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# **Cultural Adaptation of Self-management Models for Type 2 Diabetes in Saudi Arabia**

By

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BSN, MEd

A Doctoral Thesis

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## **Abstract**

According to the global prevalence of diabetes, Saudi Arabia is ranked 7th. Currently the Ministry of Health in Saudi Arabia spends around US \$6 billion, or more than 16% of its budget on treating diabetes and its complications. The focus of this thesis is type 2 diabetes. Some countries have developed their own type 2 diabetes self-management education programmes. These programmes aim to educate individuals with type 2 diabetes to become independent and capable of taking initiative in dealing with their type 2 diabetes in order to have better health and quality of life. Saudi Arabia does not have such a programme.

The main aim of this thesis was to carry out an initial need assessment for type 2 diabetes self-management education programmes to examine if the solutions provided through self-management education programmes can help individuals with type 2 diabetes in Saudi Arabia. This aim was pursued through three complementary studies, each of them aimed to cover a specific point of this need assessment. Study one aimed to evaluate needs based on the degree of success of self-management strategies used in any existing programmes or attempts. Evidence on such success was driven from published type 2 diabetes self-management studies in Saudi Arabia and sister Gulf Cooperation Council (GCC) countries. Study two examined demographic and clinical associations with type 2 diabetes in Saudi Arabia. Study three aimed to provide an insight into how health professionals dealing with type 2 diabetes and those under their care in Saudi Arabia perceive the current type 2 diabetes management options and if the solutions offered through self-management programmes are needed or could be of a benefit.

The above approach was based on a model devised by Kumpfer and colleagues for need assessment and cultural adaptation. This model describes nine steps to assess the need of a self-management programme. Part of the need assessment is to assess the need for cultural adaptation to make the programme suitable for a new setting or population. Step one in this model recommends reviewing published literature, which was done through a systematic review. It also suggests examining factors associated with the healthcare condition targeted by the programme and understanding the views of those affected by this condition.

This thesis systematically reviewed publications on type 2 diabetes self-management studies in Saudi Arabia and GCC. Although none of the reviewed studies (n=8) tested a full type 2 diabetes self-management programme, it was clear that teaching participants how to monitor their blood glucose, become more active or eat healthier, was associated with an improvement in the control of their diabetes. However, the systematic review also showed that the studies did not consider the concept of cultural adaptation. Without cultural adaptation to make the programme more suitable to the local context, one can expect the success of some aspects of such a programme to be compromised.

In order to build on these recommendations suggested in the first step of Kumpfer's model, this thesis used the Saudi Health Interview Survey, published in 2013, to investigate sociodemographic, health and lifestyle factors associated with type 2 diabetes and its control. The survey included the responses of a representative sample (n=10,827). Of Saudi adults 7.5% (n=808) had type 2 diabetes. Factors associated with type 2 diabetes were being a male, above 55 years and overweight. The analysis also showed comorbidity between hypertension and type 2 diabetes.

However, some unexpected findings were encountered in this secondary data analysis. Factors such as physical activity and smoking were not statistically significant in association with type 2 diabetes. On the other hand, people who ate more fast food were less likely to have type 2 diabetes and those who ate more fruits and vegetable were more likely to have poorly controlled type 2 diabetes.

Finally, to conclude the first step in the Kumpfer model, a qualitative study was designed to understand the views of participants who have type 2 diabetes (in-depth interviews with 12 participants with type 2 diabetes) and the health professionals (n=9 divided into two focus groups) responsible for their care at a specialised endocrinology centre. The study revealed some challenges to successful management of type 2 diabetes, which can be overcome with type 2 diabetes self-management programmes. All individuals with type 2 diabetes from the city, in which the specialised endocrinology centre is located, and the surrounding rural areas attended this one centre. This led to overcrowding in clinics. For many, particularly women, it was not easy to practice outdoor sports; indoor sport facilities were available, but not affordable for some. Many were dependent on cars, while some found it difficult to quit smoking. It was also useful to know that many, who started to eat healthier food such as vegetables, or had given up on eating fast food, had only started doing so after they were diagnosed with type 2 diabetes, which may explain some of the unexpected findings in the quantitative study.

In summary, this thesis used three different research methods, systematic review, quantitative data analysis and qualitative study, in order to advise on the need for initiating a national type 2 diabetes self-management programme in Saudi Arabia. It is clear that a culturally adapted programme to be specific to Saudi Arabia is

needed to help to tackle issues associated with clinic overcrowding, restrictions on achieving better physical activity levels and weight control for both sexes and all age groups, particularly older individuals who may require help to self-manage other chronic illnesses.

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## Publications arising from this thesis

### Conference participations

1. Thamer Al Slamah, Barbara I. Nicholl, Fatima Y Alslail, Leanne Harris, Craig A. Melville, 2018, "Systematic Review: Self-Management of Type 2 Diabetes in Gulf Cooperation Council Countries" Poster to the NADEGS Annual Conference on Thursday 26th & Friday 27th January 2017
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### Papers published

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**Author's declaration**

This thesis has been created solely to be submitted for fulfilment of my PhD degree and has not been submitted in any form for another degree or professional qualification. The work presented in this thesis is exclusively my own, and I possess the full copy write for any work that has been presented as part of co-authorship. Quotations are clearly highlighted and citations are acknowledged appropriately.

Signature:

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*Thamer Alslamah*

## **Abbreviation**

ADA	American Diabetic Association
BMI	Body Mass Index
CVD	Cardiovascular Disease
DESMOND	Diabetes Education and Self-management for Ongoing and Newly Diagnosed
DKA	Ketoacidosis
DSME	Diabetes Self-management Education
ESRD	Early Stages to end stage Renal Disease
FPG	Fasting Plasma Glucose
GCC	Gulf Cooperation Council Countries
HbA1c	Glycated Haemoglobin
HHS	Hyperglycaemic Hyperosmolar State
LEA	Lower-Extremity Amputations
MOH	Ministry of Health
PHCU	Primary Health Care Units
SHIS	Saudi Health Interview Survey
WHO	World Health Organisation

# Chapter I

# **1. Background of Type 2 Diabetes Self-Management in Saudi Arabia and Cultural Adaptation**

## **1.1 Introduction**

Type 2 diabetes is a global concern with wide social and economic impact. However, when it comes to the management of type 2 diabetes, there is a large focus on individuals learning to self-manage their condition and limit the associated complications (Chen et al., 2012). For successful self-management of type 2 diabetes, each individual needs to learn about their condition, the impact on their body and what changes they need to make to their lifestyle, diet and physical activity, and also how to monitor and deal with the complications of type 2 diabetes (Hu et al., 2001, Willi et al., 2007). For successful education of individuals with type 2 diabetes, the teaching process needs to be part of evidence based self-management education programmes (Norris et al., 2002). However, the success of any of these programmes can be altered, boosted or suppressed by context and the success in one society does not guarantee the success in another unless careful consideration is given to adapting such self-management education programmes to the relevant culture and society (Hawthorne et al., 2010). In countries with a high prevalence of type 2 diabetes, such as Saudi Arabia, self-management education programmes can be crucial in minimising the impact of this metabolic disorder on society. Self-management education programmes can also benefit the individuals with type 2 diabetes and their families, provided that the programmes are acceptable to that particular community, in this case Saudi Arabia, and their healthcare providers (Alwin Robert et al., 2017).

## **1.2 Definitions**

### **1.2.1 Type 2 diabetes mellitus**

Diabetes is characterised by disorders of insulin action and insulin secretion, either of which may be the predominant feature, although both are usually present at the time of the clinical diagnosis. Conventionally, diabetes is classified based on the time of onset and/or the predisposing factors into four types. Type 1, which is often characterised by childhood onset and absolute deficiency of insulin secretion, is mainly due to autoimmune damage or aplasia of the insulin secreting pancreatic Langerhans  $\beta$ -cells (Devendra et al., 2004). Type 2 usually starts after puberty and is associated with other factors such as overweight or lifestyle (Collins et al, 2011). Some pregnant women experience a temporary elevation of blood sugar, usually med-term or later. This is classified as gestational diabetes, which likely resolves after labour (Baz et al, 2016). There are other conditions, which have been seen in association with blood glucose elevation. Some of these conditions start as early as six months old or younger, hence described as neonatal diabetes, but unlike type 1, there is no evidence of autoimmune activity. Another condition, which is like type 1 associated with autoimmune destruction of  $\beta$ -cells, but late onset after puberty as in type 2, hence called latent autoimmune diabetes in adults, or type 1.5 diabetes (Stenström et al, 2005). Some people with family history of diabetes over two generation or more, have been described to develop diabetes early into their third decade, as a result of an inherited mutation known as maturity onset diabetes of the young (Vaxillaire et al, 2006). There are other rare genetic disorders, which are associated with diabetes among other features such as Wolfram Syndrome and Alström Syndrome (Collin et al, 2002). Finally, some diabetes cases can occur as a result of damage to the pancreas, for example due to cancer or inflammation; this type of diabetes is described as type 3 (Hart et al, 2016).

This PhD thesis is concerned with self-management of type 2 diabetes. Type 2, has a typical onset after puberty, however an increasing incidence in children is being reported (American Diabetes Association, 2019). Type 2 diabetes accounts for a variable percentage of all recorded cases of diabetes among children ranging from 8% and up to 45%, according to ethnicity and nutritional habits (American Diabetes Association, 2019). According to World Health Organisation (WHO) data, type 2 diabetes is the most common form of diabetes, accounting for 90-95% of all cases (Grove et al., 2012). Although the specific reasons for the development of insulin secretion and action disorders are not yet fully understood, type 2 diabetes has been associated with either obesity, or excess accumulation of abdominal and visceral fat, with a focus in the literature on insulin resistance (Kahn et al., 2006).

### **1.2.2 Insulin resistance and causes of type 2 diabetes**

Blood glucose level is the main criterion for the diagnosis of type 2 diabetes (Cox and Edelman, 2009, International Expert Committee, 2009). However, a normal blood glucose level does not necessarily represent the actual levels of insulin secretion from  $\beta$ -cells (International Expert Committee, 2009). As a matter of fact, what blood glucose level represents is the ability of the  $\beta$ -cells to secrete amounts of insulin, which are sufficient to induce euglycaemia, or normal glucose level in the blood (Reaven, 1988). This varies according to the cells sensitivity to insulin. In individuals with normal metabolism, cells become more sensitive in response to physical exercise (Goodyear and Kahn, 1998) or increased carbohydrate intake (Chen et al., 1988), but are usually less sensitive during physical or mental stress (Wellen, 2005), as with pregnancy (Buchanan et al., 1990), trauma (Strömmer et al., 1998), infection (Rayfield et al., 1982), puberty (Moran et al., 1999) or aging

(DeFronzo, 1979). However, with obesity the sensitivity of cells to insulin becomes impaired, and the term insulin resistance becomes more applicable (Hu et al., 2001).

With weight gain, or fat accumulation in the body especially in the abdominal area, the tissues become more resistant to insulin due to the accumulation of non-esterified fatty acids and glycerol in the blood (Polonsky et al., 1988). These lipid metabolites not only interfere with insulin sensitivity, but also impair hepatic clearance of glucose, leading to further increase of blood glucose (Yang et al., 2005). For many individuals,  $\beta$ -cells would be able to respond by producing more insulin sufficient to bring glucose to normal levels (Wellen, 2005). However, for individuals predisposed to  $\beta$ -cell dysfunction, sometimes described as prediabetes, higher insulin production cannot be sustained and hyperglycaemia becomes persistent, predisposing the individual to the development of type 2 diabetes (Kahn, 2001). Demographic studies provide further evidence for the association between type 2 diabetes and obesity, both in children (Rosenbloom, 2003) and adults (Calle and Kaaks, 2004). The higher the prevalence of obesity in a given community, the higher the prevalence of type 2 diabetes (World Health Organization, 2000a, Wild et al., 2004). Moreover, many studies show that higher physical activity levels and exercises that are associated with higher muscle gain and lower fat accumulation, are also associated with lower insulin resistance and better glycaemic control, and/or lower prevalence of type 2 diabetes, especially for individuals at risk (Henriksen, 2002). Many studies have also focused on the ethnic variations associated with fat/muscle ratio, or body composition and have linked this higher risk of type 2 diabetes or insulin resistance to specific ethnic groups. The Gulf Cooperation Council Countries (GCC) population is categorised as a Mediterranean Caucasian race. The Mediterranean ethnicity is distributed beyond the

Mediterranean countries to include the GCC countries, parts of the Sahara and sub-Saharan, the African horn and even parts of northern Europe such as some of the Welsh and English populations. Mediterranean's have specific characteristics, which are of clinical significance compared to the mother Caucasian race, including the prevalence of type 2 diabetes. Mediterranean's are at higher risk of developing type 2 diabetes, only preceded by the South Asian and followed by the Hispanics, white Caucasians then black ethnicities (Wright et al., 1998). Geographically, reports show higher prevalence of obesity and/or type 2 diabetes in the Middle East, and particularly in the GCC countries including Saudi Arabia, compared to Europe and the rest of west Asia (Majeed et al., 2014).

### **1.2.3 Detection of type 2 diabetes**

Type 2 diabetes onset is usually at middle age or older (American Diabetes Association, 2019). Many people at the onset of diabetes mistake the change in their body metabolism as part of the aging process and often let significant amounts of time pass before presenting to services for assessment and diagnosis (Harris et al., 1992). According to the American Diabetic Association (ADA), one record of a fasting plasma glucose (FPG)  $\geq 126$  mg/dL or 200 mg/dL after two hours of a carbohydrate meal is sufficient to diagnose type 2 diabetes if associated with one of the common symptoms such as weight loss, excessive urination (polyuria), thirst (polydipsia) or hunger (polyphagia); or if followed with another similar record of high blood glucose level (Cox and Edelman, 2009). The test is easy, portable and reliable based on one drop of blood, which makes screening for type 2 diabetes straight forward. Once diagnosed, the glycated haemoglobin (HbA1c) is useful to monitor glycaemic control. Most clinicians follow a recommended cut off for HbA1c at 6.5% to indicate good control and 7 % to indicate poor control among individuals with type

2 diabetes, however for normality or low risk of diabetes, they would consider 5.5% as a satisfactory cut off, while there is no indication in the literature of what would be the lowest acceptable HbA1c level (International Expert Committee, 2009).

#### **1.2.4 Complications of type 2 diabetes**

The effects of type 2 diabetes mellitus include long-term damage, dysfunction and failure of various organs. The condition may present with characteristic symptoms such as thirst, frequent micturition, blurring of vision, and weight loss, while its long-term effects include the progressive development of specific complications such as cardiovascular disease (CVD), retinopathy with potential blindness, nephropathy that may lead to renal failure, and/or neuropathy with the risk of foot ulcers, charcot joints, and features of autonomic dysfunction, including sexual dysfunction (Grove et al., 2012).

##### **1.2.4.1 CVD in type 2 diabetes**

Type 2 diabetes is progressively becoming the main risk factor for CVD (Fox et al., 2007) and is highly associated with many predisposing factors for CVD such as atherosclerosis (Schmidt et al., 1999) and hypertension (Heida et al., 2015, Rahman et al., 2019). In fact, epidemiological studies show a strong relationship between glycaemic control and the development of CVD (Zoungas et al., 2017). In many individuals, CVD is diagnosed just before the diagnosis of type 2 diabetes, or at the prediabetes stage (Huang et al., 2016). For many, both type 2 diabetes and CVD have two main and common predisposing factors, obesity or overweight and insulin resistance (Jia et al., 2015). This shows that CVD is almost inevitable if type 2 diabetes, and perhaps prediabetes, are not controlled early enough through robust

self-monitoring of blood glucose, glycaemic control and weight control. Some clinicians suggest that weight reduction for individuals with type 2 diabetes even for those who can be considered of normal weight can significantly lower the risk of developing CVD (Dixon et al., 2015, Lee et al., 2017). In other words, body mass index (BM) cannot be the only parameter to judge the ideal weight; an ideal weight is particular to each individual depending on lifestyle, ethnicity, family history, environment, age, sex and the stage of their type 2 diabetes (Dixon et al., 2015, Lee et al., 2017, Hu et al., 2001).

#### **1.2.4.2 Retinopathy**

Diabetic retinopathy is the leading cause for adulthood blindness in the developed world (Liew et al., 2014, Buch et al., 2004, Mendoza-Herrera et al., 2017). While there is a wealth of data on macrovascular conditions associated with CVD, the data available about microvascular changes affecting different organs in the body as a direct result of hyperglycaemia and insulin resistance is less. However, the available case and epidemiological studies show how a condition such as retinopathy needs to be closely self-monitored to observe alarming signs such as blurring of vision, proteinuria or increase in blood pressure, which can make a difference in the level of visual impairment from minimal effect to hand count or no light perception (Klein et al., 1984b, Klein et al., 1984a).

#### **1.2.4.3 Nephropathy**

Diabetic nephropathy is becoming a prominent burden for health planning and care due to the increasing prevalence of type 2 diabetes and longer life expectancy in the developed world (Bakris et al., 2000). Countries such as the USA spend an

excess of 15 billion dollars per year on the treatment of diabetic nephropathy (Skyler, 2000), with comparable figures reported in Latin America (Barcelo et al., 2003). More than one fifth, and up to 30 percent, of individuals with type 2 diabetes experience a degree of nephropathy that varies from early stages to end stage renal disease (ESRD). However, while diabetes in general is now the main cause of ESRD, type 1 diabetes accounts for most of these cases (Mogensen et al., 1996). As with retinopathy, monitoring blood glucose is important, but not sufficient to protect against the development of diabetic nephropathy (American Diabetes Association, 2016). People with type 2 diabetes need to be educated on how to spot albuminuria (Mogensen et al., 1996) as the earliest sign for nephropathy (Brenner et al., 2001), and there is also a need to keep blood pressure and blood lipid profile under check (Bakris et al., 2000).

#### **1.2.4.4 Neuropathy**

Neuropathy is a predominant type 2 diabetes complication (Russell and Zilliox, 2014). Many individuals with type 2 diabetes, face problems associated with loss of sensation in their limbs and recurrent foot infection, which can lead to lower-extremity amputations (LEA) (Wu et al., 2005). The problem is aggravated among those who live alone, as they may not notice the start of a lesion, or accidentally harm themselves, for example while cutting their nails (Bakker et al., 2012). It is difficult to find a robust estimate of neuropathy incidence among individuals with type 2 diabetes. For example, in Brazil, around 8.5% of the type 2 diabetes cases admitted to hospital are related to diabetic neuropathy and 20% of these would face amputation (Quarti Machado Rosa et al., 2018). What is notable is that similar figures can be found in developed countries (Centers for Disease Control and Prevention, 2018).

According to Boulton and colleagues (2005), more than half of individuals with type 2 diabetes have neuropathy and many develop serious complications (Boulton et al., 2005). Individuals with type 2 diabetes need to learn how to look after their limbs and how to independently perform body care daily routines such as trimming nails, in a proper manner in order to avoid serious complications that can lead to amputations or even loss of life (Shakher and Stevens, 2011, Llewelyn and Llewelyn, 2019, Moxey et al., 2011).

While chronic complications such as CVD, retinopathy, nephropathy and neuropathy are the main diabetic complications with a significant individual, social and financial burden, other acute complications such as diabetic coma, hyperglycaemic hyperosmolar state (Klingensmith et al., 2013), ketoacidosis (DKA) (Rewers, 2017), lactic acidosis and hypoglycaemia (Klingensmith et al., 2013) represent a threat to life for many people with type 2 diabetes. However, the level of threat can be significantly lowered if individuals are educated on how to self-manage their type 2 diabetes to reduce the risk of these complications and how to observe for symptoms and signs, which can help early intervention (Wickramasinghe et al., 2019). In addition to these acute complications, other complications are emerging from studies linking type 2 diabetes to serious conditions such as liver disease, infection and cancer (Harding et al., 2019).

### **1.2.5 Glycaemic control**

Glycaemic control is a medical term referring to the typical levels of blood sugar (glucose) in a person with diabetes mellitus. Current guidelines for glycaemic control are mostly derived from several large-scale trials that tested the hypothesis that

more intensive glycaemic control would either prevent or delay the classic diabetic complications discussed above. According to these trials, glycaemic status is categorised as poorly controlled if HbA1c > 7% (Khattab et al., 2010). However, based on a risk to benefit analysis, clinicians apply additional caution and tend to accept  $\geq 6.5\%$  as a sensible reference to start dealing with type 2 diabetes as poorly controlled (Edelman and Polonsky, 2017). As HbA1c measure the percentage of glycated haemoglobin which accumulate over time (6-8 weeks), unlike fasting blood glucose for example, it can provide a history of the glycaemic control, which can act as a prompt to help individuals with type 2 diabetes and their self-management educator discuss control of glucose level and strategies on optimising diet and physical activity (Goldstein, 1986, Kilpatrick, 2004).

### **1.2.6 Management of type 2 diabetes**

Management of type 2 diabetes has an overall aim of improving glycaemic control and boosting compromised anabolism in the body as a result of obstructed insulin mechanism (Edelman and Polonsky, 2017). However, as discussed above, the comorbidity of other chronic illnesses and health complications associated with type 2 diabetes, requires management to be tailored according to the individual (Chiniwala and Jabbour, 2011). It is believed that 25% of the type 2 diabetes individuals on their first day of being diagnosed with type 2 diabetes already live with a cardiovascular problem that is a complication of poor glycaemic control, which has often been present for at least 5 years prior to diagnosis (Harris et al., 1992). This also highlights the importance of early detection of type 2 diabetes.

### **1.2.6.1 Conventional treatments**

There are many medications that are used to lower or control blood glucose, either by hindering glucose absorption, synthesis, or promoting its breakdown; while others are thought to either enhance insulin secretion or sensitivity including insulin itself or insulin-mimics (Waugh et al., 2010). However, there are some medications, such as bromocriptine, which are effective and used with relatively good safety, although their mode of action is not exactly understood and were originally licensed for treatment of other conditions such as amenorrhea (Mikhail, 2011). Clinicians would use one or more of these medications according to the individual condition of those under their care, although some individuals may not have not started on any other medications (Waugh et al., 2010). One of the key elements that could encourage a clinician to choose one way or another for those under their care, is their ability to self-manage their condition. Each one of them may need to understand the action and complications of their medications and realize when they need to adjust or even stop using their medication (Waugh et al., 2010, Lowe et al., 2008).

### **1.2.6.2 Self-management of type 2 diabetes**

To achieve good glycaemic control, those affected need to be actively involved in the management and monitoring of their condition. Individuals need to be educated about their condition, develop awareness about possible complications and learn how to minimise their risk of developing complications. In addition, individuals should learn how to observe, measure and control their blood sugar and how to manage emergencies (American Diabetes Association, 2015).

### **1.1.7 Self-management, definition and approach**

Self-management is a life-long task for those with a chronic disease that is based on knowledge and skills, acquired by experience or taught, to manage their own condition (Creer and Christian, 1976, Paterson, 2001). To accomplish this task, individuals become adherent to a routine that enables them to accurately follow the instructions of healthcare professionals for taking medications and practicing or avoiding behaviours that are beneficial or harmful to them respectively. Also, individuals need to adapt to their physical limitations by finding alternative ways to perform daily-life activities and maintain their wellbeing (Corbin and Strauss, 1988, Lorig and Holman, 2003).

Self-management education programmes should be designed to help individuals to acquire the knowledge and core skills required to self-manage their condition. There are six key self-management skills outlined in the section below (Center for the Advancement of Health, 2002).

#### **1.2.7.1 Six self-management skills**

##### **1.2.7.1.1 Problem solving**

Those with long standing conditions are likely to be met with variable problems according to their lifestyle, commitments, background and psychology in addition to the complications associated with their condition and level of support they may or may not receive (D'zurilla, 1986). As such, it is difficult to teach an individual a solution for each problem they may face. Instead the approach of self-management education is to develop the individual's problem solving skills. Each should learn how to define their specific problem, think about the main causes of such a problem

and its main impact, and try to deal with these elements of cause and impact individually. In doing so, they may seek the help or advice of a health professional or try to work it out independently (D'zurilla, 1986, Lorig and Holman, 2003).

#### **1.2.7.1.2 Decision making**

Although the individuals should start by following the guidance from their health professional, they will come to a point when they may need to make a decision for themselves. As in problem solving, they will need to learn the core skill of decision making (Center for the Advancement of Health, 2002). For example, how to be neutral when deciding what they should or should not eat, how much they should walk or if they should visit the clinic before their visit is due. By learning to base their decisions on advantages versus disadvantages rather than their desire or averseness, they are more likely to be on course for making the right decision. They should also develop skills around how to acquire the relevant information required for each decision to make fully informed decisions. Self-management education programmes teach individuals different approaches to decision making, so that they can independently make the decision which is right for them (Center for the Advancement of Health, 2002, Lorig and Holman, 2003).

#### **1.2.7.1.3 Resource management and rationalisation**

Individuals will have different levels and types of resources available to them for self-management, such as family support, home care, financial means, clinics, transport amenities, exercise facilities, nearby parks, libraries, health clubs, internet and Wi-Fi, mobile phones and applications, baking skills and even pets (Center for the Advancement of Health, 2002). A good self-management education programme

will teach affected people how to recognise the resources they have and how to make the best use of each and all of these resources (Corbin and Strauss, 1988). Also, they will learn how to maintain these resources and not to exploit them. An individual who properly acquires the skill of resource management and rationalisation will learn when to call a family member, his neighbour or emergency services; or indeed call no one (Center for the Advancement of Health, 2002, Lorig and Holman, 2003).

#### **1.2.7.1.4 Partnership with health provider**

The self-management education programme is most often a programme which the people attend for a limited time after they are diagnosed. However, by forming a relationship with the healthcare professional or provider they can often develop a continuous source of self-management education. To make best use of their relationship with healthcare professionals, individuals will learn skills such as time utilisation, writing notes, making a report, identifying what is important and what is not, how to ask a specific question and how to learn from the answer (Center for the Advancement of Health, 2002, Lorig and Holman, 2003).

#### **1.2.7.1.5 Action planning**

Through the self-management education programme, the experience gained from an ongoing condition and discussions with health care professionals, the individuals will become fully aware of what they need to do (Lorig et al., 2006). However, successful self-management requires action planning to be able to complete any given task. For example, an individual may set a goal to be able to walk for an hour a day, while currently finding it difficult to walk to a shop next door. To work towards

their goal, they will need to learn how to implement an evolving action plan (Lorig et al., 2006). In the example above, the individual can implement an action plan by walking to a shop further away in day one, then take a longer route, and so on until they are able to walk for 20 minutes, gradually changing their action plan to reach their goal of a one hour walk.

#### **1.2.7.1.6 Appropriate intake and self-adjustment**

The above five skills mainly describe “how?” as: how to solve a problem, make a decision, utilize resources, form a partnership with a care-provider and make an action plan; but one more skill is needed to identify “what?” (Center for the Advancement of Health, 2002, Lorig and Holman, 2003). Each individual needs to identify what they are capable of, what modifications they need to make for themselves and their behaviour, and what makes them fail or succeed in doing a required task or change (Haynes et al., 1979). To be able to make the right decision, each individual will need to decide first what they are capable of. Once they have set their boundaries they can pick the choice that matches their capabilities. For example, walk one mile three times a day, or walk three miles once a day. If they chose the right task, it is likely that they will succeed and will be able to achieve further. The individuals will first need to master the above mentioned “how” skills, but they will also need to learn about self-identification and motivation, and what in themselves they can use to help themselves to achieve better, rather than simply taking the easier choice (Kreuter et al., 2013).

### **1.2.8 Self-management programmes**

Programmes such as the American Diabetes Self-Management Education (DSME) or others in the UK such as Diabetes Education and Self-Management for Ongoing and Newly Diagnosed (DESMOND) aim to provide individuals with tailored education to increase their control over their condition and to shift diabetes care to a more personalised or individual centred approach. Table (1.1) provides details for some type 2 diabetes self-management programmes in different countries. Most of these programmes follow a general structure for personal education and motivation.

**Table 1.1 Examples type 2 diabetes self-management education programmes worldwide**

Self-management programmes	Country of Origin	Description
<b>Diabetes Self-Management Education (DSME)</b>	USA	<ul style="list-style-type: none"> <li>• Enabling individuals to:               <ul style="list-style-type: none"> <li>• Acquire a behaviour of self-care.</li> <li>• Making an informed decision.</li> <li>• Acquire problem solving skills.</li> <li>• Actively cooperate with health professional to ensure continuity of knowledge delivery and skills needed for self-care.</li> </ul> </li> <li>• Guided by evidence-based standards and the life experiences of the individuals' for perusing their needs to maintain better life quality and health through improving clinical outcomes and lifestyle (Funnell et al., 2008).</li> </ul>
<b>Diabetes Education and Self-Management for Ongoing and Newly Diagnosed (DESMOND)</b>	UK	<ul style="list-style-type: none"> <li>• UK wide through National Health Service (NHS)</li> <li>• Follows guidelines of the National Institute for health and Care Excellence (NICE) of improving health quality based on evidence and better practice.</li> <li>• Main aim of the programme is to use standard methods for training diabetes self-management educators, a systematic approach for educating people with type 2 diabetes about their condition and acquiring the key skills to become independent managers of their own condition to maintain:               <ul style="list-style-type: none"> <li>• A better quality of life</li> <li>• Learn how to monitor diabetes</li> <li>• Avoid complications</li> <li>• Overcome bad habits</li> <li>• Improve diet</li> <li>• Increase physical activity</li> </ul> </li> </ul>

		<ul style="list-style-type: none"> <li>The educators approach is tailored according to each individual experience and history, whether ongoing or newly diagnosed (Gregg et al., 2007).</li> </ul>
<b>Diabetes Self-Management Program (DSMP)</b>	USA	<ul style="list-style-type: none"> <li>Developed by Stanford university, USA, with the same objectives as DSME.</li> <li>Specific routes for educating people with ongoing “chronic” diabetes, and those who are recently diagnosed (Werfalli et al., 2015).</li> </ul>
<b>Diabetes Manual (DM)</b>	UK	<ul style="list-style-type: none"> <li>Based on self-efficacy theory and a programme used for heart disease(Heart Manual).</li> <li>DM provides one to one training session between a nurse and each individual.</li> <li>Nurses receive two days of training (Sturt et al., 2008).</li> </ul>
<b>X-PERT</b>	UK	<ul style="list-style-type: none"> <li>A visual educational programme lead by nutritionists and nurses.</li> <li>Facilitate individual empowerment and health quality standards set by NICE (Deakin et al., 2006).</li> </ul>
<b>Saxon Diabetes Management Program (SDMP)</b>	Germany	<ul style="list-style-type: none"> <li>Based on different levels of professional care for individuals with diabetes to achieve a commonly agreed guideline for management of diabetes, including: <ul style="list-style-type: none"> <li>Educating individuals how to improve their life quality through self-management of their condition.</li> <li>Learning how best to utilize available clinical services and how to follow up with and learn from the health professionals caring for them (Rothe et al., 2008).</li> </ul> </li> </ul>
<b>Spanish Diabetes Self-Management Program (SDSMP)</b>	Spain	<ul style="list-style-type: none"> <li>Developed in the Spanish language for Spanish speaking populations (e.g. Spain, Argentina, Cuba)</li> <li>Led by diabetes educators, nutritionist and specialists to educate the people under their care: <ul style="list-style-type: none"> <li>How to acquire a self-maintained routine for improving their activity and nutrition.</li> <li>How to apply relaxation methods.</li> <li>How to monitor their condition through foot examination.</li> </ul> </li> </ul>

		<ul style="list-style-type: none"> <li>• How becoming able to accurately report to their caring health professionals and learning from them (Lorig et al., 2008).</li> </ul>
<b>Therapeutic Patient Education (TPE)</b>	Italy	<ul style="list-style-type: none"> <li>• Founded through the National Health Plan (NHP), which requests: <ul style="list-style-type: none"> <li>• Record maintenance by professionals.</li> <li>• The affected individuals to decide for themselves and to adopt a healthy lifestyle.</li> </ul> </li> <li>• NHP seeks the community collective effort for fighting chronic diseases and help those who are affected.</li> <li>• Initially a programme for type 1 diabetes education by diabetes therapist, but later extended to include type 2 diabetes (Marcolongo et al., 2001).</li> </ul>
<b>Rethink Organization to Improve Education and Outcomes (ROMEIO)</b>	Italy	<ul style="list-style-type: none"> <li>• For supporting diabetes education for people with diabetes through three monthly visits to monitor: <ul style="list-style-type: none"> <li>• Progress of knowledge.</li> <li>• Acquiring skills in association with progress of the condition.</li> <li>• Clinical outcomes such as: <ul style="list-style-type: none"> <li>• Body weight.</li> <li>• Blood pressure.</li> <li>• HbA1c</li> <li>• Level of physical activity (Trento et al., 2010).</li> </ul> </li> </ul> </li> </ul>
<b>Staged Diabetes Management (SDM)</b>	France	<ul style="list-style-type: none"> <li>• Developed by the International Diabetes Centre (IDC) to ensure that: <ul style="list-style-type: none"> <li>• Clinical decision making is evidence-based.</li> <li>• Diabetes care becomes a systematic and consistent process.</li> <li>• Both the health-care team and those under their care share in the management at all stages once the person is diagnosed and if complications become present (Mazze et al., 2003).</li> </ul> </li> </ul>

<b>Structured Intensive Diabetes Education Programme (SIDEP)</b>	South Korea	<ul style="list-style-type: none"> <li>• An outcome of the Diabetes Prevention Program (DPP).</li> <li>• Provides group education for type 2 diabetes (5 -10 individuals) through a multi-disciplinary educational team of health professionals including nurses or dietitians as health educators, who are supported by rehabilitation therapist, rehabilitation medicine doctor, family medicine doctor, psychologist, ophthalmologist and pharmacist (Ko et al., 2007).</li> </ul>
<b>Swedish Diabetes Education Programme (SDEP)</b>	Sweden	<ul style="list-style-type: none"> <li>• Followed the Michigan Diabetes Research and Training Centre, USA (MDRTC), guidance for training nurses and physicians to become diabetes education facilitators through theoretical and practical workshops to provide them with the theoretical framework of:             <ul style="list-style-type: none"> <li>• Empowerment.</li> <li>• Motivation.</li> <li>• Learning principles.</li> <li>• Becoming able to transmit confidence to a group of individuals to self-manage and follow-up their condition and report back to health professionals (Adolfsson et al., 2007).</li> </ul> </li> </ul>
<b>Norvo-Nordic Interactive Diabetes Training Programme (NNIDTP)</b>	Denmark	<ul style="list-style-type: none"> <li>• A longstanding private initiative (DAWN) that invests in educating health professionals to be able to understand people with diabetes:             <ul style="list-style-type: none"> <li>• Attitudes.</li> <li>• Wishes</li> <li>• Needs</li> </ul> </li> <li>• The goal of NNIDTP is to create teams who can:             <ul style="list-style-type: none"> <li>• Empower individuals to self-manage their condition.</li> <li>• Provide each individual with better understanding of type 2 diabetes.</li> </ul> </li> </ul>

		<ul style="list-style-type: none"> <li>Boost the self-confidence to address own problems by own initiatives or solutions or describe them to the health professionals (Nicolucci et al., 2013).</li> </ul>
<b>Diabetes Education Program for Bulgaria (DEPB)</b>	Bulgaria	<ul style="list-style-type: none"> <li>Translation of the NNIDTP to train health professionals in Bulgaria to use the same standard approach for educating people with type 1 and type 2 diabetes attending their clinic and following them up (Group, 2001).</li> </ul>
<b>Educational Program for People With Diabetes (EPPWD)</b>	Egypt	<ul style="list-style-type: none"> <li>Translated version of DSME, which has been culturally adapted to suit the local Muslim-Christian needs including self-managing their condition in times of specific culture as during fasting (Eid et al., 2017).</li> </ul>

### **1.2.8.1 The structure of type 2 diabetes self-management programme**

The programmes in Table 1.1 above have the common structure of training health professionals and support staff to become better educators for those under their care. In these programmes health professionals are trained on methods by which they provide those under their care with a knowledge that matches their stage of type 2 diabetes (e.g. prediabetes, recently diagnosed or complicated diabetes). However, the health professional are also trained on adapting their advice to individual abilities and capacities taking into consideration factors such as education, age, daily commitments, independence and financial status. The main focus is for individuals to learn key skills about the use of medications, how to use electronic monitoring of blood glucose, how to recognise hypoglycaemia or hyperglycaemia and also how to deal with other relevant aspects of their health, such as body weight, physical activity levels and eating a healthy diet (van Dam et al., 2003). However, knowledge about the disease and specific lifestyle guidelines are not adequate factors to facilitate the appropriate behavioural changes. In the development of an educational intervention, there has been an interest in identifying approaches that could strengthen the individuals' beliefs in their own competency to handle their diabetes, and thus, hopefully, enabling them to control the disease (van Dam et al., 2003). This process incorporates an understanding of the needs, goals, and life experiences of the person with diabetes or pre-diabetes and is guided by evidence-based standards. The overall objectives of programmes such DSME or DESMOND are to support informed decision making, self-care behaviours, problem solving, and active collaboration with health care teams, as well as improving clinical outcomes, health status, and the quality of life of people with type 2 diabetes (American Diabetes Association, 2016).

### **1.2.8.2 Effectiveness of type 2 diabetes self-management programmes**

Meta-analysis studies have shown that DSME is effective at improving glycaemic control for individuals with type 2 diabetes (Norris et al., 2002, Steinsbekk et al., 2012). The DSME programme demonstrated a positive impact on health outcomes, particularly on HbA1c levels for Mexican Americans (Brown et al., 2002). Lorig et al (2003), reported that applying the DSME programme resulted in improvements in individual behaviour, such as doing exercises and practicing relaxation, and this led to improvements in health status, which included better glycaemic control, consequently reducing the risk of developing cardiovascular disease (Lorig and Holman, 2003). Currently, there are limited attempts to introduce such programmes to countries with a high prevalence of type 2 diabetes, such as the GCC countries including Saudi Arabia.

Type 2 diabetes in Saudi Arabia is described in a recent review by Al Dawish et al as "... an epidemic of massive proportions, threatening to negate the benefits of modernization and economic revival." (Abdulaziz Al Dawish et al., 2016). However, Saudi Arabia does not have its own type 2 diabetes self-management programme, despite the above reported benefits of such programmes, which prove self-management is a cost effective way to reduce the impact of diabetes. The high prevalence of type 2 diabetes, which increases the demand on health care as well as the availability of well-developed health care infrastructure in Saudi Arabia can potentially offer a good setting for type 2 diabetes self-management programmes to take an important role in the future management of diabetes in Saudi Arabia.

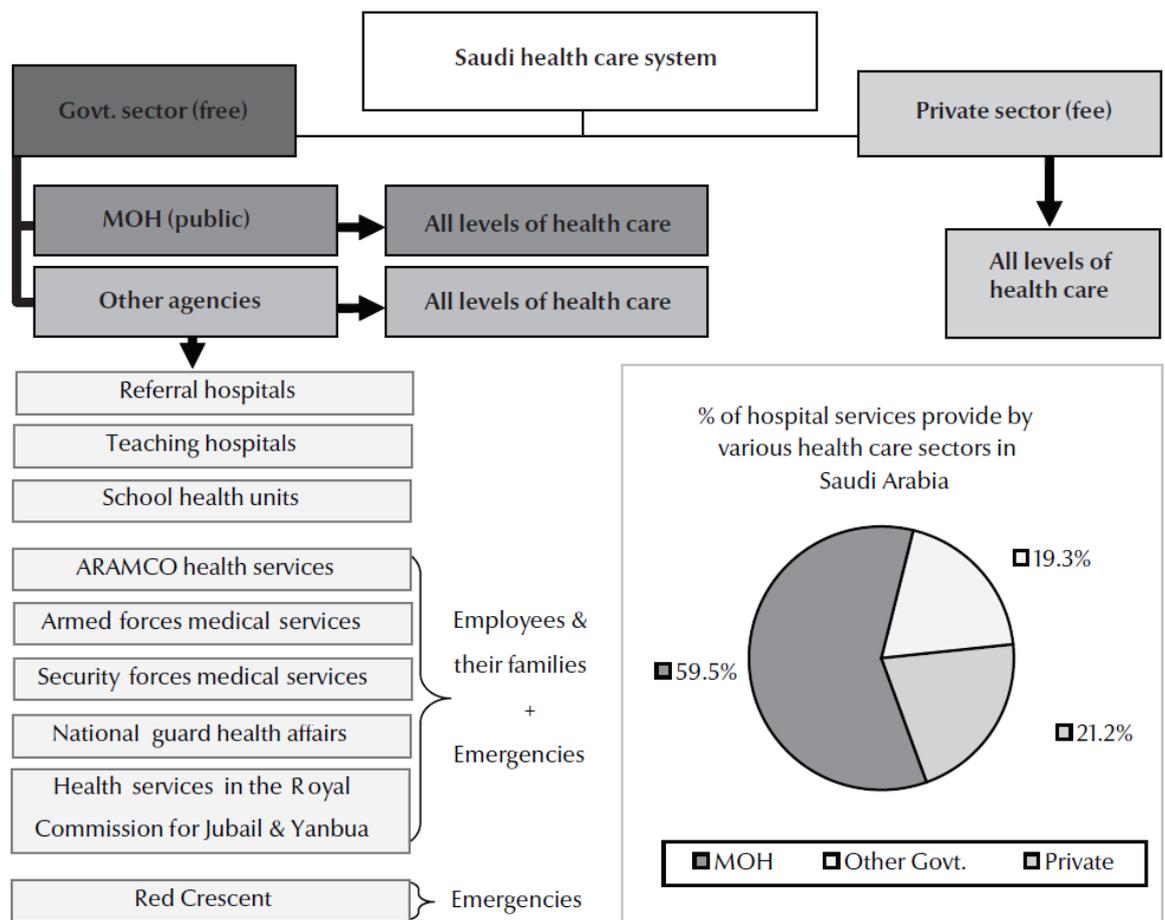
### **1.3 Health care system in Saudi Arabia**

As in most GCC countries, Saudi nationals represent less than 70% of residents in Saudi Arabia (The Ministry of Health, 2015). In addition, there are millions of short stay visitors coming to visit the holy sites in Mecca over the year (Alharthi et al., 1999). The earliest health network of hospitals and care units was in Mecca in 1925 to serve these visitors and the residents who are in contact with them (Alharthi et al., 1999). However, the official start of the current system was not until 1950, when the Ministry of Health (MOH) was formed (Alharthi et al., 1999). The MOH now provides 60% of the health care offered by the state to all residents and visitors (Saudi Arabia Ministry of Health, 2009). Saudi Arabia is a vast country with many residential communities stretched remotely from the urban locations (The Ministry of Health, 2015). Most of these communities are served through a network of 2037 primary health care units (PHCU) operated by MOH, and cases from these PHCUs would be routinely referred for specialised care to any of 244 hospitals operated by MOH and has a total capacity of 33, 277 beds. In addition, the facilities of the MOH work closely with other institutes and establishments, which provide advanced health services to sub-groups, such as the military hospitals, National Guard hospitals, security forces hospitals, university hospitals and the Saudi Arabian Oil Company (ARAMCO) hospitals. The health care provided by these designated hospitals is quite advanced, and perhaps at a higher level than that of MOH hospitals. However, it is quite usual for MOH to refer some people to one of these hospitals, as they are funded by the government. This provides MOH with an additional total capacity of 10,822 beds within 39 hospitals (Mufti, 2000). On the other hand, the private sector hospitals provide almost an equal number of beds

(N=11,833) provided by 125 hospitals, which are also used by MOH for referrals, especially for intensive care cases (Saudi Arabia Ministry of Health, 2009).

A major concern for rural populations in Saudi is that all these hospitals, from both the public and private sectors, are located in the big cities and towns, which can mean long travel to receive proper medical care (Saudi Arabia Ministry of Health, 2009).

Currently the Saudi government is working on restructuring providence of health care, by introducing medical insurance policies for residents and obliging visitors to have insurance in order to: 1) use the currently available health service establishments in a more efficient and flexible manner; 2) avoid problems associated with poor communication between services; and, 3) provide wider access for the public (Alhusaini, 2006).



**Figure 1.1 Current Saudi health system (Saudi Arabia Ministry of Health, 2009)**

#### 1.4 Prevalence of type 2 diabetes in Saudi Arabia

Based on the last official census in Saudi Arabia, which was carried out in 2010, the Saudi population increased by 4.5 million people from the previous census in 2004, which is an average of 750 thousand people or a growth rate of 3.2% per year, to reach in 2010 to 27.1 million (The Ministry of Health, 2015) and probably more than 33 million by now, and near 40 million by 2025 as per the united nations projections (World population, 2002). The Saudi population is relatively young with more than 67% under the age of 30 years, while more than half of those are under the age of 15 years. Only 5% of those living in Saudi Arabia are above 60 years. There is an

approximately equal proportion of males (50.2%) and females, with life expectancy of 72.5 years compared to 74.7 years in females (The Ministry of Health, 2015).

Previous studies show that the highest incidence of type 2 diabetes in Saudi Arabia is in individuals who are in their sixth decade and is greater among females than males and is higher in individuals with a higher BMI (Alqurashi et al., 2011). In the 2010 census, it was reported that 2.5 million individuals have diabetes (The Ministry of Health, 2015), with a predicted increase rate of 200,000 per year. This suggests that Saudi Arabia may now have 4.3 million individuals with diabetes, with a potential increase to 5.5 million by 2025 or 7.5 million by 2035 (Guariguata et al., 2014). According to these population projections, this means that more than 13% of the population in Saudi Arabia may develop diabetes, with other reports estimating that the prevalence of diabetes in Saudi Arabia may increase to 20% (Al-Rubeaan et al., 2015). It is not clear how many of these cases will be of type 2 diabetes, however an absolute majority is most likely, with reports of type 1 diabetes varying from 3.5% - 11% of all people with diabetes visiting a given centre (Fonseca et al., 1985, Famuyiwa et al., 1992).

While genetic factors can contribute to the prevalence of type 1 diabetes (Al-Nozha et al., 2004, El Hazmi, 1998) and some cultural practices such as consanguinity (Al-Hamdan et al., 2012, Al-Shehri, 1995), the increasing prevalence of type 2 diabetes is likely more associated with the current lifestyle and nutritional habits, especially when taking into consideration the precipitated higher prevalence of obesity and being overweight (Fatani et al., 1987, Al-Nozha et al., 2004). It is estimated that the direct cost of treating or managing diabetes in Saudi Arabia is nearly a billion dollars

(US) a year. This does not take into account the impact on productivity of the affected individuals or their family members, especially if the individuals with type 2 diabetes are unable to self-manage their condition (Alhowaish, 2013).

Currently, it is estimated that more than 17.5% of the MOH budget is spent on the management of diabetes and studies have shown that more than one fifth of emergency hospital visits are related to diabetes or for people with diabetes. It is also estimated that more than 80% of type 2 diabetes individuals in Saudi Arabia suffer from neuropathy (Akbar et al., 2000), 20% experience foot ulcers and one in five have LEA (Yazdanpanah et al., 2015). It is not clear if individuals with diabetes in Saudi Arabia experience CVD, nephropathy, retinopathy and other complications, at higher rates than those recorded elsewhere, but the higher prevalence of type 2 diabetes in Saudi Arabia suggests a higher utilisation and pressure on the health system by people with type 2 diabetes (Elhadd et al., 2007).

### **1.5 Chapter highlights**

Type 2 diabetes prevalence in Saudi Arabia is one of the highest globally, alongside other GCC countries and middle-eastern countries and south Asian countries. However, most Saudis are under the age of 30, which gives further emphasis to the impact of such a high prevalence, with type 2 diabetes known to concentrate among older generations. Although the health care infrastructure in Saudi Arabia is continuously developing, there is still a need for creative solutions to help to mitigate the economic and health impact of type 2 diabetes. One of these creative solutions is systemic type 2 diabetes self-management education programmes, which currently do not exist as part of the health care strategies in Saudi Arabia.

# Chapter II

## **2.Objectives and aims**

### **2.1 Overview**

Type 2 diabetes self-management education programmes have been implemented with good success in some countries such as UK, USA, Australia and Mexico. Some of these programmes were developed locally and others were imported with some adaptation, particularly cultural. However, Saudi Arabia still does not have such a programme in place and would likely benefit from one of the currently available programmes, particularly DESMOND as it is ran by the NHS, which has a system comparable to the government-lead health system in Saudi Arabia. Nevertheless, it is also likely that such a programme would need to be culturally adapted. Saudi Arabia is a conservative Muslim GCC country, where local Arabic is the main spoken language and Islam is the religion of all local nationals. The Saudi society has historically rooted traditions. On the other hand, the prevalence of type 2 diabetes is high in comparison to global averages; hence a culturally adapted self-management education programme is likely needed in order to achieve some success in managing type 2 diabetes, based on the success of such programmes elsewhere.

### **2.2 Overall aims**

The overall aim of this thesis is to assess the potential benefit “ needs assessment” of a type 2 diabetes self-management education programmes such as DSME/DESMOND for Saudi Arabia, with or without cultural adaptation. In other words, to examine if the solutions provided through self-management education programmes in general can help individuals with type 2 diabetes in Saudi Arabia in

particular. To do this, this PhD project involved three separate but related studies, each with its own specific aim.

#### Study 1:

The aim of this study was to assess any existing programmes or attempts that included type 2 diabetes self-management strategies, and the degree of success of such strategies. There were few published reports on self-management studies carried out in Saudi Arabia. However, as GCC countries have similar social environment settings to Saudi Arabia, studies from these countries were also included in the assessment.

#### Study 2:

The aim of this study was to understand the extent and characteristics of type 2 diabetes in Saudi Arabia, especially its demography and associated habits or factors, and how such factors may be considered, when attempting to apply any of the available self-management programmes. A valuable source for the data for this study was the relatively recent Saudi Health Interview Survey (SHIS) (Ministry of Health Saudi Arabia, 2013)

#### Study 3:

The aim of this qualitative study was to acquire the views of health professionals working in type 2 diabetes management. This study gathered the views of both the professional and the individuals on their experience with type 2 management, their thoughts around the self-management programmes themes such as independence and problem solving and improving life quality, and also if they know of or expect any success from self-management programmes. Another point in this qualitative

study was to understand if such success can be limited by local environment and/or cultural barriers particular to Saudi Arabia, or even the health system itself.

## **2.3 Methods in relation to objectives**

### **2.3.1 Systematic review**

A systematic review allowed for logical and systematic assessment of published studies on type 2 diabetes self-management in the GCC countries (including Saudi Arabia). This approach was used to limit the bias towards the published results. Each study is examined against pre-set criteria to determine its quality and the covered points. These criteria determine the extent by which the study can be used to inform on how beneficial the interventions used were at improving type 2 diabetes management and to what extent they reflect any of the known type 2 diabetes self-management programmes. The systematic review approach allows studies to be considered together in order to reach a universal conclusion on the success of self-management interventions in GCC.

### **2.3.2 Quantitative study**

This study involved a secondary quantitative analysis of SHIS. This survey benefited from the strong logistics of the ministry of health in Saudi Arabia, which allowed the examination of a relatively large representative sample of all 13 regions in Saudi Arabia, which is far beyond what could have been achieved through this study with the limited resources available. However, SHIS was not specifically designed for type 2 diabetes but it has allowed for the examination of the study individuals free of type 2 diabetes versus those with type 2 diabetes to understand the demographic,

health and lifestyle factors associated with type 2 diabetes prevalence and control in Saudi Arabia.

### **2.3.3 Qualitative study**

Qualitative research has the advantage of directly investigating the views of the individuals of interest. However, the design of the qualitative study is dependent on the aim, the extent and the availability of resources (Smith et al., 2009). A grounded theory approach is recognised as one of the strongest approaches in qualitative research as it can create a specific concept about a specific subject. However, this would have required collecting data from different geographically or culturally isolated populations and a research which is formed of investigators and judges, who have relevant experience but different backgrounds (Braun and Clarke, 2014). This could not have been achieved in this study. So, instead, a pragmatic approach, which matched the available resources, was used to allow the principle investigator to carry out a qualitative study that could assess the priorities and the extent of adaptation that would be needed to move any of the self-management education programmes from a western environment, for example, to Saudi Arabia. This approach has the advantage of examining the perspectives and experiences of health professionals managing type 2 diabetes and individuals living with type 2 diabetes and looking into common agreed themes in their conversations (Braun and Clarke, 2014). In order to allow the health professionals the space to discuss their experiences in a way, which would reflect the journey of person with type 2 diabetes in the medical centre, focus groups were formed of all disciplines they visit in the health centre (e.g. Doctors, nurses, health educators and nutritionists). However, in order to protect the confidentiality of the individuals with type 2 diabetes participating

in the study and avoid them any sense of awkwardness or influence by others, individual interviews were seen more appropriate.

These three distinct aims and research methods, although presented as separate studies, are linked. The systematic review helped to understand the effect of implementing type 2 diabetes self-management across GCC countries, while the quantitative study examined factors, whether in health or in disease that are associated with type 2 diabetes in Saudi Arabia. Both studies highlighted points to be addressed by participants in the qualitative study. The three studies together represent the first step in cultural adaptation of a self-management programme, which is an assessment of the need to make cultural adaptations to existing self-management programmes. Part of this needs assessment is to assess whether the self-management approach *per se* can benefit individuals with type 2 diabetes in Saudi Arabia.

## **2.4 Cultural adaptation need assessment**

### **2.4.1 Introduction**

As discussed in the previous chapter, the incidence and/or prevalence of type 2 diabetes and its complications in Saudi Arabia are higher than global rates, while it can be seen that longstanding national self-management programmes of type 2 diabetes have successfully brought down the rates of type 2 diabetes complications such as the DESMOND programme in the UK. There is nothing to suggest that a self-management programme cannot also be successful in Saudi Arabia. The main

concept of self-management education programmes is to provide the individuals with type 2 diabetes with a robust degree of autonomy and independence in managing their conditions (Ferrer-Wreder et al., 2012). Nevertheless, to achieve this, most of the currently successful self-management education programmes such as DSME or DESMOND have been developing over decades through feedback from educators and the people with type 2 diabetes themselves, which has led to optimisation of these programmes. To move such programmes to a different country/society, it is likely that cultural adaptation would be required. Cultural adaptation takes into consideration many social factors such as language, traditions and religion but also examines other local factors such as welfare, resources and environment. There are several models of cultural adaptation, which provide approaches to assess the need for cultural adaptation.

#### **2.4.2 Culture adaptation models**

To develop effective programmes for the self-management of diabetes in Saudi Arabia, programmes, such as DSME, and DESMOND should be adapted to the cultural and social environment. There are several cultural adaptation models that are widely used such as Cultural Sensitivity Model (Resnicow et al., 1999), Cultural Adaptation “Process” Model (Domenech Rodríguez and Bernal, 2012), Culturally Specific Prevention Model (Whitbeck, 2006), International Implementation of MST (Schoenwald et al., 2008), The ADAPT-ITT model (Wingood and DiClemente, 2008), and Cultural Sensitivity and Adaptation model (Kumpfer et al., 2008). However, Ferrer-Wreder and colleagues (2012) reviewed nine culturally adaptive models in relation to evidence-base and empirical or systematic approaches. In their

analysis, they concluded that Schoenwood, Wingwood and Kumpfer models were the only 'cross-national' ones as they follow a framework of systematic steps based on evidence from the intervention in a local community, rather than from a controlled research study. Therefore, these cultural adaptation models may be useful when considering implementing an established programme from one country in another; in this case utilizing, for example, the American DSME or the British DESMOND models in Saudi Arabia. The above mentioned three cross-national cultural adaptation models (Schoenwald, Wingood and Kumpfer) provide a structured step-based programme, two of which (Wingood and DiClemente, 2008, Kumpfer et al., 2008) require a "needs-assessment", which is considered an essential step in the development of a country/culture specific self-management programme. Ferrer-Wreder and colleagues identified the Kumpfer model in particular as an influential model, which can be widely used to create adaptive models suitable for specific cultural and sociodemographic characteristics of a community (Ferrer-Wreder et al., 2012). Kumpfer tested their model in 17 different countries, addressing crucial elements of the society such as religion and beliefs, traditions and customs, ethnicities, influential people or organisations, work environment and economical aspects (Kumpfer et al., 2008). The model has been successfully used to transfer management strategies for a number of health issues across diverse cultural populations, but not specifically for the management of diabetes (Africa, Hispanic, Asia, Pacific Islands, and Native America). The systematic approach in this model has proved practical, as each of nine successive steps provides the required data to be followed in the next step (Kumpfer et al., 2008, Hussong and Smith, 2018, Castro and Barrera, 2015, Barrera et al., 2017, Shlonsky and Benbenishty, 2013, Sundell and Ferrer-Wreder, 2014). The nine steps that Kumpfer proposed are:

- 1) Identifying the needs of the local population.
- 2) Initial minor adaptations to the existing programme.
- 3) Piloting the programme with these minor adaptations.
- 4) Founding the initial implementing team.
- 5) Using the outcome of the pilot study to improve the quality and support of the programme.
- 6) Revising the programme for any additional requirements or alterations.
- 7) Continuous monitoring of the service.
- 8) Concluding the final evaluation.
- 9) Dissemination of the service and publication of the results.

Each of these nine steps is described in sequence below based on an example presented by Kumpfer and colleagues (2008) for internationally transferring a local north American programme called (the Strengthening Families Program), which addressed substance abuse based on 14 sessions with the family of an affected member (Kumpfer et al., 2008).

#### **2.4.2.1 Identifying the needs of the local population (Health Needs Assessment)**

Health needs assessment is a systematic method for reviewing the health issues facing a population, resulting in agreed priorities and resource allocation that improve health and reduce inequalities (Kumpfer et al., 2008). The process describes the state of health of a population and aims to identify the major risk factors and causes of ill health. It also enables the identification of the actions needed to address these issues. A health needs assessment can address a

particular condition, here it is type 2 diabetes: how can self-management education help to ease the problem and what is needed to be taken into consideration to successfully transfer an existing self-management education programme to Saudi Arabia. A health needs assessment is not a one-off activity but a developmental process that is added to and amended over time (Wright et al., 1998). This consists of reviewing the literature and available data resources to highlight the issues of need and the best approach to tackle them and then identifying the actions needed to address them. If the available data is insufficient, then a specialised needs assessment can be designed with other methodologies suggested by Kumpfer's model, such as participant interviews and professional and policy makers' focus groups (Kumpfer et al., 2003, Rodnium, 2007). In the adaptation of the Family Strengthening Programme for Australia and Thailand settings, Kumpfer's team relied mainly on available surveys in the proposed new host country that were associated with key elements in the original programme.

#### **2.4.2.2 Initial minor adaptations to the existing programme**

Once a careful selection has been made on the programme to be implemented, for example DESMOND or DMSE, adaptations are initially made for the prominent barriers that can be found in the original programme such as language or outstanding cultural concepts that contradict with the mainstream of the recipient society. Examples include the use of the word "mosque" instead of "church", the use of an appropriate greeting approach or the use of local dialect versus formal translation. These adaptations should be addressed at this stage by means of translation and cultural filtering or censoring that are provided by a health needs assessment. However, any adaptations made should be minor, and the programme

needs to be implemented in its original format as much as possible (Chatterjee et al., 2018). Also, at this stage, if crucial items are not informed by the first step such as the quality and availability of resources, then further work needs to be dedicated for investigating this. Again, focus groups and participant interviews can be used.

#### **2.4.2.3 Piloting the programme with these minor adaptations**

Introduction of a new service can be expensive and time consuming. Piloting the service, or recommendations, within a confined community with minor adaptations to the original programme helps to practically assess such a service and identify points of strength and weakness before rolling it out to a larger or national setting.

#### **2.4.2.4 Founding the initial implementing team**

This team is responsible for implementing the initial stage of the programme. The team is nominated based on suitability and ability to deal with the needs identified in the first step. Ideally, the founder of the original existing programme (or the current available experts or institutes e.g. DEMOND or DSME groups) should lead such a team or have a key involvement in forming and training a local team. The local team is usually formed of local health professionals and potential local educators and also include some population with identified needs, members of their family or caregivers if applicable (Leggat, 2007). This team would supervise the cultural adaptation process and discuss changes with founders of the original existing programme. The team that was formed by the Kumpfer group for the Family Strengthening Programme had additional characteristics. For example, they appointed a charismatic team leader, who is quite aware of the local culture and also of the cultural adaptations advised by the previous steps. They believe that this

leader brought efficiency and harmony to the team, which enhanced the progress of the initial programme implementation.

#### **2.4.2.5 Using the outcome of the pilot study to improve the quality and support of the programme**

The formed implementation team will start by using the results from the pilot studies' to make further cultural adaptation, however the programme at this stage will remain as close as possible to the original format. They will then record the progress relying on the feedback they are getting from different sources, such as persons, the health professionals and regulatory bodies. The feedback can be obtained through focus groups, questionnaires or published reports. In the Family Strengthening Programme Kumpfer's team took on board weekly feedback from the field teams to make revisions to the programme to aid its success.

#### **2.4.2.6 Revising the programme for any additional requirements or alterations**

The implementation team can make additional alterations to the piloted study based on the feedback received from the field teams. According to the scale of alterations, minor or major, the implementation team, will determine if there is need for a second pilot study or if the service can be rolled out within the community on a limited scale. If the required changes are major, the programme founders will need to devise a second pilot study in a similar manner that they used for their own existing programme. Also they may need to examine if these changes would require updates to educator training. At this stage, Kumpfer's group in the Family Strengthening Programme recommended looking beyond the formally documented written materials from the implementation team, by looking at other possible sources of data

such as any reaction to the programme found in the social media, newspapers or TV shows, based on evidence from another study (Allen et al., 2006).

#### **2.4.2.7 Continuous monitoring of the service**

Once the service is made available to a wider sector of the community, such as a city, it needs to be carefully examined through surveys or participant interviews to accurately test for the penetration, impact and effectiveness of the service towards the needs for which it was created. The new service can also be documented through video clips, which can show for example the person journey starting at reception and during consultation with health educators. Also, some individuals may volunteer to record some of their daily routine, where they are implementing the self-management strategies that they have learnt.

#### **2.4.2.8 Concluding the final evaluation**

If the service is judged to be successful through all the aforementioned stages, then it can be rolled out to include as many as possible in the community. However, the success of the service should be measured against cost-benefit, the effectiveness or ineffectiveness of the new adaptations and if more adaptations are needed. This task needs a review of the programme to be done with a neutral expert, who was not involved in the previous steps, starting from the first step until this stage.

#### **2.4.2.9 Dissemination of the service and publication of the results**

Publications may accompany each stage of the process and work carried out until and after the service is made public. These publications, alongside their

conventional role towards enhancing knowledge, would provide a valuable resource for other communities with current or potentially similar needs. Dissemination of the service to the community also depends on availability of financial and human resources and other logistics.

#### **2.4.3 The first step of Kumpfer model as part of the thesis aim**

The systematic review covers part of the first step of the Kumpfer model, which is the review of relevant literature. In addition to assessing the impact of type 2 diabetes self-management on study participants with type 2 diabetes, the systematic review examines the quality, strength and limitations of the included studies. The quantitative study (study 2) also addresses the first step of the model, which relates to the sociodemographic, lifestyle and health-seeking behaviors' associations with type 2 diabetes in Saudi Arabia. Finally, the qualitative study, further assesses the need for cultural adaptation through the direct views of health care professionals who are providing care for individuals with type 2 diabetes and the views of these individuals themselves. In this way, the three studies work in a complementary way to complete the work required for step one of culturally adapting a self-management programme of type 2 diabetes in Saudi Arabia, based on the Kumpfer model.

## **Chapter III**

### **3. Systematic Review: Self-Management of Type 2 Diabetes in Gulf Cooperation Council Countries**

#### **3.1 Introduction**

The previous chapter reviewed part of the literature on type 2 diabetes in Saudi Arabia, particularly incidence, prevalence and the current management strategies of the health care services in Saudi Arabia for type 2 diabetes and its complications. This chapter represents a systematic review of type 2 diabetes self-management intervention studies that took place in Saudi Arabia and the rest of the GCC countries, Study 1 of the thesis. The review was published in 12 December, 2017 in PlosOne journal (Al Slamah et al., 2017) and an exact copy is used for this chapter. The systematic review was carried out by the author of this thesis under the supervision of Professor Craig A. Melville, the director of studies. Also Dr Barbara I. Nicholl was part of the supervisory team, who has contributed to screening and devising systematic review tools, while reviewed the drafts until reaching the final draft of the article. Dr. Fatima Y Alslail, the director of the National Diabetes Control and Prevention Program, Ministry of Health, Kingdom of Saudi Arabia, contributed to interpretation of results and finalising the manuscript.

**Title:**

Self-Management of Type 2 Diabetes in Gulf Cooperation Council Countries: A Systematic Review.

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## **Abstract**

**Aims:** This study aimed to systematically review intervention studies on self-management of type 2 diabetes in Gulf Cooperation Council (GCC) countries to determine if any of the self-management strategies met success with individuals with type 2 diabetes in this region, which may show a need for these strategies to be implemented.

**Methods:** A search strategy was developed using multiple databases: Medline and Embase (via Ovid), CINAHL (via EBSCO), and PubMed. Study and intervention characteristics, intervention structure, content, cultural adaptation, and outcomes were extracted from the included studies. To be included in the review the studies should have met the following criteria: have examined the effectiveness of at least one intervention involving a type 2 DSME programme, have involved participants over 18 years old diagnosed with type 2 diabetes, have taken place to in a GCC countries, have a study design that was observational, quasi-experimental or controlled, have reported at least one individual and have a quantitative outcome. A narrative data synthesis was used to describe the studies and comment on their methodological quality.

**Results:** Of the 737 retrieved papers, only eight met the inclusion criteria. Only one study was a randomised controlled trial. A statistically significant improvement in HbA1c was reported in five of the eight studies. There was a significant improvement in physical activity levels as reported in four of the eight studies. Only three studies referred to aspects of cultural design or adaptation of the intervention implemented.

**Conclusions:** Self-management interventions may have a positive impact on HbA1c levels in people with type 2 diabetes in the GCC countries area. A greater emphasis placed on culturally appropriate self-management programmes may improve the effectiveness of self-management interventions for adults with type 2 diabetes in the GCC countries.

**Keywords:** diabetes, type 2 diabetes, self-care, self-management.

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### **3.2 Background**

Diabetes attracts significant attention globally due to its rapidly increasing prevalence and high costs for individuals, and society in general (World Health Organisation, 2016). The International Diabetes Federation estimated that, worldwide, there were 410 million people living with diabetes, around which 90% have a diagnosis of type 2 diabetes (International Diabetes Federation, 2015). A stated aim of the World Health Organisation is to increase levels of awareness of the global burden and consequences of diabetes, with a particular focus on developing countries (World Health Organisation, 2015).

The number of people with type 2 diabetes in the countries of the GCC — the Kingdom of Saudi Arabia (KSA), Kuwait, Qatar, Oman, Kingdom of Bahrain, and United Arab Emirates (UAE) — has dramatically increased in the past two decades (Abuyassin and Laher, 2016), and is expected to increase by 96.3% by 2035 (International Diabetes Federation, 2015). In 2015, the estimated prevalence of diabetes in adults (20-79 years) in each of the GCC countries was higher than the global prevalence of 8.8% (International Diabetes Federation, 2015). In KSA, it was 17.6%; Kuwait, 14.3%; Qatar, 13.5%; Oman, 9.9%; Kingdom of Bahrain, 15.6%; and UAE, 14.6% (International Diabetes Federation, 2015). Studies have shown that diabetic control is poor amongst adults with type 2 diabetes living in the GCC countries (Omar et al., 2016). As a consequence, there is a disproportionate number of type 2 diabetes complications in GCC countries; for example, 40-70% of diabetes-related foot amputations worldwide are in GCC countries (International Diabetes Federation, 2015).

Diabetes self-management education (DSME) has been shown in meta-analyses to be an effective approach to improving glycaemic control and psychosocial outcomes in adults with type 2 diabetes (Norris et al., 2002, Steinsbekk, 2012). DSME has been defined as, "The ongoing process of facilitating the knowledge, skill, and ability necessary for prediabetes and diabetes self-care" (Haas et al., 2012). The objectives of DSME are to support policymakers and individuals working in the healthcare sector in their efforts to improve healthcare outcomes and, eventually, the general population's quality of life (Haas et al., 2012).

In many countries, DSME is considered to be an important part of the first line management of type 2 diabetes. Most DSME programmes were first developed in the United States, and therefore the successful implementation of such programmes in other countries or for different ethnic groups are likely to require some form of cultural adaptation. In fact, cultural adaptation was found to be a factor in the effective implementation of a DSME programme for Mexican Americans and this study demonstrated that cultural adaptation had a positive impact on health outcomes, particularly on HbA1c levels (Brown et al., 2002). Additionally, adapting a DSME programme so that it is more culturally appropriate has been shown to have a promising result on dietary behaviour among individuals with type 2 diabetes in USA (Vincent et al., 2006). Most of the evidence supporting the effectiveness of DSME and cultural adaptation comes from studies in the United States of America and other high-income, English-speaking countries. This systematic review examines the evidence for the effectiveness of DSME in adults with type 2 diabetes in GCC countries.

### **3.3 Methods**

This systematic review and its procedures were planned, conducted, and reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Liberati et al., 2009).

#### **3.3.1 Search strategy**

With support from a medical research librarian, an overall strategy was developed to identify papers relevant to diabetes self-management in GCC countries. Customised searches were devised for the databases Medline and Embase (via Ovid), CINAHL (via EBSCO), and PubMed. The most recent search range available on the database was chosen, which included publications between 1996 and October 2015. Appropriate keywords and Boolean logic were used for the terms 'diabetes mellitus' OR 'diabetes complications' and 'diabetes mellitus' AND 'self-care'. Full details of the search strategy are provided in Appendix 1.

To ensure comprehensive identification of potentially relevant studies, manual searches of specialised journals were done for the most recent years 2013-2016. The journals included in the manual searches were the International Journal of Diabetes Care, the Journal of International Diabetes Federation, Diabetes, Clinical Diabetes and Diabetes Spectrum. Since the research targeted journals and health organisations relevant to GCC countries, searches were also performed in the Saudi Medical Journal, Omani Medical Journal, Kuwait Medical Journal, Bahrain Medical Bulletin, and Qatar Medical Journal, as well as in publications of the Saudi Diabetes and Endocrine Association, MENA Diabetes Leadership Forum 2010 Dubai, and Ministry of Health Saudi Arabia, with a publication period ranging from 2013 to 2016.

Lastly, the reference lists of all publications included in the review, and relevant systematic reviews, were read in detail to identify additional potentially relevant studies.

### **3.3.2 Eligibility criteria**

Eligible studies had to meet five inclusion criteria:

- Examined the effectiveness of at least one intervention involving a type 2 DSME programme; for which interventions referred to treatments involving elements and activities intended to improve participants' knowledge, skills, and ability to perform self-management activities toward improving their glycaemic control (National Standards of Diabetes Self-Management Education and Support, 2012);
- Participants were diagnosed with type 2 diabetes and aged at least 18 years;
- Studies took place in a GCC country (KSA, Kuwait, Qatar, Oman, Bahrain, and UAE);
- The study design was observational, quasi-experimental or controlled studies. Reported at least one individual and had a quantitative outcome (e.g., glycaemic control, knowledge, adherence to medication, physical activity levels, and quality of life).

Exclusion criteria were: performed in non-GCC countries; non-primary intervention studies; studies included participants with type 1 diabetes; abstract only available; non-English language publications.

### **3.3.3 Study selection**

Studies from databases were exported to Endnote software to be saved and managed. Duplicate articles were removed. A two-stage process was used to identify papers, records, and publications for inclusion in the systematic review. Two researchers (TASA and CAM) independently screened the titles and abstracts of publications. A consensus discussion took place if there was disagreement about inclusions and exclusions. In the second stage, the same two researchers independently read the full text of the articles and completed inclusion/exclusion checklists for each paper. The disagreement was resolved through a consensus discussion. If the two reviewers could not reach consensus regarding some publications, then a third researcher (BN) was consulted to adjudicate.

### **3.3.4 Data extraction and quality assessment**

Data extraction was performed independently by the two researchers (TASA and CAM), and any disagreements were resolved with the aid of a third researcher (BN).

Study quality was rated using the Standard Quality Assessment Criteria for Evaluating Primary Research Papers tool for quantitative studies (Kmet et al., 2004). Each study was assessed against 14 criteria-oriented items. If the study met the quality criteria fully it was scored as 2; 1 if it partially met the criteria; and 0 if it did not meet the criteria. For some criteria, "not applicable" (N/A) was the rating given. A total score for each paper was calculated by adding the total score across relevant items and dividing by the total possible score [28 – (Number of N/A x 2)]. The quality assessment tool is provided in Appendix 2.

### **3.3.5 Data coding frameworks**

Guidance published by the Cochrane Collaboration was used to categorise the study design of the included studies (Van Tulder et al., 2003). Four frameworks were used to code studies based on content, structure, cultural adaptation, and outcomes.

Coding frameworks were completed independently by two researchers (TASA and CM), and any disagreements were also resolved with the aid of a third researcher (BN).

Several DSME-related frameworks were reviewed to develop a suitable framework to code the content of interventions included in the review. The final framework was developed based on criteria for defining a self-management support intervention, and incorporating aspects of education and knowledge, lifestyle, skills, and support, as defined by Galdas et al. (2015), with additional sub-categories for defining self-management intervention content adapted from Peeples et al. (2007) including problem solving, reducing risk, monitoring, and others. Appendix 3 provides an explanation for each coding category (Galdas et al., 2015, Peeples et al., 2007).

Coding of the intervention structure was adapted from Fan and Sidani (2009) and included teaching methods, teaching strategies, a format of delivery used, number of diabetes related topics included, number of sessions, total contact hours, duration of the intervention and whether a booster session was delivered (Fan and Sidani, 2009).

Coding of cultural adaptation was taken from (Bernal et al., 1995) and included eight components that are considered essential components of the process of adapting interventions to be culturally appropriate (language, persons, metaphors, content, concepts, goals, methods, and context) (Bernal et al., 1995). This coding framework was used due to the clarity of its dimensions and accompanying description of the elements. The dimensions were developed during structural family therapy for Hispanic groups in the United States, but they are also suitable for evaluating the cultural adaptation or development of interventions in other country settings, including GCC countries.

Intervention outcomes were extracted and coded using a format adapted from Alhyas et al. (2011), including key results regarding glycosylated haemoglobin (Hb1Ac), blood pressure, lipid profile, and weight and body mass index (BMI) (Alhyas et al., 2011).

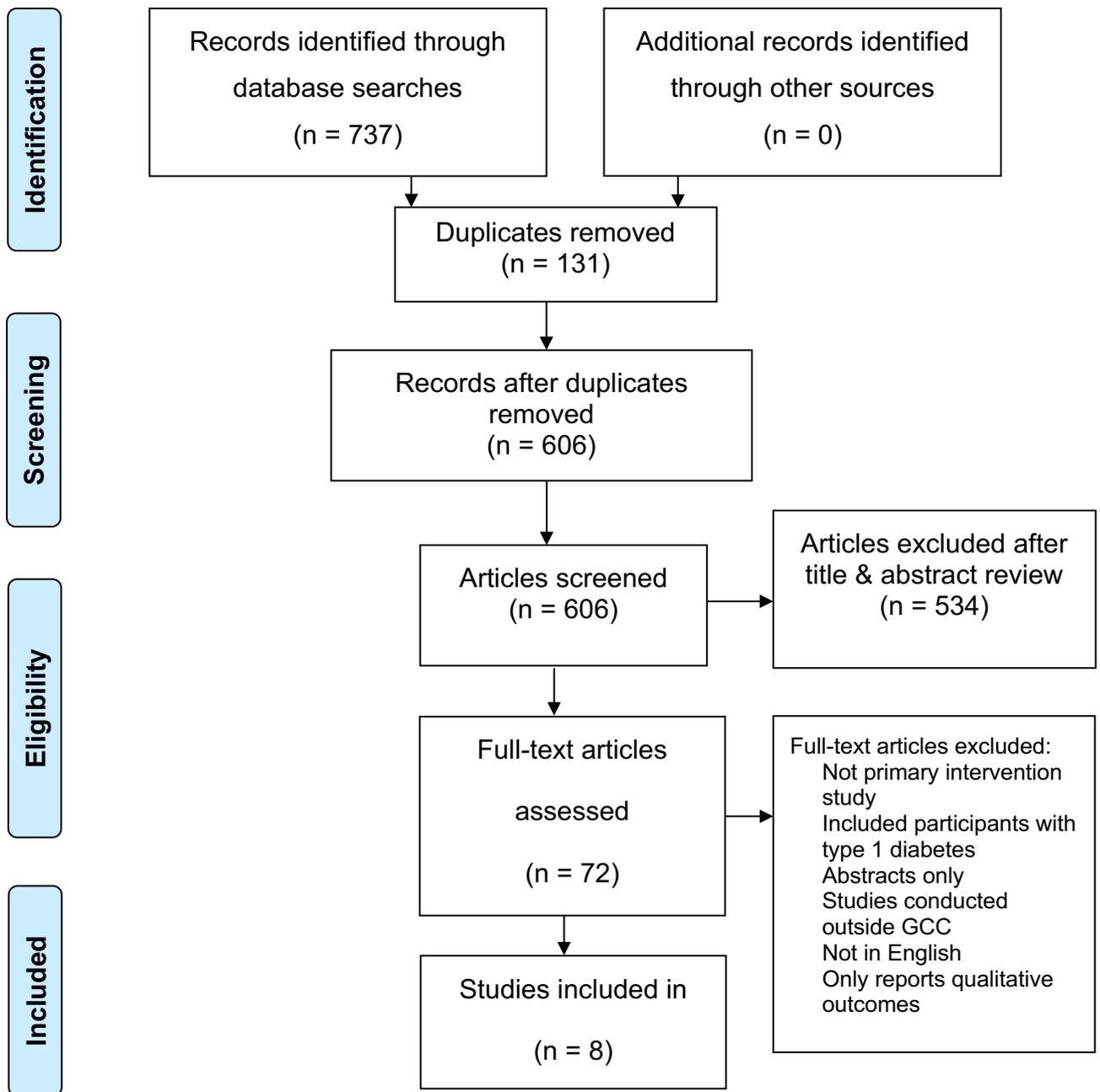
### **3.3.6 Data analysis and narrative data synthesis**

Since this study involved heterogeneous intervention study designs and only one study was a randomised controlled trial, there was a significant risk of bias in the results. Consequently, a meta-analysis was impossible, and a narrative data synthesis was used to describe the studies, comment on their methodological quality and report outcomes.

### **3.4 Results**

Figure 3.1 shows the studies retained at each stage of the study identification and selection process, with eight articles included in the review.

Figure 3.1 Study flow diagram (PRISMA flow chart)



### **3.4.1 Study and intervention characteristics**

Table 3.1 provides an outline of the eight papers included in the data synthesis and the quality ratings of the studies.

**Table 3.1 Characteristics of studies and interventions**

Study characteristics						
Authors	Study setting	Inclusion criteria	Participant traits	Study design	Measures	Assessment quality
<b>Al-Daghri et al. (2014)</b>	Primary care	Not pregnant, without diabetic complications (e.g., renal, neurologic, hepatic, and pulmonary disease), and without acute conditions needing immediate medical attention	T2DM: $N = 37$ (29 F), age $47.69 \pm 1.45$ years; Pre-diabetes: $N = 47$ (33 F), age $48.85 \pm 1.46$ ; non-DMT2: $N = 66$ (51 F), age $39.8 \pm 1.44$ years)	Controlled before-and-after study	Lipid profile, BMI, blood pressure, serum FBG, serum albumin calcium, phosphate, and vitamin D	0.68
<b>Abduelkar em and Sackville. (2009)</b>	Community based	Taking oral antidiabetic drugs for T2DM, aged <85 years, with normal renal and hepatic function, not pregnant, English or Arabic speaking, and without any cardiovascular disease, chronic disease, or psychological or physical disability	$N = 59$ (32 F), aged $51 \pm 11.3$ years (range 28–75)	Controlled before-and-after study	General diet, specific diet exercises, foot care, self-testing, body pain, physical functioning, general health, vitality social functioning, and emotional and mental health	0.59
<b>Mohammed et al. (2013)</b>	Community based	Diagnosed with T2DM and registered with primary health care centres and general hospital	Intervention: $N = 109$ (69 F), mean age = $52 \pm 8.9$ years;	Randomized controlled trial	HbA1c, FPG, BP, TC, HDL, LDL, TG, BMI, albumin-to-creatinine ratio, and diabetes	0.78

			Control: $N = 181$ (131 F), aged $55 \pm 10.7$ years		knowledge, attitude, and practice	
<b>Al-Sinani et al. (2010)</b>	Secondary care	Diagnosed with T2DM	$N = 98$ (49 F), mean age = NA (categorised)	Controlled before-and-after study	HbA1c, FPG, HDL, LDL, TC, TG, BMI, BW, BP, total energy intake per day, carbohydrate, fat, and protein intake/d, energy intake from carbohydrate and fat/d per day, and PA	0.86
<b>Al-Shahrani et al. (2012)</b>	Secondary care	Diagnosed with T2DM, aged >30 years, of Saudi nationality, and completed 5-day diabetic education programme	$N = 438$ (158 F), age = $55.84 \pm 10.0$ years (range 32–80)	Cohort study	HbA1c, TC, TG, LDL, HDL, BP, BW, and fasting blood sugar	0.77
<b>Al Hayek et al. (2013)</b>	Tertiary care	Aged 18–70 years, diagnosed with T2DM $\geq 1$ year, and of Saudi nationality	$N = 104$ (33 F), age = $57.3 \pm 14.4$ years	Controlled before-and-after study	HbA1c, HADS, adherence to dietary advice and medication, self-monitoring of blood glucose, and PA	0.59
<b>Alasmary et al. (2013)</b>	Primary care	Diagnosed with T2DM, aged >18 years, and with poorly controlled diabetes	$N = 41$ (24 F), age = $56.2 \pm 12.9$ years (26–85)	Controlled before-and-after study	HbA1c, FPG, BP, TC, HDL, LDL, TG, and BW	0.77

<b>Omer et al. (2015)</b>	Secondary care	Diagnosed with T2DM, male, aged 40–50 years, and with a BMI = 30.0–34.9 and HbA1c of 9–10%	<i>N</i> = 400, age = NR	Controlled before-and-after study	HbA1c, dietary habits, PA, and adherence to medication	0.27
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**Table 3.1 Continued**

<b>Authors</b>	<b>Intervention characteristics</b>				
	<b>T2DM intervention</b>	<b>Provider</b>	<b>Offers training</b>	<b>Theoretical model</b>	<b>Duration</b>
<b>Al-Daghri et al. (2014)</b>	Education about lifestyle modifications and need for increased exposure to sunlight; participants asked to self-monitor	Nutritionist physician, nurse, and physical therapists	No	NR	6 months
<b>Abduelkarem and Sackville . (2009)</b>	Weekly reminders on BW, PA, dietary habit, self-testing, foot care, smoking habits, BP, and dyslipidaemia	Pharmacist	No	NR	3 months
<b>Mohammed et al. (2013)</b>	Group health education and counselling sessions	Health educators	Yes	Theory of empowerment, locus of control	NR
<b>Al-Sinani et al. (2010)</b>	Nutrition and lifestyle counselling about diabetes, diet and nutrition, weight management, and exercise	Professional health care team	No	NR	NR
<b>Al-Shahrani</b>	5-day intensive health education programme	Professional health care team	No	NR	5 days

<b>et al. (2012)</b>					
<b>Al Hayek et al. (2013)</b>	Group health education programme	Nurse diabetes health educators	Yes	NR	6 months
<b>Alasmar y et al. (2013)</b>	Multidisciplinary integrated care programme	Family physician, nurse, clinical pharmacy specialist, dietician, health educator, diabetic educator, and social worker	No	NR	6 months
<b>Omer et al. (2015)</b>	Self-monitoring of blood glucose	NR	No	NR	2.5 years

BMI: Body mass index, BP: Blood pressure, BW: Body weight, F: Female, FBG: Fasting blood glucose, HADS: Anxiety and depression, HbA1c: Glycosylated haemoglobin, HDL: High-density lipoprotein, LDL: Low-density lipoprotein, NA: Not available, NR: Not reported, PA: Physical activity, T2DM: Type 2 diabetes mellitus, TC: Total cholesterol, TG: Triglycerides, 0-1: 0 = poor quality, 1= high quality

Of the included studies, one was a randomised controlled trial (Mohamed et al., 2013), one was a cohort study (Al-Shahrani et al., 2012), and six were controlled before-and-after studies, (Al-Daghri et al., 2014, Abduelkarem and Sackville, 2008, Al Asmary et al., 2013, Al Hayek et al., 2013, Al-Sinani et al., 2010, Omer et al., 2015). Five of the studies were conducted in KSA (Al-Shahrani et al., 2012, Al-Daghri et al., 2014, Al Asmary et al., 2013, Al Hayek et al., 2013, Omer et al., 2015), one study was conducted (Al Hayek et al., 2013) in the United Arab Emirates (Abduelkarem and Sackville, 2008), one study in Qatar (Mohamed et al., 2013), and one study in Oman (Al-Sinani et al., 2010). None of the studies was conducted in Kuwait or Bahrain.

A total of 1,539 participants were included in the eight studies, with a mean sample size of 139.9 and a range of 37–438. One study reported the age range of participants categorically (Al-Sinani et al., 2010), and one study did not report the age at all (Omer et al., 2015). Among the six studies that reported participants' mean age, the combined mean age was 51.5 years with the range of 39–58 years (Mohamed et al., 2013, Al-Shahrani et al., 2012, Al-Daghri et al., 2014, Abduelkarem and Sackville, 2008, Al Asmary et al., 2013).

Six studies measured participant HbA1c as an outcome (Mohamed et al., 2013, Al-Shahrani et al., 2012, Al Asmary et al., 2013, Al Hayek et al., 2013, Al-Sinani et al., 2010, Omer et al., 2015), five studies measured blood pressure (Mohamed et al., 2013, Al-Shahrani et al., 2012, Al-Daghri et al., 2014, Al Asmary et al., 2013, Al-Sinani et al., 2010), five studies measured lipid profile (Mohamed et al., 2013, Al-

Shahrani et al., 2012, Al-Daghri et al., 2014, Al Asmary et al., 2013, Al-Sinani et al., 2010), and five studies measured weight or BMI (Mohamed et al., 2013, Al-Shahrani et al., 2012, Al-Daghri et al., 2014, Al Asmary et al., 2013, Al-Sinani et al., 2010). The duration of intervention was greater than two years in only one study (Omer et al., 2015).

Only one study explicitly stated the theoretical models used to inform the design of the interventions: the DSME intervention theory of empowerment and locus of control theory (Mohamed et al., 2013).

#### **3.4.2 Content of interventions**

Table 3.2 summarises the intervention content across the eight studies.

**Table 3.2 Coding of the content of the DSME interventions used in the eight included studies**

• = Yes , Blank = No							
Authors	Education / Knowledge			Lifestyle			
	Dietary	Physical Activity Guidance	Other Sources	Healthy Food	Being Active	Monitoring	Taking Medications
Al-Daghri et al. (2014)	•	•	•	•	•	•	
Abduelkarem and Sackville. (2009)	•	•	•	•	•	•	
Mohammed et al. (2013)	•	•	•	•	•	•	
Al-Sinani et al. (2010)	•	•	•	•	•		
Al-Shahrani et al. (2012)	•	•	•	•	•	•	•
Al Hayek et al. (2013)	•	•	•	•	•	•	•
Alasmary et al. (2013)	•		•	•		•	•
Omer et al. (2015)	•	•		•	•	•	

**Table 3.2 Continued**

Authors	Skills			Support			
	Problem Solving	Reducing Risks	Healthy Coping	Monitoring & Feedback	Psychological Interventions	Peer Support	Financial Incentives
Al-Daghri et al. (2014)				•			
Abduelkarem and Sackville. (2009)							
Mohammed et al. (2013)			•		•		
Al-Sinani et al. (2010)							
Al-Shahrani et al. (2012)			•				
Al Hayek et al. (2013)					•		
Alasmary et al. (2013)				•			
Omer et al. (2015)				•			

All studies except (Al Asmary et al., 2013) included educational content about physical activity or provided information about active lifestyles in the intervention. Seven of the eight studies included monitoring of blood glucose intervention as part of the content on lifestyle (Mohamed et al., 2013, Al-Shahrani et al., 2012, Al-Daghri et al., 2014, Abduelkarem and Sackville, 2008, Al Asmary et al., 2013, Al Hayek et al., 2013, Omer et al., 2015), but only three of the studies included content about medication as part of the intervention content (Al-Shahrani et al., 2012, Al Asmary et al., 2013, Al Hayek et al., 2013). None of the studies included problem-solving skills or skills for reducing risk in the content of their interventions. Furthermore, only two studies incorporated training related to healthy coping skills in their interventions (Mohamed et al., 2013, Al-Shahrani et al., 2012), while only three studies involved monitoring and feedback (Al-Daghri et al., 2014, Al Asmary et al., 2013, Omer et al., 2015).

### **3.4.3 Intervention structure**

Table 3.3 summarises the intervention structure in the eight studies.

**Table 3.3 Coding of structure of DSME intervention in the eight included studies**

	• = Yes, Blank = No						
	Teaching Method used		Strategies				
Authors	Didactic	Interactive	Written Material	Online/ Web-based	Video	Face-to-Face	Phone Contact
Al-Daghri et al. (2014)		•				•	•
Abduelkarem and Sackville. (2009)	•		•				
Mohammed et al. (2013)		•	•			•	
Al-Sinani et al. (2010)	•	•				•	
Al-Shahrani et al. (2012)	•	•	•		•	•	
Al Hayek et al. (2013)	•		•		•	•	
Alasmary et al. (2013)	•	•					•
Omer et al. (2015)	•					•	

**Table 3.3 Continued**

Authors	Format		Number of Diabetes-Related Topics		Number of Sessions		
	One-to-One	Group	Focus on One Topic	One or More Topics	≤5	6-10	>10
Al-Daghri et al. (2014)		•		•			
Abduelkarem and Sackville. (2009)		•		•			
Mohammed et al. (2013)		•		•	•		
Al-Sinani et al. (2010)	•			•			
Al-Shahrani et al. (2012)		•		•	•		
Al Hayek et al. (2013)	•	•		•			•
Alasmay et al. (2013)	•			•			•
Omer et al. (2015)	•			•		•	

Table 3.3 Continued

Authors	Total Contact Hours			Duration			Delivery of Booster Session
	≤10	11-20	>20	≤8 weeks	9-24 weeks	>24 weeks	
Al-Daghri et al. (2014)							
Abduelkarem and Sackville. (2009)					•		
Mohammed et al. (2013)		•				•	
Al-Sinani et al. (2010)						•	
Al-Shahrani et al. (2012)			•	•			
Al Hayek et al. (2013)						•	
Alasmary et al. (2013)						•	
Omer et al. (2015)						•	

Six studies adopted a face-to-face delivery method, and no online or web-based strategies were used in any of the studies. The number of sessions was not reported in three of the studies (Al-Daghri et al., 2014, Abduelkarem and Sackville, 2008, Al-Sinani et al., 2010), and only two studies reported the total contact hours involved in their interventions (Mohamed et al., 2013, Al-Shahrani et al., 2012). Lastly, none of the studies offered a booster session following the participants' completion of the formal intervention.

#### **3.4.4 Intervention cultural adaptation**

One of the eight studies described cultural adaptation for the language used in the intervention (Abduelkarem and Sackville, 2008). This study acknowledged and addressed issues around translation. Another study reported the use of concepts and methods, linking the concepts of empowerment with the practical skills of self-management (Mohamed et al., 2013). One of the eight studies described cultural dimensions of person, content, and context; with regards to the person this study discussed, the encouragement of the population to share their knowledge, coping with content highlighted special cultural occasions, and context refers to the adaptation of self-management tools to fit the cultural environment (Al-Shahrani et al., 2012). All the remaining studies did not report the use of Bernal's eight dimensions for the development/adaptation of interventions for different cultures (Bernal et al., 1995).

#### **3.4.5 Intervention outcomes**

Table 3.4 shows the key results from the eight studies.

**Table 3.4 Outcomes reported from the DSME intervention studies**

Authors	Measures of Glycaemic Control		Measures of BP Control (mmHg)	
	HbA1c Levels MD (95% CI)	FBG Levels (mM) MD (95% CI)	Systolic BP MD (95% CI)	Diastolic BP MD (95% CI)
<b>Al-Daghri et al. (2014)</b>			0.3 (-0.09, 0.7)	-0.03 (-4.27, 3.67)
<b>Abduelkarem and Sackville. (2009)</b>				
<b>Mohammed et al. (2013)</b>	-0.55 (-0.94, -0.16)	-0.92 (-1.66, -0.18)	0.72 (-2.25, 3.69)	1.30 (-1.85, 4.44)
<b>Al-Sinani et al. (2010)</b>	Male: 0.6 (-0.21, 1.41) Female: 0.1 (-0.75, 0.95)	Male 3.8 (1.94, 5.65) Female 2.4 (0.95, 3.84)	Male -3.2 (-8.51, 2.11) Female -1.1 (-6.87, 4.67)	Male 0.9 (-1.83, 3.63) Female 2.3 (-2.01, 6.61)
<b>Al-Shahrani et al. (2012)</b>	0.91 (0.68, 1.13)	1.81 (1.49, 2.12)	8.19 (6.16, 10.22)	4.37 (3.34, 5.39)
<b>Al Hayek et al. (2013)</b>	Baseline = 8.3 After 6 Months = 7.2			
<b>Alasmary et al. (2013)</b>	1.9 (0.88, 2.91)	3.3 (1.11, 5.48)	1 (-4.41, 6.41)	-0.4 (-3.61, 2.81)
<b>Omer et al. (2015)</b>	Before: SMBG group			

	= 9.5%; Non-SMBG group = 9.3% After 30 Months: SMBG group= 7.8% Non- SMBG group = 8.9%			
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**Table 3.4 Continued**

	<b>Measures of Lipid Control (TC, LDL, HDL, TG)</b>				<b>Other measures</b>	
<b>Authors</b>	TC (mM) MD (95% CI)	LDL (mM) MD (95% CI)	HDL (mM) MD (95% CI)	TG (mM) MD (95% CI)	Weight (Kg) MD (95% CI)	BMI (kg/m2) MD (95% CI)
<b>Al-Daghri et al. (2014)</b>	0.04 (0.38, 0.42)	0.04 (0.37, 0.42)	0.23 (0.22, 0.24)	0.1 (0.08, 0.11)		0.1 (-0.01, 0.2)
<b>Abduelkar em and Sackville. (2009)</b>						
<b>Mohammed et al. (2013)</b>	0.15 (-0.08, 0.37)	0.09 (-0.05, 0.24)	0.16 (0.09, 0.22)	0.05 (-0.03, 0.12)		-1.70 (-2.81, -0.60)
<b>Al-Sinani et al. (2010)</b>	Male -0.1(-3.46, 3.26) Female 0.6 (0.07, 1.12)	Male 0.9 (-0.36, 2.16) Female 0.2 (-0.17, 0.57)	Male 0.1 (-0.11, 0.31) Female 0.2 (-0.39, 0.79)	Male 0.6 (-0.32, 1.52) Female 0.2 (-0.15, 0.55)	Male -2.7 (-7.69, 2.29) Female 4.1 (-0.57, 8.77)	Male -0.3 (-1.88, 1.28) Female 1.7 (-0.81, 3.58)
<b>Al-Shahrani et al. (2012)</b>	0.87 (0.76, 0.97)	0.56 (0.47, 0.64)	-0.04 (-0.08, 0.003)	0.47 (0.36, 0.57)	0.61(-1.18, 2.40)	
<b>Al Hayek et al. (2013)</b>						(Mean) (SD)= (31.063) (4.4)

<b>Alasmary et al. (2013)</b>	0.4 (0.05, 0.85)	0.2 (-0.10, 0.50)	0.1 (0.01, 0.18)	0.6 (-0.29, 1.49)	-1.2 (-7.45, 5.05)	
<b>Omer et al. (2015)</b>						

MD: Means Difference, BP: Blood Pressure, SBP: Systolic Blood Pressure, DBP: Diastolic Blood Pressure, SD: Standard Deviation, FBG: Fasting Blood Glucose, TC: Total Cholesterol, LDL: Low Density Lipoprotein, HDL: High Density Lipoprotein, TG: Triglycerides, BMI: Body Mass Index, HbA1c: Glycosylated Haemoglobin, SMBG: Self-Monitoring Blood Glucose, CI: Confidence Intervals.

Six of the eight studies reported the effectiveness of their intervention on glycaemic control indicators (Mohamed et al., 2013, Al-Shahrani et al., 2012, Al Asmary et al., 2013, Al Hayek et al., 2013, Al-Sinani et al., 2010, Omer et al., 2015). Of these, five reported statistically significant positive changes in HbA1c (Mohamed et al., 2013, Al-Shahrani et al., 2012, Al Asmary et al., 2013, Al Hayek et al., 2013, Omer et al., 2015), and one study reported no change in HbA1c (Al-Sinani et al., 2010). Of the five studies that reported blood pressure as an outcome, two reported statistically significant improvements in participant blood pressure (Al-Sinani et al., 2010, Mohamed et al., 2013), but the remaining three studies did not report any change in blood pressure (Al-Daghri et al., 2014, Al Asmary et al., 2013, Al-Sinani et al., 2010). Four of the eight studies reported significant improvement in physical activity in their results (Abduelkarem and Sackville, 2008, Al Hayek et al., 2013, Al-Sinani et al., 2010, Omer et al., 2015). Among the eight studies, only one study measured person knowledge and attitude using educational sessions and they observed a statistically significant improvement in this outcome in (Mohamed et al., 2013).

### **3.5 Discussion**

This review examined available evidence on the effectiveness of self-management of type 2 diabetes in GCC countries. We found that DSME interventions can have a positive impact on glycaemic control as indicated by blood HbA1c levels. However, there is a need for controlled studies in this area. The studies lacked proper theoretical models which hinders their effectiveness and reliability (Newlin et al., 2012). Most of the studies focused on education/knowledge and lifestyle and there was a lack of focus on skills and support in the intervention content, despite the fact

that both the terms 'skills' and 'support' were identified as key factors associated with improved quality of life of people with type 2 diabetes (Davies et al., 2008). The studies showed that individuals with type 2 diabetes who had received DSME felt more enabled to use their self-management skills; therefore, DSME improved their perceived self-efficacy (Bagnasco et al., 2014). A further finding, was that the DSME lacked effective cultural adaptation. This was found to be a hindrance in the effective implementation of the interventions.

Structured DSME programmes for people with newly diagnosed type 2 diabetes can lead to improved belief about illness; resulting in smoking cessation and weight loss (Davies et al., 2008). These findings were reported in a multicentre cluster randomised controlled trial by Davies et al, however, they did not observe a significant difference in the HbA1c levels during a 12-month period (Davies et al., 2008). DSME appeared to have a positive impact on HbA1c levels in some GCC countries (Saudi Arabia, Qatar and Oman) as observed in this study. This finding agreed with the recent review by Chrvala et al. (2016), conducted in the USA, who also reported that self-management education and support alongside contact time and supportive methods from health providers can positively help individuals with type 2 diabetes manage their condition and improved their HbA1c levels (Chrvala et al., 2016). Blood glucose and blood pressure both have an impact on type 2 diabetes and if poorly controlled can result in complications (Newlin et al., 2012). These findings support the role of continuously self-monitoring levels of these two elements. However, none of the studies included in this review reported long-term follow-up after the intervention, which makes it difficult to assess the long-term effectiveness of their programmes. The long-term effect is important to evaluate the

effectiveness of an intervention. For instance, a study conducted in the United States and published by Diabetes Prevention Programme Research Group (2009) has followed participants over the course of ten years, and found a reduction in diabetes incidence (Diabetes Prevention Program Research Group, 2009). Thus there is a need to establish a reasonable follow-up period for DSME interventions that allows reliable evaluation of the long-term benefits of such programmes.

Coding the content of the DSME interventions revealed that there was a lack of content addressing skills and support within the studies included in this review.

Previous studies highlight the importance of skills training and support in promoting self-management for type 2 diabetes. Having information available to individuals regarding self-assessment skills and the support that they can access is associated with a higher degree of self-care behaviours and improved outcomes (Gao et al., 2013, Bagnasco et al., 2014). However, we found that the studies included in this review lacked this information.

The success of DSME, like any other intervention, requires a clearly formulated theoretical rationale that permits assumptions about the intervention and evaluates these assumptions through its experimental design (Herek, 2010). A proper theoretical framework should consider the different circumstances of people living with diabetes, such as population demographics, socioeconomic status, lifestyle and nutritional choices, cultural values and traditions, and their access to health provision. Furthermore, the framework should also take into account the individuals physical health and general mental health and wellbeing (Riazi et al., 2016). In this review, the included studies did not provide a sufficient consideration of the

theoretical rationale of the DSME; therefore, this might compromise their effectiveness. Xu et al. (2008) suggested that the factors which have direct or indirect impact on diabetes self-management include: provider-person communication, diabetes education and its duration, as well as social support (Xu et al., 2008). All of these factors improve person knowledge leading to self-efficacy (Xu et al., 2008). In addition, the improved knowledge creates a positive belief in the intervention plan. The increased self-efficacy, person self-confidence, and improved knowledge about the disease can result in better self-management of the diabetes. Thus it is necessary that subsequent studies in this area try to develop clear theoretical frameworks encompassing these variables.

The effectiveness of self-management strategies of type 2 diabetes requires that the interventions be tailored to the specific needs of an individual in accordance with their personal characteristics (Kara et al., 2006). Interventions commonly focus on diet, physical exercise, monitoring of blood glucose, and antidiabetic medications in order to achieve an acceptable glycaemic control. The DSME intervention has to be customised to develop the required skills, attitudes, and abilities to implement self-care within the cultural and social context of each person. It is widely believed that cultural adaptation is an important aspect of DSME (Vincent et al., 2006, Kara et al., 2006). However, the studies considered in this review revealed that cultural adaptation in DSME is lacking in the GCC countries. Yet, cultural adaptation was highlighted in a study by Brown et al. (2002), which developed an intervention specifically for the Spanish-speaking population that should that it increased participants' knowledge of diabetes (Brown et al., 2002). However, cultural adaptation is more than just translation of tools and language. A full translation to

allow the DSME to be used effectively by a range of health providers and individual groups requires adaptation of language, understanding and practical application. This shows that there is need for full cultural adaptation of the DSME as an intervention for self-management of diabetes in GCC countries.

### **3.5.1 Strengths**

This review was conducted in a systematic manner, ensuring all studies related to the research aim were included. We also used a theoretical framework for coding the content of interventions in the included studies. Theoretical frameworks facilitate the comparison of interventions by characterising their content using codes (Newlin et al., 2012).

### **3.5.2 Limitations**

Despite the strengths of our review, it also has some weaknesses. This review included studies published in the English language only, which may limit its accuracy, as studies that have been reported in Arabic language were excluded. Within the same context, of the eight studies included in this review, only one was a randomised controlled trial and this limits the strength of this review and does not allow us to fully address our second research objective, to determine the most effective self-management strategies for people with type 2 diabetes in GCC countries, hence being able to highlight the extent of the need of type 2 self-management in Saudi Arabia. The studies analysed in this work are heterogeneous in their nature, accordingly it is only possible to conduct a narrative analysis. In addition, two studies which both meet the inclusion criteria had significant shortcoming: Al Daghri et al. (2014) had as its primary objective serum vitamin D

analysis in diabetes people and the report by Al Sinani et al. (2010) was based upon a three year gap between intervention and follow up measurements.

### **3.5.3 Future Research**

Considering the limitations highlighted above it is concluded that it is not possible to achieve the stated aim of determining the most effective self-management strategies for individuals with type 2 diabetes in the GCC region by reviewing the published literature. It is, therefore, important to conduct research to identify the most effective forms of intervention in GCC countries. The DSME looks promising, but its effectiveness is unknown at present. This review considered several interventions but was unable to specify the most effective one and if a type 2 diabetes self-management programme is needed in Saudi Arabia to improve the care for Saudis with type 2 diabetes. Raising awareness and knowledge of diabetes in communities seems to be an attractive area of research in the GCC countries due to the lack of studies on self-management. Minimal use of theoretical frameworks and cultural adaptation in the studies reviewed are a threat to the effectiveness of DSME interventions. Culturally, the communities in GCC countries are different from those in developed, western countries where DSME material was first developed, and thus there is a need to develop GCC countries specific interventions for type 2 diabetes self-management, which is now at epidemic levels. Thus, future work should follow guidance on cultural adaptation to make interventions more effective.

### **3.5.4 Conclusion**

In conclusion, self-management interventions appear to have a positive impact on type 2 diabetes by decreasing HbA1c levels. The reviewed studies did not always

include measures on skills and support in their interventions, which the authors feel are key to improving person self-efficacy and engagement with self-management of their condition.

# Chapter IV

## **4. Quantitative study: Correlates of type 2 diabetes and glycaemic control in adults in Saudi Arabia. A secondary data analysis of the Saudi Health Interview Survey**

### **4.1 Introduction**

Saudi Arabia carried out an extensive national survey in 2012-2013, which collected data on anthropometric, demographic and health status based from a representative sample. The report known as Saudi Health Interview Survey (SHIS) was published online at the webpage of the MOH (Ministry of Health Saudi Arabia, 2013). The author of this thesis obtained approval from the MOH to run a secondary analysis (Study 2 of this thesis) to look at the correlation between type 2 diabetes and/or poor glycaemic control and demographic, lifestyle and health parameters. The following report represents an article that has been submitted to BMC Public Health on 10 August 2019 and published on 17 April 2020 (Al Slamah et al., 2020). The author of this thesis has worked under the supervision of Professor Craig A. Melville, the director of studies on reviewing the literature, extracting the data from SHIS, running the secondary analysis, results' interpretation and writing up the article. Dr Leanne Harris has supervised the statistical work into this article. All authors advised on analysis, reviewed work drafts including the submitted final manuscript.

**Title:**

Correlates of type 2 diabetes and glycaemic control in adults in Saudi Arabia. A secondary data analysis of the Saudi Health Interview Survey

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## **Abstract**

**Background** There is evidence that type 2 diabetes self-management programmes may have a positive impact on health outcomes of adults living in GCC countries. However, none of the programmes evaluated were developed using evidence about the specific needs of adults with Type 2 diabetes living in the GCC countries. This study is part of a wider programme of research to assess the need of type 2 diabetes self-management education programmes. This study, uses a cultural adaptation framework to generate information to examine if the demographic and clinical associations with type 2 diabetes in Saudi Arabia would require cultural adaptation of type 2 diabetes self-management programmes to the Saudi context to help these programmes to meet the needs of Saudis with type 2 diabetes.

**Methods** Secondary data analysis of the Saudi Health Interview Survey (SHIS) (N=10,821) was conducted. Bivariate and multivariate logistic regression modelling assessed factors associated with type 2 diabetes and its control / self-management including sociodemographic factors (e.g. age, gender), lifestyle (e.g. diet, physical activity), and health seeking behaviours (e.g. chronic illnesses, health services).

**Results** 7% (N=808) of all participants had type 2 diabetes (59% male), however it represents 35% at or above 55 years. In multivariate analysis at older age, being overweight or obese, male, having hypertension, and reporting a reduction in health status in the 12 months prior to questionnaire completion, were significantly associated with having type 2 diabetes. Participants who reported walking for more than 10 minutes per day were less likely to report type 2 diabetes. Unexpectedly there was a significant association between type 2 diabetes and lower frequency of

fast food intake, while increased fruit and vegetable intake was associated with poor glycaemic control.

**Conclusions** Being overweight and/or hypertensive are concomitant with type 2 diabetes in Saudi Arabia. Any self-management programmes for type 2 diabetes individuals with either of these conditions should be tailored accordingly. Walking behaviours should be prioritised in Saudi self-management programmes. Prediabetes management programmes may be of special importance to the Saudi community.

**Keywords:** diabetes, type 2 diabetes, self-care, self-management.

## 4.2 Background

The prevalence of type 2 diabetes in Saudi Arabia has been increasing due to socioeconomic changes that have affected lifestyle habits including changes in diet and physical activity (Midhet et al., 2010). Approximately 13% of Saudis (Bahijri et al., 2016) are thought to have type 2 diabetes compared to the 2.8-4.4% global prevalence (Wild et al., 2004), while one in 10 of the remaining Saudi population is thought to be at risk of developing diabetes (prediabetes) (Bahijri et al., 2016). This high prevalence of type 2 diabetes is also associated with a high prevalence of cardiovascular disease (CVD) and premature mortality (Aljefree and Ahmed, 2015). 42% of mortalities in the Saudi individuals are associated with CVD. The average individual healthcare expenditure of a diabetes person is 10-fold that of the average Saudi individual who does not have type 2 diabetes (Alhowaish, 2013).

Globally, diabetes self-management programmes have led to a significant reduction of the economic burden associated with type 2 diabetes (Garrett and Bluml, 2005), and have improved the health and quality of life of diabetes individuals (Garrett and Bluml, 2005). We previously carried out a systematic review on type 2 diabetes self-management training programmes in GCC countries (Al Slamah et al., 2017), including Saudi Arabia. The review found that self-management programmes have the potential to improve the health and wellbeing of individuals with type 2 diabetes (Al Slamah et al., 2017). Five out of the eight studies included were from Saudi Arabia and used different approaches ranging from education, regular attendance at specialised clinics for check-ups, dietary advice, physical exercise or a combination of these. Half (four) of these studies reported a 0.5-2% drop in HbA1c following self-management programmes. However, these studies did not assess key

desired outcome elements of self-management programmes such as the ability to transmit and acquire skills. They also lacked a proper pilot study for any of the available structured self-management education programmes elsewhere. For example, in the UK, the Diabetes Education Self-management for Ongoing and Newly Diagnosed (DESMOND) programmes proving a success (Khunti et al., 2012) due to its focus on equipping trainers and educators to provide high quality self-management programmes in a manner suited to their audience (Carey et al., 2014, Mandalia et al., 2014). DESMOND recently introduced the 'Let's prevent diabetes' program, which encourages self-management programmes for those who are at risk of developing diabetes with an aim of preventing or at least delaying the progression of the condition (DESMOND, 2018). Other self-management programmes such as Diabetes Self-Management Education (DSME) in the USA, have addressed cultural adaptation of the programme within different ethnicities at the same geographical locations and managed to increase compliance through including families as a whole in the programme, liaising with religious leaders and providing familiar analogues to the positive and negative effects of some behaviours or habits (Yeary et al., 2017). Therefore, for any of these programmes to be more successful in a new community such as within Saudi Arabia, there is a need for specific cultural adaptation of programme content (Kara et al., 2006, Fisher et al., 2009). DESMOND has the potential to be transferred to other countries such as Saudi Arabia; however, careful cultural adaptation of the programmes necessary to shape the structure of the programme with a clearer focus on specific self-management skills that can impact on health improvement for local individuals (Jack et al., 2004).

Cultural adaptation of self-management programmes and adjusting them to the available healthcare resources, healthcare needs, sociodemographic characteristics (e.g. age, gender, education, occupation conditions) of populations and the capacities of both potential educators and individuals are crucial to the success of these programmes (Fisher et al., 2009). Identifying the unmet health needs of the population would allow for more appropriate targeting of healthcare resources (Health care evaluation, 2016, Barrera Jr and Castro, 2006, Addis, 2002) and the development of a targeted self-management programme. Therefore, the overall aim of our research is to look DSME/DESMOND model can be of a benefit for Saudi Arabia, and whether any of these programmes needs to be culturally relevant or adapted to ensure more benefit. The theoretical framework provided by Kumpfer's cultural adaptation model, which gives a progressive sequence of nine stages was used here for the research programme (Kumpfer et al., 2008). Stage one involved a systematic review of the available literature on type 2 diabetes self-management training programmes in GCC countries as discussed above (Al Slamah et al., 2017). The current study is the second stage in our overall aim to develop a culturally relevant DSME model for Saudi Arabia by determining the needs of the population based on demographic and clinical associations with type 2 diabetes in Saudi Arabia.. Our aim is to inform the development of a culturally relevant type 2 diabetes self-management programme using population level data including sociodemographic factors, lifestyle (e.g. diet, physical activity), and health seeking behaviours (e.g. chronic illnesses, health services. The aims of this study were to identify:

- 1- How sociodemographic characteristics, lifestyle, and health-seeking behaviours vary between those with type 2 diabetes compared to the rest of

the population sample. And which, if any, of the factors outlined are associated with type 2 diabetes.

2- How sociodemographic characteristics, lifestyle, and health-seeking behaviours vary between those with well-controlled and those with poorly-controlled type 2 diabetes. And which, if any, of the factors outlined are associated with poorly controlled diabetes.

### **4.3 Methods**

#### **4.3.1 SHIS Study design**

The Saudi Health Interview Survey (SHIS) (Ministry of Health Saudi Arabia, 2013), conducted in 2013, covering all 13 regions in the Kingdom of Saudi Arabia (Al Riyadh; AlQassim; Makkah Al Moukarrama; Tabuk; Hail; Al-Jouf; Al-Baha; Eastern Region; Northern Borders; Madinah; Jazan, and; Aseer; Najran) on adults aged 15 years or older. A multistage stratified probability sample was developed to recruit the study participants. Stratification was based on the 13 regions of the Kingdom. A total of 12,000 households were randomly selected and contacted from the 13 administrative regions. A total of 10,827 participants completed the survey and were invited to local health clinics. All survey weights were post-stratified to the general Saudi population and to the composition of the selected adults. Physical measures were taken including height (Van Tulder et al.), weight (kg), waist circumference (Van Tulder et al.), blood pressure(mmHg), heart rate (pulses/min) and respiratory rate (breathes/min). A questionnaire and medical record review were performed for each participant. The questionnaire provided a self-report of sociodemographic characteristics, lifestyle including nutrition, habits such as tobacco use, physical activity, and health-seeking behaviours (e.g. routine regular checks versus

admissions or emergency visits). Medical records and questionnaires were used to record chronic diseases including type 2 diabetes. Participants were referred to local clinics in hospitals and primary care health centres for blood samples to be investigated for lipid profile, Vitamin D and HbA1c.

#### **4.3.2 Secondary data analysis**

Variables collected for SHIS, of clinical relevance to type 2 diabetes and diabetes control, were carefully selected for secondary analysis by a consensus process involving all members of the research team. These variables included sociodemographic characteristics, lifestyle, health condition and chronic illness, and health-seeking behaviours relevant to the research question and are detailed in Table 4.1 and Appendix 4.

Variables including “visiting physician or health professional to manage diabetes”, “self-assessed blood sugar at home”, “distance to nearest health facility,” and “time needed to reach nearest health facility”, were excluded due to high frequency of missing data, rendering them unusable for analysis (>75% of missed data). While all variables included had a maximum of 10% missing data. The data was cleaned through visually inspecting histograms for spurious data points, and outliers. Categorical responses, were classified to binary or two responses only (Appendix 4), apart from smoking where a third response (never smoked) was considered clinically important (Marston et al., 2014). Continuous data, such as age, frequency of fruit or meat servings, were split according to the median value (MacCallum et al., 2002), others such as HbA1c, physical activity through leisure time sports activity and occupation activity were divided according to the following definitions: HbA1c

equal to or more than seven (poor control) or less (good control) (Khattab et al., 2010, Edelman and Polonsky, 2017) and 150 minutes or more /week for good physical activity of sport or work (World Health Organization, 2019). One of the known disadvantages of categorising the data in this manner is the potential loss of significance power of some factors (Owen and Froman, 2005). However, where possible categorisation of variables was based on accepted clinical benchmarks as outlined above.

#### **4.3.3 Data analysis**

SPSS 24 IBM statistical package (SPSS IBM, New York, NY, USA) was used to conduct all analysis.

Descriptive statistics were used to compare the frequency distribution of sociodemographic characteristics, lifestyle, and health-seeking behaviours between participants with and without type 2 diabetes.

Separate analyses compared participants with well controlled type 2 diabetes, to poorly controlled groups using HbA1c. As the above definition, those with HbA1c <7 were considered as well controlled and those with HbA1c  $\geq$ 7 as poorly controlled (Khattab et al., 2010, Edelman and Polonsky, 2017).

For both research questions, differences between the two groups were examined for statistical significance using binary logistic regressions in a six-step model-building approach using a series of bivariate and multivariate analyses (Hosmer Jr et al., 2013).

### Step 1:

A series of bivariate analyses between each predictor variable and the outcome variable for each model were conducted. This purposeful selection of variables was to identify variables to be taken forward to the multivariate analysis. A test significance of p-value of  $<0.25$  was used for this initial stage to screen variables for their potential relevance to type 2 diabetes or glycaemic control (dependent variables). Only variables that met the criteria were taken forward to the multivariate analysis (Hosmer Jr et al., 2013).

### Step 2:

A multivariate binary regression model (larger model) was fit to the variables, which met the criteria in stage one ( $p < 0.25$ ). A backward stepwise least squares logistic regression model was conducted to sequentially remove variables that were non-significant, developing a smaller model which contained only statistically significant variables (Wald statistic  $p < 0.05$ ). The fit of this smaller model was compared to the larger multivariate regression model (calculated by the difference in log-likelihoods and interpreted using the chi-squared distribution) (Field, 2013).

### Step 3:

The coefficient values (beta) for each variable in the smaller model were compared to the beta values in the larger model. If a change in beta of  $\pm 20\%$  between the two models was observed, this indicated that variables excluded were important to the model, in terms of adjusting an effect. These were then entered back into the smaller multivariate model.

#### Step 4:

Variables that were excluded at stage one were entered (forced entry) one at a time into the smaller multivariate model (identified at the end of step three) to test their contribution to the model (assessed using the Wald statistic  $p < 0.05$ ). Although they were not independent predictors of type 2 diabetes or glycaemic control at stage one, re-entering these variables into the smaller model tested whether they make a significant contribution to the model in the presence of other contributing variables.

#### Step 5:

The model at the end of step four is the preliminary main effects model. Interactions between the variables in the preliminary main effects model were assessed for significance, one at a time using log-likelihoods to test their significance ( $p < 0.05$ ). Interactions that were conceptually plausible and statistically significant were entered (forced entry) into the smaller model. The significance of all included interactions was then assessed using the Wald statistic, with any non-significant interactions ( $p > 0.05$ ) removed from the model. The variables remaining in the model represented the final main effects model.

#### Step 6:

The overall fit of the final main effects model was assessed by the Hosmer-Lemeshow goodness of fit statistic (Hosmer and Lemeshow, 1980). A large p-value

( $p > 0.10$ ) indicate a good fit of the model relevant to the data (Hosmer and Lemeshow, 1980). The final model was assessed to ensure it met the assumptions of logistic regression. Residuals were checked using standardised residuals (<5% outside  $\pm 1.96$ ) and Cook's assumption (<1) (Field, 2013). The assumption of multicollinearity (tolerance <0.10 and VIF>10) was also assessed (Field, 2013).

## **4.4 Results**

### **4.4.1 Participant characteristics**

#### **4.4.1.1 Type 2 diabetes**

Of the 10,821 participants completing the SHIS survey, 808 participants (7.5%) were identified as having type 2 diabetes [41% female ( $n=331$ ), mean age =  $38.38 \pm 16.1$  years]. Participants with type 2 diabetes were more likely to be overweight or have obesity (86.2% of type 2 diabetes sample had a BMI  $\geq 25$  kg/m<sup>2</sup> compared to 65.2% of participants who did not have type 2 diabetes). Based on self-report, participants with type 2 diabetes were also more likely to have hypertension (95.8%) compared to participants without diabetes (67.5%). All characteristics are summarised in Table 4.1.

#### **4.4.2 Predictors of type 2 diabetes**

##### **Bivariate analysis (Step 1)**

The bivariate analysis (Table 4.1) illustrates that older married males, who are overweight, consume higher meat or fast food, while less active at work or practice less sport, viewing TV or setting longer periods and suffer from hypertension,

chronic disease or reported themselves to have poor health or felt worse health comparing with 12 months earlier and / or not frequently visiting health services were more likely to have type 2 diabetes.

**Table 4.1 Sociodemographic, lifestyle and health-seeking characteristics of participants with and without type 2 diabetes.**

	Type 2 diabetes N=808		No type 2 diabetes N=10013		Odds Ratio (95% CI)	p-value
	Total n	n (%)	Total n	n (%)		
<b><i>Sociodemographic characteristics</i></b>						
<b>Gender</b>	808		10,013			
Male		477 (59)		4819 (48.1)	REF	
Female		331 (41)		5194 (51.9)	0.64 (0.55 , 0.74)	< 0.001
Missing	0		0			
<b>Age</b>	802		9933			
15-54		352 (43.9)		8646 (87)	REF	

<b>≥ 55</b>		450 (56.1)		1287 (13)	8.58 (7.38 , 9.99)	< 0.001
<b>Missing N%</b>	6 (%)		80 (%)			
<b>Marital status</b>	806		9978			
<b>Married</b>		619 (76.8)		4613 (64.3)	REF	
<b>Not married</b>		187 (23.2)		3565 (35.7)	0.54 (0.45 , 0.64)	< 0.001
<b>Missing</b>	2		35			
<b>Education level</b>	806		9991			
<b>Primary school or less</b>		477 (59.2)		2847 (28.5)	REF	
<b>Elementary or high school College</b>		329 (40.8)		7177 (71.5)	0.27 (0.23 , 0.31)	< 0.001

<b>degree or higher education completed</b>						
<b>Missing</b>	2		22			
<b>BMI</b>	797		9915			
<b>Overweight or obesity</b>		687 (86.2)		6466 (65.2)	REF	
<b>Normal weight</b>		110 (13.8)		3449 (34.8)	0.30 (0.24 , 0.36)	< 0.001
<b>Missing</b>	11		98			
<b><i>Lifestyle characteristics</i></b>						
<b>Smoking status</b>	808		10013			
<b>Previous smoker</b>		59 (7.3)		404 (4)	REF	
<b>Current smoker</b>		114 (14.1)		1252 (12.5)	0.62 (0.44 , 0.87)	< 0.001
<b>Never smoked</b>		635 (78.6)		8357 (83.5)	0.52 (0.39 , 0.69)	< 0.001
<b>Missing</b>	0		0			

<b>Dietary fat intake</b>	793		9828			
<b>Vegetable or olive oils</b>		731 (92.2)		8993 (91.5)	REF	
<b>Animal fat or margarine or none in particular</b>		62 (7.8)		835 (8.5)	0.91 (0.69 , 1.19)	0.509
<b>Missing</b>	15		185			
<b>Dietary meat intake</b>	744		9048			
<b>0-7</b>		559 (75.1)		5859 (64.8)	REF	
<b>8+</b>		185 (24.9)		3189 (35.2)	0.60 (0.51 , 0.72)	< 0.001
<b>Missing</b>	64		965			
<b>Dietary fruit and vegetable intake</b>	726		8885			
<b>0-2</b>		377 (51.9)		4628 (52.1)	REF	

<b>3+</b>		349 (48.1)		4257 (47.9)	1.00 (0.86 , 1.17)	0.938
<b>Missing</b>	82		1128			
<b>Dietary fast food intake</b>	698		8661			
<b>0-1</b>		603 (86.4)		5557 (64.2)	REF	
<b>2+</b>		95 (13.6)		3104 (35.8)	0.28 (0.22 , 0.35)	< 0.001
<b>Missing</b>	110		1352			
<b>Work physical activity</b>	808		10013			
<b>No</b>		800 (99)		9791 (97.8)	REF	
<b>Yes</b>		8 (1)		222 (2.2)	0.44 (0.21 , 0.89)	0.021
<b>Missing</b>	0		0			
<b>Sport physical activity</b>	808		10013			
<b>No</b>		771 (95.4)		8878 (88.7)	REF	
<b>Yes</b>		37 (4.6)		1135 (11.3)	0.37 (0.26 , 0.52)	< 0.01

<b>Missing</b>	0		0			
<b>Walking behaviour</b>	802		9904			
<b>No</b>		394 (49.1)		3991 (40.3)	REF	
<b>Yes</b>		408 (50.9)		5913 (59.7)	0.69 (0.60 , 0.80)	< 0.01
<b>Missing</b>	4		109			
<b>TV viewing time</b>	709		8644			
<b>0-3 Hours</b>		459 (64.7)		5090 (58.9)	REF	
<b>4+ Hours</b>		250 (35.3)		3554 (41.1)	0.78 (0.66 , 0.91)	0.002
<b>Missing</b>	9		1369			
<b>Sitting time</b>	732		8674			
<b>0-4 Hours</b>		345 (47.7)		4984 (57.5)	REF	
<b>5+ Hours</b>		387 (52.3)		3690 (42.5)	1.48 (1.27 , 1.72)	< 0.001
<b>Missing</b>	76		1339			

<b>Health seeking behaviours</b>						
<b>Hypertension</b>	808		9945			
<b>No</b>		34 (4.2)		2610 (26.2)	REF	
<b>Yes</b>		774 (95.8)		7335 (73.8)	8.10 (5.72 , 11.45)	< 0.001
<b>Missing</b>	0		68			
<b>Chronic disease diagnosis</b>	755		9673			
<b>No</b>		560 (74.2)		8923 (92.2)	REF	
<b>Yes</b>		195 (25.8)		750 (7.8)	4.14 (3.46 , 4.95)	< 0.001
<b>Missing</b>	53		340			
<b>Self-reported health status</b>	806		9980			
<b>Very good or good</b>		627 (77.8)		9278 (93)	REF	

<b>Fair or poor</b>		179 (22.2)		702 (7)	3.77 (3.14 , 4.53)	< 0.001
<b>Missing</b>	2		33			
<b>Self-reported health status compared with 12 months</b>	794		9896			
<b>Better or same</b>		563 (70.9)		8482 (85.7)	REF	
<b>Worse</b>		231 (29.1)		1414 (14.3)	2.46 (2.09 , 2.89)	< 0.001
<b>Missing</b>	14		117			
<b>Visited health service</b>	519		6781			
<b>Illness or injury</b>		66 (12.7)		1303 (19.2)	REF	
<b>Other services</b>		453 (87.3)		5478 (80.8)	1.63 (1.25 , 2.12)	< 0.001
<b>Missing</b>	289		3232			

REF, reference category for statistical analysis; CI, confidence interval; BMI, body mass index.

### **Multivariate analysis and final model (Steps 2-6)**

Appendix 5 provides beta percentages between the smallest and largest interactions. All interaction results are provided in Appendix 6. The final multivariate model (Table 4.2) found that participants of older age ( $\geq 55$  years), with hypertension, chronic disease, and/or poorer self-reported health status compared with 12 months ago were significantly more likely to have type 2 diabetes. Females, and individuals with normal weight, those who ate more fast food ( $\geq 2$  times per week) and walked more than ten minutes per day, were less likely to have type 2 diabetes.

**Table 4.2 Final multivariate logistic regression model for the association between sociodemographic, lifestyle and health-seeking behaviours and type 2 diabetes**

<b>Variables</b>	<b>B</b>	<b>SE</b>	<b>Odds Ratio (95% CI)</b>	<b>p-value</b>
<b>Gender</b>				
<b>Male</b>	REF	REF	REF	
<b>Female</b>	-0.64	0.09	0.52 (0.43 , 0.63)	< 0.001
<b>Age</b>				
<b>15-54</b>	REF	REF	REF	
<b>≥55</b>	1.62	0.09	5.09 (4.19 , 6.18)	< 0.001
<b>BMI</b>				
<b>Overweight or obesity</b>	REF	REF	REF	
<b>Normal weight</b>	-0.99	0.12	0.37 (0.29 , 0.47)	< 0.001
<b>Hypertension</b>				

<b>No</b>	REF	REF	REF	
<b>Yes</b>	1.52	0.20	4.58 (3.07 , 6.82)	< 0.001
<b>Chronic disease diagnosis</b>				
<b>No</b>	REF	REF	REF	
<b>Yes</b>	0.50	0.11	1.65 (1.32 , 2.07)	< 0.001
<b>Self-reported health status compared with 12 months</b>				
<b>Better or same</b>	REF	REF	REF	
<b>Worse</b>	0.47	0.10	1.61(1.31 , 1.97)	< 0.001
<b>Dietary fast food intake</b>				
<b>0-1 per week</b>	REF	REF	REF	
<b>2+ per week</b>	-0.69	0.12	0.49 (0.39 , 0.63)	< 0.001
<b>Walking behaviour more than 10 mints per day</b>				
<b>No</b>	REF	REF	REF	

<b>Yes</b>	-0.32	0.09	0.72 (0.60 , 0.86)	< 0.001
<b>Interaction</b>				
<b>Age (15-54)* Chronic disease diagnosis(No)</b>	REF	REF	REF	
<b>Age(≥ 55) * Chronic disease diagnosis (Yes)</b>	-0.89	0.22	0.40 (0.26 , 0.63)	< 0.001
<b>Age(15-54)* Self-reported health status compared with 12 months (Better or same)</b>	REF	REF	REF	
<b>Age (≥ 55) * Self-reported health status compared with 12 months (Worse)</b>	-0.62	0.20	0.53 (0.36 , 0.79)	0.002

REF, reference category; SE, standard error; CI, confidence interval; BMI, body mass index. B, beta coefficient.

Significant interactions were established between age ( $\geq 55$  years) and participants with chronic disease and/or self-reported worse health status after 12 months. Hosmer and Lemeshow test for goodness of fit for the final model was 0.450, indicating good fit ( $p > 0.10$ ). Collinearity diagnostic and the Tolerance test also confirmed a good fit of the model.

#### **4.4.1.2 Diabetes control**

Only 391 individuals with type 2 diabetes (48.4%) had a measured HbA1c. There were no statistically significant differences in the sociodemographic factors, lifestyle, and health seeking behaviours between the 164 participants (41%) defined as having poor glycaemic control and the 227 participants with good glycaemic control. The majority of this sample (62%) was only educated up to primary level or less. However, the percentage of those who were educated to elementary up to higher education was higher within the good control group (41% versus ~35%). However, 57.6% of the poor control group ate more than three portions of fruits and vegetables, which was higher than 45.1% in the other group. All characteristics are provided in Table 4.3.

#### **4.4.3 Predictors of poorly controlled diabetes**

##### **Bivariate analyses**

The key predictors identified from the bivariate analysis (Table 4.3) for the association with poor glycaemic control ( $p < 0.25$ ) among type 2 diabetes, were marital status, educational level, dietary fat intake, fruit and vegetable intake, fast food intake, occupation and sport physical activity, walking behaviour and sitting periods.

**Table 4.3 Sociodemographic, lifestyle and health-seeking characteristics of participants with poor and good glycaemic control**

	Poor glycaemic control N = 164		Good glycaemic control N = 227		Odds Ratio (95% CI)	p-value
	Total n	n (%)	Total n	n (%)		
<b><i>Sociodemographic characteristics</i></b>						
<b>Gender</b>	164		227			
<b>Male</b>		98 (59.8)		133 (58.6)	REF	
<b>Female</b>		66 (40.2)		94 (41.4)	0.95 (0.63 , 1.43)	0.817
<b>Missing</b>	0		0			
<b>Age</b>	164		225			

<b>15-54</b>		73 (44.5)		94 (41.8)	REF	
<b>≥55</b>		91 (55.5)		131 (58.2)	0.89 (0.59 , 1.34)	0.591
<b>Missing</b>	0		2(%)			
<b>Marital status</b>	164		227			
<b>Married</b>		130 (79.3)		168 (74)	REF	
<b>Not married</b>		34 (20.7)		59 (26)	0.74 (0.46 , 1.20)	0.228
<b>Missing</b>	0		0			
<b>Education level</b>	164		227			
<b>Primary school or less</b>		107 (65.2)		134 (59)	REF	

<b>Elementary or high school</b>		57 (34.8)		93 (41)	0.76 (0.50 , 1.16)	0.212
<b>College degree or higher education completed</b>						
<b>Missing</b>	0		0			
<b>BMI</b>	162		226			
<b>Overweight or obesity</b>		144 (88.9)		196 (86.7)	REF	
<b>Normal weight</b>		18 (11.1)		30 (13.3)	0.81 (0.43 , 1.52)	0.523
<b>Missing</b>	2		1			
<b><i>Lifestyle characteristics</i></b>						
<b>Smoking status</b>	164		227			

<b>Previous smoker</b>		17 (10.4)		18 (7.9)	REF	
<b>Current smoker</b>		17 (10.4)		26 (11.5)	1.44 (0.58 , 3.55)	0.424
<b>Never smoke</b>		130 (79.3)		183 (80.6)	1.32 (0.66 , 2.67)	0.425
<b>Missing</b>	0		0			
<b>Dietary fat intake</b>	161		224			
<b>Vegetable or olive oils</b>		138 (85.7)		204 (91.1)	REF	
<b>Animal fat or margarine or none in particular</b>		23 (14.3)		20 (8.9)	1.55 (0.81 , 2.97)	0.182
<b>Missing</b>	3		3			
<b>Dietary meat intake per week</b>	156		206			

<b>0-7</b>		114 (73.1)		156 (75.7)	REF	
<b>8+</b>		42 (26.9)		50 (24.3)	1.14 (0.71 , 1.85)	0.566
<b>Missing</b>	8		21			
<b>Dietary fruits and vegetables intake per week</b>	151		206			
<b>0-2</b>		64 (42.4)		113 (54.9)	REF	
<b>3+</b>		87 (57.6)		93 (45.1)	1.65 (1.08 , 2.52)	0.020
<b>Missing</b>	13		21			
<b>Dietary fast food intake per week</b>	146		198			

<b>0-1</b>		122 (83.6)		181 (91.4)	REF	
<b>2+</b>		24 (16.4)		17 (8.6)	2.09 (1.08 , 4.06)	0.026
<b>Missing</b>	18		29			
<b>Work physical activity</b>	164		227			
<b>No</b>		161 (98.2)		226 (99.6)	REF	
<b>Yes</b>		3 (1.8)		1 (0.4)	4.21 (0.43 , 40.85)	0.178
<b>Missing</b>	0		0			
<b>Sport physical activity</b>	164		222			
<b>No</b>		155 (94.5)		197 (97.8)	REF	REF

<b>Yes</b>		9 (5.5)		5 (2.2)	2.57 (0.84 , 7.84)	0.084
<b>Missing</b>	0		5			
<b>Walking behaviour more than 10 mints per day</b>	164		225			
<b>No</b>		66 (40.2)		114 (50.7)	REF	
<b>Yes</b>		98 (59.8)		111 (49.3)	1.52 (1.01 , 2.29)	0.042
<b>Missing</b>	0		2			
<b>TV viewing time / per day</b>	145		206			
<b>0-3 Hours</b>		98 (67.6)		140 (68)	REF	

<b>4+ Hours</b>		47 (32.4)		66 (32)	1.01 (0.64 , 1.60)	0.941
<b>Missing</b>	19		21			
<b>Sitting time / per day</b>	146		202			
<b>0-4 Hours</b>		61 (41.8)		100 (49.5)	REF	
<b>5+ Hours</b>		85 (58.2)		102 (50.5)	1.36 (0.88 , 2.09)	0.154
<b>Missing</b>	18		25			
<b>Health seeking behaviours</b>						
<b>Hypertension</b>	164		227			
<b>No</b>		7 (4.3)		13 (5.7)	REF	

<b>Yes</b>		157 (95.7)		214 (94.3)	1.36 (0.53-3.49)	0.518
<b>Missing</b>	0		0			
<b>Chronic disease diagnosis</b>	147		214			
<b>No</b>		147 (76.2)		159 (74.3)	REF	
<b>Yes</b>		35 (23.8)		55 (25.7)	0.90 (0.55 , 1.47)	0.683
<b>Missing</b>	17		13			
<b>Self-reported health status</b>	164		226			
<b>Very good or good</b>		126 (76.8)		170 (75.2)	REF	

<b>Fair or poor</b>		38 (23.2)		56 (24.8)	0.91 (0.57 , 1.46)	0.714
<b>Missing</b>	0		1			
<b>Self-reported health status compared with 12 months</b>	162		223			
<b>Better or same</b>		111 (68.5)		152 (68.2)	REF	
<b>Worse</b>		51 (31.5)		71 (31.8)	0.98 (0.63 , 1.52)	0.941
<b>Missing</b>	2		4			
<b>Visited health services</b>	101		147			

<b>Illness or injury</b>		13 (12.9)		15 (10.2)	REF	
<b>Other services</b>		88 (87.1)		132 (89.8)	0.76 (0.34 , 1.69)	0.514
<b>Missing</b>	63		80			

REF, reference category for statistical analysis; CI, confidence interval; BMI, body mass index.

## **Multivariate analysis**

The final multivariate model found that a dietary intake of three or more portions of fruit and vegetables was the only significant predictor in the final model associated with poorly controlled diabetes. All other predictor variables excluded earlier ( $p > 0.25$ ) were included back in this model but none of them were retained. Intuitively, individuals who consume higher portions of fruit and vegetable should be expected to have better glycaemic control; however the results here show the opposite. One possibility to explain this is that the higher fruit intake was associated with other variables that can be more linked to poor glycaemic control (e.g. To investigate this we looked at the correlations between higher fruit and vegetable intake and overweight or obesity, animal fat or fast food consumption, no work, sport or walking physical activity and long TV viewing or sitting time). However, none of these correlations were found to be significant. Beta coefficient percentage change between the largest and smallest model variable from the model was less than 10% (provided in Appendix 7), which indicates lack of influence on other variables.

## **4.5 Discussion**

### **4.5.1 Principal findings**

Our study found that the prevalence of type 2 diabetes is higher among older individuals, particularly in those over 54 years and among males compared to females. Furthermore, being overweight, and having hypertension and chronic diseases such as asthma and heart failure are prevalent among individuals with type 2 diabetes in Saudi Arabia. People with type 2 diabetes are more likely to report their ill-health or their health being worse compared to one year ago. On the other

hand, the older individuals are more likely to have chronic diseases. When it came to physical activity, it was less likely for people, who walked in particular to have type 2 diabetes, but the same correlation could not be established with other indicators of better physical activities. The risk of having type 2 diabetes or poor glycaemic control was associated with low fast food and high fruit consumption, the opposite finding observed in studies elsewhere (Epuru et al., 2014, El Bcheraoui et al., 2014).

#### **4.5.2 Predictors of type 2 diabetes**

In this study, 35% of those aged 55 years and older had type 2 diabetes and 59% of those with type 2 diabetes were male. These findings agree with a study published in 2010 by the International Diabetes Federation (IDF) (American Diabetes Association, 2015) and a further study by Al-Rubeaan and colleagues (2014) suggesting that type 2 diabetes in Saudi Arabia (among other Middle Eastern countries) was expected to double by 2030 in association with the expected higher mean age. On the other hand, a study published in 2004, which included more than 17 thousand participants from Saudi Arabia above the age of 30 concluded that nearly 24% of Saudi's had either type 1 or type 2 diabetes, with higher prevalence among males (Wright et al., 1998). Some of the discrepancies between these studies and the findings here can be attributed to inclusion of type 1 diabetes in the "no type 2 diabetes group" in this study, while the distinction of type 1 and type 2 diabetes is not always made clear in other studies. However, the findings of this study on the higher prevalence of type 2 diabetes among the older age groups is consistent with global surveys. In a survey that included 111 countries, type 2 diabetes was concentrated among males between the age of 65 and 69, and 10

years later among females (Ogurtsova et al., 2017). More or less, all these studies show the higher prevalence of type 2 diabetes in Saudi Arabia, and its concentration amongst older populations, however the discrepancies can be attributed to different sampling methods used in relation to sample size, timing, geography or source (whether self-reporting surveys or health data archives).

Being overweight or obese in particular, is thought to be the greatest risk factor for type 2 diabetes in Saudi Arabia (Fatani et al., 1987, Elhadd et al., 2007). The final model of associations with type 2 diabetes supports this finding. Being overweight and obesity are known to be associated with other factors such as unhealthy diet and sedentary lifestyle. Our results found these lifestyle factors were significant at the bivariate level, but they were not retained in the final model. However, the final model showed that participants who reported walking for more than 10 minutes per day were less likely to report type 2 diabetes. This finding agrees with several reports that link walking behaviour with enhanced insulin sensitivity and glucose metabolism (Borghouts and Keizer, 2000). In a previous pilot study in Saudi Arabia on type 2 diabetes self-management that depended only on encouraging participants to walk more frequently, the participants had a significant improvement in their glycaemic control (Omer et al., 2015). This suggests that the high percentage of people being overweight or obese has an important link to the high incidence of type 2 diabetes in adults living in Saudi Arabia, but also suggests walking to be more suited to the community there to counter both type 2 diabetes and weight gain, rather than other measures such as diet control or vigorous physical activities.

Frequent reports suggest that between 50% to 80% in participants who have

diabetes (Cheung, 2010, Landsberg and Molitch, 2004, White et al., 2010). One of the significant associations found in the final model for type 2 diabetes was hypertension; participants with hypertension were three times more likely to report type 2 diabetes. This finding is in keeping with other communities outside Saudi Arabia (Cheung, 2010, Landsberg and Molitch, 2004) and suggest that a focus should be given in any future type 2 diabetes self-management programme in Saudi Arabia, on the high risk of developing hypertension and how to minimise such risk. Guidelines for diabetes care recommend at least an annual check for blood pressure for those diagnosed with type 2 diabetes (White et al., 2010).

In addition to hypertension, the final model factors associated with having type 2 diabetes include chronic disease. The chronic disease category in this analysis included anyone with asthma, different chronic heart disease conditions, chronic renal disease, cerebral infarction or high cholesterol blood level. Diabetes is widely associated with neuropathy, chronic renal disease, adult blindness, fatty liver and chronic cardiovascular disease (Control and Prevention, 2008). This association adds to the complicated nature of diabetes and is at the core of diabetes self-management (DAVIES et al., 2005). This bidirectional relationship means that people with type 2 diabetes should be educated on making health choices that can lower the risk of other chronic diseases and vice versa.

The type 2 diabetes final model showed that participants who report a reduction in their health status compared to 12 months ago were more likely to also report having type 2 diabetes. This can be partially attributed to the above mentioned association of diabetes with chronic illness (Park et al., 2013). But more importantly may reflect

poor self-management of type 2 diabetes in Saudi Arabia.

A significant association between type 2 diabetes and lower frequency of fast food intake was found, which was unexpected. Evidence from previous studies suggests a higher risk of type 2 diabetes among those who consume fast food (Pereira et al., 2005). Potential explanations for this contradictory finding could be that this behaviour of less fast food intake was recently acquired after the people had become aware of their diabetes (Murphy and Kinmount, 1995).

This study shows the high prevalence of being overweight among individuals with type 2 diabetes, but also the high prevalence of being overweight in the overall population, which correlates with the high prevalence of prediabetes among Saudi nationals, reported elsewhere (Fatani et al., 1987, El-Hazmi et al., 1995). Although not conclusive in this study, healthy nutritional behaviours may not be acquired early enough and perhaps only after the diagnosis of diabetes. This suggests that programmes such as “let’s prevent diabetes” could be more suited for the local community and self-management of glucose level for individuals at risk of type 2 diabetes can be as important as self-management of the condition.

#### **4.5.3 Predictors of poor glycaemic control**

Increased fruit and vegetable intake was the only variable to be significantly associated with poor glycaemic control following multivariate analysis. However, the finding that higher fruit and vegetable intake is associated with poorer glycaemic control is unexpected and contradicts previous research illustrating that a healthy diet is beneficial to health and reduces the risk of type 2 diabetes (Muraki et al.,

2013). Potential explanations for this finding could be relevant to the higher frequency of diabetes symptoms among those with poor glycaemic control and that, similar to the justification provided above for lower fast food intake, higher fruit and vegetable intake behaviour may have been recently acquired but not necessary an overall healthier diet behaviour (Murphy and Kinmount, 1995). Nevertheless, fruits with high glycaemic index can be associated with poor glycaemic control (Passos et al., 2015). SHIS did not question the types of fruits consumed by each participant, however it has been reported that the average individual consumption of dates in Saudi Arabia is around 122 gram per day (Al-Mssallem, 2018), which is equivalent to additional 338 kilocalories per day (Nutritionixwebsite., 2020). A significant association between glycaemic control and BMI and/or physical exercise was expected; however such relations were not evident in this study. However, only 41% of the participants with type 2 diabetes gave a blood sample. It may be fair to assume that those who attended the clinics are particularly interested in monitoring their health parameters compared to those who did not attend for the blood sample collection, which may have carried out an intrinsic bias in the data.

#### **4.5.4 Strengths and limitations**

The strength of this study is that it was based on the SHIS which has included a large sample size from each of the 13 regions in Saudi Arabia. Obtaining the full data of the SHIS has supported running in depth analysis to address the aims of this study. However, the original SHIS survey was not designed as a needs-assessment study for diabetes self-management. The questions in the SHIS did not explore further aspects associated with a needs assessment such as accessibility to health care, availability of physical exercise facilities, and people awareness of type 2

diabetes, its complications and management. The data was cross sectional and so causality cannot be assessed, and only half of the participants diagnosed with type 2 diabetes had blood samples taken at the clinic. In addition, some of the data was missing. Also, the survey was mainly based on self-reported assessments, which are known to have bias, when reporting undesirable lifestyle stigmas including unhealthy nutritional habits or lack of physical activity (Hebert et al., 1995).

#### **4.5.5 Implications for future research**

In accordance with Kumpfer's cultural adaptation framework (Kumpfer et al., 2008) the next stage of the programme of research, based on these findings, is to investigate comprehensive interventions in self-management programmes for type 2 diabetes in Saudi Arabia. Focus groups will be conducted to further explore the needs of older adults, weight management and managing comorbidities, such as hypertension and person awareness of diabetes and its complications. Other sociodemographic and clinical factors not included in this study should be the subject of future studies, such as family history, income, disabilities, vitamin deficiencies, stress and depression.

#### **4.5.6 Conclusion**

Our findings reflect specific priorities, including age, BMI and blood pressure, for the Saudi community that merit further investigation to fully understand the needs of the Saudi type 2 diabetes individuals and that should be taken into account in the development of a self-management programme for people with type 2 diabetes in Saudi Arabia. A focus should be made on the best approach to help older individuals make changes to their persistent habits and provide them with help to make

sustainable lifestyle behaviour changes that are tailored to their age, but also to their likely comorbid chronic health conditions, especially hypertension (Yamashita and Kart, 2011). Encouraging Saudis on walking, in particular, could be developed into a long-lasting and effective habit across a person's lifetime for protection against type 2 diabetes. It is likely that Saudis would commit to better and healthier routines after being diagnosed with type 2 diabetes, but may ignore alarming signs prior to this.

## **Declarations**

## **Acknowledgements**

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## **Authors' Contributions**

CM is the director of studies for TA PhD. He has directed the concepts and provided his clinical judgement to data analysis and interpretation. TA has provided the literature review and worked on Data analysis with LH, who has provided the statistical methods. BN, DK and FA have reviewed the text and given their input to all sections, particularly the discussion.

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## **Availability of data and materials**

The dataset for SHIS can be made available through direct request to MOH in Saudi Arabia. On line extract of SHIS are available in this publication and other publications that have used SHIS. Data analysis and further details of current study are available from the corresponding author upon reasonable request.

### **Ethics relevant to Data Handling and Confidentiality**

Ethical approval was granted from the Ministry of Health in Saudi Arabia No: FWA 00018774 (Appendix 8) and from the University of Glasgow, College of Medicine, Veterinary and Life Science Research Ethics Committee No: 200160103 (Appendix 9). This study was conducted according to the guidelines laid down in the Declaration of Helsinki. All data received as collected figures, anonymous, and cannot be linked to any of participants.

### **Consent for publication**

MOH Saudi Arabia has consented the use of SHIS materials, otherwise consent for publication not applicable.

### **Competing interests**

The authors declare that none of them has competing interest related to this study.

# Chapter V

## **5. Qualitative Study: for Cultural Adaptation of Self-Management of Type 2 Diabetes in Saudi Arabia**

### **5.1 Introduction**

The work in this chapter was partially informed by the results and conclusion of the systematic review (Study 1, Chapter 3) quantitative study (Study 2, Chapter 4). The author of this thesis obtained ethical approval from the MOH in order to run a qualitative study and recruit participants from the health professionals and individuals with type 2 diabetes at Buraydah Endocrine and Diabetes Centre in King Fahad Specialist Hospital, Qassim, Saudi Arabia (Study 3 of this thesis). The author carried out focus groups with health professionals and interviewed participants with type 2 diabetes. The following article was submitted to PlosOne journal on 24 November, 2019 and published on 28 July, 2020 (Al Slamah et al., 2020). The author has agreed the moderator guidelines with his supervisors Professor Craig A. Melville, the director of studies, Dr Barbara Nicholl, Dr. Deborah Kinnear, Dr Fatima Y Alslail, and Dr Leanne Harris. The first author led the writing and analysis. All authors contributed to interpretation of results and finalising the manuscript draft.

**Title:**

Cultural Adaptation of Self-Management of Type 2 Diabetes in Saudi Arabia  
(Qualitative Study)

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## **Abstract**

**Background** Saudi Arabia is continuously working on developing its health care system, however with the high prevalence of type 2 diabetes and comorbidities, such as cardiovascular diseases, self-management education programmes are essential. As part of a planned series of studies to develop a culturally sensitive type 2 diabetes self-management programme, this study explores the need versus barriers and facilitators relevant to implementing a national programme for type 2 diabetes self-management education within the community and health care system in Saudi Arabia.

**Methods** A qualitative methodology was used to explore the views of a multidisciplinary group of diabetes health professionals and adult individuals with type 2 diabetes. The views of nine health professionals working at a specialised diabetes care centre were gathered at two focus groups (four and five) that included doctors, nutritionists, health educators and nurses. Individual interviews with 12 individuals with type 2 diabetes (six females and six males) attending the centre were also carried out. Recurring themes through the translated transcripts were studied and treated by the research group under pre-set protocols.

**Results** Focus groups with health professionals revealed three main themes. 1. Resources: availability of resources and how they impacted on performance and individuals' care; 2. Familiarity with self-management education programmes: educating people and raising awareness among them; and 3. Lifestyle: population' lifestyle and how it could affect their compliance with self-management programmes.

Interviews with individuals also revealed three main themes. 1. Habits: post diagnosis changes in individuals' attitudes and behaviours towards diet and physical activity; 2. Health education: awareness of managing type 2 diabetes through health centre advice or self-education; and 3. Culture and society: a lack of cultural or social support created by some social practices or conventions.

**Conclusion** The findings from this study highlight a gap in type 2 diabetes care system that can be breached through the development of a Saudi specific self-management programme for type 2 diabetes. The identified barriers and facilitators can be used for adapting a self-management programme to the Saudi context. However, initial training is needed for local health professionals to understand the mechanisms of self-management programmes. Such programmes will need to infiltrate to the society, and the population' families, in particular to tackle the rising prevalence of type 2 diabetes in Saudi Arabia and provide a friendlier, more supportive environment for the current individuals to self-manage their diabetes.

**Keywords:** qualitative, diabetes, type 2 diabetes, self-care, self-management.

## 5.2 Background

The risk of developing type 2 diabetes or having a poor prognosis of the condition correlates with a number of behavioural factors such as obesity, sedentary lifestyle, smoking and unhealthy diet (Fletcher et al., 2002). Diabetes self-management programmes have been shown to improve glycaemic control and decrease diabetic complications (Banister et al., 2004, West and Goldberg, 2002). There are no well-developed self-management programmes in Saudi Arabia. However, our recent systematic review suggested that type 2 diabetes self-management programmes may be effective in improving glycaemic control in people with type 2 diabetes living in the GCC countries (Al Slamah et al., 2017). Type 2 diabetes self-management programmes support individuals to adopt healthy lifestyle changes into their daily routine such as increasing physical activity and improving dietary habits. However, a key attribute for the success of self-management programmes is their suitability for the cultural and social environment that they are running in (Banister et al., 2004, West and Goldberg, 2002, Brunisholz et al., 2014). To date, none of the studies investigating type 2 diabetes self-management programmes for implementation has taken into account the cultural context in Saudi Arabia, although some of these programmes were independently set-up in Saudi Arabia (Al Slamah et al., 2017).

In the UK, diabetes education and self-management for ongoing and newly diagnosed population is standardised through a national programme (DESMOND). Similarly, in the USA diabetes self-management education (DSME) is a progressive strategy that enables individuals with pre-diabetes or diabetes to gain control over the progress of diabetic complications and positively contribute to their health care (Toobert et al., 2011). DSME was initially introduced in the USA through ethnicity-

specific programmes, and was later adopted by other English speaking countries (Yeary et al., 2017). Some other countries or societies launched the programme after adapting it to the local social environment, including appropriate translation, as in the USA with Pacific Island and Latino communities (Yeary et al., 2017, Osuna et al., 2011). DSME can improve glycaemic control as evidenced by a reported 1% reduction of glycated haemoglobin (HbA1c), which reflects higher individuals' compliance, and healthy adjustments over eight weeks or more (Ellis et al., 2004). Stern control of blood glucose level can contribute in delaying or mitigating diabetic complications such as nephropathy, peripheral neuropathy and visual impairment, reducing the risk of heart disease or stroke among diabetic individuals to near general population average levels (Banister et al., 2004, West and Goldberg, 2002). The changes in lifestyle provided by DSME may also benefit individuals known to be at elevated risk of developing diabetes, and it is wise to include them in such a programme (Al Slamah et al., 2017). Similar benefit of DSME was observed from some self-management education initiatives in Saudi Arabia and other GCC countries. However, the success of these initiatives was limited by lack of two key elements in well-developed systematic programmes, which are cultural adaptation and model repeatability (Al Slamah et al., 2017).

The health system in Saudi Arabia is based on national health insurance, which is provided to all Saudi citizens, and some of the residents. This free of charge service allows the introduction of individuals education programmes such as diabetes self-management at a national standard (Al-Hanawi et al., 2018). Large cities, such as Riyadh, Jeddah, Buriyadah and many others host highly equipped and specialised hospitals, which provide the tertiary level of health care (advanced specialities,

major surgeries and consultancy). The primary care units, such as general practices, are extensively distributed within cities, villages and remote areas. These provide a general practitioner service and are equipped with their own laboratories and radiology department (Ministry of Health Saudi Arabia, 2018). At the secondary care level, are the specialised centres, which include endocrine centres that provide care for people with diabetes among others. Health care at these centres is provided by endocrinologists, nutritionists, specialised nurses and health educators (Ministry of Health Saudi Arabia, 2018). In addition, the Saudi ministry of health (MOH) has introduced both electronic and phone services since 2017/18, through which individuals can receive tailored and confidential clinical advice and prescriptions when applicable (Ministry of Health Saudi Arabia, 2018).

The estimated 33 million Saudi population has a growth rate of 3.2% per year (The Ministry of Health, 2015) reaching near 40 million by 2025 as per the United Nations projections (World population, 2002). More than 67% are under the age of 30 years and only 5% are above 60 years. Males and females are approximately equal in number, with a life expectancy of 72.5 years in males compared to 74.7 years in females (The Ministry of Health, 2015). The highest incidence of type 2 diabetes in Saudi Arabia is in individuals who are in their sixth decade and is greater among females than males and is higher in individuals with a higher BMI (Alqurashi et al., 2011). In the 2010 census, 2.5 million individuals (9.2%) had diabetes (The Ministry of Health, 2015) with a predicted increase rate of 200,000 per year. According to population projections, more than 13% and up to 20% either will have diabetes or be at risk (Al-Rubeaan et al., 2015). Perhaps 89% to 97% of all individuals with

diabetes visiting a given centre will be of type 2 diabetes (Fonseca et al., 1985, Famuyiwa et al., 1992).

Deciding on the standards and the quality of the programmes that diabetes educators are offering for individuals under their care is difficult without previous knowledge of the suitability of such programmes to the local environment and culture (Brunisholz et al., 2014, Steinsbekk et al., 2012). The development of national standards in any country, including Saudi Arabia, requires investigating the views and readiness of practitioners and individuals with type 2 diabetes (Weaver et al., 2014). In general, people with diabetes may lack self-esteem or can be cautious towards performing physical exercise or dietary control (Jepson et al., 2012). Some doubt the benefit of doing so or believe that their medical condition would prevent them from doing so (Sohal et al., 2015). Personal, socioeconomic and cultural factors may impose further limitations. The effect of these factors will vary according to gender, age, family obligations, work responsibilities, income, residence, education, in addition to their general and diabetic-associated health status (Sohal et al., 2015, Babakus and Thompson, 2012). The process of implementing international programmes such as DSME into a new local environment may require a relatively extended period of time to allow careful examination of local social and official health policies, economic status and resources and also to thoroughly understand how to normalise the practices of these programmes within the local cultural context, which can only be achieved by high quality social and behavioural research (Barrera Jr and Castro, 2006, Kumpfer et al., 2008).

The current qualitative study looked at the views of those who are affected with type 2 diabetes and the health professionals managing them. The aim is to analyse these views to assess the “need” for type 2 diabetes self-management programmes. The “need” can be defined here as the “need” of the individuals for some of the outcomes usually achieved through self-management programmes, or the “need” of the health professionals to self-management programmes to achieve such outcomes for individuals under their care. Technically if self-management programmes are needed, one may also explore the views for factors that could assist in or hinder the implementation of these programmes in Saudi Arabia.

### **5.3 Methods**

#### **5.3.1 Research design**

In order to assess the need and benefit of cultural adaptation, the study design followed the earlier stage of Kumpfer’s cultural adaptation model (Kumpfer et al., 2008). This model represents a logical framework for conducting such research. Kumpfer suggested nine steps for the cultural adaptation of health programmes starting with identifying the needs, assessing them within a reflective population sample, discussing how to tackle them through relevant focus groups, piloting the focus group recommendations, using the outcome of the pilot study to improve the quality and support of the programme, revising the programme for any additional requirements or alterations before concluding the final evaluation prior to dissemination of results and publication (Kumpfer et al., 2008). In order to “identify the needs”, the first step in Kumpfer model, we have previously carried out a systematic review of pilot studies in Saudi Arabia and other GCC countries on type 2 diabetes self-management to assess their methods and if the subjects of any of

these studies achieved better control of their condition (Al Slamah et al., 2017). The current study employed a qualitative design (focus groups and interviews) to explore the “needs” further through the views of people with type 2 diabetes and the professionals responsible for their treatment and care on: if there is a “need” for self-management programmes, based on the common goals in these programmes such as educating individuals with type 2 diabetes and improving their independence or ability to make decisions that can improve their life quality.

### **5.3.2 Approach**

This qualitative study is meant to study the specific needs of individuals with type 2 diabetes. This approach is called by some qualitative researchers (phenomenological) (Smith et al., 2009), as it is concerned with a specific phenomenon. This phenomenon is studied within part of the local Saudi community, which further classifies the approach of the study as cultural or ethnographic (Smith et al., 2009). In order to candidate the background of participants within the settings of these two approaches we have identified the following pairs: common experience (type 2 diabetes) versus common culture (Saudi community). This pair was represented by Saudi type 2 diabetes people. The second pair was common involvement (management of type 2 diabetes) versus common environment (Saudi health system). This pair was represented by the health professionals at a Saudi specialised health centre. To ensure association between the two pairs the individuals and the health professionals were of the same health centre.

Taking into consideration the small sample size, and the limitation of the study to one centre, this study did not aim to follow a grounded theory approach, instead

themes that are common and shared among participants are used in a thematic analysis model (Braun and Clarke, 2014). The key difference between the pragmatic approach used in this study and a grounded theory approach, is that the latter would have been more refined due to inclusion of participants of wider geographical and epidemiological base, and would have included theoretical sampling from previous and current social studies (Braun and Clarke, 2014).

### **5.3.3 Rigor and saturation**

The centre where the study took place (Buraydah Endocrine and Diabetes Centre) has six outpatient clinics seeing an average of 72 visitors (12 each) per day. Repetitions of concepts was observed at early collection stage (saturation assessed during data collection). Likely this was due to the fact that , as the study was limited to one health centre For the purpose of the study, triangulation was considered sufficient to establish rigor based on consensus (repeatability) between the two focus groups, among the 12 participants and the focus groups versus the participants' interviews (Lemon et al, 2020, O'Brien et al, 2014;Kayapinar, 2014). The participants interviews provided further rigor to the study as each person was interviewed separately, but all asked the same questions in the same order (O'Brien et al., 2014).

The health professional are assumed credible due to their long experience, as inclusion criteria were set to include only those who had one year of experience or more. The same was applied to participants with type 2 diabetes, as they need to be diagnosed for one year or more (Guest et al, 2012).

Although, the study included all those who were willing to participate and fitted the inclusion criteria, testing for saturation was carried during data collection. If saturation was not achieved data collection would have continued. This strengthens transferability (Schloemer & Schröder-Bäck, 2018).

Dependability was based on two factors. The first factor, (TA), worked independently on data collection, but was dependent on (CM, BN and DK) to decide for themes validation. The second factor was that themes were derived from two distinguished ends of the phenomenon, one is the healthcare professional, who are providing care and the second are those who are receiving care (Guest et al, 2012).

Although TA (principle investigator) ensured to avoid leading or hinting to participants, he used moderator guidelines, with pre-set frames for the questions in the interviews (same questions to all) and similar introductory paragraphs for the focus groups, which supported confirmability (Lemon et al, 2020).

The authors may have had some bias towards self-management approach based on their conviction of its success elsewhere outside Saudi Arabia. However, we were keen to actively search in the transcripts for “hints” that would suggest differently, whether in the focus groups or in the participants’ interviews.

The authors of this work were divided at each stage as follows: ethical approval application (TA, BN, CM), data collection (TA), checking data collection ethics (CM, FA), initial data analysis (TA), secondary data analysis (TA, LH, DK), data analysis verification (DK, BN), final judge (BN, CM).

#### **5.3.4 Study population**

The study population were health professionals at Buraydah Endocrine and Diabetes Centre in King Fahd Specialist Hospital, Qassim, Saudi Arabia to share their experience versus individual experience; and individuals with type 2 diabetes attending the centre's clinics to be asked about their experience. All, who gave their consent were enrolled in the study. This resembled a convenient sample without specific characterisation or categorisation. All completed their participation to a satisfactory level (remain engaged and answered all questions or discussed thoughts of interest).

#### **5.3.4 Data collection**

##### **5.3.5.1 *Health professionals***

Two focus groups were carried out to explore implementable aspects, feasibility and value of self-management programmes among their individuals as well as challenges. One was formed of four and another of five professionals. Each of the focus groups included at least one doctor, nurse, nutritionist and health educator. The latter had a bachelor's degree in health education and was certified as a diabetes health educator for their speciality. All health professionals had at least one year of experience in providing care for people with type 2 diabetes and at least one year of that work experience was in Saudi Arabia.

The head of research at the Diabetes Centre, passed the invitation to the 10 doctors, four health educators, two nutritionist and 20 nurses working at the centre to attend the focus group at one of two available slots, on two separate days, each three hours, during working hours. Those who expressed willingness and availability were

allocated to the time slot of their choice. Both groups were carried out in the same lecturing room at the centre.

#### **5.3.5.2 Participant interviews**

The aim of the participants interviews was to elicit potential attitudes and behaviours towards common items within self-management programmes and the appropriate educational approach that can facilitate acquiring favourable health behaviours. No particular selection criteria were applied to approaching individuals. All individuals with type 2 diabetes who were above 18 years old and present in the outpatient clinics were potential candidates. Flyers with study information were handed over to the participants over three weeks, and all those who responded and consented to take part, at no incentive, were recruited after a thorough explanation of the study. Interviews were carried out in simple Arabic language to ensure accessibility for all participants. All individuals had type 2 diabetes (diagnosed for one year or more), were over 18 years old, lived locally, attended the out patient clinic and could speak, read and write Arabic. None of the participants had any communication difficulties or disabilities. Twelve individuals with type 2 diabetes took part in the interviews. All participants were interviewed at the same counselling room (a reasonably sized quiet room with a desk and 4 chairs). Each interview lasted for almost one hour. Interviews were used instead of focus group with individuals with type 2 diabetes attending the centre in order to protect confidentiality, and to allow each of them to express their views independently, without being influenced by others. In the health professionals groups, it was assumed that each would be mainly driven by their professional education and experience and focus groups were deemed appropriate.

### **5.3.6 Ethical approval and informed consent**

Ethical approval (number: H-04-Q-001) was granted by MOH in Saudi Arabia, on 09/01/2018 (Appendix 10) and the University of Glasgow (number: 200170169), College of Medicine, Veterinary and Life Science Research Ethics Committee, on 09/08/2018 (Appendix 11).

All participants gave their informed written consent and agreed to be audio-recorded (Appendix 12 and 13 for professionals and individuals respectively). Information sheets about this study (Appendix 14 and 15 for professionals and individuals respectively), were provided in the Arabic language to potential participants. The information sheet and consent form were also verbally communicated.

### **5.3.7 Moderator guidelines**

The moderator's guides and interview schedule for focus groups and participant interviews (Appendix 16) were developed based on a review of the literature carried out by the study team, particularly in relation to the DESMOND intervention approach, a training programme aimed at supporting participants to become experts themselves in diabetes self-management training and education (Weaver et al., 2014). The moderator (TA) is bilingual (Saudi Arabic and English) and has experience of working with individuals with type 2 diabetes and health professionals in Saudi Arabia. The moderator relied on a voice recorder to record the conversations, while he took field notes.

In the focus group, the moderator agreed with the participants for himself to start with an opening paragraph, or highlights, rather than a question, for them to share their ideas "whatever come to their mind" around the topic, from one to another.

The moderator at few occasions would use body gesture or eye contact to encourage a particular participant to talk.

### **5.3.8 Translation**

The focus groups and interviews were transcribed in Arabic. Two different experienced translators, of no less than five years as judicial translators, received copies of the original Arabic transcripts and translations were verified by a third. The translators were requested to translate verbatim (word for word) the written transcripts. As the translations were judged to be identical, the rest of the transcripts were then distributed among the two translators (a transcript of one focus group and six transcripts of participant interviews each) (Squires, 2009). The moderator (TA) also reviewed audio transcriptions to ensure that translations were as accurate as possible. Due to the direct verbatim translation, some quotes required some adjustment, as in the following example:

An original verbatim translation of a quote from a health professional:

“we began to do a consulting course for diabetologists who are being in the centre now”

Adjusted quote “We began a consulting course for diabetologists who are now in the centre” (FG1-MD)

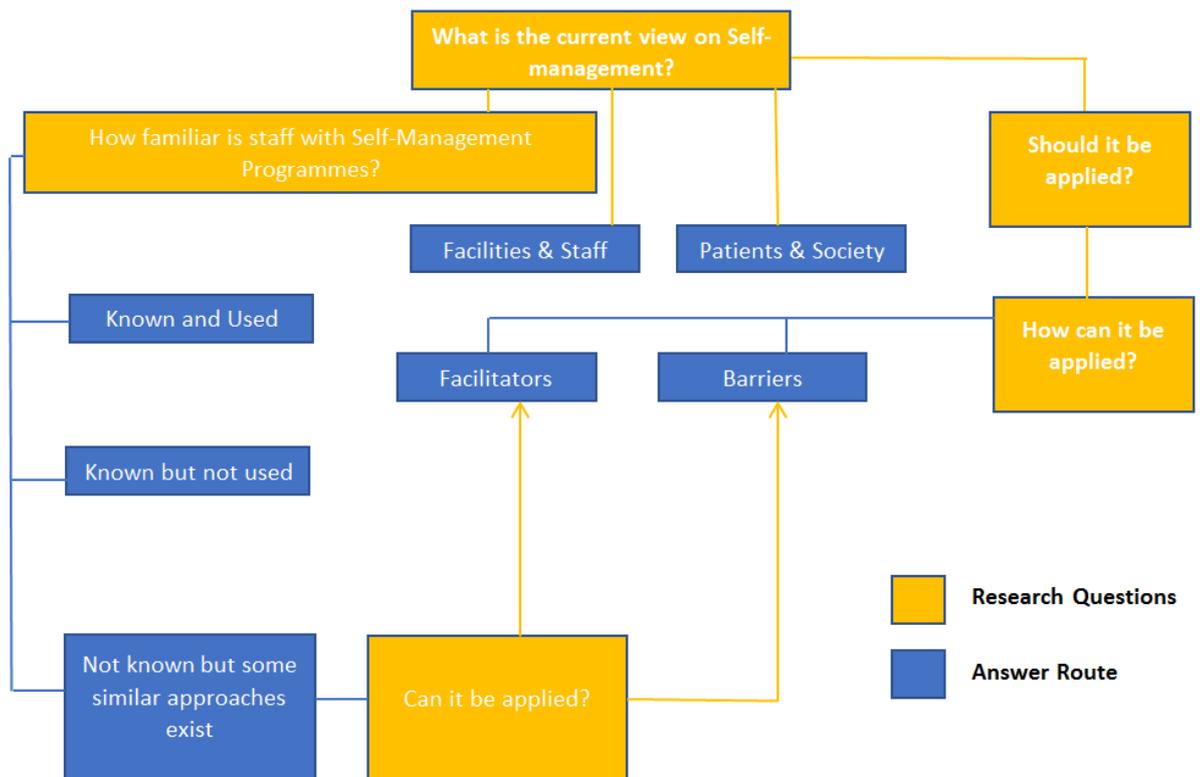
### **5.3.9 Data analysis (methods and interpretations)**

The qualitative data software analysis package, Atlas/Ti software 18 (Scientific Software Development GmbH, Berlin, Berlin-Brandenburg, Germany) was used to organise the English transcripts in order to analyse the data. The data analysis was

divided into the four stages of a thematic framework method (Snape and Spencer, 2003). At the first stage, symbolic domains that gave distinctive meaning within the transcripts were identified. The second stage aimed at identifying domains that shared a common pattern. The third stage involved investigating the crude themes among the domains to start producing codes. Each of these codes reflected a component of one investigated inquiry for any of the themes. The participants' "hints" / views were used to classify these codes as facilitators versus barriers. Once initial codes were generated, discussions took place within the research team to identify the best approach by which these codes could be classified into refined subthemes according to their similarity and their contextual ability to address the main research questions. Finally, Atlas/Ti software 18 was used to manage the analysis of the final codes.

Based on the approach of this qualitative study, the emerging themes from the discussion in the focus groups, or participants' answers to interviews' questions described the participant daily journey in managing type 2 diabetes (phenomenon) and how that can be specific to the Saudi community or Saudi health system (culture) (Braun and Clarke, 2014).

Figure 5.1 provides the theme seeking approach. Based on repetitions and shared concepts, the data deemed sufficient and no further recruitment was required.



**Figure 5.1 Thematic map development**

The themes in the study developed upon seeking answers for the main research questions of the study (in yellow), which aimed to identify the participants' view (in blue) on self-management programmes. First, we assessed the participants feedback on how familiar they were with these programmes, particularly the health professionals. Then answers for sub-research questions were sought. These questions aimed to assess the need for, feasibility of and approach to be taken to implement a self-management programme. On identifying answers for these questions, further themes and subthemes had emerged. Within the subthemes, factors that can help (facilitators) or restrict (barriers) the development of a self-management programme could be identified.

## 5.4 Results

Qualitative analysis of the transcripts revealed prominent themes in the focus groups and participant interviews. The themes were represented by frequency and exact quotes, which are provided in *italic*.

### 5.4.1 Health professional focus groups

Table 5.1 presents the participants and identifiers for each individual within each of the two focus groups.

**Table 5.1 Keys for participants' identification**

<b>Focus Group Number 1</b> Male Doctor Male Nutritionist Female Nurse 1 Female Nurse 2 Female Health Educator	<b>FG1-MD</b> <b>FG1-MNT</b> <b>FG1-FNR1</b> <b>FG1-FNR2</b> <b>FG1-FHE</b>
<b>Focus Group Number 2</b> Female Doctor Female Nutritionist Female Nurse Female Health Educator	FG2-FD FG2-FNT FG2-FNR FG2-FHE
<b>Participants' Interviews</b> Example 1: Male participant 1 Example 2: Female participant 1	MP-1 FP-1

Three main themes that surrounded the essential elements of establishing or adapting self-management education programmes emerged from the data (Table 5.2). These were 'resources', 'familiarity with self-management education' and 'lifestyle'. Within each theme, subthemes are used to describe the barriers and

facilitators for implementation of self-management education programmes in Saudi Arabia that were identified through the data analysis.

**Table 5.2 Themes and Subthemes from Health Professional Focus Group**

	<b>Subthemes</b>	
<b>Theme</b>	<b>Facilitators</b>	<b>Barriers</b>
<b>Resources</b>	Qualified experienced staff teams	High number of visitors
	Educating individuals through different communication channels	Health centre location
		Strategy for visitors follow -up
		Financial constraints
<b>Familiarity with self-management education programmes</b>	One to one tailored appointments for visitors education	Lack of previous systematic application
	Individuals taking responsibility/ownership for their own health	Individual compliance and self-monitoring methods
	Diabetes awareness raising programmes	
<b>Lifestyle</b>	Newly emerging trends towards exercising	Cultural and social attitudes
	Availability of exercise facilities	

#### **5.4.1.1 Resources**

The health professional focus groups had a recurring theme of describing the currently available resources and how they impacted on their performance and individuals' care. These included resources related to premises, staff and equipment. Their main observation was how these resources could be developed to enable them to become more available and accessible for their individuals.

## **Facilitators**

### **5.4.1.1.1 Qualified experienced staff teams**

Discussions in both groups highlighted the presence of strong teams of qualified members with complementary functions of care for individuals with type 2 diabetes. Most members spoke about coherence and collective experience as a key strength for being able to educate the individuals under their care and overcome some barriers such as time limitations and overcrowding of appointments. Also, most had robust educational qualifications. The following quotes from the second focus group show how the team members complement each other, with a highly qualified doctor leading this team.

*Sometimes the clinics are overcrowded, with 20 / 25 patients, so we can go over with them the basics only. The nutrition clinic also helps us, so if I want to talk about a treatment, I transfer the patient to the nutrition clinic, as well as the diabetes education clinic. For example, if I wrote injection and new meals, I send the patient to the education specialists who help the patients to understand the part which I did not have the time to explain to them at the clinic. (FG2-FD)*

*We as nurses can help the patients referred to us by doctors by checking out their accumulative or fasting diabetes level; of course we would do this as per the doctor's instructions. (FG2-FNR)*

*I as a nutrition specialist, write the notes, also the educator writes notes. These notes, which we take, help the doctor to identify the type of medicine and its quantity. (FG1-MNR)*

### **5.4.1.1.2 Educating individuals through different communication channels**

Good communication channels were seen as a way to strengthen health professionals' educational messages to people, avoid follow-up gaps and to be available for advice. Health professionals described making use of the already available communication channels that enabled them to talk further with the individuals under their care, which included social space in the premises, phone

calls outside working hours and social media. This was also considered suitable for the local community culture as some health professionals felt that people, for example, may prefer to receive messages via phone as a mean of communication. One doctor referred to his use of twitter, and both he and one other referred to their use of Whatsapp.

*One video clip via WhatsApp to my patients is sometimes more effective than the educational sessions, I mean that the traditional methods are no longer that useful. The video clip is sent to the patient while being at home from a reliable source, and they can repeat it over and over. Sometimes they share it. I wish if there was more educational material that can be shared via WhatsApp, Twitter, Snap and the likes. (FG1-MD)*

*There is a patient with Dialysis and Diabetes, so I had to communicate with her via WhatsApp in order to observe her condition with her. She used to brief me about the rising level of diabetes till I could control it to reach only 300 [the nutritionist is likely referring here to high random blood glucose, normally 160-200mg/dl and above 300 mg/dl represents high risk], so I have to follow up these critical cases. (FG2-FNT)*

## **Barriers**

### **5.4.1.1.3 High number of visitors**

Individuals with type 2 diabetes attend one or two main specialist centres in their region. Due to the high prevalence of type 2 diabetes, health professionals were conscious of the constant pressure on themselves and the limited time they could spend with the individuals under their care to provide adequate educational advice about diabetes and how to manage it, especially for newly diagnosed population. One Doctor, for example, described how she could not get the time to hear about the individuals attending her clinic needs, questions or concerns due to the challenge posed by the high number of visitors. The same issue was echoed by others:

*Instead of checking 20 patients, we'd be better to see 15 or 13 patients only so that we have enough time to sit with the patient and hear about his needs and concerns*

*if he needed to enquire about anything... this way, he would take the right time if the booking was not too much. (FG2-FD)*

*Honestly, we need a long time with the patient, at least 20 minutes to explain what the nutrition is and how it could be adjusted, as well as what is the relationship between nutrition and diabetes in the first place? How can he, through proper nutrition, control the sugar in his body? What is the relationship between weight gain and high blood sugar? We need more time with the patient, but as the number of patients increases we cannot cover all topics, so we are forced to give the patients frequent dates for short appointments in order to be able to complete [rather than one long session], until we feel that the patient has received a good or acceptable level of education. (FG1-MNT)*

Health professionals across different backgrounds agreed that the number of staff, compared to the number of visiting individuals per day was not sufficient enough to educate them to self-manage their type 2 diabetes and that improving the staff ratios could help to solve the problem. They highlighted that high numbers of visitors resulted in not enough time to undertake high quality diabetes education with their visitors.

*Of course the solution is possible by adding more staff as increasing the number of the staff already solves the problem of long waiting times for the patient till his appointment. (FG1-FHE)*

*As for this centre, we may increase the capacity within the centre by increasing the number of staff at the clinics, and we may increase the number of diabetes centres in the area, in general. (FG1-MD)*

#### **5.4.1.1.4 Health centre location**

According to the health professionals, the type of personal education and care needed for individuals with type 2 diabetes cannot be provided in the primary care clinics because they do not have sufficient qualified staff. This is only available in the secondary care specialised centres in the cities. This subsequently puts pressure on visitors who have to travel from rural areas, while also resulting in increased capacity pressures on these centres:

*This is the only diabetes centre in Qassim, so the people come from every village such as: Al Dawadmi Village, so when the diabetes centres increase in this area, the pressure would be less upon us. There are diabetes centres in Onaiza and Buriydah, but if there is more than one centre, it may also decrease the pressure we face. As for this centre, we may increase the capacity within the centre by increasing the number of staff at the clinics, and we may increase the number of diabetes centres in the area, in general. (FG1-MD)*

*I agree with the doctor in covering more areas, and the patients who were examined and their blood glucose check proved to be good, should be sent back to the hospitals, in order to decrease the pressure here. (FG1-FNR2)*

#### **5.4.1.1.5 Strategy for visitors follow-up**

Health professionals seemed to be using their own initiative sometimes to reduce one appointment time for the benefit of another; but eventually individuals' waiting times were often extended or the time between follow-up appointments is protracted, which adversely impacted their visitors' compliance, among other issues.

*I mean that sometimes the patient as a start, especially at the beginning of diagnosis, may need less time, but sometimes the option is not originally up to the doctor, as he [the doctor] is committed to the appointment schedule and can do little to adjust according to the patient's need. (FG1-MNT)*

*Sometimes the patient comes to the appointment after a period of time long enough for him to forget what I told him in the previous appointment, even if I gave him a paper or something to help him, he is unwilling to read. (FG1-FHE)*

#### **5.4.1.1.6 Financial constraints**

Although health care is provided free of charge in Saudi Arabia; there were some hidden costs incurred by individuals. The discussions by the health professionals revealed that individuals were sometimes unable to do physical exercise or self-monitor their condition because of the financial burden.

*I have a comment on the doctor's talk about the support matter. There are many patients who suffer from the cost; the ministry did not provide everything till now, so when I ask the patient to undergo an analysis he says: it costs too much and I can't*

*afford it. Moreover, most of them do not have a glucometer, they can't afford buying it, hence, it will affect them as well. (FG1-FHE)*

*But some patients are unable to go to the health club, for examples they do not have subscription [reduced fee membership] or the financial ability to go there, to be honest, most patients. (FG2-FNT)*

#### **5.4.1.2 Familiarity with self-management education programmes**

Health care professionals seemed to be aware of the importance of self-management education. Most were working on educating their visitors and raising awareness among them. However, their efforts were intuitive and the approaches used were variable among different professionals. The participants in this study had not seen a structured self-management education programme implemented as part of type 2 diabetes management.

### **Facilitators**

#### **5.4.1.2.1 One to one tailored appointments for visitors education**

Most individuals were seen at the beginning of their diagnosis by different professionals and were likely to benefit from health educator advice about nutrition and monitoring glucose level. Doctors also provided them with an explanation of the nature of their condition and how to ensure a good prognosis.

*The patient in his first visit must come to us in order to draw the broad lines and make him know the relationship between nutrition and diabetes. As I told you, [nutritionists use “patient-tailored strategies”] it is according to the condition of the patient, if he has any problems in terms of weight or anything else, we follow him up on a monthly basis on official appointments. (FG1-MNT)*

*We [health-educators] usually follow-on from the doctor's instructions to the patient. However, some patients come here for consultations [without being referred by the doctor], so I determine my own appointments on which I can teach them how to monitor their blood sugar and how and when to take their prescribed dosages. (FG2-FHE)*

#### **5.4.1.2.2 Individuals taking responsibility/ownership for their own health**

According to the health care professionals, some of their visitors engaged with self-monitoring activities and wrote down notes on their condition to discuss with the professionals in order to help them improve their glycaemic control:

*By the diagnosis, often, the patient is given a table, a sheet of paper in which the blood glucose check is written, its time and day, and he writes me the blood glucose check and comes with it on the next visit. (FG1-FHE)*

*Communicate via text so that I can know about his condition, especially if he is a fresh diabetic or is taking medicine, if there is injection or anything new for him. (FG2-FHE)*

*Of course there are some patients, especially the young people; keen on following the instructions, perhaps it is because the education and thinking are different from older people's, while the older people are somehow difficult to be convinced because you want to change their lifestyle to which they are accustomed, so they may take some time to be persuaded. Those patients, who are 30, 40 to 50 years, are very responsive, their blood glucose check is getting better and the doctors feel satisfied with them as they follow the directions. (FG2-FNT)*

#### **5.4.1.2.3 Diabetes awareness raising programmes**

Although self-management programmes have not been fully applied, in Qassim, the professionals were used to some awareness programmes where they contacted the individuals with type 2 diabetes and the general public to provide crucial information about type 2 diabetes and how to manage it. Self-management education programmes were applied to a limited extent but did not follow a specific curriculum:

*As I said, the programme [list of instructions from Saudi Ministry of Health to help patients to self-manage their condition] was not applied in full; we tried to apply some aspects of it (FG1-MD)*

*Other than the doctors, there are for example the awareness programmes. We go to many places and Malls; there should be something like Diabetes National Day. There are education sessions with doctors, what if the patients attend those sessions and cared about it. Moreover, what if we have a flyer, when they ask us,*

*we answer; I mean to have a reliable source, not any source, it should be a reliable one, such as the awareness programmes. (FG2-FD)*

*We already created groups [on social media] such as 'Insulin bump'; there is a new nutrition name 'carbohydrates for diabetics', in which there is the doctor and the educator along with the patients in order that if any patient asked any question regarding nutrition, I join the group and answer; if there is a question related to the medications, the doctor would reply. (FG2-FHE)*

## **Barriers**

### **5.4.1.2.4 Lack of previous systematic application**

The main line of discussion among professionals revolved around the lack of self-management education programmes such as DESMOND or DSME being used in practice or even being piloted in their centre, which serves a large province and provides health care for thousands of individuals with type 2 diabetes:

*I personally know nothing about them. [i.e. in his reply to if systematic self-management programmes have previously been applied]. (FG1-MNT)*

*As I said before, I do not know about the programme in Britain and America. Of course an initiative like a programme would be the right thing, but it was never applied here in Qassim. (FG1-MD)*

### **5.4.1.2.5 Individual compliance and self-monitoring methods**

Individuals were likely left to their own initiative, readiness or willingness to decide how they would monitor their condition. Some visitors would wait until their next visit; but others did not show up for their appointments. The same applied on following instructions or advice given by the health professionals:

*Sometimes, he is not educated or not well educated, meaning he is ignorant [of diabetes and its complications], so he needs someone to teach him in order to be more disciplined. Many patients are not interested [not compliant], not due to their ignorance, but they do not know yet know how important it is to get disciplined.*

*Moreover, sometimes the patient comes to the appointment set by the doctor, which is so far, so he has to come after a long period of time but he forgets what I told him, even if I gave him a paper or something to help him, he is unwilling to read. (FG1-FHE)*

*Some of them follow the instruction and others don't. (FG1-FHE)*

*There are some patients who can't follow the programme as it is not suitable for them. (FG1-FHE)*

*I think that some patients prefer the easy things, they do not like sitting with other persons to educate them; they just want to serve themselves. (FG1-FHE)*

*When you sit with diabetics, they all listen to some of their methods, sugar control, and attend to some of their experiences, which [from their point of view] is better than the information or more influential than the information that the doctor mentions. (FG1-FHE)*

The professionals were keen to see and follow-up their visitors. However, the booking system impacted their ability to control how frequently and when they could see a particular person. As such, some visitors were seen frequently enough, others perhaps too often, while there were individuals who did not get the chance to see all the members of the team.

*Sometimes they are educated by the doctor if he has time, and other times they are not. (FG1-FHE)*

*When there is too much booking, some patients feel stressed and the time is not enough. Sometimes, if the time is not enough, I feel that I did not give the patients all the information he needs and give him an appointment for the next day; hence the booking increases to 20 or 27, so I give him an extra appointment in order to complete the things he needs. (FG2-FHE)*

*Well, for the same patient, I may set an appointment according the condition of the patient, some of them come on a three months basis and others come every six months, also there are some patients who come for consultation at any time. (FG2-FD)*

### **5.4.1.3 Lifestyle**

The professionals discussed their visitors' lifestyle and how it could affect their compliance with self-management programmes. They gave some positive and negative examples, including the changes with current trends in society.

#### **Facilitators**

##### **5.4.1.3.1 Newly emerging trends towards exercising**

According to the health professionals, some Saudis are keen to move around and practice more physical activity, especially the younger generations. A growing interest in practicing sports was evident.

*The culture of walking spread more than before, as well as the bodybuilding. Hence, culture is subject to change and people are satisfied with this thing, but it needs some kind of support and motivation. (FG1-MD)*

*I recently read on Twitter that there was a walkway in the housing area, in which there were groups walking. (FG2-FD)*

##### **5.4.1.3.2 Availability of exercise facilities**

Health professionals talked about new residential areas that had been designed to provide walkways and fitness clubs were also available. There were also conversations in the focus groups about golf courses and swimming pools.

*The activity classes can be increased, and for example, the role of fitness can be adopted; the tracks are now common. (FG1-MD)*

*I think that [physical activity levels] can be made in sports clubs for example, which contains everything such as walkways, tracks. (FG2-FHE)*

## **Barriers**

### **5.4.1.3.3 Cultural and social attitudes**

According to the professionals, overweight and obese individuals were frequently encountered in their type 2 diabetes clinics. They believed that this was influenced by dietary habits and traditional food.

*The main problem we have in the Kingdom of Saudi Arabia is the food style or, in general, the lifestyle, which is not to practice exercises enough, and also to rely on the qualities of high-calorie foods, high amounts of fat and also high amounts of sugar. I think that anything needs a government programme to change it, needs to have a huge programme to try to change the lifestyle of the community. (FG1-MNT)*

For some professionals, they felt that they had to work hard on building trust with their visitors. Some visitors believed that traditional recipes or medications could provide them with better and safer solutions that could not be matched by modern medicine:

*Some patients come here while already convinced with their own ideas, whether traditional medicine like what I said or they are already convinced. He may come to the clinic as a duty that must be done, I mean that he is already convinced, and this is a difficult matter, not only the elders, but also other persons. (FG1-FHE)*

In Saudi Arabia, people do not simply go out of their homes and walk. Professionals believed that this would require planning, motivation and organisation. On the other hand, females still felt restricted by when, where and how they would go out for a walk.

*Because of the culture, no one would go out to walk while wearing the home dress. (FG2-FHE)*

*I suggest providing a closed building, such as the sports club, for the female patients, in which they can do every sport in such club, such as swimming, walking*

*or other things, provided to be in a closed place, but if the marathon was made in an open area, I think they won't come, even if it was the Health Day. (FG2-FD)*

A further concern for some professionals was the culture of people having a reliance on travelling everywhere by car, representing a further limitation to routine daily physical activity:

*I mean we should limit using cars because people today go to the mosque by car, or to the greengrocer's (FG1-MD)*

In summary, the themes that emerged from both focus groups were consistent and the participants shared similar views on different topics. They agreed on pressures related to the availability of resources. Participants were willing to learn a systematic programme that educates self-management; however, they had not experienced one before. They also felt the need for such programmes and believed that they were applying parts of them but without clear guidance or structure. Older individuals required special considerations to be taught new concepts and participants felt that the culture had some barriers especially for exercising in public places; traditions and customs were strong catalysts and suppressors alike; they need to be considered within any cultural adaptation for self-management education.

#### **5.4.2 Participant interviews**

Twelve (out of 31 approached) individuals with type 2 diabetes participated in a one to one interview (appendix 16). Six participants were males (mean age 47 (38-56) years) and six participants were females (mean age 44.7 (25-56) years). Table 5.1 shows the participant identifier for each person.

Three main themes emerged (Table 5.3), again presented as facilitators and barriers to diabetes self-management. Newly acquired habits (mainly post diagnosis) were identified as a facilitator, and cultural barriers and bad habits (mainly pre diagnosis) were identified as barriers.

**Table 5.3 Participants' Interviews Themes and Subthemes**

	<b>Subthemes</b>	
<b>Theme</b>	<b>Facilitators</b>	<b>Barriers</b>
<b>Habits</b>	Healthy diet	Unhealthy habits
	Active lifestyle	Unwillingness to practice sport or physical exercise
	Monitoring blood glucose	
<b>Health education</b>	Receiving education at health centres	
	Self-taught awareness diabetes awareness	
<b>Culture and society</b>		Social restrictions and attitudes

#### **5.4.2.1 Habits**

This theme reflects post diagnosis changes in individuals' attitudes and behaviours towards diet and physical activity.

#### **Facilitators**

##### **5.4.2.1.1 Healthy diet**

Many individuals expressed their interest and/or commitment to eating healthier food and their observance of what, when and how much they eat.

*Yeah. I always eat leafy vegetables as they don't raise the diabetes. (FP-1)*

*I'm on the diet they [Health centre] told me about. They say I should have one piece of fruit per day. (FP-1)*

*I keep eating the fruits and vegetables continuously because the doctor advised me to do that. The doctor advised me to eat the fruits which don't contain more sugar. (FP-2)*

*I was decreasing the calories I had as well as sugars and fats. (MP-3)*

#### **5.4.2.1.2 Active lifestyle**

Participants also talked about their commitment to a healthier lifestyle after being diagnosed with type 2 diabetes. A relatively high number of the participants described becoming more active.

*I walk every day. (FP-1)*

*When I practice sport especially walking, this is reflected in my psychological state. So, I am keen on practicing it continuously. (MP-1)*

#### **5.4.2.1.3 Monitoring blood glucose**

Some of the participants reported carefully monitoring their blood glucose level, and their awareness of its importance:

*Yes, of course I have a glucometer and I follow up the blood glucose check when fasting and after the main dishes, even the random test, sometimes I do it. In regards to the advice, I resort to the physician of the centre in the district periodically asking him for advice. Regarding the medicine, I have them regularly. (MP-2)*

*She reported the blood glucose check for me and found that proportion of glucose was 50. She said that it was low. She brought dates and juice for me, and I was able to control it and I thanked Allah. (FP-2)*

*I did a test at home and found a simple percentage, so I visited the clinic in order to undergo a complete blood glucose check when they told me that the sugar level in the blood is high. (FP-3)*

## **Barriers**

Bad habits before diagnosis' captures individuals' behaviours before they received a diagnosis of type 2 diabetes: their negative behaviours towards diet, physical activity and lifestyle. Some participants managed to stop these habits and others were feeling the need for amending such behaviours after being diagnosed with diabetes, but there were some participants, who seemed indifferent.

### **5.4.2.1.4 Unhealthy habits**

A few participants reported smoking and how they were finding it difficult to quit or adjust after being diagnosed with type 2 diabetes.

*I never took the subject of smoking seriously until now. (MP-1)*

*Unfortunately, I am a smoker (MP-5)*

There were some reports of participants' avoidance of fruits and vegetables. Old bad eating habits, which included eating fatty or fast food or not being keen on fruit or vegetable consumption.

*My relation with fruits and vegetables was not so good really especially the fruits, Is this a food routine to which I'm used to?!! Is this a social behaviour?!! I do not know but my relation with the fruits is still very superficial. (MP-1)*

*Not much, but I do eat them [fruit and vegetables] now, but I do not show great interest in them (FP-6)*

There was moderate frequency of participants' reports of earlier incautious food consumption. Some reported slipping back to these dietary habits. This can be seen associated with less awareness of the negative impact that this had on their health.

*Yes, I was eating fast food but now sometimes not usually. (MP-2)*

*Quickly I returned to the natural situation and I began to eat everything like sweets and all items. (MP-3)*

*Nevertheless, unfortunately I know many people whose diabetes levels are 400 and 500. A huge mistake. Why? If it is 200 and below, that is acceptable, but 300, 400 and 500 are the levels of those who do not take care of anything, are not interested in their treatment, nor are interested in eating healthy food. They only harm themselves. I mean, if this year everything goes well with them, they would eat openly. However, that will not last. Two or three years from now, they will find themselves complaining about all their body organs. (MP-5)*

*I mean I crave something and eat it knowing it is harmful, but it is something I desire, I cannot control it. (FP-6)*

#### **5.4.2.1.5 Unwillingness to practice sport or physical exercise**

Participants often reported their previous tendency to avoid physical activity. Some participants attempted justifying their sedentary lifestyle.

*When I suffered from diabetes, the doctors advised me to walk. I didn't used to walk at all and I didn't try. So, my mistake is that I didn't try to walk. (FP-2)*

*Walking is sport. They never said to me anything related but they told me about another sport for which I shall prepare myself; they [health professionals] never do anything for me. (FP-2)*

*I swear, there is no doubt that due to being overweight, this affects me as I suffer an attack if the weather is not pure... I cannot walk. (MP-3)*

#### **5.4.2.2 Health education**

This theme was built on the self-reported awareness of type 2 diabetes, how it could be managed and how the participants developed such awareness. However, no barriers were reported that hindered their health education or awareness.

#### **Facilitators**

##### **5.4.2.2.1 Receiving education at health centres**

Almost all participants talked about being educated on their current health condition. However, the level of such education, or their perceived judgment on the level and quality, was variable:

*The [main] source [for education] is the diabetes centre, I do not believe in anything else. (MP-6)*

*It is according to the diabetes level. I follow the instructions of the doctor. My treatment is regular and thank God my condition is stable. (MP-5)*

*I have got some of these sources from the nutrition clinic at Diabetes Centre here. (MP-2)*

##### **5.4.2.2.2 Self-taught awareness**

Some participants' reported on their self-developed knowledge of type 2 diabetes.

*I have many sources that I got and I try to read anything about diabetes. There are always lectures and seminars about diabetes and I attend them continuously. (MP-3)*

*They [health centre] are the ones who teach us and tell us whatever we want to learn. I know people at home who know about the disease and they teach me. (FP-1)*

### **5.4.2.3 Culture and society**

Unfortunately, participants did not give a sense of cultural or social support, and some implicated a barrier created by some social practices or conventions.

#### **Barriers**

##### **5.4.2.3.1 Social restrictions and attitudes**

Participants discussed how cultural barriers can interfere with their self-management or self-management education. Only two participants reported feelings of being made to feel guilt or blame for developing type 2 diabetes. However, they found it difficult at times to pass a food offer, which was not suitable to their condition. The participants explained that this may have led them to mismanage their condition.

*We need more support. I can tell you that the Saudi people have many events and occasions which contain eating food. The life became hard. [i.e. referring to the pressure of social “eating”, and the negative view for not joining in] (FP-2)*

Participants also raised the issue of how the community had some misconceptions about practicing sports, or who should be practicing sports. On the other hand, the places where sports could be practiced, including streets and playground were considered insufficient or not accommodating enough as reported by one female participant:

*Nowadays there are no tracks in the clubs for they [i.e. the males] want them only for themselves. (FP-6)*

Financial constraints to taking part in physical activity was also noted by one participant:

*We would like to, but everything here costs money, do you understand? We would like to walk and to go to the club, but everything is in return for money, we have not enough money. (FP-4)*

## **5.5 Discussion**

The current study found that health professional participants had no prior knowledge of programmes such as DESMOND or any other similar programmes. However, they attempted to create their own system for educating their visitors, when they had the time. All individuals from or outside the city were managed in the centre as they could not receive the care at their local primary health clinics. It was clear in the focus groups that there was mounting pressure on staff to treat a daily high number of visitors. However, both interviewed participants and health professionals, recognise the importance of good equipment standards, staff qualifications and experience in such specialised endocrinology centres. Outdoor physical activities are constrained by social frames, especially for women and due to dependence on vehicles; however indoor sport facilities are available, but some health professionals raised affordability as a concern. Although traditional food is almost a must in social gatherings, there are some emerging trends towards healthier diet.

While self-management programmes such as DSME and DESMOND have the common aim of educating individuals with type 2 diabetes to acquire the key skills to become independent managers of their own condition in order to maintain a better quality of health and life, the UK based DESMOND programme is applied on a national scale through the national health service (NHS), which is more similar to the health system in Saudi Arabia (The Ministry of Health, 2015, Funnell et al., 2008, Gregg et al.,

2007). However, this study, which took place in the only endocrinology centre in the Qassim provenance shows that previously trialled or piloted self-management education programmes in Saudi Arabia (Al Slamah et al., 2017) had not been disseminated or discussed at least within this part of the country, which is the fourth populated area in Saudi Arabia (Al Slamah et al., 2017). When taking into consideration that individuals with diabetes can only be seen and managed in such a centre, it is likely that health professionals are well placed for describing the pressure on them, and their visitors, during the appointments. The main aim of DESMOND is to use standard methods for training diabetes self-management educators a systematic approach by which they can educate type 2 diabetes people. This standard approach follows the guidelines of the National Institute for Health and Care Excellence (NICE) (Gregg et al., 2007). It is hard not to notice that this is quite fitting as solution of the high volume of individuals. If educators become available in primary health clinics then many of these individuals will not need to travel to the specialised centres. Moreover, if the individuals are properly educated to self-manage their diabetes, there will subsequently be a reduction in the number of individuals who need to be seen by a specialist, due to fewer complications and better ability to monitor their condition (American Diabetes Association, 2016).

Cross-sectional studies in different geographical populations in Saudi Arabia found that many communities are keen on traditional food (Al-Rethaiaa et al., 2010, Mahfouz et al., 2011), which is high in calorie and rich in fat and carbohydrates (Al-Rethaiaa et al., 2010). This was also associated with obesity or being overweight (Al-Rethaiaa et al., 2010), mainly among females (Mahfouz et al., 2011). According to these studies, the

problem is escalated by limited physical activity and sedentary lifestyle (Al-Hazzaa and AlMarzooqi, 2018, Al-Hazzaa, 2007). The views expressed by the participant interviews and the health professionals focus groups in our study gives support to these findings. However, they also show that there are emerging trends and desires for an improved lifestyle. It is possible that people in Saudi Arabia are becoming more aware of healthy diet paradigms and the importance of being active. Nevertheless, these views were expressed by individuals, who were already diagnosed with type 2 diabetes, and it should be noted that some did not adopt a healthier lifestyle until they were diagnosed. Also, the findings in this study found that cultural barriers restricted females from exercising and participants often used a car as their main form of transport, regardless of distance to their destination. As noted by some health professionals and participants, females are limited with regard to accessing physical activity facilities, likely due to the conservative traditions of the society. In a study that reviewed most of the initiatives that aimed to encourage the Saudi community to practice further activities, it was found that most of these initiatives were sporadic or short-lived and had a limited impact, especially for women, including young girls (Al-Hazzaa, 2007). In our study, for both health professionals and participants, it emerged that there were community or self-imposed restrictions on practising outdoor sport. It is unusual for Saudis to go out for walks, whether long or short. However, for females, the social barrier represents a bigger challenge. Nevertheless, the discussions showed that most participant interviews were motivated to do more to get themselves fitter, but they required proper guidance and improved community awareness about the necessity of frequent activity in general, for both males and females, and for them as individuals with type 2 diabetes in particular. A key aspect for a DESMOND educator is to be able to tailor their

approach according to the individual experience and history, whether ongoing or newly diagnosed (Gregg et al., 2007). For DESMOND to be successful in Saudi Arabia, the disseminated standard will need to take into consideration particular needs, which are shown in this study, such as availability and accessibility of sports facilities for individuals, the cost involved and managing cultural traditions associated with food. In other words, they will need themselves to be educated about the local environment and geography in order to be able to provide an efficient education to their visitors (Gregg et al., 2007).

The high number of individuals, lack and centralisation of specialist centres and specialised staff restricts the opportunity to educate people with type 2 diabetes on how to self-manage their condition and achieve better control of their diabetes. This is aggravated with the absence of national self-management education programmes. On the other hand, community traditional concepts can interfere with individuals' compliance and ability to adhere to health care professionals' advice. Social studies report the remaining influence of the family, or the community as a whole, on its members. This influence can delay, alter or impact individual's health seeking attitudes (Al-Shahri, 2002). Type 2 diabetes self-management education programmes need to be open to the community, not only to help the individuals with type 2 diabetes, but to also help reducing the number of people who develop type 2 diabetes. This will help to break the aforementioned cycle of service limitations caused by the high number of individuals. There is a need to train staff to apply a systematic approach towards educating their visitors, which can also be tailored to individual needs. Nevertheless, both staff and individuals are likely to welcome self-management education

programmes, especially if they are more suited to the community by providing, for example, advice on how and where they can do more physical exercise and how their families can support their self-management goals, such as observing dietary intake. Also, the use of an attractive medium for communication such as digital health interventions (via apps), social media and videos has the potential to save individuals travelling to distant health centres. This could benefit the Saudi community, which is quite engaged with smart screens and may also free up some time within clinics for individuals who do require an appointment with a clinician in person. As mentioned previously, the MOH has recently provided its individual care telecommunication hub services. This hub could be a suitable medium for introducing electronic diabetes self-management programmes, to enable qualified educators and trainers to reach the largest possible number of the population, including those with limited mobility. The telecommunication services can be utilised to advertise and raise awareness of such a programme or particular aspects of it, such as public health messages about diet and exercise to the whole community, which could provide one to one confidential communication between the health professionals and people under their care.

A convenient sample of participants was used from those seeking health care at the Health Centre. A sampling plan to deliberately include participants of different background, lifestyle, health condition (e.g. concomitant chronic disease), or period lapsed since diagnosis was not used. This meant that we could not compare participants' views based on their circumstances and conditions to see whether this varied by demographic, lifestyle or illness characteristics. Similarly, the limitations of this study also include it being carried out in one locality, participants views were not

re-examined by means of a lateral study to see if a different group of participants, or indeed health professionals of different specialities such as psychologists and occupational therapists, would concur with the themes and subthemes identified here. It is not possible to exclude bias or favouritism among participants in such convenience sample, who may intrinsically support additional resources or care plans. Strengths include, in-depth interviews and focus groups with a range of experienced health professionals and participants from those under their care, including both males and females.

The findings from this study, within their limited scale, provide grounds for a Saudi specific self-management programme for type 2 diabetes. According to the Kumpfer's cultural adaptation model, the above-mentioned findings can be used to make some of the adaptations to a self-management programme that could be piloted within the study locality to be robustly tested for its effectiveness. The findings also reflect supportive views of key stakeholders, namely the individuals with type 2 diabetes and the health professionals responsible for their care, of a self-management programme and highlights gaps and readiness in society, individuals with type 2 diabetes and the health care system for type 2 diabetes care. Such a programme should help to alleviate many of the challenges that are currently facing diabetes care provision in Saudi Arabia and help to tackle the rising prevalence of type 2 diabetes in the country.

# Chapter VI

## **6. Discussion**

This thesis represents an initial approach to the cultural adaption of type 2 diabetes self-management programmes for use in Saudi Arabia, guided by a cultural adaption model suggested by Kumpfer et al. (Kumpfer et al., 2008), particularly completing the first step of nine in the Kumpfer model. The thesis examined evidence for anticipated benefits and limitations of type 2 diabetes self-management programmes in Saudi Arabia. To collect such evidence, the thesis looked at previous studies on type 2 diabetes self-management education in GCC countries (Study 1), factors associated with the prevalence of type 2 diabetes or better glycaemic control (Study 2), and the experience of individuals with type 2 diabetes and the health professionals responsible for their management (Study 3). The aim of collecting such evidence was to determine whether implementation of a type 2 diabetes self-management programme or some its strategies is effective, hence needed to improve the quality of life of the affected population in Saudi Arabia, and what are the priorities to be taken into consideration if adapting an existing programme for the Saudi context, based on type 2 diabetes demographics and clinical association and the views of the affected individuals themselves and those who providing professional healthcare to them.

In Study 1, the author systematically reviewed published literature which reported on studies that had implemented a self-management approach for type 2 diabetes in GCC countries, including Saudi Arabia (Al Slamah et al., 2017). Most of the studies included self-management content such as dietary and physical education, improving lifestyle, and treatment compliance. However, there was no focus on the skills utilised by the

studies' participants and their educators in such self-management interventions and the level of support the participants had received. In general, there was evidence that self-management interventions succeeded in lowering HbA1c levels, which was the main or even the only outcome to be measured in some of these studies (Omer et al., 2015, Al Hayek et al., 2013). However, it is quite promising to see that some components of the self-management programme appeared to be associated with an improvement in HbA1c levels in most of the participants, although they were already receiving conventional care at specialised diabetes clinics, including treatments and follow-up (Al Slamah et al., 2017). Some of the studies included tailored self-management programmes (Al Asmary et al, 2013; Al Hayek et al., 2013), but most applied general instructive group sessions for all participants. Only two studies attempted to make some cultural adaptation to the original western interventions, but the focus was on linguistic elements (Mohamad et al, 2013; Al-Shahrani et al., 2012). This led to an investigation of an approach for cultural adaptation. Chapter 2 examined the cultural adaptation model presented by Kumpfer and colleagues. In summary, this is a comprehensive model that includes several elements from other cultural adaptation theories, but also provides a systematic step-wise approach to reach a "cross-national" culturally adapted self-management programme (Ferrer-Wreder et al., 2012). Kumpfer's model recommends conducting a systematic review of previous self-management studies and attempts as the first step. This was achieved in Study 1 of this thesis. In the same step, according to Kumpfer, one needs to understand the extent, distribution and characteristics of the problem in a given society and the available resources. This was achieved in the Study 2 and Study 3.

In Study 2, data available from SHIS (Ministry of Health Saudi Arabia, 2013) was accessed to run a secondary data analysis focused on type 2 diabetes people to examine the relationship between the presence and control of type 2 diabetes and examine data on diet, physical activity, health seeking behaviours, demography and education. Age, higher BMI and comorbidity with chronic illness, particularly hypertension, were the main factors associated with having type 2 diabetes. Although these associations with type 2 diabetes are almost global, as reported in the introduction of this thesis; still these findings highlight specific priorities that should be taken into consideration in the development of self-management programmes in Saudi Arabia. For example, people with older age in Saudi Arabia can be more attached to traditions and less accepting to be told what to do or not to do (Abou-Gamel et al., 2015). Another example, the large number of individuals with a high BMI in Saudi Arabia can be associated with lifestyle or social traditions associated with food, but not alcohol consumption. In other words, when formulating a self-management programme in Saudi Arabia, the specific nature and habits of Saudis in middle age and older should be investigated and programmes need to be adapted to become more fitting for individuals. Also, the self-management programme educators will need to have the skills to teach type 2 diabetes individuals how to self-manage not only their diabetes, but also possibly other chronic conditions, particularly hypertension and overweight. However, the analysis pointed to some unexpected findings such as type 2 diabetes being less likely among those who consume fast food while it was found to be poorly controlled among those who consume higher portions of vegetables and fruits. SHIS did not provide further details to examine this. For example, if those who consumed higher portions of vegetables and fruits consumed fast food, were less active, or when

diabetes was diagnosed versus when the change in diet started. However, the findings from this study, whether expected or unexpected helped to partially advise on the structure of Study 3.

In Study 3 was carried out in Saudi Arabia to explore the views of participant interviews and health care professionals on self-management programmes for type 2 diabetes. Partially informed by the previous two studies, health professionals' focus groups and interviews with participants with type 2 diabetes were conducted. Despite the well-developed free health care system in Saudi Arabia (World Health Organization, 2000b), it was clear from the discussions that the high number of visitors represented a challenge to the clinics they were attending. The health care professionals were quite clear about their inability to provide their visitors with adequate advice in order for their visitors to fully understand their condition and how to manage it. This was in part due to reducing the amount of time with the individuals in order to see as many as possible. They were also worried that their visitors might not be compliant with the treatment due to lack of close follow-up appointments. The health centre, which was located in Buraydah city, receives visitors from the city and surrounding cities and villages in the large Qassim province. Clearly this also causes the centre to be crowded with individuals. In addition, for many individuals, long travel time to clinics represents physical and financial burden.

Study 2 suggested that Saudis with type 2 diabetes might be following a healthier lifestyle, including healthier eating habits, compared to those free of type 2 diabetes. However, according to the interviewed participants, these habits were likely acquired

after being diagnosed with type 2 diabetes as a reaction to their condition. While the interventions highlighted in Study 1 focused on improving glycaemic control through physical activity, particularly walking (Al-Daghri et al., 2014, Al-Shahrani et al., 2012) or monitoring diet (Al Asmary et al., 2013, Al-Sinani et al., 2010), the health professionals and their visitors in Study 3 underlined some social factors, including exercising in public, which can render these practices unsustainable. These social factors were more of a challenge to the women interviewed compared to the men, but both genders may sense awkwardness when running or even walking down the road for example (Alsubaie and Omer, 2015, Samara et al., 2015). The health care professionals also highlighted dependency on cars for commuting, even for short distances.

In summary, together, the three studies presented in this thesis were complementary in addressing the first step of a needs assessment for the cultural adaptation of a self-management programme for type 2 diabetes in Saudi Arabia. The systematic review highlighted the lack of comprehensive type 2 self-management trials in any GCC countries. In a number of the reviewed studies, despite being limited to a few aspects of self-management strategies, showed the potential for self-management interventions in GCC countries. Nevertheless, the association between demography and type 2 diabetes could not be drawn from the small samples used in these studies, which lead to the secondary analysis of SHIS, in the quantitative study (study 2). This secondary analysis highlighted type 2 diabetes distribution and associations with lifestyle, age, health conditions and nutrition in Saudi Arabia, however the SHIS was not primarily designed to only examine type 2 diabetes. The qualitative study (study 3)

was designed not only to understand the views of people with type 2 diabetes but also those who are responsible for their care, something that could not be done using SHIS. Finally, considering the findings of the three studies together enabled a conclusion on the needs of the local population of people living with type 2 diabetes in Saudi Arabia.

### **6.1 How much of the health needs assessment was covered by the studies in this thesis?**

The aim of a health needs assessment here should be to identify if and how self-management education is needed to reduce the impact of type 2 diabetes on the Saudi community and boost the current available resources for type 2 diabetes management. One would need to understand how the current resources are utilised and how their utilisation can be improved. This includes identifying inequalities in resource distribution to the community as a whole and to the people with type 2 diabetes in particular. Finally, based on all of the aforementioned, how much a national self-management programme is needed. If such a programme is needed, what are the likely priorities and the required key adaptations of any of the currently available self-management programmes to match the cultural and demographic needs of the Saudi type 2 diabetes individuals (Kumpfer et al., 2003). The latter resembles the end target of this study. The known methods for doing so are mainly systematic reviews of relevant literature, examining surveys and available data resources and first hand interactions with the target audience, who are typically the participant interviews and the health professionals responsible for their care (Kumpfer et al., 2003). The following section will discuss how much of the aim of this health-needs assessment was covered by this thesis.

### **6.1.1 The need for a national self-management programme**

In Chapter 1 of this thesis we considered the literature and available publications from the Saudi government, particularly MOH, and also global reports in an attempt to understand how effective the current services are in Saudi Arabia at managing type 2 diabetes. Without an appropriate self-management education programme for type 2 diabetes, the prevalence of type 2 diabetes and its complications will continue to rise, which is one of the criteria of “need” in a needs assessment, according to the Kumpfer model. According to the literature reviewed in Chapter 1, an alarming 11.5% of Saudis have type 2 diabetes, while perhaps 13% of them may have one form of diabetes or another (Al-Rubeaan et al., 2015). However, there is a concern that the current incidence rate of diabetes suggests that the prevalence could reach one fifth of the Saudi population by 2030 (Al-Rubeaan et al., 2015). Currently, the Saudi national health system provides diabetes management for more than four million Saudis, not to mention other nationalities living in Saudi Arabia, who mostly come from countries with high prevalence of diabetes such as South Asian countries and the middle east (Flowers et al., 2019, Al-Rubeaan et al., 2015, The Ministry of Health, 2015, Guariguata et al., 2014, Alqurashi et al., 2011, Fonseca et al., 1985, Famuyiwa et al., 1992). In Study 3, it was evident that individuals with diabetes had to attend centres that were usually within a major city, as they were unable to receive care at their local primary care clinic. This negatively impacted the quality of the service provided to the individuals with type 2 diabetes. They were not seen frequently enough, and when they finally had an appointment, health care professionals were unable to give them sufficient time to educate them or understand the problems they were facing with managing their diabetes. This is likely to increase the occurrence of type 2 diabetes

complications, which puts further burden on the individuals and the health system in Saudi Arabia. Study 2 in this thesis, which analysed data from SHIS, showed a strong association between type 2 diabetes and chronic illness, particularly hypertension. Taking into consideration that most of these individuals were males in their sixties, who are at higher risk of comorbidity and complications (Alqurashi et al., 2011), it is sensible to accept the estimates that suggest more than 6 billion US dollars (14% of all health expenditure) as an annual direct cost for managing diabetes in Saudi Arabia (Alhowaish, 2013, Alwin Robert et al., 2017). Currently 33% of all individuals with type 2 diabetes suffer from at least one complication, while 25% suffer from at least two complications (Al Hayek et al., 2014). If a self-management education programme is established in Saudi Arabia, with educators becoming available in the primary clinics, this has huge potential to alleviate pressure on the specialised health centres, reducing the rate of complications, and improving the quality of type 2 diabetes management, not only by the health care system but by the individuals themselves in managing their own condition. This was evident in the findings from Study 1, which showed that some components of a self-management model were associated with a reduction in HbA1c, despite being applied for a relatively short time (Al Slamah et al., 2017).

In summary, Saudi Arabia has a well-developed health system and the expenditure on managing diabetes is already relatively high. However, individuals with type 2 diabetes can only receive care at specialised centre located in the big cities, which cause long travel times for many of them and overcrowding at these centres. This cannot be seen as a separate issue from Saudi Arabia being globally ranked seventh for type 2 diabetes prevalence, with nearly half described as poorly controlled. As such, one can recognise

the inequality of health service penetration and distribution, at least for individuals with type 2 diabetes. However, qualified primary care staff and facilities are available within each community setting (Saudi Arabia Ministry of Health, 2009) but they do not have a prescribed role for specialist management of specific conditions, including type 2 diabetes. A self-management programme would likely enable such staff to be part of the type 2 diabetes self-management education process, ensuring a better utilization of the already available resources. The Saudi Arabia MOH provides a telephone care system, which is designed to answer individuals health enquiries, provide them of assurance or help to manage minor health problems at home or guide them to available health facilities near them. In addition many Saudi people are keen users of social media. Both of these can be used to support type 2 diabetes self-management education programmes, as convenient channels for follow-up and sharing of educational materials.

### **6.1.2 Key adaptations and priorities of self-management programme**

According to Kumpfer's model for cultural adaptation, the initial adaptations made to any adopted programme should be kept to a minimum (Kumpfer et al., 2008). This thesis intended to inform such key priorities and adaptations from a health needs assessment. Study 2 informs two main aspects of a self-management programme for Saudi Arabia. Firstly, the expected higher numbers of males and those of older age as the predominant demographics of the type 2 diabetes individuals. This is of key importance in the Saudi community, where such groups are expected to be more adherent to tradition and local culture, including concepts associated with diet and

lifestyle, which are often not beneficial for a person with type 2 diabetes (Mobaraki and Soderfeldt, 2010). Secondly, the significant correlation between type 2 diabetes and chronic illnesses and being overweight. This requires a focus on holistic self-management programmes that can allow individuals to manage more than their diabetes, for example to develop universal self-management skills that can make an overall improvement on their health. It was quite striking in our discussions with health care professionals that they did not mention prediabetes, or at least screening family members of a person with type 2 diabetes for glycaemic control, as they are at higher risk of type 2 diabetes or prediabetes (Fletcher et al., 2002). It is not clear whether the concept of prediabetes is somehow absent from the current health strategies for combating diabetes, however, a type 2 diabetes self-management programme in Saudi Arabia could require the education sessions to include family members alongside the individuals with type 2 diabetes (Leggat, 2007). Those family members are likely to benefit from prediabetes self-management education, which is part of some type 2 diabetes self-management programmes such as DESMOND (Khunti et al., 2012).

Study 3 also showed that most participant interviews did not have a healthy lifestyle before being diagnosed with type 2 diabetes. If family members are to be included in the programme, they will need to understand that they have the same urgency, as that of the affected individual, for improving their lifestyle. The same study also highlighted the unease many have with practicing outdoor activities, especially women. In a self-management programme, educators need to be aware of such requirements so they can provide clearer messages and suggest feasible changes to ensure better compliance and opportunities for improving lifestyle and physical activity. Moreover, a

key role should be given to primary care staff as educators or follow-up educators to benefit from the fact that primary care centres have a wider geographic spread compared to centralised specialised facilities. Both the participants interviews and health care professional focus groups showed a level of interaction with social media, sometimes in preference to face to face visits. Also, a preference of video-clips over written materials. As such, using social media and video-clips as an embedded function could be advantageous to any potential self-management programme in Saudi Arabia.

## **6.2 Proposed cultural adaptation theory**

This thesis has been guided by the Kumpfer model, particularly the first step or health-needs assessment. However, this model provides a limited window for making the initial cultural adaptations (changes) to an existing self-management programme and lacks sufficient guidance for making such adaptations before piloting a programme. Based on the findings of this thesis, one can only recognise that by following the restrictions imposed by the Kumpfer model on changes before piloting, most of the adaptations suggested here cannot be made. By default, this may limit the success of a programme at the pilot stage, which may discourage the authorities at Saudi Arabia's MOH from trialling the programme. Although the Kumpfer model suggested reviewing the literature, analysing the nature and the extent of the problem and directly interacting with relevant parties, which was followed here in this thesis and resulted in the reported findings, this model limits the scope of the changes to language and minimal change of words based on the culture, such as the word "mosque" instead of "church". Such changes are intuitive, however the scope of the work done in step one, as in this thesis,

addresses wider topics that can have a direct impact of the level of success of the programme, even at the piloting stage, which would represent the second step of the work.

In Study 1, Bernal's eight dimensions model for cultural adaptation was considered when examining studies for type 2 diabetes self-management in GCC countries. This model was initially used by Bernal and his colleagues (1995) for cultural adapting interventions for psychological family therapy to make them more suitable for Hispanics. Table 6.1 provides commentary on each of the eight dimensions in Bernal's model, and why it may be more suited for the next step of adapting a type 2 diabetes self-management programme to be suitable to pilot with the population of Saudi Arabia.

**Table 6.1 Bernal's eight dimensions model in relation to developing a Saudi Arabia specific self-management programme for type 2 diabetes**

<p><b>1. Language: Culturally appropriate; culturally syntonic language</b></p>
<p>The Saudi community is attached to the local Arabic dialect, which reflects longstanding literary traditions for communication, particularly when conveying instructions (Chakrani, 2015, Kniffka, 1992).</p>
<p><b>2. Persons: Role of ethnic/racial similarities and differences between client and therapist in shaping therapy relationship</b></p>
<p>In study three, included health care professionals were either Saudis or Egyptians. Saudis are more at ease when talking to other Saudis, also Egyptians, Sudanese and Iraqis (Almutairi, 2015, Abuata and Al-Omari, 2015, Aboshaiqah, 2016).</p>
<p><b>3. Metaphors: Symbols and concepts shared with the population; sayings or “dichos” in treatment</b></p>
<p>The Saudi Muslim community is influenced in their daily conversation with Islamic quotes, which enhance communication. In study three both health care professionals and individuals referred frequently to such quotes. Social studies also report similar influence of Islamic culture on daily conversation, even in younger generations (Stanger et al., 2017).</p>
<p><b>4. Content: Cultural knowledge: values, costumes and traditions; uniqueness of groups (social, economic, historical, political)</b></p>

Gender differentiation and social acceptance were encountered in study three in relation to aspects such as physical exercise, diet and compliance with treatment and instructions. Many studies highlight the influence of the local culture of the Saudi community on behaviour and attitudes (Al-Bannay et al., 2017, DeNicola et al., 2015).

**5. Concepts: Treatment concepts consonant with culture and context: dependence vs. interdependence vs. independence; emic (within culture, particular) over etic (outside culture, universal)**

Dependence on family, community or health care professionals was clear in the discussions with participant interviews and health professionals alike. This has also been reported elsewhere (Saleh Al Mutair et al., 2014). To motivate self-management the concepts need to be with a frame that gives roles for the family and community, but in a manner that does not apprehend the self-management concept itself, which has a focus on individuals becoming independent.

**6. Goals: Transmission of positive and adaptive cultural values; support adaptive values from the culture of origin**

Some of the participants (participant interviews and health care professionals) in study three referred to traditional medicine or concepts for treatment of diabetes. These concepts need to be studied and evaluated for the educators to be able to advise on them. Rejecting these concepts without evidence may deter some individuals from the self-management programme. On the other hand, if educators can encourage the use of some traditional practices, where this is an evidence for them to be beneficial, would likely attract further person-attention to the whole programme (Al-Rowais, 2002, Al Saeedi et al., 2003, Bakhotmah and Alzahrani, 2010).

**7. Methods: Development and/or cultural adaptation of treatment methods. Examples: "modelling" to include culturally consonant traditions; "cultural reframing"; use of language (formal and informal); cultural hypothesis testing; use of genograms, "cultural migration dialogue"**

As a conservative Islamic society, Saudi people are more likely to listen more to religious figures or if advice is supported with a verse from the Quran or a quote of the Islam prophet (Al Slail et al., 2018).

**8. Context: Consideration of changing contexts in assessment during treatment or intervention: acculturative stress, phase of migration; developmental stage; social supports and relationship to country of origin; economic and social context of intervention.**

The general notion about the Saudi community as free of restrictive economic burdens in the wealthy oil country has proved controversial during the discussions with participant interviews and health professionals in Study 3. Many individuals reported a worry about the cost involved in joining health clubs to improve their health activity. Also the cost and effort to travel from villages to the health centres in the cities. The number of people living with diabetes is considerably higher than the capacity of these centres, nevertheless not much weight or trust is given by individuals in general to the nearby primary health units (Al Slail et al., 2018). This will need to be addressed when piloting the self-management programme. For example, encouraging outdoor activities, providing financial support for type 2 diabetes people to join health clubs and boosting the image of primary health units.

Based on the consideration of our findings and previous literature in relation to Bernal's 8 steps in Table 6.1, we hypothesise that cultural adaptation of any self-management programme for type 2 diabetes in Saudi Arabia should include the following stages:

1. Identifying a programme that can allow cultural adaptations to suit the Saudi community, whether this programme includes or can be developed to include the following:
  - A. Education about common comorbidities with type 2 diabetes, such as hypertension and overweight.
  - B. A focus on dealing with prediabetes and community awareness.
  - C. Training local professionals with different levels of experience and a range of different roles, including staff at primary health care centre, to become educators.
  - D. Face to face training sessions and visual materials that can be shared online.
  - E. Materials that can be translated to the local language with consideration to the local culture and concepts.
2. Training local staff to become trainers themselves, who have full understanding of the programme core and auxiliary concepts.
3. The initial cultural adaptations should be mainly carried out by trainers, who have a strong understanding and experience of the programme. These are usually the original programme founders, but also can be those who have been trained by the programme founders to become trainers themselves and have worked at the

original programmes. In all conditions, these trainers need to work locally in the new host country (for identification they are called local trainers). The adaptations made should strictly follow the aforementioned eight dimensions.

4. The local trainers, should consult religious figures, local linguistic experts and community members when carrying out the aforementioned adaptations.
5. Local trainers should be given sufficient time to ensure adequate training of staff at primary care units to become educators.
6. Piloting the project for a sufficient period: the piloted programme should continue until a targeted sample of participating individuals with type 2 diabetes are included and have followed the self-management programme long enough to see improvements. The period needed to see improvement can be judged by the programme founders.
7. Running parallel qualitative studies while piloting the programme, which include interviews with participant, their families and educators. The interviews should explore the acquired skills by all parties.
8. Re-piloting the programme after making any other adaptations as a result of the initial pilot study and parallel qualitative studies.
9. Providing the programme on a national scale, while monitoring through quantitative measures for specific outcomes such as participants' number, age, gender, financial parameters, HbA1c, BMI and blood pressure in addition to qualitative measures for satisfaction, interaction, perceived benefit and skills. The sample must be a representative sample in number and geography, while being properly categorised to reflect factors such as comorbidity and variable stages of type 2 diabetes including complications.

10. Publication and dissemination of nine steps above.

### **6.3 Study limitations and strengths**

#### **6.3.1 Limitations**

Most cultural adaptation requires a large research team, with different relevant expertise. As the health needs assessment studies were part of a PhD thesis, the author carried out all key aspects of each study, while expert advice and feedback were provided by the supervisory team. The study could have benefited from consulting one of self-management education programmes leaders, such as DESMOND trainers. However, if developing a programme for Saudi Arabia in the future such a step will be taken.

Each of the three studies has its own limitations, which were detailed in the earlier results chapters. However, for the general aim of the thesis, other limitations should be considered.

Study 1, only included self-management articles published in English. None of these studies aimed to assess an existing self-management programme. Instead each of these studies assessed a component or two of self-management. Further, only two of these studies were randomised controlled trials.

Study 2 represented a secondary data analysis for a general health survey (SHIS), which was not specifically designed to address type 2 diabetes. Further investigation

of points of interest in type 2 diabetes was limited by available data, as for example the data did not include data about prediabetes, family history, treatment received (e.g. oral hypoglycaemic, insulin), how long has the person been diagnosed with type 2 diabetes, if the person was diagnosed through screening or consultation. Moreover, the data in the original SHIS survey was based on self-response and relied less on clinical and laboratory investigations. Further, the data was cross sectional and lacked timeline, to be able to understand for example if good control proceeded or followed adapting healthy eating habits.

Study 3 involved focus groups and interviews with attendants at one health centre in Saudi Arabia. The only criteria for selection were being diagnosed with type 2 diabetes and agreeing to participate in the study. This convenience sample did not allow us to consider patient views by their clinical or personal circumstances. For example, we could have benefited from seeking the views of patients according to different clinical characteristics such as lengths of time living with diabetes and presence or absence of type 2 diabetes complications. Also, individuals with different demography such as age and education. Hypothetically people with different demography and/or different clinical conditions could have different perceptions and experiences in regards to management of type 2 diabetes. As the aim of the study was to inform the needs assessment for type 2 diabetes self-management programme in Saudi Arabia, the study could have benefited from a wider geographical distribution within Saudi Arabia. Also, the health professionals were limited to physicians, nutritionist, health educators and nurses and did not include crucial members of the health team such as occupational therapists and psychologists. Also, the health professionals did not have previous experience of any

self-management programme, likely as there was none available to them in Saudi Arabia.

### **6.3.2 Strengths**

This thesis involved multiple research methods (systematic review, quantitative and qualitative) to carry out the health needs assessment. Assessments were carried out in sequence and not parallel, which allowed the subsequent studies to be partially informed by the previous ones. By bringing the results from the three studies together, it has allowed the development of recommendations to culturally adapt a well-established self-management programme for the Saudi Arabia population.

### **6.4 Future study and proposal**

This thesis originally followed the cultural adaptation model suggested by Kumpfer and colleagues (2008); and then went on to provide a proposal (section 7.2) for the stages required to reach a culturally adapted self-management model particular to the Saudi Arabia type 2 diabetes individuals. According to this proposal the next step is to investigate the suitability of some globally available self-management programmes for type 2 diabetes, such as DESMOND and DSME. The future work will investigate this through qualitative focus groups formed of self-management education programme educators, and health leads and health professionals involved in the management of type 2 diabetes in Saudi Arabia.

## **6.5 Conclusions**

The findings from this thesis provides the only comprehensive health needs assessment to underpin the development of a national type 2 diabetes self-management programme in Saudi Arabia.

Currently, specialised health centres, which are the only source of care for people living with type 2 diabetes do not have the capacity to provide extensive self-management education for the high number of individuals with type 2 diabetes. This may result in many individuals unable to control their condition and possibly resulting in an increase in the prevalence of complications associated with type 2 diabetes. It is recommended that any self-management programme for type 2 diabetes in Saudi Arabia should include an auxiliary programme for self-management of prediabetes, which can include the family members of those, who are diagnosed with type 2 diabetes. People are likely to adopt a healthier lifestyle, after only being diagnosed with type 2 diabetes, hence the self-management programme should include awareness mechanisms for encouraging younger people to adopt healthier lifestyles before developing full diabetes. It is likely that both healthcare professionals and people with type 2 diabetes will welcome a self-management education programme. However, the programme needs to be suited to the community by tackling issues associated with the variety of cultural and local barriers identified for all genders and ages. A newly adapted programme must be piloted in cooperation with a globally recognised self-management education group, before reaching a final version to roll out nationally. The findings from this thesis provide the initial stage for this development.

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## **Appendices**

### **Appendix 1. Search strategy**

Self-Management of Type 2 Diabetes in Gulf Cooperation Council Countries: A Systematic Review

**This research will take into consideration the following aspects:**

- 1- Clear research questions and research objectives for focused and specific search results.
- 2- The research will target diabetes type 2, specifically self-management, health education, health promotion, diet and physical activity.
- 3- The focus of the research (inclusion and exclusion)
- 4- Define any alternative terminologies, abbreviation list, and other substitutes.
- 5- Use Boolean logic including “AND, OR”
- 6- Using multiple sources for the research.
- 7- Consider studies that were undertaken by the WHO and other relevant organisations.

### **Describing electronic database searches**

Using Medline and Embase (via Ovid, respectively, Midline 1996 to October Week 5 2015, Embase 1996 to 2015 Week 45). Using CINAHL (via EBSCOhost) and using PubMed.

1. (Medline) Ovid Search strategy on 25/11/2015

8- Terms	9- Search numbers
1- exp Diabetes Mellitus/	10- 214018
2- exp Diabetes Complications/	11- 65918
3- exp insulin resistance/	12- 54285
4- diabet\$.tw,ot.	13- 294010
5- (NIDDM or MODY or T2DM or T2D).tw,ot	14- 13506
6- impaired glucose toleranc\$.tw.	15- 6735
7- glucose intoleranc\$.tw.	16- 5118
8- insulin\$ resistanc\$.tw.	17- 45278
9- 1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8	18- 359966
10-exp Patient education/	19- 53005
11-exp Self Care/	20- 31786
12-exp Patient participation/	21- 14826
13-((self or symptom\$) adj (care or help or manag\$ or directed or monitor\$ or efficacy or admin\$)).tw	22- 60603
14-((health or patient\$) adj2 (educat\$ or information or promotion)).tw	23- 71733

15-10 OR 11 OR 12 OR 13 OR 14	24- 191819
16-Saudi Arabia OR Kuwait OR Bahrain OR Emirates OR Qatar OR Oman	25- 11044
17-9 AND 15 AND 16	26- 90

2. (Embase) Ovid Search strategy on 25/11/2015

27- Terms	28- Search numbers
18-exp Diabetes Mellitus/	29- 551561
19-exp Diabetes Complications/	30- 551561
20-exp insulin resistance/	31- 85314
21-diabet\$.tw,ot.	32- 527430
22-(NIDDM or MODY or T2DM or T2D).tw,ot	33- 31035
23-impaired glucose toleranc\$.tw.	34- 11316
24-glucose intoleranc\$.tw.	35- 8638
25-insulin\$ resistanc\$.tw.	36- 75214
26-1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8	37- 690141
27-exp Patient education/	38- 75667
28-exp Self Care/	39- 45305

29-exp Patient participation/	40- 16639
30-((self or symptom\$) adj (care or help or manag\$ or directed or monitor\$ or efficacy or admin\$)).tw	41- 94780
31-((health or patient\$) adj2 (educat\$ or information or promotion)).tw	42- 112481
32-10 OR 11 OR 12 OR 13 OR 14	43- 285196
33-Saudi Arabia OR Kuwait OR Bahrain OR Emirates OR Qatar OR Oman	44- 19035
34-9 AND 15 AND 16	45- 192

### 3. CINAHL (EBSCOhost) Search strategy on 25/11/2015

46-	47- Terms	48- Search numbers
49- S1	50- (MH "Diabetes Mellitus, Type 2") OR (MH "Diabetes Mellitus") OR (MH "Diabetic Patients")	51- 58725
52- S2	53- (MH "Insulin Resistance")	54- 6199
55- S3	56- (MH "Glucose Intolerance")	57- 1536

58- S4	59- ("non insulin* depend*" OR "noninsulin* depend*" OR "non insulin* depend*" OR "noninsulin* depend*").ti,ab	60- 78
61- S5	62- (NIDDM OR MODY OR T2DM OR T2D).ti,ab	63- 28
64- S6	65- S1 OR S2 OR S3 OR S4 OR S5	66- 63150
67- S7	68- (MH "Self Care")	69- 20896
70- S8	71- (MH "Self Administration")	72- 1912
73- S9	74- ti self care or ti self help or ti self manag* or ti self directed or ti self monitor* or ti self efficacy or ti self admin*	75- 11328
76- S10	77- (MH "Consumer Participation")	78- 10705
79- S11	80- (MH "Patient Education") OR (MH "Health Education") OR (MH "Diabetes Education")	81- 58825
82- S12	83- (MH "Patient Centered Care")	84- 14895
85- S13	86- ab self care or ab self help or ab self manag* or ab self directed or ab self monitor* or ab self efficacy or ab self admin*	87- 938381
88- S14	89- ti health N2 educat* or ti health N2 information or ab health N2 educat* or ab health N2 information	90- 9380

91- S15	92- ti patient* N2 educat* or ti patient* N2 information or ab patient* N2 educat* or ab patient* N2 information	93- 5771
94- S16	95- ti patient* participat* or ab patient* participat* or ti consumer* participat* or ab consumer* participat	96- 820
97- S17	98- (MH "Empowerment")	99- 7798
100- S18	101- ti empower* or ab empower*	102- 3954
103- S19	104- (MH "Saudi Arabia")	105- 1872
106- S20	107- (MH "Kuwait")	108- 395
109- S21	110- (MH "Oman")	111- 212
112- S22	113- (MH "Bahrain")	114- 183
115- S23	116- (MH "Qatar")	117- 208
118- S24	119- (MH "United Arab Emirates")	120- 476
121- S25	122- S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18	123- 982629
124- S26	125- S19 OR S20 OR S21 OR S22 OR S23 OR S24	126- 3254
127- S27	128- S6 AND S25 AND S26	129- 57

#### 4. PubMed Search strategy on 25/11/2015

((((((((((((diabetes) OR diabetes mellitus) OR diabetes type2) OR insulin dependent diabetes mellitus) OR glucose intolerance) OR insulin resistance) OR NIDDM) OR T2DM) OR MODY)) AND (((((((((((((self-care) OR self-management) OR self-administration) OR consumer participation) OR patient centred) OR patient participation) OR patient monitor) OR patient manage) OR patient measure) OR patient education) OR patient Diet) OR patient activity) OR patient adjust))) AND ((((((Saudi Arabia) OR Qatar) OR Oman) OR Kuwait) OR Bahrain) OR emirates)

Items found: 398

#### **Describing journal hand searches (2013-2015)**

- 1- International Journal of Diabetes Care
- 2- Diabetes Research and Clinical Practice
- 3- American Diabetes Association Journals (Diabetes, Diabetes Care, Clinical Diabetes, Diabetes Spectrum)
- 4- Saudi Medical Journal, Omani Medical Journal, Kuwait Medical Journal, Bahrain Medical Bulletin, Qatar Medical Journal

#### **Describing the methods used to search relevant organisation sources**

- 1- Saudi Diabetes & Endocrine Association (<http://sdea.org.sa/>)
- 2- MENA Diabetes Leadership Forum 2010 Dubai  
([https://www.novonordisk.com/content/dam/Denmark/HQ/aboutus/documents/MENA\\_Diabetes\\_briefing\\_book\\_EN.pdf](https://www.novonordisk.com/content/dam/Denmark/HQ/aboutus/documents/MENA_Diabetes_briefing_book_EN.pdf))

3- Ministry of Health Saudi Arabia Research Gate

([http://www.researchgate.net/institution/Ministry of Health Saudi Arabia](http://www.researchgate.net/institution/Ministry_of_Health_Saudi_Arabia))

4- World Health Organization

([http://search.who.int/search?q=SELF+MANAGEMENT+TYPE+2+DIABETES&spell=1&ie=utf8&site=who&client=en\\_r&proxystylesheet=en\\_r&output=xml\\_no\\_dtd&access=p&lr=lang\\_en](http://search.who.int/search?q=SELF+MANAGEMENT+TYPE+2+DIABETES&spell=1&ie=utf8&site=who&client=en_r&proxystylesheet=en_r&output=xml_no_dtd&access=p&lr=lang_en))

### **Describing others searches included**

- 1- The reference lists of all records included in the review and relevant systematic reviews will be hand searched to identify additional records for inclusion.

## Appendix 2. Quality assessment

Quality assessment	Authors	Al-Daghri et al. 2014	Abduelkarem & Sackville. 2009 [	Mohamed et al. 2013 [19]	Al-Sinani et al. 2010	Al-Shahrani et al. 2012	Al Hayek et al. 2013	Al Asmary et al. 2013	Omer et al. 2015
	Yes 2, Partial 1, No 0, N/A not applicable								
1. Question / objective sufficiently described?	2	2	2	2	2	2	2	2	1
2. Study design evident and appropriate?	1	0	2	1	2	2	2	2	1

3. Method of subject / comparison group selection or source of information/input variables described and appropriate?	1	0	2	2	2	2	2	1
4. Subject (and comparison group, if applicable) characteristics sufficiently described?	1	2	2	2	2	2	2	0
5. If interventional and random allocation was	N/A	N/A	0	N/A	N/A	N/A	N/A	N/A

possible, was it described?								
6. If interventional and blinding of investigators was possible, was it reported?	N/A	N/A	0	N/A	N/A	N/A	N/A	N/A
7. If interventional and blinding of subjects was possible, was it reported?	N/A	N/A	0	N/A	N/A	N/A	N/A	N/A
8. Outcome and (if applicable) exposure measure(s) well defined	2	1	2	2	2	1	2	1

and robust to measurement / misclassification bias? Means of assessment reported?								
9. Sample size appropriate?	2	1	2	2	2	2	0	2
10. Analytic methods described/justified and appropriate?	1	2	2	2	0	1	2	0

11. Some estimate of variance is reported for the main results?	2	2	2	2	2	0	2	0
12. Controlled for confounding?	0	0	2	0	0	0	0	0
13. Results reported in sufficient detail?	2	2	2	2	2	0	2	0
14. Conclusions supported by the results?	1	1	2	2	1	1	1	0
Summary score	0.68	0.59	0.78	0.86	0.77	0.59	0.77	0.27

### Appendix 3. Explanation for coding category

Codes	Subheadings	Description
Education / Knowledge	Dietary	Food habits correction and adopting healthy food knowledge are given to individuals. Interventionists work with participants together about a dietary program.
	Physical Activity Guidance	A guideline about how physical activities to be done.
	130- Other Sources	Sources are providing anything to improve self-management principles.
Lifestyle	Healthy Food	Incorporating nutritional management into lifestyle
	Being Active	Incorporating physical activity into lifestyle
	Monitoring	Monitoring blood glucose and other parameters and interpreting and using the results for self-management decision making
	Taking Medications	Using medication(s) safely and for maximum therapeutic effectiveness
Skills	Problem Solving	Preventing, detecting, and treating acute complications

	Reducing Risks	Preventing detecting, and treating chronic complications
	Healthy Coping	Developing personalised strategies to address psychosocial issues and concerns
Support	Monitoring & Feedback	Support in the form of health monitoring and/or feedback on a regimen/promoted lifestyle change.
	Psychological Interventions	Includes professional counselling or therapy for participants to provide psychological support.
	Peer Support	It is provided by peers that refer to other patients who have diabetes type 2. This may be in the form of buddy system or through interaction with support groups.
	Financial Incentives	The incentives are used to motivate participants to follow the steps in the whole process of the intervention. These aim to increase participants' willingness levels to perform better and enhance their enthusiasm.

### Appendix 4. Included variables

Variables	New response options	Original variable response categories	Data manipulation and the new categories
<b>Sociodemographic</b>			
Gender	Male =1 Female=2	Male =1 Female=2	No data manipulation required form original variable
Age Educational Level	15-54=1  ≥55 =2  Primary school or less=1  Elementary or high school or college degree or higher education completed=2	Age in years specified in open text field  Don't know = 77  Declined to response = 88  Can't read or write=1, Can read and write=2, Primary school completed=3, Intermediate school completed=4, High school completed=5  College/University completed=6 , Post graduate degree=7, Technical training=8 Don't know=77 ,Decline to respond=88	categories age continuous variable to one of two groups  Collapse education variables to: 1= Primary school or less 2= Elementary or high school or college / university or post graduate degree, and technical training in College degree or higher education completed

marital status	Married=1  Not married=2	Never married=1, Currently married=2 Separated=3, Divorced=4 ,Widowed=5 Don't know=77 , Decline to respond=88	Combine marital variable in two: 1= Married 2= Not married
<b>History of diagnosis</b>			
height  weight	Normal weight=1  Overweight or obese=2	Enter height (Van Tulder et al.): Specify in open text field Declined measurement or could not measure participant's height=88  Enter weight (kg): Specify in open text field Too heavy for scale=2 Declined measurement or could not measure participant's height=88	Use weight and height variables to calculate BMI calculate BMI as weight (kg)/ height <sup>2</sup> (m <sup>2</sup> ) BMI classified into: 1= normal weight, if BMI 18.5 to 24.9; 2= overweight, if BMI 25.0 to 29.9; AND obese, if BMI greater than or equal to 30.0
blood pressure	No=0  Yes=1	Yes=1      No=0  Don't know=77 Decline to respond=88	No data manipulation required form original variable
Chronic Diseases  Stroke? Mi? CHF? AFIB? Asthma? Renal Failure Hypercholesterolemia?	No=0  Yes=1	1=Yes  0=No  77=Don't know  88=Decline to respond	Yes to chronic disease if: cerebral infection, myocardial infarction, heart failure, atrial fibrillation, asthma, renal failure, and hypercholesterolemia, = Yes none of above conditions reported = No
<b>General health</b>			
Self-related health	Very good or good =1  Fair or poor =2	1=Excellent  2=Very good	collapse self-related health variable into two categories:

		3=Good 4=Fair 5=Poor 77=Don't know 88=Decline to respond	1= Very good or good 2= Fair or poor
Compared with 12 months ago	Better or same =1 Worse=2	3=Better 1=Worse 2=About the same 77=Don't know 88=Decline to respond	No data manipulation required from original variable
<b>Lifestyle</b>			
Do you smoke	No=0 Yes=1	Yes=1 No=0 Don't know=77 Decline to respond=88	If answer 0=No that mean never smoker, if answer 1= Yes, go to the smoking status question if answer 0=
Smoking current	No=0 Yes=1	Yes=1 No=0 Don't know=77 Decline to respond=88	No that mean previous smoker. If answer 1= Yes that mean current smoker
<b>Diet</b>			
Fat consumption	Vegetable or olive oils =1 Animal fat or margarine or none in particular =2	Vegetable oil=1 Olive oil=2 Butter or ghee=3 Margarine=4 Other, please specify=5 If Other, specify in open text field None in particular=6 None used=7 Don't know=77 Decline to respond=88	Collapse diet fat variable into two categories: Vegetable or olive oils =1 Butter or ghee to Animal fat =2
Fruit and vegetables intake	0 – 2 =1 3+ =2	Number of servings=1 Specify in open text field Don't Know=77 Decline to respond=88	Combine fruits and vegetables diet variable , categories diet fruit and vegetables serving

			continuous variable to one of two groups: Daily serving fruits and vegetables and will collected, if 0-2 times =1, if serving to 3 times or above per day= 2
Red meat, pro meat, and chicken serving	0-7 =1 8+ =2	Number of days=1 Don't Know=77 Decline to respond=88	Combine serving how many days per week eat of meat, processed meats, and chicken categories diet meat, processed meats, and chicken continuous variable to one of two groups: will collected, if eat at lest 0-7 time per week=1, if 8 times or above per week =2,
Eat fast food per week	0-1 =1 2+ =2	Number of meals=1 Don't Know=77 Decline to respond=88	categories diet fast food continuous variable to one of two groups: if eat at lest 1 day per week=1, if 2 days or above per week =2,
<b>Sedentary</b>			
Hours spent watch tv	0-3 =1 4+ =2	Enter number of hours _____ =1 Don't know=77 Decline to respond=88	categories tv comp time continuous variable to one of two groups: if spent at least 0-3 hours per day=1, if 4 hours or above per day =2,

Hours spent sitting	0-4=1 5+ =2	Hours per day=1 Minutes per day=2 Don't know=77 Decline to respond=88	categories sitting time continuous variable to one of two groups: if spent at least 0-4 hours per day=1, if 5 hours or above per day =2,
<b>Physical activity</b>			
Physical mod activity sport	No=0 Yes=1	Number of days=1 Don't know=77 Decline to respond=88  Hours per day=1 Minutes per day=2 Don't know=77 Decline to respond=88	categories phy sport days and time continuous variable to combined two variables how many days per week and how many time a day then counted as mints per week. According WHO guideline use 150 mints for moderate and 75 mints for vigorous.=1 that mean Yes , if not achieved the minimum for those =0 that mean No
Physical vigactivity sport	No=0 Yes=1	Number of days=1 Don't know=77 Decline to respond=88  Hours per day=1 Minutes per day=2 Don't know=77 Decline to respond=88	
Physical guide sport	No=0 Yes=1		If moderate or vigorous physical activity Yes then physical activity guidelines for sport achieved, if No then physical activity guidelines for sport not achieved.

Physical mod activity work	No=0 Yes=1	Number of days=1 Don't know=77 Decline to respond=88  Hours per day=1 Minutes per day=2 Don't know=77 Decline to respond=88	categories phy sport days and time continuous variable to combined two variables how many days per week and how many time a day then counted as mints per week. According WHO guideline use 150 mints for moderate and 75 mints for vigorous.=1 that mean Yes , if not achieved the minimum for those =0 that mean No
Physical vigactivity work	No=0 Yes=1	Number of days=1 Don't know=77 Decline to respond=88  Hours per day=1 Minutes per day=2 Don't know=77 Decline to respond=88	
Physical guide work	No=0 Yes=1		If moderate or vigorous physical activity Yes then physical activity guidelines for work achieved, if No then physical activity guidelines for work not achieved
Walking behaviour more than 10 mints per day	No=0 Yes=1	Yes=1 No=0 Don't know=77 Decline to respond=88	No data manipulation required form original variable
History of diagnosis with diabetes			
Diabetes	No=0 Yes=1	1=Yes 0=No 77=Don't know 88=Decline to respond	No data manipulation required form original variable

Type of diabetes	Type 1=1 Type 2=2	1=Type 1 2=Type 2 77=I don't know 88=decline to respond	No data manipulation required from original variable
Treatment of diabetes	Uncontrolled (Not treated) =1 Controlled (Treated)=2	Yes=1 No=0 Don't know=77 Decline to respond=88	Prescribed treated uncontrolled or controlled, combined three variables, if prescribed treated insulin or drugs (medication) or special prescribed diet then treated controlled, if not prescribed any of them then untreated controlled
Measure HbA1c	$\leq 6.99\% = 1$ $\geq 7.0\% = 2$	Enter HgbA1C (%): HgbA1C not measured=0	categories HbA1c continuous variable to defined the result to two, if between 6.5-6.99% diabetic with good glycaemic control=1 If $\geq 7.0\%$ diabetic with poor glycaemic control=2
Health seeking			
Use health services	Within the last 2 years for illness or injury=1 Within the last 2 years for other services=2	1=Enter year 995=I have never been to a hospital or clinic or doctor for medical attention. 77=Don't know 88=Decline to respond For reason Illness=1 Injury=2 Immunization=3 Other preventive service=4	Combined two variables last time of visiting and respond if visit clinic or hospital or other health professional

		Other, please specify=5 If Other, specify in open text field Don't know=77 Decline to respond=88	
--	--	--	--

**Appendix 5. Type 2 diabetes analysis: Beta percentage change between largest and smallest models**

<b>Variable</b>	<b>Beta; largest model</b>	<b>Beta; smallest model</b>	<b>% change between models</b>
Gender	-0.640	-0.567	12.87
Age	1.252	1.226	2.12
BMI	-0.928	-0.900	3.11
Hypertension	1.415	1.357	4.27
Chronic disease diagnosis	0.704	0.676	4.14
Self-reported health condition compared with 12 months ago	0.631	0.591	6.76
Dietary fast food intake	-0.743	-0.710	4.64
Walking behaviour	-0.251	-0.242	3.71

Largest model refers to the first multivariate model with all variables included

Smallest model refers to the model with the five statistically significant ( $p < 0.05$ ) variables

## Appendix 6. Results of Multivariate Analysis of Baseline Factors and Their Interactions

Variables	p-value
Gender	< 0.001
Age	< 0.001
BMI	< 0.001
Hypertension	< 0.001
Chronic disease diagnosis	< 0.001
Self-reported health condition compared with 12 months	< 0.001
Dietary fast food intake	< 0.001
Walking behaviour	< 0.001
Gender (male)*Age (van Dam et al.)	0.532
Gender (male)*BMI(obese)	0.060
Gender(male)*Hypertension (yes)	0.185
Gender (male)* Chronic disease diagnosis (yes)	0.915
Gender (male)* Self-reported health condition compared with 12 months (worse)	0.422
Gender (male)* Dietary fast food intake (no)	0.262
Gender (male)* Walking behaviour (yes)	0.670
Age (van Dam et al.)*BMI (obese)	0.596
Age (van Dam et al.)* Hypertension (yes)	0.267
Age (van Dam et al.)* Chronic disease diagnosis (yes)	< 0.001
Age (van Dam et al.)* Self-reported health condition compared with 12 months (worse)	0.002
Age (van Dam et al.)* Dietary fast food intake (no)	0.575
Age (van Dam et al.)* Walking behaviour (yes)	0.861
BMI (obese)* Hypertension (yes)	0.449













**Appendix 11. Ethical approval for qualitative study from university of Glasgow**

**Appendix 12. Consent form for professionals in English and Arabic language**



**University of Glasgow** | College of Medical,  
Veterinary & Life Sciences

Project Number:  
Subject Identification Number:

**CONSENT FORM FOR PROFESSIONALS**

**Title of Project:**

Cultural Adaptation of Self-Management of Type 2 Diabetes in Saudi Arabia  
(Qualitative Study)

**Name of Researcher(s):**

Thamer Alslamah (Interviewer)  
Professor Craig Melville  
Dr Barbara Nicholl  
Dr Deborah Kinnear  
Dr Leanne Harris

**Please initial box**

I confirm that I have read and understand the information sheet dated 22<sup>nd</sup> July 2018 for the above study and have had the opportunity to ask questions.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected.

I agree to my anonymised data being archived and those electronic versions of these will be stored in J drive on password protected University of Glasgow computers

I understand my information will be stored for additional future research and I will not be able to be identified from any analyses performed by approved researchers

I understand that if some of my views are quoted in a report or published papers, this will be done in a way that ensures that I cannot be identified

I understand that, subject to my permission, the interview will be audio recorded for the purpose of the study and that any recordings will be destroyed at the end of the study. Depersonalised transcripts of the recordings will be kept for a period of 10 years to ensure accurate reporting in any future publications.

I agree to take part in the above study

_____ Name of subject	_____ Date	_____ Signature
_____ Name of Person taking consent (if different from researcher)	_____ Date	_____ Signature
_____ Researcher	_____ Date	_____ Signature

(1 copy for subject; 1 copy for researcher)



رقم البحث:

رقم تعريف المشارك:

نموذج الموافقة للممارسين الصحيين

عنوان البحث

التكيف الثقافي للإدارة الذاتية لمرض السكري من النوع الثاني في المملكة العربية السعودية (دراسة نوعية)

اسم الباحث (الباحثون)

ثامر السلامة

الدكتورة باربرا نيكول

البروفيسور كريج ميلفيل

الدكتورة ديبورا كينير

الدكتورة ليان هيرز

يرجى وضع علامة صح في المربع:

١- أوكد أنني قمت بقراءة وفهم ورقة المعلومات للدراسة المذكورة أعلاه في تاريخ ٢٢ يوليو ٢٠١٨، وقد أتاحت لي الفرصة للإجابة على الاسئلة المطروحة.

٢- أوكد أن مشاركتي هي طوعية وأني حر في الانسحاب في أي وقت دون إبداء أي سبب ودون أن تتأثر حقوقي القانونية.

٣- أوافق على بياناتي مجهولة الهوية التي يتم أرشفتها وأن هذه الإصدارات الإلكترونية منها وسيتم تخزينها في انظمة الحفظ (ج) على أجهزة كمبيوترات جامعة جلاسكو محمية بكلمة مرور.

٤-وافق أنه سيتم تخزين معلوماتي للبحوث المستقبلية وانه لا يمكن لاي باحث تحديد أي من معلوماتي اثناء التحليلات.

٥- أوافق أنه إذا تم اقتباس بعض من وجهات نظري في تقرير أو أوراق منشورة، سيتم ذلك بطريقة تضمن عدم إمكانية تحديد هويتي.

٦- اوافق أنه بناء على إذن مني، سيتم تسجيل المقابلة الصوتية لغرض الدراسة وأن أي تسجيلات سيتم مسحها في نهاية الدراسة وسيتم الاحتفاظ بنسخ محولة من التسجيلات لفترة ١٠ سنوات لضمان الإبلاغ الدقيق في أي منشورات في المستقبل.

٧- أوافق على المشاركة في الدراسة المذكورة أعلاه.

اسم المشارك:

التاريخ:

التوقيع:

اسم الشخص الذي أخذ الموافقة إذا كان مختلفًا عن الباحث:

التاريخ:

التوقيع:

الباحث:

التاريخ:

التوقيع:

نسخة واحدة للمشارك ونسخة واحدة للباحث

**Appendix 13. Consent form for participant interviews in English and Arabic language**



**University of Glasgow** | College of Medical,  
Veterinary & Life Sciences

Project Number:  
Subject Identification Number:

**CONSENT FORM FOR PARTICIPANT INTERVIEWS**

**Title of Project:**

Cultural Adaptation of Self-Management of Type 2 Diabetes in Saudi Arabia  
(Qualitative Study)

**Name of Researcher(s):**

Thamer Alslamah (Interviewer)  
Professor Craig Melville  
Dr Barbara Nicholl  
Dr Deborah Kinnear  
Dr Leanne Harris

**Please initial box**

I confirm that I have read and understand the information sheet dated 22<sup>nd</sup> July 2018 for the above study and have had the opportunity to ask questions.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected.

I agree to my anonymised data being archived and that electronic versions of these will be stored in J drive on password protected University of Glasgow computers

I understand my information will be stored for additional future research and I will not be able to be identified from any analyses performed by approved researchers

I understand that if some of my views are quoted in a report or published papers, this will be done in a way that ensures that I cannot be identified

I understand that, subject to my permission, the interview will be audio recorded for the purpose of the study and that any recordings will be destroyed at the end of the study. Depersonalised transcripts of the recordings will be kept for a period of 10 years to ensure accurate reporting in any future publications.

I agree to take part in the above study

_____ Name of subject	_____ Date	_____ Signature
_____ Name of Person taking consent (if different from researcher)	_____ Date	_____ Signature
_____ Researcher	_____ Date	_____ Signature

(1 copy for subject; 1 copy for researcher)



رقم البحث:

رقم تعريف المشارك:

نموذج الموافقة للمرضى

عنوان البحث

التكيف الثقافي للإدارة الذاتية لمرض السكري من النوع الثاني في المملكة العربية السعودية (دراسة نوعية)

اسم الباحث (الباحثون)

ثامر السلامة

الدكتورة باربرا نيكول

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يرجى وضع علامة صح في المربع:

١- أوكد أنني قمت بقراءة وفهم ورقة المعلومات للدراسة المذكورة أعلاه في تاريخ ٢٢ يوليو ٢٠١٨، وقد أتيت لي الفرصة للإجابة على الاسئلة المطروحة.

٢- أوكد أن مشاركتي هي طوعية وأني حر في الانسحاب في أي وقت دون إبداء أي سبب ودون أن تتأثر حقوقي القانونية.

٣- أوافق على بياناتي مجهولة الهوية التي يتم أرشفتها وأن هذه الإصدارات الإلكترونية منها وسيتم تخزينها في انظمة الحفظ (ج) على أجهزة كمبيوترات جامعة جلاسكو محمية بكلمة مرور.

٤-وافق أنه سيتم تخزين معلوماتي للبحوث المستقبلية وانه لا يمكن لاي باحث تحديد أي من معلوماتي اثناء التحليلات.

٥- أوافق أنه إذا تم اقتباس بعض من وجهات نظري في تقرير أو أوراق منشورة، سيتم ذلك بطريقة تضمن عدم إمكانية تحديد هويتي.

٦- اوافق أنه بناء على إذن مني، سيتم تسجيل المقابلة الصوتية لغرض الدراسة وأن أي تسجيلات سيتم مسحها في نهاية الدراسة وسيتم الاحتفاظ بنسخ محولة من التسجيلات لفترة ١٠ سنوات لضمان الإبلاغ الدقيق في أي منشورات في المستقبل.

٧- أوافق على المشاركة في الدراسة المذكورة أعلاه.

اسم المشارك:

التاريخ:

التوقيع:

اسم الشخص الذي أخذ الموافقة إذا كان مختلفًا عن الباحث:

التاريخ:

التوقيع:

الباحث:

التاريخ:

التوقيع:

نسخة واحدة للمشارك ونسخة واحدة للباحث

## **Appendix 14. Professionals participant information sheet in English and Arabic language**



**University of Glasgow** | Institute of Health & Wellbeing

**PROFESSIONALS**  
**PARTICIPANT**

### **INFORMATION SHEET**

#### **Cultural Adaptation of Self-Management of Type 2 Diabetes in Saudi Arabia (Qualitative Study)**

My name is Thamer Alslamah, a teaching assistant from AlQassim University. As part of my research for my doctoral training in the University of Glasgow, I am conducting research with the title “Cultural Adaptation of Self-Management of Type 2 Diabetes in Saudi Arabia (Qualitative Study)”. You are being invited to take part as a participant in this research. Before you decide, please read the following information carefully. It will help you understand why the research is being done, and what will happen if you decide to participate. If there is anything that you would like to ask me regarding the research, please don't hesitate to do so. Take your time to decide whether or not you agree to take part.

#### **Purpose of the study**

This study is designed to explore local health care providers and individuals' opinions and experience on the medical and social factors that can enhance or limit diabetes self-management education (DSME). The results of the study will be shared with Saudi Ministry of Health to consider the viability of carrying larger scale qualitative and pilot studies on the feasibility and employability of DSME programmes in Saudi Arabia.

#### **Why you have been invited to take part**

You have been invited to participate, to gather data from you as professionals responsible for their treatment and care because you have more than one year's experience of working with individuals with type 2 diabetes in King Fahad Specialist Hospital (Diabetic and Endocrinology Centre) in Al Qassim.

### **Taking part in the study**

It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part, you will still be able to withdraw at any time without giving any reasons. There will be no consequences to you if you withdraw. Your participation will not affect your career or your practice.

If you agree to take part in this research, I will ask you to attend a focus group with other colleagues in King Fahad Specialist Hospital (Diabetic and Endocrinology Centre) in Al Qassim. The focus group will take about two hours. You will be asked to talk on your experience of care that you have been providing for your diabetes visitors. The focus group will be recorded with an audio recorder and then transcribed and analysed with the research team. The audio recording will be saved until the study has ended as source data. The data will be kept for 10 years.

### **What should I do if I want to take part**

If you would like to take part please contact myself, Thamer Alslamah at phone +966551307777 or email [t.alslamah.1@research.gla.ac.uk](mailto:t.alslamah.1@research.gla.ac.uk).

### **Possible benefits and risks**

You will receive no direct benefit from taking part in the research. There are also no risks for you in taking part, whether on your career or your practice. The information you provide us in this research will give us a better understanding of how to improve the control of blood glucose levels, which can contribute in delaying or mitigating diabetes complications.

### **Confidentiality**

All information that we collect from you, your personal information and the responses that you provide, during the course of the research will be kept strictly confidential. The information will be stored for additional future research and any information that can identify you such as your name and contact information will be removed. Some of your views may be quoted in a report or published papers, this will be done in a way that ensures that you cannot be identified. Therefore, all opinions

you provide cannot be traced back to you by anyone else other than the research team. However, if we feel that there is any information you provide that can be seriously harmful to yourself or others, we may be obliged to contact relevant authorities.

### **Publication of results**

The results of this research will be presented in my doctoral thesis. It will also be published in a scientific journal and presented at a scientific conference. You can contact me directly if you would like to obtain a copy of the published results. You will not be personally identified in any report/publication.

### **Funding and reviewer body**

This research is part of my doctoral training, fully funded by the AIQassim University. This study has been reviewed by the College of Medical Veterinary and Life Sciences Ethic Committee, University of Glasgow, and the Ethics Committee of Ministry of Health in Saudi Arabia.

### **Contact for further Information**

If you need to ask further questions, please don't hesitate to contact the supervisor  
Professor Craig Melville

Tel: +44 (0)141 211 3878

Fax :+44 (0) 141 211 0356

Email: [Craig.Melville@glasgow.ac.uk](mailto:Craig.Melville@glasgow.ac.uk)

Thank you for your consideration.

Best regards,

Thamer Alslamah



## معلومات المشاركين للممارسين الصحيين

### عنوان البحث

التكيف الثقافي للإدارة الذاتية لمرض السكري من النوع الثاني في المملكة العربية السعودية (دراسة نوعية)  
اسمي ثامر السلامة، عضو هيئة تدريس في جامعة القصيم كلية العلوم الطبية التطبيقية. كجزء من بحثي في دراسة  
الدكتوراه في جامعة جلاسكو، أقوم بإجراء بحث بعنوان " التكيف الثقافي للإدارة الذاتية لمرض السكري  
من النوع الثاني في المملكة العربية السعودية" (دراسة نوعية)

أنت مدعو للمشاركة في هذا البحث. قبل أن تقرر، يرجى قراءة المعلومات التالية بعناية. سيساعدك ذلك على فهم  
سبب إجراء البحث، وماذا سيحدث إذا قررت المشاركة. إذا كان هناك أي شيء تريد أن تسألني بشأن البحث، فلا  
تتردد في القيام بذلك. خذ وقتك لتقرر ما إذا كنت توافق على المشاركة أم لا.

### الغرض من الدراسة

تم تصميم هذه الدراسة لاستكشاف من مزودي الرعاية الصحية المحليين وآراء المرضى والخبرات حول العوامل  
الطبية  
والاجتماعية التي يمكن أن تعزز أو تحد من تعليم الإدارة الذاتية لمرضى السكري. وسيتم تقاسم نتائج الدراسة مع  
وزارة  
الصحة السعودية للنظر في إمكانية إجراء دراسات نوعية ودراسية على نطاق أوسع حول جدوى برامج تعليم الإدارة  
الذاتية لمرضى السكري وإمكانية توظيفها في المملكة العربية السعودية.

### لماذا تم دعوتك للمشاركة

لقد تم اختيارك كمشارك، لجمع البيانات كونك أحد المهنيين الصحيين المسؤولين عن العلاج والرعاية في مستشفى الملك فهد التخصصي (مركز السكري والغدد الصماء) في القصيم ولديك خبرة أكثر من سنة في هذا المجال.

### المشاركة في الدراسة

الأمر متروك لك لتقرر ما إذا كنت ستشارك أم لا. إذا قررت المشاركة، سيتم إعطاؤك ورقة المعلومات هذه ليتم الاحتفاظ بها وتطلب منك التوقيع على نموذج موافقة. إذا قررت المشاركة، فستظل قادراً على الانسحاب في أي وقت دون إبداء أسباب لن تكون هناك عواقب عليك إذا انسحبت. مشاركتك لن تؤثر على حياتك المهنية أو ممارستك.

بمجرد موافقتك على المشاركة في هذا البحث، سوف أقوم بإجراء مقابلة معك وشرح اجراءات مجموعة المناقشة في مستشفى الملك فهد التخصصي (مركز السكري والغدد الصماء) في القصيم. سوف تستغرق مجموعة المناقشة حوالي ساعتين كل مجموعه تحوي من ٤ الي ٦ مشاركيين. سيتم طرح أسئلة حول تجربتك مع الرعاية التي تقدمها لمرضى السكري. سيتم تسجيل مجموعة المناقشة في تسجيل صوتي ثم يتم نقلها وتحليلها مع فريق البحث. سيتم الاحتفاظ بها كامصدر حتى نهاية البحث. وسيتم حفظ البيانات لمدة عشر سنوات.

### ماذا افعل إذا اردت المشاركة

إذا كنت ترغب بالمشاركة يرجى الاتصال على ثامر السلامة هاتف رقم ٠٠٩٦٦٥٥١٣٠٧٧٧٧ او البريد

[t.alslamah.1@research.gla.ac.uk](mailto:t.alslamah.1@research.gla.ac.uk) الإلكتروني

### الفوائد والمخاطر المحتملة

لن تتلقى أي فائدة مباشرة من المشاركة في البحث. لا توجد أي مخاطر بالنسبة لك في المشاركة، سواء في مهنتك أو ممارستك. إن المعلومات التي تزودنا بها في هذا البحث ستعطينا فهماً أفضل لكيفية تحسين التحكم في مستوى السكر في الدم، والذي يمكن أن يسهم في تأخير أو تخفيف مضاعفات السكري.

### السرية

جميع المعلومات التي نجمعها منك، ومعلوماتك الشخصية والردود التي تقدمها، خلال فترة البحث ستبقى سرية للغاية. سيتم التعرف عليك عن طريق رقم معرف، وسيتم إزالة أي معلومات يمكن أن تعرف هويتك مثل اسمك ومعلومات الاتصال الخاصة بك. وسيتم استخدام المعلومات في البحوث المستقبلية. لذلك لا يمكن تتبع جميع الآراء التي تقدمها لك من قبل أي شخص آخر غير فريق البحث. ومع ذلك، إذا شعرنا أن هناك أية معلومات تقدمها والتي يمكن أن تكون ضارة جدًا لنفسك أو للآخرين، فقد نكون ملزمين بالاتصال بالسلطات ذات الصلة.

### نشر النتائج

سيتم عرض نتائج هذا البحث في رسالة الدكتوراه. كما سيتم نشرها في مجلة علمية وعرضها في مؤتمر علمي. يمكنك الاتصال بي مباشرة إذا كنت ترغب في الحصول على نسخة من النتائج المنشورة. لن يتم التعرف عليك شخصيا في أي تقرير منشور.

### التمويل والمراجع

هذا البحث هو جزء من دراستي في الدكتوراه، ممول بالكامل من جامعة القصيم. تمت مراجعة هذه الدراسة من قبل لجنة أخلاقيات الطب والطب البيطري والعلوم الحياتية بجامعة جلاسكو ولجنة الأخلاقيات التابعة لوزارة الصحة في المملكة العربية السعودية.

### الاتصال للحصول على مزيد من المعلومات

إذا كنت بحاجة لطرح مزيد من الأسئلة، فلا تتردد في الاتصال بالمشرف البرفيسور كريك مليفل

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## **Appendix 15. Participant interviews information sheet in English and Arabic language**



**University of Glasgow** | Institute of Health & Wellbeing

### **PARTICIPANT INTERVIEWS INFORMATION SHEET**

#### **Cultural Adaptation of Self-Management of Type 2 Diabetes in Saudi Arabia (Qualitative Study)**

My name is Thamer Alslamah, a teaching assistant from AlQassim University. As part of my research for my doctoral training in the University of Glasgow, I am conducting research with the title “Cultural Adaptation of Self-Management of Type 2 Diabetes in Saudi Arabia (Qualitative Study)”. You are being invited to take part as a participant in this research. Before you decide, please read the following information carefully. It will help you understand why the research is being done, and what will happen if you decide to participate. If there is anything that you would like to ask me regarding the research, please don't hesitate to do so. Take your time to decide whether or not you agree to take part.

#### **Purpose of the study**

This study is designed to explore local health care providers and individuals' opinions and experience on the medical and social factors that can enhance or limit diabetes self-management education (DSME). The results of the study will be shared with Saudi Ministry of Health to consider the viability of carrying larger scale qualitative and pilot studies on the feasibility and employability of DSME programmes in Saudi Arabia.

#### **Why you have been invited to take part**

You have been invited as a participant, to gather data from you as a individuals with type 2 diabetes in King Fahad Specialist Hospital (Diabetic and Endocrinology Centre) in Al Qassim because you are diagnosed with type 2 diabetes more than one year and your age 18 years or above.

### **Taking part in the study**

It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part, you will still be able to withdraw at any time without giving any reasons. There will be no consequences to you if you withdraw.

If you agree to take part in this research, I will interview you one to one in King Fahad Specialist Hospital (Diabetic and Endocrinology Centre) in Al Qassim. The interview will take about one hour. You will be asked questions on your experience of diabetes. The interview will be recorded with an audio recorder and then transcribed and analysed with the research team. The audio recording will be saved until the study has ended as source data. The data will be kept for 10 years.

### **What should I do if I want to take part**

If you would like to take part please contact myself, Thamer Alslamah at phone +966551307777 or email [t.alslamah.1@research.gla.ac.uk](mailto:t.alslamah.1@research.gla.ac.uk).

### **Possible benefits and risks**

You will receive no direct benefit from taking part in the research. There are also no risks for you in taking part, whether on your care you receive now or in the future. The information you provide us in this research will give us a better understanding of how to improve the control of blood glucose levels, which can contribute in delaying or mitigating diabetes complications.

### **Confidentiality**

All information that we collect from you, your personal information and the responses that you provide, during the course of the research will be kept strictly confidential. The information will be stored for additional future research and any information that can identify you such as your name and contact information will be removed. Some of your views may be quoted in a report or published papers, this will be done in a way that ensures that you cannot be identified. Therefore, all opinions you provide cannot be traced back to you by anyone else other than the research

team. However, if we feel that there is any information you provide that can be seriously harmful to yourself or others, we may be obliged to contact relevant authorities.

### **Publication of results**

The results of this research will be presented in my doctoral thesis. It will also be published in a scientific journal and presented at a scientific conference. You can contact me directly if you would like to obtain a copy of the published results. You will not be personally identified in any report/publication.

### **Funding and reviewer body**

This research is part of my doctoral training, fully funded by the AlQassim University. This study has been reviewed by the College of Medical Veterinary and Life Sciences Ethic Committee, University of Glasgow, and the Ethics Committee of Ministry of Health in Saudi Arabia.

### **Contact for further information**

If you need to ask further questions, please don't hesitate to contact the supervisor

Professor Craig Melville

Tel: +44 (0)141 211 3878

Fax :+44 (0) 141 211 0356

Email: [Craig.Melville@glasgow.ac.uk](mailto:Craig.Melville@glasgow.ac.uk)

Thank you for your consideration.

Best regards,

Thamer Alslamah



## معلومات المشاركين لمرضى السكر من النوع الثاني

### عنوان البحث

التكيف الثقافي للإدارة الذاتية لمرض السكري من النوع الثاني في المملكة العربية السعودية (دراسة نوعية)  
اسمي ثامر السلامة، عضو هيئة تدريس في جامعة القصيم كلية العلوم الطبية التطبيقية. كجزء من بحثي في دراسة  
الدكتوراه في جامعة جلاسكو، أقوم بإجراء بحث بعنوان " اللتكيف الثقافي للإدارة الذاتية لمرض السكري  
من النوع الثاني في المملكة العربية السعودية" (دراسة نوعية)

أنت مدعو للمشاركة في هذا البحث. قبل أن تقرر، يرجى قراءة المعلومات التالية بعناية. سيساعدك ذلك على فهم  
سبب إجراء البحث، وماذا سيحدث إذا قررت المشاركة. إذا كان هناك أي شيء تريد أن تسألني بشأن البحث، فلا  
تتردد في القيام بذلك. خذ وقتك لتقرر ما إذا كنت توافق على المشاركة أم لا.

### الغرض من الدراسة

تم تصميم هذه الدراسة لاستكشاف من مزودي الرعاية الصحية المحليين وآراء المرضى والخبرات حول العوامل  
الطبية

والاجتماعية التي يمكن أن تعزز أو تحد من تعليم الإدارة الذاتية لمرضى السكري. وسيتم تقاسم نتائج الدراسة مع  
وزارة

الصحة السعودية للنظر في إمكانية إجراء دراسات نوعية ودراسية على نطاق أوسع حول جدوى برامج تعليم الإدارة  
الذاتية لمرضى السكري وإمكانية توظيفها في المملكة العربية السعودية.

## لماذا تم دعوتك للمشاركة

لقد تم اختيارك كمشارك، لجمع البيانات كونك أحد مرضى السكر من النوع الثاني وتعالج في مستشفى الملك فهد التخصصي (مركز السكري والغدد الصماء) في القصيم. ومشخص أكثر من سنة في هذا المرض.

## المشاركة في الدراسة

الأمر متروك لك لتقرر ما إذا كنت ستشارك أم لا. إذا قررت المشاركة، سيتم إعطاؤك ورقة المعلومات هذه ليتم الاحتفاظ بها وتطلب منك التوقيع على نموذج موافقة. إذا قررت المشاركة، فستظل قادراً على الانسحاب في أي وقت دون إبداء أسباب لن تكون هناك عواقب عليك إذا انسحبت. مشاركتك لن تؤثر على حياتك.

بمجرد موافقتك على المشاركة في هذا البحث، سوف أقوم بإجراء مقابلة معك وشرح إجراءات المقابلة في مستشفى الملك فهد التخصصي (مركز السكري والغدد الصماء) في القصيم. سوف تستغرق المقابلة حوالي ساعة واحدة. سيتم طرح أسئلة حول تجربتك مع المرض والرعاية التي تتلقاها من المركز. سيتم تسجيل المقابلة في تسجيل صوتي ثم يتم نقلها وتحليلها مع فريق البحث. سيتم الاحتفاظ بها كامصدر حتى نهاية البحث. وسيتم حفظ البيانات لمدة عشر سنوات.

## ماذا افعل إذا اردت المشاركة

إذا كنت ترغب بالمشاركة يرجى الاتصال على ثامر السلامة هاتف رقم ٠٠٩٦٦٥٥١٣٠٧٧٧٧ او البريد

[t.alislamah.1@research.gla.ac.uk](mailto:t.alislamah.1@research.gla.ac.uk) الإلكتروني

## الفوائد والمخاطر المحتملة

لن تتلقى أي فائدة مباشرة من المشاركة في البحث. لا توجد أي مخاطر بالنسبة لك في المشاركة. إن المعلومات التي تزودنا بها في هذا البحث ستعطينا فهماً أفضل لكيفية تحسين التحكم في مستوى السكر في الدم، والذي يمكن أن يسهم في تأخير أو تخفيف مضاعفات السكري.

## السرية

جميع المعلومات التي نجمعها منك، ومعلوماتك الشخصية والردود التي تقدمها، خلال فترة البحث ستبقى سرية للغاية. سيتم التعرف عليك عن طريق رقم معرف، وسيتم إزالة أي معلومات يمكن أن تعرف هويتك مثل اسمك ومعلومات الاتصال الخاصة بك. وسيتم استخدام المعلومات في البحوث المستقبلية. لذلك لا يمكن تتبع جميع الآراء التي تقدمها لك من قبل أي شخص آخر غير فريق البحث. ومع ذلك، إذا شعرنا أن هناك أية معلومات تقدمها والتي يمكن أن تكون ضارة جدًا لنفسك أو للآخرين، فقد نكون ملزمين بالاتصال بالسلطات ذات الصلة.

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## Appendix 16. Moderator guide

### Moderator Questions Guide in English

The questions guide is related to the broad line of the DESMOND program and aim to discuss with individuals and their health professional their thoughts about diabetes and DSME. The art of the moderator is to ask almost the same questions to the health professional and the individuals with a minimum alteration.

### PARTICIPANTS' INTERVIEWS

Questions
<p><b>Questions learnt from Previous Quantitive Study, e.g.</b></p> <p>How about your fruit and vegetables consumption? Have you always being keen on consuming fruits and vegetables?</p> <p>Do you eat fast food? How frequently? Did you cut down on fast food after you became aware of your diabetes?</p> <p>Do you walk or do any physical activity? How frequently? Are these new habits?</p> <p>What is the main source of learning about your diabetes?</p>
<p>Is it easy for you to take care of your diabetes, do you need help?</p> <p>Hint: Equipment, family help/support, professional support.</p>
<p>Who can help you?</p>
<p>What do you know about diabetes, and how do you feel about having diabetes?</p>
<p>What are the challenges you have because of diabetes?</p> <p>Hint: concerns, safety, activity, food and social life.</p>
<p>How do you get advice about what is healthy food, and what would be healthy to eat for your diabetes?</p>

Hint: Traditional food, fast food, vegetables and fruits, low calories.
Do you think you (or your family) need advice on how your diabetes cannot prevent you from joining the family food?
What about physical exercises, do you do any? Would you like to receive some advice on how and when and where you would be able to do this?  Hint: walking, swimming, gym, sport, fear of injury
What would prevent from doing regular exercises? Do you think you need some guidance on this? What type of guidance should it be?  Hint: Space, time, safety, cultural barrier.
Is it easy for you to walk outdoor? Do you like walking? Is there is a way by which you can be encouraged to walk?  Hint: Advice, arranging walking groups.
Is it easy to quit smoking? Do you need help to quit?
Is there something different or special in terms of the culture or the family?
If a program could be developed that was designed especially for you, to help you eat and live healthy, what would it look like?
What about mobile phone? Can they help? Would you like to receive updates and advice texts or phone calls?  Hint: information, new skills.
What else would you like in a program?
What are your recommendations for getting people here involved in self-management program?
Consider everything that has been said today. Is there anything that anyone would like to add?

## FOCUS GROUPS

### Questions (highlights and start lines)

For example: (individuals with type 2 diabetes can be dependent in their doctor and health carers, talk to me about the person journey, please). The modulator will be looking for answers for the following questions in the conversation:

- How frequently do they see their visitors?
- Do they have enough time to explain to them how to take care of their diabetes?
- How accessible are they to their visitors?

For example :( there must be an appointment system in the centre, which dictates how and when the person will see you, and visitors will have to manage their own diabetes themselves in between, Am I correct?). The modulator will be looking for answers for the following questions in the conversation:

- How do they follow-up their visitors and their progress in controlling their diabetes?
- What medium they believe to be most efficient for increasing the awareness of their visitors?

For Example: (I'm not sure if you know about self-management education programmes such as DESMOND or DSME, is there is a way that a person can become independent and responsible for managing their condition?). The modulator will be looking for answers for the following questions in the conversation:

- How much do they know about DESMOND? Do they think it is effective?)
- How and if can DESMOND be more suitable to their visitors?
- What else would they like to be in an educational programme to their visitors?
- What are your recommendations for getting people here involved in self-management programme?

For example: (consider everything that has been said today. Is there anything that anyone would like to add?). The modulator will be looking for answers for the following questions in the conversation:

Where they engaged enough?

Do they want to see some actual change happening?

Are they keen for a self-management programme to be introduced?