs, hence, the number of participants who attended the sessions is different from that of the FGDs. (see Figure 3 Study Methods Flowchart)

### **4.3 Local Context**

The study took place in Dammam, the capital city of the Eastern Province Ash-Sharqiyah, the largest province in Saudi Arabia. In 1938, the first oil well in Saudi Arabia was discovered in Dammam. For this reason, many Saudis have migrated to this province from rural areas of the country. Dammam has a population of 1.5 million and has 5 main hospitals and 26 primary care centres (Alsaad, Abu-Grain, & El-Kheir, 2017). Patients are required to register at the centres covering the catchment area where they reside.



#### **4.4 Al-Khaleej Primary Care Centre**

Al-Khaleej primary care centre is located in the centre of Dammam. The centre offers services such as general practice services, a maternity and child health clinic, vaccinations, a basic laboratory and a chronic disease management clinic. The centre serves a population of approximately 5,000 people. Seven physicians, four men and three women, and 14 nurses work at the centre. A total of 2,763 patients with diabetes are registered at the centre, but they are not classified into types.

Although permission was granted to choose from multiple centres in Ash-Sharqiyah, this centre was chosen for the project because the medical manager of the centre is a friend who was highly enthusiastic about the study as well as a member of the advisory committee of this project. This allowed for gaining access to the centre quickly and establishing a supportive relationship with the working team. In addition, all staff members at this centre are Saudis, which allowed for the healthcare professionals to provide a better account of the adaptation of the programme due to their understanding of the Saudi culture.

#### **4.5 Population and sample**

The population of the study consisted of adult Saudi patients with type 2 diabetes at the Al-Khaleej primary healthcare centre in Dammam in the Eastern Province of Saudi Arabia. The centre is a public governmental centre operated by the GDHA through the MOH. To establish the context of the study, further information is provided in subsequent sections.

## **4.6 Inclusion and Exclusion Criteria**

Participants were included if they had been diagnosed with type 2 diabetes for a year or more. This allowed for patients to have lived with the condition and acknowledged the difficulties or lack thereof in dealing with the disease and undertaking self-care behaviours for a significant amount of time. Patients were included if they were 25-55 years of age. The reasons for choosing this age group are: a) according to the International Diabetes Federation, type 2 diabetes is usually diagnosed at age 40 and above, but in Saudi Arabia, type 2 diabetes is diagnosed at an earlier age (MOH, 2011) and b) this age group excludes issues due to old age (Suhl & Bonsignore, 2006). Only Saudi patients were included. Despite the cultural similarities between Saudis and other Arabs, there are differences in some aspects, such as traditional food and language dialects, and more importantly, the uniqueness of its culture, which makes culturally adapting the intervention relevant to all Arab groups a considerable challenge. The next chapter provides a description of the context in more detail. Patients were excluded if they had been diagnosed and/or were treated for any mental illnesses to ensure that they were competent to provide an informed consent for their participation and that a mental illness would not affect their choices while attending the sessions.

## **4.7 Sampling and Sample Size**

A convenience sampling approach was used to sample patients attending the chronic care clinic in the centre. Convenience sampling is referred to as ‘Opportunity

sampling' (Dörnyei, 2007). In convenience sampling, members of the target population are selected for a study, if they meet specific criteria, based on how easily accessible and readily available participants are (Salkind, 2010).

Dörnyei (2007) argues that although convenience sampling is characterised by easily accessing participants, it is also somewhat purposeful as the participants must meet specific criteria in order to participate in a study. (see 4.6 Inclusion and Exclusion Criteria)

The advantage of this sampling strategy is that it usually yields in participants who are willing to participate, which could be viewed as a prerequisite to producing rich data (Dörnyei, 2007). Moreover, its practicality especially in circumstances where time and financial constraints exist (Dörnyei, 2007) is of advantage in this study.

In the researcher's experience, the population seeking care in primary care centres is less affluent and less educated. Those who are affluent do not usually seek medical advice from the government sector due to their perception that the quality of services is poor. Moreover, the MOH recently implemented a compulsory employment insurance-based scheme for all expatriates and for all those working in the private sector (Saudis and non-Saudis) to minimise the healthcare expenses of the government, which has been providing free healthcare. Therefore, those with higher education and better jobs now seek medical care through the private sector, and it is reasonable to assume that the population visiting primary care centres are more or less a homogenous group in terms of their socio-economic status. Unfortunately, no data were found to support this claim.

The programme sessions were delivered to men and women separately. Gender was found to influence self-management behaviours among patients with type 2 diabetes (Chlebowy, Hood, & LaJoie, 2013). Within the Saudi context in particular, gender differences might be more apparent. For example, facilities where women can practice physical exercise are nearly non-existent. Women are also discouraged from undertaking outdoor physical activities due to social norms. In addition, most men are completely dependent on female family members with regards to food preparation; therefore, it could be difficult for them to adhere to dietary recommendations once they are diagnosed with diabetes, especially if no education was provided to the person responsible for preparing meals for the household. For most, it is considered culturally inappropriate for both genders to be mixed in a confined place, let alone participate in a discussion.

As recommended by Stanford University, the sessions ideally involve 12-16 participants. Therefore, a sample size of 24-32 women and men in total was required.

#### **4.8 Recruitment and Response Rate**

Prior to actually inviting the patients to the sessions, it was important to determine whether they were interested and whether changes were needed for the recruitment process. Personal face-to-face communication is considered a more respectable way to communicate in the Saudi culture. Therefore, patients are more likely to participate if they are invited verbally rather than through a written invitation. I approached prospective patients directly while they were in the chronic disease clinic's waiting room. The inclusion and exclusion criteria of participation were discussed with the

nurse attending the clinic. After patient registration, patients would wait in the waiting room. When the patient's file reached the clinic from the filing room, the nurse checked whether the inclusion criteria applied to the patient. The nurse informed me of the patients' names, and I approached them while they were waiting to be called to see the specialist. As mentioned, patients were approached directly in the chronic disease clinic. This approach had a disadvantage because it was inevitable that the opportunity to recruit some patients would be missed, especially during busy periods.

A total of 111 patients were approached in the clinic's waiting room, which amounted to 39 and 40 in each recruitment period, respectively. As mentioned, 24-32 participants were needed for the sessions; however, it is recommended to overrecruit by approximately 25% (Green & Thorogood, 2009) because not everyone will be able to follow through with the commitment and there can be dropouts during the programme. Therefore, more participants were recruited (n=32-40). A total of 20 women and 19 men were recruited for the first set of sessions, and 20 women and 20 men were recruited for the second. The chronic disease clinic was only run three days a week, so recruitment was done on these days and was completed in two weeks for the first set of sessions. It took four weeks to recruit for the second set of sessions because it was the end of Ramadan and the Eid holiday, so the number of patients visiting the clinic was lower than usual. Recruiting in the holiday period was not intentional. Due to logistic and sponsorship issues, it was not possible to extend the duration of the fieldwork and postpone recruitment till after the holiday period.

It was incredibly surprising to both the healthcare professionals and the researcher that the recruitment process went smoothly and that several of those approached agreed to attend. Some wanted to invite their friends to the sessions. There was a concern that the patients were being polite or that they might have thought they would get better care if they agreed to participate since they were approached before they were seen by the chronic disease specialist. Therefore, I began to approach the patients after being seen by the specialist and approached some after they had collected their medication from the pharmacy. I was met with the same reaction from the patients; however, I was still doubtful that they would attend and believed that their reactions were based on respect for me as a physician and a researcher.

Verbal consent was initially obtained from the participants. A translated information sheet (Appendix 4) explaining the study and containing my contact details was then provided and discussed with the patients. Patients were given an ample amount of time to read the information sheet and to ask questions if needed, either personally in the centre or later via phone. The information sheet was also read and explained to some patients who had difficulties reading.

#### **4.9 The Stanford Chronic Disease Self-Management Programme**

The Chronic Disease Self-Management Programme was developed by Lorig, Gonzalez and Laurent while working in the Division of Family and Community Medicine in the Department of Medicine at the University of Stanford (Kate R. Lorig

& Holman, 2003). The programme's concept was based on the investigator's experience with self-efficacy. The content of the programme was based on the results of conducting focus groups with people with various chronic disease conditions, such as arthritis, heart disease, hypertension and diabetes. The programme was conceptually founded on the self-efficacy construct of the Social Learning Theory by Bandura (Bandura, 2004). This theory emphasises self-efficacy as an influential factor on behaviour. Self-efficacy is described as the individual's belief in his or her capability to perform a certain behaviour in a specific situation (Bandura, 2004). Therefore, the stronger the perception of the ability to perform a task, the more likely the person will be to accomplish the task. Moreover, the theory incorporates perceived facilitators and barriers that influence behavioural goals.

#### **4.10 Licensing and Training**

It is compulsory to obtain a license as well as training through Stanford University to implement the Chronic Disease Self-Management Programme. Licenses can either be a single programme license with which only one programme, such as the Chronic Disease Self-Management Programme, is implemented at a centre, or a multiple programme license with which more than one programme is offered, such as the Chronic Disease Self-Management Programme along with the DSMP. For this project, a single programme license was obtained to deliver the DSMP. I personally attended the training. It was difficult for my scholarship sponsor to sponsor someone else; such as a health professional to obtain the training.

The programme has a trainer system. Trainees can be leaders, master trainers or T-trainers. Leaders are trained to facilitate workshops in community centres for people with chronic diseases. Master trainers can facilitate workshops as well as train leaders. T-trainers can perform master trainers' tasks as well as train master trainers. The training is ordinarily provided to become master leaders; however, when completing the training successfully, trainees are initially leaders. Leaders can only be master trainers after facilitating two or more full workshops.

Training for the Chronic Disease Self-Management Programme took place at Stanford University in Palo Alto, California, in October 2014 for four and a half days. It was conducted by two certified T-trainers and involved workshops and training activities. The workshop activities are similar to those offered to participants with chronic diseases. Trainees pretended to be someone with a chronic disease attending the programme's workshop. On the other hand, the training activities involved discussing training-related issues, such as making decisions regarding who to recommend as leaders and implementation and administrative-related matters. Assuming both roles recurrently throughout training was initially confusing. To avoid confusion, the T-trainers wore hats when performing the workshop activities and removed them during the training activities. The training was interactive, and trainees were expected to actively participate during all activities. During the activities, all trainees had to assume the role of a patient with a chronic disease or use their own experience with a chronic disease if they were affected by one. The workshops were also overwhelming in terms of the information received, the time required to attend the sessions, the need to prepare homework in the evenings, the need to practice teaching and the need to



perform in front of the trainers and the other trainees. Each trainee was required to facilitate two group teaching sessions and were evaluated by the T-trainers. Trainees may not be considered for certification if a full understanding of the programme and required skills are not demonstrated successfully.

On the third day of training, a session for questions was scheduled with Dr Kate Lorig, the Director of the Stanford Patient Education Research Centre, and one of the programme developers. I was fortunate to have the opportunity to discuss my PhD project with her. She was highly enthusiastic about the study and recommended obtaining a research licence rather than a regular license to implement the programme in Saudi Arabia. The research license is free of charge. I was required to send my study proposal and to sign a research license agreement (Appendix 22).

I also met Professor Fusae Abbott in San Francisco during training for the Chronic Disease Self-Management Programme at Stanford University in California. She was accompanying two trainees from Japan. Abbot is of Japanese origin but has been living and working in the US for several years. She has been a director of a non-profit organisation in Japan called the Japan Chronic Disease Self-Management Association since 2005. I wanted to learn from her experience in adapting programmes to be more relevant to the Japanese culture, especially since the Saudi and Japanese cultures are relatively similar in many aspects, such as gender roles, social norms, hierarchy and collectivism. I sought to arrange a meeting with her via Skype, and she kindly agreed to share her experiences with me.

The Japan Chronic Disease Self-Management Association began conducting Stanford's CDSMP after Abbot translated the English manual in 2006. They were concerned that the programme would not be effective because it is interactive, and patients in Japan are shy and might not interact well during the sessions. Moreover, they were concerned that due to the hierarchy between health professionals and patients, patients would not be able to be expressive during the sessions. After offering a few sets of sessions as per the manual, they sought feedback from the participants and the trainers on the aspects of the programme that should be adapted to make the programme more relevant and therefore more beneficial in the Japanese context. It was difficult for them to receive funding to conduct a research study, so they considered taking a pragmatic approach. Professor Abbott began to meet with the trainers via skype to obtain feedback and to brainstorm ideas. The main lesson learned from Professor Fusae's experience is to never make assumptions regarding what is or is not acceptable to a cultural group.

The programme was designed on the basis that patients with chronic diseases have similar concerns and problems and should possess similar skills to manage their disease; however, although the Chronic Disease Self-Management Programme is the core programme, Stanford has designed three other programmes specific to those with diabetes, cancer and HIV. These programmes share the same components with the Chronic Disease Self-Management Programme. They all focus on coping strategies through action planning, problem solving and decision making. Moreover, in all the programmes, patients are taught to control their symptoms through healthy eating, relaxation techniques, medication management, exercise and communicating with

healthcare providers, which are applicable to all chronic diseases; however, some chronic diseases require additional skills, such as chronic pain, HIV and cancer. Therefore, Stanford designed other programmes that include topics that are specific to these diseases. For example, the Positive Self-Management Programme for HIV includes additional activities, such as making treatment decisions and dealing with sex, intimacy and disclosure.

It is compulsory to obtain training for the CDSMP before training for any of the other programmes. Cross-training for the DSMP is web-based. I obtained the cross-training certificate in November 2014. Completing exercises by watching videos and reading manuals and then submitting them to the trainers were requirements prior to attending the webinar. I attended the webinar with 13 other participants, and it lasted approximately three hours. It was facilitated by T-trainers.

#### **4.11 The Diabetes Self-Management Programme (DSMP)**

As mentioned, due to the differences between diabetes and other chronic diseases, Stanford decided to design a programme specific to those with diabetes. The Diabetes Self-Management Programme includes additional activities, such as monitoring blood glucose levels, preventing hyperglycaemia and hypoglycaemia, formulating a healthy eating plan and delaying and preventing diabetes complications. A table provided in Appendix 19 compares the CDSMP and the DSMP.

The DSMP has the same format as the CDSMP. They both include six 2.5-hour weekly sessions.

While discussing the study with Dr Kate Lorig, she mentioned that it is advisable to initially deliver the programme with its original content and to only change the external factors. This is also supported by Chen et al., (2013), where they recommend that the new target group is introduced to the full original programme prior to adaptation.

#### **4.12 Delivering the intervention**

As mentioned, the DSMP involves six 2.5-hour weekly sessions. The following description is a description of the programme exactly as it appears in the manual. It was initially delivered without any changes due to the advice given by the programme developer, Dr Kate Lorig.

Following discussions with the healthcare professionals, it was decided that the sessions would be conducted outside of the primary care centre. As community centres are not common in Saudi Arabia and most do not allow women, the sessions were conducted in a large mosque in the same catchment area as the primary health care centre. A room was booked in the neighbourhood mosque near the centre. Mosques are generally only used for religion-related lectures; however, the same mosque had recently been used for social activities as well as a lecture that encourages screening for colon cancer. The sessions were conducted separately for men and women on different days of the week.

There are activities that are repeated in most sessions. For example, starting from the second session, all sessions begin with feedback related to action plans developed the

previous week and problem solving for unaccomplished action plans. Moreover, at each session, there are one or more brainstorming activities. This involves asking a question and asking the participants to provide answers. The answers are not corrected or discussed by the facilitators during the brainstorming activity. Participants are asked to provide short answers and not to tell stories about their experiences on the subject discussed. They are also asked to respect others and not comment on the answers either positively or negatively. The answers participants provide are written on the board. At the end of the brainstorming activity, the answers are discussed, corrected if incorrect and more points are added if not mentioned during the activity (Appendix 13) provides A description of session delivery (pre-adaptation). Charts that are used during the delivery of the programme can be viewed in (Appendix 21).

#### **4.13 Focus Group Discussions (FGDs)**

Quantitative methods, such as surveys and questionnaires, use ‘pre-defined’ opinions, whereas qualitative methods allow for exploring a wider range of points of view and producing more ideas. Hence, using qualitative methods in this study was the most appropriate method to elicit participants’ opinions regarding the cultural adaptation of an intervention.

FGDs have been used as a preliminary step to inform the development or adaptation of health promotion preventative interventions (Vincent et al., 2004; Rosal et al., 2006). During this study, FGDs explored the perception of participants regarding how to best adapt the intervention to meet their specific needs. Core elements of the intervention, such as the number of sessions, teaching method and format (group vs.

individual), cannot be changed to avoid impacting the effectiveness of the intervention. Therefore, patients were asked about their preferences regarding elements such as persons delivering the intervention (lay workers vs. health professionals), materials used and duration between sessions. For example, participants might lose interest in the programme if there is one week between sessions, as per the programme's recommendations. Therefore, FGDs allowed for utilising effective communication strategies to aid in the adaptation of the intervention. FGDs are also the most appropriate method to use, especially in this context, for the following reasons:

- The group dynamic could generate ideas that cannot be generated by other methods (Rabiee, 2004)
- FGD interactions could also help to understand patients' own metaphors and vocabulary (linguistics), which is useful when adapting the sessions of the programme. In my experience as a clinician, patients often use a different vocabulary than that of clinicians, such as 'glucometer'.
- If, for example, one-on-one interviews are conducted, a power differential could exist between the participant and the researcher. Group interactions could prevent the hierarchy between the researcher and the participants and consequently motivate participants and empower them to give their opinion rather than feeling anxious and uncomfortable when speaking with an interviewer.

- One-on-one interviews have more potential to lead to interviewer or social desirability bias than focus groups; however, during FGDs, participants might not discuss their own views and might provide accounts that are consistent with social standards. Therefore, to activate an informal conversation, it might be worthwhile to make it clear to participants (patients specifically) that they are not tested on their knowledge.

A topic guides was developed to guide the discussions for both the patient and health professional groups. The guides were developed based on SDSMP session topics and were informed by the EVM. The guides were translated to Arabic and translated back to English by someone else to ensure the accuracy of the translation. See Appendix 1 for the Topic guide for FGDs.

FGDs were conducted at the end of the sessions, specifically on the day of the last session, with one group for men and another one for women.

#### *4.13.1 Data Collection*

Once the patients agreed to participate, their background and demographic data, such as age, gender, education level and occupation, were collected using a questionnaire. Verbal and written consent (Appendix 2 and Appendix 3) was obtained initially prior to completing the questionnaires. Saudi patients are not accustomed to completing questionnaires without assistance or returning completed questionnaires by post, so I assisted those who agreed to participate when completing the questionnaires.

## **4.14 Delivery of the sessions**

I was the only one able to facilitate the sessions as I underwent the training in Stanford.

A description of the delivery of sessions is provided in (Appendix 13).

### *4.14.1 Informal Discussions with Health Professionals*

Informal meetings were conducted with health professionals who worked in the centre, which included three female physicians, two male physicians and four nurses. The aim of these discussions was to elicit the opinions of the health professionals regarding the programme and the adaptations that should be made to make it more relevant and acceptable to Saudi patients. All the professionals were approached personally. These discussions took place in a meeting room in the primary care centre.

## **4.15 Transcribing and Translation of Field Notes and Audio**

### **Recorded Data**

All the FGDs were digitally recorded and transcribed verbatim in Arabic and then translated to English. As a discourse or conversation analysis was not intended, no attention was paid to features of speech, such as pauses and interruptions.

## **4.16 Theoretical Approach**

Behaviour change is a central aspect of self-management (Newman et al., 2009). Theories of behaviour change have been used in self-management interventions to enhance patients' capacities to manage their illnesses. Theory-based interventions



have been found to be more effective in yielding behaviour changes than those developed on a pragmatic basis (N. Elder, Ricer, & Tobias, 2006). The use of theories assists in identifying the variables that require modification to facilitate behaviour changes.

The notion of 'health behaviours' stems from psychology and could be defined as the actions adopted by an individual that are linked to developing and/or preventing a health condition (Holman & Borgstrom, 2016). There is an assumed association between health behaviours and health outcomes in which outcomes are improved by altering or eliminating these behaviours. For diabetes, health behaviours are categorised into diet, physical exercise, blood glucose monitoring and adherence to medication. Health behaviours are often considered to be solely the individual's responsibility, and the ways an individual articulates these behaviours across gender, culture and place are often overlooked. Hence, considering context is essential.

Different theoretical approaches have been used in the development of self-management interventions for different diseases, such as the Health Belief Model and the Social Learning Theory; however, the most commonly used theory is the Social Cognitive Theory developed by Bandura (2004). This theory emphasises self-efficacy as an influencing factor on behaviour. Self-efficacy is described as the individual's belief in his or her capability to perform certain behaviours in a specific situation (Bandura, 2004). Therefore, the stronger the perception of the ability to perform a task, the more likely the person will be to accomplish the task.

Based on the studies in the literature, it is difficult to pinpoint which stage of an intervention is informed by these theories or how it is explicitly operationalised (put into practice). The use of bio-medical models appears to be predominant when informing the conceptualisation of disease self-management (Newman et al., 2009). Moreover, these theories have been criticised for only focusing on the individual's autonomy and cognitive functions related to behavioural changes, neglecting the impact of the socio-cultural context (Holman & Borgstrom, 2016).

Holman and Borgstrom (2016) argued that due to the complexity of 'health behaviours', using social theories to understand such behaviours can help identify the interactions between psychological and social factors. They asserted that it is not only important to focus on the individual's cognitive aspects of performing a behaviour but also to locate these aspects within the social context. Moreover, by understanding the meanings of these behaviours, the roles they play for individuals and how these behaviours are influenced by an individual's situations and circumstances, the knowledge obtained can be utilised to develop relevant interventions and clinical programmes (Holman & Borgstrom, 2016).

If taken into account during intervention development or adaptation, understanding and highlighting the socio-cultural aspects of behaviours could potentially lead to a more relevant and effective intervention. Therefore, a sociological perspective drawn from symbolic interactionism as a theoretical framework was adopted for this study.

#### **4.17 Symbolic Interactionism**

Symbolic interactionism was developed based on the ideas of the American philosopher George Mead (1863-1931). The theory is influenced by psychological behaviourism and was adopted from the themes of the pragmatist theory, which include the focus on the interaction between actors and the social world, viewing these interactions as a dynamic process, and the centrality of the ability of actors to interpret the social world (Mik-Meyer & Obling, 2012). Mead's ideas were further developed by Herbert Blumer (1969), who formulated the theory itself.

Blumer's interpretation of Symbolic Interactionism (SI) was applied, and in the next subsection, the reason that SI is a suitable theoretical framework for this study is explained.

According to Blumer, SI has three basic principles: 1) people act towards things according to the meanings they attach to them; 2) meanings and symbols are learned and attached to things or situations through social interactions; and 3) the meanings and symbols used in interactions can be altered and modified through an interpretive process used by individuals when dealing with things they encounter depending on the situations they engage in.

This interactive meaning-making process forms individuals' identities through how they view the world as well as their subjective position (Holman & Borgstrom, 2016). Hence, behaviours are considered to be a social performance that is associated with social roles, leading to the construction of a social identity. Roles are an essential

aspect of a person's identity, and they shape people's responses during social interactions (Holman & Borgstrom, 2016).

It is acknowledged that through social interactions, rationales for behaviours are developed (R. S. Barbour, 2007). Situating diabetes self-management within this theory indicates that the act of managing diabetes is aligned with the meaning patients hold for diabetes, and these meanings arise from their interactions with their sociocultural groups. Therefore, patients would take advice regarding self-management into account; however, self-management requires agency and is an individual process that can only be undertaken depending on the individual's own interpretation of his or her condition.

SI is relatively less utilised in health research compared to the grounded theory or ethnomethodology (Denzin, 2007). Nonetheless, it is of particular interest for chronic disease self-management because it indicates that knowledge construction is a result of social interactions between individuals, and it also emphasises individuals as key agents for change.

It is important to closely observe Saudi patients with diabetes to identify the meanings they assign to their actions regarding managing their condition and how they define their situation. Based on Blumer's three main principles of SI mentioned previously, he argued that a qualitative methodology is the only way to understand how people understand and interpret the world (Liamputtong, 2011). Therefore, SI influenced the methodology utilised in this study. Utilising ethnographic methods, including clinic observations and focus group discussions, provides an opportunity that places people

in a social setting in which such interactions can be observed. These methods also allow for the generation of data that can be analysed through the symbolic interaction lens (Barbour, 2007). Furthermore, the non-participatory observation that took place in the chronic disease clinic and the participatory observations conducted during the sessions of the programme allowed for describing and explaining the meanings and social symbols of managing diabetes from the participants own sociocultural perspectives.

#### **4.18 Clinic Observations**

According to Gray (2004), ‘observation involves the systematic viewing of people’s actions and the recording, analysis and interpretation of their behaviour’. Overt observations occur when those being observed are aware of the presence of the observer (Gray, 2004). Although participant observations have more merits than non-participant observations, they were not possible in this study.

Observations of patients in a clinic might not be the same as observing them at home when undertaking self-management behaviours; however, because the aim of this study was to adapt an intervention, it was useful to observe patients’ experiences and how they interacted with healthcare providers to identify aspects that could inform the adaptation of the programme. This type of observation is likely to be influenced by the researcher’s preconceptions, which could lead to overlooking some aspects that could be important (Gray, 2004). Moreover, conducting an overt observation could influence occurring events (Gray, 2004). For these reasons, an account of reflexivity

is provided at the end of the chapter to discuss some of the issues that may have influenced this research study.

#### **4.19 Field Notes**

Field notes are considered a mainstay of collecting and analysing data from observations (Gray, 2004). It is recommended that researchers pay considerable attention to detail and record the notes as soon as possible (Hammersley & Atkinson, 2010). It is optimal for the notes to be taken while the observations take place; however, it is not always possible (Hammersley & Atkinson, 2010). Fortunately, the clinical setting context allowed for following these recommendations. Those who agreed to allow the researcher to attend their clinic consultations and to be observed were informed of the rationale of the observations, but they did not consider the request to be particularly unusual because the centre frequently accommodates medical students and interns by allowing them to attend clinic consultations alongside the treating physician to observe and to take notes. Hence, writing notes was an unexceptional activity in the clinic, which allowed for overtly taking notes in a small notebook during the actual observations. Notes were also made at the end of each session because it was not possible to do so during the session as it was not possible to do so while delivering the session. Gray's (2004) recommendations were applied during the data collection process, which are as follows:

- *'Primary observation'*: making notes of what is being observed without explanation or analysis, such as the surroundings, the people, their behaviours and their conversations. The notes are labelled according to

date and time. Quotations are used to differentiate between quotes and general conversations.

- *'Reflection and recall'*: On break times or at the end of each day, read the notes to add any aspects recalled that were not written down as well as reflections on the observations.
- *'Pre-analysis: ideas and inferences'*: Add a margin to the field notes to add any insights and themes that began to emerge while taking notes.
- *'Experiential data: impressions and personal feelings'*: Add extensive impressions and feelings and interpretations of the researcher's reactions to events, people and conversations, which can be a source of analytical insights.
- *'Forward planning'*: Take notes regarding aspects that might have been missed to revisit them when conducting subsequent field work.

In addition to notes, photos of the city, the neighbourhood where the centre is located, and the centre were taken when allowed to add them to the diary.

The initial field notes contained:

- Important words and phrases as well as some verbatim quotations

- Details of the personal characteristics and some aspects of the physical appearance of individuals present in the observed events, such as gender, attire and age
- Details of conversation features, such as who dominated or interrupted a conversation and tones of the conversation (polite, hostile or formal)
- The use of pseudonyms to maintain the confidentiality of those observed
- The researcher's impressions and feelings during the observations

#### **4.20 Ethics**

##### *Informed consent and ethical considerations*

During the observations of the patients' clinic visits, consent was obtained from the attending doctor, the nurse and the attending patient. I assumed the responsibility instead of the nurse of calling the patients from the waiting room when it was their turn and introduced myself as a doctor and a researcher. I then asked whether they would allow me to attend their consultations with them. In other instances, the attending physician would ask the patients for their permission for me to attend. None of the patients refused. I also emphasised to the attending physician and nurse that I was not attending to criticise or evaluate the way they managed patients or their medical discretion and judgment; however, it is possible that they behaved differently both consciously and unconsciously. I established rapport with the physicians and



nurses in the centre prior to data collection, and with time, I was treated as their colleague.

Although I was open about my presence as a researcher, I did not explain the reason for my attendance to the patients in the clinic in great detail. I eventually realised that some patients thought that I was a doctor in training because they said a short prayer to wish me well in my training when leaving the clinic.

It is often acceptable in ethnography not to share 'everything' about the research with the participants (Hammersley & Atkinson, 2010) It could be considered intrusive, considering that not all those participating are interested in the research (Hammersley and Atkinson, 2007). It could also have an effect on the behaviours of those observed, which could invalidate the research results (Hammersley and Atkinson, 2007). For example, participants might respond differently when the doctor or nurse asks them questions related to the management of their diabetes if they are informed in detail that the research specifically focuses on diabetes self-management.

This was only applicable to those observed during their clinic visits; it was not applicable to those who attended the sessions. Those who were approached to participate in the programme were provided with detailed information about the study to ensure that they made an informed decision before committing to attend (information sheet in Appendix 4).

Providing incentives for participation is considered inappropriate in the Saudi context. Therefore, patients were told that they would be reimbursed for transportation and that refreshments and healthy snacks would be provided at each session.

To comply with Saudi social customs, genders were segregated when conducting the focus groups and delivering the programme sessions. More details about gender segregation in the Saudi context are provided in the following chapter.

#### **4.21 Gatekeepers**

Gatekeepers are those whose official permission is sought to gain access to a setting (Hammersley and Atkinson, 2007) to ensure that vulnerable populations, such as patients, are protected and to guarantee that researchers abide by ethical regulations.

Although Saudi governmental organisations are mostly bureaucratic, how to obtain permission and who grants permission were not discernible. There were no directions on the MOH's website regarding the requirements to obtain permission or approval to conduct research studies. My attempts to contact the research department of the MOH as well as the GDHA in the Eastern Province by telephone and email before conducting research in the field failed. This is somewhat expected, especially from governmental bodies in Saudi Arabia.

The largest concern was that this process would take longer than anticipated. It is always preferable to visit a research location in person. As soon as I arrived in the country, I visited the GDHA in the Eastern Province. It was initially difficult to identify the office that I should visit. Introducing myself as a physician and a current

doctorate student studying in the UK encouraged whomever I approached for help. I was directed to the Department of Planning and Training and discussed my project with the deputy of the department. It seemed that he was not familiar with research studies that are not sponsored by and proposed within the MOH. As my study was sponsored and funded by The Ministry of Higher Education, it was not clear which steps should be taken to obtain permission to conduct the research study. I was advised to meet the President of the Research Studies Committee, who was located in the Maternity and Children Hospital in the same city of Dammam. I received conflicting information regarding who to approach and the time the process of obtaining permission could take. I visited the GDHA and the maternity hospital several times to identify the correct source for obtaining permission and approval. I was finally able to obtain permission after submitting a proposal of my research project and a supporting letter from my sponsors (UKSACB and LSHTM) to the GDHA, which was then submitted to the Committee of Research Studies. I received permission to conduct my study in two weeks (Appendix 7Appendix 8Appendix 9Appendix 10).

Ethical approval was also sought from the London School of Hygiene and Tropical Medicine (LSHTM) (Appendix 5). Due to the interventional nature of the study, the study proposal had to be assessed, reviewed and registered by the Clinical Trials Subcommittee of LSHTM. Although this study is an intervention study, it is not considered a clinical trial and does not fall under any of the clinical trial phases (I – III). Clinical trials are defined as ‘any research study that prospectively assigns human participants or groups of humans to one or more health-related interventions to evaluate the effects on health outcomes’ (WHO, 2014). Their aim is to evaluate the

safety, effectiveness and efficacy of an intervention or to test a hypothesis regarding a specific outcome. This study did not test a hypothesis, and outcomes on health were not evaluated. Therefore, the registration of this study as a clinical trial was not necessary; however, as an intervention study, it is compulsory under LSHTM's ethics regulations to register such a study for insurance. Therefore, this study was covered by Negligent Harm Insurance and Professional Harm Insurance.

#### **4.22 Harm**

It was not anticipated for the study to pose any risk to participants in terms of harm; however, sharing experiences in group settings could cause discomfort or distress. To avoid this, participants were reminded to respect the confidentiality of other group members. Participants were also reminded that they could choose not to answer questions if they felt uncomfortable and could withdraw at any time during the study. Moreover, they were assured that audio tapes would be stored in a private place and would be destroyed as soon as the study concluded. Written consent was obtained from each participant in the study. No adverse events occurred during the study. During the initial sessions, the participants seemed to be somewhat anxious. This could be because they felt that they were evaluated or judged. Another reason could be that the participants were not accustomed to interacting, discussing their personal information or sharing details of their daily lives with strangers in a group setting. I sought to establish trust and rapport with the participants to reduce the impacts of these effects.

### **4.23 Access**

After obtaining the official documents to conduct field work, the field work began at the centre. Gaining access was somewhat easy because I had networking connections who worked at the centre. Most employees in the centre were not familiar with the research methods I used, particularly in a primary care setting. It was surprising to the staff that I had no questionnaires or surveys to be completed.

My presence was welcomed by the healthcare professionals and patients. Being a physician had undeniably facilitated the process of gaining access to the centre; however, being introduced to the centre's team by the medical manager of the centre, who is a member of the project's advisory committee (Dr Karimah Alsaihati), made me more accepted as an outsider. I was given access to all the areas of the centre and permission to speak to all staff and patients at any time during operation hours without a limited time frame.

### **4.24 Data Processing**

This study primarily drew from data collected from patients and healthcare professionals as well as observations of patient consultations in the chronic care clinic and the DSMP sessions to inform the adaptation of the programme. As mentioned, an inductive iterative approach was utilised; hence, the data collected were analysed throughout the study. Moreover, an additional analysis took place after field work and while drafting the thesis. The following sections provide a comprehensive description of the management, analysis and interpretation of the data.

#### 4.24.1 Data Management

Textual and audio data were generated by the various data collection methods utilised during this study. The textual data included: 1) field notes of the clinical observations, 2) notes from informal meetings with healthcare professionals, 3) field notes from the sessions, and 4) transcripts from four FGDs. The audio data consisted of: 1) recordings of some informal meetings with healthcare professionals and 2) recordings of four FGDs with patients with type 2 diabetes.

Table 2 demonstrates the types of the collected raw data and their sources.

	<b>Types of Raw Data</b>				
<b>Source</b>	<b>Audio</b>	<b>Textual</b>			
	<i>Recordings</i>	<i>Clinic observation notes</i>	<i>Informal meetings notes</i>	<i>Notes from sessions</i>	<i>FGDs transcripts</i>
<b>Healthcare professionals</b>		✓	✓		
<b>Patients</b>	✓	✓		✓	✓

**Table 2 Types of raw data and their data sources**

#### 4.24.2 Data Analysis

Due to the iterative approach undertaken for this study, themes that emerged from the data were noted and tabulated in a Word document. Noting the initial emerging broad themes allowed for further exploring the themes in the subsequent FGDs, and more

importantly, discussing them with healthcare professionals to inform the First Adaptation of the programme.

A thematic analysis was utilised to analyse the data. This approach analyses the content of the data by producing overarching themes based on the simplification of complex narratives (Green and Thorogood, 2009). It recognises patterns within the data where themes emerge, which become the categories to be analysed (Fereday & Muir-Cochrane, 2006). A thematic analysis aims to provide knowledge and understanding regarding a particular phenomenon (Mills et al., 2010). Therefore, utilising the thematic analysis approach is suitable for understanding the participants' current self-management behaviours to inform the adaptation of the programme, hence achieving the principle aim of this study.

The following steps describe the stages of the analysis process utilised for this study. These steps are influenced by Braun and Clarke's phases of thematic analysis (2006).

1. Familiarisation with the data and broad coding:

To become familiar with the data, I immersed myself in the data by listening and re-listening to the audio recordings of the FGDs and the informal meetings with the healthcare professionals. Moreover, I read and re-read the field notes and translated transcripts. I generated broad codes and added notes and reflections to the transcripts and the field notes. I also labelled key quotations to aid in the following steps.

## 2. Organising and tabulating data according to broad codes:

Coding is a process of labelling, compiling and organising data (Green & Thorogood, 2009). Hence, to attain an overview of the multiple data sources in this step, I summarised and organised the transcripts of the FGDs, the transcripts and the notes from the informal meetings with healthcare professionals and the field notes. I achieved this by creating an Excel spreadsheet in which segments of data extracted from the transcripts were indexed under each broad code created in the previous step.

## 3. Distillation of data for each code:

The One Sheet of Paper (OSOP) approach developed by the Health Experience Research Group (HERG) at the University of Oxford (Ziebland & McPherson, 2006) was used to distil data from the broad codes. The aim of the OSOP is to ‘find a story’ in each code and develop an explanation of ‘what is going on in the data’ and to take into account not just the most common but all the issues raised (Ziebland & McPherson, 2006). I developed a handwritten OSOP for each code on A1 sized papers. I read through all the extracted data for each code from the Excel spreadsheets developed in the previous step, and then for the OSOP, I noted all the different issues raised within the code and included the participants’ pseudonyms.

## 4. Active coding process

This step involves further coding the textual data of each code. The codes and analyses were handwritten on the OSPOs created in the previous step. This process allowed for further data extraction and reducing the data to more focused information. During this



process of coding, the aim was to view the data critically to identify non-literal meanings of the data, such as social and gender norms, subject positions and the patient–doctor power dynamic. A complete OSOP provided a summary of all the issues within a code and the participants’ IDs (Ziebland & McPherson, 2006).

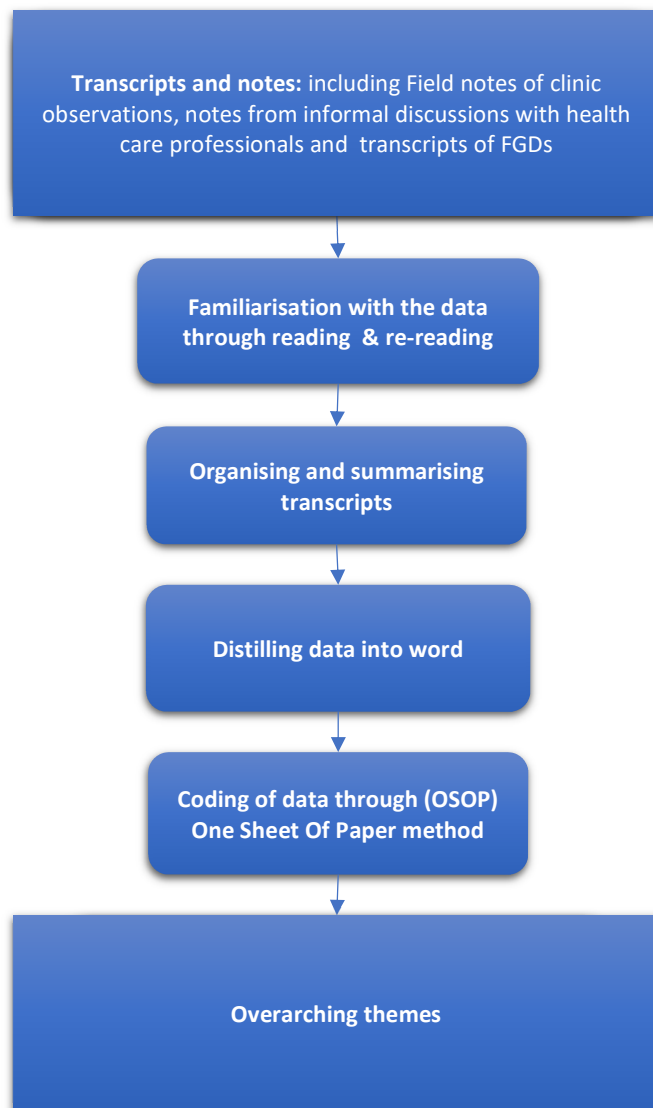
#### 5. Generating a thematic map

This step entailed determining connections, commonalities or contradictions between the generated codes, which led to the identification of the overarching themes presented in the result chapter of this thesis.

#### 6. Re-checking the meanings of narratives

The final step of the analysis process involved returning to the original data to ensure that the new interpretations generated from the data corresponded with the original meanings and contexts.

Organising and processing the data by following these steps allowed for thoroughly exploring, rearranging and navigating the data to interpret the data. Figure 4 demonstrates the steps utilised in the analysis process described.



**Figure 4** Flowchart of data analysis process

#### *4.24.3 Interpretation, Quote Selection and Analysis Enrichment*

In accordance with the methodology utilised in this study in which ethnography highlights the perspectives of participants, the interpretation of the data was done primarily on an emic level. Employing an emic level in an analysis involves presenting the participants' views of the world (Green & Thorogood, 2009). At the same time, to present the findings according to the theoretical approach utilised in this study, an etic level of analysis was applied. This level of analysis is concerned with explaining the data by using the data (Green & Thorogood, 2009).

To enrich the data and to provide an in-depth and more comprehensive explanation of the participants' accounts, I explored the literature to see where my insights fit (Ziebland & McPherson, 2006), which informed as well as supported the data (as presented in the discussion chapters). In addition, I discussed my findings with my supervisors and colleagues to seek new insights and interpretations that I may have overlooked.

I challenged my findings and interpretations by repeatedly questioning whether my understanding was influenced by potential biases prompted by my personal characteristics. It was essential to be aware of the potential impact of my background and identity (Robson, 2002) on the analysis process and the research process as a whole. Therefore, I was reflective in my approach. I explored the insights based on my subjectivity through an account of my reflections of the research process, which is discussed in the next section.

The process for selecting quotes to support the interpretations and analytical points (Corden & Sainsbury, 2006) presented in the results chapters of this thesis entailed examining all quotes under each theme to choose the quotes that were representative of a theme. I aimed to be inclusive rather than exclusive, so I often selected more than one quotation from different participants to highlight my interpretations (Corden & Sainsbury, 2006). In addition, quotations were included that illustrated discrepancies and contrasting views to highlight the variable perspectives of the same issue. The quotes presented in the result chapters were edited as little as possible to improve their readability.

## **4.25 Study Participants: Demographic and Contextual**

### **Information**

#### *4.25.1 Clinical observation*

Demographic information was not collected from those who were observed. Some contextual information was recorded during the observations in the field notes when relevant.

#### *4.25.2 Informal meetings with healthcare professionals*

The team of health care professionals consists of three doctors and one nurse. They all received their qualifications for universities in Saudi Arabia. Their age ranges between 32-40 years of age.

#### *4.25.3 FGDs with participants who attended the programme*

The 39 who participated attended the programme were locals of Dammam. Their ages, both men and women, ranged between 37 and 55. Regarding occupation, women participants range from school teachers to home makers. For men, their occupations ranged from bank employees to retirees. All the participants in this study are married except for one man.

#### **4.26 ‘Insider’ or ‘outsider’: Reflections on the research journey**

McGhee and colleagues (2007) argued that reflexivity is important to eliminate the possibility that prior knowledge would distort the researcher’s view of the data. It is crucial for researchers to be aware of the potential impact of their backgrounds and social identities (Robson, 2002) as well as their positionality on the research process. Providing insight into the subjectivity of the researcher and its impact on the research process enhances the transparency, accountability and trustworthiness of the research (Finlay, 2002). Hence, in this account, I reflect on my research journey and the factors and biases that could have influenced the research process.

#### **Insider or Outsider: My Field Role**

The categorisation of the researcher as an ‘insider’ or ‘outsider’ in relation to the community studied has been subject to extensive debate, especially among sociologists and qualitative researchers. Although an ‘outsider’ researcher, who is not a member of the community studied, might experience difficulties in accessing research participants (Kerstetter, 2012), they are also commonly viewed as

emotionally distant and more objective (Hammersley & Atkinson, 2010). An ‘insider’ is a member of the community studied; however, there are benefits due to the ease of engaging participants as well as using shared experiences with participants to produce rich data (Dwyer & Buckle, 2009). The concern for insiders is that it may be difficult for them to distinguish between their personal experiences and those of the participants, which could potentially lead to research bias (Kerstetter, 2012).

When approaching patients, I was frequently asked which city I came from, and after informing them that I am from Safwa, a neighbouring city, ‘*bentna bentna*’—*our daughter. our daughter*—was the response I often received, emphasising that I am their ‘daughter’ and indicating that they considered me a local, hence an insider. This encouraged participants to be more engaged. I had to nevertheless be aware of developing the comfortableness of being an insider. Hammersley and Atkinson (2010) referred to this as a ‘danger signal’. It is crucial to somewhat decrease familiarity.

Being an insider has commonly been viewed to potentially undermine the legitimacy of the research as well as the researcher (Langhout, 2006); however, being a member of the studied community does not necessarily have a negative effect. Recently, there has been a shift towards considering the researcher’s social identity and position (Kerstetter, 2012). Taking a stance of being an insider and an outsider concurrently can nevertheless generate creative insight.

Being an insider in society and the field and working as a physician previously in similar settings led to a strong familiarity; hence, there was a high probability of

overlooking aspects that outsiders might perceive differently. Nevertheless, living in the West has inevitably led to viewing the studied community through a different lens.

It could be argued that being in one's own society does not allow for adopting a novice role. It can be difficult to avoid preconceptions (Hammersley & Atkinson, 2010). Being a native Saudi Arabian who is accustomed to Western culture does allow for a multi-dimensional perspective when examining how the Saudi culture influences diabetes management; however, at the same time, being an insider was advantageous with regards to being familiar with several dialects, which allowed me to develop the topic guides, conduct the sessions and FGDs and translate the transcripts using wording that is more specific and understandable for the target population.

Being a Saudi researcher and a member of the community researched, I was more likely to be considered an insider by the participants, especially in terms of cultural and traditional issues. Hence, participants might have been less expressive in their answers because they might have assumed that I somewhat had an understanding of the issues they described and that they were common knowledge to me. Nevertheless, being interviewed by a complete outsider would have probably led to similar results at best because participants would have been more reserved and cautious in their responses to avoid conveying a poor impression of themselves, their community (Kelleher & Islam, 1996) or their country.

#### 4.26.1 Initial responses

Having networks in the medical field had advantages and disadvantages. Although the healthcare professionals contacted acknowledged the importance of diabetes self-management, they perceived patients to lack the willingness to learn, especially related to self-care for chronic diseases. I was discouraged from conducting this study, especially because it required participants to commit to participating for long periods of time.

The appearance of the researcher is an important factor in shaping relationships with people in the field (Hammersley & Atkinson, 2010). On my first day, I was wearing an *Abaya*, which is a black traditional cloak and a headscarf women wear in public. I felt that patients were perplexed when I approached because they believed I was a patient. They required a clear explanation to realise that I was not a patient and to understand the reason for my approach. On the other hand, for ethnography studies, it is necessary in some instances to dress in a manner that distinguishes the researcher from a specific group (Hammersley & Atkinson, 2010). Hence, I wore a lab coat and a black veil similar to those that female doctors wear at the centre. Consequently, the patients were less confused when I approached them.

Many healthcare professionals and academics in Saudi Arabia are not familiar with 'social research', especially ethnography and FGD research. It was frequently expressed both when I was applying for ethical approval and when I visited the centre for the first time that no other researcher has used such methods. It was mentioned that data collection through surveys or questionnaires using a retrospective sample and



using patients' records was more common. The nurses mentioned that it was the first time that a researcher visited the centre in person. They are frequently given surveys that they are asked to complete on behalf of the researchers. It seemed that being a student pursuing a research degree at a foreign university caused the participants as well as the healthcare professionals at the centre to place more trust in my skills and competence.

## **4.27 Personal Characteristics of the Researcher**

### *4.27.1 Physician*

As a physician, I strived not to instil a sense of authority that could pose social distance when approaching the participants; however, delivering the sessions myself was an advantage to an extent because I could disclose my profession as a physician, and Saudis have high respect for and trust in doctors, which was advantageous during the recruitment process. Hence, it was necessary to emphasise to the participants that they were not compelled to participate, that they could drop out any time they wished and that the services provided to them would not be affected if they chose not to participate.

Being a physician was advantageous in that the health professionals at the centre considered me a colleague rather than an intrusive researcher. It also led to more trust between us.

Health research, especially social research, is not common in Saudi Arabia. Therefore, the requirements are somewhat unclear, and much depends on networking in the field. If I did not mention to healthcare professionals that I am a physician who has previously worked in Saudi Arabia, they were not as enthusiastic or as helpful.

The skills and expertise I have acquired in approaching patients and establishing rapport were also highly valuable during the field work.

#### *4.27.2 Female*

I could not escape the implications of being a woman in Saudi society as well as pursuing a profession in which women are perceived as weaker than men. Being a woman inevitably shaped my research journey as well as my relationship with the gatekeepers, the healthcare professionals and the participants. The disadvantages usually involve access, especially in institutions and management. Women are allowed access; however, it can become awkward because there are men-only offices. Male researchers in this context would likely face more difficulties in terms of obtaining access to female patients. For example, at the centre, female doctors are allowed to access the male clinics, but it is forbidden for male doctors to access women's clinics at all times. Because women are perceived as unthreatening to their male counterparts, more help is sometimes provided to women.

There are difficulties related to mobilisation in the Saudi context, and it is therefore difficult for patients to travel, especially females. In addition, contacting an organisation, such as a hospital or an administrative office, via telephone or email is

almost impossible. The best way to contact an organisation is to arrive in person. This could be highly inconvenient for patients who need to enquire about test results or even simply confirm the date of an appointment.

#### *4.27.3 Other characteristics*

Managing a chronic disease myself made it possible to relate to and empathise with the frustrations and difficulties participants encounter, especially in accepting the chronicity of an illness, becoming acclimated to new treatments, adopting self-care behaviours, attending follow-up appointments and communicating with medical professionals. Moreover, during programme training, all trainees had to assume the role of a participant with a chronic disease of their choice if they were not affected by one, or they could use their own experiences if they were. Experiencing the programme not only as a trainee but also as a patient with a chronic disease provided me with better insights into how the participants of this study experienced each session.

#### *4.27.4 Data Collection*

There was a concern that healthcare professionals as well as the management of the centre would perceive me as a critic, especially because I was mainly observing and speaking with patients with an agenda that was not clear to all staff members. My background as a physician might have given healthcare professionals a sense of camaraderie, which might have increased their cooperation. In addition, as I was

familiar with the setting, it was possible to recognise when doctors behaved differently than usual during their daily routines.

#### **4.28 Summary**

This study utilised a qualitative approach that consisted of various qualitative methods. This chapter described the research process in detail and in chronological order and provided a section that reflected on my positionality as a researcher in the field.

## Chapter 5: **STUDY CONTEXT**

### **5.1 Overview**

The aim of this chapter is to provide a description of the context of this study. This includes the city and primary care centre where the study took place as well as the extent to which Saudi society is influenced by religion and gender and how these two factors are interrelated.

Because health and illness are not merely biomedical entities but are also enmeshed in the broader social, cultural, historical and political context (Horrocks & Johnson, 2014), illness narratives are hence socially and culturally situated. It is also essential to recognise that health-related behaviours are not merely individually determined but are influenced by the social, political and economic contexts in which these behaviours take place.

Understanding social norms is becoming an important aspect for predicting health behaviours as well as the development of behaviour change intervention (Ball, Jeffery, Abbott, McNaughton, & Crawford, 2010). Because behaviours occur in the social environment, it is essential to take the social context into consideration if efforts are to be made to change them (Kelly & Barker, 2016). Therefore, it is necessary to contextualise the social, gender and religious norms of Saudi society, given that this is the context in which the intervention was delivered and the data were collected.

Saudi Arabia has a distinctive narrative in which it enforces strict gender segregation legally, politically and religiously. Its complexity lies in its conservative but modern society where 'gender politics and religion' are intertwined (Al-Rasheed, 2013). As mentioned, the sessions and FGDs were conducted with women and men separately. The gender divide in this study was not done intentionally to simply differentiate between and compare the results; this was done due to the Saudi interpretation of Islam, and gender segregation has become the religious and social norm in Saudi Arabia. Unlike Western societies and other Arab and Muslim societies, Saudi society is highly segregated and gendered as well as patriarchal. Hence, there is a clear effect on the way everyday life is navigated. This chapter highlights gender roles and expectations in society and the way these roles are constructed through the influence of Islamic interpretations as well as the way the legal system aids in maintaining the status quo. Nonetheless, it is important to note that society in Saudi Arabia is subjected to a unique and strict theocratic system in which there is no homogeneity of law enforcement. Therefore, it is highly complicated to describe and explain.

The aim of providing this brief account is to contextualise the narratives of the participants in the study. An overview is provided of the extent to which the Saudi society is gendered and patriarchal, and the extreme disparities in gender roles and expectations between women and men, which inevitably influence illness narratives, are highlighted. Comprehensively describing the patriarchal structure is beyond the scope of this thesis; however, its implications on society are briefly discussed.

At the end of this chapter, a brief description of the context of this study is provided. More specifically, the city of Dammam, where the primary care centre is located, and the primary care centre where the study took place as well as its cadre are described.

## **5.2 Gender Norms and Social Expectations**

The global gender gap report published in 2016 emphasised the gap between genders in Saudi Arabia, and its global index was ranked 141 of 144 countries (World Economic Forum, 2016). Although it performed better in terms of education and health, it ranked low in political and economic empowerment and opportunity (World Economic Forum, 2016).

Saudi Arabia's culture is distinctive in that gender roles and their expectations are derived from specific interpretations of Islamic Sharia (Aldosari, 2017). A man is assigned the role of the head of the family who works outside the home and the provider who maintains the safety of his wife and children (Alhazmi & Nyland, 2010). Women, on the other hand, are assigned the responsibility of working inside the home, caring for their husbands and children and becoming caregivers and nurturers (Alhazmi & Nyland, 2010). These roles are also reflected in school curriculums. Girls are taught skills such as cooking and sewing to prepare them to be good wives and mothers, whereas boys focus on physical skills. The Saudi school curriculum positions women in the domestic sphere, whereas men are positioned in the public sphere. The curriculum is also used as a tool to maintain gender hierarchy and roles. After a long period of rejecting introducing education for girls due to the fear of Westernisation and the independence of women, education was introduced in the 1960s after

assurance to the religious authority that ‘the purpose of educating girls is to bring her up in a proper Islamic way so as to perform her duty in life, be an ideal and successful housewife and a good mother, ready to do jobs suitable to her nature such as teaching and nursing and medical treatment’ (Hamdan, 2005).

Both genders are taught according to the societal expectations of gender roles. As men are expected to be the financial providers, they are advised to choose specialities that would easily lead to a career. For women, they are encouraged to choose specialties that do not interfere with their wifely and/or their motherly duties, and more importantly, that do not expose them to ‘mixing’ with men. Women are predominantly encouraged to seek careers in teaching because it is a profession that has flexible working hours and guarantees gender segregation and is therefore socially acceptable (Boserup, Kanji, Tan, & Toulmin, 2013). Specialities such as engineering or politics are not offered to women at Saudi universities. Although women are allowed to study medicine and health sciences, it is generally frowned upon for women to work in such careers due to the long working hours, which could impede their obligations as wives and/or mothers as well as lead to the inevitability of ‘mixing’.

The allocation of work to men and women according to gender roles, which is referred to as the ‘gender division of labour’, is variable and significantly diverse among different societies and cultures. This division is often ascribed to the biological differences between men and women (Baker & Jacobsen, 2007), where men are the financial providers and women are the child bearers. Gender differences in occupations are often imposed by customs and social norms (Baker & Jacobsen,



2007). This disparity has reduced over time in Western countries, but it remains significant in Saudi Arabia. Although Saudi women constitute more than 60% of university graduates in the country (Young, 2016), they only comprise 16% of the total Saudi labour force compared to 78.3% of men (The World Bank, 2017). In the UK, for example, women constitute 46.5% of the total labour force (The World Bank, 2017).

The factors that lead to this binary division worldwide are relevant for Saudi society, but there are factors that are unique to the Saudi system. There are obvious socio-cultural barriers, such as the mixing between sexes, religious norms, the lack of public transportation and the driving ban for women. This ban has recently been lifted, and women will be able to start learning to drive in June 2018; however, there are currently economic constraints due to the need to hire a private driver to commute. Women are not merely discouraged by these socio-cultural barriers but also by governmental policies and legislation. For example, the government states that women have the right to work, but it legislates that women are only allowed to work in selected industries (Ministry of Labour and Social Development, 2015). This legislation has been incorporated into labour law policies. Article 149 of the Saudi Labour Law states that the Ministry of Labour is the authority that determines which jobs are suitable for women (Ministry of Labor and Social Development, 2015). Moreover, the existence of the guardianship system is a factor. The issue of women's employment is more nuanced than it appears. It emphasises the exclusion of women and highlights their perceived roles and expectations in society. Moreover, there is an entrenched belief in gender roles and expectations in which it is expected that men are the financial

providers of their families, and thus the employment of men is prioritised over women. The prevailing religious discourse also plays a major role in discouraging women from employment by emphasising that the correct place for a woman is in the home. The financial obligation for men and the lack of a financial obligation for women to support their families is also an influential factor (Al-Rasheed, 2013).

Marriage is perceived as a ritual that honours both partners with social approval and status enhancement, especially for women (Rashad, Osman, & Roudi-Fahimi, 2005). It is a social expectation and is considered the destiny of all women, and it takes precedence over all other entities of life, such as education or employment. Being a 'good' wife is a major part of women's identity in society. Women are judged based on their success in marriage and bearing children. Fear of polygyny is a sign of failure in marriage, and there is also a risk for women and their children to be abandoned by their husbands and to therefore become unable to manage their own lives. In (Alsharekh, 2007), Al-Khateeb states that Saudi women are made to feel that they cannot live without a man. She states that marriage is *'an identity card for a Saudi woman to enjoy her rights as a human being'*. Al-Khateeb attributes this to several factors, including women's inability to seek governmental services without relying on a man. This situation is gradually changing, and some government offices currently accommodate women; however, most services still require the consent of the woman's guardian. Another factor is that it is still socially unacceptable for a woman to live on her own, even if she is financially independent (Al-Khateeb, in (Alsharekh, 2007)). It is only acceptable for women to live in their parents' homes, and they can only move once they are married. They are expected to return to their parents' homes in the event

of a divorce or becoming widowed. The same is not expected of men. It is expected and favoured for divorced or widowed men to quickly marry again to be nurtured and cared for. Marriage also provides the opportunity for individuals to fulfil their sexual desires in a culturally, legally and a socially acceptable manner (Rashad et al., 2005).

Marriage is not merely a social expectation; it is perceived as an important religious devotion. Verses in the Quran encourage marriage, for example:

‘And marry those among you who are single and those who are fit among your male slaves and your female slaves; if they are needy, Allah will make them free from want out of His grace; and Allah is Ample-giving, Knowing’. (Surah an-Nur, 24:32)

Prophet Mohammad’s *Hadith* states that:

‘The best people of my nation are those who get married and have chosen their wives, and the worst people of my nation are those who have kept away from marriage and are passing their lives as bachelors’ (Athar & Rizvi, 2018).

### **5.3 Gender Laws and Patriarchy**

Generally, gender roles and their expectations are socially constructed and influenced by social and cultural factors (Lefkowitz, Shearer, Gillen, & Espinosa-Hernandez, 2014); however, in the context of Saudi Arabia, these constructions are influenced by the Islamic beliefs of society, and thus these roles are still perceived and portrayed as tradition. Moreover, these roles are enforced through stringent legal as well as societal measures (Aldosari, 2017). Legally, Saudi men have a superior status over women,

which undoubtedly has an impact on gender roles. The following are some examples of laws that are stated in the Personal Status Law, which is the legislature related to ‘the part of Shari’a that applies to family relations’, such as marriage and divorce (Aldosari, 2016):

- Women are not allowed to marry without their male guardian’s approval
- Women’s role as wives and mothers is the priority, and the husband has the right to allow or reject the wife assuming other roles outside the home for work or education
- The right to divorce is granted to men only, and if a woman pursues a divorce, a judicial order is required
- In the case of divorce, the mother is granted the custody of her children until she remarries or until her children reach a certain age
- The father has the legal authority over his children even if the children are in the mother’s custody
- Polygyny is permitted for up to four wives

A family-oriented society is the epitome of a patriarchal system; hence, the Saudi family laws support gender roles and challenge women’s agency (Al-Rasheed, 2013). The existence of these laws suggest that women play a subordinate role compared to men because men can assert their authority over women legally. Women’s autonomy

is therefore restricted by legal measures, such as the existence of the male guardianship system.

The male guardianship system is an institutionalised patriarchal system in which women, regardless of age or status, are required to obtain and provide her male guardian's authorisation to seek education, employment, travel, marriage and release from prison (Aldosari, 2017). Therefore, under this system, women are perpetually treated as minors and as dependents of their fathers, husbands or their next-of-kin male relative, including sons (Human Rights Watch, 2016). Fathers are legally obligated to carry the responsibility for their unmarried daughters. This responsibility is passed to the husband upon marriage, and in the case of divorce or the death of the husband, the responsibility shifts back to the father; however, if a woman has a male child who has reached puberty, which could sometimes be as young as 13 years of age, the son would assume the responsibility of the guardianship of the women in the family.

Most societies still experience gender inequality; however, countries in the Middle East are well-known for adhering to patriarchal structures. The Middle Eastern and North African regions have been labelled by Caldwell (1978) as the 'patriarchal belt' (Kandiyoti, 1988). Patriarchy is present in many societies, but in Saudi Arabia, it is heavily emphasised. Al-Rasheed (2013) argued that there is a public form of patriarchy representing the state and a private form that depicts the male guardian, and these forms of patriarchy enforce each other. Both forms are religiously controlled by the state to reinforce the legitimacy of the state (Al-Rasheed, 2013). Doumato (1992) stated that 'women's modesty, family values, and women's dependency on men

represent support for the integrity of the patriarchal family', meaning the family is the private patriarchy and the state is the public patriarchy.

Patriarchal societies perceive women as powerless in the public sphere and men as powerful in both the private and public spheres. It is important to note that women in Saudi Arabia are affected differently by the patriarchal system depending on the discretion of the male guardian. Resisting the patriarchal system strongly depends on the family. Therefore, women have different experiences under the same system. Generally, this system inevitably affects the identity of both men and women because it assigns men complete authority over women and therefore strips women of agency and power.

The role of Saudi women and their rights has been receiving considerable attention locally as well as internationally. This issue has caused controversial debates between the conservatives and the liberals in the country. On one hand, the liberals argue against the measures imposed on women and highlight the negative consequences of these measures. On the other hand, the conservatives are in favour of the status quo and thus accentuate the disadvantages that could result from attempting to change the role of women for families and society. The authority of the state and the religious authority are not the only influential factors in this debate. Due to the tribal nature of society in Saudi, both women and men are expected to be loyal to their kinship. A kinship system exists in Saudi Arabia through marriage and decent. Due to this system, the needs of women are contingent on the greater good of the tribe (Alsharekh, 2007), and hence any efforts to change the perceived traditional gender roles are often met

with rejection to maintain the existing kinship. Aldosari (2016) stated that *'in kinship societies, such as Saudi Arabia, the change in women's perceptions of gender roles with education and exposure increases the tension surrounding the established gender norms and expectations'*.

#### **5.4 Religion and Religious Norms**

The strict religious nature of society permeates all aspects of everyday life. As explained in the following sub-sections, religious norms also have a major influence on gender and social norms. The country has a high influence and status in the Islamic world due to the presence of two holy mosques in Makkah and Madinah, where Islam was born. Therefore, as Saudi Arabia is the custodian of these two holy mosques, it considers itself to have the responsibility of leading the preservation, promotion and practices of Islam and its teachings. Saudi Arabia is proud to be a distinctive nation due to its religiosity and claims 'exceptionalism' from other countries (Al-Rasheed, 2013).

The state claims that the laws are derived from the Islamic *Shari'a*. It is governed by the *Qur'an* and *Hadith* as the constitution, and hence there is no formal constitution (Ministry of Foreign Affairs, 2011). The laws are generally highly subject to the Islamic interpretations of scholars. There is no standard legislature in Saudi Arabia. In 1992, the Basic Laws of Governance was issued by the government, which included 28 articles (Ministry of Foreign Affairs (MOFA), 2011). These laws are used as an informal constitution, and the first article establishes the *Qur'an* and the *Sunnah* as the formal constitution (MOFA, 2017). New laws originate from the Council of Ministers

(*Majlis Al Wozar'a*) and the Advisory Council (*Majlis Al Shura*); however, the approval or rejection of any law is solely subject to the king's discretion, given that he complies with *Shari'a* law. The king can also issue royal decrees any time without consultations from any of the bodies.

There is ambiguity in the laws regarding practices that are considered by *Wahabism* to preserve the morality and virtue of Saudi society, such as shops closing for prayer, coercing all individuals in public to attend prayer at the mosque at prayer time, the ban on women travelling without a male guardian and the separation of sexes in public. These laws are justified by abiding by with Articles 11 and 12 of the Basic Law of Governance:

*Article 11: 'The Saudi society shall cling to the Allah's Shari'ah. Its citizens shall cooperate to bolster benevolence, piety and mutual assistance; and to avoid dissension'*

*Article 23: 'The state shall protect the Islamic creed and shall apply Islamic Shari'ah. The state shall enjoin good and forbid evil, and shall undertake the duties of the call to Islam'*

*Article 26: 'The state shall protect human rights in accordance with Islamic Shari'ah'*

Islamic practices dominate daily life in Saudi Arabia. For example, prayers are called for publicly five times a day. During prayer times, men are expected to go to the mosques to pray, and shops and all client-based services are closed until prayers are



complete (Hilal, 2013). The observance of Islam is also evident in the attire men wear but mostly in the attire women wear. Men commonly wear a white *Thawb*, which is a long white robe with sleeves, and a *Shemagh*, which is white-and-red checkered, scarf-like head wear. Women, on the other hand, are expected to wear an *Abaya*, which is a long black cloak, and to cover their hair with a veil. Depending on the social and religious norms of where they live, some women prefer to also cover their faces with a *Niqab*, which is a piece of clothing covering the face and only revealing the eyes. People are generally religious, conservative and conform to social and traditional norms. It is considered Islamic not only to conform to appearance in dress but to also conform in behaviour. Those who do not are often reprimanded by what is referred to as the religious police (van Geel, 2016). A government authorised agency officially entitled the Commission for the Promotion of Virtue and Prevention of Vice, or *Alhay'a*, has the authority to monitor social behaviour and enforce what is considered Islamically moral, such as monitoring women's public attire to impose modesty, forcing shops to close during prayer and enforcing segregation (van Geel, 2016).

In 2016, the duties of the Commission for the Promotion of Virtue and Prevention of Vice were curtailed by a royal decree (Reuters, 2016). They are no longer allowed to question or arrest suspects who are considered religiously immoral. Instead, they are required to report to police to carry out law enforcement (Reuters, 2016); however, the doctrine of the Commission for the Promotion of Virtue and the Prevention of Vice is regarded by scholars as an obligation for all Muslims and not only the state, and therefore ordinary citizens can use their judgment to police other citizens according to what they perceive as moral and Islamic.

As mentioned, the laws are claimed to be derived from Islamic *Shari'a*; however, secular laws are issued when there is a political need (Aldosari, 2016) or an economic necessity (Wald, 2017). The interpretations change according to the state's ideology. For example, women were only allowed to work in a limited number of sectors, such as education and health. It has always been prohibited for women to work in retail, such as saleswomen in shops or supermarkets, to avoid mixing and to enforce segregation, but subsequent to a royal decree issued by the late king in 2011, Saudi women are permitted to work in the retail industry (Alhussein, 2014). The rules of segregation have been overlooked due to the economic situation the country has continued to suffer from. More importantly, the recent lift of the driving ban for women that was announced in September, 2017, which goes into effect in June 2018 (Saudi Press Agency, 2017), also strongly emphasises this point.

Al-Rasheed (2013) argued that the *Wahhabi* form of religion that the state adopts is not merely used to assert conformity and devotion to Islamic teachings but is used as 'religious nationalism'. She defined it as 'a form of politicised collective representation, embedded in institutions, the purpose of which is to create a godly community' (Al-Rasheed, 2013) 16). The *Wahabi* religious discourse has produced devout and conformist individuals with limited social agency. Through its 'religious nationalism', the state has controlled many aspects of individuals' lives, such as religiosity, appearance, education and social life. This framework has shaped the culture and has therefore shaped the gender roles and identities of society. It has weakened the autonomy of individuals and has focused on strengthening the family

instead (Al-Rasheed, 2013). Women are the primary victims of religious nationalism because they are perceived as the ‘symbols of piety’, as Al-Rasheed stated.

## 5.5 Gender Segregation

To contextualise the current study, a brief description of gender segregation and the way it is exhibited in the public sphere in Saudi Arabia at the present time is provided.

In Islam, gender segregation is often used as a term to describe the prohibition of free mixing between men and women (Buisson, 2013). It is only permissible for men and women to have mixed interactions with their spouses or their *Mahram*. It is often justified as a method of protection for individuals and society because it is believed that free mixing would lead to temptation, adultery and moral corruption, causing social chaos (Buisson, 2013).

In the Saudi context, this phenomenon is a social and cultural custom that is evident in everyday life, especially in the country’s institutions. Although it is considered an Islamic phenomenon, Saudi Arabia is the only Islamic country that strictly enforces it (van Geel, 2016). Gender segregation essentially stems from the *Wahhabi* or *Salafi* interpretations of the holy book, the *Qur’an*, and the prophet’s written speeches, the *Hadith*, which the state abides by and has used to derive its Basic Law of Governance (Baki, 2004). It is also commonly referred to as *Shari’a* law. Scholars of *Wahabism* believe that Islam emboldens purity and honour. Therefore, they claim that gender separation is a basic Islamic teaching because it is a way to preserve the chastity and virtue of both men and women. Its aim is to keep women from men who are not

consanguineously related to prevent adultery (Alhazmi & Nyland, 2010). Society has been constructed in such a way that women are inaccessible, therefore making it difficult or rather impossible for women to lose their sexual virtue (Mackey, 2002).

Segregation in Saudi Arabia has always been justified by society's conservatism and traditionalism; however, van Geel (2016) argued that gender segregation was influenced by the discovery of oil and the urbanisation that ensued as well as the rise of the Islamic awakening movement (*Sahwa*). She explained that the discovery of oil and urbanisation in the 1970s led to a substantial rise in men's incomes, which was sufficient to support the family, and therefore the contribution of women was no longer needed. Hence, women who did not work were a symbol of morality and wealth (Le Renard, 2008). Van Geel (2016) also stated that segregation had an impact on the discourse of the Islamic awakening movement that occurred in 1979. Conservatism flourished in the country after a group of religious rebels led by the religious militant Juhayman Al Otyabi, who distrusted the legitimacy of the monarchy and claimed that Al-Saud was corrupt and was influenced by the West, took hundreds of hostages under a siege in a holy mosque in Makkah. After the siege, the movement progressed, and for the royal family to consolidate its power, it was forced to rule by 'true Islam'. Therefore, it began to require women to wear the *Abaya* and to cover their faces with the *niqab*, and most importantly, it restricted their presence in public spaces, leading to segregation (van Geel, 2016).

The extent of segregation is sustained by the state's authority through laws and by designating separate spheres for men and women. Surprisingly, there are no explicit

laws or rules regarding segregation in Saudi Arabia. In the labour laws, for example, laws regarding segregation are stated in the same manner as the Basic Law of Governance. Until 2016, the separation of genders in public and some governmental institutions was enforced by members of the Commission for the Promotion of Virtue and Prevention of Vice.

Segregation is typically strictly enforced in the education sector; all public and private schools, colleges and universities are stringently segregated by sex. In 2009, the late King Abdullah founded King Abdullah University of Science and Technology (KAUST), a university established for international postgraduate research. Due to its co-educational system, the king was harshly criticised by some religious scholars and also by conservatives in society (Meijer, 2010). Moreover, restaurants in the country commonly either serve only men or have two sections. One is for men only, and another is for families. Women and men who are related sit in a partitioned seating arrangement. Recently, some restaurants opened that only serve women. Segregation is not only a public phenomenon; it pervades private spaces. House designs are affected by segregation (Abu-Gazzeh, 1993), and hosting guests of both genders at the same time requires two separate living rooms. In addition to the physical segregation these laws have created, a social segregation has resulted, which has produced a gap between both genders in society.

I have never reflected on this issue until I attempted describing it for the purpose of this thesis. As a Saudi citizen, I found it perplexing and challenging to comprehend, which makes it complicated to precisely describe and dispel the perception of strict

segregation, especially to outsiders or foreigners. The complication lies in that the rule is vague, and law enforcement is not homogenous and hence inconsistent. In some places, there is absolute segregation in which genders are physically in different places, such as governmental agencies and educational institutions (Alhazmi & Nyland, 2010). In most public places, such as hospitals, shopping malls, some companies in the private sector and the two holy mosques of Makkah and Madinah, genders are physically in the same place; however, it is not acceptable for unrelated women and men to intermingle. There is also free mixing in some private sector companies, where the rules of segregation as well as attire are overlooked. Therefore, contrary to common belief, segregation in Saudi Arabia is not absolute. It highly depends on the social norms of a place, such as the location, the city—sometimes a part of a city because some cities are known for being more conservative than others and vice versa—the institution and the layout practicality, which force some segregation norms. The confusion regarding the definition of segregation was studied in detail by (van Geel, 2016), and she illustrated that the term ‘segregation’ is actually not the term used in Arabic. The term commonly used is *ikhtilat*, meaning ‘mixing’. ‘Mixing’ had different meanings and descriptions according to the Saudi women she interviewed. Some women believed that it means that ‘it is allowed for men and women to be together in public spaces but not socialise’, and to others, it meant ‘being in separate places at all times’. Based on the interviews, she found that the term is ambiguous in both public debates and private conversations and that it does not have an official definition.

It is essential to note the implications of the segregation of gender identities for both genders in Saudi Arabia. The legal restrictions imposed on women and their lack of social participation has generated an image that women are inferior, dependent on men and require being guarded and financially supported by men. Moreover, 'it has formed a uniform image of women and obliterated their identity'. The social and physical segregation emphasises that both genders are identified as separate groups that have specific roles and duties in society.

It is challenging to enforce absolute gender segregation in the health system (Aldosari, 2017). Segregation is occasionally more behavioural than physical. In the next subsection, the way segregation occurred at the centre where the study was conducted is described.

## **5.6 The Centre**

This study took place in the Al-Khaleej primary care centre in the city of Dammam. Dammam is the regional capital and the largest city in the Eastern Province of Saudi Arabia. It is a metropolis located on the coast of the Persian Gulf. The city is considered the major administrative centre of the oil industry in the country. It has some modern areas, which are mainly closer to the coast, where the city's modern shopping centres, restaurants and tourist attractions are located. Other parts are less modern and more traditional with old buildings, old-style restaurants and unpaved roads (pictures provided in Appendix 16).

The pictures of the city were taken from inside a car. It is uncommon for individuals to walk on main roads because most are not designated for walking and can be quite dangerous. Even if the risk was taken, there would still be those who would most likely harass a woman walking because it is socially unacceptable for women to do so, especially on main roads. Moreover, photographing public buildings, especially those that are governmental, i.e. hospitals, schools and mosques, can be considered suspicious for security reasons, but the predominant concern would be that the photographs would be used to criticise government buildings or roads in the media. The enforcement of the public photography law is somewhat perplexing. The only law regarding public photography available was issued in 2007 as part of the cybercrime law that prohibits photographing people in public and posting the photos on the internet or social media websites. Undertaking such an act puts the individual at risk of being punished by a jail sentence of one year and/or a fine of up to 100,000 Saudi Riyals (Approximately £20,000) (Ministry of Communications and Information Technology, 2007); however, both the police and the public confuse the law with tradition and can personally object to any person photographing anything in public, even if it is a photograph of a landscape, on the premise that it is *Haram*, or forbidden by religion. I asked my husband to accompany me to take photos of the city and the centre where the study took place. Most of the photos were taken from the car while driving through the city. Because people are warier when a professional camera is used, we utilised a mobile phone's camera. We encountered an objecting passer-by while taking photos of the primary care centre's façade. He asked whether we obtained a permit to take photos. My husband explained that I was a physician conducting a project at the centre, that an approval was obtained through the MOH and that the



management of the centre was informed. People are usually understanding if they are not personally being photographed without their permission and if the situation is politely explained. It was also somewhat difficult to take photos of the waiting rooms and the clinics while patients and staff were present. I asked permission from everyone there individually. The men generally had no problems with having their pictures taken. The women, both patients and staff, were mostly averse to appearing in any photos, sometimes even when their faces were covered with the *niqab*. The reasons behind this opposition are complicated and difficult to explain. This could be explained by the possible connotation of a notorious reputation. There is a fear that the reputation of a woman as well as her family is dishonoured if her picture is downloaded and found online or in anyone's possession. There have been many cases in which photos have been used, especially by men, to blackmail women. This fear existed before the era of the internet but has undeniably become stronger, specifically among the older generation.

The *Al-khaleej* primary care centre is named after the neighbourhood it is located in. The neighbourhood is located in the centre of Dammam, and it is approximately two miles from the coast. Its location is strategic because it is easy to reach, and it is easy to reach other parts of the city from the centre. Although the neighbourhood is one of the oldest neighbourhoods in the city, all municipal services are provided. It was called *Hai* (Arabic word for neighbourhood) *Alkahraba'a*, which is the Arabic word for 'electricity'. This is because the first electric generators for the entire city of Dammam were located in this neighbourhood. In approximately 2010, it was renamed by the authorities as *Hai Alkaleej*. My hometown, Safwa, is approximately 25 miles from *Hai*

*Al-Khaleej*, which is a 30-minute drive by car. Due to the ban on women driving as well as the almost non-existent public transportation in the country and the inconvenience of locating safe and reliable taxis, I arranged for family members or friends' chauffeurs to drive me there beforehand. This was a challenge because as I needed to work around their schedules of taking female employees to work and taking children to school. It was not possible for male relatives to drive me due to their work schedules. Although I have lived in the UK for the past six years as an independent woman, especially in terms of freedom of movement, I have not forgotten these challenges. When I returned to Saudi Arabia for field work, this predicament reminded me of the extreme difficulty women experience to move freely when needed without depending on someone else and without compromising time and money (the lack of autonomy). I especially understood that it must be extremely difficult and inconvenient for patients who are not able to drive in general, especially female patients, to seek health services when needed. Saudi health services do not provide a transport system for patients. This might lead to women either delaying care or not seeking care at all. Although the lack of transportation has been shown to be a barrier to accessing healthcare services in countries such as, the US (Strauss, MacLean, Troy, & Littenberg, 2006) and the UK (Ali et al., 2013), the extent of this problem has not been studied in Saudi Arabia, especially for women due to the former driving ban that is still in effect and because it is not acceptable to walk. The walking distance is also usually far and often impossible due to heat and social norms (for women only). Although it is culturally and socially acceptable for men to walk or cycle in public, it is rare to see men walking or cycling. Those who do so are usually labour workers.

This is usually attributed to the hot weather and the poorly designated roads for pedestrians.

In terms of segregating genders at the centre, *Al-Khaleej* primary care centre is an example of a layout that does not allow for strict segregation. The MOH is highly dependent on rented buildings rather than constructing buildings that are dedicated to becoming primary healthcare centres. Although there has been remarkable development over the past years in constructing new health centres, some are still housed in old rented buildings, and the *Al-Khaleej* centre is not an exception. The centre is located in an apartment building that is rented by the MOH, and hence the layout indicates that it was not intended to be a healthcare centre when it was built. Upon reflecting on my time there, I found it fascinating that despite the absence of signage, everyone seemed to navigate the centre with ease and merely depended on social cues.

## **5.7 The Cadre**

Al-Khaleej primary care centre is a rare centre in that it has an all-Saudi cadre except one Egyptian female doctor. The Saudi healthcare system still highly relies on foreign healthcare professionals, and Saudi physicians and nurses working in the public sector constitute only 26% and 52%, respectively (MOH, 2016). Expatriate physicians working in the public sector can either be from Arab countries, such as Egypt, Jordan, Sudan or Syria, or from South Asian countries, such as India, Bangladesh or Pakistan. Expatriate nurses, on the other hand, are mostly from the Philippines and India. Expatriates from Western countries, such as the US or UK, mainly work in the private

sector. There is no requirement for healthcare professionals to speak Arabic to work in Saudi Arabia, and interpreters are not provided for patients. Expatriate healthcare professionals are typically given a brief Arabic language course that their employing organisation provides before they begin working; however, it is not compulsory, and there are only two private institutes that provide Arabic language courses in the west of the country in the city of Jeddah. Saudi dialects are also widely varied, even among neighbouring cities. After working for a period of time in the country, healthcare professionals that do not speak Arabic acquire some words and phrases from their patients and their Arabic-speaking work colleagues. The medical and nursing degrees provided by Saudi universities are all delivered in English, and English is also used by healthcare professionals in all daily medical communications, such as updating patients' records and writing referrals; however, verbal communications with patients are always conducted in Arabic. It is not common for patients to speak English, so healthcare professionals are required to make an effort to converse with patients in Arabic, though their speech is often unstructured and broken. Doctors and nurses are paired so that one has better Arabic language skills, although this is not always possible.

## **5.8 Summary**

This chapter describes the context of this study. It focuses on the factors that highly influence society and thus inevitably impact illness narratives and health-related behaviours based on gender and religion.

Despite the recent developments in which women have been given more rights, such as driving and more opportunities in the workplace, they are still limited by the strict patriarchal system and have not fully acquired agency. This continues to influence illness narratives as well as health-related behaviours.

Although the study included both male and female participants, this chapter primarily discusses the impact of gender and religion on women. The study as a whole is strongly influenced by gender, and existing literature regarding Saudi society focuses mainly on women. Studies on men are scarce and almost non-existent.

## Chapter 6: CLINIC OBSERVATIONS

*Non-participatory observations of patient's consultation in the chronic disease clinic*

### 6.1 Overview

The aim of observing the clinical consultations of patients with type 2 diabetes in the clinic was to identify other aspects that might aid in an adaptation that is more relevant to the patients. This chapter discusses the observation phase of this study, including reflections on this process. The inclusion and exclusion criteria that applied to those who were invited to participate in the sessions did not apply to those who were observed during their consultations.

Despite the fact that I previously worked in a hospital in Dammam, the first time I visited this neighbourhood was during the field work for this project. The neighbourhood is largely a residential area. It has an open-roof shopping centre and a few small corner shops as well as two girl's schools and two boy's schools. Driving into the neighbourhood instils a sense of travelling through different eras because both old houses and modern houses are observed. The roads are empty with the exception of a few cars passing by.

The centre is located on a quiet residential road in what initially seems to be a flats building. It is a small, old building (Figure 5, Appendix 16) in a neighbourhood that is known to be less affluent than other neighbourhoods in the city. The building has two entrances: one for women and the other for men (Figure 7, Appendix 16). It

consists of two floors that are connected by two white-and-grey tiled flights of stairs. The ground floor is dedicated to women and consists of seven rooms. Four rooms are GP consultation clinics. The other three rooms are designated for taking vital signs, administering vaccinations and maintaining files. The general area outside the clinic is designated as a waiting area. The first floor consists of two rooms that are general clinics for men, a laboratory, the chronic disease care clinic and the management offices. There are two waiting areas on the first floor. One is for men attending general clinics, the laboratory or the chronic care clinic, and the other is for women attending the chronic care clinic or the laboratory. The laboratory is simply a room where blood samples are drawn, or urine samples are received by a nurse on mornings only. The samples are then picked up to be delivered to the city's central laboratory for analysis.

Men are not allowed to enter the ground floor under any circumstances; however, female physicians as well as female patients can go to the first floor to visit the chronic care clinic or the laboratory. Although nurses and/or patients' relatives assist those using a wheelchair or who have difficulties walking to access the first floor by using the stairs, the absence of an elevator or a ramp in the centre makes it difficult to easily access the first floor for those with disabilities. Many patients complained about this during my field work.

On arriving to the centre at the opening hour of 7:00 AM, it is typical to find women, sometimes with their children still wearing pyjamas and sleepy, already in the waiting room. The doors of the centre are opened by the cleaners about one hour, and sometimes more, before the official opening hour. The morning is the busiest time

because it is most convenient for many women who do not have a chauffeur or other convenient transport means, which includes most of the women at the centre, to find a ride either from a husband or a son before they go to work. Jobs and schools in Saudi Arabia typically begin at 7:00 AM. Some women mentioned that they arrive one hour early. The fact that some women are accompanied by their children who are below school age to the centre because they do not have childcare at home certainly contributes to the disarray.

Primary healthcare centres in Saudi Arabia are similar to hospital settings, unlike GP practices in the UK, where they are typically more comfortable and inviting. When entering the centre, the smell of disinfectant, the bright white lights and the steel, three-seater waiting room chairs are a strong reminder of a hospital setting. A small TV screen hangs from one of the walls with its black wires showing until they reach the electricity socket towards the end of the wall.

Unlike GP practices in the UK where staff wear smart-casual attire, health professionals in Saudi Arabia wear white lab coats, and doctors place stethoscopes around their necks. Receptionists and administrators wear a beige-coloured lab coat. Female staff are mandated to wear a headscarf to cover their hair, which is white for nurses and black for doctors, but they can also wear a *niqab* if they wish. The opening hours are fixed at all centres. Not all centres are computerised yet and still use paper records. Most rely on nurses. Staff can be called to report to another centre if they have a shortage of staff in their centre on a given day. The patients' health-seeking behaviours are also somewhat different from those of the UK, which affects the



atmosphere of the clinic. For patients in Saudi Arabia, there is a norm that patients must show and prove to others that they are ill because doctors would not take them seriously if they do not appear to be ill. There is also a lack of awareness regarding when to visit the GP or the emergency room, unlike patients I have observed in GP practices in the UK, where the majority of cases do not require emergency treatment.

## **6.2 Patients' Visits/The Process**

When a patient first arrives at the centre, they register their names with reception. Most primary care centres in Saudi Arabia are paper-based but are slowly changing to an electronic system. The *Al-Khaleej* centre is still paper-based, and computers are not available. Patients usually wait until their paper-based records (files) are manually retrieved from the file room, which is located behind reception. The file is then given to the patient. At the same time, the receptionist gives the patient a small piece of paper with the number of the clinic they are assigned to according to how busy each clinic is. Patients are not assigned to any specific physician in the centre because physicians change continuously. Moreover, there is no appointment system in place. Patients can walk in any time unless they were given an appointment for a follow-up visit, which is usually by date and not by time.

Before patients report to their assigned clinics, they are asked to visit the vitals room where a nurse measures their pulse, oxygen saturation, blood pressure and weight. The measures are handwritten by the nurse in charge on a small form, which is enclosed within the patient's file. The patient then takes the file and gives it to the nurse in charge of the clinic assigned to them. Each clinic is attended by a physician—male

physicians for men and female physicians for women—and a nurse. All nurses in the centre are women.

I found the process of patients navigating the centre to be quite chaotic. Patients frequently lost their way to the clinic that they were assigned to, which led to confusion amongst patients regarding who registered at reception before the other and who gave their files to the clinic first. Female patients tended to be impatient to be seen as soon as possible. They would often knock on the door of the clinic they were assigned to as soon as their vital signs were taken to ask if they could be seen as soon as possible. The main justification they provided was that their ride could only wait for ten or fifteen minutes, or they would not be able to go home. Another was that they could not wait because their children would return from school, and they must be at home either to cook lunch before the children arrive or to be present to open the door for them. During my observations, I witnessed many women negotiating with other patients who were due to be seen before them for permission to be seen first. These negotiations became intense several times during my observations, especially when the other women refused because they both had similar reasons for wanting to be seen as soon as possible. Men, on the other hand, tended to be more inclined to wait. Nevertheless, if the wait was long, they would sometimes leave without negotiating to be seen first and sometimes without notifying anyone. On the occasions when they informed the staff that they needed to leave, it was mainly because they either needed to pick up their children from school or occasionally to pick up their wives. It is apparent that transport is a barrier to health access for both men and women in Saudi Arabia. There are certainly patients who either delay or do not seek medical advice at

all due to transport issues. Women in Saudi Arabia, in particular, are inevitably hugely disadvantaged.

Furthermore, insufficient attention is paid to the confidentiality of patients. The clinic's door is often kept slightly or widely open. Consultations are often disrupted by other patients knocking on the door to submit their files to the nurse or sometimes to ask about the number of patients to be seen before them. It was surprising that when another patient walked in during a consultation—even if the patient was being examined—refusal to such an act was never expressed. It is unclear whether they merely did not vocalise frustration or were not aware of their rights to privacy and confidentiality, and thus it has become acceptable. It was also interesting to observe some patients who did not register when they arrived and simply approached any clinic to consult the doctors about a health situation that was 'minor' according to the patient. These patients expressed that it would take too long to wait if they registered and would not require much time from the doctors. Altercations occasionally occurred when doctors insisted that patients needed to register and have their record files retrieved to be seen. Although no doctors assented to such a request, patients continued to return and demand to be seen without registering.

### **6.3 The Chronic Disease Care Clinic**

The chronic disease care clinic operates three days a week. There is only one male doctor who is trained to specifically deliver care to patients with chronic diseases at this centre. The clinic treats conditions such as diabetes, hypertension, cardiovascular diseases and asthma; however, patients with diabetes and/or hypertension are seen

most often. The patients treated at this clinic are either referred by the other clinics in the same centre if their blood sugar or blood pressure reading is high during a visit or have already been diagnosed and require a follow-up. If the condition is stable, patients are asked to follow-up every three months. Those whose disease is not controlled and require further monitoring are given appointments according to the physician's discretion.

The clinic is located on the first floor of the centre. It is a small room that can be reached via the women's waiting room. The doctor's desk occupies most of the room. It also has a small examination table, and unlike the other rooms in the centre, it is not covered by a curtain or surrounded by a partition. There is also a large cabinet with shelves that holds large files with the patients' diabetes monitoring forms organised by numbers. As mentioned, the building was not constructed with the intention of becoming a primary care centre, hence the unsuitable layout of some of the rooms.

Patients are given an appointment on a specific day but not at a specific time, which sometimes leads to long wait times if patients arrive at similar times. Waiting rooms are allegedly segregated for men and women; however, as mentioned, the ground floor is designated for women, and under no circumstances can men enter. They are restricted to the first floor. Nonetheless, women have no choice but to go to the first floor when they are required to visit the chronic care clinic or the laboratory. Although there are separate waiting rooms for men and women on the first floor, the clinic and the laboratory are located within the women's waiting room, and it is therefore inevitable that men will pass by the women when called to be seen.

Patients are called to be seen by the nurse according to the sequence in which their records were given to the clinic's nurse on a first-come, first-served basis.

## **6.4 The Observations**

As dress plays an important role in the way health professionals are perceived (Barbour, 2013). I asked the centre's manager and the healthcare professionals whether it would be preferable to wear a lab coat and a black scarf or to wear the black *Abaya*, which is what women wear in public. I was advised to wear a lab coat to blend in and therefore to gain more trust from patients.

I obtained verbal consent from patients in the waiting room prior to attending their consultations in the clinic. The consent of the physician and the nurse was obtained at the beginning of the field work, and it was emphasised that they could ask me to leave or to not observe at any time. I observed a total of 15 consultations with patients with type 2 diabetes and sometimes with other accompanying co-morbidities, which most often was hypertension.

I rotated between the clinic observing consultations and the waiting room obtaining consent and speaking with patients. I introduced myself as a doctor and a researcher studying in the UK.

Some patients seemed relatively anxious while they were waiting to be seen. One male patient mentioned that every time he comes, he feels as though he is preparing to take

an exam. Another patient said that he sometimes loses hope of ever being told that he is doing well.

The consultation with the patient is usually initiated by the specialist nurse, who is specifically trained as a chronic disease specialist nurse. The nurse measures patients' weights and blood sugar levels before asking questions about their general health and whether they exercise and are adherent to a healthy diet and medications. The nurse then completes a form that is used at each visit. This form allows the health team to observe trends regarding patients' weights, blood glucose levels, HbA1c and blood pressure over time. The end of the form contains 'yes' or 'no' questions regarding whether the patient is adherent to a proper diet, exercise and a medication regimen (Appendix 15).

An example of a common scenario of a clinic consultation in the chronic care clinic from the time that a patient with type 2 diabetes is called in by the nurse until they leave can found in Appendix 14.

During the observations, the health team did not seem to consider discussing the social or emotional impacts of diabetes on the patients' lives. Moreover, they did not seem to make an effort to learn details about patients' lives, their priorities or what motivates them. The physicians did not deter patients from voicing their concerns, but at the same time, they did not encourage it. It is understandable that physicians might not have the time to ask or might think that listening to patients' problems could distress them without the means to offer help; however, the doctors' avoidance might cause

patients to be unwilling to disclose their problems, and hence they may not receive the advice they actually need.

After a few days of observations at the clinic, I thought it would be interesting to observe consultations with patients who were newly diagnosed with diabetes to observe the interactions between the doctors and patients as well as how information regarding lifestyle changes and behaviour change was provided. I was interested in observing how the news was given to the patients and in observing whether physicians enquired about the patients' backgrounds, barriers and facilitators to self-management. No newly diagnosed patients visited the clinic, and I realised that patients did not come to the chronic disease clinic unless they were referred by the general clinics. Therefore, I obtained permission to attend consultations at the general clinic for a few days.

During the observations of the consultations at the general clinics, the news that a patient had diabetes was casually presented to the patient. All the patients I observed had a family history of diabetes, and they mentioned that they knew what they needed to do to manage their disease. They seemed to easily accept the diagnosis. The high prevalence of diabetes in society and the patients' familiarity with the disease might have led to the reduction in the patients' anxiety towards the diagnosis.

Unlike the GP consultations in the UK where the time limit of a consultation is a maximum of ten minutes, in Saudi Arabia, the consultation times are not limited because there is no rule regarding how much time each patient is allocated. The doctors did not spend much time with each patient to explain or to give advice regarding disease management. The information given to the patient was general. In some

instances, if a patient said that they were familiar with the management of diabetes, the attending physician would not elaborate to provide the patient with comprehensive information about the disease or disease management unless the patient enquired. Sometimes, the patient would be given a booklet and brochures about diabetes, and when a patient was illiterate, they were asked to have a family member read it for them. Consultations were therefore 'performative', as though there was a checklist to complete. The responses seemed set and generic and lacked individuality.

It might be difficult for physicians to incorporate self-management advice during patient consultations because no programmes exist, and the main focus of the health system still follows the medical model of disease management. One physician mentioned that it should not be the physician's responsibility to give patients detailed information and that it should be the responsibility of the nurse or someone who specialises in health education. Another physician working at the centre stated that the medical education they received did not prepare them to deal with chronic diseases because the main emphasis is on acute care and on 'fixing the patient and letting them go home'. Hence, the current medical education system seems to contribute to the negative attitudes physicians sometimes have towards patients with chronic diseases. It is certainly frustrating for physicians who are accustomed to the current medical model and who believe they have the power to 'fix' a patient to deal with chronic diseases. These diseases could deny the physician the opportunity to receive the affirmation and praise of people who recover from illness.



Physicians expressed that it is challenging for them to encourage patients to change their behaviours, especially when they do not understand the challenges patients face when changing behaviours. The knowledge patients acquire by living with a disease causes them to have a deeper understanding of their disease than the physicians themselves.

There was a general sense of frustration conveyed by physicians towards patients and vice versa. It was difficult for the physicians to understand the struggles in the daily lives of patients; however, they seemed to make assumptions about how patients progressed based on the limited time of their visits. On the other hand, patients seemed to adopt a passive role during consultations. This could have been due to their high trust in physicians and the inherent belief that they know best.

The health team seemed to have an unrealistic expectation that patients should easily adopt healthy behaviours as soon as they are diagnosed or as soon as the physician asks them to. This leads to patients being labelled as 'difficult' and 'incapable' of caring for themselves.

Throughout some consultations, it seemed that physicians tended to minimise some of the problems patients disclosed and to blame them for not controlling their disease. This is somewhat clear in the following scenario involving a man whose HbA1c was high, indicating that his condition had not been well-controlled in the past three months:

**Patient:** *Doctor, I feel like I am not seeing well these days. What is causing it? Would I need glasses?*

**Doctor:** *Diabetes ruins everything and because you are not controlling it your eyes will be affected for sure.*

## 6.5 Summary

Healthcare professionals seem to face challenges in encouraging patients to adopt self-management behaviours. There seem to be discrepancies between what the patients faced in their daily lives and what the physicians expected from patients. It is clear from the observations that physicians use a didactic manner to deliver advice regarding diabetes management. Moreover, the advice they give is often general and a similar advice is given to all patients without considering the barriers they face. The following chapter will discuss the findings from the FGDs.

## Chapter 7: **FINDINGS OF FOCUS GROUP DISCUSSIONS**

### **7.1 Overview**

This chapter presents the results of the FDGs with the participants who attended the programme sessions. The topic guide used to conduct these focus groups was based on the EVM, which was used for cultural adaptation (Appendix 20). As mentioned, the sessions and the group discussions were conducted in single-sex groups to conform to the social and religious norms of gender segregation. Two FDGs were conducted with those who attended the sessions after the end of each delivered programme. The results of both FDGs were similar therefore they were collapsed into one analytical set.

A total of five female and six male participants separately attended the first set of FDGs.

### **7.2 Deflecting Responsibility and negating change**

Deflecting responsibility was evident throughout the FDGs for both men and women. Men justified the lack of disease management, such as failing to perform physical activities, by being busy with work and being the financial providers of the household.

*“I don’t exercise because I don’t get a chance because I am busy”*

*“I don’t have time . till 7:30. My doctor is making me tired to be honest , he has to be patient with me.. he always tells me to walk.. walk. He is right. From*

*7:30 to 2:30 at work then at home,, a lot of errands but god willing I will try to walk”*

They also justified not adhering to a healthy diet by not being responsible for cooking or providing the meals.

*“I have a family and I’m busy and it is hard for me to take care of myself. My wife cooks for me and I eat the same food”*

Although most men justified not adhering to a healthy diet by blaming their wives, there were a few participants who stated that not having someone to cook for them was the difficulty in controlling their diet.

*“It is hard when you are single or not living with your family. It is easier when there is someone who cooks for you. I don’t eat from outside. I cook at home but it’s food for singles you know”*

Interestingly, when asked if they would prefer for their wives or the person responsible for the cooking in the household to attend the sessions, they did not welcome the idea.

*“My wife’s cooking is delicious”*

*“I would prefer to attend alone, leave my children alone”*

Women justified their lack of diabetes self-care differently. For example, they indicated that it was difficult for them to control their diets because they are responsible for the cooking, and they felt they needed to cook in a certain way to please their husbands and children.

*“If I don’t cook my other children will not come home.”*

*“what I find hard is when I have to have the feast in my house.. my husband knows a lot of people.. you know we are Hasaweeyah.. whenever they come to Dammam.. it is on me.. I cook all meals.. breakfast.. we put a Rahash and Alhalwa and al fowl and Albalaleet.. and Kabsah and Thabayh in dinner and lunch and the fruits.. dates and coffee back and forth.. it is not just about the food.. I get tired.. I can’t tell him not to bring them over.. he might marry someone else who would cook if I refuse”*

Women also justified their lack of exercise by stating they had other physical problems.

*“I don’t walk because I have osteoporosis. I can’t walk”*

Household chores were a common theme amongst women. Most women expressed that being responsible for the household chores is a hindrance to self-care.

*“Can’t do exercise. I get tired. I finished the house chores and I’m already tired. The problem walking back and forth for two minutes is not enough.. the doctor said it has to be half an hour”*

*“The house chores take more than half an hour so that is enough [talking about exercise]*

*“Exercise! House chores are enough”*

Women also indicated that the availability of house help helped them to better manage their condition.

*“Exercise! House chores are enough. I don’t have any house help and the all the chores are my responsibility and I’m very clean and I hate dirt”*

*“I have a daughter in high school. She cleans and does the laundry but cooking is on me and you know the difficult circumstances we can’t get house help and I suffer from my knees. May god make it easier inshallah”*

One participant expressed that having help with the household chores is actually a disadvantage to disease management.

*“We have this Sri Lankan lady who’s messing us up in the kitchen. Every time I want to go in the kitchen she refuses. She tells me don’t come in”*

*“She cooks and she uses lots of fat and lots of salt”*

*”because mashallah she’s experienced she pretends to be the boss”*

*“To be honest she became our boss”*

Women also expressed a fear of marital problems due to changes and a fear that their husbands would eventually leave them if they changed.

### **7.3 Religion and Reliance on Allah**

As explained, Saudi Arabia is a Muslim country. People's lives revolve around Islam and its practices, and because it is the country of Kabaa, those descended from the *Qur'an* believe that they have a duty to conserve it. Islam vastly influences the traditions to the extent that people have confused them with each other (Al Alhareth, Al Alhareth, & Al Dighrir, 2015).

The influence of religion is evident throughout the narratives of both groups. The use of religious phrases, such as *alhamdulillah*, *allah yaeen*, *inshallah* and *Wallah*, reflects that religion is interwoven into the Saudi culture.

Some female participants prioritised religion and religious activities over their health. They believed that Allah would care for them when they forgot their medication or in the event of *Omrah* or *Hajj*. From their perspective, Allah serves as an important factor responsible for maintaining their well-being and influencing their efforts to engage in self-care for diabetes.

*“I'm going next week [to omrah] although I have an appointment to have a colonoscopy in the central hospital but I'll pray and inshallah I'll be good and I will not have to do it “*

*“Diabetes can wait”* [speaking about going to Omrah without consulting the doctor]

*“The doctor told me that I don’t have to fast but I doubted him and I fasted”*

It is clearly apparent from these quotes that although the participants perceived physicians as an authority, the authority of Allah takes precedence. The patients would rather fast, which could be problematic when attempting to control blood sugar and taking medications, even if they are advised not to by their doctor. The patients are concerned about being stigmatised as weak for not being able to fulfil their Islamic duties as well as being stigmatised in society for prioritising their health and their bodies rather than prioritising Allah.

Some male participants deflected the responsibility of managing their diabetes to Allah (surrender to God’s will):

*“I eat randomly and leave it to Allah”*

*”it is god’s will. You just need to take your precautions. Take care of yourself and leave the rest to Allah”*

Surrendering to God’s will is also a reflection of the concept of fatalism. Fatalism is defined as *“a religious concept which attributes all life’s events to the will of God or supernatural powers”* (Ahmed, 2003-P.227). This concept is viewed theologically not only for Islam but also for other religions (Ahmed, 2003). Viewing health through a



fatalistic lens leads individuals to believe that health outcomes are not within their control but are destined by a higher power (Franklin et al., 2007).

The way individuals perceive fatalism has an impact on the way they perceive having an illness because they either have the motivation to manage the disease or adopt a passive role. Despite fatalistic views and believing that some life events are out of their control, most participants did not feel that their health was not within their control. Rather, they believed that they were in control of their health but that they should accept what they cannot control. For example, they still attended their follow-ups and did their best to care for themselves; however, they believed they must accept situations in which matters are not within their control, such as having complications, regardless of their efforts.

*“Alhamdolellah. I am accepting it. This thing [diabetes] is from Allah. Healing is from Allah. You have to do what you have to do to take care of it and Allah will grant you health”*

*“Allah has written it [diabetes] in our book but he [Allah] also created everything so we take care of ourselves. Allah created medicine for our sake. The prophet said” Make use of medicine. Allah has not created a disease without creating a remedy for it”*

These excerpts indicate that the participants attribute diabetes to Allah. They believe that Allah is in control of their diabetes and its consequences more than they are. They perceive Allah to be their health locus of control. Locus of control is a concept that

refers to the belief that the outcomes of actions are in our control or outside our control (Macaden & Clarke, 2010). In health, locus of control reflects the individual's belief about what controls their health. An internal locus of control is when the individual believes that their health condition is within their control and that their health behaviours dictates their health outcomes (Nazareth et al., 2016). An external locus of control, however, is when one believes that their health outcomes are outside their control (Nazareth et al., 2016). Having an external locus of control, like the participants in this study, was found to impact health negatively (Nazareth et al., 2016).

Moreover, participants believed that having an illness is fate, but they also believed that they are responsible for their health and the consequences of caring for their disease or the lack thereof. It is interesting that participants acknowledged that they are responsible for their health and the consequences of not managing the disease but still provided justifications for not altering aspects of their lifestyle. Interestingly, participants who had family members with diabetes also viewed being diagnosed as foreseeable and something that could not be avoided and therefore due to external factors beyond their control.

Some participants expressed that 'Allah will not give you something you cannot handle', which highlights the acceptance of the responsibility for their well-being and their belief that people 'given' diabetes by Allah have more potential to accept the disease as well as the will to make an effort to manage the disease. This could be

related to several aspects, such as financial, circumstantial aspects, and not only related to self-care. This assertion could also be viewed as a coping mechanism.

Some participants believed in the healing ability of *al shaikh*, who is a religious healer who heals illnesses by reciting verses of the *Qur'an* or making water that religious verses was read over it as a form of healing. Participants did not entirely believe that '*shaikhs*' would heal them, but they stated that '*having a shaikh reciting Qur'an on you or drinking water that Qur'an had been read over won't hurt. If it didn't work just consider it a blessing*'.

Participants also showed that they accepted the disease and were motivated to tolerate the difficulties they faced. They expressed that diabetes is a test of their faith, and if they prove patience, Allah will reward them in the afterlife. They also believed that any sickness is a '*mahee al thnoob*', or an eraser of sins.

*"Allah doesn't give you a disease for no reason. He [Allah] gives you righteous deeds for it"*

*"It is true that living with it [diabetes] is hard sometimes but my sins will be erased inshallah"*

Some participants expressed that some religious practices, such as their daily prayers or fasting, are regarded as a sanctuary from their daily struggles with diabetes and offer them hope that they are doing their best for Allah to grant them good health. Some also expressed that they employed religious practices, such as payers and reciting the *Qur'an*, to alleviate minor pain and illness:

*“I often feel very fatigued in the early evening so I start with dua’a [prayers of supplication] to Allah or I recite some verses [of the Qur’an] and I immediately feel better”*

It could be argued that religion in the context of health and behaviours is only used as a rhetorical device, though it is difficult to determine whether this is true. Islam is unlike Christianity, and Saudi Arabia is unlike any other country. People are immersed in Islam with reminders of their religion wherever they go, such as by prayers five times a day. Also, this could be a manifestation of the strict enforcement of religion.

#### **7.4 Knowledge demonstration**

The demonstration of knowledge was more obvious amongst women. Throughout the FGDs, women tended to give advice or correct each other regarding disease management and lifestyles.

*“Go around your living room” [talking about exercise]*

*“Tell her [house help] that you guys are sick and fat and sugar and salt are not good for you”*

*“You know (tasbeerah) it has the calories on the back of the packaging ..they deceive us with it you know.. they call it Tasbeerah (snack) but it equates a whole meal .. it has maybe 300 calories or more and a lot a lot of it is just fat .. where is the protein? Just a bit if you are going to eat the one with cheese.. that one has more fat in it too.. it is not good”*

*“it is not hard.. check your feet and if there is any wound go to the doctor”*

## **7.5 Family Support**

Letting others take control or share control

Female participants stated that members of their family, i.e. sisters, daughters and sons or granddaughters, helped them manage diabetes, either by managing their diet, monitoring their blood sugar or reminding them to take their medications.

*“My granddaughter measures for me.. my family are the opposite they help me because they tell me off all the time.. my granddaughters. For example if I ate something not good and they check on me at night”*

*“She takes care of me all the time .. all the time.. but she already knows more than me anyway”*

*“yh my granddaughter told me it is not useful .. preservatives and things.. I never tried it in my life”*

The presence of family members was often considered to have a positive effect on managing the disease. Alternatively, at times, the presence of family members was a hindrance to maintaining a dietary regimen or performing physical activities.

*“If I don’t cook my other children will not come home”*

*“Wallah it’s hard.. I cook anything for the kids. Whatever they want I make for them”*

Women believed that their husbands did not adopt a supportive role and were a hindrance to self-care, especially because women are responsible for the household chores and cooking.

*“My problem is that my husband is very old, ancient and I have to take care of him”*

*“Ramadan is the hardest especially with the house chores and the husband, I want this and I want that and they are pampered like pregnant ladies”*

*“He might marry someone else who would cook if I refuse”*

*“He doesn’t allow me to walk in the street”*

Although women believed their husbands did not play a supportive role, they did not agree that their husbands should attend the sessions.

*“My husband? He barely allowed me to come to the programme, he thinks I’m just pampering myself or maybe so I don’t do the house chores”*

*“No, he’ll just think you are exaggerating with all of this”*

*“My husband is too busy to come to something like this.. maybe my daughters..  
no one will take care of you like yourself”*

This is understandable because the attendance of other family members might expose more details regarding how they actually manage the disease and may provide a different view than the way they represent themselves in the group.

## **7.6 Unavailability of Structured Education Regarding Management after Diagnosis**

The high attendance of the sessions reflects the interest of participants to learn about diabetes and diabetes self-management. This was also reflected when participants stated that there should be an education programme available for all patients at the time of diagnosis. They believed that it would have been highly beneficial to have such a programme available to them when they were newly diagnosed with diabetes. One participant, who was 52 years old and had diabetes for the past 12 years, stated that learning about self-care behaviours would have been more beneficial if it were provided at the time of his diagnosis:

*“Wallah I am sure if I attended this programme 12 years ago I would have  
been more careful. An expert! It is easier for a person to change things while  
they are young and without responsibilities. If you change your lifestyle when  
you are young, with time you just get used to it”*

Another participant stated that the concern he had when he was initially diagnosed would have motivated him to change his lifestyle, but the confusion he experienced regarding how to manage diabetes in the best way prevented him from taking action:

*“There was no one to tell us specifically what we need to do. They did not say you have to change most of your lifestyle. The doctor who told me that I had diabetes made it seem so simple. You go home and not know what to do and then you just put it the back of your head and go on. I needed to know this a long time ago”.*

## **7.7 The Doctor-patient Relationship**

### *7.7.1 Power Dynamic*

Although most participants regarded healthcare professionals, physicians specifically, as the most credible source of information and sometimes support, they occasionally— with hesitation— criticised them for not providing patient-centred management. Participants stated that they often felt that healthcare professionals are *“only concerned with the numbers [laboratory results]”* and *“What is of importance to them [doctors] is to give you your medication and let you go”*.

Some participants perceived that they are treated as ‘the disease’ and not as a person with a disease. They expressed that they acknowledge that each patient has individual personal circumstances and thus faces different barriers to managing diabetes, but they indicated that doctors should inquire about the barriers that patients face when



attempting to apply changes to their lifestyle and perform self-care behaviours to provide applicable advice.

*“They tell you a list of things to do for you to be better but they don’t know anything about your life circumstances. For example when they [health care professionals] tell you: do exercise..OK.. where and how? How do we know what they mean and we never in our whole lives did we do exercise?”*

Interestingly, despite criticism, the participants rationalised the doctors’ attitudes with being busy and being overwhelmed by the number of patients they treat.

*“I don’t know...maybe it is not the responsibility of the doctors to ask me about my life circumstance. Their job is to treat the diabetes not my never ending problems. Each individual has their speciality. To be honest who would listen... husband, children and their children and the house chores”*

*“Allah y’eenhom..their [the doctors] job is very hard but I am sure that they try to do their best. The centre is always busy and they have to see a lot of patients everyday”*

This is a reflection of the power dynamic and a power differential in doctor-patient interactions. Most patients in Saudi Arabia inherently perceive doctors to have authority, which they tend to view positively, and expect that doctors will act according to the patients’ best interests. The effect of this dynamic is immediately evident when entering the waiting room of the centre. As mentioned in the observation chapter, some patients are somewhat anxious prior to being called to the clinic.

Interestingly, contrary to participants' beliefs that physicians should enquire about the barriers they face, they tended to underestimate their own knowledge and defer the responsibility of making a decision regarding their care to their physician.

*“The doctor has the knowledge and they know best”*

*“Even if they give me choices about what I should do [treatment plan] I ask them what they think is best. I go see them to tell me what to do otherwise what is the point”*

Thus, it is not surprising that they unanimously preferred for the sessions to be delivered by physicians only.

The patients believed that being passive and complaining less makes them ‘a good patient’ and that engaging with the physicians would lead to them being labelled as ‘difficult’. They were concerned that they would not receive good care at future visits (Joseph-Williams, Edwards, & Elwyn, 2014). This was observed during the clinical observations. This belief is inherent among Saudi patients, especially those who are older and less educated.

The power differential became evident when patients mentioned that they considered asking the doctor questions to be a challenge to the physician's authority:

*“it is inappropriate to say no to them because that means you don't trust them [doctors] or their expertise. They don't like it I think”*

### 7.7.2 Doctor-patient Dyads

The majority of female participants deemed that the gender difference between them and their treating physicians inevitably explains the physician's lack of understanding that they perceive:

*“The doctor advises me to do things to take care of myself. He tells me to eat better and do exercise etc. but at the end of the day he is a man. He will not understand what I have to go back home to. Too many responsibilities that don't even cross his mind at all”*

*“It is hard and embarrassing to open up about difficulties with a male doctor. Of course it is different if it is a women”*

In this study, the doctor-patient gender relationship was only discussed among women. This could be explained by the fact that all participants were recruited from a centre in which the chronic disease specialist is a male, and therefore the issue might not have been applicable to the male participants in this study.

## 7.8 Gender Norms

Some women are concerned that they could seem unfit to their husbands if they complain or if they do not cook meals that their husbands prefer, and there is a concern that their husbands may seek another wife because Islam allows polygyny.

*'if I don't cook what my husband wants he might just go and marry someone else. Where would I go? They say the key to a man's heart is his stomach. They are right'*

On the other hand, men expressed that their role as the heads of the family and the breadwinners is a major hinderance to self-care.

*'It is my wives job to do everything inside the house. I take so much responsibility in taking care of my children, so I don't need more thinking and more responsibilities. It is just food in the end'*

## **7.9 The perception that the Saudi culture is inherently problematic.**

This finding was more common amongst the female participants than the male participants. Female participants expressed that being Saudi in itself was an impeding factor to adopting self-management behaviours. They compared the difficulties for Saudis to adopt healthy behaviours with the ease of adopting these behaviours in the West.

*'You see the foreigners in the movies.. they go to a picnic and they only bring a small basket that has a few sandwiches in it, that is it. we bring "mafattah". We think about food when we do everything. if we are going to a trip, the first thing we think about is what food we bring with us and what we are going to eat there'*

Nurah, who's son is studying in the US said *'I went to visit my son in America. It's not compulsory for women to cook .they appreciate women there ..not like*

*here..everything is on our back [women]. If they want to cook sometimes everything is ready, the salads are washed and chopped including the onions'*

On the other hand, Fatmah found that because her husband is not Saudi, he is more understanding when it comes to cooking

*'I don't find it difficult to deal with my family [talking about diet and cooking]. Maybe my husband is more understanding because he is not Saudi'*

## **7.10 Other Aspects**

### *7.10.1 Location*

It was agreed after the informal meetings with healthcare professionals for the first set of sessions to be conducted in a local mosque; however, almost all of those who participated in the first FGDs agreed that they preferred that the sessions take place in the primary care centre. This indicates that participants wanted the sessions to be considered part of their treatment. They might take the programme more seriously if it was conducted in medical settings.

*'My husband will laugh at me if I told him I was going to the mosque for medical teaching'*

*'keep the medical thing for the medical place. We visit here almost five times a day. Let us change'*

There was unanimous agreement among participants across all the FGDs that they preferred for the programme to be conducted by a physician, preferably a specialist in diabetes. This shows that participants have high trust in medical doctors. ‘quotes’

### **7.11 Motivators to participate in the programme**

Participants shared the reasons behind their participation in the programme. The women’s group mainly focussed on sharing their diabetes lifestyle-related problems with others without feeling judged, and they socialised and met other women hoping to learn simpler ways to change their lifestyles and adopt healthy behaviours.

*“I chose to participate because I thought the sessions will be an opportunity to meet other women that might have the same problems I face. We all live in similar circumstances, you know, the home and the family. By sharing how we deal with it all, we might learn something”*

*“When you have the chance to join something that will teach you useful information and you can also share some of your diabetes problems with other women that are not your family members, why not attend? I share my diabetes problems with my sister, who also has diabetes, but it is not the same. No matter what, she [sister] will be stricter with me because she cares about me, she shouts at me [laughs]”*

The men’s group, on the other hand, expressed that they were motivated to participate because they wanted to feel that they were actively engaging in positive behaviours to improve their health.

*“It is good to have something that offers guidance to deal with this [diabetes]. I thought I will not lose anything if I participate. If it is useful, my health will improve”*

*“I have been diagnosed for a long time now, but I always feel that I’m not doing enough to take care of the diabetes. I take my medications as the doctors tells me, but I still feel that I am not doing enough”*

## **7.12 Barriers to Attend the Programme**

Participants across all FGDs agreed that the time commitment is the main barrier that could discourage others from opting to attend the programme.

### *7.12.1 Group-based vs. Individual-based Programme*

A few participants indicated that they were initially apprehensive that the programme was group-based because they did not know the level of disclosure expected from them during the sessions.

A woman stated that *‘when you told me it was going to be a group, I was not too sure. I am generally shy but also was worried about having to share private matters. It was reassuring when we were told we can only say the things if we want’*.

Another women said that *‘to be honest, I was concerned that I will be with people I know and they know me or a member of my family. You know how it is in our society. They will go and talk about you and say Fatimah does this and doesn’t do that. To be*

*honest I would have probably only attended only one session if there was someone I know participating. I don't trust some people even though you told us that we were not allowed to talk about what happens in the session outside'.*

A few participants also mentioned that they were concerned about feeling embarrassed in front of other participants if they lacked knowledge about diabetes or that they might be stigmatised as lazy in terms of managing diabetes, so they needed to place effort into convincing themselves to attend.

*“.....we are all in the same boat”*

### **7.13 Summary**

This chapter discussed the main themes that emerged from the FGDs. The main themes are gender norms, religion and reliance on Allah and patient-doctor relationship. The upcoming chapter demonstrates the adaptation that took place after being informed by the data collected from the FGDs and the sessions.



# Chapter 8: **THE CULTURAL ADAPTATION OF THE PROGRAMME**

## **8.1 Overview**

This chapter will show the aspects of the programme that were adapted in line with the conclusions drawn from the collected data. The adaptations were heavily informed by the findings of the FGDs as well as issues and challenges that arose during the delivery of the sessions. The synthesised data were discussed with a team of health care professionals (two physicians and a nurse) in informal meetings to decide which aspects to adapt.

I will present the results of the adaptation in in three sections;

1. Phase 1 – Preliminary Adaptation: which only involved choosing the location of where the sessions will be conducted and the timing of the sessions.
2. Phase 2 – The First Adaptation.
3. Phase 3 – The Second Adaptation.

The main aspects that were adapted in the First Adaptation were omitting any mention of alcohol in the sessions, addressing misconceptions about some foods and including the nutritional composition of Saudi traditional dishes. The Second Adaptation included adding information about Ramadan and fasting with diabetes.

## **8.2 Phase 1: Preliminary Adaptation**

As mentioned previously, it is recommended by The Stanford Self-management Programme developers to initially deliver the programme without any adaptations (informal conversations with Kate Lorig and Dr Fusae Abbott during the training). This is also supported by Chen et al.(2013). This was to ensure that assumptions regarding the aspects that need adaptation were not made prior to exploring the programme with the target group. Also, to maintain the fidelity of the programme as much as possible. Therefore, only practical and logistic aspects such as the location of where the sessions of the programme were to be delivered and the time (the day of the week and the specific time of the day) were the only aspects discussed with the health care professionals prior to recruitment for the first set of sessions during phase 1.

Although the developers of the programme suggest that the programme is likely to be more effective when facilitated by lay people than when it is delivered by health care professionals, it was assumed that participants would prefer that the sessions are facilitated by health care professionals due to doctor-patient power dynamics as previously discussed in Section 7.7. It was also logistically and financially unfeasible to recruit and send a lay person to undertake the training in Stanford University.

### *8.2.1 The Location*

The aim in these discussions was to choose a location that is somewhat community oriented such as a local mosque or a school, and not the primary health care centre itself, as the target audience may feel more comfortable and interested in participating

if they perceived it to be a social programme rather than a medical one. Conducting the programme in a local school proved difficult. Since schools are segregated by gender, it would be therefore necessary to select two schools; a girls' school for the women's group and a boys' school for the men's group. The process would also entail seeking the approval of The Ministry of Education and going through a lengthy bureaucratic process, therefore, due to time constraints, this option was excluded. We decided to choose a local mosque where both men and women were allowed as some mosques are designated for men only.

### *8.2.2 Timing of Sessions*

It was agreed to deliver the sessions in the evenings. This was to ensure that we do not exclude those who are employed in morning jobs as the majority of the centre's working population held governmental jobs. Moreover, to include those who maybe unemployed or retired.

### *8.2.3 Other Aspects Considered for Adaptation*

A discussion took place in the informal meetings with the health care professionals about some aspects that participants may find offensive or be sensitive to. These were mainly the following aspects:

- In the first session of the programme, an activity on 'getting a good sleep' includes a section which notes that alcohol interferes with sleep. Moreover, in the second session, a small lecture about hypoglycaemia included a discussion about alcohol as a cause of hypoglycaemia. There was a debate

whether to omit these sections or to include them in the session. Some of the health care professionals recommended including them in the session. Those who did not agree expressed that assuming that participants drink alcohol may be offensive to some participants. On the other hand, the professionals who suggested to deliver these sections of the sessions, justified it by the fact that it is a good opportunity for participants who might be consuming alcohol, and who might otherwise not mention it to their physician due to the stigma attached to it, to know this information. Although alcohol consumption is forbidden religiously hence banned legally in Saudi Arabia (Al-Haqwi, 2010), alcohol use is not uncommon (Bell et al., 2017; Sweileh, Zyoud, Al-Jabi, & Sawalha, 2014), especially amongst young adult males (Al-Haqwi, 2010). Therefore, it was decided to deliver both sessions without omitting the sections about alcohol.

- The fifth session of the programme includes a section about communication skills. To demonstrate good communication skills, the manual provides dialogues between partners about sex and intimacy. Most health care professionals were against discussing this taboo subject with both men and women groups, but they were especially against a female facilitator and a female assistant discussing such subject with the men group, in particular. They expressed that participants may view introducing the topic of sex and intimacy as inappropriate and that it would cause embarrassment among the participants. They therefore worried that it would affect attrition rates. Despite the subject of sex being a taboo in

Saudi Arabia and in the Islamic and Arab world in general (Dupont, 2016), it was decided not to make assumptions regarding how participants may view the discussion of this topic in a public space as the dialogue is not in any way explicit. Unfortunately, at the time of delivering this section of the session I felt quite reserved to deliver it to the men group. However, I made a note to bring this topic up in the FGDs to explore their view about discussing such topic publicly.

### **8.3 Phase 2: First Adaptation**

As mentioned in the methods chapter, after the Preliminary Adaptation took place, the six-week programme was delivered to two groups; a group of women and a group of men. This was followed by FGDs with each group of participants. The following issues arose during the delivery of the sessions in phase 2 and/or were informed by findings from the subsequent FGDs. The decision regarding adaptations were made after these aspects were discussed with the health care professionals:

- As part of first session an overview of all the sessions was included. The aspect that participants made note of was that there is no activity dedicated to demonstrating and teaching how the glucometer is used to measure blood glucose levels or how insulin injections are administered. The manual of the programme suggests that participants speak to their physician and/or seek other community resources that may be able to provide such services. In the FGDs, the participants mentioned that they expected for the programme to include some practical training and wished

for such training to be added, however, the programme manual explicitly states that the programme is not a replacement for medical care. Unfortunately, community sources are not widely available in Saudi, therefore, the participants were instructed to speak to their physician or nurse to train them to use the glucometer. This type of training could not be adapted in the programme as such an adaptation would deviate from its fundamentals.

- In the FGDs findings, participants state that alcohol is forbidden for them as Muslims, therefore it is inappropriate to mention it during the sessions. This coincides with the theme ‘Religion’ in the findings of the FGDs. Therefore, all sections that mention alcohol were omitted.
- Reading nutritional labels from food packaging proved challenging during the delivery of the fourth session. Participants were asked in the third session to bring packaging of foods they regularly consume. It was revealed during the session that most packaging did not include nutritional labelling. Despite the existence of a policy that was issued in 2013 by The Saudi Food and Drug Authority (SDFA) that requires food products to display nutritional information (H. Ahmed & Mousa, 2013), products are rarely labelled.
- On packaging that included labelling, the labels did not explicitly state the portion size or was written in a very small font, making it almost impossible to read. Exported products usually have a sticker on the

nutritional label that translates the list of the ingredients of the product to Arabic (Pictures in Appendix 16). Participants also mentioned they often purchased food products that do not include labels, such as food purchased from traditional markets or commonly consumed grains such as rice and wheat which are normally purchased in large burlap sacks (Figure 16 in Appendix 17). To adapt this aspect, it was decided that it would be best to provide samples of food packaging with clearly displayed nutritional labels and emphasise the importance of nutritional facts per portion size. For example, the nutritional properties for a cup of rice. Al-Mssallem (2014) provides a list of the nutritional composition as well as the glycaemic Index of common traditional Saudi dishes. Although the methods of cooking these dishes were not mentioned, we decided to use this list as a rough guide when delivering the next set of sessions (Appendix 17 and Appendix 18).

- Participants expressed in the FGDs that the programme did not address certain foods that are consumed on a daily basis by most Saudis, particularly rice, buttermilk (yogurt drink), Arabic coffee and dates. Without scientific evidence, Saudi people with type 2 diabetes are often instructed not to consume dates (Al-Mssallem, 2014). Dates surely affect blood glucose levels, however, the glycaemic Index for most types of dates is low (Al-Mssallem & Brown, 2013). Therefore, it was decided to emphasise the programme's messages about eating in moderation and addressing the foods mentioned above.

- As mentioned in the findings of the FGDs, participants were unanimous in preferring that sessions are delivered in a hospital or a primary care setting rather than a community setting.

Table 3 summarises the adaptations and challenges arising during the delivery of the phase 2 sessions and/or the findings of the subsequent FGDs

<b>Identified challenge</b>	<b>Data source</b>	<b>Adaptation</b>
How to measure blood sugar, use the glucometer and/or administer insulin	During the delivery of session 1 and FGDs	Not possible to include glucometer training and/or insulin administration as it is against programme's principles.
The section of the lecture about Alcohol as a cause of hypoglycaemia as well as affecting quality of sleep	FGDs	All sections that mention alcohol will be omitted in the next delivery of the programme
The importance of foot examination only mentioned but with no instructions provided	During the delivery of session 6 and FGDs	Not possible to include practical instructions for foot examination.
Reading nutritional labels from food packaging	During the delivery of session 4	Provide packaging with clear labels, however, emphasise the importance of nutritional facts per portion of commonly consumed food.
Communication skills (the sex and intimacy dialogue)	During the delivery of session 4 and FGDs	The dialogue was omitted (for the men group)
Reduce medication expenses	During the delivery of session 6	This was not relevant to the participants in this study therefore it was omitted in the delivery of the programme
Location	FGDs	Changed to the primary care centre
Misconceptions about certain foods that are not addressed.	FGDs	These misconceptions were address through emphasising the programme's messages about these certain food items

**Table 3 Summary of adaptations considered after phase 2 sessions**



## 8.4 Phase 3: Second Adaptation

The programme was adapted with the aspects selected from the First Adaptation and delivered to a different group of participants. As mentioned previously, both sets of FGDs were very similar, therefore, aspects that were not possible to adapt such as the lack of practical training with using the glucometer and instructions to foot examination were also among the findings of this phase.

The following findings that arose during the delivery of the sessions and/or were findings of the FGDs:

- The first session in the programme included a ten-minute lecture about “Getting a good night’s sleep”. During the session, participants discussed that a good night’s sleep can be achieved by reciting the Quran and specific prayers that help to fall asleep. The topic was also mentioned in the FGDs. Participants preferred to be taught about specific verses in the Quran and prayers that may help them fall asleep. The participants expressed that aspects of the programme such as ‘Dealing with difficult emotions’, ‘The body scan’ and ‘depression management’ also need to include religious messages specifically about recompense from Allah for having diabetes and how such messages could instil hope and therefore encourage self-care. It is not possible to adapt this aspect because the programme material was developed to be inclusive and not mention religion specifically. It is allowed to mention Allah, for example, but it is not recommended to convey any religious messages during the sessions.

- Surprisingly, the participants who attended sessions in the first phase did not mention the need to address managing diabetes during Ramadan as well as voluntary fasting. The reason behind this could be that the delivery of the second set of sessions took place directly after Ramadan. Fasting involves abstaining from eating and drinking from dawn till dusk (M. H. Ahmed et al., 2017). However, it is also considered a month of celebration where families often get together to break their fast over abundant amounts of food (M. H. Ahmed et al., 2017). Fasting can have detrimental effects on the health status of people with diabetes. It is essential for those who fast to consult with their physician to change their medication schedule and/or change their medications (Hassanein et al., 2017). Although Ramadan is also a religious practice, incorporating this into the programme is essential due to its direct impact on the person's health. The guidelines developed by IDF and Diabetes and Ramadan International Alliance (DAR) (Hassanein et al., 2017) can be used in the future.

Table 4 summarises the adaptations and challenges arising during the delivery of the phase 3 sessions and/or the findings of the subsequent FGDs.

Identified challenge	Data source	Adaptation
Getting a good night sleep-providing Quranic verses and prayers	During session 1 and FGDs	Not possible to adapt
Dealing with difficult emotions through religious messages	During session 2 and FGDs	Not possible to adapt
Depression management	FGDs	Not possible to adapt
Information about Fasting and Ramadan and diabetes	FGDs	An essential aspect to address using guidelines developed by IDF and Diabetes and Ramadan International Alliance (DAR)

**Table 4 Summary of adaptations considered after the second delivery of Phase 3.**

## 8.5 Summary

This chapter presented the aspects of the programme that were brought up in the FGDs and the sessions, discussed whether the programme was adapted for them, and the justifications for the decisions made with the health care professionals regarding their adaptation. The Preliminary Adaptation involved choosing a location and timings for the session. The aspects adapted in the First Adaptation were: omitting any mention of alcohol in the sessions and the dialogue about sex and intimacy, addressing misconceptions about some foods, include the nutritional composition of Saudi traditional dishes and omit the section of session 6 about reducing medication expenses. The location where sessions take place was changed from a community setting (mosque) to a health care setting (primary health care centre). The Second Adaptation mainly involved adding information about Ramadan and fasting with diabetes.

To maintain the fidelity of the programme as much as possible, the aspects selected for adaptation were minimised and applied judiciously. More adaptations need to be addressed for this programme to be relevant to the Saudi context. Most factors involved are external factors such as availability of community resources and involving the patient in their own care. For example, most participants mentioned that they have never been taught how to examine their foot and they did not think that they should learn, as they perceived it to be an examination that should be done by a specialist.

The following chapter discusses the findings of this study and provides an account on the requirements for self-management interventions in general to be more relevant to the Saudi context.

# **Chapter 9: HOW CAN A SELF-MANAGEMENT PROGRAMME BE RELEVANT TO PATIENTS WITH TYPE 2 DIABETES ATTENDING A PRIMARY HEALTH CARE CENTRE IN SAUDI ARABIA?**

## **9.1 Overview**

This chapter discusses the aspects that need to be addressed for a self-management programme to be relevant to patients with type 2 diabetes attending primary health care centres in Saudi Arabia. These will be discussed in light of the reviewed literature and findings of this study. It will also provide some insight on self-management models of care that are potentially relevant to the Saudi context.

In the process of adapting the programme, aspects relating to alcohol, and the sex and intimacy dialogue were omitted. Misconceptions relating to food and the nutritional composition of some traditional foods were added after the first phase. Information about dealing with diabetes during Ramadan was added in the second phase (which was not further delivered). However, The FGDs findings revealed that participants face more challenging issues with regards to self-managing their diabetes which need to be addressed in order to produce a more relevant programme to those participants. Unfortunately, as mentioned previously, it was not possible to adapt or completely change some aspects of the programme due to the threat to its fidelity. Moreover,

cultural adaptations should not lead to developing a new programme but to generate a culturally equivalent version (Castro et al., 2010).

Although the participants voiced the need for the availability of a diabetes self-management programme, and had appreciated the programme they attended (Section 7.6), the findings of the FGDs indicate that the Stanford DSMP does not fully fit their needs, and more importantly, does not seem to be completely in concordance with their day-to-day lives. The aim of a diabetes self-management programme is to help patients deal with their daily lives in order to effectively self-manage their disease. However, due to the extent of the effect of gender norms, social expectations, and religion on self-management in the Saudi context, as seen from the findings of this study, the DSMP is not realistic for this specific context.

In hindsight, this study would perhaps have been more fruitful if the target population were involved before deciding on delivering a specific intervention (The DSMP) and were asked about their needs and their perceptions on the best way to help them self-manage their diabetes. This could have led to the decision to develop a new programme that is more consistent with the participants daily lives.

The next section will discuss how to possibly address gender roles, religion and other aspects such as the availability of resources in a future diabetes self-management programme that is relevant for the Saudi context.

## **9.2 Aspects to address in future programmes to be more relevant for the Saudi context**

### *9.2.1 Gender and social norms*

The DSMP would not aid the individual to adopt healthy behavioural change if they prioritise other aspects over their health. Its content and messages rely on the individual to adopt a healthy behaviour without considering other influencing factors and priorities the individual may have over their health. For example, participants in this study mentioned that they face difficulties in changing their eating habits. As discussed under Gender Norms and Social Expectations (5.2) as well as the findings of the FGDs (Section 7.8), women prioritised the gender role and social expectation of being a wife and a mother over adopting healthy eating. Their needs seem to be governed by those of other family members, mainly children and husbands, who favour an “unhealthy diet”. Women perceived change as a potential threat to their marital status. They worried that if they do not provide the food their husbands prefer, their husbands would leave them and/or marry other women (polygyny). As mentioned in Section 5.2, this is considered to be a sign of failure of marriage socially, and as a consequence, women would not be able to control their lives or that of their children due to the legal authority their husbands have over them. Therefore, women in the Saudi context experience profound pressures relating to diet change which others are unlikely experience in the same way. This would inevitably make the idea of change seem insurmountable to them.

Men, on the other hand, deflected the responsibility of changing their diet to their wives (Section 7.2). They justified this with their preoccupation with being the breadwinners, as expected of them socially. Interestingly, single male participants dismissed change to their diets due to not having someone that would prepare meals for them (mother or wife).

It is apparent from the findings of this study that women and men experience self-management behaviours differently. Social norms significantly influence an individual's behaviour, hence merely raising awareness and providing education may not be enough to elicit behavioural change in some individuals (Grace, Begum, Subhani, Kopelman, & Greenhalgh, 2008). Both gender and social norms are extremely difficult to change especially in the short term. Therefore, gender specific self-management advice is warranted. For example, it has been suggested that diabetes self-management should specifically target women because they are the caregivers and the ones that bear the responsibility for providing family meals (Bertran, Pinelli, Sills, & Jaber, 2017).

### *9.2.2 Religion and reliance on Allah*

As discussed in the context chapter (Section 5.4), religion is deeply rooted in the daily lives of Saudis. It strongly influences most aspects of life including social and gender norms, as well as adopting health behaviours. This was evident in the findings of this study (Section 7.3).



The findings of this study suggest that Allah is the participants external locus of control (section 7.3). They have a strong conviction that Allah is in control of their health despite any measures they could take to improve it. They also perceived diabetes as fate and a source of reward in the afterlife. Moreover, they prioritised religious activities, such as fasting despite their ill health, and missing important medical appointments to go to Omrah, as they believed that Allah will compensate them with good health.

The instructions of the DSMP highly prohibits mentions of a specific religion during the sessions, as they predict that it could cause conflict between the attendees. However, during the delivery of the sessions and the FGDs participants mentioned that the reference to Islam and Allah was necessary. The programme content and messages assume that the patients' locus of control is internal therefore it does not address behavioural change from an external locus of control perspective.

It is essential to recognise the role religion plays in patients' lives and attempt to employ it to encourage and promote behavioural change for overall health. A self-management programme for the Saudi context should address locus of control and aim to improve patient's internal locus of control. Messages of hope could be incorporated to the programme. For example, that Allah will heal and reward them for their efforts.

Religious scholars and mosque Imams may have a big impact on patients with diabetes as they are trusted individuals in the community. As religious activities such as going to the mosque are an everyday activity to some, messages about diabetes care may be incorporated in their teachings (Grace et al., 2008). They may also address some

religious misinterpretations that patients may have; such as fatalism (Grace et al., 2008) and taking responsibility for one's health.

### 9.2.3 *Other aspects*

Viewing collectivistic cultures such as the Saudi culture with an individualistic lens, hence promoting health through messages directed only to the individual, may prove problematic. Participants in this study perceived aspects of the collectivist culture positively, such as receiving emotional and practical support from family members where daughters or granddaughters helped with using the glucometer or with advice regarding their diabetes (Section 7.5). However, some aspects were perceived negatively, especially by women, who feel they must subjugate their family's needs over theirs (Section 7.8). A programme for the Saudi context may need to consider a collectivist approach, where family members are all involved.

Practical and clinical aspects such as using the glucometer, injecting insulin, and foot examination technique are not part of the programme. The programme emphasises their importance as part of optimal diabetes care, however, due to legal liability, it refers participants, who ask for instructions on them, to their physician. During the delivery of both phases, as well as during the FGDs, participants highlighted the need to be trained to use the glucometer, effectively examine their feet and use insulin injections. These are an important part of diabetes self-management and it is essential for patients to learn them as part of daily diabetes care. Participants in this study, as seen under family support theme from the FGDs (Section 7.5), rely on family members to measure their blood glucose daily. Therefore, in the Saudi context, these skills

should be part of a self-management programme. The inclusion of such aspect may increase the confidence of patients in managing their diabetes.

Participants perceived that being Saudi is inherently problematic with regards to self-management (Section 7.9). They cited the abundance of resources in the West that help individuals to adopt positive health behaviours relative to those in the Saudi context. The availability of resources aids in adopting and adhering to self-management behaviours (Mathew, Gucciardi, De Melo, & Barata, 2012). Having resources available; such as readily available healthy foods, designated areas for exercise, or an environment where walking is possible, might encourage patients to change.

Participants in this study considered sharing their diabetes experience with other patients with diabetes to be a motivator for their attendance (Section 7.11). Moreover, during the sessions as well as the FGDs participants tended to demonstrate their knowledge and give each other advice on diabetes care and management and correct each other (Section 7.4). Patients in the Saudi context could benefit from The Sharing Story Model developed by Greenhalgh et al (2009). The model was developed for South Asian communities in the UK. Greenhalgh et al (2009) research revealed that story telling between peers, rather than a structured educational self-management programme, may trigger behavioural change. The sharing story intervention involved informal and unstructured story sharing between participants, facilitated by a trained lay worker. Input from a clinician must be provided as a response to these stories (Greenhalgh et al., 2009). When tested in a randomised control trial, it showed to have

minimal impact on clinical outcomes, however, it was better attended and yielded better patient enablement when compared to the structure nurse led educational programme. Saudi patients with diabetes may benefit from the Sharing Story Model as one aspect of a newly developed programme incorporated within a structured self-management programme.

### **9.3 Summary**

This chapter noted that the DSMP adaptation does not fully meet the needs of the participants in this study. A new programme should be developed specifically for the Saudi context.

The chapter discussed the aspects that need to be addressed for a self-management programme to be relevant to patients with type 2 diabetes attending primary health care centres in Saudi Arabia. Gender and social norms, religion and other aspects such as the availability of resources were discussed as essential aspects to consider when developing a self-management programme that is relevant to Saudi patients.

It is recommended to use a gender specific approach when developing self-management programmes. Programme developers should aim to improve the internal locus of control of patients. Moreover, employ religious messages through Imams and scholars to correct misconceptions about fatalism.

## Chapter 10: **DISCUSSION**

### **10.1 Overview**

This chapter discusses and critically appraises the findings of this study in relation to the relevant existing literature. This study aimed to culturally adapt an existing diabetes self-management programme to be more relevant for patients with type 2 diabetes in primary health care in Saudi Arabia. An evidence-based diabetes self-management programme originally developed at Stanford University was chosen for adaptation. In order to achieve this, an iterative process utilising a qualitative approach was conducted. It involved three phases as well as conducting a non-participatory observation of patient's consultations in the chronic disease clinic prior to any adaptations. Phase 1 involved discussions with healthcare professional to adapt location and timing aspects of the programme. Phase 2 involved delivery of the programme and subsequently conduct FGDs with participants who attended the programme to inform the subsequent adaptation. Phase 3 involved repeating the second phase using the data that emerged from the first phase for a further adaptation of the programme. The EVM dimensions were used to guide the adaptation of the programme.

This section will discuss the findings of this study through addressing the prominent themes that emerged from the data. It will also discuss and critique the cultural adaptation process.

## **10.2 Study findings**

The following findings are the main themes that emerged from the data:

### *10.2.1 Gender and Social Norms and Roles*

Gender norms and roles were prominent findings in this study. As explained in the contextual chapter (Chapter 5:) due to the segregation of the sexes, the gender norms and roles are very much segregated and rigid. Both women and men who participants in this study perceived gender norms and roles as hindering factors to adopting self-management behaviours. Women for example prioritised their roles as wives and mothers over their health. On the other hand, men prioritised their bread-winning and head of the family role and delegated the responsibility of the house affairs to their wives. The social pressures to assume these roles inevitably has an influence on how self-management behaviours are perceived and adopted. For example, men relegate the food choices and cooking to their wives/mothers, on the other hand, women consider their husbands and/or children food preferences hence limiting their ability to fully manage their diabetes.

Gender and gender differences were reported as factors that influences self-management behaviours (Chlebowy et al., 2013; Mansyur, Rustveld, Nash, & Jibaja-Weiss, 2016; Mathew et al., 2012).

This finding is similar to that in a study by (Burner, Menchine, Taylor, & Arora, 2013), who explored the perception of Latinos of a diabetes self-management programme, found that gender had an influence on the participants' diabetes management

strategies. The study reported that content and educational material that participants believed should be added to the programme also differed by gender.

Similarly, another study conducted by Bertran et al.,(2017) to adapt a diabetes prevention programme to be culturally relevant for the general Arab-American community (people without diabetes) reported gender norms as a main finding. However, unlike this study, where the participants preferred to receive content that is more relevant to their gender roles, the Arab-American participants considered women to bear the responsibility for health education and promotion within the family. Therefore, the authors of the study believe that a family centred programme with an emphasis on women would be more successful within the Arab-American community. However, their recommendation to develop programmes that involve the family with a focus on women might be due to the fact that the programme they are adapting is a diabetes prevention programme rather than a self-management programme.

#### *10.2.2 Religion and Reliance on Allah*

The participants in this study, as with most Saudis in the community, are firm believers of Islam. Religion is one of the main findings in this study. In some instances, religion appeared to present a hinderance to self-care behaviours. For example, some participants prioritised their religious activities such as Omrah, Hajj or fasting over the management of diabetes which might have affected their health. Opposing findings were found in a qualitative study exploring the role spirituality and religious beliefs in diabetes self-management in an urban population in the United States (Gupta &

Anandarajah, 2014). In their study, religious and spiritual beliefs were not perceived as a priority over diabetes self-management.

Some participants mentioned that they deflect the responsibility of managing diabetes to Allah. This may indicate that the participants hold fatalistic views of health. Viewing health through a fatalistic lens leads individuals to believe that health outcomes are not within their control but are destined by a higher power (Franklin et al., 2007). Other than the religious fatalism which is defined as '*a religious concept which attributes all life's events to the will of God or supernatural powers*' (A. Ahmed, 2003), Walker et al.,(2012) defined diabetes fatalism as '*a complex psychological cycle characterized by perceptions of despair, hopelessness, and powerlessness*'. They found that diabetes fatalism is associated with poor adoption of self-management behaviours hence they recommend considering this aspect in diabetes life-style intervention development.

Although some of the statements in this study seem to imply that participants perceive diabetes with a fatalistic lens, they further explained that they take responsibility and actions for matters they can control such as attending follow ups with their physician and taking their medication. This could be an area for future research in Muslim communities.

Religion also appeared to have a positive influence on the participants. Participants perceived Allah as a form of support helping them endure the effects of living with diabetes. Also, they perceived being diagnosed with diabetes as a reward for afterlife. Moreover, religious activities were perceived by some participants as a respite from



the daily struggles of a chronic disease. Lundberg and Thrakul (2013) explored the influence of religion on self-management of Buddhist and Muslim women in Thailand. The study reports that religion and religious activities were utilised as a coping strategy to the struggles of the illness.

Regarding the adaptation of the programme, participants expressed that the programme lacks the use of religious prayers as well as messages, especially sessions and activities that involved aspects of depression, mood and sleep. Rounding et al.,(2012) concluded that when religious messages were emphasised, the ability to self-manage diabetes is amplified.

Several research studies selected places of worship such as churches (Baig et al., 2015; Carmen D Samuel-Hodge et al., 2006; Watkins, Quinn, Ruggiero, Quinn, & Choi, 2013). The Muslim participants in Bertran et al.,(2017) study suggested that a diabetes prevention programme would be more culturally relevant if delivered in a mosque. This was not the case for the participants in this study who preferred for the sessions to be conducted in the primary health care centre rather than the mosque. This was a surprising finding because the mosque was chosen as a religious and social setting where people generally, but men specifically, go more than once a day to perform their prayers hence it was not expected for all participants to unanimously prefer otherwise. It is somewhat understandable that women participants would have such a preference because women do not generally attend the mosque on a daily basis. However, for men, it could be due to the fact that they do not want to be seen by other people in their community to attend a religious setting for a non-religious purpose therefore

become stigmatised for prioritising their health and their bodies rather than prioritising Allah.

### *10.2.3 Doctor-patient Relationship*

Doctor-patient relationship emerged as a main theme in this study. Although the participants cautiously criticised physicians for being dismissive of them as a person but instead treating their disease, they still stated that physicians are the experts in health matters. The participants rationalised the behaviour of physicians with being busy or being short with time. A power dynamic is inevitably created when physicians do not pay enough attention to the person but rather pay attention to the disease.

### *10.2.4 Concordance by Gender*

Women who participated in this study expressed that they perceive that the gender difference between them and their male physician is a cause of misunderstanding. They stated that a male physician is not able to provide them with relevant information to self-manage their diabetes because they can never relate to what women go through on a daily basis. Evidence suggests that doctor-patient interactions are influenced by gender (Bertakis, 2009; Schieber et al., 2014). The literature reveals a growing interest among health researchers regarding the influence of the gender of physicians and/or patients on the dynamics and communication styles during medical consultations. For example, studies have shown that female physicians, particularly those in primary care, are more likely to practice a patient-centred approach to communication (Jerant, Bertakis, Fenton, & Franks, 2013), to discuss psychosocial aspects, to encourage patient participation during interactions (Bertakis, 2009) and to involve their patients

in decision making (Sandhu, Adams, Singleton, Clark-Carter, & Kidd, 2009). On the other hand, male physicians are more likely to direct the consultations they carry out (Sandhu et al., 2009) and to focus on technical aspects, such as history taking, physical examinations and the treatment plan (Bertakis, Franks, & Epstein, 2009). The influence of the gender of the patient on communication during consultations was also explored. When compared to male patients, who were found to be task-oriented (Bertakis, 2009), female patients provided a more thorough medical history, had more enquiries (Sandhu et al., 2009) and used less medical jargon (Bertakis, 2009).

Studies have specifically explored the effect of the doctor-patient gender dyads in which both the patient and physician are of the same gender, which is referred to as gender concordant, or in which both are from the opposite gender, which is referred to as gender discordance (Bertakis, 2009; Pickett-Blakely, Bleich, & Cooper, 2011; Sandhu et al., 2009; Schieber et al., 2014; Schmittdiel et al., 2009). It has been indicated that a concordance of the doctor-patient gender amplifies patients' trust in the physician, positively influencing prevention services (Schmittdiel et al., 2009), and improves the quality of communication during consultations (Sandhu et al., 2009). A study conducted by Schieber and colleagues (2014) amongst GPs and patients in France showed that doctor-patient gender concordance is associated with a better agreement between them during consultations. Moreover, the agreement regarding advice concerning lifestyle aspects, such as nutrition and exercise, was more associated with the female gender dyad (Schieber et al., 2014). Another study involving patients and doctors in the US demonstrated that gender concordance has a modest positive association with heart disease and diabetes risk factors, such as

HbA1c, blood pressure and lipids (Schmittiel et al., 2009). Pickett-Blakely, Bleich and Cooper (2011), who also conducted a study in the US, supported such findings. They found that there is a positive association between male doctor-patient gender concordance and receiving obesity and nutrition-related counselling. These findings are attributed to the influence of gender norms, beliefs, the discrepancies in the status level between doctors and patients and the differences in patients' expectations of doctor-patient interactions (Bertakis et al., 2009).

This issue cannot be overlooked in the Saudi context and its gender, social and cultural norms. It is of more importance and relevance in the Saudi culture in which individuals of both genders are unaccustomed to engaging with any person of the opposite sex who is not considered an immediate family member. This is attributed to the interpretations of Islam that the country adheres to. It is not surprising that interacting with the opposite sex was found to be among the top medical ethical challenges for both patients and doctors in Saudi Arabia (Alkabba et al., 2012). Female patients experience a power asymmetry during their interactions with male doctors due to an entrenched belief that men are more powerful in addition to the power of doctors perceived by patients. There is less power and tension involved in a one-gender dyad (Sandhu et al., 2009). Female physicians could be more empathetic towards females and could understand their struggles, especially related to social and gender norms, and thus may provide more relevant advice (Sandhu et al., 2009).

Participants in this study might not have mentioned issues with concordance related to language and ethnicity because they are treated by Saudi doctors and Saudi nurses who are either from the same city or from neighbouring cities where the dialect is

similar, as mentioned previously. The discordance in language affects communication, which affects the quality of care. A systematic review conducted to determine the elements that affect the quality of primary healthcare in Saudi Arabia showed that the quality of doctor-patient interactions is hindered by language barriers and the differences in culture, traditions and habits (AL-Ahmadi & Roland, 2005).

As mentioned previously in Section 5.7 that health care professionals within the Saudi system are often not Saudi but have different ethnic backgrounds (MOH, 2016). Studies have explored the impact of discordance on ethnicity between doctors and patients. According to Street and colleagues (2008), *'the relationship is strengthened when patients see themselves similar to their physicians in beliefs, values and communication'*. In order to overcome this, Almutairi (2015) recommends offering further language and cultural education programmes for expatriate health care professionals.

### **10.3 Adaptation using The Ecological Validity Model**

The EVM by Bernal, Bonilla and Bellido (1995) was utilised as a framework to guide the cultural adaptation in this study. The model's eight dimensions shown in Table 5 also influenced the topic guide used in the FGDs that were conducted after each set of sessions. This framework was selected because it provides a comprehensive list of dimensions to take into consideration when culturally adapting interventions. The following table gives an indication of how the dimensions were implemented in this study.

<b>Ecological Validity Model Dimensions</b>	<b>Definition</b>	<b>Implementation</b>
<b>Language</b>	The use of culturally appropriate and culturally syntonic language that is responsive to the cultural group	Achieved fully through delivering the programme in Arabic, using the participants' local dialect. Some words or phrases in the manual was discussed with health care professionals to confirm accuracy and appropriateness.
<b>Persons</b>	Consideration of the role of cultural similarities and differences between patient and provider	Achieved. The facilitator of the sessions (myself) and the participants are from the same geographical area hence hold the similar cultural background
<b>Metaphor</b>	The use of metaphors and/or symbols d by the target group	No metaphors have emerged from the collected data or were heard during the observations
<b>Content</b>	Addressing cultural knowledge of values, customs and traditions shared by the target group	Sessions were conducted in segregated gender groups in order to respect the Islamic values. Information about cultural foods were incorporated into the nutritional sessions
<b>Context</b>	The consideration of the targets' group broader social, economic and political context	The clinic observations pose as an attempt to consider the context of the primary health care centre where participants receive their treatment. The literature review also attempted to examine the wider context. However, macro level assessment of the influence of 'context' as referred to here, on diabetes self-management may be needed.
<b>Concept</b>	The use of a theoretical framework to inform the development of the intervention.	The Stanford diabetes self-management programme is informed by the Social Cognitive Theory.
<b>Methods</b>	The use of culturally appropriate methods and strategies to achieve the outcomes of the intervention and the methods used to generate culturally relevant strategies.	FGDs conducted to explore the participants' opinions of the programme, in order to generate culturally relevant strategies were segregated by gender.
<b>Goals</b>	Establishing goals between patients and deliverer of the intervention, taking into consideration the cultural values, customs and traditions of the target group,	Participants set their own goals during the action planning activity in each session.

**Table 5 Implementation of EVM dimensions**

## **10.4 Summary**

This chapter discussed the findings of this study in the context of the existing literature.

The following chapter will sum up the research study, highlight the strengths and limitations of the study. It will also outline recommendations for future research and implications for practice.

## Chapter 11: CONCLUSION AND RECOMMENDATIONS

### 11.1 Overview

This chapter provides a summary of the findings of this study and offers recommendations for future research in line with these findings. It also highlights the strengths and limitations of this study. Implications for practice are also suggested at the end of the chapter.

### 11.2 Summary of Findings

This study aimed to culturally adapt the Diabetes Self-Management Programme developed by Stanford University to be culturally relevant to people with type 2 diabetes attending a primary health care centre in Saudi Arabia. The study utilised a qualitative approach involving various qualitative methods. First the clinic context was explored through non-participatory observations of clinic consultations taking place at Al-Khaleej primary health care centre. The cultural adaptation process consisted of three phases. Phase 1 included informal meetings with a team of health care professionals to achieve a preliminary adaptation of the programme. Phase 2 included three components; delivery of sessions, FGDs and informal meetings with the health care professionals to achieve the first adaptation. Phase 3 involved an iteration of the second phase with different participants to achieve a second adaptation.



15 encounters of patients with type 2 diabetes were observed in the clinic. The team of health care professional consisted of two physicians and a nurse who work in the centre. A total of 39 participants attended the programme and 27 attended the FGDs. Participants were recruited using convenience sampling.

The observations of clinic encounters were conducted in order to explore the context of the clinic. The main findings of these observations are; didactic nature of self-management advice, giving generalised advice and labelling patients.

Phase 1 achieved a preliminary adaptation where a decision regarding the location (mosque) and the timing of the delivery of sessions (evenings) was made.

Regarding phase 2, the findings emerging from the FGDs and aspects noted during the delivery of the programme have led to omitting references to alcohol, dialogue about sex and intimacy and the session titled “reducing medication expenses” and addressing misconceptions about traditional foods. The finding also led to changing the location from a community setting to a primary health care setting.

In phase 3, knowledge and guidance for diabetes in Ramadan was the only aspect that could be adapted.

The findings of the FGDs also showed other aspects that have an impact on the participants’ diabetes self-management. These findings are; Gender and social and gender roles, religion and reliance on Allah and doctor-patient relationship. The findings of this study, supported by the reviewed literature, demonstrate that the Stanford DSMP cannot be adapted for the Saudi context because such an adaptation

would result in a completely different programme, hence inevitably compromising its fidelity.

Further formative work is warranted prior to developing a diabetes self-management programme for the Saudi context; which includes assessing the health care system as well as the availability of resources for such an intervention to be implemented.

### **11.3 Strengths of the Study**

- This exploratory study can be a starting point for the development of a diabetes self-management intervention that is relevant for Saudi patients.
- The majority of diabetes research studies conducted in the Saudi context are mainly concerning the indicators of diabetes control, such as HbA1c and blood glucose levels. This study gave patients a voice and took their perspective and experience into account to potentially influence the quality and level of care they receive.
- The cultural adaptation in this study utilised the EVM as a cultural adaptation stage model in order to culturally adapt the SDSMP in a systematic manner. The dimensions of the EVM allowed for a comprehensive examination of the Saudi context that yielded aspects which could inform future development of health promotion and behavioural change interventions in Saudi Arabia.

## 11.4 Limitations of this Study

- This study took place in one geographical area in Saudi Arabia, therefore the results may not be generalisable to other populations. Due to the distinctiveness of the Saudi culture in comparison to other gulf and Arab countries, the results may not apply to other Arab cultures. Participants in this study were recruited from a governmental primary health care centre, hence the results may not be applicable to those attending private centres, secondary or tertiary hospitals, especially those from different socio-demographic groups. Moreover, conducting this study in this particular centre, in which all of the employees were Arabic speakers, does not reflect the doctor-patient relationship and communication style in other centres where physicians do not speak Arabic or are not fluent Arabic speakers, which is the case in most centres in Saudi Arabia. It is possible that patients who attend such centres have different perspectives on their diabetes management.
- Health outcomes such as data regarding participants' glycaemic control and other diabetes control indicators were not collected in this study. This is because the study aimed to culturally adapt an intervention and not measure its effectiveness.
- The use of a convenience sampling approach and the choice of Al-Khaleej primary health care centre is a source of selection bias in this study. However, due the qualitative study design, generalisability is not expected.

The characteristics of the researcher may have posed researcher bias on the results (this is addressed in Section 4.26).

## **11.5 Recommendations and Implications for Practice**

This study has the following implications for diabetes self-management and diabetes care practice:

- Due to the extent of segregation in society and how it operates, for the gender roles to be sustained, there is necessity for a gender sensitive health approach to health especially in terms of life-style behaviour change. Future research may achieve this by utilising a gender transformative approach to health promotion (Pederson, Greaves, & Poole, 2015). This approach aims to transform gender roles and norms by addressing the causes of gender-based health inequalities (Pederson, Greaves, & Poole, 2015).
  
- It is important to assess and evaluate the broader organisational and the health system culture to determine where the programme fits in the organisation and how it can be sustained. Cabassa & Baumann (2013) refer to this as '*expanding the contextual lens*'. They recommend utilising a cultural adaptation model and integrating it with what is referred to as Implementation Science study (Cabassa & Baumann, 2013). Implementation science uses methods to aid the integration of the evidence-based intervention into practice through examining the inner and

outer context of where the intervention will be implemented (Cabassa & Baumann, 2013). Context here is defined by Damschroder et al. (2009) as *'the set of circumstances or unique factors that surround a particular implementation effort'*. Assessing the inner context involves examining organisational factors such as; the leadership, structure; which include the size of the organisation, its workflow and the services it provides; as well as the social context of the organisation (Mendel, Meredith, Schoenbaum, Sherbourne, & Wells, 2008). On the other hand, the outer contextual factors include; existing policies, community resources, the political environment as well as cultural and community beliefs and attitudes regarding the health condition and their expectations towards treatment methods (Mendel et al., 2008). Although This study's findings revealed some of the participants beliefs and attitudes towards diabetes and the availability of a self-management diabetes programme within primary health care, which are underpinned under the outer contextual factors, it did not assess any of the organisational inner contextual factors. Moreover, it did not explore the political environment or the existing policies and the available community resources that would further facilitate the implementation and the maintenance of such intervention within the Saudi system.

- The findings in this study indicate that health care professionals highly focus on medication more than other self-management practices which are also required to achieve glycaemic control. Therefore, health care

professionals must promote and emphasise the importance of adopting other self-care practices.

- Develop appropriate training for health care professionals to assist them with providing relevant advice to patients.
- The findings in this study provide evidence that the barriers to adopting self-management behaviours do not just lie on the individuals' level but also include environmental, social and cultural factors. Hence there is a need to improve the environmental factors and develop programmes that include messages that help patients overcome the cultural and social barriers.
- Employing qualitative methods more often in Saudi Arabia especially in health promotion and intervention development research.
- This study has highlighted the ways in which gender norms affect self-management. It is worthwhile studying this further specifically the effect of gender norms on men's health in Saudi Arabia as this is a gap in the literature.
- Physicians in Saudi Arabia are trained through curriculums that have been developed in the West, hence the advice they provide to their patients may not be relevant.

- Explore the challenges the health care professionals face that hinders their ability to deliver self-management advice, such as: training, availability of resources and organisational context.
- Utilise The Medical Research Council (MRC) framework for developing complex interventions (Campbell et al, 2000) to develop a diabetes self-management intervention in the future. The framework consists of five stages that guide the process of developing complex interventions (Theory, Modelling, exploratory trial, definitive RCT and lastly long term implementation). The MRC emphasises the need to start with a modelling phase prior conducting the other phases. The current study is still at the modelling phase and further modelling is required prior to conducting an exploratory trial.

## **11.6 Conclusion**

This study aimed to culturally adapt the diabetes self-management programme to be culturally relevant for patients with type 2 diabetes attending a primary health care centre in Saudi Arabia. According to my knowledge, this study is the first to culturally adapt an evidence-based intervention for patients with type 2 in Saudi Arabia. Adapting the evidence-based intervention through using a cultural adaptation framework was not fully successful. This is due to complexity of incorporating findings such as gender and gender roles into the adaptation and at the same time maintain fidelity of the original programme.

Adaptations should not be attempted without initially assessing the needs of the target population as well as assessing the health system and the availability of the resources needed.

The findings of this study suggest that content and messages of behaviour change intervention would benefit from being gender-specific, especially in Saudi Arabia. The study contributes to more understanding of barriers to self-management among Saudi patients.



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## **APPENDICES**

## **APPENDIX 1 TOPIC GUIDE FOR FGDS**

Consent forms for focus group participants will be completed in advance by all those agreeing to participate. Below is a summary of the information that will be included in the consent form, and the broad themes that will be explored in the focus group discussions.

### **Introduction**

#### **1. Welcome**

*Thank you for agreeing to participate. We are very interested to hear about your opinions and perspectives regarding the programme you attended. We would like to hear about aspects of the programme that were useful to you and aspects that were not so we can design a programme that is relevant to patients with diabetes in Saudi Arabia in the future.*

#### **2. Introduction**

Introduce yourself and the note taker, and send the Sign-In Sheet with a few quick demographic questions (age, gender, education, employment and income) around to the group while you are introducing the focus group.

*Review the following:*

- Who we are and what we're trying to do
- What will be done with this information
- Why we asked you to participate

### **3. Explanation of the process**

Explain that focus groups are being used more and more often in health and human services research.

#### *About focus groups*

- We learn from you (positive and negative)
- Not trying to achieve consensus, we're gathering information

#### *Logistics*

- Focus group will last about two hours
- Feel free to move around
- Bathroom? Exit?
- Help yourself to refreshments

### **4. Ground Rules**

Ask the group to suggest some ground rules. After they brainstorm some, make sure the following are on the list.

- Everyone should participate.
- Information provided in the focus group must be kept confidential
- Stay with the group and please don't have side conversations
- Turn off cell phones if possible



## 5. Turn on Tape Recorder

Ask the group if there are any questions before we get started and address those questions.

Make sure to give people time to think before answering the questions and don't move too quickly. Use the probes to ensure that all issues are addressed but move on when you feel you are starting to hear repetitive information.

## Broad Topics for Discussion

1. I'd like to start off our discussion by asking each of you if you would mind saying a little bit about how you are taking care of your diabetes at the moment.
2. We're interested in finding out a little bit about the sorts of things that might influence how you deal with your diabetes? In your opinion, how well were they addressed in the programme? (This covers the "*Context*" dimension)

[Leave open for spontaneous responses and then probe]

*Probes:*

- *Family life /social life*
  - *Traditional remedies*
  - *Diet*
  - *Religious activities*
  - *Financial constraints/availability of resources*
3. We would like to know whether the challenges you face in taking care of your diabetes were covered in the programme. How well were the challenges

addressed? If they were, were they addressed enough? If they were not, is there anything you would like to be addressed (*This covers the “Content” dimension*)

[Leave open for spontaneous responses, and then probe]

*Probes:*

- *Knowledge or information*
- *Diet*
- *Exercise*
- *Glucose monitoring*
- *Complication detection*
- *Medications/ injections*
- *Emotional issues*

4. We would like your opinion on the on the following:

***Language*** (*dialect or standard formal Arabic*)-written material

***Persons*** (*qualifications and experience- gender*)

5. We are interested in some of the factors that might affect your attendance to the programme. Are there any things you can think of that would make it more or less likely for you to attend the programme? (*This covers the “methods” dimension*)

[Leave open for spontaneous responses, and then probe]

*Probes:*

- *Family members*
- *Invitation method*
- *Transport*
- *Time of the day*
- *Venue*
- *Manual*

6. Based on our discussions today, and your own experiences of living with diabetes, do you have any recommendations for how we could encourage patients with type 2 diabetes to become involved in such a programme?
7. Consider everything that has been discussed, is there anything that anyone would like to add?

That concludes our focus group.

Thank you so much for coming and sharing your thoughts and opinions with us.

## APPENDIX 2 CONSENT FORM (1) PROGRAMME PARTICIPATION

[Every participant is provided with Arabic translation and the form will be read with the participants to ensure everything is understood and to allow participants to ask questions]

*Thank you for agreeing to take part and attend the sessions of the type 2 diabetes self-management programme.*

- The purpose of this study is to adapt a diabetes self-management program that is used in the United States to be relevant to Saudi Arabian type 2 diabetes patients. You will be taking part in a programme that consists of 6 sessions (one session per week). Each session lasts for approximately two hours and thirty minutes. You will be attending the sessions with other (men/women) patients.*
- Your participation in the programme is entirely voluntary. You may refuse to attend or withdraw from the study at any time. If you choose not to participate in the programme this will not affect the medical care you receive from the health centre.*
- As the programme sessions are interactive, you may share your personal experiences of living and dealing with diabetes. We understand how important it is that this information is kept private and confidential. We will ask participants attending the sessions to respect each other's confidentiality.*
- A researcher will attend to observe the sessions to ensure they are delivered as intended and to improve future deliverers' training.*
- The information you give us is completely confidential, and we will not associate your name with anything you say during the sessions.*
- If you have any questions now or during or after the programme sessions, you can always contact a study team member. Contact numbers will be provided.*
- Please sign to show you agree to participate in attending the programme*
- Please sign to show you agree to participate in attending the programme*

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Name of Person taking consent

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Principal Investigator

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

### APPENDIX 3 CONSENT FORM (2) FGDS

[Every participant is provided with Arabic translation and the form will be read with the participants to ensure everything is understood and to allow participants to ask questions.] *Thank you for agreeing to participate. We are very interested to hear about your experience and valuable opinion regarding the diabetes self-management programme you attended*

- *The purpose of this study is to adapt a diabetes self-management program that is used in the United States to be relevant to Saudi type 2 diabetes patients. Now that you have attended the programme, you will be taking part in a discussion group with other (men/women) patients for approximately two hours. We hope hear you opinion on what aspects worked and others that did not in the programme so we can use the results it to make it more useful to you and other patients with diabetes.*
- *Your participation in the focus group is entirely voluntary. You may refuse to answer any question or withdraw from the study at any time. If you choose not to participate in a focus group, this will not affect the medical care you receive from the health centre.*
- *During the focus groups, participants may share their personal experiences of living and dealing with diabetes. We understand how important it is that this information is kept private and confidential. We will ask participants in the group discussions to respect each other's confidentiality.*
- *The information you give us is completely confidential, and we will not associate your name with anything you say in the focus group.*
- *We would like to tape the focus groups so that we can make sure to capture the thoughts, opinions, and ideas we hear from the group. These tapes will be transcribed, but no names will be attached to the transcripts and the tapes will be destroyed as soon as the study ends.*
- *If you have any questions now or after the focus group discussion, you can always contact a study team member. Contact numbers will be provided.*
- *Please sign to show you agree to participate in this focus group.*
- *Please sign to show you agree to participate in this focus group.*

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Name of Person taking consent

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Principal Investigator

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

## **APPENDIX 4 INFORMATION SHEET**

[Information sheet is provided in Arabic and it will be read through with the participants to ensure everything is understood and allow for questions]

**Project:** Culturally adapting a diabetes self-management programme for patients with type 2 diabetes attending primary care in Saudi Arabia

### ***Introduction***

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

### ***What is the purpose of this study?***

This study aims to adapt a diabetes self-management programme that has been established and used in the United States and in many other countries all over the world, to be more relevant for patients with type 2 diabetes who attend primary health care centres in Saudi Arabia.

### ***What is a self-management programme and what to expect?***

It is a six-week group sessions that takes place once a week for 2.5 hours for patients with type 2 diabetes. The purpose of the programme is (1) to help you know how to

take day-to-day responsibility of your diabetes care; (2) to help you develop the skills necessary to manage your diabetes; (3) to help you work effectively with your health care providers. The programme can help you learn problem-solving and decision-making skills which enable you to confront the daily challenges of living with diabetes.

Attending the programme will give you the opportunity to meet others with similar experiences in an open, friendly environment. A combination of facilitator led learning, group discussion, and other Interactive activities are involved in covering a range of topics. You will learn practical skills including:

- Symptom relief and management
- Safe use of medications
- Effective communication
- Goal setting and problem solving
- Relaxation
- Improve partnership with doctors and health providers

***What will I have to do if I take part?***

If you agree to take part, you will be asked to complete a questionnaire. This questionnaire asks about your age, education level and your diabetes history; such as, years since diagnosis and medications. You will be able to complete the questionnaire

privately, or with the help of the researcher. You will be asked to attend a weekly group session with other (women/men) with type 2 diabetes for 6 weeks. Each session will last 2.5 hours.

At the end of the programme you will be invited to take part in a group discussion. These discussions will ask about your views on which aspects of the programme worked or did not work as well as your recommendations to make the programme more effective and relevant to you. You can decide later whether you want to take part in the group discussions.

***What are the possible benefits?***

The programme has been designed to help you gain the confidence to self-manage your diabetes on a daily basis. We cannot promise that the study will help you but the information we get from this study will help us design a programme that is more relevant to you and other patients with type 2 diabetes in Saudi Arabia in the future.

***What is the possible risk or harm of taking part?***

There are no risks with the attending the programme or participating in interviews. Blood work or lab investigations will NOT be needed before, during or at the end of your participation in this study.



***What if I get harmed or injured as a result of participating in this study?***

Harm and injury are unlikely. *The London School of Hygiene & Tropical Medicine holds insurance policies which apply to this study. If you experience harm or injury as a result of taking part in this study, you may be eligible to claim compensation without having to prove that the School is at fault. This does not affect your legal rights to seek compensation*

***Will the information obtained in the study be confidential?***

All information that is collected about you during the course of the research will be kept strictly confidential. The group discussions at the end of the programme may be tape recorded with your consent, if so, the tapes will remain anonymous and identified only by a participant study number. They will be stored and locked in a secure place. Any information, which will have your name, will be removed so that you cannot be recognised from it.

***Do I have to take part? What will happen if I do not want to carry on with the study?***

It is up to you whether or not to take part. If you do not wish to, then you need not give any reason at all. We can assure you that your treatment will not be affected if you decide not to take part. If you do start participating in the study and then change your mind at a later date, you will be free to withdraw without it in any way affecting the standard of care that you receive.

***What do I do now?***

If you agree to take part, you will be given this information sheet and asked to sign a consent form. This is now an ethical requirement for all research studies to ensure that every participant has been provided with information and had the chance to ask questions before agreeing to take part. For this study we have two consent forms. The first is the consent form for participating in the six-week programme. You will only be asked to complete the second consent form if you agree to a later interview/group discussion at the end of the programme. If you wish, you may take a few days to think about the study or discuss it with someone else, such as your family or friends, before deciding whether you agree to take part.

***What if there is a problem?***

Any complaint about the way you have been approached or treated during the study or any possible harm you might suffer will be addressed.

If you have any further questions at this time or during the course of the study then you can contact;

Dr Donna Alabdulbaqi

Tel: 05xxxxxx/ 66xxxxx

**Thank you for taking time to read this and for thinking about taking part.**

# APPENDIX 5 LSHTM ETHICAL APPROVAL

## London School of Hygiene & Tropical Medicine

Keppel Street, London WC1E 7HT  
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LONDON  
SCHOOL of  
HYGIENE  
& TROPICAL  
MEDICINE



### Observational / Interventions Research Ethics Committee

LSHTM

13 March 2015

Dear

**Study Title:** a cultural adaptation of a diabetes self-management programme for patients with type 2 diabetes attending a primary care centre in Saudi Arabia

**LSHTM Ethics Ref:** 8439

Thank you for responding to the Interventions Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

#### Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

#### Conditions of the favourable opinion

Approval is dependent on local ethical approval having been received, where relevant.

#### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document Type	File Name	Date	Version
Investigator CV	CV.docx	13/07/2014	1
Information Sheet	INFORMATION SHEET.docx	13/07/2014	1
Information Sheet	Consent forms.odt	13/07/2014	1
Protocol / Proposal	PhD project.odt	24/07/2014	1
Local Approval	Project agreement letter.pdf	18/08/2014	1
Sponsor Letter	Sponsor Letter QA 627.pdf	20/08/2014	1
Protocol / Proposal	PhD proposal DAB.odt	26/08/2014	1
Protocol / Proposal	Topic guides DAB.odt	26/08/2014	1
Information Sheet	information sheet DAB.docx	26/08/2014	1
Information Sheet	Consent forms DAB.docx	26/08/2014	1
Covering Letter	ethics covering letter.odt	06/10/2014	1
Covering Letter	Cover letter re provisional approval	10/03/2015	1
Local Approval	Saudi approval	10/03/2015	1
Local Approval	NCBE email correspondence	10/03/2015	1

#### After ethical review

The Chief Investigator (CI) or delegate is responsible for informing the ethics committee of any subsequent changes to the application. These must be submitted to the Committee for review using an Amendment form. Amendments must not be initiated before receipt of written favourable opinion from the committee.

The CI or delegate is also required to notify the ethics committee of any protocol violations and/or Suspected Unexpected Serious Adverse Reactions (SUSARs) which occur during the project by submitting a Serious Adverse Event form.

An annual report should be submitted to the committee using an Annual Report form on the anniversary of the approval of the study during the lifetime of the study.

At the end of the study, the CI or delegate must notify the committee using an End of Study form.

All aforementioned forms are available on the ethics online applications website and can only be submitted to the committee via the website at: <http://leo.lshtm.ac.uk>

Additional information is available at: [www.lshtm.ac.uk/ethics](http://www.lshtm.ac.uk/ethics)

Yours sincerely,



**Professor John DH Porter**  
Chair

[ethics@lshtm.ac.uk](mailto:ethics@lshtm.ac.uk)

<http://www.lshtm.ac.uk/ethics/>

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**Improving health worldwide**

## APPENDIX 6 GDHA ETHICAL APPROVAL (OFFICIAL TRANSLATION FROM ARABIC)

Mansour M.M. Al-Obaid Office

For Authorized Translation  
Licence No.: 82

رقم اشتراك الغرفة التجارية ٤ / ٢٠٩٢٧

محمد منصور العبيد

مترجم معتمده

رقم ٨٢

مكتبة منصور العبيد  
للترجمة - ترميز - الدمام  
Mansour Al Obaid's Office  
For Authorized Translation  
Dammam - License No. 82

Kingdom of Saudi Arabia  
Ministry of Health  
General Directorate of Health Affairs  
in Eastern Province

No:1175439/17/41  
Date : 11/5/1436H

From	President of the Committee for Researches & Studies in Maternity & Children Hospital in Dammam Dr. Hussam Tamimi (signed)
To	Assistant Director General for Planning & Training in Health Affairs, eastern Province
Subject	Facilitation of Researcher's assignment

Dear Sir

As a reply for your letter # 1175439/13/41 dated 4/5/1436H regarding the student "DONNA QAIS ALABDULBAQI", who is dispatched by the Ministry of Higher Education for Doctorate Study in the specialization of public health and researches of health services, requesting the approval for making of field research titled (Cultural adaptation of diabetes self-management program for patients with type 2 diabetes attending a primary care centers in Saudi Arabia),

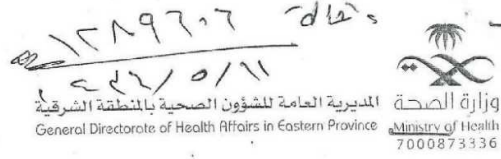
We hereby inform you that the Committee for Researches & Studies approved the making of such research and so we kindly request you to write to the hospitals to facilitate the job of the above mentioned researcher.

Best regards

مكتبة منصور العبيد  
للترجمة - ترميز - الدمام  
Mansour Al Obaid's Office  
For Authorized Translation  
Dammam - License No. 82

هاتف : ٨٣٣٣٧٤٠ - ص.ب. ١٠٧٨ - الدمام ٣١٤٣١ - المملكة العربية السعودية  
Tel.: 833 3740 - P.O. Box 1078 - Dammam 31431 - Kingdom of Saudi Arabia

## APPENDIX 7 GDHA ETHICAL APPROVAL (IN ARABIC)



الرقم: ٤٣٩٥٤١١٧٠١١  
التاريخ: ١١ ٥ ٢٠١١  
المهمل = ١

من	رئيس لجنة البحوث والدراسات بالمنطقة الشرقية بمستشفى الولادة والأطفال بالدمام	الدكتور/ حسام التميمي
إلى	سعادة / م. المدير العام للتخطيط والتدريب بصحة الشرقية	المحترم
الموضوع	تسهيل مهمة باحث	

السلام عليكم ورحمة الله وبركاته

رداً على خطابكم ٤٣٩٥٤١١٧٠١١/١٣/٤ وتاريخ ٤/٥/١٤٣٦ هـ ، بخصوص قيام الطالبة / دانا قيس حسين العبد الباقي ، مبتعثه من قبل وزارة التعليم العالي لدراسة الدكتوراه في تخصص الصحة العامة وأبحاث الخدمات الصحية ، والذي تطلب فيه الموافقة على عمل بحث ميداني بعنوان (التكيف الثقافي لبرنامج الإدارة الذاتية لمرضى السكري من النوع الثاني للمراجعين بمركز الرعاية الأولية بالمملكة العربية السعودية)

نفيدكم بأن لجنة البحوث وافقت على عمل هذا البحث ونأمل مخاطبة المستشفيات لتسهيل مهمة الباحث المذكور اسمه بعاليه.

وتقبلوا فائق تقديري واحترامي،،،

قسم الأطفال

عبير الشمري

## APPENDIX 8 GDHA APPROVAL OF FACILITATION OF DATA COLLECTION (OFFICIAL TRANSLATION)

Mansour M.M. Al-Obaid Office

For Authorized Translation  
Licence No.: 82

رقم اشتراك الغرفة التجارية ٤ / ٢٠٩٢٧

محمد منصور العبيد

المترجم

رقم ٨٢

Kingdom of Saudi Arabia  
Ministry of Health  
General Directorate of Health Affairs  
in Eastern Province  
Planning & Training Department

No. 1175439/12/41  
Date : 13/5/1436H (4/3/2015)

To Whom It May Concern

To Assistant Director General of Public Health  
In Health Affairs, Eastern Province

Dear Sir

Herein attached copy of the letter of the President of the Committee for Research & Studies in Eastern Province under # 1175439/17/41 dated 11/5/1436H regarding the student : DONNA QAIS ALABDULBAQI, who is making a field research titled " Cultural adaptation of diabetes self-management program for patients with type 2 diabetes attending a primary care centers )in Saudi Arabia.

We kindly request you to facilitate the job of the researcher for collecting the necessary data in a manner that ensures there would be no any effect on service of the patients during her carrying out the assignments of her research.


Best regards

Assistant Director General  
For Planning & Training , Health Affairs in Eastern province  
Dr. Osama Mohamed Al Madani  
(signed)

هاتف : ٨٣٣٣٧٤٠ - ص.ب ١٠٧٨ - الدمام ٣١٤٣١ - المملكة العربية السعودية  
Tel.: 833 3740 - P.O. Box 1078 - Dammam 31431 - Kingdom of Saudi Arabia



## APPENDIX 9 GDHA APPROVAL OF FACILITATION OF DATA COLLECTION (IN ARABIC)

الرقم: ٤١/١٣/ ١١٧٥٤٣٩	المملكة العربية السعودية	
التاريخ: ٥/١٣/ ١٤٣٦هـ	المديرية العامة للشؤون الصحية بالمنطقة الشرقية General Directorate of Health Affairs in Eastern Province إدارة التخطيط والتدريب	
المرفقات:	هاتف / ٨٤٣٦٧٧٣	
الموضوع:	فاكس / ٨٤١٦٦٧٣	
	Pln Trn-DM@moh.gov.sa	

إلى من يهمه الأمر  
سعادة / م/ المدير العام للصحة العامة بصحة الشرقية  
المحترم  
السلام عليكم ورحمة الله وبركاته :

برفقة صورة من خطاب رئيس لجنة البحوث والدراسات بالمنطقة الشرقية رقم  
٤١/١٧/١١٧٥٤٣٩ وتاريخ ١١/٥/١٤٣٦هـ بخصوص قيام الطالبة / دانا قيس حسين  
العبد الباقي بعمل بحث ميداني بعنوان (( التكيف الثقافي لبرنامج الإدارة الذاتية لمرضي  
السكري من النوع الثاني للمراجعين بمراكز الرعاية الأولية )) بالمملكة العربية السعودية .  
نأمل من سعادتك تسهيل مهمة الباحثة بجمع البيانات اللازمة بما يضمن بان لا  
يكون هناك أي تأثير على خدمة المراجعين خلال قيامها بمهام بحثها.

ولكم اطيب تحياتي

م/ المدير العام للتخطيط والتدريب بصحة الشرقية

[Redacted Signature]

الدكتور/ أسامة بن محمد المدني

ص/ للتخطيط والتدريب  
ع/ الفرع (٨٦٤٢) في ١٢/٥/١٤٣٦هـ



## APPENDIX 10 WIDELY USED SELF-MANAGEMENT INTERVENTIONS

Models	Background	Duration	Group vs. individual	Tutor	Benefit	Limitations
<b>Stanford Chronic Disease self-management Program</b>	Developed at Stanford University in the USA in the 1990s. Initially developed for arthritis then extended to other chronic diseases. It is based on Social Cognitive Theory. It has been widely used worldwide and translated to other languages. It covers the following topics: medication taking, physical activity, problem solving, nutrition and effective communication.	6 weeks	A group of 10-15 participants	One health care-professional and one expert patient	<ul style="list-style-type: none"> <li>* The group environment could enhance self-efficacy.</li> <li>* Learning and sharing with peers could enhance empowerment.</li> <li>* Focuses on goal setting and problem solving.</li> </ul>	<ul style="list-style-type: none"> <li>* Not all individuals respond within group settings</li> <li>* Group setting hinders addressing individual barriers</li> </ul>
<b>The Flinders Program</b>	Developed in Flinders University in Australia in the 1990s. It provides health providers with tools to assess patients' capability to self-manage their disease. It emphasises seven characteristics of a good self-manager: having knowledge of your disease, agreeing and adhering to a care plan, share in decision making, monitor signs and symptoms of disease and its impact on physical and psychosocial wellbeing, adopt a healthy lifestyle and have the ability and confidence to access and use support services. This offers a systematic approach to the barriers of continuous self-care. Health care providers are required to undergo a two day training program to use this model.	On going	One-to-one	Health care provider	<ul style="list-style-type: none"> <li>* Very individualised therefore emphasising patient goals.</li> <li>* Training of providers ensures that providers distinguish between acute and chronic models of care.</li> </ul>	<ul style="list-style-type: none"> <li>* Accreditation is needed for a provider to be certified, however, online certification is available.</li> <li>* Time consuming as doctors' visits might have to be extended to conduct the interviews with patients.</li> </ul>
<b>The EXPERT Patient Programme</b>	Developed in the UK by adapting The Stanford model.	6 weeks. Weekly sessions	Group	Expert patients	<ul style="list-style-type: none"> <li>* Beneficial for patients at different stages of readiness to change.</li> </ul>	<ul style="list-style-type: none"> <li>* Evidence on the effectiveness of this program is limited.</li> <li>* Group settings may not be suitable for all individuals</li> </ul>

<b>Models</b>	<b>Background</b>	<b>Duration</b>	<b>Group vs. individual</b>	<b>Tutor</b>	<b>Benefit</b>	<b>Limitations</b>
<b>DESMOND</b>	Developed in the UK. It emphasises patient empowerment and self-efficacy and mainly focuses on lifestyle changes, such as physical activity, food choices and cardiovascular risk factors.	One full day or two half days	Group	Healthcare professionals	* Distinguishes between newly diagnosed patients and those who have been previously diagnosed. * Offers sessions for minority groups and people at high risk of diabetes	*The short contact time may reduce effects.

**Table 9 Widely Used Self-management Interventions**

## APPENDIX 11 OVERVIEW OF SYSTEMATIC REVIEWS OF TYPE 2 DIABETES SELF-MANAGEMENT INTERVENTIONS

Study/yr.	Setting	Tutors	Mode / format	Content	Outcomes	Underpinning of Theories	Outcome significance
<b>Eakins et al.,2002</b>  N= 10	community centres, hospitals, clinics , telephone.	Not mentioned	DSM E group+ individual sessions, mailings, media campaign, peer support, home visits, unstructured sessions, hand-outs, video tapes, nurses, phone calls.	DM knowledge, exercise, nutrition, lifestyle , compliance, access to primary care	PHYSIOLOGICAL: HbA1C, cholesterol, BP, weight, FBG, BMI, body compositions, glucose tolerance and symptoms. BEHAVIOURAL: diet, PA, Smoking KNOWLEDGE: DM SM, changes in medication regime. PSYCHOSOCIAL: depression, social support, self- efficacy, QoL.	4 trials: not specified	5/9 showed significant reduction in weight. 3/9 reported improvement in one of the blood glucose measurement. 3/5 reported positive changes in dietary behaviours and PE. no improvement in QoL (0/2)
<b>Glazier et al.,2006</b>  N= 11	Primary health care centres, hospitals, community based clinics, churches.	Not mentioned	individualised asses SM and goal settings, individual education, reminder cards, support groups, evidence based guidelines, group visits.	DM knowledge, exercise, nutrition, foot care, life style, glycaemic control, co-morbidities and complications.	PHYSIOLOGICAL: FBG, HbA1C, BP, BMI, lipids, DM complications. BEHAVIOURAL: glucose monitoring, diet , exercise, medication adherence, self-adjustment and appointment attendance. PSYCHOSOCIAL: One RCT reported SE	None	8/13 showed significant improvement in HbA1C. 2/9 showed improvement in weight and BMI 2/7 showed improvement in lipids 2/4 improvement of BP None of 4 studies examining dietary intake showed improvement 2/3 improvement in PE 2/2 improvement in DM knowledge 1/1 social and mental wellbeing

Study/yr.	Setting	Tutors	Mode / format	Content	Outcomes	Underpinning of Theories	Outcome significance
<b>Norris et al.,2002</b>  N= 30	clinic, home and community centres.	Nurse, dietician	Didactic or collaborative DSM E, individual and group education, support groups, home visits, dietician, lay health workers, meal, demonstration, telephone follow up, weight loss program, empowerment techniques.	diet, physical activity, foot care, coping , complications, goal setting	PHYSIOLOGICAL: HbA1C	None	
<b>Heinrich et al.,2010</b>  N= 19	Not mentioned	Researcher, Nurse, dietician	home visits, personal experience, goal setting, diabetes care booklet, motivational guidance, phone calls, group, sessions, life style asses SM	psychosocial strategies, coping skills, diet, exercise, drug therapy, DM knowledge, foot care, blood sugar testing, social support, recipe instructions, skill training.	PHYSIOLOGICAL: HbA1C, BMI, Cholesterol,BP, weight. BEHAVIOURAL: medication adherence, diet. PSYCHOSOCIAL: Qi , SE, DM related distress, social support.	7 trials: not specified	8/10 significant effect on diet 5/10 showed significant increase in PE. 4/5 showed positive effect on blood glucose monitoring ¼ effect on foot care 5/13 showed lower HbA1C 1/10 lower BMI No effects were found on BP and lipid profiles 2/4 better Qi 3/5 increased self-efficacy

Study/yr.	Setting	Tutors	Mode / format	Content	Outcomes	Underpinning of Theories	Outcome significance
<b>Norris et al.,2001</b>  N= 72	Not mentioned	Nurse, doctor, dietician, psychologist, nursing student, pharmacist	group sessions, didactic or collaborative education, discussions, psychologist led group sessions, instructional videos	empowerment, DM knowledge, diet, exercise, behavioural modification, foot care, dietician instructions.	PHYSIOLOGICAL: HbA1C, FBS, weight, lipids, BMI BEHAVIOURAL: diet adherence, problem solving. PSYCHOSOCIAL: decreased anxiety, QoL, SE	5 trials: health belief model, social action theory, cognitive motivational theory, social cognitive theory	29 trials/35 showed increased DM knowledge. 24/26 showed significant improvement in HbA1C. 1/3 Showed improvement in QoL 1/1 showed decreased anxiety 4/9 showed increase in physical activity
<b>Steibnsbekk et al.,2012</b>  N= 21	primary care and hospital diabetes centres	Dietician and nurse, dietician alone, physicians, community workers, nurse alone, diabetes specialist nurses, lay health advisors.	group sessions	Not reported	PHYSIOLOGICAL: HbA1C,FBS,Cholesterol,TG,BP, weight BEHAVIOURAL: self-monitoring of blood glucose, physical activity, reduction of high fat food, consumption of fruits and vegetables, diabetes, self-management skills PSYCHOSOCIAL: QoL, SE DM knowledge, DM complications, deaths.	N=10 studies  5 used single theories/ 5 used a combination: social cognitive theory, empowerment model, systematic education approach, theories of planned behaviour, personal models of sickness, discovery learning theory, social ecological theory, self-efficacy and self-management theories, operant reinforce theory.	(Meta-analysis was done)showed significant improvement in HbA1C, DM knowledge, self-efficacy and self-management skills. No significant improvement in cholesterol, triglycerides, BP. No significant impact on DM complications  No effect on mortality rate

Study/yr.	Setting	Tutors	Mode / format	Content	Outcomes	Underpinning of Theories	Outcome significance
<b>Deakin et al.,2009</b>  N= 11	Primary healthcare centres or hospital diabetes centres.	physician, educationalist, dietician and nurse, dietician alone, physician assistance	grouped based sessions	Not reported	PHYSIOLOGICAL: HbA21C, BMI, body weight,BP,lipids BEHAVIOURAL: activity level, dietary intake PSYCHOSOCIAL: QoL, SE, Empowerment. Diabetes knowledge, group satisfaction, change in medication, number of deaths diabetes complications.	5 studies that used a theoretical model showed less effect of the intervention 5 studies reported the use of theoretical models: Diabetes Teaching and Treatment Program, empowerment model, adult learning model, public health model, health belief model,transtheoretical model	(meta-analysis) No effect on mortality rate. Significant reduction in diabetes medication, HbA1C and triglycerides. No impact on weight, BMI and cholesterol Meta-analysis could not be performed for DM knowledge,QoL,SM skills and BP (due to the use of different measuring tools and questionnaires.
<b>Egginton et al.,2012</b>  N= 52	primary healthcare centres, hospitals, community settings, university clinics, DM speciality clinics	pharmacists , nurse educator, lay health educator, computer based intervention , peer led	telephone, pharmacist led, group visits	Not reported	PHYSIOLOGICAL: HbA1c, LDL, cholesterol PSYCHOSOCIAL: QoL BEHAVIOURAL: glucose self-monitoring, foot exam	not reported although authors commented on the importance of using the Chronic Care Model components in designing interventions.	(meta-analysis was done) Statistically significant improvement in HbA1C, LDL.

Study/yr.	Setting	Tutors	Mode / format	Content	Outcomes	Underpinning of Theories	Outcome significance
<b>Loveman et al,2008</b>  N= 13	primary healthcare centres	nurse, dietician, physicians, community workers, diabetes research technician, physicians assistance	individualised, groups	nutrition, diet, self-monitoring (blood/urine), exercise, importance of body weight, DM complications and/or their management, foot care, handling sick days, handling hypoglycaemia .	PHYSIOLOGICAL: HbA1C, BP, lipids, BMI, weight PSYCHOSOCIAL: QoL  DM knowledge	7 studies: empowerment model, cognitive behavioural strategy, precede-proceed model, social learning theory.	6/9 showed significant improvement in HbA1C No significant difference in weight, BMI, cholesterol and triglycerides. 1/13 considered QoL and showed significant improvement
<b>Duke et al,2009</b>  N= 9	Not mentioned	Physician, nurse educator	Restricted to individualised interventions (face to face)	Weight management, dietary habits physical activity, foot care, medication administration, equipment usage.	PHYSIOLOGICAL: HbA1C, DM complications , weight, BMI,BP, lipids PSYCHOSOCIAL: QoL, depression BEHAVIOURAL: Dietary habits, physical activity levels, Smoking  Diabetes knowledge,	none	(Meta- analysis was done) No significant improvement in DM knowledge Lipids and HbA1C

**Table 6 Overview of Systematic Reviews of Type 2 Diabetes self-management interventions**

## APPENDIX 12 STUDIES INCLUDED IN THE SYSTEMATIC REVIEW

Author/year/ Study design	Target group	Language	Persons	Metaphor	Content	Context	Concept	Methods	Goals	Effects
<b>Brown et al., 2002 RCT</b>	Mexican Americans	- Spanish with a blend of English -Minimise written materials -Reading questions aloud -Use of video tapes	Bilingual Mexican American staff	NM	-incorporation of cultural health beliefs -Typical Mexican dietary preferences and recipes incorporated into dietary recommendations - Food demonstrations	-Video tapes showing community leaders describing their DM experience *Family participation	NM	-Providing transport -Providing free glucose monitors and strips -grocery store visits -Emphasise social support	NM*	-Significantly lower levels of HbA1c -Higher diabetes knowledge scores
<b>Teufel-Shone et al., 2005 pre-post study</b>	Hispanics in USA	-Spanish -Reading aloud -Pictorial flipcharts	-Hispanic lay workers	NM	-Recipes, food sampling and preparation of traditional food -Educational games	-Celebratory events -Family sessions -Addressing the family's collective behaviour	*Social Learning Theory	-Home visits if requested - Family support -Providing transportation and child care -Study investigators and lay workers' knowledge and experience	-Family cohesion, resilience and unity	-Significant decrease in sweetend drink consumption -Significant reported increase in family members participating together in physical activity -Significant increase in reported family support
<b>Anderson et al., 2005 RCT pre-test/post-test design</b>	African Americans (urban)	-Appropriate reading level	NM	NM	*Ethnic recipes	NM	Empowerment Behaviour Change Model	NM	Individually set goals	-Modest changes in HbA1c *No significant difference



Author/year/ Study design	Target group	Language	Persons	Metaphor	Content	Context	Concept	Methods	Goals	Effects
<b>Gucciardi et al., 2007 RCT (2 RCTs; individual counselling and Group classes)</b>	Portuguese Canadians	-Portuguese -Appropriate literacy level -Visual aids	-Portuguese speaking health professionals	NM	-Traditional Portuguese food -cooking demonstrations -Coping with eating at social and familial events	- Family participation -Cultural values, beliefs and customs	Theory of Planned Behaviour	-Family participation -Focus groups assessed the cultural appropriateness of the intervention	-Goals established between educators and participants	-Significant decrease in HbA1c during the first three months
<b>Utz et al., 2008 RCT (individual vs. group sessions)</b>	African Americans (rural)	-The use of figurative language characteristic of the region*Posters depicting self-care actions	-Delivered by African American women	The use of the word "Sugar" in the title of the programme	-Label reading *Meal planning and cooking lessons*Exercise practices using videotapes	-Story telling - Family and/or friends participation - Involve African American leaders and role models	Social Cognitive Theory	-The use of cultural understanding through focus groups - interviews to determine satisfaction	-Goals established between educators and participants	-Modest change in HbA1c but not significant

Author/year/ Study design	Target group	Language	Persons	Metaphor	Content	Context	Concept	Methods	Goals	Effects
<b>Vincent, 2008</b> pre-test/post-test control group design	Mexican Americans	-Spanish -Materials for low literacy	-lay-workers bilingual educators	NM	*Cooking demonstrations *Low fat modification of traditional food *Culturally appropriate exercise *strategies such as walking and dancing *Discussion regarding traditional home remedies	*Family involvement	Social Cognitive Theory	-Focus groups to determine satisfaction -Review of the content and activities by members of a community advisory council	NM	-Significant decrease in weight and BMI -No significant changes in HbA1c -Significant increase in the number of steps taken each day
<b>Samuel-Hodge et al, 2009</b> RCT (individual vs. group sessions)	African Americans	-Activities designed for persons with low literacy skills *Use of visuals *limited writing *Game format	-Church diabetes advisors -Peer counsellors with DM	NM	NM	-Opened sessions with prayers (Religion and spirituality* Post cards tailored to behavioural goals selected by participants were sent.	-Social Cognitive Theory -Adult Learning Theory -The Stages of Change Model	-Motivational interviewing techniques	-Post cards tailored to behavioural goals selected by participants were sent	-modest decrease in HbA1c but No significant improvement
<b>Osborn et al, 2010</b> RCT	Puerto Ricans in USA	-Spanish (Puerto Rican dialect) -Material sensitive to participants with limited literacy and numeracy skills	-Bilingual community health workers of Puerto Rican heritage	-teach-back method	-Dispel common myths regarding diabetes care. *monitoring carbohydrate intake and portion size of culturally familiar foods -Culturally tailored, individualised meal plan booklets -Ways to manage stressful life events,	-Patient barriers to self-care were assessed individually	-The Information-Motivation-Behavioural Skills Model	-focus groups with patients and providers to identify barriers and facilitators of self-care behaviours	-Formulation of two goals by patients	-Significant effect in reported self-care behaviours (food label reading and diet adherence -No significant effect on physical activity -Significant improvement in HbA1c in intervention group

Author/year/ Study design	Target group	Language	Persons	Metaphor	Content	Context	Concept	Methods	Goals	Effects
					family expectations and cultural barriers					
<b>Rosal et al., 2011RCT (Rosal et al., 2009)</b>	Latinos in USA	-Spanish Literacy sensitive materials (using pictures and videos )	Health professionals and lay workers who speak Spanish	NM	-The use of soap operas to *Introduce self-management information and desired behaviours in culturally relevant situations -Bingo games to reinforce the taught information*Food preparation lessons to emphasise making traditional food healthier	-Family involvement - Home visit for personalised counselling and cooking lessons	Social Cognitive Theory	Previously identified needs in the target population (from the literature)	Behavioural goals were set between patient and interventionist	-Significant difference in HbA1c *Significant difference in diabetes knowledge, self-efficacy and blood glucose monitoring
<b>Spencer et al., 2011RCT</b>	African American and Latinos	Both English and Spanish	Community health workers ethnically matched to the assigned participants	NM	NM	NM	Empowerment Behaviour Change Model	Community based participatory research informed the development of the intervention	individual specific self-management goals were set between participants and programme deliverers	-Significant improvement in HbA1c*Significant improvement in self-reported self-care behaviours (physical activity, diet, glucose monitoring and adherence to medications)

**Table - Studies included in the Systematic Review**

NM= Not Mentioned

## **APPENDIX 13 A DESCRIPTION OF SESSION DELIVERY (PRE-ADAPTATION)**

### ***Session one:***

This first session started with introductions. The research assistant and I introduced ourselves to the participants as the facilitators of the sessions and asked participants to turn off their mobile phones and indicated the location of the toilets and emergency exits. The participants were then asked to introduce themselves to each other and share with the group two or three ways of how diabetes affected their lives. The problems mentioned by participants were written on a chart and a check mark was drawn next to the problems each time it is repeated in the group. At the end of this activity, participants were made aware that they face the same problems.

The second activity of this session involved giving an overview of all the sessions. This was done by referring to the chart of shared diabetes problems and indicating in which weeks these problems will be addressed using chart 2 (-). For example, participants mentioned sadness and depression, thus it was indicated that this topic will be discussed in weeks four and five. (it was a bit hard to deal with some of the topics mentioned by the participants as some are not addressed in the manual, for example; how to administer insulin and how use a glucometer. It was suggested in the manual that if this occurs that participants are asked to find other community sources or consult their physician). This is more relevant to countries where community sources are available but in this context community resources are scarce and hard to identify. Participants were not satisfied with this answer and some mentioned that this is one of their aims for coming to the sessions. This activity of session also involves

giving some guidelines (Appendix 21) in order for participants to gain the maximum benefit from attending the session, for example; to respect each other's ideas and to maintain confidentiality.

The third activity starts with a small lecture on diabetes and its causes. The lecture emphasises that diabetes is a chronic disease that has no cure so far and the importance of self-management to prevent complications and maintain a healthy life. The five tasks of self-management were explained during this activity (appendix #). These tasks are: taking care of diabetes, carrying out normal activities and doing things that are important, managing emotional changes, taking part in planning and carrying out a management programme and providing information to your doctor.

After a 20-minute break the session was recommenced with the sixth activity. It started with a short lecture on blood glucose monitoring. It provided basic information on HbA1c and blood sugar normal, low and high levels. This activity continued with a brain storming activity. The concept and guidelines of brain storming were explained to the participants which are; anyone can share their ideas, no one will comment positively or negatively on other people's ideas, no questions are allowed during the brainstorm and clarifications will be sought in the end. The first question was: *what things make your blood sugar go up?* The responses were written on the board. When participants stopped giving responses they were asked if they needed any clarification to any of the responses on the board. The second question in the brainstorming activity is "*what things make your blood sugar go down?*". The third question for the brainstorming activity is "*What are some things we can do to help keep our blood sugar in balance?*". Points that were not mentioned by the participants were added at

the end of each brainstorm. the brainstorm activity, the Diabetes Self-Management Tool Box was explained (Appendix 21).

The fifth activity was an introduction to healthy eating. A short lecture was given aided by a chart explaining what health eating means (Appendix X). The points discussed were; eating a variety of foods, eating meals and snacks regularly, eating breakfast every day, eating regularly throughout the day and eating the same amount of food from day to day. At the end of the lecture, participants were asked to choose a week day and one weekend day and monitor their blood sugar once before a meal, once two hours after a meal and once after exercise. The manual suggests that those who do not know how to monitor their blood glucose to call The American Diabetes Association to find out the nearest place for them to learn this skill. Unfortunately, there is no such service available in Saudi Arabia, therefore participants were asked to visit the chronic disease specialist nurses to learn how to use the glucometer and monitor their blood sugar. Participants were also asked to write a food diary and write down all the foods they eat on the chosen days.

The last activity in this session was an introduction to action plans. It starts with a small lecture explaining the concept of goal setting which emphasises that it is easier to achieve a goal when it is broken into smaller steps or tasks. This is then put in practice by demonstrating action plans by the facilitators while reviewing a chart that summarises the steps of action planning (Appendix #) which are;

1. Think of something you want to do
2. Achievable

### 3. Action-specific

Then answer these questions: What? How much? When? How often?

Confidence level

The participants were then asked to divide themselves into pairs and help each other make an action plan to be achieved before the following session. It was explained that action plans do not have to be something related to what was covered in this session, it can be anything that they want to achieve. The participants had ten minutes to finish this exercise. Each participant was then asked “what will you do this week?” Participants are not allowed to say “I will try” but they should say “I will” instead. After each participant completes telling the group about their action plan, they were asked “on a scale of 0 to 10, with 0 being not at all confident and 10 being totally confident, how confident are you that you will (action plan is repeated verbatim). If the answer is 7 or below, then the action plan is reassessed through asking the participant why they are uncertain and what barriers do they have. The other participants in the group were asked to offer solutions first before facilitators offer their recommendations. Once the problem solving was completed, each participant was asked to repeat the new action plan.

This session was closed by reminding the participants to carry out their action plans and to prepare to tell the group about them in the next session. They were also reminded to keep a diary of what and when they eat for two days in the next week, as well as monitor their glucose and bring this with them to the next session. The manual

suggests calling the participants during the week to support them to do their action plan, if they give consent to do so.

***Session two:***

This session consists of five activities.

This session as with every upcoming session starts with a problem-solving session where participants and facilitators feedback on their action plans from the previous session. Facilitators started first then participants. They were asked to state their action plan and report how well it was accomplished. When it is not successful, the participant were asked to describe the barriers that prevented them completing the action plan. Only two minutes were allowed per participant to talk about the problems they faced, if any, to achieve their plan. The participants who faced a problem were then asked if they have any idea of how to solve them and whether they like to hear suggestions from the group. If the participant agrees, the group is asked to brainstorm possible solutions without comment or discussion. Most participants did not agree to hear suggestions from the group, however, they asked the facilitators for suggestions. The participant who faced the problem is then asked to choose one of the strategies suggested they think is doable. The manual commends to move to the next person if the participant says “yes but” three times when discussing a suggestion. If no suggestion seems practical, then the participant was told that their problem will be discussed during the break or at the end of the session.

The second activity involved a short lecture about healthy eating. The lecture highlights the importance of making heathier food choices rather than following a diet



and it offers guidelines for making such choices. It also emphasises that the guidelines are relevant not only to those with diabetes. It is important to emphasise this point, so the participants understand that these guidelines can be used for their whole family and not just for them. The healthy eating chart from the previous session was explained briefly again (Appendix 21). A brief explanation of the role of proteins, fats and carbohydrates in the body was provided. At the end of the lecture, the participants were asked to brainstorm for “*what are the examples of starchy and sugar food?*” The food guide in the “*living a healthy life*” book was briefly explained after some facts about carbohydrates were provided. The guide categorises food into proteins, vegetables low in starch, starchy vegetables, fruits, fats and problem foods and a free food list. Portion sizes for each food is also provided. Finding the recommended nutrients and portions was then practiced by asking the participants to find the answers to a few questions from the book, for example, *how many grams of carbohydrates are there in a cup of rice?* A chart displaying the guidelines for a healthy meal is then discussed (Appendix 21). The chart emphasises that in any one meal an individual should not have more than:

- *A total 45-60 grams of carbohydrates*
- *15-35 grams of protein*
- *10-15 grams of fat*
- *Each snack should not have more than 25 grams of carbohydrates*

To practice this, the participants were grouped into three groups. Each group was assigned to plan a meal (breakfast, lunch or dinner) for a guest with diabetes by using

the book and a chart that gives an example of a meal (Appendix 21). They had 15 minutes to plan the meal then report back their menu mentioning the number of grams of proteins and carbohydrates. The menus created by the participants were written on the board and checked to ensure they follow the formula for the recommended portion sizes etc. suggestions and corrections were given when needed. The manual recommends that participants use the internet to search for foods that are not mentioned in the book.

The “Plate method” was then explained as another way to be used for healthy eating. Half the plate should be low carbohydrate vegetable, one fourth should contain a portion of protein and the other fourth should have one or two portions of starchy food (Appendix#).

In the 20 minute break women had a lot of questions to ask about their daily meals. Most were sharing how they actually cook their daily meals and were asking whether they were healthy or not. Some also had misconceptions about some foods, most commonly dates and rice.

The session was resumed by a small lecture about “*preventing low blood sugar-hypoglycaemia*”. It starts by asking the participants about the effect of exercise, food, not eating, medications and stress on blood sugar. The manual has a question on the effect of alcohol on blood sugar however it was not asked out of respect to the participants as most will find it offensive. The causes of low sugar are then explained using a chart (Appendix 21). A brainstorm activity was then started with the question: “What do you feel like when your blood sugar is too low?”. The steps for dealing with low blood sugar was then explained and the situations when they should call for help

were highlighted (Appendix 21). Participants were encouraged to always carry an emergency snack with them.

The last activity was “making an action plan”. This time it was easier for the participants to decide on an action plan.

In the closing activity, the participants were asked if they agree for others participants to call them by phone to support them stick to their action plan. Most of the men group did not mind exchanging phone numbers, however, only two women exchanged phone numbers. The rest mentioned that they were either too busy to answer their phones or that they do not usually receive calls and only use their phones for emergencies. The participants were also asked to keep a food diary again for at least two days of the week.

***Session three:***

This session includes eight activities. The first is the feedback on action plans and problem solving. The second activity is a short lecture on preventing and delaying complications. The lecture starts with a brainstorm on “what are the complications of diabetes?”. The lecture highlights the importance of maintaining normal blood sugar levels on a day to day basis through physical activity and making healthy food choices. It also provides a list of the type of tests that patients with diabetes need on a regular basis, for example, blood pressure, foot exams and HbA1c. Some participants asked if they can be taught the way to examine their feet. As this was not a part of the programme, they were asked to ask their health care provider.

The third activity includes a short lecture and discussion about planning low fat meals. The activity started with a brainstorm to the question: “*why is it important to reduce fat*”. A lecture was then given on the types of fat and the benefits of weight loss. Another brainstorm activity is then started with the question “*What are some ways we can reduce the amount of fat we eat?*”. After listing some of the ways to reduce fat, the participants were asked to bring food packaging they usually buy that include the nutrition facts. This is in order to practice shopping smart to reducing fat and carbohydrates.

After a 15-minute break, the fourth activity of this session is an introduction to physical activity and exercise. It starts with a brainstorm to “*why is physical activity or exercise important?*”. A short lecture then introduced three types of physical activity; flexibility, strengthening and endurance activities (Appendix 21). The lecture emphasised that physical activity can be as little as one minute per hour up to an hour for five days a week. Physical activity goals were then suggested through a chart (Appendix#). It also discussed some tips on how to deal with some symptoms that could arise from performing physical activities, such as; dizziness and disorientation, muscle or joint pain and shortness of breath. The lecture ended by giving some tips for physical activity and exercise, e.g. performing physical activity at the same time every day, coordinating physical exercise with meals and doing about the same amount of activity each time and work up gradually.

The fifth activity is about “dealing with stress”. A short lecture was first given highlighting the effect of stress on blood sugar. The lecture is followed by two brainstorm activities on “what are the signs of stress?” and “what can you deal with stress?”.

The sixth activity involved a muscle relaxation activity. A script that is provided in the manual was read to the participants. Before starting the exercise, it was explained to the participants that this exercise should relax the mind and the muscles.

The last activity was making an action plan.

At the end of the session the participants were reminded to bring two food packages that display nutritional facts. They were also reminded to consider what was learned about reducing fat in their meals

#### ***Session Four:***

The first activity is an action plan feedback and problem-solving activity.

The second started with discussing dealing with difficult emotions. A short lecture was started by ensuring the participants that it is normal and common for people with diabetes to be stressed and to have emotions such as anger, frustration and depression. It also emphasised the impact of such emotions on blood sugar. The participants were asked to raise their hand if they have experienced any of these difficult emotions. Almost all women raised their hands, but most of men did not. The participants are then asked to gather in pairs and share with each other two things; the difficult emotion they encounter because they have diabetes and what they think the causes of these emotions. After ten minutes each participant had to share their participant's experience with the group. The reason for this is to ensure that it is a learning activity and not merely a problem sharing exercise. Participants were reminded that if there is something they do not wish to be shared with the whole group, they should either not share it at all or ask their partner not to share it. After this exercise, a brainstorm

activity was commenced to the question: “*what are some ways to deal with difficult emotions like frustration, anger and fear?*”. Before a 20 minute break, participants were informed that writing their thoughts and feelings and also engaging in any physical activity are good ways to help deal with these emotions.

The third activity involves reading nutrition labels. First, the “living a healthy life” book was used to show the participants a food label. They were asked to answer a few questions using the label in the book regarding the serving size, calories, total carbohydrates and total fat. Each of these was discussed in detail. The participants were asked in the previous session to bring a few food packaging of foods they regularly eat. This activity proved challenging as most of the food packages the participants brought with them, did not have any nutritional labels, and the packages that had a label, the font size was very small making it very difficult to read.

The fourth activity in this session introduced endurance activities. The activity started by defining endurance activity as any activity that raises the heart rate, increases breathing and causes sweating. It also emphasised the impact of such activity on blood sugar and weight. Two charts were then shared with the participants; one summarises what activity is considered a moderate endurance activity (appendix#) and the other explains the “FIT” formula (Frequency, Intensity and Time) (Appendix#). Monitoring exercise intensity through a talk test, a self-rating of exertion and counting of pulse was discussed (appendix#). This was practiced by asking the participants to move around for one minute or march in their own place. After one minute the participants were asked to rate their exertion levels from 0(no work) to 10 (very hard work). They were reminded to substitute walking with another activity, if it is convenient.

Participants were then asked to keep track of the physical activity they undertake in one weekday and one weekend day and share it with the group in the coming session.

The fifth activity was making an action plan.

The session was closed by reminding the participants to monitor their physical activity.

***Session five:***

As with every session, this session started by feeding back on action plans made in the previous session and problem solving for unsuccessful plans.

The second activity is about depression management. It started with highlighting that depression is common in people with diabetes and can hinder the ability to manage the disease. A brainstorm activity was then commenced with the question “*What are some things people might do to feel better when they are feeling down, blue, unhappy, or depressed?*”

The third activity is about positive thinking. It started with a short lecture explaining the negative impact of negative thinking on health. Examples of negative and positive statements were then shared; for example (from the manual);

*Negative: "I just can't lose weight. It is difficult, and diets just don't work for me. I am always hungry. I just look at food and I get fat!"*

*Positive: "I have diabetes and it is important for me to maintain a healthy weight to prevent complications. Instead of dieting, I will make small changes in the way I eat. I'll start by reducing fat and eating more vegetables.*

Examples of negative thoughts were then shared with the participants and were asked to change them to positive statements. A chart displaying the steps towards positive thinking was explained (Appendix 21).

After a 20-minute break, an activity about communication skills was commenced. It started with a lecture emphasising the importance of good communication. The lecture also explained the importance of learning to use "I message" which allows to express frustration and anger without blaming others, rather than using "you messages". Two examples of two dialogues between partners and friends was then read to the participants. The manual provided a dialogue between partners about sex and intimacy, but this was shared with the women group but not the men group. This would have been culturally inappropriate to share this with the men for the reason that facilitators were women. A chart listing steps to improve communication skills was then discussed (Appendix 21).

The fifth activity discussed medication usage. A lecture discussed, using charts, the purposes of medications (Appendix 21), types of medication used for diabetes, medication effects (Appendix 21) and medication responsibilities (Appendix 21). This was then followed by a brainstorm activity using the question "*What are some ways to remember to take medications?*". The manual provides ideas on how to cut on medication expenses. This was not discussed as the participants were following up in



a governmental primary care centre where medications are provided free of charge. The participants were asked to complete a personal medication list for homework.

The last activity was making an action plan.

***Session Six (The final session):***

The first activity was the feedback and problem solving from the previous session.

The second activity discussed the strategies for sick days. A short lecture provided advice on things to do on sick days and when to seek medical help. The question “*What are the things you can do now to prepare for when you are sick?*”.

The third activity was a lecture about foot care and its importance. A chart summarising what good foot care involves was discussed. It also provides tips on dealing with a foot wound.

After a 20-minute break the session commenced with an activity on working with health care system and healthcare professionals. A brainstorm activity was started using two questions “*What problems do you have with your health care organization?*” and “*What problems do you have with your health care providers?*”. A chart was then discussed on the effective way to deal with health care professionals.

The last session was closed by encouraging the participants to call each other for support if they wanted to. The participants were also invited to a small party on the next day after participating in the focus group discussion. It was emphasised that they are welcome to attend the party even if they do not agree to participate in the focus

group. Participants were offered certificates of completion and were thanked for their participation in the study.

## APPENDIX 14 EXAMPLE OF A CONSULTATION IN THE CHRONIC CARE CLINIC

Nurse: *Fatimah Mohammad* (calling the patient from the waiting room)

Fatimah enters the clinic: *Alsalamu alaikum*

Nurse and doctor: *wa alaikum alsalam*

Nurse: *How are you Fatimah?*

Fatimah: *Alhamdolellah*

Nurse: *Before you sit I am going to check your weight, check your pressure and blood sugar then will ask a few questions before the doctor talks to you.*

Fatimah gets on the mechanical column scale to be weighed.

Nurse: *Your weight is the same as last time. It is good that it has not increased but you should lose some weight Fatimah. Come sit.*

Fatimah sits on a chair opposite the nurse while the nurse puts on her stethoscope to measure the blood pressure with a manual sphygmomanometer, writes the result down then uses a glucometer to check the blood sugar level with a glucometer.

While this is taking place, the doctor was sitting behind the office and finishing up the notes for the previous patient then checking Fatimah's record and her latest laboratory results and medication list.

The nurse asks the questions while filling the form “of trends” mentioned above with the vital signs

**Nurse:** *Did you have something to eat before you come here Fatimah?*

**Fatimah:** *I had breakfast early morning. Maybe at 7:30.*

**Nurse:** *What did you have for breakfast?*

**Fatimah:** *I had a cup of tea with just a tiny bit of sugar and toast with low fat cheese and a cucumber and tomato.*

**Nurse:** *your blood sugar is high today. It is 216*

**Fatimah:** *Wallah I do not why it is high. The sugar I put in the tea today was just a tiny bit. not even a full teaspoon. And the toast I had was also brown. the one special for diabetics. My daughter got for me. she said it is good for me.*

**Nurse:** *Go and sit on the other chair for the doctor to see you.*

Fatimah moves to sit on the chair on the side of the desk facing the doctor

**Doctor:** *How are you Fatimah? How is it going with your diabetes since I have last seen you?*

**Fatimah:** *Alhamdolellah. I am taking my medications regularly. I eat healthy but you know it is hard sometimes but I would say I am consistent in term of diet and medication. I also do some exercise sometimes too. I do what I can and the rest I leave to Allah.*

**Doctor:** *Do you have any chest pains or palpitations? Any difficulty in breathing?*

**Fatimah:** *No alahamdolellah*

The doctor examines Fatimah's chest using his stethoscope over her *Abaya* while her face is covered

**Doctor:** *Do you have any pain, numbness or burning sensations? Any injuries in your feet?*

**Fatimah:** *No.*

**Doctor:** *Can I examine your feet please?*

He examines her feet while she is sitting on the chair and putting her bare feet on a small stool

**Doctor:** *How is your vision? Any blurriness or any changes?*

**Fatimah:** *No. Alhamdollelah*

**Doctor:** *Did you see the eye doctor recently?*

**Fatimah:** *No I could not go. I missed it. I did not have someone to take me that day.*

**Doctor:** *I will refer you again but you have to go this time. It is very important to check your eyes once a year at least. Diabetes affects the eyes, the kidneys and nerves so it is important to follow up Fatimah.*

**Fatimah:** *Inshallah. I know I should but you know the circumstances.*

**Doctor:** *Let us go through what medications you are taking currently. So you are taking the big yellow pill how many times?*

**Fatimah:** *three times a day. Before the meals*

**Doctor:** *Good. What about the small round blue one?*

**Fatimah:** *Once a day after dinner.*

**Doctor:** *O.K. Do check your blood sugar daily and log the results in the diary?*

**Fatimah:** *I do most of the time.*

**Doctor:** *Can I see the diary?*

**Fatimah:** *I did not bring it with me today. I have run out of the strips this week so I could not fill it in.*

**Doctor:** *O.K. we will give you a box of strips today and next time you come I need to see your diary.*

**Fatimah:** *Inshallah*

**Doctor:** *Looking at your laboratory results; your red and white blood cells are good and your kidney functions are also good. You have some protein in the urine so we need to keep an eye on that. It could affect your kidneys if you do not control your sugar. Your cholesterol is a bit high Fatimah. Higher than last time. Your HbA1c is more than %7 which means you are not are not taking care of yourself. You must not be eating healthy. Do you? Do you exercise?*

**Fatimah:** *I do doctor. I try to do exercise. At home a bit. . And I eat healthy. I eat a lot of vegetables and fruits. I grill the food in the oven and have just little bit of rice, not too much at all. I have brown bread and I do not have a lot of dates. Just sometimes if I am really craving it. A couple only not to much. I even reduced the sugar in my tea. What else can I do?*

**Doctor:** *Make sure that you are eating healthy Fatimah otherwise you could be badly affected. We talked about how high blood sugar is bad for your organs.*

**Fatimah:** *Allah ya'een inshallah*

**Doctor:** *O.K. We will have to increase the dose of the yellow pill Fatimah. Take one more pill before dinner. So two pills before dinner instead of one. I want to see you next week to see if you are doing well on it but I need you to measure your blood glucose from today every day until I see you next week. Log the results in the diary. I want to see it next week. Are you O.K with that?*

**Fatimah:** *Inshallah*

The doctor writes her a prescription and hands it to her.

**Doctor:** *I will see you next Wednesday Fatimah. Ma'a alsalamah*

**Fatimah:** *Thank you doctor. Ma'a alsalamah*

**Another Scenario (Not expressing facing difficulties)**

**Doctor:** You need to lose weight. Your diabetes will not be controlled if you don't lose weight.

**Patient:** *I know doctor, I am trying wallah. I'm not eating much*

**Doctor:** *Exercise is very important. You must exercise.*

**Patient:** *But it is hard and I don't have time*

**Doctor:** *What can you do, you have to.*

Similar scenarios occurred during observations at the clinic. I felt that the health team did not always believe the patients, which might seem intimidating and patronising at times. For example:

**Doctor:** *What is going on with you sister, your blood sugar is very high today. You must be adding a lot of sugar to your tea or eating a lot of rice?*

**Patient:** *Oh, really! Wallah I am controlling my diet very well these days. I'm trying my best*



**Doctor:** *Are you sure? it does not seem like it from your blood sugar. What did you have for breakfast today?*

**Patient:** *A slice of toast with cheese and a cup of tea without sugar.*

**Doctor:** *Are you sure? you did not have dates?*

**Patient:** *No. No dates*

**Doctor:** *It is better if you change your toast to brown bread rather than white.*


**Patient:** *Inshallah.*

# APPENDIX 15 CONSULTATION ASSESSMENT FORM

CMR 4

## CMR Annual Assessment

التقييم السنوي لمتدربات القلب والسكر



File no. \_\_\_\_\_ Sex:  M  F

Name: \_\_\_\_\_

Tel: \_\_\_\_\_

DOB / Age: \_\_\_\_\_

Job: \_\_\_\_\_

Diagnosis<sup>a</sup> 1 on \_\_\_\_ / \_\_\_\_ / 14

Diagnosis<sup>a</sup> 2 on \_\_\_\_ / \_\_\_\_ / 14

Diagnosis<sup>a</sup> 3 on \_\_\_\_ / \_\_\_\_ / 14

Diagnosis<sup>a</sup> 4 on \_\_\_\_ / \_\_\_\_ / 14

Diagnosis<sup>a</sup> 5 on \_\_\_\_ / \_\_\_\_ / 14

Family Hx:

DM  F

HTN  M

Prem. CVD  B


(Sudden Death, Stroke, MI, PAD)  S

Color Code: Problem List

Date (month/year)	Year /	Year /	Year /	Year /	Year /	Year /
Smoking since ____ cig./day						
Symptoms (complications & side effects); & Update Family Hx.						
Weight/BMI (Ht=)						
Average BP (Last 3 mon)						
P.E. General						
Peripheral pulses (radial, carotid, femoral, dorsalis pedis, posterior tibial)						
Foot (Inspect: Cap, PFI, SW Filament, T, Fork)						
Oral / Dental Exam	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mood						
Fundoscopy / Eye / V. Acuity	<input type="checkbox"/> referred	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ECG	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Average FBS / PPBS						
HbA <sub>1c</sub>						
Cholesterol / Triglycerides						
LDL / HDL						
ALT / AST						
K <sup>+</sup> / Na <sup>+</sup>						
Creatinine / BUN						
Uric Acid / Ca <sup>2+</sup>						
Urine dipstick	K P S	K P S	K P S	K P S	K P S	K P S
eGFR / ACR						
Hb / Hct						
Others (if indicated)						
Compliance <sup>b</sup>	D *E M O S	D *E M O S	D *E M O S	D *E M O S	D *E M O S	D *E M O S
Other Complications						
CVD Risk <sup>c</sup>	L M H VH	L M H VH	L M H VH	L M H VH	L M H VH	L M H VH
Vaccination, Mammogram, DEXA						
Doctor's Initials						
CMR / IVP (____ / ____ / 14 ____)		USS (____ / ____ / 14 ____)		Ex.ECG / Echo (____ / ____ / 14 ____)		

<sup>a</sup> Use CVD Risk Assessment Chart CMR3 to estimate CVD Risk. <sup>b</sup> Needed for estimation of CVD risk. <sup>c</sup> Refer to CMR3 to help you exploring risk and PE.  Tick  if referred.

<sup>d</sup> Diet E-Exercise M-Meds O-Others (Foot Care, Oral Care, Self Monitoring, ...) S-smoking. Mark with X = Non-compliant; / = Semi-compliant; O = Compliant. Refer to CMR3 to estimate compliance in the last 1 year.



**Primary Health Care**

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CMR Annual Work-up Chart (CMR-4)

## APPENDIX 16 CITY AND PRIMARY HEALTHCARE CENTRE PICTURES



Figure 5: Al-khaleej Primary Health Care Centre



Figure 6 Primary Health Care Centre Street



**Figure 7: Al-khaleej Primary Healthcare Centre Male Entrance**



**Figure 8 Al-khaleej Primary Healthcare Centre Male Waiting Room**





**Figure 9: Healthcare Centre Consultation Room**



**Figure 10: Dammam City Centre**

## APPENDIX 17 TYPICAL FOOD PRODUCT NUTRITIONAL LABELLING



Figure 11 Evaporated Milk Nutritional Label

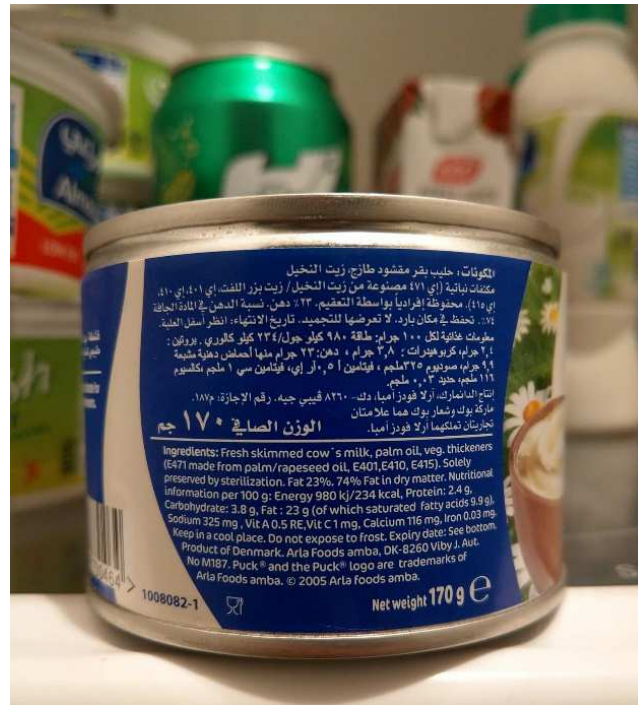


Figure 12 Double Cream Nutritional Label







Figure 15 Fruit Drink Concentrate Nutritional Label



Figure 16 Basmati Rice



## APPENDIX 18 NUTRITIONAL COMPOSITION LISTS FOR COMMON SAUDI DISHES (AL-MSSALLEM, 2014)

food	Serving size	Moisture (g)	Energy (cal)	CHO (g)	Protein (g)	Fat (g)	Fibre (g)	B1 (mg)	B2 (mg)	Fe (mg)	Ca (mg)	Na (mg)
Arabic coffee	25	24.7	1	0.15	0.03	0	0	0	0	0	0	0
Aseeda	75	49.43	99	18.6	3.6	1.13	1.5	0.03	0.07	0.06	-	219
Basmati rice Kabsa	150	97.1	213	43.2	4.2	2.5	1.2	0.06	0.96	0.3	1.5	301.5
Briani	150	89.4	252	48.1	5.1	4.3	1.5	0.03	0.03	1.35	1.5	378
Bukhary	150	98.2	207	39.3	4.8	3.4	1.6	0.05	0.05	1.2	7.5	465
Dates	60	12	183	43.8	1.32	0.36	1.44	0.05	0.06	1.26	43.2	0
Dates stuffed with nuts	90	12.78	369.9	45.9	7.68	17.37	3.69	0.09	0.23	2.19	115.2	0
Dates with Arabic Coffee	85	36.7	184.6	43.9	1.35	0.36	1.44	0.05	0.06	1.26	43.2	0
Dates with sour milk or yoghurt	185	122.1	257.3	50.5	5.3	3.6	1.44	0.05	0.06	1.26	193.2	0
Harees	150	119.2	105	43.2	3.6	0.6	4.05	0.06	0.06	2.7	0	165
Hassawi rice Kabsa	150	94.5	202.6	24.2	12.5	6.2	1.2	0.10	0.92	2.60	17.16	88.5
Klaja	30	2.6	114.6	15.03	2.58	4.92	1.8	0	0	0.69	1.5	28.2
Loqaimat	50	8.35	189	33.6	1.95	5.15	0.8	0	0	0.25	10.5	8.5
Maamool Tamer	40	2.6	187.6	24.48	2.68	8.56	1.32	0	0	0	0	-
Mahalbia	75	46.2	114	23.85	2.85	0.75	0.6	0.03	0.06	0.53	12	105.75
Mandi	150	92.8	235	45.7	5.1	3.6	0.9	0.03	0.03	1.2	3	1.5
Marassia	150	73.9	309	47.1	10.05	9	6.9	0.04	1.41	3.15	1.95	285
Marqooq	150	121.8	99	15.6	4.65	1.95	3.9	0.08	0.54	2.1	3	457.5
Mataziz	150	114.9	142.5	20.85	5.55	4.05	2.55	0.05	0.29	1.65	52.5	190.5
Moaddas	150	104.7	198	29.5	6.3	6.1	0.6	0.12	1.37	3.3	40.5	885
Qors Tamer	65	19.75	216.45	31.21	3.02	8.51	1.38	0.1	0.08	1.23	28.8	15.75
Qorsan	150	115.05	18.75	6.45	3.45	3.75	4.05	0.09	0.78	1.35	1.5	390
Saleeq	150	115.3	141	25	5.8	1.9	0.3	0	0	1.05	64.5	483
Siyadiyah	150	99.1	223	30.6	9.9	6.9	1.6	0.03	0.14	0.6	0	375
Yoghurt, full fat-plain	125	110.1	73.7	6.7	4	3.25	0	0	0.23	0	150	0

**Table 7 Nutrition composition for some traditional Saudi foods. CHO, Carbohydrate; B1, Thiamine; B2, Riboflavin; Fe, Iron; Ca, Calcium; Na, Sodium**

Food	GI	II
Baked Motabbaq	56	-
Dates with Arabic Coffee	63	62
Dates with sour milk or yoghurt	29	-
Dates, Khalas variety	55	64
Foul (mashed)	55	-
Foul (whole)	45	-
Fried Motabbaq	52	-
Gerish	89	-
Harees	52	-
Hassawi rice, cooked in water only	59	56
Kabsa	60	-
Klaja eneazaa	58	-
Klaja malakee	51	-
Mahalbia	56	-
Marassia	51	-
Qorsan	61	-
Saleeq	52	-
Siyadiyah	14	-
Stuffed grapevine leaves	30	-

**Table 8 The Glycaemic Index (GI) and Insulinaemic Index (II) for some Saudi foods.**

## APPENDIX 19 CDSMP AND THE DSMP COMPARISON

### Comparison of the Diabetes Self Management Program (DSMP) and the Chronic Disease Self-Management Program (CDSMP2012)

Session One	Diabetes vs. CDSMP
Activity 1: Introductions	Same, except participants are asked to identify <b>problems caused by diabetes only</b>
Activity 2: Workshop Overview	Same, except with <b>diabetes focus</b>
<b>Activity 3: What is Diabetes?</b>	Activity not in CDSMP. Replaces the chronic vs. acute disease activity. Covered in cross training.
<b>Activity 4: Monitoring</b>	Activity not in CDSMP. Replaces the Mind-Body Connection/Distraction activity. Replaces symptom cycle with the Diabetes Self-Management Tool-Box. Covered in cross training.
Activity 5: Introduction to Healthy Eating	Similar to the Health Eating activity in CDSMP but shorter. The CDSMP activity is covered much later (Session 4) and includes topics covered earlier in DSMP like the Plate Method, review of food diary experience and how to search for portions in the book. <u>Reviewed in cross training.</u>
Activity 6: Introduction to Action Planning	Same
Activity 7: Closing	Same

Session Two	Diabetes vs. CDSMP
Activity 1: Feedback and Problem-Solving	Same, except diabetes course includes feedback not only on the action plan but <b>also what was learned by doing the diary and glucose monitoring</b> . Diabetes course also includes some additional problem-solving around glucose monitoring
<b>Activity 2: Formula for a Healthy Eating Plan</b>	Activity not in CDSMP. Covered in cross training.
<b>Activity 3: Preventing Low Blood Sugar: Hypoglycemia</b>	Activity not in CDSMP. Covered in cross training.

Activity 4: Making an Action Plan	Same
Activity 5: Closing	Same

<b>Session Three</b>	<b>Diabetes vs. CDSMP</b>
Activity 1: Feedback and Problem-Solving	Same, except <b>includes feedback on food diary as well.</b>
<b>Activity 2: Preventing or Delaying Complications</b>	Activity not in CDSMP. Covered in cross training.
<b>Activity 3: Planning Low Fat Meals</b>	Activity not in CDSMP. Covered in cross training.
Activity 4: Introduction to Physical Activity and Exercise	Similar, but adds a <b>diabetes focus</b> . Takes out problem solving for obstacles in achieving physical activity goals. Adds guidelines for safely exercising and maintaining balance of blood sugar.
<b>Activity 5: Dealing with Stress</b>	Activity similar to the Depression Management activity in CDSMP. Covered in cross training.
Activity 6: Muscle Relaxation	Similar to CDSMP's Body Scan activity
Activity 7: Making an Action Plan	Same
Activity 8: Conclusion	Same

<b>Session Four</b>	<b>Diabetes vs. CDSMP</b>
Activity 1: Feedback and Problem-Solving	Same, except includes <b>feedback on eating plan and monitoring of blood sugar</b>
Activity 2: Dealing with Difficult Emotions	Same
<b>Activity 3: Reading Nutrition Labels</b>	Activity similar to Making Healthy Food Choices in CDSMP but more extensive and interactive. Includes pairing up participants. Covered in cross training.
Activity 4: Endurance Activities	Same, except for <b>diabetes focus</b> at the beginning of the activity.

Activity 5: Guided Imagery	Activity no longer in CDSMP. <u>Reviewed in cross training</u>
Activity 6: Making an Action Plan	Same
Activity 7: Closing	Same

<b>Session Five</b>	<b>Diabetes vs. CDSMP</b>
Activity 1: Feedback and Problem-Solving	Same, except includes feedback on changes in eating plan, glucose monitoring and/or physical activity and fitness.
Activity 2: Depression Management	Same, but <b>uses diabetes self-management tool-box rather than symptom cycle</b>
Activity 3: Positive Thinking	Same, but with <b>diabetes focus</b> .
Activity 4: Communication Skills	Same, but with <b>diabetes focus</b> .
Activity 5: Medication Usage	Similar, but with a focus on <b>diabetes-specific medications</b> .
Activity 6: Making an Action Plan	Same
Activity 7: Closing	Same

<b>Session Six</b>	<b>Diabetes vs. CDSMP</b>
Activity 1: Feedback and Problem-Solving	Same
<b>Activity 2: Strategies for Sick Days</b>	Activity not in CDSMP. Covered in cross training.
<b>Activity 3: Foot Care</b>	Activity not in CDSMP. Covered in cross training.
Activity 4: Working with Your Health Care Professional and Health Care System	Same
Activity 5: Looking Back and Planning for the Future	Same
Activity 6: Closing	Same

## APPENDIX 20 STANFORD CHRONIC DISEASE SELF-MANAGEMENT PROGRAM AGENDAS BY SESSION

<b>Workshop Overview</b>						
	Week 1	Week 2	Week 3	Week 4	Week 5	Week 6
Overview of self-management and chronic health conditions	•					
Using your mind to manage symptoms	•		•		•	•
Getting a good night's sleep	•					
Making an action plan	•	•	•	•	•	•
Feedback and problem-solving		•	•	•	•	•
Dealing with difficult emotions		•				
Physical activity and exercise		•	•			
Preventing falls		•				
Making decisions			•			
Pain and fatigue management			•			
Better breathing				•		
Healthy eating				•	•	
Communication skills				•		
Medication usage					•	
Making Informed treatment decisions					•	
Dealing with depression					•	
Working with your health care professional and organization						•
Weight management						•
Future plans						•

## Agendas by Session

Agendas should be posted each session, either as a pre-made chart or on a part of the board that is not erased until the end of the session. Agendas help with time management.

### Session 1

- Activity 1: Introduction to Workshop (20 minutes)
- Activity 2: Group Introductions (30 minutes)
- BREAK (20 minutes)
- Activity 3: The Mind-Body Connection/Distraktion (20 minutes)
- Activity 4: Getting a Good Night's Sleep (10 minutes)
- Activity 5: Introduction to Action Plans (40 minutes)
- Activity 6: Closing (10 minutes)

### Session 2

- Activity 1: Feedback/Problem-Solving (30 minutes)
- Activity 2: Dealing with Difficult Emotions (40 minutes)
- BREAK (20 minutes)
- Activity 3: Introduction to Physical Activity and Exercise (25 minutes)
- Activity 4: Preventing Falls and Improving Balance (10 minutes)
- Activity 5: Making an Action Plan (20 minutes)
- Activity 7: Closing (5 minutes)

### Session 3

- Activity 1: Feedback (25 minutes)
- Activity 2: Making Decisions (20 minutes)
- Activity 3: Pain and Fatigue Management (20 Minutes)  
BREAK (20 minutes)
- Activity 4: Endurance Exercise (25 minutes)
- Activity 5: Relaxation: Body Scan (10 minutes)
- Activity 6: Making an Action Plan (15 minutes)
- Activity 7: Closing (5 minutes)

### Session 4

- Activity 1: Feedback (20 minutes)
- Activity 2: Better Breathing (15 minutes)
- Activity 3: Healthy Eating (25 minutes)  
BREAK (20 minutes)
- Activity 4: Communication Skills (25 minutes)
- Activity 5: Problem-Solving (25 minutes)
- Activity 6: Making an Action Plan (15 minutes)
- Activity 7: Closing (5 minutes)



### Session 5

- Activity 1: Feedback (20 minutes)
- Activity 2: Making Healthy Food Choices (20 minutes)
- Activity 3: Medication Usage (20 minutes)  
BREAK (20 minutes)
- Activity 4: Making Informed Treatment Decisions (10 minutes)
- Activity 5: Depression Management (15 minutes)
- Activity 6: Positive Thinking (25 minutes)
- Activity 7: Making an Action Plan (15 minutes)
- Activity 8: Closing (5 minutes)

### Session 6

- Activity 1: Feedback/Problem-Solving (20 minutes)
- Activity 2: Working with Your Health Care Professional and Health Care Organization (25 minutes)
- Activity 3: Weight Management (20 minutes)  
BREAK (20 minutes)
- Activity 4: Looking Back and Planning for the Future (40 minutes)
- Activity 5: Closing (10 minutes)



# APPENDIX 21 DIABETES SELF-MANAGEMENT PROGRAM-HANDOUTS AND CHARTS

Chart 1

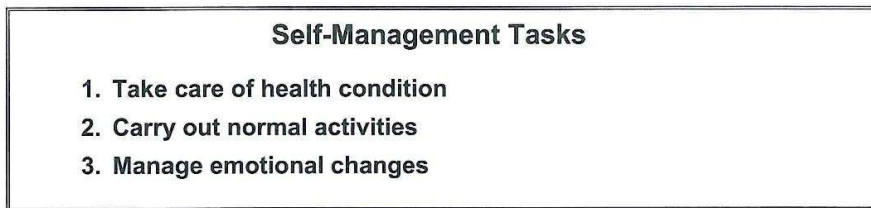
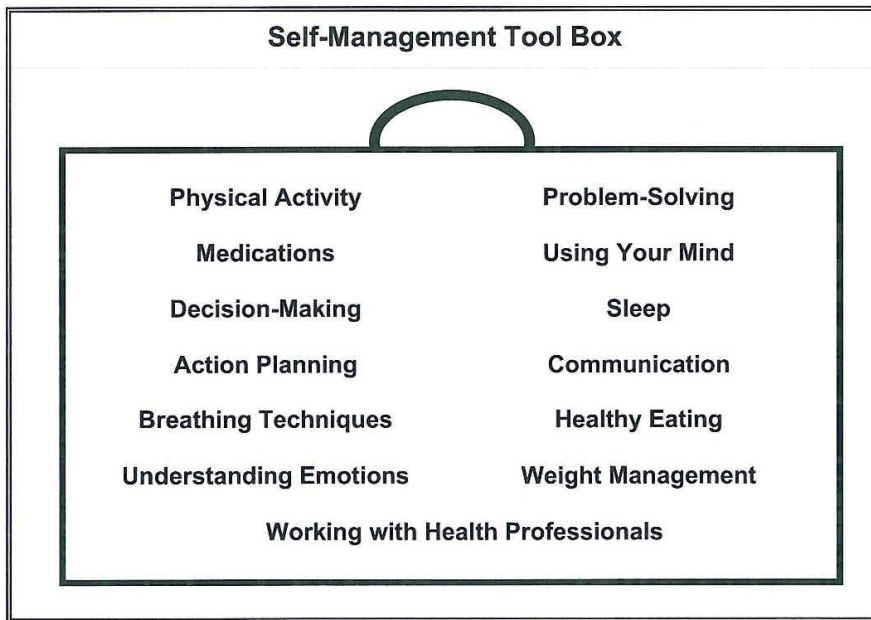


Chart 2



*Chart 3*

<b>Guidelines</b>
<ol style="list-style-type: none"><li><b>1. Come to every session</b></li><li><b>2. Be respectful of others and their ideas</b></li><li><b>3. Maintain confidentiality</b></li><li><b>4. Give any new activities at least a two-week trial</b></li><li><b>5. Make and complete a weekly action plan</b></li><li><b>6. Turn off your cell phones</b></li></ol>

*Chart 4*

<b>Brainstorming</b>
<ul style="list-style-type: none"><li><b>• Anyone can share</b></li><li><b>• No commenting during brainstorm</b></li><li><b>• No questions until after</b></li><li><b>• Clarification waits until after</b></li></ul>

Chart 5

- Parts of an Action Plan**
1. **Something YOU want or decide to do**
  2. **Achievable**
  3. **Action-specific**
  4. **Answer the questions:**
    - What? (specific action)**
    - How much? (time, distance, amount)**
    - When? (time of day or which days of the week)**
    - How often? (number of days in the week)**
  5. **Confidence level of 7 or more**

Chart 6

- Problem-Solving Steps**
1. **Identify the problem**
  2. **List ideas**
  3. **Select one**
  4. **Assess the results**
  5. **Substitute another idea**
  6. **Utilize other resources**
  7. **Accept that the problem may not be solvable now**

Chart 7

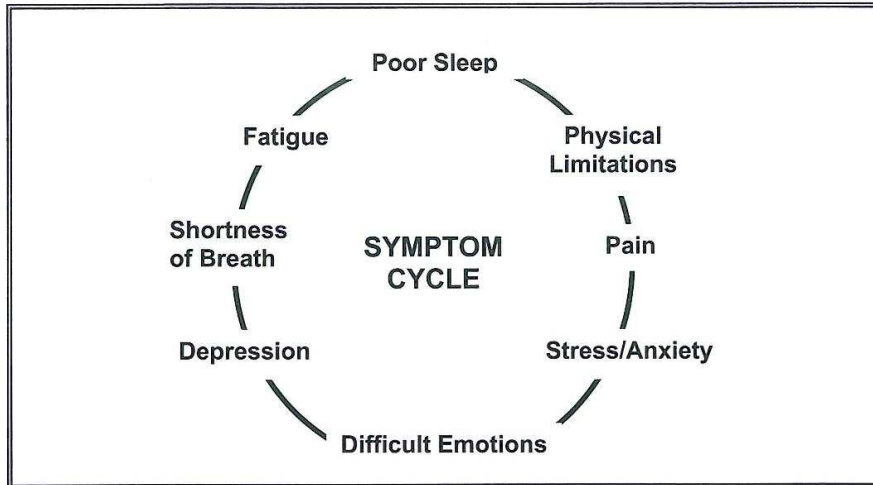


Chart 8

- Three Kinds of Physical Activities and Goals**
- **Flexibility**  
Goal: 10 minutes without stopping
  - **Strengthening**  
Goal: 8-10 strengthening exercises 2-3 days a week
  - **Endurance or Aerobic**  
Goal: Moderate aerobic activities 30-40 minutes, 3-5 days a week

*Chart 9*

### **Reduce the Risk of Falling**

- **Exercise**
- **Have your vision and hearing checked**
- **Take care of your feet**
- **Make your home safer**
- **Talk to your healthcare professional**

*Chart 10*

### **Decision Making**

- 1. Identify the options**
- 2. Write down the 'fors' and 'againsts' for each option**
- 3. Give a score to each statement from 1 being not important to 5 being very important**
- 4. Add each column and compare the results to find the higher score**
- 5. Ask yourself how this option meets the "gut test"**

*Chart 9*

### **Reduce the Risk of Falling**

- **Exercise**
- **Have your vision and hearing checked**
- **Take care of your feet**
- **Make your home safer**
- **Talk to your healthcare professional**

*Chart 10*

### **Decision Making**

- 1. Identify the options**
- 2. Write down the 'fors' and 'againsts' for each option**
- 3. Give a score to each statement from 1 being not important to 5 being very important**
- 4. Add each column and compare the results to find the higher score**
- 5. Ask yourself how this option meets the "gut test"**

Chart 11

**Decision to be made: "Should I start this new medication?"**

<b>Fors</b>	<b>Score (1 - 5)</b>	<b>Againsts</b>	<b>Score (1 - 5)</b>
It might make me feel better	5	There may be side effects I don't like	3
It could help prevent complications	4	It's yet another pill I have to remember to take	1
I might be able to do more	5	It costs too much. I may not be able to afford it	3
		It may not work	4
<b><u>"Fors" Total</u></b>	<b><u>14</u></b>	<b><u>"Againsts" Total</u></b>	<b><u>11</u></b>

The "Fors" total is greater than the "Againsts"

Decision result is : To start the new medication

Ask the question: "Does this meet the 'gut test'? – answer is Yes

Chart 12

**Moderate Endurance Exercise**

**You will feel**

- Slightly faster heart rate
- Faster, deeper breathing
- Slightly warmer

**You should be able to:**

- Continue for at least 10 minutes
- Talk or recite a poem
- Recover after 30 minutes

Chart 13

**Monitoring Exercise Intensity**

- Talk Test
- Self-Rating of Exertion
- Count your pulse



Chart 14

**Be FIT**

**F**requency - 3-5 days a week

**I**ntensity - how hard you work

**T**ime - how much you exercise each day

Chart 15

**Reasons for Shortness of Breath**

- Damaged lungs
- Weakened heart
- Increased demands
- Narrowed breathing passages
- Low number of red blood cells
- High altitude
- Excess body weight
- Anxiety
- Smoking or secondhand smoke

Chart 16

**Healthy Eating Means . . .**

- Eating a variety of foods
- Eating our meals and snacks regularly
- Watching portion size
- Eating breakfast

Chart 17

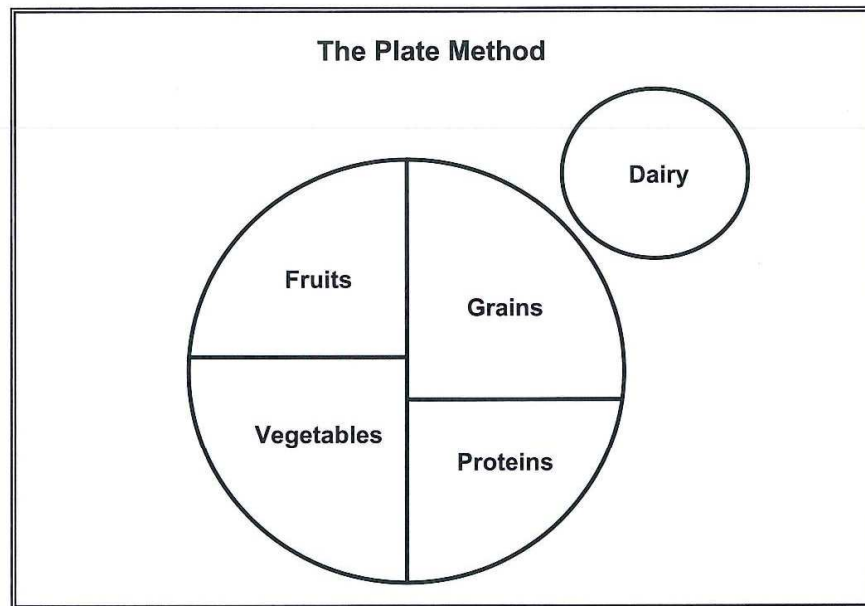


Chart 18

### **Communication Skills**

- 1. Identify**
- 2. Express your feelings**
  - Use direct “I” messages
  - Use “When this happens...I feel...”
- 3. Listen attentively**
- 4. Clarify**

Chart 19

### **Healthy Eating Guidelines**

- 1. Work toward 7 portions of fruit and/or vegetables a day**
- 2. Choose foods lower in fat**
- 3. Limit foods that can raise cholesterol**
- 4. If you have diabetes or prediabetes watch carbohydrates**
- 5. Reduce the amount of salt or sodium**
- 6. Maintain a healthy weight**

Chart 20

### **Purposes of Medications**

- 1. Relieve symptoms**
- 2. Prevent further problems**
- 3. Improve the disease or slow its progress**
- 4. Replace substances body normally produces**

Chart 21

### **Medication Effects**

#### **No noticeable effect**

- **Medication is working but the symptoms don't change**
- **Medication is working but you feel the same**
- **Medication hasn't started to work yet**
- **Medication just isn't working**

#### **Negative effects**

- **Allergy: dangerous and need immediate reporting**
- **Side effects: annoying and unwanted but often not dangerous**



*Chart 22*

### **Medication Responsibilities**

1. **Inform ALL your health providers of ALL medications and dosage**
2. **Make and carry a medication list**
3. **Know why you are taking each medication and how to take it**
4. **Report effects of each medication or if you are not taking it as prescribed**
5. **Use medications as prescribed**
6. **Use your mind**

*Chart 23*

### **Evaluating Treatments**

1. **Where did I learn about this?**
2. **Were the people who got better like me?**
3. **Could anything else have caused these positive changes?**
4. **Does treatment suggest stopping other medications or treatments?**
5. **Does treatment suggest not eating certain foods?**
6. **Can I think of any possible dangers/harm?**
7. **Can I afford it?**
8. **Am I willing to go to trouble/expense?**

Chart 24

**Steps Toward Positive Thinking**

1. **Write down self-defeating thoughts**
2. **Change them to rational and helpful thoughts about yourself**
3. **Rehearse**
4. **Practice**
5. **Be patient**

Chart 25

**Take PART**

**Prepare**

- **Keep track**
- **Report**
- **List**

**Ask**

**Repeat**

**Take action**

Chart 26

**Maintaining a Healthy Weight**

- 1. Pay attention to portion size**
- 2. Use the plate method of choosing foods**
- 3. Limit foods with more than 5 grams of fat per portion**
- 4. Eat 5-7 portions of fruit and vegetables a day**
- 5. Drink water or broth-based soups**
- 6. Plan your meals and snacks and plan for regular eating times**
- 7. Eat breakfast**



# APPENDIX 22 STANFORD DIABETES SELF-MANAGEMENT PROGRAM LICENCE AGREEMENT



Stanford Patient Education Research Center  
<http://patienteducation.stanford.edu>

## Research License Agreement Between [The London School of Hygiene and Tropical Medicine] and Stanford University Research Study for Chronic Disease Self-Management Program

This Agreement between THE BOARD OF TRUSTEES OF THE LELAND STANFORD JUNIOR UNIVERSITY ("Stanford"), an institution of higher education having powers under the laws of the State of California, and [THE LONDON SCHOOL OF HYGIENE AND TROPICAL MEDICINE] ("Research Licensee"), an entity having a principal place of business at [KEPPEL STREET, LONDON, WC1E7HT, UNITED KINGDOM], is effective [15]<sup>th</sup> day of [October], [2014] ("Effective Date").

### BACKGROUND:

Stanford has an assignment of copyrighted content developed over 30 years of research for the training of program leaders and of trainers in the area of self-management of chronic conditions and caregiving. Content includes methodologies, strategies, and structure for successful chronic disease management that has been validated and shown efficacy. It is entitled "Chronic Disease Self-Management Program," ("Program") was invented in the laboratory of Dr. Kate Lorig, and is described in Stanford Docket # S02-117.

Stanford has broadly distributed for public use and benefit. Due to the volume of licenses to the Program, managing the rights is complex.

Research Licensee desires to use the Program to perform research and/or create a derivative to [CULTURALLY ADAPT THE DIABETES SELF-MANAGEMENT PROGRAMME FOR PATIENTS WITH TYPE 2 DIABETES ATTENDING PRIMARY HEALTH CARE CENTRES IN SAUDI ARABIA]. The detailed research plan for the Research Project and scope of distribution of the derivative is described in the attached Appendix A ("Research Project").

### DEFINITIONS:

"Program" means Stanford's copyrighted content (Please circle Program you would like to license from the list below):

- (A) Stanford Docket #S02-117 "Chronic Disease Self-Management Program;"and,
- (B) Stanford Docket #S05-238 "Tomando Control de Su Salud, Spanish Chronic Disease Self Management Program (Spanish CDSMP);"and,
- (C) Stanford Docket #S05-286 "Curso de Manejo Personal de la Artritis (Spanish Arthritis Self-Management Programs);"and,
- (D) Stanford Docket #S05-287 "Positive Self-Management Program" a workshop for people with HIV; and,

- (E) Stanford Docket #S06-294 "Pain Self-Management Program" developed in conjunction with Dr. Sandra LeForte; and,
- (F) Stanford Docket #S06-436 "Programa de Manejo Personal de la Diabetes" a Spanish Diabetes Self-Management workshop; and,
- (G) Stanford Docket #S09-131 "Small Group Diabetes Self-Management Workshop;" and,
- (H) Stanford Docket #S09-132 "Small Group Arthritis Self-Management Workshop,"
- and,
- (I) Stanford Docket #S14-062 "Cancer Thriving and Surviving small group"

"Research Project" means a detailed description of the research proposed by Research Licensee described in the attached Appendix A.

"Research Project Derivative" means any changes, derivatives adaptations or works based on or created from Program including, but not limited to, any accompanying manuals, materials or images.

**TERMS:**

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 (Initial: \_\_DA\_\_)
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3. Research Licensee will cause its employees and contractors to execute an assignment to Stanford to the extent necessary. Research Licensee will deliver a copy of the Research Project Derivative to Stanford (preferably MS Word files). (Initial: \_\_DA\_\_)
4. Research Licensee will contact Stanford if the Research Project changes in any way from the detailed project description described in Appendix A and may only use the Program and Research Project Derivative as outlined in this agreement.

5. Research Licensee agrees to make written reports yearly on the anniversary of the Effective Date of this Agreement to Stanford detailing Research Licensee's progress and dissemination of the Research Project. Specifically Research Licensee will report:
  - a. Stage of development.
  - b. The number of workshops given, the dates of the workshops, the number of attendees for each workshop, and identify the leaders of each workshop.
  - c. If Research Licensee has trained any Leaders, Research Licensee will also submit the number by leader trainings they have held, the dates of the trainings, the numbers of leaders trained in each workshop, how many of the trained leaders are active (facilitating workshops) and the names of organizations represented in the training.
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I represent that I am authorized to sign this Agreement and agree to the terms above.

  
Signature

Donna Alabdulbaqi

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PhD candidate at The London School of Hygiene and Tropical Medicine

Title

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