TOWARDS THE HOLISTIC MANAGEMENT OF DIABETES IN SAUDI ARABIA: A MULTI-METHOD STUDY

By

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DEDICATION

I dedicate this work to the souls of My mother Munerah, My father Sahal, and My brother Ali.
ACKNOWLEDGMENTS

I would like to express my gratitude to everyone who supported me in my undertaking of this research project. First of all, I would like to sincerely thank my supervisors, Professor Simon de Lusignan and Professor Simon Jones, who have provided me with extensive support of an outstanding quality. I thank them very much for all their efforts. Also, I would like to thank the Director of Studies for Integrated PhD, Dr Debbie Cooke, for her continuous support, guidance and motivation throughout my PhD study.

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ABSTRACT

The purpose of this study was to explore the managing of Type 2 Diabetes Mellitus (T2DM) in the Saudi healthcare system. This country was chosen for examination because it has been undergoing major demographic, social and economic changes which have caused an increase in the prevalence of chronic diseases, including diabetes. This study adopted the World Health Organization’s (WHO) Innovative Care for Chronic Conditions Framework (ICCCF). This framework provided a comprehensive basis for assessing the Saudi healthcare system by addressing its components at the macro (policy), meso (healthcare organizations and community), and micro (patient and family) levels. In accordance with these three health system strata, a flexible multimethod approach was adopted by using primary and secondary data in three phases. To explore the policy environment of the Saudi health care system, the first phase involved analysing 35 national and regional T2DM documents according to four dimensions of Walt and Gilson’s health policy analysis framework: content, actors, context, and process. The second phase aimed to explore healthcare professionals’ perceptions of the barriers and facilitators of an effective healthcare organization and of community partnerships to enable T2DM management. Semi-structured interviews were conducted with 33 participants from various healthcare fields and thematic analyses were applied. The third phase aimed to assess the patients’ experiences and their interactions with healthcare providers. In this phase, the Patient Assessment of Chronic Illness Care (PACIC) survey was translated into Arabic using the WHO Steps of Translation and Adaptation of Instruments, and distributed among 575 diabetes patients in four specialized diabetes clinics. Although T2DM has highly recognised at the macro level, several challenges were identified through the documents analysis and were also highlighted during the second phase of the study. These challenges included: unreliable health information systems, a lack of multisectoral collaboration, and a lack of public awareness. At the meso level, the interview data identified three themes: the cultural determinants of T2DM, the limitations of key support systems, and recommendations for improving the support systems for T2DM patients. Within the identified themes, a number of subthemes were identified, including: physical inactivity, reliance on traditional treatments, unhealthy dietary patterns, poor primary healthcare services, lack of reliable data, shortage of qualified staff, poor guidelines dissemination, enhancing the multisectorial collaboration, and community partnerships. At the micro level, the mean score of the PACIC survey was lower in comparison to similar studies conducted internationally (mean = 2.55 out of 5). Patients scored on average 2.69 for ‘patient activation’, 3.02 for ‘delivery system/practice design’, 2.29 for ‘goal setting/tailoring’, 2.10 for ‘follow-up/coordination’, and 2.84 for ‘problem solving/contextual domain’. In addition, the reported glycaemic control measures indicated that only 17% of participants had controlled blood glucose levels (≤ 7%) which is equivalent to 8.6 mmol/L. The ICCC framework was a useful tool for exploring the main weaknesses and strengths of the Saudi healthcare system. However, it was observed that the ICCC did not significantly recognize community sensitivity, particularly community culture, religion, norms, and beliefs. Nevertheless, this study generated new knowledge about T2DM management systems in Saudi Arabia by exploring how the performance of the healthcare system is shaped by the processes occurring at the different levels; therefore. It contributes to the body of knowledge on health system research.
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ABBREVIATIONS

American Diabetes Association (ADA)
Chronic Care Model (CCM)
Electronic Medical Record (EMR)
Fasting Blood Glucose (FBG)
Glycated Hemoglobin (HbA1c)
Gulf Cooperation Countries (GCC)
Health Information Technologies (HIT)
Innovative Care for Chronic Conditions framework (ICCC)
International Diabetes Federation (IDF)
Kingdom of Saudi Arabia (KSA)
Ministry of Health (MOH)
Non-communicable disease (NCD)
Patient Assessment of Chronic Illness Care (PACIC)
Primary Health Care (PHC)
Saudi’s Charitable Association of Diabetes (SCAD)
Type 1 Diabetes Mellitus (T1DM)
Type 2 Diabetes Mellitus (T2DM)
World Health Organization (WHO)
Chapter 1: Introduction

1.1 Background

There is an increasing global interest in managing detecting and controlling chronic conditions (Nolte & McKee, 2008; Szecsenyi et al, 2008, Atun et al, 2013, Gilson, 2013; Beran, 2015) and this is due to two main factors. The first is the concern of national healthcare systems about the growing prevalence of non-communicable diseases (NCDs). Secondly, there is the impact on individual well-being and the strain the diseases might place on the wider socio-economic structures, especially those of developing countries (World Health Organisation, 2005; World Health Organisation, 2007; Beran, 2015). Chronic diseases management requires a well-functioning healthcare system which integrates the following: access to appropriate medication, proper laboratory facilities, appropriate data collection instruments, adequate training for staff and education for patients. These should be developed in a way to suit the social and cultural practices of the patients (Donabedian, 1980 Nolte & McKee, 2008; Mendis & Chestnov, 2013; Beran, 2015).

Diabetes mellitus is one of the most prevalent NCDs. According to the International Diabetes Federation (IDF), Type 2 Diabetes Mellitus (T2DM) is the most common type and a disease from which millions of people are suffering as well as its many associated complications (IDF, 2013). The World Health Organisation (WHO) (2014) considers T2DM as a critical problem seriously affecting many individuals and for healthcare institutions the resulting social costs are high. Developing a program of T2DM management is dependent on putting into place a comprehensive healthcare system which should provide services that prevent, detect, treat delay or reduce the harm caused by the complications arising from this NCD

1.2 Overview of Chronic Diseases

Chronic diseases (also known as NCD) are the primary cause of mortality worldwide. The WHO defines chronic diseases as those not spread from person to person, but ones that progress slowly over a long period of time. The four main types are: cardiovascular disease (e.g. heart attacks and stroke), cancer, chronic respiratory disease (such as chronic obstructive pulmonary disease and asthma) and diabetes.

There are multiple reasons for the development of chronic diseases and the WHO estimated that they were responsible for 60% of the total 58 million deaths that occurred globally in 2005 (WHO, 2006; WHO, 2011).

Apart from the morbidity and mortality directly caused by chronic diseases, they have a great impact on society both emotionally and economically. Emotional strain not only affects their families and friends, but also diminishes their capacity for work and this also has a wider economic impact (World Bank 2006; Paez, Zhao & Hwang, 2009; Brod et al, 2011).

There are no concrete figures about the cost of healthcare for chronic diseases globally, but it is estimated to be very significant. For example, one estimate puts the cost of treating patients with one or more chronic diseases in the United States to be more than 75% of $2 trillion annually spent on healthcare (Gerteis et al, 2014). The reasons for the increasing burden of chronic diseases worldwide are multifaceted and are not easily identified. At the macro level, there are such factors as demographic shifts, aging populations, urbanization, environmental problems as well as economic development and globalization. On the individual level, poor diet, a lack of physical
exercise, alcohol consumption and smoking have all been identified as some of the other leading causes of chronic diseases (Epping-Jordan et al. 2005; Huang et al., 2009). The next section will look more closely at diabetes, one of the four major types of chronic diseases.

1.3 An Overview of Diabetes

Diabetes mellitus is a group of metabolic disorders characterised by hyperglycaemia resulting from a defect in insulin secretion, insulin action or both. The two common features of diabetes are hyperglycaemia and glucose intolerance. To produce energy for the body, insulin regulates the blood sugar level and in the body cells extra glucose stores as glycogen in the liver and skeletal muscles. When the glucose level exceeds the amount required by the body for energy as well as the storage capacity in both of liver and skeletal muscle, it is stored in the fat cells, leading to an increase in weight (American Diabetes Association [ADA], 2010; White & Kahn, 1994; Harris & Zimmet, 1997).

Broadly, diabetes is classified to type 1 diabetes (T1DM), type 2 diabetes (T2DM), genetic diabetes (monogenic), and secondary diabetes (type 3c diabetes) (Falmer & Fox, 2011; Hassan Sadek et al, 2012; Hattersley & Patel, 2017; Woodmansey et al, 2017). Five to ten percent of people with diabetes have T1DM (Ballard, 2009) which occurs when the body’s auto-immune system damages the insulin-producing cells. T1DM is usually discovered before the age of 30, but can potentially occur at any age. The aetiology of T1DM remains poorly understood, but environmental variables, genetic factors, viruses, and auto-immune processes may contribute to the onset of the disease (IDF, 2013).

T2DM is more common than T1DM and accounts for more than 90% of total diabetes cases internationally. Generally, T2DM develops after the age of 30 in
individuals often with a positive family history (Ballard, 2009). The underlying pathological process of T2DM appears in the form of insulin resistance or when the body is unable to utilize insulin properly. Due to a decrease in insulin production, the blood glucose level increases and leads to the development of T2DM and the long-term medical complications associated with it. (WHO, 2006; ADA, 2011). It was estimated that the number of people suffering from any type of diabetes in 2011 was 366 million and it was expected to reach 552 million by 2030. Over 4.6 million adult deaths were caused by T2DM globally in 2011 and which meant someone died from it every seven seconds. (ADA, 2011; Whiting et al., 2011).

People with T2DM require on-going healthcare. They are regular visitors to primary healthcare centres and they are hospitalized frequently. According to Carral (2002), diabetic patients stay in the hospital on average four days more than other patients. A systematic review aimed at estimating the direct and indirect costs of T2DM worldwide found that direct costs of diabetes varied from $242 in a study of out-of-pocket expenditures in Mexico to $11,917 per person, in the USA. The indirect costs varied from $45 in Pakistan to $16,914 in the Bahamas (Seuring et al., 2015).

The main economic outcome that impact people with T2DM is a reduction in their working capacity that consequently leads to loss of income (Gore et al., 2006). Brod et al. (2011) did a small survey of 1,404 participants with T1DM and T2DM from Germany, France, the U.S. and the U.K, and they found that the estimated loss of productive working hours per person was about 14.7 hours per month. In terms of the reduction in income, the figure was US $2,294 per person per year (Brod et al., 2011).
The economic burden of diabetes also includes medical costs, especially the cost of medication. According to Morsanuttoa et al. (2006), hospitalisation, diagnostic examinations and drugs accounted for 52%, 11% and 28%, respectively, for the patient’s annual medical costs. Generally speaking, diabetic patients utilised five times more health resources than those without diabetes (Lucioni et al., 2000). The increased costs has a huge effect at the national level as, for instance, 9% of the total National Health Service budget in the U.K. is spent on diabetes patients, and in Taiwan the portion is 12%. In Italy, people with diabetes consume 7% of the total healthcare bill. According to the U.K.’s Economic Intelligence Unit (2007), direct and indirect costs of diabetes total a loss of 1.2% of Britain’s gross domestic product. Similarly, in the U.S. and India the loss has been estimated to be 1.2% and 2.1%, respectively (Currie et al., 1997; Lucioni et al., 2000).

Chronic diseases are characterised by episodic acuity and require a comprehensive system of healthcare that incorporates diagnosis, patient self-management, psycho-social support, and ongoing medical monitoring and treatment (Hogan, Linden, & Najarian, 2002; Kacerovsky-Bielesz et al, 2009; Atun et al, 2013; Amin et al, 2014). Considering the high social and economic costs of T2DM, this study will focus on this type of diabetes for four flowing reasons: managing the disease is a significant burden to any healthcare system; it incurs a high cost; there are risk factors that are of a behavioural kind; and there are parallels in how chronic diseases are managed. It is also important to argue that due to the weakness of biomedical models in tackling the issue, further attention needs to be paid to the socio-medical issues (Engel, 1997; McLaren, 1998; Hatala, 2013; Sud & Sud, 2017).

The problems associated with the disease are social, familial, environmental, psychological, nutritional and physical. Diet and physical activity, two of the most
influential factors, are also social and behavioural and, thus, obesity and physical inactivity can lead to a prevention of the disease. This can be done by properly understanding the social, cultural, political, psychological and economic factors which influence eating and exercise habits (Parchman et al, 2007; Huang et al, 2009; IDF, 2013; Al-Khudairy et al, 2014; Beran, 2015; Alneami & Coleman, 2016). Since the research focus will be on T2DM in the Kingdom of Saudi Arabia (KSA), the next section describes the relevant social and medical issues in this country.

1.4 The Saudi Arabia Case

KSA is the largest country of the Arab Gulf as well as in the Middle East with 2,149,690 km² of territory. Desert covers more than 90% of the land and this country in the Arabian Peninsula is bordered by Jordan, Syria, Kuwait and Iraq in the north, and Yemen Oman and to the south. The Red Sea constitutes the entire western border of the country and it shares its eastern border with the United Arab Emirates, Bahrain, Qatar and the Arabian Gulf. (World Atlas, 2015)

Figure 1 Map of Saudi Arabia (Einstein, 2007)
KSA is a member of the Gulf Cooperation Council (GCC) along with Oman, Bahrain, United Arab Emirates, Qatar and Kuwait (Figure 1). The kingdom was established by King Abdul-Aziz Bin Saud on the 23rd of September 1932. Huge reserves of oil were discovered soon after, and within six years the commercial production of oil began. This led to a dramatic rise in the country’s wealth which soon put Saudi Arabia on the path to becoming a modern, industrial state. Today, Saudi Arabia holds a 25% share of the total Arab gross domestic product (GDP), with a total international reserve of US $ 737,797 billion (World Bank, 2014).

Islam plays a central role in KSA society. For Saudis, Islam is more than a religion as all aspects of life are enforced by Islamic codes such as the strict principles of gender segregation in most of the public institutions. Although the government does not conduct any census on religion, all the Saudi citizens in the country are Muslims (Elhadd & Al-Amoudi, 2006; Meijer, 2010; Mobarakí & Söderfeldt; 2010).

Table 1 presents some of the most important demographic features of the country.

<table>
<thead>
<tr>
<th>Indicators</th>
<th>2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total estimated population size</td>
<td>30,770,375</td>
</tr>
<tr>
<td>Urban population (%)</td>
<td>83.1</td>
</tr>
<tr>
<td>Annual population growth rate (%)</td>
<td>2.9</td>
</tr>
<tr>
<td>Percentage of population under 15 years of age (%)</td>
<td>30.8</td>
</tr>
<tr>
<td>Percentage of population 15–64 years of age (%)</td>
<td>66.2</td>
</tr>
<tr>
<td>Percentage of population 65 years and above (%)</td>
<td>3</td>
</tr>
<tr>
<td>Life expectancy at birth (years)</td>
<td>74.4</td>
</tr>
<tr>
<td>Expected years of schooling (years)</td>
<td>16.1</td>
</tr>
<tr>
<td>Mean years of schooling (years)</td>
<td>9.6</td>
</tr>
<tr>
<td>Gross national income per capita ($)</td>
<td>55,760</td>
</tr>
<tr>
<td>Human Development Index</td>
<td>0.847</td>
</tr>
</tbody>
</table>


In 2016 the estimated population of KSA was 30,770,375 with a growth rate of 2.9% and which is considered as the 41st highest one in the world, according to the United Nations report (2016) (Table 1). The population is expected to increase in the
future and it is likely to reach 39.1 million by the end 2030. Saudis account for 67% of the total population, while non-Saudis make up the remaining 32.7%. The number of Saudis below 30 years of age makes up 67% of the total Saudi population. Classification of the population according to gender indicates that the male population is 55.5%, and the female is 45.5%. Of the total population, 3% were aged 65 or older (52% of them male and 48% female). In 2015, the life expectancy in KSA increased for both genders to 74.4 years (Central Department of Statistics, 2015).

Most statistical indicators suggest that KSA, globally and comparatively speaking, qualifies as one of the world’s richest societies. According to the latest report of the United Nation (2017) Human Development Index which is a composite indicator with a summary of the average achievement on the life expectancy, education, and income per capita, KSA ranked 38th among 182 countries with the value of 0.84. Comparing this number with the international figures (Figure 2), KSA has engaged in a multi-dimensional transition demographic, economic, epidemiological and geographic.

Figure 2 World map indicating the Human Development Index (2016)
1.5 Statement of the Problem

KSA is a high income country with the largest population in the Middle East. The country has been facing a changing demographical pattern in its population structure, including higher life expectancy rate, a large urban population and a higher level of educational achievement. The national health system’s ability to respond to chronic diseases is usually driven by socioeconomic factors. Increasing evidence on the health and social costs of chronic diseases in KSA made it crucial to assess the monitoring of the chronic disease burden. Despite the economic and educational developments, the healthcare system operating in KSA at the time of the study was ill-equipped to provide effective chronic illness care (Rahim et al. 2014; Alwan 2014; Alsulaiman, Mahmoud & Fadlallah, 2015; Alneami & Coleman, 2016). Since healthcare systems in the country were not properly designed for long-term care, the management of chronic illnesses, such as diabetes, has been very much neglected (WHO, 2002; WHO, 2010). However, the Saudi government has identified diabetes as a significant challenge. Given that diabetes diagnosis rates were increasing sharply, there was a pressing need to develop a healthcare system designed to provide efficient and effective diabetes care from a long-term, socio-medical perspective (Khoja, 2010; Alharbi et al, 2014; Majeed et al, 2014).

Given the rise in diabetes onset rates, the healthcare system in place in the KSA was likely to deteriorate as thirty two percent of the Saudi adult population were thought to have diabetes and the prevalence of onset in the country was expected to increase 0.8% and 0.6% per year for men and women, respectively (Alharbi et al, 2014). The MOH has put in place several programmes and initiatives designed to manage diabetes, but their effectiveness needed to be critically assessed.
This study critically explored the extent to which these programmes worked in tandem with the socio-cultural environment since the existing studies were primarily focused on medical interventions (Al-Khaldi & Al-Sharif, 2002; Khoja, 2010; Midhet et al, 2010; Alkadi, 2016). A literature review conducted in the early stages of the research for this thesis revealed limited scholarly consideration was given to the assessment of the healthcare system relative to diabetes management in the KSA. Furthermore, there was a gap in the literature about how the chronic management models informed the national healthcare system, particularly in developing countries. The researcher focused on T2DM as an example of the NCDs because of the multiple challenges it poses to the healthcare system and its prevalence as well as the dramatic rate at which it is predicted to increase in the next few decades. This study set out to start to address this research gap by identifying the important socio-economic factors in relation to the disease burden.

1.6 The Primary Objectives and Research Questions

These study objectives were to explore the public healthcare system provisions in KSA for people with T2DM in the KSA. The researcher sought to explore the health system levels from the central government policy down to the level of local practice to identify the gaps and opportunities by seeking to answer the following research questions:

1- How has the previous literature described the management of T2DM in KSA?

2- How has the current KSA healthcare system been setting out to organise and manage T2DM?

3- What lessons can be learnt from the experience of the KSA healthcare system in managing T2DM and what recommendations can be made?
In order to collect data from the different healthcare system levels, the researcher adopted a multi-method approach to examine the response of the KSA national healthcare system to the increased prevalence of T2DM (Brewer & Hunter, 1989; Atun et al, 2006; Risso-Gill et al, 2015). The thesis set out to make a two-fold contribution. First, it aimed to contribute to current lack of empirical evidence on how the healthcare system was integrated within the KSA. The second aim was based on the information collected; to make policy recommendations about managing chronic diseases as this information could be useful for planning and for making healthcare reforms.

1.7 The Structure of the Thesis

Chapter 2 explores the theoretical frameworks relating to diabetes care and management. It begins by conceptualising the KSA healthcare system and identifying the concept of the system and discussing its basic functions. Then it discusses and compares the common models of chronic diseases management. At the end of this chapter, the conceptual framework for the present study is discussed. This conceptual framework is designed to investigate the key levels of diabetes management, namely, those of policy (macro), the health service organization (meso) and the patient self-management (micro) (WHO, 2002; Epping-Jordan et al., 2004).

Chapter 3 analyses existing official documents relating to policies and programmes designed to control and prevent T2DM in Saudi Arabia. It does so by using the Walt and Gilson's triangle framework to analyse the current situation and to identify gaps in the literature regarding diabetes management in the country (Walt & Glison 1994; Gilson et al, 2008; Gilson, 2013). Considering the general lack of
information on the topic, the specific theoretical and methodological approaches used for this research will be explained in the following chapters.

Chapter 4 provides the rationale for applying multiple methods in the current study. It describes the instruments used and the sampling method and it also gives a more detailed account of the methods used for the analysis of the quantitative and qualitative data. The chapter will conclude with a summary of the ethical considerations.

The findings for the third and fourth questions will be presented in Chapters 5 and 6. Chapter 5 presents the results of the semi-structured interviews, while chapter 6 presents the survey results, thus by doing both, demonstrating the broad coverage achieved by the study.

A discussion of the study’s findings and conclusion are presented in Chapter 7 with the main findings coming first, followed by their discussion within the context of the extant literature. Lastly, the strengths and limitations of the study are identified and concluding remarks are provided.

1.8 Chapter Summary

This chapter gave a brief introduction and overview of the research problem and the rationale for the study. The aims and objectives of the thesis are identified and the layout of this thesis presented. In order to address this question "What models can be used to examine the response of the Saudi healthcare system to T2DM?" the next chapter introduces the reader to the KSA healthcare system before delving into the details of its assessment framework.
Chapter 2: The Literature Review of Diabetes Prevalence, the Saudi Health Care System and Organisation in the Management of Chronic Disease

2.1. Introduction

Chapter 1 described how the significance of the pressure of chronic diseases on the healthcare systems. The patients with chronic diseases rely extensively on the healthcare services as they experience complications from their conditions (Nolte & McKee, 2008; Beran, 2015). Reactive approaches that just respond to the situation are inadequate when it comes to the need to provide a proper or a comprehensive system. This requires a more sustained, nuanced and holistic approach (Wagner et al, 1995; Wagner et al, 2001; Nolte & McKee, 2008; Atun et al, 2013; Mendis & Chestnov, 2013; Beran, 2015). Examining the response of the national healthcare system to chronic diseases is a complex task. Therefore, this chapter reviews previously identified literature that describes the model and frameworks appropriate for assessing healthcare systems. This includes a detailed description of the Chronic Care Model and Innovative Care for Chronic Conditions framework which was adopted as the study’s conceptual framework (Wagner, 1998; WHO, 2002; Epping-Jordan et al., 2004).

2.2 The Saudi Healthcare System

The origin of healthcare in the region predates the formation of the Kingdom itself. First measures were taken to establish a healthcare service in 1925 when the first Health Directorate Department was established in Makkah based on a royal decree from King Abdul-Aziz Al-Saud. Prior to that time, there was no organized healthcare system in the region which became Saudi Arabia in 1932 (Alharthi et al., 1999). The department provided free healthcare for the population and pilgrims by
establishing hospitals and clinics. Millions of pilgrims visiting the Kingdom every year for Hajj somewhat overburdened the healthcare system. The healthcare services provided were ill-equipped to meet most medical needs, and therefore, the majority of people continued to depend on herbal medicine. As a consequence, the incidence rates of several major diseases were high among Saudis and pilgrims alike. In 1951 the MOH was established under royal decree (8697/11/5), and twenty years later, the Five-Year Development Plan was introduced by the government. The plan aimed to improve all government sectors, including healthcare. Since that time, significant improvements have been achieved in the country (Alharthi et al., 1999; Mufti, 2000).

Since its inauguration, the MOH has passed through three stages of development. In the 1970s, the healthcare services were mainly provided by tertiary healthcare institutions. The second phase was in 1980s when the WHO encouraged the Saudi MOH to implement the ‘Health for All’ strategy to emphasize the role of primary health care (PHC) in managing the population health in KSA. Thus, early attention was paid to primary health services, including diabetes care, and this resulted from international recommendations rather than from the Saudi health planners’ belief in primary care as being essential to improving health outcomes. The last phases were in 2002 when a royal decree was issued emphasizing that ‘health services should be provided in an equitable and affordable manner for all persons’ (Regional Health Systems Observatory, 2004).

The Saudi government provides full and free access to all healthcare facilities for all Saudis and expatriates working within the public sector (Yusuf, 2014). Allocation of governmental funds to the MOH rose from 2.8% in 1970 (WHO, 2011), to 6.6% in 2013 (Table 2) (MOH, 2015). The MOH is responsible for the planning, implementation and supervision of the healthcare policies in Saudi Arabia as well as
for the monitoring of the health services in the private sector (Al-Yousuf, Akerele, & Al-Mazrou 2002; Almalik et al., 2011; Alkadi, 2016).

Table 2: Approximations of governmental funds allocated to the MOH (by US dollar per capita*), 2007-2013

<table>
<thead>
<tr>
<th>Year</th>
<th>Government Budget*</th>
<th>%**</th>
</tr>
</thead>
<tbody>
<tr>
<td>2007</td>
<td>16,000</td>
<td>5.6</td>
</tr>
<tr>
<td>2008</td>
<td>18,000</td>
<td>5.6</td>
</tr>
<tr>
<td>2009</td>
<td>14,000</td>
<td>5.6</td>
</tr>
<tr>
<td>2010</td>
<td>16,000</td>
<td>6.5</td>
</tr>
<tr>
<td>2011</td>
<td>20,000</td>
<td>6.9</td>
</tr>
<tr>
<td>2012</td>
<td>24,000</td>
<td>6.8</td>
</tr>
<tr>
<td>2013</td>
<td>25,000</td>
<td>6.6</td>
</tr>
</tbody>
</table>

**As % of the MOH from total government budget

2.3 The Burden of T2DM in KSA

Saudi Arabia has a high occurrence rate of T2DM, globally speaking, with an estimated 32.1% of population suffering from it (Alqurashi Aljabri, & Bokhari 2011). The prevalence of T2DM has increased rapidly, not only in Saudi Arabia, but also in all Arabic countries over the past 30 years, with no fewer than five of the GCC countries ranking among the top ten countries with the highest T2DM prevalence rate in the world. The total estimated number of adults from the Middle Eastern/North African region with T2DM was 32.8 million in 2011, a number that is expected to reach 60 million by 2030 (IDF, 2013). In order to assess changes in prevalence rates of T2DM and obesity as an explanatory risk factor of T2DM over the last 30 years, the researcher conducted a systematic review of 1,388 identified studies and 37 articles of which 13 of the studies dealt with an estimation of the prevalence of diabetes in KSA (Table 3) (Alharbi et al, 2014).

In this review, the prevalence estimates of T2DM in the Saudi adult population ranged from 10% in 1989 to 32% in 2009, which is similar to the
worldwide trend (Haghdoost et al., 2009; Saquib et al., 2012). By using standardised scores (z-scores), it appeared that there was no significant difference in the prevalence of T2DM between male and females. However, there was a significant difference in the rate of increase between men and women with T2DM as the results showed that the prevalence of T2DM was estimated to increase by about 0.8% in males and 0.6% in females each year. By contrast, a higher prevalence of obesity was observed in Saudi females (Ogbeide et al., 1996; Wary & el-Hazmi, 1999; Alsaifa et al., 2002; Al-Daghri et al., 2011). Seven studies reported a significant difference according to gender as a higher prevalence of T2DM was observed in men in three of the studies (El-Hazmi et al., 1995; El-Hazmi, et al., 1998; Alqurashi et al., 2011), while there was a significantly higher prevalence among women in two other studies (Fatani Mira, & El-zubier, 1987; Al-Baghli et al., 2010). Two studies showed a significantly higher prevalence of T2DM in males when participants under 20 years old were excluded, yet after their inclusion, women bore a higher prevalence rate (Anokute, 1990; MOH, 2010). However, three studies showed no significant gender differences (Al-Nuaim, 1997; Al-Nozha et al., 2007; MOH 2010).
Table 3: Summary of epidemiological studies of diabetes in KSA, 1982–2013

<table>
<thead>
<tr>
<th>Author, Date of Study*</th>
<th>Area</th>
<th>Sample</th>
<th>Sample Composition</th>
<th>Diagnostic Criteria</th>
<th>Diabetes Type</th>
<th>Prevalence</th>
<th>Note</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bacchus et al., 1982</td>
<td>Al-Kharj</td>
<td>847</td>
<td>Age range: &gt;15M</td>
<td>OGTT</td>
<td>DM</td>
<td>-</td>
<td>4</td>
</tr>
<tr>
<td>Anokute et al., 1987</td>
<td>Riyadh</td>
<td>1346</td>
<td>Age range: &gt;20 M</td>
<td>Urine/FBG</td>
<td>DM</td>
<td>-</td>
<td>6</td>
</tr>
<tr>
<td>Fatani et al., 1987</td>
<td>Western province</td>
<td>1368</td>
<td>Age range: Population M&amp;F</td>
<td>RBG/OGTT</td>
<td>DM</td>
<td>12.4</td>
<td>8.1 17.1</td>
</tr>
<tr>
<td>Abu-Zeid et al., 1989</td>
<td>Abha</td>
<td>529</td>
<td>Age range: &gt;10 M</td>
<td>FBG</td>
<td>DM</td>
<td>10.6</td>
<td>7.4 13.8</td>
</tr>
<tr>
<td>El-Hazmi et al., 1993</td>
<td>Riyadh</td>
<td>1149</td>
<td>Age range: 3–70 M</td>
<td>FBG</td>
<td>T2DM</td>
<td>13.6</td>
<td>15.6 11.9</td>
</tr>
<tr>
<td>Al-Nuaim et al., 1993</td>
<td>National</td>
<td>10165</td>
<td>Age range: &gt;15 M</td>
<td>RBG/OGTT</td>
<td>DM</td>
<td>12.9</td>
<td>12 13.8</td>
</tr>
<tr>
<td>El-Hazmi et al., 1995</td>
<td>National</td>
<td>7785</td>
<td>Age range: 2–70 M</td>
<td>FBG</td>
<td>T2DM</td>
<td>14.4</td>
<td>17.3 12.2</td>
</tr>
<tr>
<td>Al-Nozha et al., 2000</td>
<td>National</td>
<td>16806</td>
<td>Age range: 30–70 M</td>
<td>FBG</td>
<td>DM</td>
<td>23.7</td>
<td>26.2 21.5</td>
</tr>
<tr>
<td>Al-Baghli et al., 2005</td>
<td>Eastern province</td>
<td>196769</td>
<td>Age range: &gt;30 M</td>
<td>FBG</td>
<td>DM</td>
<td>15.6</td>
<td>14.4 17</td>
</tr>
<tr>
<td>Ministry of Health, 2005</td>
<td>National</td>
<td>3603</td>
<td>Age range: 15–64 M</td>
<td>FBG</td>
<td>DM</td>
<td>19.2</td>
<td>20.1 18.3</td>
</tr>
<tr>
<td>Al-Qurashi et al., 2009</td>
<td>Jeddah</td>
<td>5560</td>
<td>Age range: &gt;12 M</td>
<td>Review M.CH</td>
<td>DM</td>
<td>32.1</td>
<td>36.9 29.2</td>
</tr>
<tr>
<td>Al-Dagheri et al., 2011</td>
<td>Riyadh</td>
<td>6630</td>
<td>Age range: 7–80 M</td>
<td>FBG</td>
<td>T2DM</td>
<td>27.7</td>
<td>25.6 30.9</td>
</tr>
<tr>
<td>Ahmad et al., 2013</td>
<td>Makkah</td>
<td>141</td>
<td>Age range: &gt;20 M</td>
<td>OGTT/FBG</td>
<td>DM</td>
<td>-</td>
<td>27.7</td>
</tr>
</tbody>
</table>

M = Males; F = Females; OGTT = Oral Glucose Tolerance Test; FBG = Fasting Blood Glucose; RBG = Random Blood Glucose; M.CH = Medical Charts. *The date when the study was conducted (not the publication date). Source of data: (Al-Harbi et al, 2014)
2.4. The Healthcare System

The term “system” can be recognised as an arrangement of interdependent and interrelated elements that come together for a purpose. What sets apart a healthcare system is that it is concerned with people’s health. Healthcare systems are complex with many different parts. These include patients, their families and carriers, the community, healthcare service organisations, commissars and funders from other sectorial organizations. It was noted that there are many complex interactions and interconnections between policymaking, regulations, health service provision, health promotion, health prevention, financing, and the management of resources (von Bertalanffy, 1968; Epping-Jordan et al, 2005; WHO, 2005: European Observatory for Health Systems and Policies, 2007).

2.4.1 The Healthcare System: Definitions

In an attempt to describe the interconnections and the purposes of the different parts, Roemer (1991) defined a health system as "the combination of resources, organization, financing and management that culminates in the delivery of health services to the population. (P.31)"

According to the European Observatory for Health Systems and Policies, a healthcare system is defined as people, institutions and resources, arranged together in accordance with established policies, to improve the health of the population they serve, while responding to people’s legitimate expectations and protecting them against the cost of ill-health through a variety of activities whose primary intent is to improve health. (European Observatory for Health Systems and Policies, 2007; Kuo et al, 2011). The most widely used definition comes from the World Health Organization’s World Health Report 2000, which defines health systems functionally
as “all the activities whose primary purpose is to promote, restore or maintain health” (P.9) This definition allows for an analysis of both the public and private sectors of any healthcare system within a country. However, as described in the previous chapter, the Saudi MOH is the major provider of healthcare in the country, therefore, the current study will focus exclusively on the government’s healthcare system (WHO, 2011).

2.4.2 The Health Care System: Functions

In 1991, Roemer defined five categories of the healthcare system functions as the following:

- Services delivery (primary, secondary, and tertiary services; preventative health services; curative health services; public health services; services for specific populations and/or conditions).
- Services management (planning, administration, regulations and legislations)
- Resource production (staff training, supplies including drugs and equipment)
- Financing (finding sources for this, such as, tax, and insurance)
- Programme organization (by governmental, the private sectors or voluntary agencies.)

In 2000, the WHO redefined the Roemer’s healthcare system functions in their report "Health Systems: Improving Performance" (p.44). This report was built on three essential goals: to improve the public’s health, to respond to public expectations, and to provide equality in financial contribution (WHO, 2000). It operationalised these goals through four major functions: stewardship, services provision, managing resources, and financing (Table 4). Assessing the achievement of these goals was the aim of WHO and remained an ongoing challenge to healthcare systems globally.
Table 4: Roemer’s health system functions

<table>
<thead>
<tr>
<th>Function</th>
<th>Explanation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stewardship</td>
<td>Policy and context framework for the overall system (e.g., setting the health priorities, services planning, generating appropriate data, and assessing health system performance)</td>
</tr>
<tr>
<td>Service provision</td>
<td>Public and private health service provision (e.g., education, preventive and curative services)</td>
</tr>
<tr>
<td>Managing resources</td>
<td>Health service inputs (e.g., human resources, medications, and equipment’s)</td>
</tr>
<tr>
<td>Financing</td>
<td>Collecting revenues, pooling financial risk, and allocating revenue</td>
</tr>
</tbody>
</table>

In 2007, the WHO, yet again, extended their work in healthcare systems through their report “Everybody’s Business: Strengthening Health Systems to Improve Health Outcomes” (WHO, 2007, p.2). This report aimed to practically organize health systems into six operational “building blocks” to strengthen the system. They were service delivery, health workforce, information system, medical products, vaccines and technology, financing and leadership (Table 5).

Table 5: WHO health system building blocks

<table>
<thead>
<tr>
<th>Building Block</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service Delivery</td>
<td>Delivery of effective, safe, quality personal and non-personal health interventions to those who need them, when and where needed, with minimum waste of resources</td>
</tr>
<tr>
<td>Health workforce</td>
<td>Working in a responsive, fair, and efficient way to achieve the best health outcomes possible, given available resources and circumstances; e.g. there are sufficient numbers and mix of staff, fairly distributed, and they are competent, responsive and productive.</td>
</tr>
<tr>
<td>Information system</td>
<td>Ensuring that ensure the production, analysis, dissemination and use of reliable and timely information on health determinants, health systems performance, and health status</td>
</tr>
<tr>
<td>Medical products, vaccines, &amp; technologies</td>
<td>Ensuring equitable access to essential medical products, vaccines and technologies of assured quality, safety, efficacy, and cost effectiveness, and their scientifically sound and cost-effective use.</td>
</tr>
<tr>
<td>Health financing</td>
<td>Raising adequate funds for health in ways that ensure people can use needed services and are protected from financial catastrophe or impoverishment associated with having to pay for them</td>
</tr>
<tr>
<td>Leadership/governance</td>
<td>Ensuring that strategic policy frameworks exist and are combined with effective oversight, coalition-building, the provision of appropriate regulations and incentives, attention to system-design, and accountability.</td>
</tr>
</tbody>
</table>

Nevertheless, they included the extra objective of improving the efficiency of the first three which had been understood in the model, yet portrayed as execution.

The measurement of the outcomes consisted of: health improvement (weighted 50%); responsiveness (25%); and social and financial risk protection (25%). The
measurement for efficiency was relative to the resources. **Figure 3** illustrates how, by fitting these elements together, the building blocks converge to provide highly accessible and safe quality care covering the population, thereby, ultimately achieving the system’s goals (WHO, 2007).

![WHO health system framework](image)

**Figure 3: WHO health system framework**

As discussed earlier, a healthcare system has multiple components and functions. Therefore, it is challenging to explore these layers of such an interactive system. The assessment of such a system is a complex process that involves paying attention to a wide range of multi-level variables related to the system itself as well as to the local context (von Bertalanffy, 1968; Rommer, 1991; WHO, 2002; WHO, 2010). There is currently no single theory or set of theories that offer testable hypotheses about when and why specific constructs of the system will predict specific outcomes. What does exist, however, are a plethora of frameworks that identify general factors that are predicted to affect the success of healthcare systems. In the next section, a framework for the main chronic diseases will be discussed (Wagner, 1998; WHO, 2002; Epping-Jordan et al., 2004).
2.5. Models for Chronic Disease Care

Globally, the majority of national healthcare systems have traditionally been organised around acute care. This traditional approach is built on the concept that diseases with a short duration and sudden onset can usually be treated by healthcare professionals (WHO 2002; Mills & Ranson, 2006; Mills, Rasheed, & Tollman, 2006). However, chronic diseases do not fit into this model. For the purpose of the current study, T2DM was selected as a case in point of a chronic disease that is characterised by slow development, long duration and the unlikelihood of a cure (IDF, 2013). In the traditional healthcare system, the interventions of the system in its response to a patient’s initiated search of care are related to an acute episode of illness. There is a limited participation of a variety of healthcare providers in this model which results in a physician-centred care model. The whole set of tasks is usually undertaken by one healthcare provider, mainly the physician, who provides unplanned consultation over a short period of time. Nonetheless, the majority of these consultations are due to chronic disease symptoms (Engel, 1997; Anderson; 2003; Ghaemi, 2009). In relation to this, under the present model of healthcare, patients leave their clinics not fully informed about half of physician’s instructions. In fact, just 45% of physicians believe that individuals with chronic diseases get sufficient healthcare (Anderson, 2003; McGlynn et al, 2003). Furthermore, fragmented care is conventional, leading to patients receiving low quality care. This can be detrimental to patients with chronic diseases who would benefit more from regular and continued contact with the healthcare system (Wagner et al, 1995; Nolte & McKee, 2008; WHO 2014; Beran, 2015).

Given all this, the failure to integrate care is the major obstacle to an effective national healthcare system. There are deficiencies in coherence, coordination, and
communication which can lead to the ineffective use of resources and, thereby, reduce the quality of care. Therefore, the concept of "integration" has been the foundation of several chronic disease approaches that have been developed over the past two decades (Nolte & McKee, 2008; Mendis & Chestnov, 2013; Beran, 2015; Scott & Davis, 2015). Other expressions like "continuity" "coordination" "cooperation" and "collaboration", with meanings closely similar to integration, have been applied to reinforce the importance of this concept. Chronic care management is a complex system and requires multifaceted interventions, therefore, these models recognize the complexity of care. Different parts of the healthcare system have to work together in this complex structure to achieve the goal of providing high quality of care for chronic disease patients. These models conform to the focal point of organisational theory which says that "the greater the differentiation, the greater the need for integration" (Axelsson & Axelsson, 2006; Nolte & McKee, 2008; Mendis & Chestnov, 2013).

Axelsson and Axelsson suggest that the idea of integration has its underlying foundations in organisational theory, specifically contingency theory, developed by Lawrence and Lorsch in 1976 (Lawrence & Lorsch, 1967; Axelsson & Axelsson, 2006, Scott & Davis, 2015). Lawrence and Lorsch suggested that organizational design is contingent on its environment and the organization’s attempt to align itself as a whole and to the structure its sub-elements to match the demands of its specific environments (Lawrence & Lorsch, 1967; Scott & Davis, 2007).

Integration was considered in the healthcare field for the first time when doctors started applying system and organisational theory to the healthcare sector (Kodner, & Spreeuwenberg, 2002). As cited by Axelsson and Axelsson, the definition of integration is “the quality of the state of collaboration that exists among departments that are required to achieve unity of effort by the demands of the
environment" (Axelsson & Axelsson, 2006, p.16). Leutz has also defined the integration in the healthcare field as “the search to connect the healthcare system (acute, primary medical, and skilled) with other human service systems (e.g. long term care, education, and vocational and social services) in order to improve outcomes (clinical, satisfaction, and efficiency)” (Leutz, 1999, p.78). Similarly, another author has defined integration as “a coherent set of methods and models on the funding, administrative, organizational, service delivery and clinical levels designed to create connectivity, alignment and collaboration within and between the cure and care sectors” (Kodner & Spreeuwenberg, 2002, p.13).

The aim of integration for a chronic care system has also been described by all the previous authors mentioned above. For instance, in a paper about the goal of integrated models and approaches, it was described as "enhancing quality of care and quality of life, consumer satisfaction and system efficiency for patients with complex, long term problems, cutting across multiple services, providers and settings" (Kodner & Spreeuwenberg, 2002, p.72). Other authors focus the aim around those persons with "physical, developmental, or cognitive disabilities - often with related chronic illness or conditions" (Leutz, 1999, p.98).

The concept of integration is a useful way of thinking about a variety of methods that are developed to enhance collaboration and communication through the different elements of the healthcare system. There have been numerous attempts to develop a classification of integration in healthcare that would allow a systematic examination of the structures and processes involved as well as their fundamentals and their effects on healthcare organization and delivery and, eventually, on user outcomes. A significant challenge is that, unlike in many other industries, in healthcare, the borders between the products and production phases are not always
easy to identify (Simoens & Scott 1999). Importantly, chronic disease patients do not progress linearly through the healthcare system towards a common final result. Given the probabilistic nature of the treatment process, healthcare providers need to be able to deal with unexpected demands at each stage of the process. Therefore, variations in integration in healthcare are unavoidably common.

Integration can be classified according to type which can be based on the breadth, degree and the process. There are several types of integration, namely, organisational integration (e.g. mergers), functional integration (the extent to which the function are coordinated e.g. human resources, information management, and financial management), professional integration (e.g. coordination within health care providers between different organisations), and clinical integration (the extent to which healthcare services are coordinated across various providers, functions, and operating units of the system). Integration can also be classified according to its breadth, such as integration between different levels of care (primary, secondary, and tertiary) which is seen as “vertical”, whereas integration that merges different sectors is described as "horizontal". Nevertheless, the difference between horizontal and vertical are overly simplistic (Simoens and Scott 1999; Leutz, 1999; Kodner & Spreeuwenberg, 2002; Russell et al, 2009). Further, the degree of integration ranges from collaboration (separate units retain their own service and funding responsibility) to full integration. Several authors stated that there are more complex types of integration, for example, process integration - structural, cultural, and social integration (Simoens and Scott 1999; Leutz, 1999; Kodner & Spreeuwenberg, 2002). The general message from these authors is that there are numerous types and forms of integrated care and patients with especially complex conditions, for example, those with chronic diseases, require a multi-dimensional solution. This means a more
organized combination of approaches from some of the operational areas depicted above (Kodner & Spreeuwenberg, 2002).

Basically, integration and contingency theory are the foundation of this study. As described by Donaldson, contingency theory is useful in explaining barriers and enablers relating to efficiency drivers in organizations (Donaldson, 2001). This theory attracted attention regarding how a healthcare system should be organized internally and it received acceptance from a wide audience, especially those involved with the dramatic increases of T2DM which is complex and requires continuous care provided by a multi-disciplinary healthcare team. T2DM burdens require an integrated approach by the healthcare system. Although the concept of integration is very logical, Nolte and McKee put forward the idea that there is a lack of empirical evidence about the outcomes of the different types of coordination, integration and chronic care models (Nolte and McKee, 2008). The next section will explore some of these chronic care frameworks based on the concept of integration.

2.5.1 The Kaiser Permanente Triangle

The Kaiser Permanente Triangle is one of the chronic care frameworks described as a "fully integrated system" which was developed by a health maintenance organisation in the USA. According to Goodwin et al. (2004), Kaiser Permanente has identified some key attributes that should characterise an integrated health care system. These include: an emphasis on primary care, ensuring the quality of care and the control of costs, and a networking multi-disciplinary team (Figure 4).
This model classifies individuals into three levels based on their degree of need. Level 1 constitutes the majority of the population with chronic diseases and who have a relatively low level of healthcare need. In addition, their condition is reasonably under control through self-management and the support provided by the primary care services. At level 2, the patients’ conditions are unstable so they are considered at increased risk, therefore, at this level, patients have structured support through specialized disease management. Finally, at level 3, the patients are classified as having highly complex needs that require active management through case management (Goodwin, 2004).

This approach has demonstrated significant improvements in the care process and the health outcomes (Nolte & McKee, 2008; Beran, 2015). However, healthcare organisations recognised the need to move away from a condition-centric approach to broader approaches that emphasize prevention. Consequently, this framework has evolved over time, with Wagner and his colleagues developing this framework by
taking an explicit community perspective. The next section will discuss this framework (Wagner, 1998).

2.5.2 The Chronic Care Model

The pioneer to, perhaps, the most well-known model for addressing chronic care is the Chronic Care Model (CCM), originally developed by Edward Wagner in 1996 to guide the provision of healthcare for primary care patients with chronic illnesses. The project contributed to the output of the Health Cooperative of Puget Sound in the State of Washington (Wagner, 1998). The development of the CCM was a result of reviewing the effectiveness of 72 chronic disease management programmes and the logistic support from the Health MacColl Institute for Healthcare Innovation (Bodenheimer et al., 2002a). Since most of the patients were treated in the primary care setting, this model represents a re-organization of primary healthcare delivery (Bodenheimer et al., 2007; Coleman et al., 2009; Nutting et al., 2007). This re-organization of care delivery created a new environment in which the focus of healthcare professionals was shifted to a patient-engaged and proactively planned approach to chronic-disease management (Bodenheimer et al., 2007; Coleman et al., 2009). The CCM forms and organizes the changes required in the healthcare system and by the patient to improve outcomes (Wagner et al., 2001). While the CCM does not offer a quick fix to the primary healthcare system, it is a multi-dimensional solution to the complex problem of chronic illness management (Bodenheimer et al., 2002a). Wagner et al. (2001) intended for the CCM to be broad in nature, making it applicable to several chronic illnesses and healthcare settings. According to Fiandt, the CCM is a model that can improve a healthcare system’s outcomes as well as facilitate individual and population health interventions (2006).
The transfer to a chronic care method is accomplished by integrating six key components of the CCM especially designed to improve the relationship between patients and healthcare providers as well as the patients’ health outcomes (Coleman et al., 2009) (Figure 5). The components are: organisation of healthcare; delivery system re-design; decision support; support for the self-management of diseases; optimization of community resources or linkages; and the use of clinical information systems (Bodenheimer et al., 2002a).

Figure 5: The Chronic Care Model (CCM) (Wagner 1998)

Healthcare Organisation

According to the WHO, the healthcare organisation element in the CCM constitutes the macro level of the entire healthcare system and facilitates healthcare provision for people with chronic illnesses (WHO, 2010). In order to manage chronic illnesses, healthcare systems must organize an effective, comprehensive and supportive system of healthcare. Improving the ability of healthcare systems to monitor the burden of chronic diseases requires its leaders and decision-makers to
achieve the following objectives: set a clear, official plan for managing chronic illnesses across healthcare organisations; develop a strategy for improving chronic care; secure resources needed for chronic care; include the treatment of chronic diseases in the organisational objectives and plan; provide full support to healthcare organisations; enhance the continuing quality improvement strategies and control errors; make quality-of-care indicators the basis for incentives; support changes to improve the implementation of best practices; apply evidence-based interventions to enhance system change, and motivate the healthcare providers through financial and nonfinancial incentives (Wagner et al., 2001; Gugiu et al., 2013). If healthcare managers do not view chronic care as a priority, innovation and improvement will not take place (Bernheimer et al., 2002).

The method of organizing healthcare systems is one of the most important factors governing the quality of chronic illness interventions. For instance, the efficient application of a new case management programme will more expeditiously achieve the goal. In contrast, if the new program is not applied efficiently, it may overlap with other services, resulting in duplication of healthcare services and a subsequent wasting of resources (Plsek & Greenhalgh, 2001). The organisational plan for the healthcare setting should be clear and detailed in order to implement any new programme or services. Atun et al., (2009) have argued that it is important to bear in mind both the horizontal and vertical dimensions of initiatives designed to implement new programmes. The horizontal programme designs are combined within the system to compensate for the limitations of other programmes while vertical programmes are adopted as stand-alone programmes that do not interfere with the available ones. According to Greenwood, Suddaby and Hinings (2002), the decision to adopt new programmes emerges from the views of the decision-makers and healthcare providers
with regard to the positive and negative outcomes of each approach. It is also important to bear in mind, however, that wider political, social, economic, and cultural factors have the strongest effect on the adoption decision (Atun et al., 2009).

**Delivery System Design**

This element refers to the organisation of the medical practice. The delivery system design highlights the following: the importance of formulating a multi-disciplinary clinical team that contains different healthcare providers; designing the role of a care manager; the delegating of the responsibilities between healthcare providers; implementing of planned individual visits or group visits; reaching out to special cases (high-risk patients); enhancing communication between the patient and different healthcare providers in a single visit; following up with the patients regarding behavioural changes, symptoms, or use of medication; and changing medication when needed (Wagner et al., 2001; Brown & Nichols, 2003; Willens et al., 2011; Gugiu et al., 2013).

**Decision Support**

This aspect of diabetes care seeks to enhance the decision-making and patient care for the healthcare providers by implementing, updating or utilizing evidence-based guidelines; increasing interactions between the providers to share experiences and information; educating the healthcare providers; reviewing high-risk patient cases on a regular basis to improve their treatment and diagnosis; training healthcare providers in goal setting, empowerment, and problem-solving methodologies for patients; and utilizing and improving patients assessment methods (Wagner et al., 2001; Gugiu et al, 2013). Supportive tools for decision-making have the ability to improve clinical practices. According to the Improving Chronic Illness Care Organization (2015), if the guidelines are integrated into the system with access
available to the healthcare providers and patients, improvements to healthcare practices will succeed. This integration includes timely reminders and feedback (Wiley et al, 2015). According to the Institute for Healthcare Improvement (2015), there are several steps that must be taken in order to integrate the evidence-based guidelines designed to improve the practices of the healthcare providers.

Self-Management Support

Self-management refers to the ability of the patient to understand and apply basic healthcare skills that enable him or her to manage the disease (Lorig, 1993; Lorig, 2003). This component of the CCM is designed to motivate patients and their families by supporting patient self-management; cooperating between healthcare providers and patients to set goals and make decisions; determining gaps in patients’ self-management behaviours; establishing action plans; assessing patients’ readiness to change; promoting healthier lifestyle choices; identifying barriers that lead to unhealthy behaviour and suggesting tools for eliminating them; and providing educational materials resources and training staff in the use of these materials (Rickheim et al, 2002; Parchman et al, 2007; Nutting et al, 2007; Gugiu et al., 2013).

In order to enhance the patient’s confidence in taking care of his or her own medical condition and to improve the clinical outcomes, according to Lorig (2003), there are some key self-managements skills that should be integrated into the patient’s self-management activities. These skills are: problem-solving skills that assist patients to act independently to overcome everyday problems; decision-making skills e.g. how to adjust the patient’s physical exercise load; resource utilization skills where the patient is trained to reach the best outcomes of the provided resources, such as support groups and local community programs; patient-provider communication skills to improve relationships and collaboration; and taking action (Lorig, 2003).
Community Resources and Policies

Disease management is directly related to the values and practices of one’s community as well as the kind and availability of resources (Chacko, 2003). Cultural factors govern the accessibility of healthcare institutions and the ways in which families engage with healthcare practitioners (Tripp-Reimer et al, 2001). However, in general, a stigma is not attached to diabetes (Tripp-Reimer et al., 2001; Campos, 2006). Nevertheless, efforts to prevent diabetes are lacking as is participation in screening and care programmes. This is largely as a result of cultural beliefs, the priority given to other needs, and poor access to services. Poor health literacy, a lack of awareness of diabetes services, a lack of family and social support, and poor levels of patient involvement are some of the cultural determinants blamed for the general ineffectiveness of diabetes care programmes (Alhyas & McKay, 2010; Al-Khudairy et al, 2014). The misguided belief that diabetes results from divine intervention often leads to an ineffective reliance on folk medicine. This prevents early management of the disease leading to the increased likelihood of emerging complications (Tripp-Reimer et al, 2001; Epping-Jordan et al, 2005; Campos, 2006; Alhyas & McKay, 2010). Familial and wider social support is key to successful adherence to diabetes care. Strong family support correlates with obedience to the recommendations of diabetes care providers. Where this is lacking, barriers to achieving effective diabetes care are thus multiplied (Tripp-Reimer et al, 2001).

The CCM is a programme designed to practically accommodate the cultural, social and personal obstacles and conduits to successful diabetes care. CCM involves linking and using community resources in order to support healthcare efforts (Dancer & Courtney, 2010). According to Uchino (2004), the clinical outcomes for diabetes sufferers improve when they are motivated to participate in physical exercises with
their friends. In addition, Hogan, Linden and Najarian (2002) conducted a systematic review of 100 published studies with the results revealing that 80% of the studies reported positive outcomes when social support interventions were used.

Looking at diabetes management from a local perspective, the community is considered to play an active role in healthcare organisation. Schools, universities, media and religious institutions play an important role in addressing community needs and developing public health programmes. Some healthcare systems fail to provide effective T2DM interventions due to a lack of community linkage and its participation in the intervention planning (De Maeseneer et al, 2003; Anschutz, Van Strien and Engels, 2008; De Maeseneer et al, 2008; Otero-Sabogal et al, 2010; Gardner et al, 2011).

**Clinical Information System**

A critical component of CCM is a clinical information system which aims to provide timely access to data (Siminerio, 2010). Effective clinical information systems provide reminders for patients and healthcare providers about important services; identifies patients who need additional care; facilitates patient self-management; and monitors the performance of healthcare providers (Wagner, 1998). In addition, clinical information systems provide structured data relating to patient or population disease management that leads to effective and efficient healthcare practices (Metzger, 2004; Fiandt, 2006).

CCM puts a strong emphasis on the use of information technology (IT) as a basic component of the clinical information system (Wagner et al., 2001; Warm, 2007). Indeed, IT can be effectively used to support other components of CCM (Adaji Schattner, & Jones, 2008; Alharbi et al, 2016a). Health information technology (HIT)
can improve information flow and enhance communication among healthcare providers and patients. In fact, HIT is essential for implementing CCM. The management of T2DM is well suited to the use of HIT because it is characterized by easily quantifiable processes and outcomes (Piette, 2007; Siminerio, 2010). Managing diabetes effectively requires the identification of people with diabetes, a synthesizing of data relating to population health, the creation of patient health summaries which enhances care coordination, and the delivery of knowledge that gives patients the skills and resources needed for effective self-management (Bu et al., 2007). HIT interventions for diabetes CCM, such as diabetes registry, electronic decision support tools, computerized prompts, electronic medical records (EMR), personal health records (PHR), and other kinds of electronic reminders and feedback have been found to prevent the development of complications resulting from diabetes, to save on medical costs, and to improve care processes and clinical outcomes (Joshy & Simmons, 2006; Bu et al., 2007).

There are several types of HIT used to support people with T2DM. These include the disease registry, EMR, computer-based self-management systems, and electronic decision support systems (Piette, 2007; Siminerio, 2010; Alharbi et al 2016a). Previous studies indicated that there was no universal definition of a diabetes registry; rather, it can be defined as a systematic collection of data relating to incidences of the disease or disease groups or data relating to the performance of an intervention within one or more defined geographical areas (Van & Musen, 1997). Brooke has defined a patient registry as an organized system which collects a defined set of data on identifiable individuals for a specific purpose (Brooke, 1974). According to Metzger (2004), the disease registry is a computer application ‘used to capture, manage, and provide information on specific conditions to support organized
care management of patients with chronic disease’. The disease registry is not an EMR. Some are stand-alone systems and some EMRs contain simple registry functionality. The use of an integrated registry together with EMR can have a potentially positive impact on the treatment of people with T2DM.

Diabetes registries track patients with diabetes to enable several outcomes. The diabetes registry generates performance feedback reports to be viewed by the physician and they also tracks clinical indicators, such as the proportion of patients with HbA1c level > 9% and retinal screening (Stroebel et al., 2002; Bu et al., 2007; McEvoy & Laxade, 2008). Registries can also compare diabetes status with clinical guidelines to provide reports identifying patients who are not receiving care and can provide ‘point-of-care reminders’ for the physician to order specific interventions (Fiandt, 2006). Patients can receive reminders when the registries identify who needs to be contacted in order to receive a recommended test or treatment. This may help to shift the emphasis away from reactive to proactive health care and improve adherence to treatment regimens (Stroebel et al., 2002; Bu et al., 2007). From an organisational perspective, diabetes registries support the delivery of care and enhance the quality-of-care coordination. They can also be used to obtain information about the performance of the healthcare providers (Ortiz, 2006). Indeed, diabetes registries remind healthcare workers of their obligation to provide comprehensive care. In fact, it has been suggested that diabetes management programmes effectively improve diabetes outcomes only when a registry is put in place (Hummel, Norris, & Gibbs 2003). A further benefit of the use of registries is that they can be used for clinical trial recruitment (Brooke, 1974).

EHRs are used by a variety of different healthcare providers, including physicians, nurses, pharmacists, radiologists and laboratory technicians. Furthermore,
EHRs are also used by administrative staff and patients (Häyrinen, Saranto & Nykänen, 2008). There are several benefits associated with EHRs, including their ability to be easily accessed as computerized records and their capacity to reduce the poor documenting of information (Rodriguez-Vera et al., 2002). EHR systems hold many potential benefits, but three basic functionalities have great promise for improving healthcare systems. These include clinical decision support tools, computerized physician order entry systems and health information exchange (Grant et al, 2008; O’Connor et al, 2011).

A Decision Support System (DSS) is one designed to support the decision-making process of an individual or organisation through the use of data retrieval, modelling, and reporting. It is an active knowledge system that uses patient data to generate case-specific advice (Van & Musen 1997; Austin & Boxerman, 2003). Computerized clinical decision support systems (CDSSs) are information systems designed to improve clinical decision-making. Patients’ information is matched to a computerized knowledge base, and software algorithms generate patient-specific recommendations. Many CDSSs provide several modes of decision support, including reminders of overdue preventative health tasks, alerts for critical values, advice for drug prescribing, reviews of existing healthcare orders, and suggestions for various active care issues (Garg et al., 2005). CDSSs have been shown to reduce serious errors in prescribing medication, to increase adherence to recommended care standards, to improve practitioners’ performance, and to enhance the surveillance and monitoring of patients suffering from a wide variety of conditions (Shea et al., 1996; Hunt et al., 1998; Bennett & Glasziou, 2003; Eslami, Keizer & bu-Hanna, 2008).

CCM has been implemented internationally in such countries as the UK, USA, the Russian Federation and Canada. However, the effectiveness of the CCM has
received mixed reviews in numerous studies. Bodenheimer, Wagner and Grumbach (2002b) systematically reviewed 39 published intervention studies in which the CCM was either completely or partially implemented. The review showed that implementation of the CCM in 32 studies improved at least one process or outcome for diabetes patients. The researchers determined that integrating the CCM into diabetes healthcare services improves their quality. In another review, Nolte and Mickee (2008) stated that there was little evidence supporting the implementation of the entire model as essential for achieving the same results. However, the majority of the empirical evidence surrounding CCM implementation was mainly focused on patient-self management, delivery system design, clinical information system, and decision support. Similar outcomes were reached by Alharbi et al (2016a) who found that different pieces or combinations of CCM elements were more critical where the role of community resources and policy and the healthcare organisation had not been addressed in the review. In addition to the mixed findings about which elements or combination of elements are essential to improve health outcome, the adoption of the CCM has been critiqued for a number of reasons. For example, some noted that the implementation of CCM required a significant amount of time and resources (Coleman et al., 2009). Others suggested that the CCM at a national level required political support and the involvement of decision-makers. From a macro-level perspective, financial support and leadership vision were seen as essential for integrating the model into the system (Epping-jordan et al., 2004). Lastly, one of the most important criticisms was that patients did not appear at the centre of the model, but rather were active players or recipients of care that must "fit within a clinical pathway or map" of a larger encompassing organisation of care (Lubkin & Larsen, 2013).
In response to these criticisms, the WHO joined the CCM developer (MacColl Institute for Healthcare Innovation) to adapt the model for international use. The result of the cooperation was the Innovative Care for Chronic Conditions framework (ICCC) (WHO, 2002; Epping-Jordan et al., 2004). The modified version of CCM could be applied internationally, especially in developing countries. These modifications took place on the low, middle and top levels of the CCM. On the top level, ICCC emphasizes more the role of political leaders. The middle level addresses the linkage between health service organisations and the community, while at the low level, the word ‘prepared’ was added to the word ‘patient’ for the purpose of describing patients in countries where health-service availability is a major concern. Therefore, the term ‘prepared patients’ referred to those who had healthcare support.

2.5.3 The Innovative Care for Chronic Conditions Framework

The ICCC Framework is theoretically based on the CCM, but unlike the CCM, it addresses different aspects of what is considered to be ‘good’ care for chronic diseases (Figure 6). This means it highlights the role of policy and community for improving care while also stressing the role of patients as ‘health producers’ and recognizing that chronic diseases may be most effectively managed with the support of both the community and their healthcare providers (WHO, 2002; Epping-Jordan et al., 2004). This model places the patients at the centre, emphasizes the importance of the health-care team and community partners ("micro level") which is affected by the broader healthcare organisation and community (the "meso level"), and the positive policy environment ("macro level").
This model proves to be much better within the context of a comprehensive, national healthcare system than its forerunner and it is strongly oriented towards providing practice. A combination of activities at various levels is at the heart of this model. In this sense, it mirrors the central idea of the bio-psychosocial model which places the individual at the centre of the expanding concentric environmental circles of the interpersonal, organizational, community, and public policy environments (Engel, 1977).

The significant conversion of the CCM to the ICCC is based on the emphasis on community partnership with the most noteworthy change being the extension and recognition of the need for patients and their families to be more than "informed and activated" but to be "informed, motivated, and prepared". This means that, as the WHO (2002) recommends, patients need to be informed about their health condition and any chronic illnesses they have, such as T2DM. Nevertheless, they must also be
informed about the expected course of treatment as well as the management and possible progression of the disease along with any expected complications they may encounter. Moreover, patients need to know what effective strategies are available for managing symptoms and preventing complications. Patients also need the motivation to change and maintain their health behaviours, to adhere to long-term treatment and to self-manage their condition. Contributory to this is the recognition and understanding those patients and their families must also be prepared with the needed behavioural understanding and skills to effectively manage their illnesses at home. However, in order to do so, patients and their families must also have access to the healthcare facilities, medications and medical equipment, as well as the self-management tools and skills to ensure that optimum health outcomes are possible (WHO 2002, Epping-Jordan et al, 2004).

Moreover, with the need for patients to be more than just “activated,” the ICCC Framework emphasizes the critical need for the healthcare team to be more than just “prepared” from a professional standpoint. It suggests that the healthcare team needs to “informed and motivated” as well, requiring a greater degree of cooperation, integration and accountability to accept the roles and responsibilities for their tasks in keeping with their professional abilities. Nevertheless, in doing this, each team member must be willing to recognize the need for a flattened hierarchy within the care provision processes as well as to accept that there must be a move away from physician dominated models to where each team member is valued for his or her unique contribution to the management of chronic illnesses (WHO 2002).

As described earlier, a major difference in the transformation from the CCM to the ICCC Framework is the presence of community partners. The emphasis upon the presence and the integration of the community by the ICCC Framework
recognizes and reflects the significant roles that communities undertake in many developing countries when it comes to issues concerning public health and economic development. This emphasis on them being “prepared, informed, and motivated’ community partners suggests that in order for this presence to be effective, community partners must be equipped with the information and skills that are essential for successfully managing chronic diseases. It recognizes that they provide an “untapped collection of individuals” that can complement and support the care that is provided by the broader healthcare organization. Thus, they may be able to reduce unnecessary demands for tertiary care or follow-up and monitoring services that in many countries are typically provided by an already over-extended formal healthcare organization (WHO 2002). Therefore, community partners can provide a critical bridge for the gap that often exists between the more formal organized clinical care and the real world challenges faced by patients and their families (Epping-Jordan et al., 2004).

The ICCC framework has been applied as a reference for designing, organising and piloting care for chronic conditions in different countries. In Australia, the policy-makers applied this model as a guide for the New South Wales Chronic Care Program for the period 2003-2006. The Ministry of Health in Rwanda used the framework for their strategic planning for preventing and controlling HIV/AIDS. It has also served as an evaluating tool for the healthcare system in Morocco (Epping-Jordan et al, 2004; Si et al, 2005). In spite of the above-mentioned influence of the ICCC framework, the literature has not identified any studies that assessed its implementation in a comprehensive manner throughout a total healthcare system. However, the use of many components of the ICCC framework has been verified in the literature on CCM.
2.6 The Study’s Conceptual Model

A review of the aforementioned models points to a clear area of overlap of the healthcare organisation and the workforce. However, all the models, except ICCC, fail to address all elements (Roemer 1991; Wagner, 1998; WHO, 2002; Epping-Jordan et al., 2004; WHO, 2007) (Table 6). Therefore, the ICCC can be used to identify the strength, deficiencies and interconnectivity of existing T2DM care management in the KSA (WHO, 2002; Epping-Jordan et al., 2004). This model places the patient at the centre of an environment consisting of several factors ranging from the micro to the macro. At the macro level, policy represents "government’s efforts, including strengthening partnerships, promoting financing, providing leadership and allocating human resources". The meso level includes health service organisation that "promotes continuity and coordination, organises and equips the healthcare team, and supports self-management and prevention, and at the micro level, there is partnership between patients, the healthcare team and the community. This is seen in Table 6.

<table>
<thead>
<tr>
<th>Identified elements</th>
<th>Chronic management model</th>
<th>Health system model</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>CCM</td>
<td>ICCC</td>
</tr>
<tr>
<td>Policy</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Self-management support</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Health care organization</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Workforce</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>HIS</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Community support</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Prevention</td>
<td>✓</td>
<td>✓</td>
</tr>
</tbody>
</table>

The ICCC framework recognises that the policy environment plays an intervening role in the healthcare system’s response to T2DM. Healthcare policy is closely linked to monitoring, controlling and organising the healthcare system at all levels (Epping-Jordan et al, 2004). The role of prevention strategy is started at this level and providers need to be trained in order to work with patients on prevention. In
addition, the public awareness strategy, starting from the Health Education Institute along with the media, will greatly affect the population’s knowledge and behaviour.

**Figure 7: Conceptual modification of ICCC framework**

The model then moves to the meso level of the health service organisation and community. This level addresses the orientation of care, self-management and the use of the information system and community support. These elements represent the three most important factors that affect diabetic patients and they speak to the basics of healthcare, that is, the supporting systems and the healthcare providers.

At the micro level, effective patient and care providers’ interaction is recognised as one part of the total healthcare system puzzle. At this level, the researcher set out to assess the extent to which patients believed that their providers empowered them to engage or take an active role in their healthcare. As mentioned
previously, this framework divides the healthcare system into three strata which Figure 7 illustrates, showing the conceptual modification of the ICCC framework.

Examining the response of the Saudi healthcare system to the management and control of T2DM is a complex task. In order to simplify the approach, the researcher provided specific indicators under each of the ICCC levels (Table 7). By adopting this framework, the researcher sought to link the healthcare system levels from the central government policy down to that of the local practice to identify the gaps and opportunities at the macro (policy), meso (healthcare organisation and community), and micro (patient interaction) levels through the following objectives:

1-To assess critically the national policies and programmes related to the prevention and control of T2DM.

2-To assess the problems regarding the role of the healthcare organisation and community in T2DM management from the healthcare providers and community members’ perspective.

3-To assess patient experience with diabetes management, their interaction with healthcare providers, and their experiences concerning their personal support from the patient’s perspective.

<table>
<thead>
<tr>
<th>level</th>
<th>indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td>Macro</td>
<td>Policy</td>
</tr>
<tr>
<td></td>
<td>-National clinical guideline</td>
</tr>
<tr>
<td></td>
<td>-Prevention programme</td>
</tr>
<tr>
<td></td>
<td>-Monitoring process</td>
</tr>
<tr>
<td>Meso</td>
<td>Health service organisation</td>
</tr>
<tr>
<td></td>
<td>-Promote continuity and coordination</td>
</tr>
<tr>
<td></td>
<td>-Organise and equip healthcare team</td>
</tr>
<tr>
<td></td>
<td>-Health information system</td>
</tr>
<tr>
<td>Community</td>
<td>-Public awareness</td>
</tr>
<tr>
<td></td>
<td>-Mobilise resources</td>
</tr>
<tr>
<td></td>
<td>-Provide complementary services</td>
</tr>
<tr>
<td>Micro</td>
<td>Self-management support</td>
</tr>
<tr>
<td></td>
<td>-Patients-providers interaction</td>
</tr>
</tbody>
</table>
3.7 Chapter summary

This chapter describes what is a healthcare system and gives key definitions. It describes the CCM in detail as this was one of the first models for the integrated management of chronic diseases like diabetes. However, with its link to policy, the ICCC framework was selected for the study as a means of exploring the Saudi healthcare system. The researcher set out indicators for the macro, meso, and micro levels and these were considered as the most appropriate ones at the time although there was the understanding that other useful indicators might be found during the process of data collection. This was likely to happen as the availability of data in many cases drives the selection of such indicators. The next chapter goes on to explain the macro level of the KSA healthcare system in managing T2DM.
Chapter 3: Diabetes Care Services in KSA: Document Analysis

3.1. Introduction

This chapter analyses health policies relevant to T2DM in KSA. I address the research first research question by using Walt and Gilson’s policy triangle as my approach to analysis (Walt & Glison 1994; Gilson et al, 2008; Gilson, 2013). Health policy aims to explain how political, economic and socio-cultural environments interact with the macro level of the healthcare systems. Over preceding decades, the scientific literature on health policy analysis has noticeably increased (Walt et al, 2008; Faraji et al, 2015; Ahmed et al, 2015; Kilic et al, 2015; Ben Romdane et al, 2015). Many international healthcare systems have introduced national health programmes, but they have not often succeeded in improving the healthcare outcomes due to several aspects associated with the health policy actors, content, context, and process (Walt & Glison 1994; Gilson et al, 2008; Gilson, 2013). In order to assess the national Saudi’s healthcare system for managing diabetes, this chapter is intended to address the following research question:

How has the current KSA healthcare system been responding to T2DM?

This will be done by extensively reviewing the official documents to explain the existing policy frameworks and the organisational structure. This analysis intends to answer the following sub-questions:

1-Who are the main actors who are developing and implementing the diabetes control policy in the KSA?

2-What are the Saudi diabetes healthcare policy content and is it compatible with the principles of the WHO “Health for All” strategy?
3-What are the contextual factors (political, economic and socio-cultural) that influence the healthcare policy for diabetes management in the KSA?

4-How is T2DM control policy process (implementing, monitoring, and evaluation) executed in the KSA?

5-What are the main issues that have not been adequately covered in the existing research?

3.2. The Method

3.2.1. The Research Framework

Healthcare policy analysis has many different concepts and some researchers mainly focus on the content of the policy, while others are more concerned with the context and process of the policy. Generally speaking, there are two main approaches to health policy analysis - the rationalist and the behaviourist (An, Huang & Baghbabian, 2015). The rational school tends to focus more on the policy contents and deals with values and how policy-making should be undertaken (Renny, 1968; Walt & Gilson, 1994; Walt et al, 2008; Gilson, 2013). Therefore, this approach is seen as a problem-solving method where the problem is defined, alternative approaches to solve the problem are considered and the best approach is selected (Sutton, 1999; Gilson et al, 2008; Gilson, 2013). The advantage of this approach is that it allows for a more objective analysis of previous and present health policies and it provides a framework of how policy-making should to be undertaken.

On the other hand, the behavioral approach focuses more on the policy context and process within which the policies are designed and implemented (An et al., 2015). This school of analysis attempts to provide insights as to why several healthcare problems are not solved, why policies are not applied successfully and why the health strategies do not reach their goals (Sutton, 1999; Walt, 1994; Walt & Gilson, 1994;
Gilson et al, 2008; Baeza, Bailie, & Lewis, 2009; Gilson, 2013). Within the behavioral school, various models and theories are developed. Sabatier has developed the Advocacy Coalition Framework, one of the policy analysis frameworks used in the USA and many other developed counties. An advocacy coalition contains "people from a variety of positions who share a particular belief system and who show a non-trivial degree of coordinated activity over time" (Sabatier 1988, p.134).

Kingdom has analyzed the policymaking in USA, and developed the ‘Theory of Stream’. According to this theory, agenda setting is the first step. This agenda argues the need for three important elements - problems, proposals, and politics flowing along in independent streams. The problems stream includes the broad problems facing the society, some of which become recognized as problems that require policy-makers to pay attention. The proposal stream refers to a set of policy alternatives that the researchers propose for serious consideration, while the politics stream refers to political factors that influence the agenda, e.g. national attitude and social pressure. In general, the Kingdom theory aims to explore how specific healthcare issues have arisen on public policy agendas (Kingdon, 1995).

Within the wide variety of models and theories, the choice of the method has to be determined by the research question and the availability of data. The researcher believes that for an analysis of the healthcare policies in the KSA, many theories and models "including Advocacy Coalition Framework and Theory of Stream" are not suitable since cultural, political, and the context in which policy process takes place in the developed world is quite different than in developing countries. Analysing healthcare policy requires a comprehensive approach designed for a developing country like KSA. Therefore, in this project, a known healthcare policy analysis framework (Walt & Gilson 1994; Walt et al, 2008; Gilson et al, 2008; Gilson, 2013),
that is, the triangle framework has been adopted to analyse the evidence, including the data extracted from the documents. Walt and Gilson’s triangle framework for policy is considered as an appropriate tool for analysing healthcare in this study because this it has been designed for investigating public health policies in developing countries (Faraji et al, 2015; Ahmed et al, 2015; Kilic et al, 2015; Ben Romdane et al, 2015). It was created especially for analysing data produced in scientific research on health, and for identifying four dimensions for understanding the processes of the political and cultural implementation of healthcare policies. These include the content, the actors the context, and the process (Figure 8) (Walt & Gilson, 1994; Gilson et al, 2008; Gilson, 2013). Despite the importance of each element and its interactions with other elements, the researcher decided to adopt the behavioural approach in analysing the healthcare policy while paying particular attention to the process and the context within which diabetes healthcare policies are constructed and implemented. However, it is understood that this perspective can limit involvement of normative analysis (An et al., 2015).

<table>
<thead>
<tr>
<th>Actors</th>
<th>The individuals and groups who influence the creation and implementation of policy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Content</td>
<td>The substance of the policy and action plan</td>
</tr>
<tr>
<td>Context</td>
<td>The environment or situation in which policy processes occur</td>
</tr>
<tr>
<td>Process</td>
<td>The overarching process of making and implementing policy</td>
</tr>
</tbody>
</table>

**Figure 8: Analysis questions in accordance to the model for health policy analysis.**

Q: Question (Adopted From Walt And Gilson (1994))
3.2.2 The Search Strategy

To explore Saudi Arabia's healthcare system in managing T2DM at a macro level, a review of relevant policy documents was conducted. The documents reviewed dealt with providing information about prevention or control programmes, and assessing the political, economic, social, and historical contexts of T2DM management in the KSA. The search was limited to the first healthcare initiative GCC Action Plan from 2001 until May 2017.

The data search began with an examination of the grey literature (government website, mass media website). The published policy documents were not indexed nor listed in any academic databases in a standardised and timely manner. In an attempt to increase the number of the documents and to ensure reliability, the researcher expanded the scope of the search for information to GCC Health Council, IDF and WHO, as these organisations are the most globally recognised institutions that report information regarding health system responses to T2DM.

In addition, a literature search for academic papers about diabetes management in KSA was conducted on PubMed and Embase databases using the following key words "diabetes", "policies", "programs", "process", "strategies", "intervention", "KSA", "Saudi Arabia" and "GCC" countries, apart from the official policy documents about diabetes programmes. The national and local survey reports, guidelines, national conferences reports were also examined. The included documents are listed in Table 8.
<table>
<thead>
<tr>
<th>Document (Reference)</th>
<th>Type</th>
<th>Area</th>
<th>Policy elements identified</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Khoja, 2010)</td>
<td>Conference report</td>
<td>GCC</td>
<td>✓</td>
</tr>
<tr>
<td>(Khoja, 2015)</td>
<td>Conference report</td>
<td>GCC</td>
<td>✓</td>
</tr>
<tr>
<td>(WHO, 2007)</td>
<td>International report</td>
<td>KSA</td>
<td>✓ ✓</td>
</tr>
<tr>
<td>(WHO, 2013)</td>
<td>International report</td>
<td>KSA</td>
<td>✓</td>
</tr>
<tr>
<td>(IDF, 2013)</td>
<td>International report</td>
<td>KSA</td>
<td>✓</td>
</tr>
<tr>
<td>(WISH, 2015)</td>
<td>International report</td>
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3.2.3. Data Extraction and Synthesis

The primary aim of the document analysis was to categorise the contents and identify dominant themes within them. In order to obtain an adequate analysis, the researcher adopted a neutral stance to the data to prevent personal views from affecting judgement. “Bracketing” was used to analyse the documents and this technique involves putting aside one’s own beliefs, not making judgments about what one has observed or heard and remaining open to the data as they are revealed (Braun & Clarke, 2006; Corbin & Strauss, 2008; Kodish & Gittelsohn, 2011). Following the principles of the ‘Framework Synthesis’ approach, the researcher deductively extracted, summarised and synthesised data drawn from the document (Barnett-Page and Thomas 2009). In order to be able to do this, it was necessary to read each document thoroughly and assess to what extent the elements of the Walt and Gilson’s framework were reflected in it. In addition to themes already identified by the framework, new themes were developed and included as they emerged from the data. The initial paper coding was conducted using deductive coding (Bradley et al., 2007) (see Appendix A). Data were coded under multiple themes when it was appropriate, allowing all such data and the themes to be re-classified according to the study framework. To do this, a data extraction Excel sheet template was designed, based on the framework presented in Figure 8. It included four sections: actors, content, context, and process. However, the researcher’s perspective on this framework was to look for interactions between that the first three elements that act together to generate and inform the dynamics of the system (process).
3.3 The Results

3.3.1 The Actors

The term ‘Actors’ refers the set actors or organizations who develop, implement and evaluate the health policy. Health policy actors include the range of organizations involved in activities that are likely to influence health (Walt & Gilson, 1994; Gilson et al, 2008; Gilson, 2013). At the population level, the Saudi MOH is responsible for developing healthcare sector policies which implementation programmes through healthcare promotion, early detection, and disease treatment for Saudis. It is a free healthcare system. While the MOH has always aimed to provide an adequate number of health facilities at all levels, a wide range of medical services were also provided by the Defence, Education, National Guard ministries, all of which ran hospitals or provided some form of healthcare services. Primary healthcare was also the responsibility of the MOH (Al-Khaldi & Alsharif, 2002; WHO, 2011; Almalki et al, 2011; MOH, 2013c; MOH, 2015; MOH, 2013c).

The MOH is the major healthcare provider with a total of 268 hospitals (38,970 beds) and 2,259 PHC centres (MOH, 2015). These facilities comprise about 60% of the total healthcare services in the country. The other governmental sectors include referral hospitals such as the Security Forces Medical Services, King Faisal Specialist Hospital and Research Centre, National Guard Health Affairs, Army Forces Medical Services, Arabian-American Oil Company (ARAMCO) hospitals, Ministry of Education Hospitals (university hospital and school health units), Red Crescent Society, and Royal Commission for Jubail and Yanbu health services (Almalki et al., 2011). According to latest report from MOH, the private sector operates only 20% of the Saudi healthcare facilities (MOH, 2015) (Figure 9).
Figure 9: The current structure of the healthcare sectors in KSA (Almalki, 2011)

The MOH provides health services at three levels: primary, secondary and tertiary (MOH, 2009). Prevention and curative services are provided through PHC centres. Cases that require a higher level of healthcare are referred to the secondary level of service (that is, a public hospital), whereas cases that need more complex levels of healthcare are transferred to the tertiary level of healthcare (i.e. central or specialized hospitals) (MOH, 2009). The relationship between different facilities at different levels was not well organized, and there was a lack of clear channels of communication or policies for sending patients from specialized hospital to PHCs or public hospitals (Almalik et al., 2011).

According to World Bank (2014) statistics, there were about 2.5 physicians per 1000 people in Saudi Arabia. During the third stage of the healthcare system’s development, cost containment strategies were implemented at several levels. Conversely, the privatisation of healthcare services started in 2006 due to the yearly increase in the Ministry of Health’s budget. The number of people who were covered by health insurance has also increased gradually due to a law stating that recruiters of
foreign workers must pay for workers’ health insurance themselves. These cost containment strategies were aimed at reducing the pressure on the Ministry of Health’s expenditure. Nevertheless, T2DM care poses a significant challenge to the Ministry of Health’s efforts to improve health outcomes (Khoja, 2010).

Other actors who have a role in implementing policy for controlling T2DM are community organizations which are very rare in the KSA. Saudi’s Charitable Association of Diabetes (SCAD) was established in 2007 with the approval of the Ministry of Social Affairs. The Association was started in an attempt to raise awareness among the community and to reduce the increasing number of affected individuals by providing health education and essential support. This also included social, psychological, financial, scientific and charitable activities and medical support for diabetes. Since 2007, this was considered to be the only diabetes community association in KSA (SCAD, 2017). No studies have examined the role of the community in supporting T2DM in the KSA even though the actors play a major role in the success or failure of any healthcare policy implementation. In order to gain more insight into the role of the actors, the researcher attempted to gain additional information on the topic by conducting semi-structured interviews with some of the main actors involved in the diabetes management in the KSA.

3.3.1 The Content

Policy content refers to the aim and objectives of a specific policy and the special action plan to achieve these objectives (Walt & Gilson, 1994; Gilson et al, 2013). In this phase of analysis, the content was examined to determine what the policy was mainly about and to what extent the plans and initiatives for diabetes were recognized in the Saudi’s healthcare system. Furthermore, the researcher summarized
the national diabetes plans and initiatives and presented them in a timeline figure (Figure 10).

During the last few years, the Saudi MOH had introduced three national initiatives to control chronic diseases and the diabetes epidemic. In comparison with the importance given to the infectious diseases by the long-established committee of “Gulf Cooperation Council States Ministers” in 2001, the MOH’s initiative was just in its initial phase of tackling the disease due to the rapid rate of increase in T2DM. The GCC ministers had assigned the specialized Gulf committee to undertake the process of developing and updating the programme through several resolutions (Khoja, 2010; Gulf Health Council [GHC], 2017). The second official recognition of the T2DM challenge was introduced as the Country’s Cooperation Strategy (2006-2011) which was developed by the Saudi’s Ministry of Health in cooperation with the WHO (WHO, 2013). The strategy recommended that Saudi’s healthcare system needed to prioritize the promotion of a healthy lifestyle, especially among the younger people.

The strategy also made a recommendation for the development of an integrated
program for health education and for research to be undertaken which should be commensurate with the situation in Saudi Arabia.

The third initiative was the National Executive Plan of Diabetes Control for 2010-2020 developed by the MOH and which primarily focused on diabetes control. The overall goal of this plan was to control and prevent T2DM from getting more complicated. The specific objectives and strategies are shown in Table 9.

**Table 9: National Executive Plan of Diabetes Control (2010-2020).**

<table>
<thead>
<tr>
<th>Objectives</th>
<th>Primary</th>
<th>-To reduce the incidence and prevalence of T2DM</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Secondary</td>
<td>-To reduce the prevalence of comorbidity risk factors -To prevent, delay or reduce the complications of T2DM</td>
</tr>
<tr>
<td></td>
<td>Tertiary</td>
<td>-To improve the quality of healthcare services delivered to patient with T2DM -To develop tools of detecting, following up, and assessing patients through the national diabetes registry -To enhance the researches and the studies about T2DM -To enable T2DM patients and their families to contribute to controlling diabetes and its complications -To encourage community engagement in T2DM management</td>
</tr>
<tr>
<td>Programmes</td>
<td>Anti-diabetes Education National Programme -National Campaign for Diabetes Control -World Diabetes Day</td>
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</tr>
</tbody>
</table>

Although the objectives of the national plan were quite consistent with those of the global action plans for the prevention and control of NCDs in 2013 (WHO, 2013), collaboration with the other governments and the private sector was not mentioned. Furthermore, the plan did not provide specific information about policies, strategies, and the expected outcomes for preventing and monitoring T2DM programmes, even though a clinical guideline was on the MOH official website (MOH, 2013a).

The WHO suggested that governments needed to formulate new policies beyond just updating their existing ones in accordance with “Health for All” strategy which was designed to guide health policy at national and global levels (WHO, 1998).
However, in order to formulate clear healthcare policies, the policy-makers should consider the importance of the wider aspects of healthcare such as: culture, environment, and the healthcare services. The “Health for All” strategy, in a broader sense, was a public health idea based on three fundamental principles which focused upon all elements of health issue as follows.

- The first principle was equity, which referred to enabling the system to achieve its goal by material resources.
- The second principle was participation which was intended to involve people and consider their needs in the healthcare policy process.
- The third principle was collaboration which was about working together with others on shared projects.

In comparing the Saudi’s healthcare policy on managing and controlling T2DM with the “Heath for All” principles, the documents reveal that in T2DM prevention and control programmes, the policy-makers paid little attention to the principles of the “Health for All” strategy. In Saudi’s healthcare policy, there was little emphasis on the second and third principles (Al-Khaldi & Alsharif, 2002; Midhet et al, 2010; Khoja, 2015; Gulf Health Council, 2017).

3.3.2 The Context

Health policies do not take place in a political vacuum, but are embedded within a country’s administrative, economic, and socio-cultural contexts. These contextual factors significantly influence the healthcare policy process and the outcomes (Sutton, 1999; Walt, 1994: Walt & Gilson, 1994; Gilson et al, 2008; Gilson, 2013). Analysing these contextual factors is an important component of Walt and Gilson’s policy triangle framework (Walt & Gilson, 1994). In KSA, there have been some major shifts in the political and economic contexts during the last 20 years.
At the central level, the MOH revised its institutional structure in 2012 as a part of the third initiative (MOH, 2013c). The Health Ministry established “The Health Programs and Chronic Diseases Control General Department” which included the Diabetes Unit Administration with responsibility for supervising 22 specialized centres and 270 diabetes units in hospitals across the Saudi Arabia’s regions and governorates. The Chronic Disease Control Department was responsible for developing projects and allocating resources for the education of the community on NCDs with the aim of increasing the health awareness of the public (MOH, 2013b; World Innovation Summit for Health [WISH], 2015; MOH, 2013c).

Saudi’s diabetes healthcare system is based on a predominant public sector model organised on three levels: primary healthcare centres, secondary "diabetes units in hospitals"; and tertiary "specialised diabetes centre". The primary care centres provide the communities with screening tests and essential health education. After the screening the patients are classified into three categories - normal HbA1c < 5.7; pre-diabetes HbA1c 5.7 to 6.4, and diabetic HbA1c ≥ 6.5 (Almalki, 2011, MOH, 2013a; MOH, 2013c; MOH, 2015, WISH, 2015).

As it was described in the earlier chapters, T2DM is a major public health concern in the KSA due to its heavy economic burden (Alhowaish, 2013; Alharbi et al, 2014; Mokdad et al, 2015; WISH, 2015). The document analysis suggests that the Saudi government has committed itself to increasing the healthcare expenditure in the national budget partly to address the challenges of diabetes. The total expenditure of Saudi’s MOH healthcare system accounted for about over $9.4 billion with approximately $0.9 billion of these expenditures being made for the treatment of diabetes. This figure illustrates that about 9% of the MOH healthcare budget was allocated for the direct cost of diabetes. On average, people diagnosed with diabetes
spent about ten times more ($3,686 vs. $380) than non-diabetic patients. The figure has increased four years later. Therefore, in 2014 the MOH budget was estimated to be about $4.5 billion being spent on the direct management of diabetes for Saudi citizens alone. This figure was expected to increase to about $7 billion in the future. The Saudi’s MOH spent 72% of the total insulin costs on T2DM, and the annual insulin cost per patient for was $375 (Alhowaish, 2013; Al-Rubeaan et al, 2013). It is worth noting that these costs estimates did not account for indirect costs such as diabetes patients’ work redundancy, the cost for care providers and to the patients’ families. Furthermore, these costs did not reflect the impact of the resultant lower quality of life. Considering all these issues, T2DM places a significant pressure on the healthcare system as well as the society. This pressure is likely to rapidly escalate in light of the epidemiology trends in the country (Mokdad et al, 2015). Another report on the assessment of the health-related quality of life among T2DM patients who attended a diabetes unit in a hospital in Riyadh city, found that the level of the health-related quality of life among the Saudi’s T2DM patients was generally low, and even lower among the female patients when compared to male ones (AL-Aboudi et al, 2015).

In addition to the political and economic transformations taking place in the country, Saudi Arabia has also witnessed a demographic shift over the last 20 years which has been associated with behavioural changes. These shifts can be identified in terms of increase in calorie, fat and carbohydrate intake accompanied by a reduction in physical activities (Aljoudi & Taha, 2009; Midhet et al,2010; Washi & Ageib, 2010; Al-Hazzaa, Abahussain & Al-Sobayel, 2011; Awadalla et al, 2014; Al-Rubeaan et al, 2015a; Bani, 2015), all of which are contributory factors to diabetes. There is a lack of data on the effect of the environmental risk factors involved with T2DM in
KSA. However, in this country, the food choices are predominantly indigenous. For instance, the regular intake of bread, dates, rice, and meat dishes are high in fats and carbohydrates. The evidence indicates that in the KSA, young adults are the main consumers of fast foods, whereas the daily use of vegetables and fruit is very low (Aljoudi et al, 2009; Al Quaiz & Tayel, 2009; Washi & Ageib, 2010; Al-Hazzaa et al, 2011; AL-Aboudi et al, 2015; Al-Rubeaan et al, 2015a). It would seem as if the traditional approaches to eating in Saudi Arabia are increasing the chances of obesity and the onset of T2DM. Moreover, the evidence available clearly indicates that physical inactivity was extremely prevalent among all age groups and both sexes in the population in KSA.

In the GCC countries, two factors were identified as significant for causing physical inactivity. The first was the environmental factors, including an inhospitable climate and the lack of transport and infrastructure; and the second factor was a behavioral one, which included cultural and social norms (AlQuaiz & Tayel, 2009). Generally, the majority of the KSA population is not physically active enough to reap the benefits of exercise. It was found in one report from the Astir Region that 99.5% of females had no exercise of any intensity at all, while 81% of Saudi males in Riyadh city were inactive. A major factor in explaining the physical inactivity in the KSA was related to the constant use of cars and the lack of sport programmes in female schools. Thus, it would seem that Saudi’s cultural practices have further affected women’s health negatively (Al-Alfi et al, 2004; Al-Nozha et al., 2004; Aljoudi et al, 2009; Aljoudi Taha, 2009 Al Quaiz & Tayel, 2009; Midhet et al, 2010; Awadalla et al, 2014; AL-Aboudi, 2015).

The evidence suggests that cultural beliefs not only create health problems arising from a lack of physical activities, but also increase the risk of developing other
health problems. Thus, community support in encouraging all-round healthy lifestyles is essential for facilitating proper diabetes management in Saudi Arabia (Al Quaiz & Tayel, 2009; Al-Hazzaa et al., 2011; Bani, 2015). In fact, Saudi cultural practices negatively affect women’s health more generally. For example, Saudi girls are not allowed to play sports as it is believed that they may lose their virginity by breaking their hymens. Even apart from this, the culture barriers limiting even visual contact between males and females affect the ability of females to engage in sporting activities. The document analysis concluded that cultural beliefs not only create health problems arising from a lack of physical activity, but it also made people at risk for developing other health problems. Community support in encouraging all-round healthy lifestyles is therefore essential for facilitating the management of diabetes in Saudi Arabia. (Al Quaiz & Tayel, 2009; Al-Hazzaa et al, 2011; Bani, 2015).

Community support is also a key factor in diabetes management within the Saudi’s traditional context and has a direct influence in the form of traditional healing practices. Traditional medicinal practices are common in Saudi Arabia, especially among the older generations and poorly educated people in both rural and urban areas of the KSA. These treatments include: herbal medicine, cauterizing, dietary treatments, chiropractic, fracture reduction, cupping, and spiritual healing (Al-Saeedi et al, 2003; Bakhotmah & Alzahrani, 2010; Sabra et al, 2010). Al-Saeedi’s report indicated that 15.6% of Saudis with diabetes believed that traditional herbal medicine was safe and effective for treating the disease. As much as 25.85% believed that traditional healers were of help to them; and 30% of patients had used a medicine traditionally applied for treating diabetes. Furthermore, the report revealed that the Saudi’s diabetes patients believed that the dates and honey were useful for their diet. The popularity of traditional medical practices among a large number of Saudis was
very high. Most of the participants in some of the survey reports claimed to have used it based on the recommendation of their friends or family members. The findings reveal a widespread confidence in traditional medicine among the population. The report also highlighted a tendency in Saudi culture for people to seek help from non-qualified individuals in their social circles (Al-Saeedi et al, 2003; Aljoudi & Taha, 2009; Bakhotmah & Alzahrani, 2010; Sharaf et al, 2013).

3.3.3 The Processes

The process analysis is about the activities that aim to maintain the health of T2DM patients. It is important to pay attention to this element of the policy triangle as it is valuable in the assessment of diabetes policies and plans, if they are to achieve their goals. Various deficiencies emerged from the document analysis which the findings identified mainly as the following: a poor referral system, the lack of effective health promotion programmes, and the shortage of qualified medical staff. In Saudi Arabia, the treatment of diabetes is usually integrated into the public healthcare system through primary healthcare in that, persons with diabetes are usually referred from primary healthcare centres to the specialized diabetes units.

Several research documents have investigated the referral system for T2DM from the primary care clinics to the secondary and tertiary healthcare institutions. The majority of these studies focused on the quantity of referrals, while there have been limited studies on the quality of the referral system in KSA. However, the referral rate has been reported to be high, although the quality of referrals was not yet at a world standard. The quality of referrals was poor in terms of recorded information related to medical history, physical examination and investigation, and so needs much improvement (Al-Khaldi & Alsharif, 2002; Al-Alfi, 2004; Al-Qahtani & Imtiaz, 2004; Ahmed, 2007; Al-Ghamdi et al, 2007; Al-Saigul et al, 2007; Baghdadhi, 2007;
Abdelwahid et al., 2010; Al-Kaabba et al., 2010; Al Wadaani & Balaha, 2012; Al Shahrani, & Baraja, 2014).

Besides the inadequate referral system, dieticians and diabetic educators were not available in PHC clinics. Also, there was a shortage of resources, for example, drugs and lab items for diabetic patients. In Saudi PHC clinics, only general practitioners were available as the first line of treatment of diabetes. However, most of the physicians in the PHCs found themselves to be not very effective in the early management of diabetes and preferred to refer the patients to the diabetes units. This was the reason for the high referral rate of diabetic patients from primary to secondary levels (Al-Khaldi & Alsharif, 2002; Alfi, 2004; Khan et al., 2010). The documents examined explored the referral system in different cities in the KSA, such as, Riyadh, Makkah, Eastern province, Qassim, Tabuk, Gurayat, and Sharurah. The documents covered the north, south, east, west, and the center of the KSA. Although the MOH has published their clinical guideline for diabetes management, "including the referral policies" in 2013, the documents published after that date recommended that the guidelines should be available for physicians to improve the referral system (MOH, 2013a; Al Shahrani, & Baraja, 2014).

Health education services in PHC centers were expected to be performed by nurses. The studies, however, showed that the most nurses in Saudi Arabia were expatriates from non-Arabic speaking countries, and only 30% of the nursing workforce was Saudis. Thus, the expatriates were unable to communicate effectively with the patients. Moreover, these nurses, and even the native healthcare professionals, had not received sufficient or appropriate training in public health or health promotion. In addition to the problem of the health education services, healthcare providers in Saudi Arabia did not seem to be properly supporting the measures necessary for the

Overall, the evidence suggests that the lack of proper public educational services to raise awareness of diabetes in the whole Saudi’s health care system was problematic. Therefore, it was not surprising to find out that the knowledge of diabetes among Saudi diabetes patient was very low. The studies also revealed some further related issues such as an unawareness of T2DM in terms of medications, diet and the symptoms of hypoglycemia. Many diabetic patients believed that medications should be stopped when the symptoms of diabetes were absent, while other misconceptions such as dried bread being good for diabetes was widespread. Considering these points, therefore, diabetes education in the KSA has not comply with WHO’s recommendations (Al-Khaldi & Alsharif, 2002; Al-Saeedi et al, 2003; Abahussain & El-Zubier, 2005; Ahmed, 2007; Aljoudi & Taha, 2009; Al-Elq, 2009; Midhet et al, 2010; Sabra et al, 2010; Mohieldein et al, 2011; Sharaf et al, 2013; Al Shahrani, & Baraja, 2014; Alsunni, Albaker & Badar 2014; Bani, 2015; Rubeaan et al, 2015a).

Access to an advanced health information system can improve diabetes care management (Wagner et al., 2001; Warm, 2007; Alharbi et al, 2016a). The Saudi Arabian healthcare system was still in the early stages of implementing its health strategy. From the current data available on the prevalence of T2DM, it was very clear that this disease had reached an epidemic stage in the KSA (Alqurashi et al, 2011; Alharbi et al, 2014; Bani, 2015). Therefore, the Saudi National Diabetes Registry which was established in 2000 aimed to develop a national database for all Saudi diabetic patients in the country. To avoid the data duplication, the national
identification number was used as an identifier. Beside the demographic information, the registry included clinical, laboratory and lifestyle-related measures. The most recent evidence indicated that the current database hosted 111,115 patients from different government and private healthcare sectors. With an annual growth rate of 10%, it is hoped that all Saudi diabetic patients will be registered by 2023 (Subhani & Al-Rubeaan, 2012; Al-Rubeaan et al, 2013; Al-Rubeaan, 2015b). A limited number of studies have evaluated the current healthcare information system available to support patient care in general in the KSA. However, only one report specifically targeted diabetes care (Alkadi, 2016). This document addressed several challenges which the Saudi’s healthcare system was facing in terms of providing comprehensive, reliable, compatible, correlating, accessible and timely patient information for each healthcare team, whether in PHC clinics or in the diabetes units and centers. The treatment and control of type 2 diabetes in the KSA were found to be sub-optimal and the study based its conclusion on the three prime intermediate outcome measures: lipid control, blood pressure and glycaemic indicators. The clinical outcome targets were met by less than 50% of patients (Al-Shaikh, 2006; Eledrisi et al, 2007; Ghamdi et al, 2007; Al-Hussein, 2008; Al-Elq, 2009; Kharal et al, 2010). It was obvious that there were few studies on the evaluation of the issues in the KSA. According to an IDF report (2014), there is a national diabetes plan in development, but no NCD plans or policies. No Ministries apart from Health are discussing the response to the diabetes challenge. Diabetes was discussed in the context of several other categories of health issues, for example, in nutrition reports issued by the MOH where the emphasis was on the need for adequate nutrition as a means of reducing the likelihood of non-communicable diseases. Saudi Arabia has not adopted the Global Monitoring Framework for diabetes. The latest IDF (2014) report suggests that the Saudi MOH did not use any
framework for the monitoring and surveillance of diabetes. According to the IDF report: "the health system provides services for early diagnosis and treatment, although not universally. Less than 50% of the costs are covered and no services exist for diabetes prevention. Specialised services are provided for women but availability of self-education management is limited." (P1)

3.4 Chapter Summary

Having reviewed the existing literature regarding diabetes management in the KSA, the documentary analysis found that the performance of process state healthcare was limited. Importantly, the analysis revealed that there was not any universally adequate framework to manage or control diabetes in the KSA. Considering the documents have their limitations in providing a complete picture of the healthcare system’s response, the researcher recognised the need to look at the meso and the micro levels of KSA healthcare system. In the following chapter, the research methodology used to explore these levels in this study will be presented.
Chapter 4 : The Research Methodology

4.1. Introduction

This chapter has two aims: to elaborate on the aims and objectives of the study and to provide an account of the study's design, research methodologies and the rationale for the choice of methods. It is divided into two main parts: the first explores the nature of social science inquiry and the different research designs commonly practised in healthcare research; the second provides a detailed account of the design and rationale for this study and the empirical research undertaken. It explains how the study used an exploratory, multi-method strategy which combined qualitative and quantitative data (Brewer & Hunter, 1989; Atun et, 2006; Risso-Gill et al, 2015). The study setting, participants, sampling, data collection, and analyses for both the qualitative and quantitative phases are also described.

4.2 The Research Aims and Objectives

The main aim of this thesis was to explore T2DM care in KSA from a holistic perspective using the ICCC framework to assess the healthcare system at macro, meso, and micro levels (WHO, 2002; Epping-Jordan et al, 2004). In Chapter 3, the study described the macro level of the KSA healthcare system by analysing relevant national and regional documents. In this chapter, the methodological approaches that were utilized to explore KSA healthcare at meso and micro levels from healthcare providers’ and patients’ perspectives are explained.

The literature review provided comprehensive literature related to diabetes health service providers, facilities, and socio-cultural factors in KSA. However, it also revealed a relative paucity in the literature regarding the ways that these elements interacted and were integrated to achieve the desired outcomes. This thesis aimed to
contribute to filling this gap in the literature by exploring the difference between T2DM policies and actual clinical practice. To achieve this aim, the following objectives were set:

1-To critically assess the national policies and programmes related to the prevention and control of T2DM.
2-To assess problems regarding the role of healthcare organizations and the community in T2DM management from the perspectives of healthcare providers and community members.
3-To assess patients’ experiences of diabetes care in their interactions with healthcare providers and their experiences of support from their perspectives.

From the background information provided by the literature review in this thesis, several pieces of information relating to diabetes prevalence and management in Saudi Arabia should be reiterated here for their significant impact on the justification for and the approach of this project. The first is that during the last few decades, KSA has experienced a demographic shift. The number of Saudi citizens who are over 65 years of age now amounts to 3% of the total population, and average life expectancy is 74 years. This emergence of a large elderly population of 920,000 (over the age of 65 years), and the rapid economic and social changes which have occurred in KSA has caused the rate of chronic diseases – including T2DM – to increase, and it is predicted to reach 1 in 5 by 2020 (Abdulkarim & Alhowaish, 2013; Alharbi et al., 2014; MOH, 2016; United Nation Development Program, 2016). Simultaneously, the KSA government is struggling to deliver comprehensive treatment and services for diabetes at all levels of healthcare. National efforts have been initiated to address the prevalence of this disease, with 9% of the MOH healthcare budget allocated only to diabetes (MOH, 2014; 2016; Alharbi et al.,
This study sought to understand how the KSA healthcare system elements (macro, meso, and micro) were responsible for T2DM management from the perspective of the policymakers, stakeholders and the patients. It is, therefore, an exploratory study (WHO, 2002; Epping-Jordan et al., 2004).

4.3 The Research Context

This study was conducted in Riyadh, the capital city located in the central region of Saudi Arabia. Riyadh was chosen as the research context because it is the business centre of Saudi Arabia where most of the ministries and healthcare facilities are situated. It is the largest city in the Kingdom and has an estimated population of 7,717,467. Riyadh was also chosen as the study location because both the MOH and the Saudi health services situated in the city provide working evidence of the primary healthcare and healthcare structures in the country. There are 418 primary healthcare centres and 47 hospitals in the Riyadh region (Central Department of Statistics, 2015).

Table 10: Study workforce locations

<table>
<thead>
<tr>
<th>Diabetes centre</th>
<th>Physicians</th>
<th>Health educators</th>
<th>Dietitians</th>
<th>Podiatrists</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>King Fahad Medical City</td>
<td>8</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>12</td>
</tr>
<tr>
<td>King Salman Medical City</td>
<td>5</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>11</td>
</tr>
<tr>
<td>King Khalid Medical City</td>
<td>7</td>
<td>4</td>
<td>1</td>
<td>1</td>
<td>13</td>
</tr>
<tr>
<td>King Abdul-Aziz Medical City</td>
<td>9</td>
<td>3</td>
<td>1</td>
<td>1</td>
<td>14</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>29</strong></td>
<td><strong>12</strong></td>
<td><strong>5</strong></td>
<td><strong>4</strong></td>
<td><strong>50</strong></td>
</tr>
</tbody>
</table>

The study was conducted at two sites: the tertiary diabetes centres and at the SCAD diabetes community association. Four main diabetes centres in Riyadh city covering the diabetic patients in the Riyadh region (total population 96,651) were included in this study (MOH, 2014) (Table 10). The centres provide specialized patient care, from first diagnosis to the management of all complications associated
with diabetes, and offer diabetes prevention, education and treatment services. SCAD was established under the approval of the Ministry of Social affairs in 2007, to offer their services and work to achieve their goals in community service and reduce the prevalence of diabetes. The association is comprised of members: two business directors and seven physicians (SCAD, 2017).

4.4 The Research Philosophy

The research philosophy implemented in this thesis was pragmatism (Murphy & Rorty, 1990; Guba & Lincoln, 1994; Johnstone, 2004; Creswell, 2014). A research philosophy can be viewed as the researcher’s set of assumptions, beliefs, values, and feelings about the world and how it can be known and understood. In other words, the specification of a conceptualization (ontology) in social science, as in any investigation, should represent a particular philosophical knowledge of reality (epistemology) and of methods through which knowledge can legitimately be obtained from the world (methodology) (Sim & Wright, 2000; Bryman, 2008; Creswell, 2014). The research philosophy, therefore, represents “a worldview that defines, for its holder, the nature of the world, the individual’s place in it, and the range of possible relationships to that world and its parts” (Guba & Lincoln, 1994, p.107.). The aforementioned elements of a research philosophy can have a significant impact on the research design and methods of a study which should be consistent with the research philosophy (Guba & Lincoln, 1994; Saunders, Lewis, & Thornhill, 2009).

It has been debated that because research philosophies represent the researchers’ beliefs, it is impossible to prove their ultimate accuracy. (Lincoln & Guba, 1985; Guba & Lincoln, 1994). Indeed, they are not open to proof in any
conformist sense; then they must be accepted simply on faith. Guba and Lincoln (1994) have argued that if there was a way to establish the trustworthiness of each research philosophy, the philosophical arguments surrounding them would have been resolved a long time ago. Therefore, there is a broad agreement among researchers that no one research philosophy is better than another. Better research philosophy depends on the contexts and research questions (Guba & Lincoln, 1994; Saunders et al., 2009).

Different accounts of epistemology, and subsequently how research should be carried out, can roughly be characterized as being poised between three views: positivism, constructivism and pragmatism (Sim & Wright, 2000). This study has adopted a pragmatic philosophy. According to Creswell (2014), “pragmatism derives from the work of Peirce, James, Mead, Dewey and recently Rorty (1990), Murphy (1990), Patton (1990) and Cherryholmes (1992)” (p. 10). Approaches to pragmatism are multiple, but they all share the belief that knowledge arises out of actions and scenarios as opposed to pre-existing conditions (O’Cathain, Murphy, & Nicholl, 2007; Creswell, 2014). In other words, pragmatism is a problem-centred approach which gives priority to the problem rather than the methods used. That is to say, pragmatism focuses on solving individual problems as opposed to adhering to or developing an abstracted and all-purpose method (Creswell, 2014).

Pragmatism has gained much in the way of approval and usage since the 1960s (Johnstone, 2004; Creswell, 2014). For example, Frankfort-Nachmias and Nachmias disregarded debates over whether deductive or inductive methods should gain supremacy as the chosen method of research, since:...clearly both strategies regard theory as a manifestation of scientific process. The real dilemma is over the place of theory in the research process. We contend that no dogmatic commitment to either
strategy is necessary for the conduct of research. The social sciences have progressed in spite of this controversy, and scientific undertakings have been pursued under both strategies. In fact, theory and research interact continuously. Furthermore, as Ernest Nagel maintains, the contrast between the two strategies is more apparent than real. (Frankfort-Nachmias & Nachmias, 1996, p.47)

Pragmatic philosophy assumes that mixing deductive and inductive methods of research produces scientific knowledge. According to Reynolds (1971), “a composite of these two strategies may provide a more efficient overall procedure and simultaneously provide a more accurate representation of the process that actually occurs in building scientific knowledge” (p.154). This composite approach produces three types of research: explanatory (also defined as as causal) research, descriptive research, and exploratory research (Reynolds, 1971; Bryman, 2015).

As previously discussed in Chapter 2, like all systems, healthcare systems are extremely complex social structures - multi-layered, nonlinear and highly sophisticated (Roemer, 1991; WHO, 2002; Kuo et al, 2011). Therefore, exploring a healthcare system is a complex task. However, there are a multitude of conceptual frameworks for how chronic diseases are managed. As this health system research aimed to explore and understand how different healthcare system components respond to T2DM in KSA, the pragmatist philosophy was well suited for this study. As will be seen in the following sections, this research philosophy informed the choices of research strategy, data collection techniques, and data analysis procedures used in the investigation.

4.5 The Research Design

This thesis used a flexible multi-method approach, and this is in the health system research domains (Brewer & Hunter, 1989; Frank 1992; Atun et, 2006; Risso-
Gill et al, 2015). According to Bowling (2014): “Research is the systematic and rigorous process of enquiry which aims to describe phenomena and to develop and test explanatory concepts and theories. Ultimately, it aims to contribute to a scientific body of knowledge. More specific, in relation to the focus of [health], it aims to improve health, health outcomes, and health services” (p.1).

One field within the large health research domain is that of health systems research. Frank (1992) has defined health system research as a "scientific study of the organized social response to health and disease conditions in populations" (p.470). This field of research is largely characterized by research questions and answers that can assist in understanding the context of the system and in turn strengthen it. As stated by Remme et al. (2010), health system research "... addresses questions that are not disease-specific but concern systems problems that have repercussions on the performance of the health system as a whole. It addresses a wide range of questions, from health financing, governance, and policy to problems with structuring, planning, management, human resources, service delivery, referral, and quality of care." (P.5)

Gilson (2013) has categorized health policy and system research methodology into two main areas: fixed designs and flexible designs. Fixed designs are adopted when the investigator has little control over events, or limited knowledge about the mechanisms involved. Fixed designs are characterized by pre-specified data collection methods; the overarching study design types are usually experimental, quasi-experimental, and non-experimental; and research data is generally numerical. On the other hand, flexible designs are adopted when a researcher has control over events, and existing knowledge about the mechanisms involved. Fixed designs evolve during the study process; the overarching study design types are case study and grounded theory; and they deal primarily with qualitative data.
Based on the aforementioned definitions of health system research, the research questions of this thesis were driven by ICCC framework levels (Table 11). More precisely, they sought to explore the KSA health system from three different angles: national, sectorial, and individual levels. As the layers of health systems react to and interact with each other, the choice of research methodology depends on the nature and context of the research questions asked (Pope & Mays, 1995; L; Denzin & Lincoln, 2005; Silverman, 2010).

Table 11: Contribution of each ICCC level to the research questions and data collection strategies

<table>
<thead>
<tr>
<th>Research Question</th>
<th>Macro</th>
<th>Meso</th>
<th>Micro</th>
</tr>
</thead>
<tbody>
<tr>
<td>How has T2DM been addressed in KSA’s national policies and programmes?</td>
<td>What is the role of healthcare organizations and the community in T2DM management?</td>
<td>To what extent do patients effectively interact/partner with health service organizations and the community?</td>
<td></td>
</tr>
<tr>
<td>Study Sample</td>
<td>National and regional T2DM documents</td>
<td>Healthcare providers, managers, IT specialists, and community members</td>
<td>T2DM patients</td>
</tr>
<tr>
<td>Data Collection Method</td>
<td>Literature review</td>
<td>Semi-structured interviews</td>
<td>Cross-sectional survey</td>
</tr>
<tr>
<td>Data Analysis Method</td>
<td>Documentary analysis</td>
<td>Qualitative analysis</td>
<td>Quantitative analysis</td>
</tr>
</tbody>
</table>

Research questions that begin with ‘how’ or ‘what’, which typically arise to explore a phenomenon, tend to lend themselves to qualitative research methodology. Flexible research methods are appropriate when studying topics that are poorly understood in order to determine the nature of the area of study (Saunders et al., 2009; Gilson, 2013; Creswell, 2014). These characteristics make a qualitative methodology particularly well-suited for health system research; however, a qualitative approach was not the method that adopted to answer all the research questions in this thesis (Figure 11).
To answer the above research question, this study used a flexible multi-method approach divided into three phases. As described in more detail in Chapter 3, the first phase of this thesis aimed to explore KSA’s healthcare system in terms of T2DM management at macro level. Data were extracted and analysed from fifty-three documents using a health policy analysis framework (Walt & Gilson, 1994; Gilson, 2013). This phase had two main important contributions: first, it served as a conceptualization of this thesis; second, it helped to identify some of the key informants included in the second phase. The second phase planned to assess the meso and micro levels of the KSA healthcare system through interviews conducted with healthcare providers and patients. However, as this study utilized a flexible methodological design, the plan changed. After designing and validating the interview
instruments, the researcher found that it was impossible to conduct an interview with male patients because she was prohibited from entering the male waiting areas in the study sites. Therefore, semi-structured interviews were conducted with healthcare providers to explore T2DM management at meso level, and questionnaires were administered to explore patient interaction at the micro level of the healthcare system. The following sections describe the quantitative and qualitative phases of this study.

4.6 Qualitative data collection

The first phase of the study provided information about national diabetes management in KSA. This included a review of national and regional governmental documents related to four main aspects of health policy: actors, content, context, and process (Walt & Gilson, 1994; Gilson, 2013). However, it did not examine the difference between policy and actual clinical practice at health service organization level. The second phase of the study aimed to fill this gap and explore the response of health services organizations and the community to T2DM management in KSA, by conducting semi-structured interviews with healthcare providers, IT specialists and members of the SDAC, which were undertaken in Riyadh, Saudi Arabia.

4.6.1 The Sampling Strategy

Four major stakeholders were determined according to the predefined ICCC indicators in Chapter 2. These were:

- Healthcare providers
- Managers
- IT specialists
- Community members.
Since this is an exploratory qualitative research study, it could use a much smaller sample size than that required in quantitative research (Pope & Mays, 2001). As Barbour (2001) stated, this is because “rather than aspiring to statistical generalizability or representativeness, qualitative research usually aims to reflect the diversity within a given population” (p.1115). This phase of the thesis sought to explore the healthcare system’s response to T2DM from the perspectives of different actors who could describe the meso level of ICCCF, and not to provide a statistical generalization about it. For the sample of this phase, the researcher purposefully selected persons with relevant knowledge of the topic being studied (Creswell, 2014; Bowling, 2014).

Purposive sampling ensures that key study populations are related to the topic being studied. This means that cases are selected based on predetermined criteria to cover the range of characteristics relevant to the study (Mays & Pope, 1995; Saunders et al., 2009; Creswell, 2014). In this stage of the thesis, a maximum variation sampling approach was utilized for each of the four predetermined groups so that the sample was selected in a way that provided a broad range of information (Lincoln & Guba, 1985; Patton, 2002; Saunders et al., 2009). Maximum variation sampling includes purposely selecting participants with a wide range of variation on the criteria of interest (Lincoln & Guba, 1985; Patton, 2002; Saunders et al., 2009). This sampling method ensured the inclusion of a variety of experiences within each stakeholder group. For example, within the healthcare provider group, it ensured that clinicians of different characteristics (for example, physicians, health educators, and nurses) were sampled. The sampling process began with an initial selection of individuals who were identified through a review of the official documents in the first phase of this study, and then this was supplemented by new cases through
snowballing (Polit & Beck, 2009). Many qualitative researchers recommend continuing to collect data until the point at which it becomes repetitive in content; that is, data saturation is reached (Silverman, 2010). This study included thirty-three participants – eleven females and twenty-two males (Table 12).

Table 12: Summary of the demographic characteristics of study participants

<table>
<thead>
<tr>
<th>Respondent</th>
<th>Gender</th>
<th>Interview language</th>
<th>Job title</th>
<th>Experience</th>
<th>Interview duration</th>
<th>Health care provider</th>
<th>Manager</th>
<th>IT-specialist</th>
<th>SCAD member</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>♀</td>
<td>E</td>
<td>Endocrinologist</td>
<td>27 Y</td>
<td>55</td>
<td>√</td>
<td>√</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>♂</td>
<td>A</td>
<td>Director of diabetes centre</td>
<td>4 Y</td>
<td>45</td>
<td></td>
<td>√</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>♂</td>
<td>A</td>
<td>Director of general affairs</td>
<td>3 Y</td>
<td>45</td>
<td>√</td>
<td>√</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>♀</td>
<td>E</td>
<td>Director of the quality department</td>
<td>3 Y</td>
<td>40</td>
<td></td>
<td>√</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>♀</td>
<td>E</td>
<td>Endocrinologist</td>
<td>25 Y</td>
<td>50</td>
<td>√</td>
<td>√</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>♀</td>
<td>E</td>
<td>Endocrinologist</td>
<td>4 Y</td>
<td>45</td>
<td></td>
<td>√</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>♂</td>
<td>E</td>
<td>Endocrinologist</td>
<td>20 Y</td>
<td>59</td>
<td></td>
<td>√</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>♂</td>
<td>E</td>
<td>Endocrinologist</td>
<td>12 Y</td>
<td>120</td>
<td></td>
<td>√</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>♀</td>
<td>A</td>
<td>Health educator</td>
<td>5 Y</td>
<td>45</td>
<td>√</td>
<td>√</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>♀</td>
<td>A</td>
<td>Health educator</td>
<td>6 Y</td>
<td>45</td>
<td></td>
<td>√</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>♀</td>
<td>A</td>
<td>Health educator</td>
<td>3 Y</td>
<td>45</td>
<td></td>
<td>√</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>♂</td>
<td>E</td>
<td>Endocrinologist</td>
<td>14 Y</td>
<td>60</td>
<td>√</td>
<td>√</td>
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<tr>
<td>13</td>
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<td>E</td>
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<td>√</td>
<td></td>
<td></td>
</tr>
<tr>
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<td>♂</td>
<td>E</td>
<td>Endocrinologist</td>
<td>20 Y</td>
<td>66</td>
<td></td>
<td>√</td>
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<tr>
<td>15</td>
<td>♀</td>
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<tr>
<td>16</td>
<td>♀</td>
<td>A</td>
<td>Health educator</td>
<td>5 Y</td>
<td>45</td>
<td>√</td>
<td>√</td>
<td></td>
<td></td>
</tr>
<tr>
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<td>♂</td>
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<td>Endocrinologist</td>
<td>10 Y</td>
<td>62</td>
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<td>√</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18</td>
<td>♀</td>
<td>A</td>
<td>IT technician</td>
<td>4 Y</td>
<td>40</td>
<td></td>
<td>√</td>
<td></td>
<td></td>
</tr>
<tr>
<td>19</td>
<td>♀</td>
<td>A</td>
<td>Project manager</td>
<td>4 Y</td>
<td>42</td>
<td></td>
<td>√</td>
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</tr>
<tr>
<td>20</td>
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<td>Project manager</td>
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<td>√</td>
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<td></td>
</tr>
<tr>
<td>21</td>
<td>♂</td>
<td>E</td>
<td>Deputy minister</td>
<td>7 Y</td>
<td>62</td>
<td>√</td>
<td>√</td>
<td></td>
<td></td>
</tr>
<tr>
<td>22</td>
<td>♀</td>
<td>A</td>
<td>IT manager</td>
<td>7 M</td>
<td>39</td>
<td></td>
<td>√</td>
<td></td>
<td></td>
</tr>
<tr>
<td>23</td>
<td>♂</td>
<td>A</td>
<td>IT manager</td>
<td>12 Y</td>
<td>45</td>
<td></td>
<td>√</td>
<td></td>
<td></td>
</tr>
<tr>
<td>24</td>
<td>♂</td>
<td>A</td>
<td>IT technician</td>
<td>15 Y</td>
<td>45</td>
<td></td>
<td>√</td>
<td></td>
<td></td>
</tr>
<tr>
<td>25</td>
<td>♂</td>
<td>E</td>
<td>IT professor</td>
<td>12 Y</td>
<td>45</td>
<td></td>
<td>√</td>
<td></td>
<td></td>
</tr>
<tr>
<td>26</td>
<td>♂</td>
<td>E</td>
<td>Project manger</td>
<td>7 Y</td>
<td>45</td>
<td></td>
<td>√</td>
<td></td>
<td></td>
</tr>
<tr>
<td>27</td>
<td>♂</td>
<td>A</td>
<td>Training manager</td>
<td>1 Y</td>
<td>55</td>
<td></td>
<td>√</td>
<td></td>
<td></td>
</tr>
<tr>
<td>28</td>
<td>♂</td>
<td>A</td>
<td>Project manger</td>
<td>1 Y</td>
<td>37</td>
<td></td>
<td>√</td>
<td></td>
<td></td>
</tr>
<tr>
<td>29</td>
<td>♂</td>
<td>E</td>
<td>IT assistant professor</td>
<td>1 Y</td>
<td>45</td>
<td></td>
<td>√</td>
<td></td>
<td></td>
</tr>
<tr>
<td>30</td>
<td>♀</td>
<td>A</td>
<td>Nurse</td>
<td>10 M</td>
<td>45</td>
<td></td>
<td>√</td>
<td></td>
<td></td>
</tr>
<tr>
<td>31</td>
<td>♂</td>
<td>A</td>
<td>Director of SCAD</td>
<td>16 Y</td>
<td>45</td>
<td></td>
<td>√</td>
<td></td>
<td></td>
</tr>
<tr>
<td>32</td>
<td>♂</td>
<td>E</td>
<td>Endocrinologist</td>
<td>12 Y</td>
<td>45</td>
<td>√</td>
<td>√</td>
<td></td>
<td></td>
</tr>
<tr>
<td>33</td>
<td>♂</td>
<td>E</td>
<td>Director of diabetes centres</td>
<td>20 Y</td>
<td>45</td>
<td>√</td>
<td>√</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: Interview duration in minutes. Abbreviations: A: Arabic; E: English; M: Month; Y: Year.
The participants held a variety of job roles at varying professional levels so the researcher interviewed the deputy minister, the general director of diabetes centres in Saudi Arabia, as well as those working at lower ranks, such as IT technicians.

4.6.2 The Research Instrument

A semi-structured interview technique was utilized to explore the opportunities and challenges at the meso level of the current T2DM healthcare system. As the name suggests, such an interview is less rigid than a structured interview, but is not totally lacking in structure, so the researcher could obtain the required data (Saunders et al., 2009; Creswell, 2014; Bowling). This style of interviews was chosen by the researcher as it allowed her to engage in a two-way conversation with each participant. In using semi-structured interviews, the researcher had a flexible interview protocol that outlined the ICCC themes and issues to be explored, but the exact wording of questions was not determined beforehand (Table 13).

<table>
<thead>
<tr>
<th>Steps</th>
<th>Phase</th>
<th>Guide</th>
</tr>
</thead>
</table>
| 1 | Objectives | To explore available services with the purpose of facilitating T2DM management in KSA from four perspectives: 
- Health service organizations 
- Community support 
- Health information systems 
- Patient self-management 
To understand the perceptions of healthcare providers 
To understand the factors shaping such perceptions 
To identify opportunities for T2DM care in KSA 
To identify barriers that may prevent optimum T2DM management |
| 2 | Introduction | Introduce the study, confidentiality statement, and interview length. 
Introduce participants’ rights 
Start audio recording |
| 3 | During the interview | Demographic data 
Guide the participant through the study questions 
Clarify each answer by asking sub-questions |
| 4 | Ending the interview | Finish covering the issues raised during the interview 
Thank the participant and mention how their contribution is valuable to this study 
Reassure the confidentiality of information 
Turn off the recorder |
Different sets of questions were also applied for each stockholder group. The interview schedules were prepared by the researcher and the contents of the schedules were reviewed by the research supervisor (see Appendix B). In a semi-structured interview, both the researcher and the participant may diverge from the loose topic guide of the interview in order to pursue related ideas in more detail. Similarly, the interviewer may choose to omit or add some questions depending on the context of a particular interview (Saunders et al., 2009; Creswell, 2014; Bowling).

4.6.3 The Interview Schedule

Participants were provided with interview questions prior the interviews in order to increase the reliability of the data collection (Denzin & Lincoln, 2005). All of the interviews were conducted by the researcher, and most of them took place at each participant’s office. The interviews lasted between 37 and 120 minutes, and almost half of them were conducted in Arabic language, as some of the participants did not speak English fluently. This meant that it was time consuming to transcribe and translate the transcripts from Arabic to English.

During the interviews, the researcher was not only concerned about what the participants said, but also the way they said it, and noted the non-verbal cause and body gestures expressed by the participants (Saunders et al., 2009; Creswell, 2014; Bowling, 2014). To enable the researcher to focus on the non-verbal cues expressed by the participants, the interviews were audio recorded. (Saunders et al., 2007). Through the transcription process, particular care was taken to record the contents of all relevant verbal and non-verbal expressions. This process, while labour-intensive and time-consuming, was used by the researcher as a way of familiarizing herself with the collected data, in order to gain an overview of its depth and scope, which was very
useful during data analysis. The time spent transcribing all this was, therefore, not wasted (Braun & Clarke, 2006).

4.6.4 Data Analysis

Qualitative data analysis is conducted along with data collection. The interpretation of each datum collected is informed by the learning gained from the previous data collected. Thus, qualitative data analysis begins with the collection of qualitative data. This means that questions asked during a second interview will be refined based on what the researcher learnt during the first one. However, the qualitative data analysis process continues well beyond the data collection process, as information from all data collection processes is compiled, compared, and analysed together. The iterative process of qualitative data collection and its intertwining with data analysis ensures that the data obtained become more relevant and focused as the data collection process is carried out. This is different from quantitative data collection which maintains the same structure throughout. Thus, in a qualitative study, the researcher can alter the interview questions, add more questions, or remove irrelevant ones as the data collection process advances (Pope et al., 2001; Bowen, 2008).

While qualitative data are analysed as the data is still being collected, the process does not stop with the data collection. The researcher must still compile and analyse the data as a complete whole, which can only be done once the data collection process is complete (Pope et al., 2006). The purpose of qualitative data analysis is to make sense of the collected data by analysing and interpreting the underlying meaning of what the data are conveying (Polit & Beck, 2009). Thematic analysis is one of the most common techniques for analysing qualitative data (Braun & Clarke, 2006).
Several authors have suggested that thematic analysis is not a separate technique for analysing qualitative data, but is an inherent aspect of any qualitative data technique adopted by a qualitative data researcher (Bernard & Ryan, 2000). Ryan & Bernard (2000) argued that thematic analysis is actually part of other qualitative data analysis methods, such as grounded theory.

The data analysis method is often guided by the research questions and the research aim itself (Denzin & Lincoln, 2005; Pope et al., 2001; Silverman, 2010). Thematic analysis was used in this research along with grounded theory. Grounded theory is a common approach to qualitative data collection and analysis (Robson, 2002; Saunders et al., 2015). According to Robson (2002), it is possible to use only parts of the grounded theory approach while ignoring the rest; i.e., it is not essential for a researcher to use each and every aspect of the grounded theory approach.

Thematic analysis involves identifying the common and re-occurring themes in the qualitative data (Bowen, 2006; Braun & Clarke, 2006). The researchers familiarize themselves with these themes during the data collection process, but it is not possible to identify all the themes without a systematic analysis of the qualitative data. Immersion in the data is the first stage of qualitative data analysis (Braun & Clarke, 2006; Bradley et al., 2007). In this study, the researcher wrote memos and made a list of reoccurring themes as well as any thoughts that she had about the data. Memo-writing is a technique commonly used in qualitative research for making connections and identifying links within the data during the data collection process itself. It informs the subsequent stages of the data collection process as it helps the researcher refine the questions and therefore the information sought as they proceed with the data collection (Kodish & Gittelsohn, 2011).
After reading and comprehending the data, the researcher had a general overview of its context and scope. Then, the researcher started to code the data to put them into categories for the purpose of interpretation. Coding is a form of qualitative data analysis in which data is categorized under common themes, known as codes (Corbin & Strauss, 2008). The researcher can then identify the relationship between different codes to form a chain of codes (Kodish & Gittelsohn, 2011). According to Saldaña (2009), codes are tags (or descriptive labels) that are applied to segments of data to help catalogue the key concepts described in them while preserving the contexts in which they are described. These codes represent the most basic components of raw data that the researcher can access in a useful manner in relation to the phenomenon under study (Braun & Clarke, 2006). The researcher can combine and analyse data within the same code to identify what meaning the data is conveying. The next stage of the process involves forming a family of codes and using it to analyse the data (Saldaña, 2009). Coding is similar to data mining, whereby the researchers mine the data in order to uncover their true meaning (Corbin & Strauss, 2008).

There are three approaches to coding qualitative data: inductive, deductive, or abductive (which is a combination of inductive and deductive) (Bradley et al., 2007). In a deductive approach, the data coding is done on the basis of pre-identified themes. It is structured, comparatively easier to analyse and less time- and effort-consuming. However, it often ignores new themes which would have been difficult to identify prior to the data collection process, so the secure structure and other benefits come at the expense of quality and scope. Thus, this research adopted an inductive coding approach. Under this approach, the coding is guided by the data. The researcher remains open to any codes that the data may reveal and focuses on identifying the
themes in the data (Kodish & Gittelsohn, 2011). This study drew upon emergent issues raised by the interviewees themselves and views or experiences that showed recurrence or patterning in the data. However, this did not mean that the knowledge established prior to the study was completely irrelevant. Instead, it was used to carry out the data collection process itself and guide the interview questions. However, the researcher was careful not to guide the respondents based on her prior knowledge of the subject. Instead, the researcher focused on listening to what the respondents said. Furthermore, the researcher ensured that she did not develop the codes based solely on her prior knowledge but also on the newly-collected data (Kodish & Gittelsohn, 2011). The constant comparative method was used for identifying and classifying codes. This is a commonly-used approach to identifying and understanding the key concepts within qualitative data (Floersch et al., 2010).

The process began with open coding, whereby the data were analysed to identify reoccurring themes. The researcher aimed to maximize the number of themes identified (Pope et al., 2006) by reviewing the data in detail and assigning a code once the underlying concept was clarified. Under thematic analysis, the researcher can assign any part and length of text to a particular code. In this study, codes were developed and refined to ensure a proper fit with the data (Floersch et al., 2010). NVivo software was used to code the data wherever possible, using the reoccurring words used by the interviewees. For example, the terms ‘traditional medicine’ and ‘traditional method’ occurred many times during the interviews (Table 14).
Table 14: Interview excerpt

I think one of the problems with Saudi society is that they still rely on natural medicines more. They do consult each other but they often tend to try and cure the symptoms but not the root cause. They will find the root cause only if they go to a doctor and go for diagnosis but they tend to rely on traditional wisdom.

<table>
<thead>
<tr>
<th>Line by line coding</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rely on natural medicines more</td>
<td>● Traditional medicine</td>
</tr>
<tr>
<td>They do consult each other</td>
<td>● Care seeking behaviour</td>
</tr>
</tbody>
</table>
| Cure the symptoms but not the root cause | ● Inaccuracy of information  
| | ● Lack of awareness       |
| Find the root cause only if they go to a doctor and go for diagnosis. | ● Lack of diagnosis  
| | ● Lack of awareness       |

Patients often do not follow the full treatment plan. I have had this problem with so many patients. They come to us for diagnosis and then seek their own treatments. Many of them prefer traditional treatments. These people come to us only when the problem is too bad. We need a system to keep track of people who have a high likelihood of diabetes and then implement mechanisms to keep them engaged with the system. We do not have this right now.

<table>
<thead>
<tr>
<th>Line by line coding</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients often do not follow the full treatment plan</td>
<td>● Lack of awareness</td>
</tr>
<tr>
<td>Come to us for diagnosis and then seek their own treatments</td>
<td>● Care seeking behaviour</td>
</tr>
</tbody>
</table>
| Prefer traditional treatments       | ● Lack of awareness  
| | ● Social consultation       |
| People come to us only when the problem is too bad | ● Failure to diagnose early |
| Need a system to keep track of people who have high likelihood of diabetes | ● Integrated model of care  
| | ● Early diagnosis of diabetes   |
| | ● Setting up diabetes registry |

The suitability of the assigned codes was determined by a comparison of texts within the codes. By comparing the text segments within the same code, it was possible to determine whether the text segments reflected the same information. After this, a cross comparison of the texts under different codes was carried out to see whether the codes had been suitably allocated. In-code comparisons can help uncover the different properties and dimensions of the code (Bradley et al., 2007; Corbin & Strauss, 2008).

The researcher asked several questions during the text comparison to identify similarities, differences, and patterns within the codes: “What are the characteristics of the code?”; “What forms does it take?”; “How is this text segment similar to or different from preceding segments?” This enabled the researcher to cross-compare the
properties and dimensions of different codes (Corbin & Strauss, 2008) and also helped to identify any previously unknown codes. If any new codes were discovered, then previous transcripts were analysed to see if a piece of text was uncoded or coded under a different code and could be moved to the new code.

Back-and-forth data analysis was carried out until the researcher was satisfied that all relevant concepts and codes had been identified (Bowen, 2008). The researcher kept reviewing the interview transcripts to identify all data related to the already identified codes and coded them. In qualitative data analysis, segments of a paragraph or even different segments of a single sentence may be encoded under different codes. In some cases, the same segment of text may fall under different codes; hence, it is the researcher’s responsibility to determine the most suitable code for the text (Pope et al., 2006). NVivo does not allow cross-coding, which means a piece of text should belong to one code only.

Loss of context is one of the most common criticisms of coding as sentences and paragraphs are cut into small segments. For this reason, it is advisable to include as much information as possible within the codes and leave out as little as possible (Braun & Clarke, 2006). Furthermore, the process of constant comparisons involves continually searching for negative cases or disconfirming evidence (Corbin & Strauss, 2008). These negative cases may refute the conceptions established prior to the study and may suggest that the creation of a new conception is appropriate. However, identifying a negative case does not necessarily mean that previous conceptions of the researcher should be rejected altogether. The negative case often represents a dimensional extreme or variation in the conceptualization of the data. Thus, by looking for the negative exceptions, the researcher can fully explain the concepts in the data (Corbin & Strauss, 2008).
In this study, the researcher developed a codebook during the coding process. This acted as a reference source which contained information on the codes, their specifications and definitions, as well as a full, detailed description of each code along with details of when to apply it and when not to apply it. It acted as a guide for the researcher during the process of developing the codes as well as during data coding, and ensured consistency in the coding process. Codebooks are useful for data analysis and researchers should develop a comprehensive codebook for qualitative research analysis (Kodish & Gittelsohn, 2011). For example, in this study, code inclusion criteria were developed for every code. This codebook helped the researcher to identify dependencies and relationships, among other things, between different codes and to prepare a code chart at the end of the coding process (Bowen, 2008). This visual representation is helpful for readers to understand the codes and their links with the overall research.

Towards the end of the open coding process in the investigation, the larger mass of textual data was reduced into manageable groupings of codes which were used to identify relationships between the concepts in the data. This is a process called axial coding (Bowen, 2008; Corbin & Strauss, 2008). During data analysis, “open coding and axial coding go hand in hand” (Corbin & Strauss, 2008, p.198); the distinction made between them is for explanatory purposes.

As the process of coding continued, coded data were constantly compared and scrutinized. Data segments were coded and recoded and as a result the codes became more refined. Several of the initial or ‘first cycle’ codes were re-labelled, subsumed by other codes or dropped altogether. Codes underwent multiple iterative revisions, refinements, and rearrangements until high-level concepts emerged (Bowen, 2008; Saldaña, 2009).
As the identified codes were compared with each other, some codes seemed to cluster together. Conceptually similar ones were grouped together under higher-level descriptive concepts called themes (or categories). For example, several codes or first-order concepts—such as knowledgeable and educated—were grouped together to form the second-order category or theme ‘aware’. This constant comparative method allowed the researcher to differentiate themes from one another and to identify the properties and dimensions specific to each theme. Besides comparing the units of texts in the transcripts with each other, as illustrated earlier, the discovered themes were compared with the literature to identify patterns in the data.

The researcher axially categorized and grouped together lower-level concepts (codes) according to their shared properties (Corbin & Strauss, 2008; Floersch et al., 2010). In addition, the researcher attempted to identify how concepts related to each other. In doing so, some of the initial codes went on to form themes (or subthemes). The frequent use of key terms by the interviewees may suggest their relevance as conceptual categories or themes (Braun & Clarke, 2006; Bowen, 2008). However, the significance of a theme is not determined by its frequency but by its consistency across and within interviewees. A theme is also significant when it deepens understanding of existing knowledge (Floersch et al., 2010).

A collection of themes was identified towards the end of the axial coding. These were developed into higher-level concepts that can be referred to as central themes (or core categories). This final stage of coding is known as selective coding, which is “the process of selecting the central or core category, systematically relating it to other categories, validating those relationships, and filling in categories that need further refinement and development” (Strauss & Corbin, 1990, p.116). This process involves connecting and consolidating the axial codes and analysing them to
identify central themes that cut across the data (Braun & Clarke, 2006; Bowen, 2008). To ascertain whether the identified themes adequately captured and accurately represented the data, they were judged for both internal homogeneity – the extent to which data within them cohered in a meaningful way, and external heterogeneity – the extent to which there were clear and identifiable distinctions between them (Patton, 1990). The interview transcripts were re-read to ascertain that the identified themes formed a coherent pattern and captured the essence of the data, and also to code any additional data that might have been missed during earlier rounds of coding (Braun & Clarke, 2006). At the end of the coding process, a thematic map was created that identified the characteristics of the different themes, how they related to each other, and how – together – they represented the meanings evident in the data (Braun & Clarke, 2006; Bowen, 2008).

4.7 Quantitative Data Collection

The third phase of the study aimed to explore the micro level of the KSA healthcare system with regard to T2DM management. In particular, the researcher aimed to explore the patients’ experiences of diabetes care management and their interactions with the healthcare teams and the community. As explained previously in Chapter 1, gender segregation is the most important defining feature in all public sectors in KSA (Meijer, 2010). In terms of working environments, there is no gender segregation in health facilities; however, due to strict religious standards, patients have separate waiting areas in clinics, which made reaching male participants as a female researcher very difficult. Since the patients’ voices are very important in exploring any health system as they make up the central stratum of the ICCC model, the self-administered questionnaire was the best alternative method to overcome this
challenge (WHO, 2002; Epping-Jordan et al., 2004). The self-administered questionnaire is the most common survey method. Bowling (2014) defined a survey as “a method of collecting information, from a sample of population of interest usually by interviews, or other self-completion questionnaire methods” (p.215). Questionnaires can be categorized according to survey type: analytical or descriptive. A descriptive survey is used to measure specific phenomena (e.g. events, behaviours, and attitudes) and is calculated by descriptive measures. In this type of survey, which is also known as cross-sectional, data are collected at one point of time (Saunders et al., 2009; Creswell, 2014; Bowling, 2014). An analytic survey is used to investigate causal association between variables and to test hypotheses. Also known as longitudinal, it is carried out at more than one point of time (Saunders et al., 2009; Creswell, 2014; Bowling, 2014). As this stage of the study aimed to describe the patients’ levels of interaction with health service organizations and the community, the cross-sectional survey was the best method for achieving the study objective. Furthermore, the researcher required a survey method that allowed her to collect data with minimum contact with the study population. Thus, a self-administered questionnaire was a pragmatic choice. This section begins by providing the rationale for selecting the Patient Assessment of Chronic Illness Care as the study instrument, moving to the translation process, sampling strategies, and data analysis plan (Glasgow et al., 2005a).

4.7.1 Instrument Identification

The researcher searched for a self-administered questionnaire that could provide information about diabetes healthcare covering one or more of the ICCC elements (WHO, 2002; Epping-Jordan et al., 2004). The inclusion criteria for
instrument selection were developed by the researcher, and a tool was selected based on it being in English or Arabic, relevant to the study objective, and if it showed evidence of having been tested for reliability and consistency (Table 15).

<table>
<thead>
<tr>
<th>Table 15: Instrument selection criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Criteria</td>
</tr>
<tr>
<td>1 Tool is relevant to study objectives</td>
</tr>
<tr>
<td>2 Published in English or Arabic language</td>
</tr>
<tr>
<td>3 Applicable to T2DM</td>
</tr>
<tr>
<td>4 Published in a peer-reviewed journal by at least two researchers, one of whom did not develop the questionnaire</td>
</tr>
<tr>
<td>5 Reliability testing</td>
</tr>
<tr>
<td>- internal consistency (Cronbach a or Kuder–Richardson formula, reliability coefficient of $\geq 0.7$)</td>
</tr>
<tr>
<td>- stability: test–retest reliability (Pearson, Kappa, Spearman’s Rho, rank order correlation coefficient of $\geq 0.7$ for group comparison)</td>
</tr>
<tr>
<td>Validation methods used</td>
</tr>
<tr>
<td>- content and face validity: evidence that the items clearly address the intended subject matter and that the range of aspects are adequately covered</td>
</tr>
<tr>
<td>- construct validity: evidence that supports a proposed interpretation of scores based on theoretical implications associated with the construct being measured</td>
</tr>
<tr>
<td>6 Interpretability: ability to assign easily understood meaning to an assessment tool’s quantitative scores</td>
</tr>
<tr>
<td>7 Feasibility: should take no longer than ten mins to complete; minimal effort for scoring and data collection required</td>
</tr>
<tr>
<td>8 Acceptability: acceptability of tool for respondents is addressed</td>
</tr>
</tbody>
</table>

The databases searched were Medline and Embase. Only eight instruments had potential relevance for the study (Anderson et al, 2000; Toobert, Hampson & Glasgow, 2000; Van et al, 2003; Glasgow, 2005a; Broadbent et al, 2006; Osborne, Elsworth, & Whitfield, 2007; Eikelenboom et al, 2013; Schmitt et al, 2013) (Table 16). Once the predetermined appraisal checklist was applied to these eight tools, only three were determined relevant to the study - The Summary of Diabetes Self-Care Activities Measure, The Diabetes Self-Management Questionnaire, and the Patient Assessment of Chronic Illness Care (Toobert et al, 2000; Glasgow, 2005a; Schmitt et al, 2013) (Table 17).
**Table 16: Identified instruments**

<table>
<thead>
<tr>
<th>Name</th>
<th>Topics covered/domains.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health Education Impact Questionnaire (heiQ)</td>
<td>Positive and active engagement in life, health-directed behavior, skill and technique acquisition, constructive attitudes and approaches, self-monitoring and insight, health services navigation, social integration and support and emotional wellbeing.</td>
</tr>
<tr>
<td>Self-Management Screening Questionnaire (SeMaS)</td>
<td>Burden of disease, locus of control, self-efficacy, social support, coping style, anxiety, depression and skills.</td>
</tr>
<tr>
<td>The Summary of Diabetes Self-Care Activities Measure (SDSCA)</td>
<td>General diet, specific diet, exercise, blood-glucose testing, foot care and smoking.</td>
</tr>
<tr>
<td>The Diabetes Self-Management Questionnaire (DSMQ)</td>
<td>Glucose management, dietary control, physical activity and healthcare use.</td>
</tr>
<tr>
<td>Patient Assessment of Chronic Illness Care (PACIC)</td>
<td>Patient activation, delivery system/practice design, goal setting/tailoring, problem solving/contextual and follow-up/coordination.</td>
</tr>
<tr>
<td>The Brief Illness Perception Questionnaire (Brief IPQ)</td>
<td>Consequences, timeline, personal control, treatment control, identity, concern, emotions and illness comprehensibility.</td>
</tr>
<tr>
<td>Diabetes Empowerment Scale (DES)</td>
<td>Managing the psychosocial aspects of diabetes, assessing dissatisfaction and readiness to change, and setting and achieving diabetes goals.</td>
</tr>
<tr>
<td>The Confidence in Diabetes Self-Care (CIDS) scale</td>
<td>Socio-demographical and clinical characteristics, Diabetes-related emotional distress, fear of hypoglycaemia, self-esteem, anxiety and depression, self-care behaviors, and diabetes treatment self-efficacy.</td>
</tr>
</tbody>
</table>

**Table 17: Most relevant instruments**

<table>
<thead>
<tr>
<th>SDSCA</th>
<th>DSMQ</th>
<th>PACIC</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Theoretical ground</strong></td>
<td>Not specified</td>
<td>Not specified</td>
</tr>
<tr>
<td><strong>Scale description</strong></td>
<td>25 items related to performance of self-management behaviours during the previous week. Scales ranged from 0 to 7</td>
<td>16 items related to self-care activities during the last 8 weeks. 4 scales ranged from “Does not apply to me” to “Applies to me very much”</td>
</tr>
<tr>
<td><strong>Reliability</strong></td>
<td>Internal consistency: inter-item correlation r (mean) = 0.47, except for specific diet (r = 0.07–0.23)  Test–retest reliability: r (mean) = 0.40, range (0.05 to 0.78), 3–4 months.</td>
<td>Internal consistency = 0.84</td>
</tr>
<tr>
<td><strong>Validity</strong></td>
<td>Content validity: evaluated in previous studies (Toobert &amp; Glasgow, 1994). Criterion validity: use of several scales related with food records and exercise. r (range) = 0.54–0.58.</td>
<td></td>
</tr>
<tr>
<td><strong>Availability</strong></td>
<td>Permission is needed from the author</td>
<td>No permission needed</td>
</tr>
</tbody>
</table>
The Patient Assessment of Chronic Illness Care (PACIC) was considered as the most relevant instrument for this thesis. This questionnaire was produced by the MacColl Center for Health Care Innovation, Group Health Cooperative in 2003 for the purpose of measuring specific practices or qualitative aspects of care, as modelled by the CCM, and as reported by patients and their experiences of said care (Glasgow et al., 2005a). The PACIC was developed as a tool for assessing the “level of CCM-congruent activities that patients receive” (Glasgow et al., 2005b, p.2655). As previously discussed, the CCM and ICCC frameworks share a common conceptual underpinning in terms of their approaches to how chronic care provisions are organized and provided, and thus it was expected that the PACIC would provide a basic demonstration of care given to diabetes patients from the patients’ perspectives, and subsequently provide insight into how patients are informed, motivated, and prepared for diabetes management (an integral component of the ICCC Triad). The tool was initially developed as a 20-item instrument using a 5-point Likert scale, and the aim was to use it to find out the extent to which patients had engaged with CCM-based services over the previous six months (Glasgow et al., 2005b). The PACIC was found to possess sound psychometric properties and could be used to assess care for multiple chronic conditions. Shortly after publishing the initial results of the PACIC tool, Glasgow et al. (2005a) added 6 more functions to the instrument, which were assessed for effectiveness among a larger sample of diabetic patients, Latino patients, and patients receiving care from multiple providers. These functions followed the ‘5As’ principle of the PACIC tool. The ‘5As’ (Assess, Advise, Agree, Assist, and Arrange) is an empirically evaluated model of behaviour change endorsed by the U.S. Preventative Services Taskforce (Whitlock et al., 2002; Goldstein, Whitlock & DePue, 2004) and applied to diabetes self-management and quality improvement.
initiatives. Its approach is consistent with that promoted by the CCM and has been used to encourage better links with wider communities as well as self-management (Glasgow et al., 2002; Glasgow et al., 2003)

The first component of the 5As model, Assess, relates to the assessment of the patients’ beliefs and practices regarding their condition as well as what motivates them to enact care. The assessment can consist of three activities: jointly establishing the aim of the assessment, gathering the information required, and assessing the extent to which the patient is ready to engage in self-care. The second of the 5As, Advise, consists of informing patients of their particular health risks. Such advice is shaped around each patient’s particular goals, habits and needs, and needs to be exacting and clear. Agree refers to patients’ with regard to a realistic set of goals. The fourth of the 5As, Assist, denotes the responsibility of healthcare providers to help remove barriers to enacting the self-management of a disease, encourage patient motivation to make changes, and assist them in developing the self-help skills needed to bring about successful behavioural changes. The fifth A, Arrange, refers to post-care contact with the patient, in person or by telephone, to provide continued assistance, to adjust care plans as circumstances possibly change, and to potentially arrange referrals for more intensive or specialized treatment (Newman, Steed & Mulligan, 2008).

Having incorporated the 5As, the PACIC became the PACIC-5As, with 26 items and 5 subscales for the PACIC portion representing multiple facets of providing patient-centred care congruent with the CCM (i.e. Patient Activation, Delivery System/Practice Design, Goal Setting/Tailoring, Problem Solving and Follow-up/Coordination) as well as the 5 subscales for the 5As (Assess, Advise, Agree, Assist, and Arrange) component of the tool. This study implemented the PACIC-5As tool because it provided the researcher with an effective means of gaining an initial or
‘baseline’ comprehension of the patient’s perceptions regarding the current quality of healthcare provisions for chronic conditions such as diabetes. With the addition of the 5As, the tool was particularly useful with regard to the aims of the study because it enabled one to gain insight into the patient’s perceptions of how organized care supports patient management of disease in particular, as well as how care systems interact with resources available in the community, both of which are integral to achieving optimal health outcomes, as promoted by the ICCC Framework (Glasgow, 2005a; Newman et al., 2008).

The new tool possesses similar psychometric properties to those featured in the original PACIC-5As tool and is, thus, useful for assessing the extent to which care is provided according to ICCC activities and principles. Several studies have made use of the tool, and it has been translated into twelve languages (Danish, Spanish, French, Dutch, and Japanese) although not into Arabic (Aragones et al., 2008; Maindal, Sokolowski & Vedsted, 2012; Koley et al., 2015). As Arabic is a formal language in KSA, it was extremely important to translate and validate the Arabic version of the instrument for this study. The next section provides detailed information about the translation process of the original English PACIC-5As into Arabic.

4.7.2 Instrument Translation

The World Health Organisation (WHO) recommendations regarding the translation and adaption of instruments were used to guide the translation of the PACIC-5As, with the aim of achieving the highest possible content validity (WHO, 2008). The steps of translation and adaptation of instruments are shown in Figure 12.
In the first stage, the English version of the PACIC-5As was translated from English to Arabic. A forward translation of the full PACIC-5As instrument (26 items) was performed by the researcher. The translation process was conducted over the course of a week and the result of the forward translation, ‘Arabic- PACIC-5As _1’ is attached in Appendix C.

The version translated into Arabic was reviewed by Expert Panel 1. This panel comprised an endocrinologist, two health educators and the researcher. Following a careful study of the Arabic version, the researcher questioned the accuracy of the vocabulary, especially the health terms vocabulary, which might be understood differently by respondents due to dialectical variations found all Arabic speaking countries. In the next stage, the expert panel met on two separate occasions. Before the review began, a protocol was developed by the researcher to systematically identify the relevance of the translated words and sentences (WHO, 2008). Three important questions were addressed:
1- Is the translated word in Arabic the exact equivalent meaning of the word in English?

2- If the Arabic word is not the exact equivalent, is there any better alternative Arabic word to use?

3- Is it likely that the alternative word will be easily understood by the general Arabic speaking population completing the questionnaire?

If an English word could have multiple meanings for a research participant, the most appropriate Arabic word was used in its place. For example, Item 10 of the PACIC-5As contained the question, “encouraged to go to a specific group or class to help me cope with my chronic illness”, the Arabic translation of the English word ‘encouraged’ was ‘osha'ga’, which was replaced by the panel with the word ‘ohafaz’. In total, five words used in the initial translation were replaced with words the panel believed to be more appropriate. The second version of the Arabic PACIC-5As is presented in Appendix D (Arabic- PACIC-5As _2). Upon completion of this stage, the translated instrument was ready for the content validity assessment conducted by Expert Panel 2.

At the next stage, the researcher applied a snowballing method to recruit a larger expert panel to undertake a content validity analysis of the instrument (Polit & Beck, 2006). The researcher contacted the director of the quality management department at a large hospital specializing in diabetes treatment in Riyadh. The researcher already knew the director and this person identified colleagues who were subsequently asked to participate in the content validity assessment.

According to recommendations made by Polit & Beck (2006) and Squires et al. (2013), five to ten members are enough to establish a second expert panel. In this study, seven individuals were recruited who were deemed to be expert in the field of
diabetes healthcare. All members of the panel worked at King Khaled Hospital in Riyadh. The majority of the experts were female (Table 18). The age of panel members ranged from twenty-five to forty-seven, and the group’s mean age was thirty-five years. Four participants were clinicians who worked in the diabetes management field and had a mean experience of thirteen years. Aside from being experts in the field, one member – who was the director of the quality control department – was an expert in translating surveys as a part of her job in the department. In addition, there were variations among panel members in terms of professional background, general healthcare experience, and specialized diabetes experience. There was also a lecturer who taught in a medical college. These variations in the characteristics of the panel members were important because they enriched the process of establishing the content validity of the instrument.

<table>
<thead>
<tr>
<th>ID</th>
<th>Gender</th>
<th>Age</th>
<th>Profession</th>
<th>Experience years</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>F</td>
<td>36</td>
<td>Director of quality control department</td>
<td>15</td>
</tr>
<tr>
<td>2</td>
<td>F</td>
<td>42</td>
<td>Health educator</td>
<td>20</td>
</tr>
<tr>
<td>3</td>
<td>F</td>
<td>25</td>
<td>Health educator</td>
<td>2</td>
</tr>
<tr>
<td>4</td>
<td>M</td>
<td>30</td>
<td>Hospital administration specialist</td>
<td>7</td>
</tr>
<tr>
<td>5</td>
<td>F</td>
<td>29</td>
<td>Lecturer</td>
<td>2</td>
</tr>
<tr>
<td>6</td>
<td>M</td>
<td>40</td>
<td>Endocrinologist</td>
<td>15</td>
</tr>
<tr>
<td>7</td>
<td>M</td>
<td>47</td>
<td>Endocrinologist</td>
<td>18</td>
</tr>
</tbody>
</table>

The purpose of the content validity analysis was to determine whether the language, content, and the structure of the Arabic version of the PACIC was appropriate for measuring the quality of chronic illness care in an Arabic-speaking population, based on the ICCC influence. The approach to establishing the Content Validity Index (CVI) was identified by Polit and Beck (2006). The CVI consists of two domains: the representativeness domain (R-CVI) – which identifies how the item is representative of a scale within an instrument, and the clarity domain (C-CVI) – which identifies how clear the item is to the reader.
The R-CVI and the C-CVI are applied to each item and then to the scale as a whole in the form of the Item CVI (I-CVI) and the Scale CVI (S-CVI). The ICVI represents the number of raters scoring an item with a 3 or 4 (very or highly relevant) divided by all participating experts, while the S-CVI is the averages of all the raters’ scores (Polit & Beck, 2006). An I-CVI agreement proportion of .78 or above indicates acceptable content validity (Denise et al., 2007). The overall S-CVI score is calculated by taking the average of the items’ scores (Lynn, 1986). Following a review of the Arabic PACIC instrument, participants were instructed to record their responses in the content validity questionnaire (Wynd et al., 2003; Polit & Beck, 2006; Schilling et al., 2007; Squires et al., 2013). The protocol involved the following steps: the panel members were asked to rank each item for its representativeness and clarity on a four-point ordinal scale:

1- Item is not representative/clear
2- Item needs major revision to be representative/clear
3- Item needs minor revision to be representative/clear
4- Item is representative/clear.

<table>
<thead>
<tr>
<th>Table 19: Content validity questionnaire example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Item</td>
</tr>
<tr>
<td>Representativeness score</td>
</tr>
<tr>
<td>Comments</td>
</tr>
<tr>
<td>Clarity score</td>
</tr>
<tr>
<td>Comments</td>
</tr>
<tr>
<td>Given choices about treatment to think about.</td>
</tr>
</tbody>
</table>

Additional space on the form was available for comments and suggestions (Table 19). Following the ranking process, the researcher identified the dichotomous outcome variables by computing categories one and two (1) and categories three and four (2). A score of one indicated an unsatisfactory outcome while a score of two indicated a satisfactory outcome. The items that required minor revision were revised according to the suggestions made by panel members and in discussion with the
researcher. Seven experts were involved in assessing the content validity index of the translated PACIC-5As questionnaire. The representativeness analysis identified one item with 87.5% representativeness: Item 14 (‘It helped to plan ahead so I could take care of my illness even in hard times’). All remaining 25 items demonstrated 100% representativeness. Consequently, all items were retained in the translated questionnaire.

The results of a clarity analysis revealed that a total of 11 items did not reach the perfect clarity score of 100%; the remaining 15 items did. The items that did not reach a perfect score were 1, 2, 3, 4, 7, 10, 11, 20, 21, 22, 24, which scored 87.5%. All items were modified in accordance with the respondents’ recommendations. For example, the Arabic meaning of the word ‘asked’ did not make clear if the word ‘asked’ or the phrase ‘I was asking’ was being implied. The reason for this is that the translated word in Arabic had no Arabic diacritic (ـ). When the script added this, the items became clearer. The change satisfied all of the respondents who had not understood the use of the term ‘asked’ in this context.

In summary, the content validity analysis revealed a representativeness score (R-CVI) of 95.3 (95.3%) and a clarity score (C-CVI) of 94.8 (94.8%). These scores indicate good agreement among panel members. The calculation process was performed through presenting the I-CVI results as percentages and dividing the result by the total number of items (26). The final result of the content validity analysis revealed satisfactory representativeness and clarity outcomes. The panel members’ comments were very helpful in providing a wider perspective about the translation process. The modification process made a significant contribution to the quality of the final instrument because words in the formal Arabic language that were difficult for many people to understand were replaced by informal words in everyday use in the
Arabic speaking population. The end result of the validation process was the third version of the Arabic version of the Patient Assessment of Chronic Illness Care questionnaire (Arabic- PACIC-5As _3) (Appendix E).

Following the translation recommendations of WHO, the third version of the A-PACIC-5As _3 was back-translated into English by an independent professional translator who was a native speaker of English and unaware of the original English PACIC (WHO, 2008). The back-translated version was similar to the original instrument. The back-translated version of the A- PACIC-5As is presented in Appendix F. While the outcomes of the previous systematic steps resulted in the development of the Arabic Patient Assessment of Chronic Illness Care (A- PACIC-5As) measure, the psychometric properties of the translated instrument had yet to be examined thoroughly.

4.7.3 Pre-testing the instrument

Assessing the reliability, construct validity and internal consistency of an instrument is a vital part of its overall evaluation (Mark, 2003). Before collecting data, it was important to explore the PACIC-5As instrument’s ability to consistently elicit answers from respondents and accurately measure the quality of care based on the ICCC elements. For ease of understanding, this stage of the evaluation process is divided into the following steps: a description of the pilot sample used for this purpose and the procedure used to undertake the psychometric validation.

The first sample was randomly recruited from the database of one of the diabetes centres in Riyadh city, which served a population of 5,000 people. Participants were recruited through mobile messages to fill in online. The questionnaire was sent to 300 people and thirty-three agreed to participate in the
The average age of the participants was forty-eight years (range: thirty-five to seventy years). Seventeen of the participants were male (52%). No other socio-demographic data were collected because the aim of this phase was to test the assessment tool, not to investigate these independent variables. All statistical analysis was undertaken by the researcher and all statistical calculations were undertaken using SPSS (v.22) software (Norušis, 2005). There was a common agreement between the researchers who validated the translated PACIC-5As instrument that the following tests were appropriate for investigating the psychometric properties of instruments (Glasgow, 2005a; Glasgow, 2005b; Aragones et al., 2008; Maindal, Sokolowski & Vedsted, 2012; Koley et al., 2015):

- **Cronbach’s alpha (internal consistency).** The aim of using Cronbach’s alpha was to evaluate the instrument’s internal consistency. Cronbach’s alpha was employed to assess the instrument and its subscales’ internal consistency. The minimum acceptable alpha score for internal consistency is .70 (DeVon et al., 2007).

- **Test-retest (reliability/stability):** The PACIC-5As questionnaire was administered to the first sample of participants on two separate occasions and one-week apart so that test-retest could be calculated. This statistical procedure assesses the level of agreement between the same participants’ answers on two different occasions (Aday & Cornelius, 2006). The Pearson product moment correlation coefficient (r) indicates the strength of the association between participants’ responses to the questionnaire on the first and second times of completion (Munro, 2005).

- **Inter-Item correlation:** The aim of examining the Inter-item correlation is to assess the extent to which items on a scale are assessing the same content. To be
acceptable, the average inter-item correlation should be between .20 and .40 (Munro, 2005).

- **Conformity factor analysis**: The researcher performed a factor analysis to identify the agreement between self-management as a theoretical concept and the PACIC-5As measure. Such an analysis is designed to verify clustered items under each subscale of an assessment tool (Maindal et al., 2012). Performing factor analyses at this stage required assessing the extent to which the data was suitable by inspecting the correlation matrix using the Kaiser-Meyer-Olkin test, as well as Bartlett’s test of Sphericity (Bartlett, 1954).

Before moving on to describe the data analysis plan, the next sections present the additional socio-demographic variables that were measured in this study and the sampling procedures used.

### 4.7.4 Socio-Demographic Variables

The socio-demographic and clinical questions that were added to the questionnaire were based on the review of previous PACIC-5As literature (Glasgow, 2005b; Aragones et al., 2008; Maindal, Sokolowski & Vedsted, 2012; Koley et al., 2015). Gender, age, educational level, and marital status were the socio-demographic factors, while the type of diabetes, glycaemic control level, smoking status, treatment status, incident of diabetes, and comorbidity were the clinical variables. These variables were important for exploring the cultural differences between the results of this investigation and other international studies. Although this was a descriptive study, it was worth exploring the differences of PACIC-5As according to these variables (Table 20).
<table>
<thead>
<tr>
<th>Table 20- Socio-demographic variables</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
</tr>
<tr>
<td>Male</td>
</tr>
<tr>
<td>Female</td>
</tr>
<tr>
<td>&lt; 18</td>
</tr>
<tr>
<td>18.39-39</td>
</tr>
<tr>
<td>40-59</td>
</tr>
<tr>
<td>&gt;60</td>
</tr>
<tr>
<td>Age</td>
</tr>
<tr>
<td>&lt; 18</td>
</tr>
<tr>
<td>18-39</td>
</tr>
<tr>
<td>40-59</td>
</tr>
<tr>
<td>&gt;60</td>
</tr>
<tr>
<td>Blood glucose level</td>
</tr>
<tr>
<td>Report the HbA1c or FBG</td>
</tr>
<tr>
<td>Educational background</td>
</tr>
<tr>
<td>Less than high school</td>
</tr>
<tr>
<td>High school</td>
</tr>
<tr>
<td>Diploma</td>
</tr>
<tr>
<td>Bachelor</td>
</tr>
<tr>
<td>Postgraduate</td>
</tr>
<tr>
<td>Comorbidity</td>
</tr>
<tr>
<td>Heart</td>
</tr>
<tr>
<td>Eye</td>
</tr>
<tr>
<td>Kidney</td>
</tr>
<tr>
<td>Amputation</td>
</tr>
<tr>
<td>Skin</td>
</tr>
<tr>
<td>Other</td>
</tr>
<tr>
<td>Nothing</td>
</tr>
</tbody>
</table>

In order to describe the characteristics of the study sample, each of the above-mentioned variables had a group of categorization or values. Gender, Educational Background, Marital Status, Comorbidity, Smoking Status, Diabetes Type and Treatment Status were categorized as nominal values. While Age and Incidence of diabetes were categorized as ordinal values (Simpson, 2015). For the blood glucose level, as it was important to make a comparison between controlled and uncontrolled glycaemic groups, the participants were asked to report their exact HbA1c or fasting blood glucose measures. Where this information was not available, the tests were categorized as ‘controlled blood glucose’ and ‘uncontrolled blood glucose’. On the basis of a recent recording, participants were identified as having a controlled blood glucose level if they had HbA1c ≤ 7% or FBG ≤ 130mg/dl (ADA, 2008). Any value above these thresholds was considered to be an uncontrolled blood glucose level status. The degree of blood glucose control was presented as a binary outcome variable and as either controlled or uncontrolled.
4.7.5 The Sampling Procedure

There are a variety of potential sampling methods, however, a good sampling choice depends on objective of the study and accessibility of the population (Saunders et al., 2009; Daniel, 2011; Creswell, 2014; Bowling, 2014). In this study, the objective was to explore patient experience according to the ICCC by applying a descriptive analysis using the PACIC-5As survey. Due to gender segregation in KSA, the accessibility of any researcher to the opposite gender was extremely challenging. Therefore, as an exploratory research that sought to understand T2DM management at the micro level of the KSA healthcare system, this study did not use a rigorous sample design. According to Daniel (2011), for an explanatory study, “A nonprobability sample with a small sample size may suffice (P.24)”.

However, the researcher distributed the questionnaires to all patients who were attending four diabetes clinics from March 2017 to May 2017 during the working days (Sunday to Thursday) in Riyadh city. This sampling method is called ‘convenience sampling’ as the contacted participants were recruited from the population. Although this method is not always recommended due to its potential inability to accurately represent a population, it was selected in this study as the most appropriate option due to the recruiting challenges identified previously in this chapter (Saunders et al., 2009; Creswell, 2014; Bowling, 2014).

The researcher asked the receptionists in each clinic to distribute the questionnaire to each patient and ask them to complete it in the waiting room and return it to the receptionist once their appointment was over. In order to ensure the accurate collection of data, the researcher met with the receptionists weekly to discuss collection protocol.
4.7.6 The Data Analysis Plan

Following the successful translation and validation of the PACIC-5As in the first phase of the study, the data collection phase used the PACIC-5As to identify socio-demographic characteristics and factors affecting healthcare provider interaction among people with T2DM. The researcher performed an analysis of the data while taking advice from a statistician and her supervisors. Data analysis was performed using SPSS v.22 software and occurred in several stages (Norušis, 2005). To begin with, the raw data were scoured for omissions, inconsistencies, and potential errors. The researcher corrected errors by checking the data against hard copies of the questionnaires. The data was then checked for missing values. According to Munro (2005), a researcher must identify missing data patterns confidently before progressing to data analysis. In other words, the researcher must know why there is a missing value in the data and whether this could interfere with analysis outcomes (Norušis, 2005). Through use of the Missing Values analysis function available in SPSS, the researcher found that the pattern of missing data was completely random. Since scoring of the PACIC-5As tool was possible even if a portion of the data was missing, no data imputation was performed. The scoring of the PACIC-5As and the identification of additional variables is discussed below.

A clear analysis plan is very important for guiding the researcher when choosing the type of statistics to use for a study. The choice of the most appropriate statistical method depends on how values are distributed (Simpson, 2015). Mathematical formulas used to organize and interpret data are commonly conducted in two modes - descriptive and inferential statistics (Bartlett, 1954; Simpson, 2015). The value of the demographic variables in the study were summarized into numbers and percentages. With regard to the PACIC-5As, the researcher summarized the
information using parametric statistics of means, standard deviations, and confidence intervals (Simpson, 2015).

Moving to the inferential step, the researcher considered the research questions, the study design and the levels of measurement before selecting the kind of inferential statistics to be used. As the researcher aimed to explore the patients’ experience at the micro level of the KSA healthcare system by using the PACIC-5As instrument, she compared the mean values of the PACIC-5As with the independent variables. For the dichotomous variables – gender, smoking habits, blood glucose monitoring – t-tests with two tailed significance were performed to assess the association of the means of the instrument subscales with the independent variables. Statistical significance was defined as the p = 0.05 level (2-tails) (Bartlett, 1954; Simpson, 2015). While the other variables that were categorized for more than two sub-groups, a one-way ANOVA test was performed. Finally, to compare the PACIC-5As domains with the ICCCF dimensions, continuous PACIC scores were dichotomized at the mid-point – (≥3) for high PACIC and <3 for low PACIC. Then a Chi-square test was performed to test the significance of the changes between the PACIC-5As level and glycaemic control, and the smoking status variables (Bartlett, 1954; Simpson, 2015).

4.8 The Data Synthesis

As described earlier in Chapter 2, healthcare systems are extremely complex social structures. Like all complex systems, they are multi-layered, nonlinear, and highly cultured. They usually include a set of complex elements and functions that aim to improve the health of a population. In this thesis, these elements were grouped into three categories or three healthcare system levels: macro (system as a whole),
meso (institutions), micro (individuals) (WHO, 2002; Epping-Jordan et al, 2004; Kuo et al, 2011). The research question were also divided in accordance with these healthcare system levels. As a result, it was very difficult for these questions to be answered using a single method. Therefore, this study adopted a flexible multi-method design that evolved during the research process in three stages: a review of publicly-available documents, interviews with healthcare providers, and a survey of patients (Brewer & Hunter, 1989; Seawright, 2016)

A primary challenge of healthcare system research is framing the boundaries of each system level. While the boundaries used in this study were determined from the theoretical perspectives of the ICCC framework, the researcher acknowledged the reality that health system levels are interrelated and interdependent with each other (WHO, 2002; Epping-Jordan et al, 2004). From a methodological point of view, as this thesis adopted a multi-method approach, the sampling, data collection, and analyses were conducted independently for each health system level (Brewer & Hunter, 1989; Seawright, 2016). However, as the layers of any health system are related to each other, the researcher integrated the overlapping findings into the discussion stage.

4.9 Ethical Considerations

Saunders et al. (2009) defined ethics as “the appropriateness of the researcher’s behaviour in relation to the rights of those who become the subject of a research project, or who are affected by it” (p.600). Multiple ethical issues are likely to arise throughout any research process, from deciding on and devising a research topic, designing the research framework, collecting data, to finally presenting it. These ethical issues require careful consideration. Not just the methodology of a research project should be sound, so should the extent to which one can morally
defend it (Gomm, 2004; Saunders et al., 2009). Ethical issues pertaining to the present study are discussed below.

Ethical clearance was obtained from the University of Surrey’s Ethics Committee at the outset of the research process (Appendix G). Participants were granted the right to remain anonymous and the information they provided was kept confidential by having the names of participants replaced with codes as a form of identification, and all information provided being duly kept confidential (Gomm, 2004; Saunders et al., 2009). Participants gave voluntary consent prior to data collection. The researcher read an informed consent statement to all participants at the outset of each interview. The statement was written in a language which participants understood and it outlined the nature and aim of the research and procedures, as well as asking for consent to be given. Non-maleficence is essential for conducting ethically sound research (Gomm, 2004; Saunders et al., 2009). Thus, participants were informed that their participation was voluntary and that they were free to withdraw from participation at any stage, especially if they felt it compromised their wellbeing.

4.10 Chapter Summary

This chapter provided a detailed description of the research design and methodology use in this study. The research aim and objectives were described together with the research questions. The research context was also briefly described. The chapter explained that this study adopted a pragmatic research philosophy and used a multi-method research design. The methods of sampling, data collection, and analysis used in the research were described, and the rationale for choosing these methods was explained. Finally, the chapter presented the ethical considerations relating to this study. The next two chapters present the findings of the healthcare provider interviews and the patient surveys.
Chapter 5: Qualitative Interview Study

5.1 Introduction

This chapter presents the perceptions of the interviewees of the health services for T2DM at the meso level. The chapter aims to inform how to improve of the KSA healthcare system. It aims to answers to the following research question:

What are health care professionals’ perceptions of the barriers and facilitators of an effective healthcare organization and of community partnerships to enable T2DM management?

This chapter reports on the various perceptions and perspectives given by the stakeholders about the healthcare service organizations and the community partnerships involved in the management of the T2DM population. More detailed information about the sampling, recruiting and data analyzing procedures are provided in Chapter 4. This chapter begins with an overview of the main themes and the sub-themes identified during the interviews. The findings of this research revealed three over-arching themes:

1. The cultural determinants of T2DM management;
2. The limitations of the support systems provided for T2DM management, and
3. Recommendations for improving the support systems for T2DM patients.

The themes and the sub-themes within them are summarized in the following table.
Table 21: Overview of identified themes

<table>
<thead>
<tr>
<th>Themes</th>
<th>Subthemes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Culture determinants of T2DM in KSA</td>
<td>• Physical inactivity</td>
</tr>
<tr>
<td></td>
<td>• Dietary pattern</td>
</tr>
<tr>
<td></td>
<td>• Awareness</td>
</tr>
<tr>
<td></td>
<td>• Reliance on traditional treatments</td>
</tr>
<tr>
<td>Limitations of key support systems in assisting patients in management of T2DM</td>
<td>• Poor PHC services</td>
</tr>
<tr>
<td></td>
<td>• Lack of reliable HIS</td>
</tr>
<tr>
<td></td>
<td>• Shortage in qualified staff</td>
</tr>
<tr>
<td></td>
<td>• Poor guidelines dissemination</td>
</tr>
<tr>
<td></td>
<td>• Lack of community partnership</td>
</tr>
<tr>
<td>Recommendations for improving the support systems for T2DM patients</td>
<td>• Strengthen PHC services</td>
</tr>
<tr>
<td></td>
<td>• Upgrading HIS</td>
</tr>
<tr>
<td></td>
<td>• Staff training</td>
</tr>
<tr>
<td></td>
<td>• Multi-sectorial collaboration</td>
</tr>
<tr>
<td></td>
<td>• Enhancing community partnership</td>
</tr>
</tbody>
</table>

5.2 KSA’s cultural determinants of T2DM

The participants identified the cultural determinants of T2DM in KSA through two main narratives - lifestyle and care seeking behaviours. With regard to the Saudis’ lifestyle, urbanisation narratives which included information about the sedentary lifestyle emerged during almost all the interviews. The participants suggested that rapid urbanisation in KSA accounted for a significant shift in physical activities and dietary patterns resulting in a reduction in the former and unhealthy behaviours in the latter. According to the interviewees, the prevention of T2DM was dependent primarily on to these two modifiable factors.

Physical activity was mentioned frequently during interviews. All the participants agreed that the level of physical activity among Saudis was low. An endocrinologist who held an academic job said:

"Most of Saudis are simply not active enough to achieve the benefit of physical activity." (P7)

The participants explained that a lack of physical activity among Saudis was due to their sedentary behaviours at all ages and also to gender. They mentioned examples of this passive lifestyle such as watching TV, playing video games for long
periods of time and depending on servants to do the majority of the housework which was a norm among Saudi families. These are some of their comments:

"While in many cultures parents would want their kids to go out and play and live a healthy lifestyle, parents in Saudi Arabia often discourage their kids from doing so. They think that kids playing on mobile phones and laptops are at a high standard of living because it signifies brain development. But in reality they are promoting a sedentary lifestyle." (P17)

"In the past, you would see children playing football and other games which required physical activity. But most of them now play video games." (P32)

"There is no house without a maid. Mother and children depend on the servants doing all the tasks in the house. So I'm not surprised by the spread of obesity in the region." (P8)

In addition to the factors mentioned in the above quotes, cultural barriers add further challenges to their engagement in physical activity. For example, customs and social norms restrict females from going out and living an active lifestyle. This is changing somewhat, but by and large, most Saudi females are restricted by choice from living an active lifestyle in KSA. Most of the female participants commented on these societal constraints as follows:

"Girls from a very early age are conditioned into a lifestyle which is about sitting at home and not playing outdoors too much. Over time, this leads to an inactive lifestyle. You will find most Saudi women engaging in social activities which by no means can be considered active." (P1)

"We, as Saudi women, face social pressures that limit our practice of physical activity in public. It is not acceptable at all to run in the street." (P4)

"The availability of foreign workers in Saudis' homes has led to the spread of laziness among us." (P16)

Men shared some of these views too as one male respondent said:

"Cities are not designed to motivate physical activities in KSA... women suffer more due to social restrictions that place them in indoor places." (P12)

Another key narrative that emerged during the interviews was dietary behaviors. The urbanization shift in the kingdom during last three decades has not
only affected the level of physical activities, but also the dietary patterns have changed significantly. In this regard, one participant commented:

"Eating outside is becoming cheap and is becoming the norm. I know families who eat out almost every day. Also the choice of food is changing; most people eat only fast food, meat and bread and cola instead of water. With this lifestyle, I am surprised that we do not have a diabetes epidemic." (P4)

Several other participants shared the same view about Saudis’ eating habits:

"It is highly alarming that people are eating quite unhealthy food in this part of the world. This is particularly true for young children, who will become the next generation." (P11)

"I have often seen parents who consider being overweight as a sign of good health. They do not see it as a sign of poor lifestyle. Actually, they see lean kids as possessing poor health, even if the kid is lean because of an active lifestyle". (P3)

"People are usually eating fast food, and when they cook, they mostly cook the unhealthy contents of the national dish (Kabsa) which has lots of fat and lots of carbohydrates." (P33)

It appears from all previous quotes that both physical inactivity and unhealthy eating patterns have contributed to the increase in the prevalence of T2DM in the Kingdom. However, a professor of medicine and a consultant endocrinologist remarked that these factors can be changed:

"The diabetes triangle is physical inactivity, obesity, and insulin resistance. We have physical inactivity, we have obesity already in the menu and we have some amount of genetics. Of course, diabetes is inherited. T2DM has some genetic components, and so we will probably have all of these three points of the triangle in position for diabetes to develop, but at least physical inactivity and obesity are modifiable because these are lifestyle issues." (P7)

The next theme that emerged during the interviews was with care seeking behaviour. The respondents identified a lack of awareness among patients as one of the primary factors that led to ineffective care seeking behaviour. Participants used words like ‘knowledge, ‘literacy’, 'educating' and ‘understanding’ to convey their conceptions of awareness. In addition, a lack of awareness about the disease was
frequently cited in different contexts. These included participants reporting that, besides knowing about an unhealthy lifestyle, they lacked awareness of what might cause the disease, what were its symptoms and how to manage T2DM once they were diagnosed with it. Generally speaking, this lack of awareness among individuals about what might contribute to the onset of diabetes, what were its symptoms and the consequences would seem to be largely responsible for the high prevalence of diabetes. This dearth of knowledge within the society could also lead to people’s dependence on unreliable information to improve their health. One of the health education team members who worked in the Diabetes Society Association, in commenting on the patients’ attitude towards unreliable information said:

"People here disseminate wrong information on WhatsApp, such as "I did this and my diabetes went away!" and they propagate this message in multiple groups. And when you explain to them that this is totally wrong information you can easily see the shock in their face." (P30)

Several other participants made similar remarks that many patients were not aware of the signs and symptoms of T2DM, but this was due to their seeking information from non-qualified persons:

"Many patients often come up to my clinic with misconceptions about diabetes. When I asked them about the source of their information, the answer is usually (it's Known), (my relatives) or (my friends)." (P13)

"In Saudi culture, people prefer seeking help from their close family and friends. Although they do not know what the problem is and how to solve this, but they give the advice, nevertheless, and their advice is followed as well. Doctors struggle to convince the patients to seek formal help. If I advise a patient to go and get checked for diabetes, he will instead go to his family and friends asking for alternative cures. There is general mistrust about doctors." (P5)

Respondents commented on the relationship between lack of awareness among patients and their poor self-care. Due to a lack of awareness, patients fail to have their diabetes diagnosed and so they do not know how to self-manage. Self-management is essential for someone with diabetes, but this can only be achieved after a proper
diagnosis of the disease. Due to this lack of awareness, effective self-management is
difficult to achieve. Self-care of diabetes is not only about adhering to a medication
regimen, but also about understanding and adhering to lifestyle recommendations. A
physician mentioned that only 50\% of his patients complied with his advice. He
commented:

"They don’t take their medication, they don’t do exercise, if I give them 10
pieces of advice, they do five and ignore the other five, especially if it has to
do with exercise, diet or smoking habits." (P14)

In addition, this lack of awareness among patients has contributed to poor
diagnoses. According to a medical practitioner:

"Patients often hide their medical history. This may be deliberate or due to
ignorance, but they do not realise how important it is for doctors to know their
medical history. In some cases, doctors also fail to diagnose the real
problem." (P1)

"Most patients falsify their readings. When you check their glucometers, they
give high readings, whereas the reading that they told you are totally different.
Or they tell you that they check four times a day, and when you check the
glucometer, you will be able to tell that they only did it once in the last week."
(P6)

This lack of awareness about T2DM makes patients seek informal advice from
unqualified sources which often leads to erroneous approaches to the management of
diabetes.

Another narrative that closely related to poor care seeking behaviour was
traditional treatment practices. According to the participants, the use of traditional
medicines is quite prevalent in Saudi culture. In many cases, people consult their
family and friends and try a number of traditional remedies. The problem is that there
is a general mistrust of professional doctors which results in a misinformed faith in
traditional health practitioners. As noted by some of the participants:

"I’ve heard of at least 30 to 40 different traditional treatments of diabetes from
my patients: people tell you about moringa, garlic, and unknown herbs. Some
people believe that it is some sort of envy or magic, so we just need to go to traditional healers or an Imam to perform an exorcism." (P17)

"People believe that they [herbs] provide long-term and effective solutions, while medicines are considered short-term solutions. So when they do not benefit from use of traditional medicines, they do not feel disappointed because they are not expecting a short-term cure anyway. In fact, they are not getting cured at all." (P9)

"Patients believe that traditional medicines will not cause any harm, if not any good. The problem is that they delay their treatment and this causes a lot of problems. They have to be taught that traditional medicines are not proven to treat diabetes." (P6)

The excerpts above demonstrate that many people with diabetes in KSA will consult traditional healers who are mainly religious leaders. This, therefore, reflects the dominance of religious beliefs in the KSA society. According to one of the participants:

"We find that many Saudis, as a religious community, are extremely trusting of the views and practices of the traditional healers." (P31)

Health beliefs and practices are influenced by the teachings of Islam. For example, Muslims are instructed strongly by the holy book Quran or Prophet Mohammed (Peace upon him) to eat dates and honey:

"Then eat from all the fruits and follow the ways of your Lord laid down [for you]. There emerges from their bellies a drink, varying in colors, in which there is healing for people. Indeed in that is a sign for a people who give thought?" (Quran 18:16-69)

In addition, Prophet Mohammed (Pace upon him) advised people to eat seven dates per day in the morning he said:

"He will not harm by anything until he reaches the evening" (Sahih Muslim, 2047)

Many people follow religious texts strictly, without any effort to think about the impact and meaning of these instructions. In this regard, two Muslim physicians
commented on the above statement and one of them has a logical explanation of the Quran’s instruction. He said:

"Honey is mentioned in the Quran: but I told them [patients] that this healing mentioned without specification is just like a kind of cure. If a diabetic drinks honey he will not be cured from diabetes and the sugar will be very high.” (P14)

Dietary management is one of the most important elements for diabetes care; however, a health educator felt that this was one of the most difficult things to change when it contradicted Islam instructions. She said:

"It is a big problem and it is really difficult to solve because some diabetes patients tell me I have to eat a lots of dates because it is Sunnah of Prophet. You can't convince them that this is not Sunnah, of course it is, but if the prophet Mohammed, peace be upon him, knew that someone has diabetes, I am sure he would not tell them to eat that amount of dates." (P15)

The dominance of religious beliefs and conservative traditional values has important consequences for the healthcare delivery system in KSA. Participants reported that there were relying on traditional healers in the KSA society, and this deterred them from seeking medical care. While T2DM do not show any signs and symptoms in the early stages of the disease, depending on traditional medicine can delay the detection of the disease. Participants believe that poor care seeking behaviors can affect access to the healthcare facility as most of the patients who rely on traditional medicine enter the system only when complications arise. As some of the participants stated:

"Patients often come to us with problems which can be directly related to diabetes. When we ask them for blood tests, they ignore us. They think blurred vision and tiredness are natural in middle and older ages and link it to stress, but not to diabetes. There is a serious lack of awareness of diabetes. Many individuals seek alternative care from traditional healers for symptoms which are actually caused by diabetes."(P32)

"This is a big problem. We try to be doctor ourselves and think that what our ancestors did is the best thing. Now our ancestors did not have the kind
medical knowledge that we have today. If we are going to rely on what our ancestors told us then why do we need hospitals? Let’s close them all." (P8)

Patients often revert to traditional medicines to heal the symptoms of T2DM without even knowing that they have T2DM. This creates a problem because they often seek treatment for the symptoms and not the root cause. For example, many people do not know that diabetes can lead to blindness. So they try to get treatment such as spectacles for blurred vision but do not consider getting checked or treated for diabetes. The lack of knowledge about the symptoms of diabetes is a major reason why many people discover their diabetes at a very late stage. According to one medical practitioner:

"Most people do not know about diabetes symptoms. So they do not know that the problems they are facing have resulted from diabetes." (P3)

Another health educator commented:

"Many people think that they will not develop diabetes because they do not eat much sugar. In reality diabetes can develop because of numerous reasons – even stress and tension. They do not understand the pathology of the illness and are often misinformed. So patients will not seek treatment for diabetes, even if the doctors suspect it. I have encountered many cases in which I asked the patients to get their blood checked for sugar and they never returned to me." (P10)

It seems that social and cultural beliefs affect nearly all aspects of diabetes care in KSA. The respondents believe that the individual is primarily responsible for caring for their own health by increasing awareness and avoiding health risks. The participants view is very important regarding the effectiveness of the T2DM management support system and this will be presented in the next section
5.3 The limitations of the Support Systems Provided to T2DM Management in KSA

According to the respondents, there were very few formal support systems for diabetes patients. Even when the support systems existed, they did not function widely or successfully in Saudi society. Respondents suggested that this could be due to the poor strategy adopted by Saudi authorities to establish the support systems. The main weakness identified in the current KSA healthcare system was categorised under five main themes: poor primary healthcare, unreliable health information, the shortage of medical staff, poor dissemination of clinical guidelines, and a lack of community partnerships.

PHC was initiated in KSA by MOH IN THE early 90s. According to the MOH’s plan, these centres were responsible to detect, promote and provide clinical services to diabetic patients until any complications arose (MOH, 2009; MOH, 2015). However, this was not the case in reality. According to the participants, the PHC system in KSA was ill-equipped to manage and control T2DM cases for several reasons. First of all, the participants believed that there was no effective screening program at the primary care level in KSA. One of the diabetes centre managers referred to the unqualified medical team as a reason of poor PHC system:

"PHCs are supposed to be the first point of entry to the healthcare system for any patent, and all the physicians who work there are untrained GPs. What happens here is that any patient suspected to have T2DM is referred to higher level of care" (P2)

This view, which was shared by several physicians, suggests that it was widely believed among the workers in the healthcare organization that the pattern of primary care used was disproportionate to the actual health needs of the population. Another physician, who managed a specialised diabetes centre, complained about her overcrowded clinic. She said:
"Unfortunately many people enter the PHCs when they already have complications from T2DM due to lack of early detection... (P1)

...I have many simple diabetes cases without complications in my clinic, they could have been treated at the PHC clinic if there were qualified GPs.” (P5)

Although the interview sample did not include any PHC physicians, however, the participants recognized the weakness of the general practitioners through their experience with transferred patients. According to one of the participants:

"For some patients, when I give them treatment, they say, ‘OK, doctor, if the sugar comes back normal, can I stop it?’ A lot of them may stop even before asking me this question. Their friends tell them, ‘Oh, now your sugar is ok, if you keep taking the medication it might cause a problem’. So there is a misguided belief that the medication is harmful, so they usually try to stop it. And I can't blame them because sometimes they tell me that the doctor at PHC told them that the diabetes can go away. And sometimes they even tell them to stop taking their medication! Part of it related to misunderstanding and erroneous beliefs held even by healthcare providers”. (P12)

This lack of qualified staff in the PHC centres forced patients to seek care at a higher level facility.

However, the health information system was identified as another lack in the PHC clinics. According to the respondents, the problem was the referral made contained limited information on the patient’s situation. According to the medical care practitioners, their clinics almost never had access to the PHC patient’s full medical record. If the patient could not remember the previous diagnoses and treatment and their test result, there was no way for the providers to be aware of this, as can be supported by the following comments:

"Absolutely no exchange of information. The only exception is when the patient moves from one doctor to another within the same hospital.” (P9)

This sentiment was echoed by several other participants:
"Exchange of information is not there at all. Also the patients have little knowledge of medical science, so in many cases they cannot even convey accurately to the doctor what the problem is." (P13)

"Imagine how much we could save on the cost and time if we had a database linked to PHC centers. This would enable us to get all the information needed." (P17)

In addition to this lack of this relationship, several physicians complained about the use of the current EMR:

"Number 1, it's very slow; number 2, it's very complicated. It is not like one tick and you get what you want. For example, if you are in a patient's file and you want to refer the patient to another specialised form of care, you have to enter who you are, why you are referring the patient, and what diagnosis the patient has. It is not a smart system." (P5)

Another major issue about the electronic HIS was that the data were not organized chronologically. According to one physician:

"For the lab results, it is very difficult to find the recent result because they are entered randomly. You have to keep clicking on different visits until you find it." (P13)

The lack of a shared information system between various levels was due, in part, to the fact that many PHCs were still using paper-based records. Furthermore, there was no interconnectivity among healthcare facilities that adopted the EMR. Nevertheless, the HIS in KSA was still in its early developing stages according to the IT specialists who said:

"The Ministry of Health set up a new e-health project. We are going to upgrade all paper records across the Kingdom" (P24)

"We are still on the beginning. Do you know that there are some rural areas in the Kingdom where there are not covered by Internet communications network? So how can we can set up HIS? However, I am optimistic that, in time, we will cover all areas of the kingdom" (P18)

As is apparent in the quotes above, gathering diabetes data from across the various healthcare organizations in KSA remains a challenge. The participants believed that there was no accurate national estimate of the number or percentage of
T2DM cases and for those patients who are following recommended treatment.

According to one of the deputy ministers from the health information department:

"The Ministry of Health has a registry, although it is private, it has very important information about diabetic patients. The Public Health Department has developed the registry apart from the IT system and so, the IT system has no access to it. This has always been a challenge to integrate both systems." (P12)

However, this registry did not include all the people with diabetes in Saudi Arabia, according to the project manager of this system:

"I don’t know who describes it as national because if it’s national, it should be the Ministry of Health, because MOH is the only agency in charge of the national approach in general." (P26)

An important point discovered through the interviews was that some of the healthcare providers were not even aware of the diabetes registry. Actually, all of them had no access to this system. According to one of the physicians:

"I am not aware of the diabetes registry, but what we are doing is calculating the number of patients and we send it to the Ministry of Health. We have a census completed by nurses and I am not sure what happens after they collected the data." (P8)

The development of an accurate comprehensive national diabetes register has been challenging for the Ministry of Health. According to one of the respondents who held a high managerial position, the reason was:

"You really can’t find people who only have diabetes. You find people with diabetes, usually with co-morbidity, like hypertension or something else. So then it becomes complicated. You have a person in this registry and we have a person in another registry so how do you follow? You follow the same registry with the same organisations to make sure when you update this that you also update the other. “(P28)

Another issue is that, in Saudi Arabia, there are different diabetes registries developed by different healthcare organizations under the umbrella of the MOH. According to one of the IT specialists:

"Why have we not been able to implement an information system? There is no national vision, in order to have a national vision we will need to have a direct
line coming from the council minister and that council minister should define what kind of information should be collected and stored for all the people in the country. What has happened now is that each organisation was left to develop its own strategy... Unfortunately, the challenge here is that the minister was not given the power to influence the different healthcare providers." (P25)

Another key narrative that recurred in the interviews was that of limited access to care at the specialized diabetes clinic. As commented on previously about the lack of PHC services, there was an over-reliance on the secondary and tertiary levels of care. Once patients are referred to a higher level of care, they will then be seen by a group of healthcare providers which includes physician, dietitians, nurses, and health educators. However, the problem identified by the majority of the participants was the shortage of specialist staff such as endocrinologists, educators, and local nurses. One of the diabetes centre managers complained that:

"We are faced with the fact that most of our clinics are overbooked due to shortage of staff..." (P2)

This claim was echoed by several other participants:

"We suffer from the scarcity of health specialist and specially certified diabetes educators..." (P16)

"The diabetic patient is the first person responsible for his condition. I try as much time as I have to educate him, but most cases I refer to the health educators, who are, unfortunately, very few" (P11)

"Nutrition and physical activity are major parts of diabetes treatment. We have health nutrition educators at the highest level of competence. But with the large number of patients, it is not easy for them to follow-up patients regularly." (P9)

"We have such a long waiting list. T2DM is a progressive disease which needs a progressive change of treatments. Maybe, if not every two or three days, every week or two." (P4)

Furthermore, there was a shortage of local nurses which, according to the participants, the KSA health facilities especially had a chronic shortage of Saudi
nurses. This has contributed to an increased demand for foreign nurses. One of the respondents reported in this regard, by saying:

"In our centre, like any other healthcare facility, nurses constitute the largest group of healthcare providers. Sadly, the majority of the nursing workforce in Saudi Arabia is from the Philippines." (P7)

In fact, there is no formalised training for diabetes care in Saudi Arabia. According to another physician:

"The health educators and the nurses here are not certified diabetes specialists. So, if the educator or nurse is not qualified, she will not be able to self-adjust insulin independent of the physician. The educators here deal with diabetes in general and cardiac problems." (P13)

As mentioned by the participants, many expatriate nurses did not speak Arabic which created a communication gap between the nurses and patients. In this regard, one of the physicians said:

"We have one Saudi nurse in the clinic. I can say that during her shift, I can see more patients as they communicate easily with her" (P3)

In light of the existing communication barrier, it can be said that the role of nurses in the management of T2DM is largely disregarded by the healthcare providers. One physician commented:

"We have competent nurses, but unfortunately, I could not rely on them for all the tasks due to the language barrier" (P14)

Moving to medical practice inside the clinics, it appears that in most of their practice, healthcare providers did not generally use treatment guidelines and protocols. However, some of the participants adopted different clinical guidelines in treating and managing the T2DM patient.

"I follow IDF international guidelines for type 2 diabetes..." (P6)

"With regard to achieving the target goal of care, we actually follow the American diabetes guidelines." (P12)
Although the Department of Non-communicable Diseases at the MOH made significant efforts to establish clinical guidelines for the diagnoses, treatment and management of T2DM for all providers in KSA health care system, these guidelines were not used by all participants. This was due mostly to the fact that the healthcare personnel were not aware of them as seen by these statements:

"We need a local framework and guidelines to guide the delivery of care in KSA" (P11)

"They will be a good addition if we had standardised guidelines adopted by all medical team." (P12)

"I have not heard about any national guidelines." (P15)

There was also a problem with the follow-up of patients. At the time of the study, doctors said they asked the patients to return for follow-up treatments, but very few patients did so. The problem seemed to be with a lack of guidance as well:

"Doctors do not have clear guidelines on how to follow up patients. When doctors refer the patients for treating diabetes, they just refer them and forget about it. There is no linked clinical system for the doctor to follow up with the lab or with the patient. The doctor will only know if the patient actually returns with the test results. In reality, it happens in only twenty percent of the time." (P5)

Although local diabetes clinical guidelines are available on the MOH website, it seemed like there was little knowledge of these guidelines by the clinical practitioners. The participant who was aware of the local guidelines was actually one of the team of editors of the document. According to him, there was a lack of an effective implementation strategy that included coordination to ensure proper dissemination and the training of the medical staff to use the guidelines. He said:

"These guidelines may not be optimally followed due to their poor dissemination. The MOH has to improve the relationship among all departments to better distribute our own clinical guidelines." (P3)

The general director of the diabetes centres added the absence of authority as the reason for the poor dissemination of the guidelines. He claimed that the national
guidelines had been distributed through means outside of his control and he had no role in their implementation. He said:

"It is the responsibility of the centres managers, it is not my fault if they did not perform any efforts in ensuring the implementation of the diabetes policy guidelines." (P3)

During the documentary analysis conducted for this study, the researcher identified the Saudi Arabia Diabetes Association as the only community organization for diabetics. Since one of the objectives of this study was to explore the role of the community in managing and preventing T2DM in KSA, this will now be discussed. In general, there appears to a lack of awareness of the diabetes community members and the medical practitioners in their views on the effectiveness of the role of community organizations as it applies to the control of diabetes. The Diabetes association was established 20 years ago in response to the increase in the number of diabetic patients in KSA. According to the general director of Saudi Arabia Diabetes Association:

"The number of people infected with diabetes in the Kingdom exceeded the most common diseases. It was estimated that the prevalence of diabetes was 25% of the population.....the establishment of the Saudi Diabetes Association was a serious attempt to contribute to a raising of the awareness in community." (P31)

The view expressed by the Diabetes Association members is that the healthcare system has a responsibility to detect, treat, and control diabetes cases in KSA, but the Association’s role was to prevent this disease. The same view was expressed by some of the participants interviewed:

"Our mission here is to reduce the load on the healthcare organization through providing health education, social, and psychological support." (P30)

"There are many activities run by the association ranging from public awareness campaigns to educating diabetics about the use of insulin pumps, and foot care."(P17)
"...Every year, we conduct health conferences, awareness campaigns at universities and schools, in addition to educating health counselors at schools." (P32)

In contrast, the view of the diabetes community organization held by the healthcare providers was different. According to an endocrinologist who had 25 years work experience:

"I haven't heard publicly about any diabetes community program." (P5)

This view, which was shared by several physicians, suggested that it was widely believed among the workers in the healthcare organizations that there was a lack of coordinating and partnership with community organizations. This can be seen from the following statements made by the workers:

"I am not really aware of any community support system. There might be, but I have not heard this publicly announced for any community programme." (P16)

"We need to create a community program in KSA, and I believe that there is a room for it." (P6)

"We need to recruit participants from the local community. People are not as used to talking to professionals and many do not understand medical practitioners. We need to recruit people who can talk to these patients in their language and in a manner they understand." (P8)

Only few of the participants from the group of healthcare providers knew about the diabetes community organization and these were actually members of it. As stated by one of the participants:

"We have an effective community program, but it is the only association in the Kingdom. How can it be expected to cover the numbers of diabetics in the region? "(P17)

In this section under discussion, the interviewees assessed the effectiveness of the healthcare system with regard to managing T2DM in KSA from four main perspectives: managerial, health practice, information technology, and the
community. In the next section, the interviewees provided recommendations for improving the support systems.

5.4 Improving the Support Systems for T2DM Patients

Finally, the respondents were asked for their recommendations on improving the support systems. All these clustered around four main areas with the foremost one being the strengthening of the role of the PHC services. Participants had previously talked about the overcrowding of the specialized clinics due to the inability of the PHC centers to examine and treat diabetics. They suggested that the MOH should pay more attention to PHC services in terms of:

"...an efficient PHC access for all patients to meet the patients’ needs allowing them to visit hospitals annually, if necessary." (P2)

Strengthening the PHC centers in KSA could improve their preventive services, according to one endocrinologist:

“The PHC certainly has to be improved by making sure that people are being screened appropriately, have regular HbA1c, lipids etc... I think that's probably the most significant change that we need.” (P8)

Furthermore, the respondents believed that training the PHC physicians could reduce the clinics’ workload:

"We see patients who are stable enough and do not need to be seen every one year, but they could be seen by a GP every 6 months, if we had trained GPs." (P1)

The shortage of qualified medical staff was not only limited to PHC services, but was also related to the qualified medical team in the clinics. Increasing training opportunities for these staff members in KSA would help to fill in this gap, as stated by some of the respondents:
"There is a huge number of diabetics, and so we need a corresponding increase in the number of personnel to be able to deliver the service in a more efficient way." (P12)

"The prevalence of diabetes is exploding, so we must match this by increasing the number of staff available for treating them." (P3)

"We need more health educators to tackle this problem. The number is far less than the standard" (P15)

In order to increase the number of qualified staff on the medical team, the respondents suggested the need to consider multi-sector collaboration between the MOH and the Ministry of Education. This idea was proffered by an endocrinologist who held an academic job and who said:

"We need to start teaching about such things in the medical schools because people just don’t know. We have a different approach to teaching medicine. We talk about the technical aspects, but we do not put enough emphasis on other approaches to teaching patients such as providing them any kind of support for self-treatment. If the doctors don’t know this, it is very unlikely that the patients would know. I think the best approach is that we include knowledge about such systems in the curriculum and then the new doctors coming from these colleges will know about it." (P7)

Another respondent made similar comments:

"Collaboration between health and education is definitely needed. But this could take a long time. There is a Saudi Medical board of lots of specialties and I think in some area of family medicine has an interest in chronic diseases" (P10)

The participants explained that seeing to it that the other allied medical staff, like the nurses and health educators, was qualified could also help to reduce the workload on the endocrinologist and, thus, shorten the waiting list:

This will cut the waiting list hugely because if you have four or five diabetes consultant nurses, they will be able to deal with most of diabetes issues, and to refer these patients to the endocrinologist only when needed. I think most of the time; they would not need to do this... If we promote the nurses to the highest level by making them consultants in their own right because it is a chronic disease about which they know quite a lot, then why don’t we go further and certify them for this? And they can even create this clinic in the community, the Saudi medical council needs to look into this. (P1)
Similarly, according to another physician:

Now we have a huge waiting list, and just one example, if the patient is on insulin at a level of, let's say 10, and the blood sugar is not controlled, it might be difficult for the patient to get an appointment soon enough to come to our clinic before the insulin rises from 10 to 14. But if we educate the nurses about how to do it, this will be more beneficial for us. (P8)

The other key narrative that emerged during the interviews was the need to build an integrated healthcare system. According to the respondents, the Saudi MOH has expressed its strong intention to develop a support system, but what has been missing was a plan than can be effectively implemented for the integration of all the strategies used to treat the disease. The participants used word like ‘continuity’, ‘coordination’, ‘fragmentation’ and ‘collaboration’ to express their suggestions regarding the need to shift the current healthcare paradigm toward a more integrated care. Here are two examples:

"Saudi health care system must guard against fragmented services." (P30)

"There is indeed a lack of synchronisation among various elements of the system; policy makers must work to develop a well-coordinated system" (P2)

According to the participants, an integration of the primary and secondary care services would be an important step in the continuity of care as seen here:

"There is no educated structure for the PHC to deliver care to patients in that community. Therefore, all of the patients in the hospital and, I think most of them, they don’t need to be here. I wish if we had an efficient healthcare system that integrated all healthcare levels and referral systems from tertiary to primary and vice versa." (P1)

"The model of shared care for diabetes would be very suitable and very successful in KSA in that, it entitled trained PHC physicians to deal with most of the patient with diabetes and only refer those who needed secondary or tertiary care to the hospitals." (P7)

However in order to enhance the collaboration between the different levels of the healthcare system, the respondents mentioned that it was crucial for the MOH to establish a multi-level information sharing system:
"Patients keep on changing doctors and hospitals with no system for tracking them. Now when a doctor sees a patient, he has no way of finding out his past history of treatment unless the patient himself reveals it. We need to have a coordinated system where each patient is recognised in the unified system and the doctor can immediately see the past history of the patient." (P17)

"We need to have one system where doctors can share information about the patients. This will make sure that each doctor is aware of all relevant factors affecting the patient he is treating." (P1)

The newly automated health information system in the specialised clinics was regarded as an important development in this direction, but it was not yet practical. One of the physicians who worked previously in Ireland commented that:

"I think, in my opinion, HE is not user-friendly. I struggled a lot to try to understand how it works. I worked before in Ireland with a system called (DIAMOND) which is an absolutely fantastic system where everything is incorporated into one screen. This includes medications, notes and the results of the retinal camera. It was a comprehensive database. For me, I would see 40 to 45 patients per session. So we can see a lot of patients because the system was efficient." (P14)

"I need a robust efficient HIS that allows me to audit my own practices and to see where I heading to..." (P8)

The participants explained that the development of the EMR would not only improve coordination between the various components of the health system, it would also become the cornerstone for creating an accurate national surveillance system and for effectively treating the disease as indicated by these statements:

"We need to start having big diabetes registry, knowing what the number of diabetic patients is and then tailor our program and adjust the resources to suit this big number." (P3)

"In order to develop an accurate diabetes registry, we have to upgrade the existing health information system." (P20)

"Reliable data are scarce so it is necessary to build the infrastructure for collecting patient information." (P19)
Finally, the last suggested solution from the participants was for the strengthening of community partnerships. The participants believe that T2DM management extended far beyond the clinic walls:

"We have new needs brought by new health problems, T2DM management is not limited to treatment and drugs, and it must integrate interventions on its causes and the environment within which this occurs." (P6)

"The MOH initiatives in managing any chronic disease must prioritise the health of the overall community, rather than only that of the single patient." (P15)

"T2DM does not start or end in the clinic; it extends beyond the healthcare facilities. And to successful managing diabetes, the government must strengthen community partnership which can fill the existing gap in the healthcare services." (P8)

The participants suggested the need to provide healthcare services that were more suited to the cultural context of the Saudi society. According to one of the participants:

"I agree that there is a need of such a system and the Ministry of Health also agrees. The problem is that we cannot simply take the systems from the West and try to implement them in Saudi Arabia. I have read hundreds of papers which ask for a culture-based approach and yet we keep on adopting systems which are formulated for Western countries and not Saudi Arabia." (P1)

Another respondent agreed and commented that:

"Many things that we invest the money in simply do not work here. What we need is someone who understands what works." (P33)

"Chronic diseases, including diabetes, compose a huge ratio of the disease burden in KSA. We need policies and an action plan that emphasize long-term and different levels of interventions." (P16)

Finally, the respondents suggested the establishment of dialogue with community members, particularly religious leader, in order to systematically provide people with information that can reduce the risk of developing T2DM. Healthcare workers reported earlier that public awareness was an important measure for preventing T2DM, and so the current healthcare system should be prepared to raise
the awareness of public and improve patients’ self-management. For example, every at Friday prayer, most of the Saudis watch the speech of the Imam before praying. Sending messages about healthy eating and the need for engagement in physical activity via this speech could spread the information publicly. This was also suggested by one of the endocrinologists and another participant:

"Who doesn't listen to the Friday sermon? I imagine, if the Imam speaks about that the importance of giving attention to well-being how much this will s impact on society!" (P12)

"For most of Saudis, like other Muslims, their religion affects all aspects of their lives. If Islamic power could be harnessed to increase cultural awareness in society, I think that will be very influential." (P7)

Another key social issue need to be considered, according to the participants, was motivating the community to become engaged more in physical activities. Some said:

"The government should direct municipality centre to create space for sports activities in every neighbourhood." (P31)

"The urban development policy is the main thing to blame. I see lot of constructions and posh houses, but in terms of sports and recreational facilities, all we have are a few patches of grass. Why don’t we provide indoor sports stadiums for our kids and even adults to engage in some form of physical activity?" (P20)

Another participant expressed the desire to have sport classes in female school when she said:

"I hope one day that physical sports classes are started in girls' schools, we are definitely in need of this." (P22)

"You also look at government policy. I don’t see a government policy which promotes an active lifestyle. We need proper coordination. So, I say the education policy should be formed to promote both physical and mental well-being among female students." (P31)

Overall, the participants suggested to need to strengthen the role of the PHC centres by training GPs and the medical workers. In order to achieve this, the participants believed that it was crucial to enhance the multi-sectorial collaboration
between the MOH and the Ministry of Education. In addition, building an integrated health care system was stressed by the interviewees as this was seen as the way to improve the relationship of the various aspects of the health information system and to bridge the existing gaps and to facilitate the development of a proper referral system. Lastly, the respondents believed that the policymakers should fight with the disease and not with the diabetic patients. In other words, the government should seeks ways of encouraging a healthy lifestyle among its people by providing sports facilities and improving public awareness through community partnerships.

5.5 Chapter Summary

This chapter presented an overview of the interviewees’ perceptions of the current KSA healthcare system in managing T2DM at the institutional level. Chapter 6, which immediately follows, will present the micro findings. These include the results of the patients’ experiences of diabetes management and their interactions with the healthcare providers.
Chapter 6: The Survey Findings

6.1. Introduction

This phase of the research explores the micro level of the T2DM in Saudi healthcare system by assessing the patients’ experience and their interactions with healthcare providers. In order to assess patient’s experience according to ICCC, the researcher applied exploratory descriptive analysis using PACIC-5As survey. The justification of using quantitative method was described previously in chapter 4. (Appendix E). The original PACIC-5As instrument was mapped to CCM (Wagner, 1998). The researcher instead, mapped this to ICCC framework (WHO, 2002; Epping-Jordan et al., 2004) (Table 22)

The primary purpose of collecting these data was to explore the patients’ experience in terms of the interaction between the healthcare system and their support in managing T2DM in KSA.

The specific healthcare system support for the ICCC framework studied is:

- Patient self-management
- Health information system
- Health service organisation
- Community support
Table 22. Mapping of PACIC-5As subscales onto the ICCC study elements

<table>
<thead>
<tr>
<th>The PACIC and Subscales</th>
<th>Definition</th>
<th>The ICCC Components</th>
<th>Assesses the patient’s experience on the extent to which…</th>
</tr>
</thead>
<tbody>
<tr>
<td>PACIC (Items 1-20)</td>
<td>A survey instrument that measuring specific actions of care congruent with ICCC</td>
<td>The care is congruent with the ICCC</td>
<td></td>
</tr>
<tr>
<td>Patient Activation (Items 1-3)</td>
<td>Enabling patient participation in their care.</td>
<td>Self-Management Support</td>
<td>The healthcare team motivated and supported the patient to be involved in decision making and the process of care</td>
</tr>
<tr>
<td>Delivery System Design/ Decision Support (Items 4-6)</td>
<td>Promoting clinical care that is consistent with scientific evidence by sharing information with patients.</td>
<td>Health Information System</td>
<td>The patient is satisfied with the organization of the healthcare; the patient received information/support to manage his or her condition and improve his or her health</td>
</tr>
<tr>
<td>Goal Setting/Tailoring (Items 7-11)</td>
<td>Establishing goals and plans with patients to better manage their chronic condition.</td>
<td>Self-Management Support</td>
<td>Health-related instructions and suggestions were adapted to the patient’s personal situation</td>
</tr>
<tr>
<td>Problem Solving/ Contextual (Items 12-15)</td>
<td>Managing health beyond their medical care.</td>
<td>Self-Management Support</td>
<td>The healthcare team helped the patient to deal with problems that interfered with achieving pre-defined goals</td>
</tr>
<tr>
<td>Follow-up/Coordination (Items 16-20)</td>
<td>Linking patients with other healthcare services.</td>
<td>Health Service Organization</td>
<td>The care is coordinated with referrals and follow-up visits</td>
</tr>
<tr>
<td>5As (Items 1-4 &amp; 6-16)</td>
<td>A patient-centered model of behavioral counseling that is congruent with the ICCC.</td>
<td>The patient and healthcare providers interaction is congruent with the Behavior Change Model</td>
<td></td>
</tr>
<tr>
<td>Assess (Items 1,11,15,20,21)</td>
<td>Assessing patients’ level of behavior, beliefs and motivation.</td>
<td>Self-management support</td>
<td>The healthcare team explored patients’ beliefs, behavior and knowledge.</td>
</tr>
<tr>
<td>Advise (Items 4,6,9,19,24)</td>
<td>Advising the patient based upon personal health risks.</td>
<td>Health information system</td>
<td>The healthcare team provided information about health risks and the benefits of change</td>
</tr>
<tr>
<td>Agree (Items 2,3,7,8,25)</td>
<td>Agreeing with the patient on a realistic set of goals.</td>
<td>Self-management support</td>
<td>The healthcare team collaboratively set goals based on the patient’s interest</td>
</tr>
<tr>
<td>Assist (Items 10,12,13,14,26)</td>
<td>Assisting to anticipate barriers and develop a specific action plan.</td>
<td>Community support</td>
<td>The healthcare team identified personal barriers and social/environmental support</td>
</tr>
<tr>
<td>Arrange (Items 16,17,18,22,23)</td>
<td>Arranging follow-up support.</td>
<td>Health service organization</td>
<td>The healthcare team specified plan for follow-up (e.g., visits, phone calls, mailed reminders)</td>
</tr>
</tbody>
</table>

Source Glasgow et al, 2003; Glasgow et al, 2005a; Glasgow et al, 2005b.
6.2 Psychometric validation

The PACIC-5As was translated from Arabic to English following the steps for instrument translation recommended by WHO and which also included analysing the validity of the translated instrument (WHO, 2008) (chapter 4). Following these steps, the researcher performed psychometric validation of the PACIC in terms of stability, internal consistency, and confirmatory factor analysis.

6.2.1 Internal consistency (Cronbach’s alpha) analysis

To assess the internal consistency of the instrument, Cronbach’s alpha ($\alpha$) was estimated where the acceptable level of $\alpha$ is ranged between .7 and .8. For the overall A-PACIC questionnaire, the Cronbach’s alpha $\alpha$ was .93 (Table 23). The Cronbach’s $\alpha$ was the same for the original Danish version and higher than the Indian and Spanish translated version. The Cronbach’s $\alpha$ scores for the original Danish, Indian, and Spanish versions were .93, .93, .80 and .87, respectively. Cronbach’s $\alpha$ scores for the subscales varied from .70 to .90 for the Arabic version (Glasgow et al., 2005a; Aragones et al., 2008; Maindal et al., 2012; Koley et al., 2015).

<table>
<thead>
<tr>
<th>Scale</th>
<th>Cronbach’s $\alpha$</th>
<th>N of Items</th>
</tr>
</thead>
<tbody>
<tr>
<td>PACIC</td>
<td>0.93</td>
<td>20</td>
</tr>
<tr>
<td>Patient activation</td>
<td>0.76</td>
<td>3</td>
</tr>
<tr>
<td>Delivery system/practice design</td>
<td>0.79</td>
<td>3</td>
</tr>
<tr>
<td>Goal setting/ tailoring</td>
<td>0.74</td>
<td>5</td>
</tr>
<tr>
<td>Problem-solving/contextual follow-up/</td>
<td>0.77</td>
<td>4</td>
</tr>
<tr>
<td>coordination</td>
<td>0.82</td>
<td>5</td>
</tr>
<tr>
<td>5As</td>
<td>0.90</td>
<td>15</td>
</tr>
<tr>
<td>Assess</td>
<td>0.70</td>
<td>5</td>
</tr>
<tr>
<td>Agree</td>
<td>0.78</td>
<td>5</td>
</tr>
<tr>
<td>Advise</td>
<td>0.79</td>
<td>5</td>
</tr>
<tr>
<td>Assist</td>
<td>0.72</td>
<td>5</td>
</tr>
<tr>
<td>Arrange</td>
<td>0.79</td>
<td>5</td>
</tr>
</tbody>
</table>
6.2.2 Pre-testing stability (test-retest analysis)

Test-retest analysis was undertaken to evaluate the stability of the PACIC over one week (Table 24). Twenty-five participants completed the questionnaire twice. The outcome of this test showed a statistically significant reliability score \( r = 0.912, p = < 0.001 \). The Arabic PACIC-5A version showed a higher reliability score than the original Spanish and Indian versions. Pearson correlation scores were 0.58, 0.77, and 0.74 respectively (Glasgow et al., 2005a: Aragones et al., 2008: Koley et al., 2015). The Arabic version of the instrument displayed a higher test-retest score than the original instrument because of the long interval (3 months) between the two measurements points used in the study. As expected, a reduction of the time delay to one week in this study resulted in an increased test-retest reliability.

<table>
<thead>
<tr>
<th>Correlations</th>
<th>Correlation</th>
<th>Sig. (2-tailed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Test-retest-Pearson Correlation</td>
<td>.91</td>
<td>.00</td>
</tr>
</tbody>
</table>

6.2.3 Inter-item correlation

The average inter-item correlation ranged from .36 to .56. Item-rest correlation (internal item convergence) ranged from .35 to .75 which is considered as a good correlation where the acceptable level of consistency ranged from .20 and .40 (Munro, 2005) (Table 25). The average mean inter-item correlation for the Arabic instrument was similar to the Danish version, except the goal-setting and the problem-solving scales were lower than the Danish version. The Arabic version gives a score of .36 for the goal-setting scale and .46 for the problem-solving scale; while the Danish version gives .46 and .60 scores for the same scales, respectively (Maindal et al., 2012).
Table 25. Correlation between items and (i) the rest of the items in its own scale (item-rest correlation) and (ii) the other subscales (scale 1-5)

<table>
<thead>
<tr>
<th>While receiving medical care for my diabetes over the past six months, I was:</th>
<th>Item-rest</th>
<th>Scale 1</th>
<th>Scale 2</th>
<th>Scale 3</th>
<th>Scale 4</th>
<th>Scale 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scale 1 (Patient activation) inter-item correlation = 0.52</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Item 1</td>
<td>0.60</td>
<td>-</td>
<td>0.38</td>
<td>0.45</td>
<td>0.38</td>
<td>0.20</td>
</tr>
<tr>
<td>Item 2</td>
<td>0.65</td>
<td>-</td>
<td>0.45</td>
<td>0.51</td>
<td>0.48</td>
<td>0.32</td>
</tr>
<tr>
<td>Item 3</td>
<td>0.60</td>
<td>-</td>
<td>0.56</td>
<td>0.45</td>
<td>0.50</td>
<td>0.31</td>
</tr>
<tr>
<td>Scale 2 (Delivery system design/decision support) inter-item correlation = 0.56</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Item 4</td>
<td>0.54</td>
<td>0.54</td>
<td>-</td>
<td>0.53</td>
<td>0.53</td>
<td>0.47</td>
</tr>
<tr>
<td>Item 5</td>
<td>0.71</td>
<td>0.43</td>
<td>-</td>
<td>0.49</td>
<td>0.60</td>
<td>0.53</td>
</tr>
<tr>
<td>Item 6</td>
<td>0.73</td>
<td>0.46</td>
<td>-</td>
<td>0.50</td>
<td>0.58</td>
<td>0.56</td>
</tr>
<tr>
<td>Scale 3 (Goal setting/tailoring) inter-item correlation = 0.36</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Item 7</td>
<td>0.59</td>
<td>0.65</td>
<td>0.60</td>
<td>-</td>
<td>0.58</td>
<td>0.49</td>
</tr>
<tr>
<td>Item 8</td>
<td>0.71</td>
<td>0.45</td>
<td>0.57</td>
<td>-</td>
<td>0.68</td>
<td>0.52</td>
</tr>
<tr>
<td>Item 9</td>
<td>0.61</td>
<td>0.45</td>
<td>0.61</td>
<td>-</td>
<td>0.52</td>
<td>0.54</td>
</tr>
<tr>
<td>Item 10</td>
<td>0.53</td>
<td>0.18</td>
<td>0.21</td>
<td>-</td>
<td>0.44</td>
<td>0.49</td>
</tr>
<tr>
<td>Item 11</td>
<td>0.35</td>
<td>0.25</td>
<td>0.09</td>
<td>-</td>
<td>0.33</td>
<td>0.33</td>
</tr>
<tr>
<td>Scale 4 (Problem solving/contextual) inter-item correlation = 0.46</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Item 12</td>
<td>0.45</td>
<td>0.26</td>
<td>0.36</td>
<td>0.35</td>
<td>-</td>
<td>0.50</td>
</tr>
<tr>
<td>Item 13</td>
<td>0.74</td>
<td>0.55</td>
<td>0.54</td>
<td>0.72</td>
<td>-</td>
<td>0.55</td>
</tr>
<tr>
<td>Item 14</td>
<td>0.73</td>
<td>0.50</td>
<td>0.71</td>
<td>0.62</td>
<td>-</td>
<td>0.62</td>
</tr>
<tr>
<td>Item 15</td>
<td>0.62</td>
<td>0.40</td>
<td>0.49</td>
<td>0.57</td>
<td>-</td>
<td>0.46</td>
</tr>
<tr>
<td>Scale 5 (Follow-up/coordination) inter-item correlation = 0.48</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Item 16</td>
<td>0.70</td>
<td>0.17</td>
<td>0.24</td>
<td>0.43</td>
<td>0.43</td>
<td>-</td>
</tr>
<tr>
<td>Item 17</td>
<td>0.66</td>
<td>0.33</td>
<td>0.42</td>
<td>0.60</td>
<td>0.53</td>
<td>-</td>
</tr>
<tr>
<td>Item 18</td>
<td>0.63</td>
<td>0.25</td>
<td>0.38</td>
<td>0.52</td>
<td>0.44</td>
<td>-</td>
</tr>
<tr>
<td>Item 19</td>
<td>0.72</td>
<td>0.21</td>
<td>0.61</td>
<td>0.45</td>
<td>0.56</td>
<td>-</td>
</tr>
<tr>
<td>Item 20</td>
<td>0.75</td>
<td>0.36</td>
<td>0.64</td>
<td>0.61</td>
<td>0.65</td>
<td>-</td>
</tr>
</tbody>
</table>

6.2.4 Conformity factor analysis

The psychometric elements of the PACIC were examined in two parts. The less sensitive, additional-fit indices are recommended (using the non-centrality parameter and taking into account sample size and the degrees of freedom) (Spicer et al, 2010).

Comparative fit index (CFI) assesses fit relative to a null model and ranges from 0 to 1 with values of 0.90–0.95 indicating acceptable and over 0.95 good fit.

Tucker Lewis index (TLI) adjusts for the number of model parameters and is interpreted as CFI.
Root mean square error of approximation (RMSEA) expresses the lack of fit per degree of freedom of the model. Values are interpreted as follows: $\leq 0.05$ indicates very good, $0.05 - 0.08$ good, and $\geq 0.10$ poor fit.

Standardized root mean square residual (SRMR) is the average of the differences between the observed and predicted correlations and has a range from 0 to 1. Values of $<0.08$ indicate good fit.

The CFA showed that, in terms of factor analysis, there was a bad fit between the questions and specific subscales (Table 26). Spicer and colleagues (2010) deem the PACIC to be a formative as opposed to reflective measure, where formative measures are not expected to correlate unlike the reflective measure which are expected to have a good CFA fit between the instrument items and the subscales which, however, invalidates traditional analyses and the validity of factors (and internal consistency). Eight prior studies attempted to evaluate the structure of PACIC, but only two studies identified a good model fit for a five-factor structure (Aung et al., 2014).

Table 26. The model statistics of the CFA of the Arabic version of the PACIC questionnaire

<table>
<thead>
<tr>
<th>Statistics</th>
<th>$\chi^2$</th>
<th>Df</th>
<th>P</th>
<th>CFI</th>
<th>TLI</th>
<th>RMSEA</th>
<th>SRMR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Model fit for basic model with 5</td>
<td>5698.72</td>
<td>190</td>
<td>&lt;0.00</td>
<td>0.69</td>
<td>0.64</td>
<td>0.16</td>
<td>0.08</td>
</tr>
<tr>
<td>dimensions</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Number of free parameters=50. CFI (reference: 0.90–0.95 = acceptable, >0.95 = good). TLI (reference: 0.90–0.95 = acceptable, >0.95 = good). RMSEA (reference: ≤ 0.05 = good, ≥ 0.10 = poor fit). SRMR = standardized root mean square residual (reference: <0.08 = good fit).

In conclusion, a comparison of the results of the Arabic PACIC with the Indian and Spanish versions shows the Arabic version to be more reliable and valid. Moreover, it was expected that the form of Arabic language used in the A-PACIC
would make it suitable for use in all Arabic-speaking countries (taking into consideration the potential need for further validation).

6.3 Participants’ Characteristics
The sample was recruited from diabetes healthcare centres in Riyadh. The convenience sampling approach involved simultaneously recruiting patients from three clinics over the period of ten weeks. All clinics were public and hospital-based and provided standard care to people with T1DM and T2DM (GPs do not provide diabetes care in Riyadh). The goal was to obtain a representative sample of adults with diabetes. All patients (1,743) were offered the questionnaire, 63% of the patients declined to complete the questionnaire, while 641 patients (36%) accepted it, but only 89% of these fully completed it.

As Table 27 shows, the majority of the participants were men (62%) with almost 48% between 40 and 59 years old. More than half of the participants had a university degree and 73% from the total sample were married. Seventy per cent of the recruited sample had been diagnosed with T2DM and almost 60% had been diagnosed for more than four years. Only 15% of the participants were smokers and medical complications had already affected 20% of the participants in the form of retinopathy (14.9%), cardiovascular disease (3.1%), renal disease (1.6%), amputations (0.2%), and skin ulcers (0.7%). The participants were asked to write down their last HbA1c and/or fasting glucoses level, only 5.9% of them record the numbers while the majority classified themselves as being in the controlled or uncontrolled glycaemic group. However, the results showed that only 99 (17.8%) participants had controlled levels of blood glucose, while 458 (82.2%) participants displayed uncontrolled levels of the same. Controlled was defined as having an HbA1c level equal to or below 7% (ADA, 2008).
Table 27. Characteristics of DM patients (n=575)

<table>
<thead>
<tr>
<th>Patient Characteristics</th>
<th>N (575)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sociodemographic Characteristics</strong></td>
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<td>18–39</td>
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<td>40–59</td>
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<td>Post Graduate</td>
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<td><strong>Medical Characteristics</strong></td>
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<td>T1DM</td>
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<td>T2DM</td>
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<td>72</td>
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<td>Pregnancy</td>
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<tr>
<td>Don’t know</td>
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<td>9.2</td>
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<tr>
<td>Duration Of DM</td>
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<tr>
<td>&lt; 1 Year</td>
<td>70</td>
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<tr>
<td>2–3 Years</td>
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<td>15.6</td>
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<td>4–10 Years</td>
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<td>&gt; 10 Years</td>
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<td>Treatment Status</td>
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<td>Using Insulin</td>
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<td>Taking Oral</td>
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<tr>
<td>Complications</td>
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<td>Cardiovascular Disease</td>
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<td>3.1</td>
</tr>
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<td>Renal Disease</td>
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<td>1.6</td>
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<tr>
<td>Diabetic retinopathy or other visual problem</td>
<td>83</td>
<td>14.9</td>
</tr>
<tr>
<td>Amputations</td>
<td>1</td>
<td>0.2</td>
</tr>
<tr>
<td>Skin Ulcers</td>
<td>4</td>
<td>0.7</td>
</tr>
<tr>
<td>Nothing</td>
<td>443</td>
<td>79.5</td>
</tr>
<tr>
<td>Do You Smoke?</td>
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<td></td>
</tr>
<tr>
<td>Yes</td>
<td>88</td>
<td>15.8</td>
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<tr>
<td>No</td>
<td>469</td>
<td>84.2</td>
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<tr>
<td>Blood Control</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Controlled</td>
<td>99</td>
<td>17.8</td>
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<tr>
<td>Uncontrolled</td>
<td>458</td>
<td>82.2</td>
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</table>

6.4 The PACIC-5As scores

The results based on the mean score of PACIC-5A in this study are provided in Figure 13 and Table 28 presents descriptive statistics for the 26 PACIC-5A items grouped into the 5 factorial domains as proposed by Glasgow and colleagues
The achievement level of each of these items was rated by patients on a 5-point rating scale with the following anchors: Almost never (1), generally not (2), Sometimes (3), Most of the time (4), Always (5). The overall PACIC-5A score was 2.52 (.74), with individual items ranging between 1.31 (.59) for item 17 "Encouraged to attend programmes in the community that could help me" to 3.44 (1.25) for item 6 “Shown how what I did to take care of my illness influenced my condition.”

Mean scores of PACIC scale and subscales in a study population with DM (557)

<table>
<thead>
<tr>
<th>Mean (SD)</th>
<th>Poor</th>
<th>Average</th>
<th>Good</th>
<th>Very Good</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall PACIC</td>
<td>2.52 (.74)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient activation</td>
<td>2.69 (1.0)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Delivery system design/decision support</td>
<td>3.02 (1.0)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Goal setting/tailoring</td>
<td>2.29 (.76)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Problem solving/contextual</td>
<td>2.84 (1.0)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Follow-up/coordination</td>
<td>2.10 (.76)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overall 5 As</td>
<td>2.58 (.76)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Assess</td>
<td>2.62 (0.83)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Advice</td>
<td>2.84 (0.95)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Agree</td>
<td>2.62 (0.84)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Assist</td>
<td>2.48 (0.76)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Arrange</td>
<td>1.89 (0.64)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Figure 13 Distribution of PACIC-5As mean scores

When the scores are viewed as grouped into the five predetermined domains, they ranged between 2.10 (.76) for “Follow-up/coordination” and 3.02 (1.15) for “Delivery system design/decision” (Table 28). The mean score of the PACIC-5As scales and subscales ranging from 1 to 5 were categorized into 4 groups: Poor (≥ 1.95), Average (2 ≤ 2.95), Good (3 ≤ 3.95), and Very good (≤ 4). Regarding the overall PACIC-5A score, less than 30% of the patients reported that they had received
good healthcare services (mean score 3 or more out of 5). Around 60% of the
participants reported that the ways that care was organised and the information
provided to them to enhance their understanding of care (Delivery System
Design/Decision Support) were good level in diabetes centres. Around 60% of the
patients reported that their healthcare providers extensively considered their social
and cultural environments as well as barriers to making treatment plans (Problem
solving/Contextual), while less than 50% of participants reported that they were
actively involved in decision-making (Patient activation), and only around 20% of the
patients reported that they were likely to set specific, collaborative goals with their
healthcare providers (Goal Setting/Tailoring). Finally, less than 15% of participants
had proactive contact with their healthcare teams in order to assess progress and
coordinate care (Follow-up/Coordination).
The instrument included additional items to assess the extent to which healthcare provided counselling that reflected the 5As approach. The overall mean 5A score was 2.5 out of a possible 5 and all of the subscale scores were below the centre point of the scale, ranging from 1.89 (.64) for “Arrange” to 2.84 (.95) for “Advice”. In general, patients were unlikely to receive arrangement of follow-up support and assistance with problem-solving with: "mean scores for subscale “Arrange” and “Assist” being 1.89 and 2.48, respectively". In comparison, around half of the patients

<table>
<thead>
<tr>
<th>Table 28 Mean scores for PACIC-5As items in a study population with DM (557)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Over the past 6 months, when receiving medical care for my diabetes, I was:</td>
</tr>
<tr>
<td><strong>Patient Activation</strong></td>
</tr>
<tr>
<td>1. Asked for my ideas when we made a treatment plan.</td>
</tr>
<tr>
<td>2. Given choices about treatment to think about.</td>
</tr>
<tr>
<td>3. Asked to talk about any problems with my medicines or their effects.</td>
</tr>
<tr>
<td><strong>Delivery System/Practice Design</strong></td>
</tr>
<tr>
<td>4. Given a written list of things I should do to improve my health.</td>
</tr>
<tr>
<td>5. Satisfied that my care was well-organised.</td>
</tr>
<tr>
<td>6. Shown how what I did to take care of my illness influenced my condition.</td>
</tr>
<tr>
<td><strong>Goal Setting/Tailoring</strong></td>
</tr>
<tr>
<td>7. Asked to talk about my goals in caring for my illness.</td>
</tr>
<tr>
<td>8. Helped to set specific goals to improve my eating or exercise.</td>
</tr>
<tr>
<td>9. Given a copy of my treatment plan.</td>
</tr>
<tr>
<td>10. Encouraged to go to a specific group or class to help me cope with my chronic illness.</td>
</tr>
<tr>
<td>11. Asked questions, either directly or on a survey, about my health habits.</td>
</tr>
<tr>
<td><strong>Problem-solving</strong></td>
</tr>
<tr>
<td>12. Sure that my doctor or nurse thought about my values and my traditions when they recommended treatments to me.</td>
</tr>
<tr>
<td>13. Helped to make a treatment plan that I could carry out in my daily life.</td>
</tr>
<tr>
<td>14. Helped to plan ahead so I could take care of my illness, even in hard times.</td>
</tr>
<tr>
<td>15. Asked how my chronic illness affects my life.</td>
</tr>
<tr>
<td><strong>Follow-up/Coordination</strong></td>
</tr>
<tr>
<td>16. Contacted after a visit to see how things were going.</td>
</tr>
<tr>
<td>17. Encouraged to attend programmes in the community that could help me.</td>
</tr>
<tr>
<td>18. Referred to a dietitian, health educator, or counsellor.</td>
</tr>
<tr>
<td>19. Told how my visits with other types of doctors, an eye doctor or surgeon, helped my treatment.</td>
</tr>
<tr>
<td>20. Asked how my visits with other doctors were going.</td>
</tr>
<tr>
<td><strong>5As Additional Items</strong></td>
</tr>
<tr>
<td>21. Asked what I would like to discuss about my illness at that visit.</td>
</tr>
<tr>
<td>22. Asked how my work, family, or social situation related to taking care of my illness.</td>
</tr>
<tr>
<td>23. Helped to make plans for how to support from my friends, family, or community.</td>
</tr>
<tr>
<td>24. Told how important the things I do to take care of my illness (e.g., exercise) were for my health.</td>
</tr>
<tr>
<td>25. Set a goal together with my team for what I could do to manage my condition.</td>
</tr>
<tr>
<td>26. Given a book or monitoring log in which to record the progress I am making.</td>
</tr>
</tbody>
</table>

The instrument included additional items to assess the extent to which healthcare provided counselling that reflected the 5As approach. The overall mean 5A score was 2.5 out of a possible 5 and all of the subscale scores were below the centre point of the scale, ranging from 1.89 (.64) for “Arrange” to 2.84 (.95) for “Advice”. In general, patients were unlikely to receive arrangement of follow-up support and assistance with problem-solving with: "mean scores for subscale “Arrange” and “Assist” being 1.89 and 2.48, respectively". In comparison, around half of the patients...
reported that they received a high level of advice from physicians regarding their particular health risks, while about 60% of them are unlikely to contact their healthcare providers to seek continued assistance and collaboratively set goals with physicians based on their interests. The mean scores for the “Assess” and “Agree” scales were 2.62. Furthermore, compared to different data for diabetic patients from USA, Germany, and Switzerland with the current study sample, showed that Saudi patients fell short in receiving aspects of care on the sum-score and all subscales of the PACIC-5A and the 5As in the tertiary diabetes healthcare settings (Table 29).

Table 29. Results for PACIC summary score, 5A summary score and PACIC subscales in comparison to the original data and international studies

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<th></th>
<th></th>
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<tbody>
<tr>
<td>KSA</td>
<td>Glasglow et al. (2005a)</td>
<td>USA</td>
<td>Germany</td>
<td>Switzerland</td>
</tr>
<tr>
<td>n=575 T2DM 72%, F 37.5%, college graduate 71.8%, complications 20.5%</td>
<td>n = 336, T2DM 100%, F 47.2%, college graduate 32%, complications 61%</td>
<td>n = 864, T2DM 100%, F 53%, college graduate 61%, complications 70%</td>
<td>n= 326, T2DM 100%, Mean education years 11.6</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>PACIC summary score</th>
<th>Mean (SD)</th>
<th>Mean (SD)</th>
<th>Mean (SD)</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient activation</td>
<td>2.69 (1.0)</td>
<td>3.6 (1.1)</td>
<td>3.26 (1.2)</td>
<td>3.83 (1.13)</td>
</tr>
<tr>
<td>Delivery system design</td>
<td>3.02 (1.0)</td>
<td>3.5 (0.9)</td>
<td>3.52 (0.9)</td>
<td>3.87 (0.82)</td>
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<tr>
<td>Goal-setting/tailoring</td>
<td>2.29 (0.76)</td>
<td>3.0 (1.0)</td>
<td>2.91 (1.1)</td>
<td>2.86 (0.98)</td>
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<tr>
<td>Problem-solving/contextual</td>
<td>2.84 (1.0)</td>
<td>3.4 (1.1)</td>
<td>3.39 (1.2)</td>
<td>3.26 (1.22)</td>
</tr>
<tr>
<td>Follow-up/coordination</td>
<td>2.10 (0.76)</td>
<td>2.9 (1.0)</td>
<td>3.13 (1.1)</td>
<td>3.26 (1.22)</td>
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<table>
<thead>
<tr>
<th>5A summary score</th>
<th>Mean (SD)</th>
<th>Mean (SD)</th>
<th>Mean (SD)</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assess</td>
<td>2.62 (0.83)</td>
<td>3.3 (1.0)</td>
<td>3.26 (1.1)</td>
<td>3.20 (1.07)</td>
</tr>
<tr>
<td>Agree</td>
<td>2.62 (0.84)</td>
<td>3.4 (1.0)</td>
<td>3.24 (1.1)</td>
<td>3.68 (0.96)</td>
</tr>
<tr>
<td>Advice</td>
<td>2.84 (0.95)</td>
<td>3.3 (1.0)</td>
<td>3.32 (0.9)</td>
<td>3.22 (0.91)</td>
</tr>
<tr>
<td>Assist</td>
<td>2.48 (0.76)</td>
<td>3.1 (1.0)</td>
<td>3.21 (1.1)</td>
<td>2.98 (1.05)</td>
</tr>
<tr>
<td>Arrange</td>
<td>1.89 (0.64)</td>
<td>2.7 (1.0)</td>
<td>2.87 (1.0)</td>
<td>2.51 (1.05)</td>
</tr>
</tbody>
</table>

Differences in the ICCC study dimensions according to consistent low or high PACIC-5As scores are presented in Figure 14. Continuous PACIC-5A scores were dichotomized at the mid-point – (≥3) for high PACIC-5A and <3 for low PACIC-5A – to differentiate between the participants who reported receiving chronic care elements ‘some of the time’ or more on average and those who reported receiving it
less frequently than the identified mid-point. Although it would be ideal to receive the various practices of care ‘most of the time’ on average (the PACIC-5A score of 4) or more frequently in theory, the overall PACIC-5A score was <3 in the current study. Overall, the majority of patients reported low PACIC-5A scores. However, when categorising these scores according to the study dimensions, the health service organisation ranked as the lowest mean where more than 90% of patients reported that the healthcare services was poorly organised which indicates that the care provided was not coordinated with referrals and the healthcare team did not have a specific plan for follow-up. Similarly, the healthcare team did not identify any community support (80%) for the participant who scored a low level on the “Assist” scale. In addition, more than 60% of the patients reported that they did not receive effective self-management support. On other hand, the highest score related to the health information system where almost half of the participants said they received information on how to manage their condition.
Figure 14: ICCC dimensions according to consistent low (<3) and high (≥ 3) PACIC-5As scores
6.5 The Relationship between demographics and medical characteristics

Differences in patient characteristics according to consistent low or high PACIC-5As scores are presented in Table 30. Continuous PACIC-5A scores were dichotomized at the mid-point – (≥3) for high PACIC-5A and <3 for low PACIC-5A.

Figure 15: Patient demographic characteristics according to consistent low (<3) and high (≥ 3) PACIC scores

Regardless of the patient’s characteristics, overall, the PACIC-5A is quite low in all of the patients’ demographic characteristics as the majority of the participants (more than 70%) reported as low level in the PACIC-5A score (Figures 15 and 16).
Figure 16: Patient disease characteristics according to consistent low (<3) and high (≥3) PACIC scores

Socio-demographic and clinical characteristics are presented by mean values and standard deviations in Table 30. As shown in the table, smoking status and glycaemic control levels were the only patient characteristics that correlated with the PACIC-5A scales. No other demographic or medical condition variable was consistently related to the PACIC-5A scales (p value <0.05). In order to explore the data findings further, a chi-square test was conducted to examine the difference between high (≥3) and low (<3) values of the PACIC-5As scales with regard to the status and glycaemic control variables (Tables 31 and 32).
Table 30. PACIC-5As scores according to population characteristics

<table>
<thead>
<tr>
<th>Patient Characteristics</th>
<th>PACIC Mean</th>
<th>PACIC SD</th>
<th>P</th>
<th>5As Mean</th>
<th>5As SD</th>
<th>P</th>
</tr>
</thead>
<tbody>
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<td>Gender</td>
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<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>2.55</td>
<td>0.73</td>
<td>0.23</td>
<td>2.63</td>
<td>0.75</td>
<td>0.07</td>
</tr>
<tr>
<td>Female</td>
<td>2.47</td>
<td>0.75</td>
<td></td>
<td>2.51</td>
<td>0.77</td>
<td></td>
</tr>
<tr>
<td>Age</td>
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<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>&gt;18</td>
<td>2.32</td>
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<td>0.14</td>
<td>2.50</td>
<td>.047</td>
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<tr>
<td>18–39</td>
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<td>2.67</td>
<td>.71</td>
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<tr>
<td>40–59</td>
<td>2.39</td>
<td>.74</td>
<td></td>
<td>2.43</td>
<td>.76</td>
<td></td>
</tr>
<tr>
<td>&lt;60</td>
<td>3.28</td>
<td>.85</td>
<td></td>
<td>2.92</td>
<td>.86</td>
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<td>Marital Status</td>
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<td>Single</td>
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<td>0.62</td>
<td>2.67</td>
<td>.69</td>
<td>0.56</td>
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<tr>
<td>Married</td>
<td>2.49</td>
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<td>2.54</td>
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<tr>
<td>Divorced</td>
<td>3.15</td>
<td>.43</td>
<td></td>
<td>3.34</td>
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<td>Lower Than High School</td>
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<td>2.83</td>
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<td>Diabetes type</td>
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<tr>
<td>T1DM</td>
<td>2.68</td>
<td>.62</td>
<td>0.39</td>
<td>2.73</td>
<td>.62</td>
<td>0.06</td>
</tr>
<tr>
<td>T2DM</td>
<td>2.51</td>
<td>.77</td>
<td></td>
<td>2.56</td>
<td>.80</td>
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</tr>
<tr>
<td>Duration Of DM</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 1 Year</td>
<td>2.76</td>
<td>.72</td>
<td>0.17</td>
<td>2.85</td>
<td>.71</td>
<td>0.23</td>
</tr>
<tr>
<td>2–3 Years</td>
<td>2.18</td>
<td>.88</td>
<td></td>
<td>2.21</td>
<td>.90</td>
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<tr>
<td>4–10 Years</td>
<td>2.57</td>
<td>.64</td>
<td></td>
<td>2.62</td>
<td>.65</td>
<td></td>
</tr>
<tr>
<td>&gt; 10 Years</td>
<td>2.45</td>
<td>.72</td>
<td></td>
<td>2.61</td>
<td>.67</td>
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</tr>
<tr>
<td>Smoking status</td>
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<tr>
<td>Smoker</td>
<td>2.67</td>
<td>.64</td>
<td>0.04</td>
<td>2.72</td>
<td>.51</td>
<td>0.05</td>
</tr>
<tr>
<td>Non-smoker</td>
<td>2.50</td>
<td>.78</td>
<td></td>
<td>2.56</td>
<td>.88</td>
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</tr>
<tr>
<td>Complications</td>
<td></td>
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</tr>
<tr>
<td>Complications</td>
<td>2.47</td>
<td>0.75</td>
<td>0.60</td>
<td>2.48</td>
<td>0.71</td>
<td>0.96</td>
</tr>
<tr>
<td>No complications</td>
<td>2.54</td>
<td>0.76</td>
<td></td>
<td>2.61</td>
<td>0.74</td>
<td></td>
</tr>
<tr>
<td>Blood Control</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Controlled</td>
<td>2.70</td>
<td>0.61</td>
<td>0.04</td>
<td>2.74</td>
<td>0.65</td>
<td>0.04</td>
</tr>
<tr>
<td>Uncontrolled</td>
<td>2.48</td>
<td>0.76</td>
<td></td>
<td>2.55</td>
<td>0.78</td>
<td></td>
</tr>
</tbody>
</table>
Table 31. Glycaemic control level according to consistent low (<3) and high(≥ 3) PACIC scores

<table>
<thead>
<tr>
<th>PACIC summary score</th>
<th>Controlled N (%)</th>
<th>Uncontrolled N (%)</th>
<th>$\chi^2$</th>
<th>df</th>
<th>Effect size</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>PACIC summary score</td>
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<td></td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>High</td>
<td>33 (33.3%)</td>
<td>106 (23.1%)</td>
<td>4.51</td>
<td>1</td>
<td>0.09</td>
<td>.03</td>
</tr>
<tr>
<td>Low</td>
<td>66 (66.6%)</td>
<td>352 (76.8%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient activation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>48 (48.4%)</td>
<td>150 (32.7%)</td>
<td>8.70</td>
<td>1</td>
<td>0.12</td>
<td>.00</td>
</tr>
<tr>
<td>Low</td>
<td>51 (51.5%)</td>
<td>308 (67.2%)</td>
<td></td>
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</tr>
<tr>
<td>Delivery system design</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>54 (54.5%)</td>
<td>226 (49.3%)</td>
<td>0.88</td>
<td>1</td>
<td>0.04</td>
<td>.34</td>
</tr>
<tr>
<td>Low</td>
<td>45 (45.4%)</td>
<td>232 (50.6%)</td>
<td></td>
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</tr>
<tr>
<td>Goal-setting/tailoring</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>High</td>
<td>16 (16.1%)</td>
<td>67 (14.6%)</td>
<td>0.83</td>
<td>1</td>
<td>0.03</td>
<td>.36</td>
</tr>
<tr>
<td>Low</td>
<td>83 (83.8%)</td>
<td>491 (85.3%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Problem solving/contextual</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>37 (37.7%)</td>
<td>187 (40.8%)</td>
<td>0.40</td>
<td>1</td>
<td>0.02</td>
<td>.52</td>
</tr>
<tr>
<td>Low</td>
<td>62 (62.6%)</td>
<td>271 (59.1%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Follow-up/coordination</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>11 (11.1%)</td>
<td>42 (9.1%)</td>
<td>0.36</td>
<td>1</td>
<td>0.02</td>
<td>.55</td>
</tr>
<tr>
<td>Low</td>
<td>88 (88.9%)</td>
<td>416 (90.8%)</td>
<td></td>
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</tr>
<tr>
<td>5A summary score</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>36 (36.3%)</td>
<td>113 (24.6%)</td>
<td>5.67</td>
<td>1</td>
<td>0.10</td>
<td>.01</td>
</tr>
<tr>
<td>Low</td>
<td>63 (63.6%)</td>
<td>345 (75.3%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Assess</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>48 (48.4%)</td>
<td>110 (24%)</td>
<td>23.9</td>
<td>1</td>
<td>0.20</td>
<td>.00</td>
</tr>
<tr>
<td>Low</td>
<td>51 (51.5%)</td>
<td>348 (75.9%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Agree</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>34 (30.3%)</td>
<td>110 (24%)</td>
<td>4.52</td>
<td>1</td>
<td>0.09</td>
<td>.03</td>
</tr>
<tr>
<td>Low</td>
<td>65 (69.6%)</td>
<td>348 (75.9%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Advice</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>High</td>
<td>45 (53.5%)</td>
<td>203 (44.3%)</td>
<td>0.04</td>
<td>1</td>
<td>0.09</td>
<td>.83</td>
</tr>
<tr>
<td>Low</td>
<td>54 (54.5%)</td>
<td>255 (55.6%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Assist</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>19 (19.1%)</td>
<td>87 (18.9%)</td>
<td>0.002</td>
<td>1</td>
<td>0.02</td>
<td>.96</td>
</tr>
<tr>
<td>Low</td>
<td>80 (80.8%)</td>
<td>371 (81 %)</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Arrange</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>9 (9%)</td>
<td>13 (2.9%)</td>
<td>8.03</td>
<td>1</td>
<td>0.12</td>
<td>.08</td>
</tr>
<tr>
<td>Low</td>
<td>90 (90.9%)</td>
<td>445 (97.1%)</td>
<td></td>
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</table>

As shown in Table 31, the percentage of patients who had a higher score for the PACIC-5As scales scored higher in the control glycaemic control group. This was the case for all scales except for the goal-setting and problem-solving ones. However, only small correlations were found relating to the 5As ($r= 0.10$ p =0.01) and “Assess” ($r= 0.20$ p =0.00). Similarly, the smoking status (Table 32) was weakly correlated to the PACIC-5As scales and “Goal-setting/tailoring”, “Asses” and “Assist” subscales ($r$ ranged from 0.10 to 0.14).
Table 32. Smoking status according to consistent low (<3) and high (≥ 3) PACIC scores

<table>
<thead>
<tr>
<th></th>
<th>Smokers N (%)</th>
<th>Non smokers N (%)</th>
<th>$\chi^2$</th>
<th>Df</th>
<th>Effect size</th>
<th>P value</th>
</tr>
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<tbody>
<tr>
<td><strong>PACIC summary score</strong></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>High</td>
<td>11 (12.5%)</td>
<td>128 (27.2%)</td>
<td>8.65</td>
<td>1</td>
<td>0.12</td>
<td>.003</td>
</tr>
<tr>
<td>Low</td>
<td>77 (87.5%)</td>
<td>341 (72.7%)</td>
<td></td>
<td></td>
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</tr>
<tr>
<td><strong>Patient activation</strong></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>26 (29.5%)</td>
<td>172 (36.6%)</td>
<td>1.64</td>
<td>1</td>
<td>0.54</td>
<td>0.20</td>
</tr>
<tr>
<td>Low</td>
<td>62 (70.4%)</td>
<td>297 (63.3%)</td>
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<tr>
<td><strong>Delivery system design</strong></td>
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</tr>
<tr>
<td>High</td>
<td>55 (62.5%)</td>
<td>225 (48%)</td>
<td>6.26</td>
<td>1</td>
<td>0.10</td>
<td>0.12</td>
</tr>
<tr>
<td>Low</td>
<td>33 (37.5%)</td>
<td>244 (52%)</td>
<td></td>
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<tr>
<td><strong>Goal-setting/tailoring</strong></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>5 (5.6%)</td>
<td>73 (15.5%)</td>
<td>6.01</td>
<td>1</td>
<td>0.10</td>
<td>0.01</td>
</tr>
<tr>
<td>Low</td>
<td>83 (94.3%)</td>
<td>396 (84.4%)</td>
<td></td>
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<tr>
<td><strong>Problem-solving/contextual</strong></td>
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</tr>
<tr>
<td>High</td>
<td>30 (34%)</td>
<td>194 (41.3%)</td>
<td>1.63</td>
<td>1</td>
<td>0.52</td>
<td>0.20</td>
</tr>
<tr>
<td>Low</td>
<td>58 (65.9%)</td>
<td>275 (58.6%)</td>
<td></td>
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</tr>
<tr>
<td><strong>Follow-up/coordination</strong></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>High</td>
<td>7 (8%)</td>
<td>46 (7.8%)</td>
<td>2.96</td>
<td>1</td>
<td>0.02</td>
<td>0.58</td>
</tr>
<tr>
<td>Low</td>
<td>81 (92%)</td>
<td>423 (92.1%)</td>
<td></td>
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</tr>
<tr>
<td><strong>5A summary score</strong></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>12 (13.6%)</td>
<td>137 (29.2%)</td>
<td>9.17</td>
<td>1</td>
<td>0.12</td>
<td>.002</td>
</tr>
<tr>
<td>Low</td>
<td>76 (86.3%)</td>
<td>332 (70.7%)</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td><strong>Assess</strong></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>15 (17%)</td>
<td>143 (30.4%)</td>
<td>6.59</td>
<td>1</td>
<td>0.10</td>
<td>0.01</td>
</tr>
<tr>
<td>Low</td>
<td>73 (82.9%)</td>
<td>326 (69.5%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Agree</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>18 (20.4%)</td>
<td>128 (26.8%)</td>
<td>1.58</td>
<td>1</td>
<td>0.53</td>
<td>0.20</td>
</tr>
<tr>
<td>Low</td>
<td>70 (79.5%)</td>
<td>343 (73.1%)</td>
<td></td>
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<td></td>
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</tr>
<tr>
<td><strong>Advice</strong></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>47 (53.4%)</td>
<td>101 (21.5%)</td>
<td>3.34</td>
<td>1</td>
<td>0.07</td>
<td>0.68</td>
</tr>
<tr>
<td>Low</td>
<td>41 (46.5%)</td>
<td>268 (57.1%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Assist</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>5 (5.6%)</td>
<td>101 (21.5%)</td>
<td>12.08</td>
<td>1</td>
<td>0.14</td>
<td>0.001</td>
</tr>
<tr>
<td>Low</td>
<td>83 (94.3%)</td>
<td>368 (78.4%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Arrange</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>6 (6.8%)</td>
<td>16 (3.4%)</td>
<td>2.26</td>
<td>1</td>
<td>0.06</td>
<td>0.13</td>
</tr>
<tr>
<td>Low</td>
<td>82 (93.1%)</td>
<td>453 (96.5%)</td>
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</tr>
</tbody>
</table>

6.6 Summary of the findings

The findings resulting from the official documentary analysis, the health care providers semi-structured interviews, and the patients’ survey are presented in Table 33. The results are categorised according to ICCC levels from the macro to micro strata (WHO, 2002; Epping-Jordan et al., 2004). However, working through the different sources of the data revealed an overlapping of community and HIS elements through all ICCC levels. In the next chapter will be presented further explanations and discussion of the utility of ICCC and the response of KSA health care system to the management of T2DM.
Table 33: Summary of barriers and opportunities to T2DM control in KSA results by source of data and ICCC level.

<table>
<thead>
<tr>
<th>ICCC domain</th>
<th>Macro Level</th>
<th>Meso Level</th>
<th>Micro Level</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Policy</strong></td>
<td>+ High investment in diabetes services, Doc</td>
<td>- Lack of specific diabetes target goal, Doc</td>
<td>- Lack of multisectorial collaboration, Doc, Int</td>
</tr>
<tr>
<td></td>
<td>+ National clinical guideline, Doc</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>+ National Executive Plan, Doc</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>HIS</strong></td>
<td>+ National Diabetes registry, Doc, Int</td>
<td>- Undeveloped EHR, Int</td>
<td>- Lack of information provided in clinic, Sur</td>
</tr>
<tr>
<td></td>
<td>- Gathering data from various sectors, Int</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Community</strong></td>
<td>- Culture belief/religion, Doc, Int</td>
<td>+ Comprehensive community group, Doc, Int</td>
<td>- Lack of social/environmental support, Sur</td>
</tr>
<tr>
<td></td>
<td>- Use traditional therapy, Doc, Int</td>
<td>- Few community based program, Doc, Int</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Poor lifestyle, Doc, Int</td>
<td>- Lack of collaboration between MOH SCAD, Int</td>
<td></td>
</tr>
<tr>
<td><strong>Health Service Organization</strong></td>
<td>+ Specialized diabetes unit/centers, Doc</td>
<td>- Poor PHC services, Doc, Int</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Over reliance on secondary/tertiary care, Int</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Shortage of expert staff, Doc, Int</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Poor referral system, Doc, Int</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Poor guideline dissemination, Int</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Lack of screening program, Int</td>
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<td><strong>Patient Self- Management</strong></td>
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<td>- Follow-up/coordination, Sur</td>
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+Opportunity; - Challenge; Doc: Documents; Int: Interviews; Sur: Survey

6.7 Chapter Summary

This chapter presented an overview of the patients’ perceptions of the current KSA health care system in managing T2DM. The next chapter will discuss the challenges identified in health care system under three streams, the macro, meso, and micro level.
Chapter 7: Discussion and Conclusion

7.1 Introduction

This thesis aimed to explore the KSA healthcare system in managing T2DM. Specifically, using the ICCC framework, it examined how healthcare system layers react to the increased burden of T2DM. The chapter consists of the following sections: a summary of the main findings with regards to the study questions and then a discussion of the findings according to the ICCC strata (macro, meso, and micro) in the context of existing published works. This is followed by a presentation of the strengths and limitations of the study; and lastly, the recommendations for policy, future research, and the conclusion.

7.2 Principal Findings

KSA has a heavy diabetes burden over the last three decades as a comprehensive systematic review conducted at the early stages of this thesis showed that the prevalence of T2DM and obesity was increasing rapidly among GCC citizens (Alharbi et al, 2014). In response to this burden, the Saudi government has addressed the need for improvements by introducing several strategies and launching many plans (Khoja, 2010; Alharbi et al, 2016b; Yusuf, 2014). While the subject of diabetes was mentioned in fifty-three national and regional policy documents, this study found that these were very limited in scope as only three documents addressed as many as three of the four Walt and Gilson’s elements, namely, content, actors, context, and process (Walt & Gilson, 1994; Al-Khaldi & Al-Sharif, 2002; Midhet et al, 2010; MOH, 2013c). Overall, the documents largely ignored the fact that T2DM management has specific features irrespective of whether it is related to individuals, organizations, communities and polices (Wagner et al, 2001; WHO, 2002; Epping-
Jordan et al., 2004; Fiandt et al, 2006; Gugiu et al., 2013). Nevertheless, there was much similarity in the methodologies used as most of them followed a cross-sectional quantitative design. This thesis intends to contribute to the filling of this gap in the literature by conducting a multi-method approach combining primary and secondary data and, as such, will be one of the first pieces of research of this nature on the healthcare system (Brewer & Hunter, 1989; Atun et al, 2006; Atun et al, 2013; Risso-Gill et al, 2015). Therefore, it is expected to generate new knowledge about the T2DM management system in KSA by exploring how the performance of the healthcare system is shaped by the processes occurring at the different levels.

There are a plethora of chronic disease management models as described in chapter 2 and by reviewing some of these models, the researcher found out that the ICCC was the most appropriate one to be used for the conceptual framework of this thesis (Wagner et al, 2001; WHO, 2002; Epping-Jordan et al., 2004). The ICCC is a framework that guides healthcare systems by providing a flexible and comprehensive basis on which to design and evaluate a healthcare system by addressing its components at the macro (policy), meso (healthcare organization and community), and micro (patient and family) layers (WHO, 2002; Epping-Jordan et al., 2004). It is important to note that this thesis does not aim to evaluate the KSA healthcare system, but rather, it is an exploratory study that seeks to examine the responsiveness of the current system by adopting the ICCC framework. In addition to this, it set out to further examine the applicability of the ICCC, especially in a high-income developing country like KSA.

Starting from the macro level of the ICCC framework, the documentary analysis revealed that in KSA, the government had initiated a wide range of policy interventions in accordance with WHO strategies for the strengthening of the
healthcare system, health promotion and the control of NCDs (WHO, 2013; Alharbi et al, 2016b). Consequently, the MOH had invested in a health network that provides the PHC services with a referral system from the general practitioners and family physicians’ level at the centers to that of the advanced specialist curative services provided at the secondary and tertiary level facilities (MOH, 2013c). However, despite the high value of recognition and the investments at the macro and the meso levels, the inadequacy of the healthcare system became evident at the micro level of the KSA healthcare system. This inadequacy was made even more evident after applying the two important measures, namely, the high rate of uncontrolled blood sugar levels and low mean score obtained on all PACIC-5As scales among the Saudi diabetic patients.

Much of the KSA healthcare system’s inadequacy can be traced to the lack of integration at all the ICCC levels which was not only identified during the documentary analysis, but was also highlighted later during the interviews and the survey of the patients (Al-Khaldi & Alsharif, 2002; Midhet et al, 2010; Khoja, 2015; Gulf Health Council, 2017). At the macro level, Saudi policies and plans focused on the biomedical model of care instead of on the integrated, population-based one that emphasizes patients’ needs. The national diabetes plan promotes a model of acute, episodic care resulting in fragmentation and waste in the healthcare system. Although the MOH has established a national diabetes registry as a prerequisite for an integrated healthcare system, however, the interviewees indicated that the current Saudi registry lacked reliable data and was without any coordination at the macro level. As a result, the quality and coherence of the services were affected negatively (Subhani & Al-Rubeaan, 2010; Al-Rubeaan et al, 2013; Al-Rubeaan, 2015b; Alkadi, 2016).
Furthermore, this lack of integration has also been identified at the meso level of the healthcare system as revealed by several issues. Both the documents and the interviews identified the lack of a referral system between PHC and other healthcare levels (Abdelwahid et al, 2010; Al-Kaabba et al, 2010; Al Wadaani & Balaha, 2012; Al Shahrani, & Baraja, 2014). This was the reality although a referral protocol was described in the national diabetes clinical guidelines (MOH, 2013a). Unfortunately, this important information did not systematically reach the healthcare providers due to a lack of coordination in distributing the guidelines among them. Another reason for this problem was that most of the PHC centers used paper-based records and where EMRs were used in the hospitals, these were not sufficient (Alkadi, 2016). Thus, without an integrated health information system and the use of clinical guidelines, the referral system was rendered ineffective.

Moreover, this lack of integration was also identified among different organizations. This thesis found a lack of multi-sectorial links between the MOH and Ministry of Education, and the lack of SACD partnerships. At the micro level, the lack of integration was revealed in two of the PACIC-5As domains, namely, “Follow-up/Coordination” and "Arrange". These two scales were rated as the lowest. The principal guideline of the ICCC framework emphasizes partnership between the patients and the community (WHO, 2002; Epping-Jordan et al., 2004). When the PACIC-5As instrument was applied, the lack of community partnership became evident by the low level of the ‘Assist’ score as well.

The ICCC framework was very effective in exploring the main weakness and strengths of the Saudi healthcare system. However, the main elements of the ICCC captured the key components of the country's healthcare system with one exception - cultural norms and the beliefs of the community - which were not strongly addressed
in the ICCC mode (WHO, 2002; Epping-Jordan et al., 2004). This is one area of weakness since the community culture and beliefs are essential factors that should be used to re-design the healthcare system to effectively help to manage this chronic disease (Sachdeva et al., 2015; Sud & Sud, 2017). Understanding the broader KSA cultural context can serve as important background information for the effectiveness of health care organisations and community partnership. This is a key aspect of the present thesis because exploring T2DM contributing is critical to identifying the possible role that each system element can play. Gaining such information will also help in identifying the kind of support systems that will provide holistic care for people with diabetes (Mendis & Chestnov, 2013; Sachdeva et al., 2015).

In this thesis, Saudi’s cultural beliefs influence how they perceive their overall health and their cultural attitude towards their health was found to be a major factor contributing to the increasing prevalence of obesity and T2DM (Elhadd & Al-Amoudi, 2006; Abdoli, 2011; Mohieldein et al. 2011; Yahya et al. 2015; Alneami & Coleman, 2016). Cultural determinants that influence access to the healthcare delivery system and the way in which patients interact with the medical team were identified as religion, care seeking behavior and health literacy (Sachdeva et al., 2015; Alneami & Coleman, 2016). These factors were seen as responsible for the way in which T2DM was perceived by the community as well as the symptoms and signs related to diabetes and its complications. The Islamic principles affect almost every single aspect of social life in KSA. For example, many people believe that honey and dates as holy foods are effective in treating every kind of illness, including diabetes. In addition, cultural barriers often become hindrances for patients, especially women, for whom it is not culturally acceptable to engage in sporting activities. Therefore, it is crucial to also assess the healthcare system through a cultural lens (Elhadd & Al-
The lack of cultural coherence is one of the key challenges of the healthcare system as identified at the macro level. (Midhet, 2010; Mobaraki & Söderfeldt; 2010; Alhowaish, 2013). According to the respondents, Saudi Arabia did not need a highly modernised system, at least for now, but what was required was an effective and functional one. There were many discrepancies in the current system and in many ways there was some amount of cultural conflict between the culture and the support system. Respondents recommended that instead of adopting any of the systems used in the West, what the policymakers should do was to invite scholars from the field and solicit their suggestions for developing a culture-conscious support system.

In examining healthcare at the meso level, it appears from the results of the documentary analysis and the interviews that due to a lack of proper care seeking behaviours identified previously at the macro level, most of the T2DM patients reported mainly at the primary healthcare level after the complications had already developed (Al-Khaldi & Alsharif, 2002; Al-Saigul et al, 2007; Al Shahrani, & Baraja, 2014). However, the PHC centres in KSA are run by untrained GPs who cannot effectively manage the T2DM conditions. Consequently, there was an over-reliance on the secondary and tertiary healthcare facilities in the country. Even with this advanced level of healthcare service, there was a lack of qualified diabetes healthcare workers. Therefore, there were also obvious problems concerning continuity in treatment at the heavily burdened clinics in the hospitals because T2DM is not a series of disconnected complaints (Al-Khaldi & Alsharif, 2002; Abahussain & El-Zubier, 2005; Al Shahrani, & Baraja, 2014). Moreover, most of the healthcare workers came from different linguistic and cultural backgrounds (Aldossary et al, 2102). This might
have led to the low mean score for the sharing health information domain in the PACIC-5As.

KSA healthcare system was ill-prepared to recognise the importance of the patients’ behavioural and cultural norms and the effective community partnership and healthcare team interactions. The lack of effective health preventive strategies and an adequate health information system identified previously at the meso and macro levels has led to the failure to motivate patients to participate in their own care (Al-Khaldi & Alsharif, 2002; Abahussain & El-Zubier, 2005; Al Shahrani, & Baraja, 2014). A more detailed explanation of the findings at the micro, meso and macro levels as found in the literature will be discussed in the following sections.

7.3. **The Macro level**

A great deal of inadequacy in the healthcare system can be mapped out at the macro or policy level where overall values, main beliefs, and the plans for healthcare are developed. This section will discuss the results of the earlier documentary analysis done in Chapter 3. By reviewing national and regional documents, the researcher identified gaps in managing and controlling T2DM due to various factors related to policy content, actor, process, and context (Walt & Gilson, 1994; Gilson, 2013). At the level of policy content, the growing burden of T2DM and the proposed intervention measures were highly recognized. On the other hand, by analyzing the actor aspect of the healthcare policy documents, it was observed that KSA was a centralized healthcare system with only the MOH having responsibility for managing and controlling T2DM. Moreover, it was seen that the MOH had undergone changes in its healthcare plans. There was an overlapping of the implementation dates of the second official T2DM plan - "Country’s Cooperation Strategy (2006-2011”)) - and the third initiative, the "National Executive Plan of Diabetes Control for 2010-2020"
It should be noted that both plans were quite similar in terms of their goals, objectives and interventions. However, this could have been due to a high turnover of health ministers which might have allowed for little consideration being given as to how to improve the initiative instead of adopting the same approach (Alharbi et al, 2016b).

At the level of the policy process, both the documents consulted and the interviews revealed that the shortcoming in the MOH plan was due to the way the policy was designed with "other stakeholders’ participations" and the "multi-sectorial action" taken in its implementation. According to the principles of the contemporary healthcare models, including the “Health For All” strategy, there was wider participation and collaboration between different government sectors outside the MOH, including agriculture, sports, education and transportation as well as the community for the pursuit of good health (WHO, 2002; Mendis & Chestnov, 2013). The Saudi healthcare policy did not emphasize the importance of decentralizing the healthcare system in order to provide room for participation from other organizations and the community. This kind of participation could also address the problem of gender segregation and the restriction of women, in terms of mobility, from gaining access to and participating in decision-making as was seen in this study. The researcher was not able to conduct an interview with the male patients. Male domination is culturally sanctioned in KSA and the study showed that only 33% of the interviewees were females. However, the MOH did not consider wider participation in its health plan as was noticed by many documents. Comparing the Saudi healthcare plan to the WHO country capacity assessment for prevention and control of NCDs, among the 184 member state mentioned, 32% of them in developing their policies referred to facilitating multi-sectorial action in implementing their...
NCDs activities. However, the percentage presented by the WHO member states has not been confirmed in terms of the implementation, therefore, the number could be lower than one third of all the countries (Mendis & Chestnov, 2013).

The lack of collaboration in designing and implementing healthcare plans for chronic disease management has been observed in many developed and developing countries. In Australia, the ICCC framework was used in conducting semi-structured interviews with 21 key informants to evaluate the chronic disease policy in a rural area of the country (WHO, 2002; Epping-Jordan et al., 2004). The result of this study indicated that despite the successes in developing a national strategy for controlling and managing chronic diseases, there was the need to improve the collaboration between and within governmental and non-governmental departments. The researchers suggested that in order to enhance the collaboration, there was the need for a pooled budget between the ministers (e.g. Health and Education) and clear incentives for all those who involved in chronic disease management. Although this study focused only on one element of the ICCC - “policy environment” - and used only one source for the data, it provided a snapshot of the main healthcare and political issue (Baeza et al, 2009). In China, another study adopted all elements of the same theoretical ICCC model to assess the national healthcare system in managing and preventing diabetes in the country by using a qualitative analysis of both primary and secondary data. The study indicated that there were no links between the Chinese MOH, government agencies, and the community groups. This study stressed the role of leadership in establishing a national integrated system that aligned the health service organizations with other government sectors and the community (Le Rouge & De Leo, 2010; Scott & Davis, 2015).
In addition, other recent Middle Eastern studies referred to the lack of partnership and collaboration as a key challenge for the healthcare system. With regard to health policy analysis, four international studies had adopted the Walt & Gilson’s policy triangle framework to assess the policy environment for managing and controlling diabetes and cardiovascular diseases (Walt & Gilson 1994; Gilson et al, 2008; Gilson, 2013). In Iran, the political response to the rise in the prevalence of diabetes in the country was well recognized in the 1990s. The government implemented two phases (rural and urban) of the national diabetes plan in 2004 and 2010, respectively. Although wider participation from the community and other government agencies was involved in the policy design, the national policy did not address the inter-sectorial collaboration and coordination between the MOH and other stakeholders. However, unlike the current study, the Iranian healthcare system analysis had two limitations – they did not use any secondary data or official government documents (Faraji et al, 2015).

The other three studies had included primary and secondary data as the researchers applied the policy triangle framework to analyze and synthesize both the documents and the semi-structured interviews as part of the findings. The first country from among these studies that started their first national diabetes initiatives was Tunisia in the early 1990s. The WHO “Health for All Strategy” was used to shape the five years national health plan (WHO, 1998). When comparing the KSA government’s spending on healthcare to that of Tunisia, the latter spent more than 4% above that of KSA. However, the key informants pointed out many limitations that hindered the Tunisian healthcare system from effectively meeting the growing burden of NCDs. This included a lack of inter-sectorial and cross-department collaboration. According to the primary data results, the problem was that the policymakers were
resistant to considering chronic diseases management as a part of a wider socio-economic development strategy (Ben Romdane et al, 2015).

In Syria, the government’s recognition of T2DM was more recent. The first official plan was in 2006 with the Syrian MOH establishing a chronic disease department responsible for the diabetes health plan. Despite this, according to the researcher, a Syrian diabetes national plan did not exist. Similar to Iran and Tunisia, there was an absence of multi-sectorial collaboration. Despite the fact that the researchers conducted the assessment of the Syrian healthcare system during the national crisis, the data contributed to an understanding of the barriers that may have led to the poor response (Ahmed et al, 2015). In Turkey, like the Iranian and Syrian policies, the importance of multi-sectorial collaboration was strongly emphasized in their national plan for controlling and managing diabetes and cardiovascular diseases. However, although the strategic plan was developed for a longer period than that of the previously mentioned countries, the key informants reported that collaboration between the MOH and other government organizations was lacking (Kilic et al, 2015). The challenge of improving multi-sectorial collaboration and wider participation in the Arab world is described by Jabbour and Rawaf (2012) as the result of governments too readily seeing healthcare provision as a “gift handed by the state” to the people (2012, p. 354).

With regard to the policy context, the findings from both the documents consulted and the interviews indicated that economic and cultural factors were mentioned most frequently as contributing to the inability of the Saudi healthcare system to control the increasing prevalence of T2DM in the country. Several documents have raised the issues of rapid urbanisation and changing lifestyles as also being among the primary contributors to the rising prevalence of diabetes in Saudi
Arabia (Mohieldein et al. 2011; Badran & Laher, 2012; Majeed et al., 2014). This is due, in part, to the rapid rise in oil prices which have led to a significant increase in disposable income over a short period of time. This has also attracted many foreign fast food brands to the kingdom and these, through their aggressive marketing, have further encouraged a sedentary lifestyle (Al-Daghri et al. 2007; Al-Attas et al. 2010; Al Hayek et al, 2014; Murad et al., 2014; Al-Aboudi et al, 2015). Respondents in this research also confirmed that within the last few decades, the rise in oil prices and the increased welfare spending by the government has led to rapid economic growth in Saudi Arabia. This, in turn, has led to changes in the lifestyle of individuals. In addition, the increased employment of cheaper labour from South East Asian countries has also fuelled the sedentary lifestyle as most Saudis tend to avoid physical work completely. Badran and Laher (2011) also recognized this trend in their research and found that it was leading to a general change in the thinking of individuals who sought comfort and tended to opt for situations that required minimal physical effort.

According to the respondents, the nature of entertainment has also changed over the years with most individuals now preferring sources of entertainment which require no physical movement, such as watching TV and playing video games. These factors were highlighted by Sheikh-Ismail et al. (2009) as well. In fact, most of the past research concerning the rise in the prevalence of T2DM in Saudi Arabia or even the GCC region, in general, has spoken about rapid urbanisation and changing lifestyles and eating patterns as contributing to obesity and T2DM. Based on these findings, it can be confirmed that government, in its own way, is also contributing to this change in lifestyle. According to the respondents, the rapid infrastructural development and the lack of focus on open spaces for physical activities for all family members, especially females, were also contributing to the rise of a culture which
focused on leisure and comfort and minimal physical activity (Midhet et al., 2010; Awadalla et al., 2014; AL-Aboudi, 2015). This was confirmed by previous studies which found that the prevalence of obesity and physical inactivity was higher among females in KSA (Al-Alfi et al., 2004; Al-Nozha et al., 2004; Aljoudi et al., 2009; Aljoudi Taha, 2009; Al Quaiz & Tayel, 2009; Alharbi et al., 2014). Thus, apart from the above-mentioned urbanization, the absence of sports education in girls’ school and the prohibition of females from undertaking physical activities in public have posed a greater challenge to the healthcare system in trying to control diabetes (Midhet, 2010; Mobarak & Söderfeldt, 2010).

The findings from the documentary analysis and the interviews revealed three culture determinants that affected nearly all aspects of T2DM care in KSA. These were identified as religion, care seeking behaviour and health literacy. Saudi society is based on strict Shariah principles in which religion plays a very critical role in almost each aspect of life and society and, in many cases, it also affects the care that individuals give to themselves when treating T2DM (Abdoli, 2011). The problem is that all individuals view everything through the lenses of religion and apply it according to their understanding even though in the religion it is clearly mentioned that people should fast only when medically fit (Elhadd & Al-Amoudi, 2006). For example Pew (2010) and Habibzadeh (2012) also noted that a large proportion of T2DM patients continued to fast during Ramadan as they consider it their supreme duty which takes precedence over all their body needs. On the other hand, their medical condition may not permit them to fast. Nevertheless, they consider their sickness as an even greater challenge that God has presented them with and so, overcoming it will help them to absolve their sins.
Diabetes care seeking behavior is another cultural factor that influences diabetes care delivery (Midhet, 2010; Mobaraki & Söderfeldt; 2010; Al-Khudairy et al, 2014). Poor care seeking behavior can lead to the individual ineffectively accessing the healthcare system and this can also affect the way the patient interacts with healthcare providers. According to the interviewees, due to a lack of awareness, many patients considered diabetes as a stigmatized disease and so they did not regularly participate in diabetes prevention, screening and care programs due to this cultural belief. According to the information gathered through the documentary analysis and from the respondents, the major misbelief among diabetic patients in KSA was that diabetes could be treated by traditional medicine. This belief usually leads to a delay in seeking care for diabetes until the symptoms of some form of complication emerge (Al-Saeedi et al, 2003; Bakhotmah & Alzahrani, 2010; Sabra et al, 2010; Sharaf et al, 2013). According to the findings of this study, a large number of patients relied on traditional medicines which negatively affected their ability to treat T2DM. In KSA, traditional healers are usually the first port of call for people seeking treatment. According to some estimates (for example, Al-Saeedi et al., 2003), about one third of T2DM patients used traditional medicines and this figure did not include people who were ignorant about their T2DM illness and were merely treating the symptoms by using traditional medicines.

According to findings reported by Suleiman (2012), 91% of Saudi patients tried to treat T2DM symptoms with traditional medicines before seeking expert medical care. This supports the findings of Khalaf and Whitford (2010) who commented that large numbers of patients in other Middle Eastern countries also used complementary remedies to treat diabetes, often to the exclusion of other treatments, and usually without informing their physician. According to the respondents of this
research, the use of traditional medicines had a dual impact on T2DM. Firstly, it often led to a late diagnosis because patients often tended to treat the symptoms rather than T2DM. For example, a person suffering from weakness may start taking herbal medicines for this without realising that the actual cause of his tiredness is T2DM. Secondly, traditional medicines may sometimes make the problem worse. According to the respondents, a late diagnosis was a far bigger problem compared to anything else when it came to the use of traditional medicines. The delay in diagnosis is what the medical practitioners are really worried about. Ali and Mahfouz (2014) and Yahya et al. (2015) recommended that because the use of traditional medicines was so common among Saudis, there was a real need to include this in medical studies and educate practitioners on the use of both traditional and western medicines. However, the respondents in this thesis argued that it would be a wrong practice to expect the medical practitioners to possess the combined knowledge of traditional and western medicine because the effectiveness of traditional medicines was not clinically proven. They argued that medical practitioners should rely only on scientifically proven medicines and herbal medicines should be included in medical curriculum only after a through scientific analysis of their effectiveness.

The reliance on traditional medicine could lead to inadequate accessing of the healthcare system, not only in KSA, but it could also affect the use of traditional medicine in many developing countries. Beran and Higuch (2013) conducted a comparison of two studies to explore the barriers to diabetes access care and medicine in the Philippines and Vietnam. The study applied the Rapid Assessment Protocol for Insulin Access as a multi-level assessment method that has been used widely to assess services for diabetes. The data were collected from different sources such as a document review, observation and a survey of healthcare providers. Both countries
showed a lack of the use of the healthcare services due to an over-reliance on traditional healers. Furthermore, reliance on traditional medicine was also a challenge to individuals accessing healthcare in a high income countries. A group of researchers conducted a multi-method healthcare system appraisal for hypertension management in different areas of Malaysia. The study revealed that despite the existence of a well-funded healthcare system, the policymakers needed to consider in their interventions how patients sought treatment from traditional sources in combination with or instead of recommended medications (Risso-Gill et al, 2015).

Health illiteracy was highlighted as another key issue contributing to a rise in the prevalence of T2DM. Several researchers support the view that the low level of awareness of T2DM is one of the key factors that contributes to its prevalence in Saudi Arabia (Aljoudi and Taha, 2009; Alhyas & McKay, 2010; Sharaf et al, 2013; Al-Khudairy et al, 2014; Al Shahrani, & Baraja, 2014; Bani, 2015). On the contrary, Mohieldein et al. (2011) found that individuals in the Al-Qassim region had a high level of awareness about the symptoms of diabetes, however, in the same study, they found out that the diabetic patients had a very poor knowledge of the complications of T2DM. Aljoudi and Taha (2009) however, argued that the level of awareness about T2DM remains low, especially among people from poor socio-economic backgrounds. Education was also considered as one of the factors affecting patients' compliance with treatment in a study conducted by Alhyas and McKay (2010).

According to the respondents in this thesis, there were many ways in which a lack of awareness about T2DM affected the patients. Firstly, due to lack of awareness, patients often delayed treatment which served to exacerbate their T2DM problem. This was one of the key issues concerning a number of medical practitioners. Mohieldein et al. (2011) supports the view that the majority of Saudi patients sought
treatment for T2DM only when they were left with little choice but to get medical advice. Patients often sought medical care at the very late stages of their illness when there was no effective treatment available. In many cases, patients did not show patience with modern medical treatments. T2DM is a long term illness and unlike many others, it will not and cannot disappear in the short term. Continuous support and monitoring are required to manage T2DM (Barrera et al. 2006). In the case of Saudi Arabia, the overall lack of awareness and seriousness with regard to managing T2DM has led to an apathetic attitude towards T2DM. Elhadd et al. 2007 also found in her study that the majority of Saudi patients stopped the treatment for T2DM after some time because they believed that if T2DM was controlled for a few months then it was all right to stop taking the treatment.

Besides failing to consider the cultural determinants in the diabetes national plan, the planners also failed to specified measurable targets for reducing the prevalence of T2DM in the kingdom. This was made even worse by the poor collection of data and the use of a surveillance system that made it impossible to audit the quality of diabetes care (Subhani & Al-Rubeaan, 2010; Al-Rubeaan et al, 2013; Alkadi, 2016). A lack of reliable data in the diabetes registry was not unique to KSA, but rather was also observed in many other countries like Turkey, Syria, Tunisia, Sub Sahara Africa and China (Azevedo & Alla, 2008; Le Rouge et al, 2010; Ahmed et al, 2015; Ben Romdhane et al, 2015; Kilic et al, 2015). However, Saudi Arabia had recently invested in the development of a national diabetes registry at the Ministry of Health. This should be a significant development, but it has been quite limited for several reasons. According to the respondents, many Saudis do not even know they have T2DM because they have not undergone adequate diagnosis. In addition, the healthcare service providers were not adequately connected to this registry which
meant that not all medical service providers were uploading and accessing information from it. In fact, the use of electronic information systems was quite new to the Saudi public healthcare system, especially in the primary healthcare services. According to the respondents, the adoption of information technology will be slow and gradual. Furthermore, the medical service providers needed to be educated about the existence and purpose of this registry.

According to the findings of this thesis, many medical service providers were not aware of the existence of this registry and, consequently, they were still using the old methods for submitting T2DM patient data. The problem with this approach was that only the number of patients diagnosed with T2DM was being recorded with no way of tracking the management of their T2DM over an extended period of time (Alkadi, 2016). This made it difficult to identify which methods of T2DM management were working in the Saudi Arabian society. It also affected the quality of data regarding the main causes of T2DM among patients, although knowing this is critical for the development of strategies to reduce the prevalence of T2DM. The respondents also suggested the need to integrate this T2DM registry with that for other types of sickness so that a person with multiple illnesses did not have conflicting records. This is essential because T2DM patients often have other related illnesses for which they also seek treatment (Al-Khaldi & Al-Sharif, 2002; Midhet et al, 2010; MOH, 2013c). According to the respondents, developing an integrated system would help the medical service providers to link some of the other illnesses to T2DM and refer a person for diagnosis if there was a possibility that his illness maybe related to T2DM. Such action would facilitate better management of T2DM. However, developing such a system is extremely complex and difficult, especially given that the researcher was unable to identify the existence of any similar system.
7.4. The Meso level

The principal guideline of the ICCC framework at the meso level emphasizes the need for continuity and coordination as well as for an organized and well equipped healthcare team (WHO, 2002; Epping-Jordan et al., 2004). In this section, several critical issues that hinder the ability of KSA healthcare system to effectively meet the growing burden of T2DM at the meso level will be discussed. At the healthcare organizational level, the MOH initiated a PHC approach in the early 80s with more than two thousand PHC clinics established across the country. Moreover, as a part of National Executive Plan for Diabetes Control, the MOH also established diabetes centers and units bringing the total number of such units and centers to about 300 (MOH, 2013a; MOH, 2013b; MOH, 2013c; MOH, 2015;). This emphasis on PHC in KSA means that they will be the entry points into the healthcare system for patients and, therefore, those identified at the PHC centers as diabetic will continue to receive their treatment at this level until or unless complications arise. On the other hand, according to the findings obtained from the healthcare providers who were interviewed, there was an over-reliance on the secondary and tertiary healthcare services because most patients entered the system when they already had complications from diabetes due to a lack of early detection. Although KSA government has built up a large public network of PHC centers, the findings from this thesis have shed light on the institutional limitations of their services and their inability to effectively meet the growing burden of T2DM in the country. The lack of qualified staff and the poor referral system in KSA are two fundamental challenges brought to light from the document analysis and were later confirmed during the interviews.
PHC physicians are the foremost providers of diabetes healthcare particularly in developing countries where the health system is ill-equipped to address the rising demand due to a shortage of qualified medical staff (Al-Khaldi & Alsharif, 2002; Alfi, 2004; Khan et al, 2010; Willens et al, 2011; Al Shahrani, & Baraja, 2014; Beran, 2015). PHC practitioners should, therefore, be highly qualified to provide optimal diabetes care in order to prevent further complications for their patients. In fact, a lack of knowledge and inconsistent practices relating to T2DM diagnosis, evaluation and management by care providers create major impediments to the achievement of diabetes related goals for therapy (Brown & Nichols, 2003; Epping-Jordan et al, 2005). The PHC services in KSA are provided through a network of PHC centers where medical interventions are carried out by general practitioners, family physicians and nurses. Despite the fact that T2DM is the third most common disease treated in the PHC in KSA, healthcare providers receive limited T2DM training opportunities (MOH, 2016). According to the interviewees, particularly the endocrinologist and health educators, there were few extensive training opportunities for existing medical workers in providing diabetes care in KSA. Furthermore, there was only one university hospital offering “diabetes education courses" in the whole kingdom. The result is that the PHC facilities were equipped with untrained providers who and so they were often bypassed.

On the other hand, the diabetes centers and units were overwhelmed with patients, resulting in a short examination time and frustration on the part of the patients and the healthcare providers. According to a recent report, PHC physicians in KSA saw 20 to 30 patients per day, while endocrinologist in secondary and tertiary clinics saw between 60 to 70 diabetic patients per day (WISH, 2015). Although the PHC physicians were not participating in the interviews, a similar conclusion was
drawn from a cross-sectional study among 150 PHC physicians which was undertaken in KSA using questionnaires to assess their knowledge, practice and attitude towards T2DM patients. The findings revealed that only 34.7% of the physicians knew the correct angle for an insulin injection; 23.2% of them considered that they were professionally well prepared to manage T2DM on diagnosis for the initiation of treatment; while 64% of them preferred to refer patients to secondary and tertiary levels of care for this (Khan et al, 2011). The results from Khan et al’s study contradicted a local survey that found that about 80% of diabetic cases were managed by general practitioners. However, the inconsistency in these results could be have arisen from the fact that the earlier study was conducted at the university healthcare facilities supervised by the Ministry of Higher Education where the clinics were managed by better trained physicians than the MOH facilities (Al-Rubeaan et al, 2015b). However, this lack of knowledge about proper diabetes management has also been reported in studies from developed and developing countries like Australia, Zambia, China and Sri Lanka (Baeza et al, 2009; Beran, 2015; Le Rouge et al, 2010).

According to the findings from the documentary analysis, one of the key achievements was the National Executive Plan for Diabetes Control that established clinical guidelines for the diagnosis, treatment and referral of complicated cases (MOH, 2013c; MOH, 2015). However, the healthcare providers who were interviewed said that not everyone was knowledgeable about these guidelines due to the poor dissemination of the document. As mentioned previously in Chapter 3, the clinical guidelines for diabetes were available on the MOH website. However, there was no coordinating and monitoring system to ensure that healthcare providers were complying with them. The problem of the poor dissemination of such guidelines have also been documented elsewhere internationally (Azevedo et al, 2008; Le Rouge et
al, 2010; Ahmad et al, 2015; Kilic et al, 2015; Risso-Gill et al, 2015) and was evident in a local study (Al-Ahmadi & Roland, 2005). As a consequence of the above-mentioned limitations, the KSA healthcare system lacked an effective referral mechanism. The poor referral system was also observed in a local study aimed at determining the referral rates for diabetic retinopathy among diabetics who were referred from a PHC center. The study revealed that almost a quarter of the diabetic patients were referred to eye clinics (Al-Khaldi, Khan, & Khairallah, 2002).

Coordination between primary and secondary care remains a challenge in KSA where there is no system for information sharing. The secondary and tertiary facilities never had access to a patient’s full medical record at the primary level and, furthermore, the referrals from PHC physicians to the diabetes centers often included insufficient information (Alkadi, 2016). In fact, in KSA, like many other countries, the use of the health information system was quite new in public healthcare, especially the primary healthcare services where some of centres still stored patient information in traditional paper files. Subsequently, there was a lack of information sharing and the availability of an inadequate amount of data (Ben Romhane et al, 2015; Beran, 2015; Maruthappu et al, 2015). The limitations of the health information system were not the only challenge facing the PHC centers. With regards to the specialized diabetes level, the healthcare providers acknowledged a lack of the current EMR functionalities. KSA used different EMR systems among different healthcare institutions so that persons with diabetes were not effectively tracked and monitored. Respondents in this research strongly advocated for a unified clinical information system before the development of other support systems. According to the respondents, a unified clinical information system would help in tracking the progress of the patient which was often very critical. If the patient was not showing progress,
doctors could develop a specific plan, including a support system for the patient. As argued by Wagner and colleagues, without robust EMR platforms, the integration of the chronic health care services is stifled (Wagner et al., 2001).

Inside the specialised diabetes healthcare clinics at the secondary and tertiary facilities, the shortage of medical staff creates another challenge. KSA performs poorly with regard to the number of Saudi nurses and health educators. According to the WHO statistics report, there are 9.4 physicians and 21 nurses per 10,000 people which is lower than the global ratio (13, and 28 per 10,000 people, respectively) (WHO, 2011). Moreover, 71% of the nurses in KSA are non-Arabic speakers (MOH, 2015). In KSA, there was a shortage of local healthcare providers, according to the interviewees, and most of the nurses did not speak the Arabic language and were not trained sufficiently to speak about T2DM. The Saudi Arabian healthcare sector employs a large number of foreign professionals who do not speak Arabic and are not well versed with the Arabic culture, making it extremely difficult for them to provide the level of care that native Saudi Arabian medical professionals can provide (Almalki, 2011; Alkadi, 2016). Another statistical report indicated that there were only around 100 certified diabetes educators in the whole public sector, resulting in 0.25 diabetes educators per 10,000 people (WISH, 2015). As mentioned by the interviewees, particularly nurses and health educators, the specialised diabetes educational sessions were carried out by female educators and nurses who faced restrictions in their interactions with male patients due to cultural values and gender segregation (Elfaki & Aedh, 2015).

As a consequence of these staffing challenges, newly diagnosed patient were not formally educated on T2DM, especially if it was detected in the PHC clinic (Al-Kaabba et al., 2010; Al Wadaani & Balaha, 2012; Al Shahrani, & Baraja, 2014).
Furthermore, T2DM health education programs in KSA were targeted at individuals in tertiary clinics during the health educator's visits, rather than at families. This ignores the international trend to manage diabetes through different levels - the patient, their family, their community, the health organizations and the country (Bodenheimer et al., 2002a; Bodenheimer et al., 2002b; Epping-Jordan et al., 2004). To overcome this challenge, previous literature suggested adopting regular health educational group sessions. Even though group and individual diabetes education programs have been shown to be equally effective, group education allows for more efficient and cost effective methods in the delivery of diabetes care in light of the limited number of local certified health educators (Rickheim et al, 2002).

Looking at the issue of community support, the results of this study highlighted the lack of a diabetes community setting in KSA. Despite the establishment of the Saudi Arabia Diabetes Association charity, the majority of the interviewees had no knowledge of this organisation which has only few members. In fact, it is the only formal community group that exists in the whole central region of KSA, yet formal connections between health institutions and community agency were rarely established (SCAD, 2017). This highlights the lack of awareness among all stakeholders about the role played by the community group. On one hand, patients did not understand how these support systems could help them, while the doctors were unaware of their responsibility to refer patients to these support systems. At the same time, government was not actively interested in promoting these systems. The focus was still on clinical treatments and, as mentioned in a previous subsection, the clinical systems were severely limited in treating T2DM patients because of several reasons stated already.
7.5 The Micro level

The principal guideline of the ICCC framework at the micro level is to emphasize the partnership between patients, the healthcare team, and the community (Bodenheimer et al., 2002b; WHO, 2002; Epping-Jordan et al., 2004). At this level of the KSA healthcare system, patient interactions were quantitatively assessed from the patients` perspective. The study sample characteristics were similar to some extent to the socio-demographic and clinical characteristics of previous studies samples from KSA. Particularly, the gender, age and marital status distribution were similar to those which were reported in other local studies (Al-Aboudi et al, 2015; Al-Baghli et al., 2010; Al-Daghri et al, 2011; Salam & Siddiqui, 2013; Al-Shahrani et al, 2016; Al Hayek et al., 2014; Amin et al., 2014; Murad et al., 2014).

In this thesis, there was an apparent gender difference in the prevalence of T2DM with the majority of participants being males. This gender distribution was in agreement with many samples studied in the country, for example, a group of researchers conducted a large screening program in the central region of the KSA by reviewing the patients’ medical data to assess the current prevalence of major chronic diseases including T2DM. The researchers found that prevalence was higher in males (Al-Daghri et al, 2011). Another recent study in KSA observed that the frequency of diabetes was also higher among men (Al-Shahrani et al, 2016). The trend has been also confirmed in the prior rationale paper for this thesis that was published. The systematic review and meta-analysis done indicated that the estimated future growth rate among Saudi men and women was 0.8% and 0.6% per year, respectively (Alharbi et al, 2014). In addition, a similar distribution was also reported in the neighboring countries of Oman and Kuwait (El-Shafie & Rizvi, 2010; Ahmed et al, 2013), and similar international studies that utilized the PACIC-5As instrument in China,
Australia, Netherland and Switzerland (Cramm & Nieboer, 2012; Liu et al, 2013 Aung et al, 2014; Iglesias, Burnand, & Peytremann-Bridevaux, 2014). While it is known that males generally have a shorter life expectancy than females, Bassiony, in his systematic review of the lifestyle risk factors in KSA, reported that the habit of smoking was more frequent among Saudi males (Bassiony, 2009). Similarly, in this thesis, the majority of the smokers were males. Perhaps, because KSA is a highly patriarchal society this might place men at risk for higher levels of chronic psychological stress than women. In turn, this might contribute to stress over time leading to several cell aging mechanisms and ultimately to T2DM. These factors taken together, could partially explain why there were more Saudi men than women with T2DM (Al-Nuaim, 1997; Al-Attas et al 2010; Al-Daghri et al, 2011).

Marital status and age distributions for this thesis were consistent with other reports form Riyadh and different cities in KSA. These reports indicated that diabetes was higher among married individuals compared to the unmarried, and among individuals over forty years of age. Salam and Siddique found that married individuals had a greater risk of diabetes when compared to unmarried people (Salam & Siddiqui, 2013). This is compatible with other findings of studies conducted in different regions in KSA (Al-Aboudi et al, 2015, Al-Baghli et al., 2010). Salam & Siddiqui argued that this distribution could be explained by the fact that the unmarried individual was free of social commitment, thus he or she might have more time for doing exercises and also had greater freedom to control their diet (Salam & Siddiqui, 2013). In addition, age was an important risk factor associated with diabetes as the majority of participant in this study was over 40 years which concurs with reports from other parts of KSA (Al Hayek et al., 2014; Amin et al., 2014; Murad et al., 2014; Al-Shahrani et al, 2016)
Regarding the clinical characteristics of the sample, because the information was self-reported, the data included very limited clinical indicators. This thesis has shown that about 20% of the diabetic patients were suffering from disease complications which was much lower than that observed in other local and international studies in Malaysia, Libya, India, China, and Iran where the prevalence ranged from 50-78% (Afkhami-Ardekani & Zahmatkash, 2009; Abougalambou et al., 2011; Roaeid & Kadiki, 2011; Vaz et al, 2011; Liu et al, 2013; Khan et al, 2014). However these dissimilarities might be due to differences in assessment methods as the current study was based on self-reported data.

On the other hand, the glucose control level was reported as poor among 82% of the study sample. Poor glycemic control in this thesis was also found in different healthcare settings as in other local studies. Comparing this figure with the sample characteristics from previous studies at the primary and tertiary healthcare settings, the percentage of poor glycemic control in this thesis was lower than some samples studied in diabetes clinics, and similar to other samples recruited from the PHC setting. For example, Qari compared the glycemic control among the patients with diabetes who were regularly followed up at a government and private hospital in the western area of KSA. Poor glycemic control was reported in 42% of the government hospital patients and 46% of those in the private hospital (Qari, 2005). Another similar study in the same government hospital which was compared with another private hospital, reported that 88.5% of patients with diabetes in the former and 39.1% in the latter did not achieved the glycemic control goal (Al-Shaikh, 2006). Al-Rowais, who has conducted a hospital-based study in Riyadh, found that the rate of "uncontrolled HbA1c" for diabetics attending a university hospital was about 87% (Al-Rowais, 2014). By comparing these results to the PHC sample characteristics, a
retrospective medical record-based study found approximately the same distribution where 80% of the patients had poor HbA1c levels (Azab, 2001). On the other hand, the rate of uncontrolled diabetes in another PHC clinic in Riyadh was 59% (Alsulaiman et al, 2015). The differences of uncontrolled diabetes rate in the above-mentioned studies might be because of the clinical measurement of the glycaemic control level in Qari and Alsulaiman studies had a higher threshold (HbA1C of > 8%) (Qari, 2005; Alsulaiman et al, 2015).

Another matter to be considered is the central stratum of the ICCC framework which is represented by patient-healthcare and provider/community interaction within the micro level of KSA health care system. This thesis assesses the patients’ experience with T2DM management by utilising the PACIC-5As instrument. While there were more than ten different language versions of the questionnaire available on the official website of the MacColl Center, none of them were suitable for Arab nations. Therefore, it was necessary to translate the instrument into the Arabic language. As described previously in Chapter 4, the translation process of the PACIC-5As items into the Arabic language was performed following a forward/backward multi-step procedure in the line with the WHO recommendations for translating and adapting an English instrument into different languages (WHO, 2008). A comparison of the Arabic translated instrument with the original and other international translated versions demonstrated high reliability, internal consistency, and test-retest reliability. This confirmed the applicability of the instrument to Arabic-speaking patients (Glasgow et al., 2005a: Aragones et al., 2008; Koley et al., 2015). Moreover, the developers of the original English version noted that the PACIC-5As scores should not be related to the patients' demographic characteristics (Glasgow et al, 2005a). Indeed, the literature and this thesis found that the PACIC-5As scores were not
significantly correlated with the medical or socio-demographic characteristics (Rosemann et al, 2007; Aragones et al, 2008; Spicer et al, 2012). This suggests that, overall, the translated questionnaire could be used in other Arabs countries and still maintain its excellent psychometric properties.

The results of the overall mean score of the PACIC-5As (reflecting elements of the ICCC) and the mean 5A score (reflecting structured behaviour change counselling) demonstrated that diabetic patients perceived they were receiving a low level of patient-centred, structured and collaborative care according to the ICCC, particularly the areas of health service organisation and community. When compared to the different data for the PHC diabetic patients from USA, Germany, and Switzerland with the current study sample, the Saudi patients fell short in receiving aspects of care on the sum-score and all subscales of the PACIC-5As and the 5As in the tertiary diabetes healthcare settings. For instance, on the overall PACIC-5As and 5A scores, the patient scored 2.5 vs. 3.2 in the U.S. study. In the U.S. study, patients scored, on average, 3.6 for ‘patient activation’ in comparison to 2.6 identified in the present study; 3.5 for ‘delivery system/practice design’ vs. 3.02 in the present study; 3.0 for ‘goal setting/tailoring’ vs. 2.29 in the current study; 2.9 for ‘follow-up/coordination’ vs. 2.10 in the current study, and 3.4 for ‘problem solving/contextual’ vs. 2.82 in the current study. Higher scores have also been reported in other international studies carried out in Switzerland and Germany. In a Swiss study (Frei et al., 2014) researchers compared the normal care of people with T2DM with a new and better-structured chronic care, incorporating elements of the CCM. In the ‘usual care’ group the mean PACIC and 5A scores were 3.1 and 3.0, respectively, and these figures were higher than the scores reported at the diabetes care centre in the present study. (Glasgow et al, 2005a; Aragones et al, 2008;
Szecsenyi et al, 2008; Frei et al, 2014). However, like the above-mentioned studies, in this thesis, "Follow-up and coordination", "Arrange" and "Goal Setting/Tailoring" were subscales that were rated as the lowest. The Saudi patients felt that their care was poorly organised in terms of the follow-up of the cases and incorporating their personal preferences. This is in contrast to the prior findings of the above-mentioned studies. A possible explanation for the results found here might be the lack of adequate support systems, the success of which, as noted earlier, depended on the different cultural contexts of the patient-providers’ relationship.

Based on the PACIC-5As subscales mapping with the ICCC framework elements in Chapter 6, the results of this thesis revealed that the healthcare services organisation elements were rated the lowest. According to the Saudi diabetes clinical guidelines, diabetic patients should visit the diabetes clinic at least once every three months (MOH, 2013a). However, this thesis found that the ‘Arrange’ and "Follow-up and coordination" constructs for providing specified plan for follow-up and making referrals to more intensive or specialised treatment had the lowest mean score (1.89) and (2.10) out of 5. The lack of follow-up systems was also identified in local studies. For example, a study was conducted to assess the factors contributing to non-compliance among the diabetic patients in the Al-Hasa region of KSA by utilizing questionnaires. It found that irregularity of follow-up and the appointment system were important factors for the non-compliance (Khan et al, 2012). Another study conducted at a university health clinic about diabetics’ annual follow-up showed that 58.6% of diabetics had their HbA1c tested at least twice, 29.3% had one retinal screening and only 4.3% had a formal podiatry visit (Alsulaiman et al, 2015).

The second lowest element of the ICCC framework was related to community support. In accordance with the findings from the macro and meso levels, there was a
lack of community support at the micro level as well. In this thesis, the mean score of the "Assist" construct for providing social and environmental support to the patient was (2.48) out of 5. Particularly, by looking at the mean score of the 26 PACIC-5As items, the lowest mean scores were related to these statements “Encouraged to attend programs in the community that could help me” and “Encouraged to go to a specific group or class to help me cope with my chronic illness” which were (1.40) and (1.31) out of 5, respectively. The developer of PACIC-5As instrument argued that community and cultural factors had a major impact on diabetes care (Glasgow et al, 2005a). There is evidence to support this argument from cross-sectional study studies done in China using the PACIC-5As instrument to evaluate the relationship between the questionnaire scales and the utilisation of the community centre by 960 patients with T2DM. The study showed that the role of the community centre had the highest summary score of the PACIC-5As and was positively associated with the utilization of the community health centres for monitoring and treating diabetes (p<0.001) (Liu et al., 2013).

As discussed previously at the meso level of the KSA healthcare system, despite the effective programs provided by the SCAD, the medical practitioners interviewed were not aware of the existence of such groups or the community support systems. This indicates the lack of a coordinated and unified system of diabetes management. Although there have been very few studies that assessed community support in diabetes management in KSA, one was conducted using face-to-face interviews with Saudi T2DM patients. The researchers found that a lack of family and community support was one of the major barriers to healthy eating (Al-Khudairy et al, 2014). In another study, Alneami and Coleman conducted a systematic review to explore barriers to control T2DM in KSA and suggested that effective partnership
between healthcare providers and community leaders could lead to effective diabetes prevention and management in each Saudi community (Alneami & Coleman, 2016). Indeed, providing social and community support groups and having access to community institutions have been consistently linked to better health outcomes for patients with various chronic illnesses (Glasgow et al, 2005a; Liu et al., 2013)

Consideration will now be given to the third element of the ICCC framework, the self-management support scales that were identified in the PACIC-5As instrument as "Patient Activation", "Goal Setting/Tailoring", "Problem Solving/Contextual", "Assess", and "Agree". Like other subscales in the instrument, these measures had a low medium ranged score from 2.29 to 2.69. These results were much lower than those from other international studies utilizing the PACIC and PACIC-5As instruments. For example, a study conducted in German used the PACIC5As to compare the experience of T2DM patients enrolled in diabetes self-management programmes with patients receiving the usual care services. The findings showed that the mean scores of the self-management support scales for non-diabetes self-management programme patients and those enrolled in the programme ranged from 2.50 to 3.04, and 2.91 to 3.39, respectively. In addition, generally, the patients enrolled in the program scored significantly higher (3.21 of a possible 5) than the patients who did not (2.86) (p 0.001) (Szecsenyi et al, 2008). In the USA, a cross-sectional survey conducted to examine the relationship between the PACIC-5As scores and self-management behaviour measures for 4,108 adults with several chronic diseases, including diabetes. It found that the use of self-management resources and self-reported adherence to medications was positively associated with the PACIC-5As, odds ratio ranging from 1.20 to 2.36 (Schmittdiel, et al, 2007).
The low scores reported for Saudi diabetic patients are in line with the lack of qualified diabetes educators which was also found in the meso level of this thesis. Previous studies in KSA have confirmed the limitation of self-management programs in the healthcare setting. For example, a group of researchers assessed the effect of the 5-day intensive diabetes health education program provided by a trained healthcare team on metabolic control among patients with T2DM in the University Diabetes Center in Riyadh. For this course, different educational methods were used, including writing boards, photographs, various demonstrations and videos, and log books for recording. Furthermore, all materials used for this were in the Arabic language. After one year, body weight, blood pressure (both systolic and diastolic), fasting blood sugar, triglycerides, total cholesterol, and low density lipoprotein all had improved significantly (P<0.0001) (Al-Shahrani, et al, 2012). Another group of researchers conducted a prospective cohort study to assess the effectiveness of an education program on T2DM patients in a tertiary hospital in KSA. The result after the patients were subjected to the program revealed that there was a definite correlation between good patient self-management and good glycemic control where the percentage of patients who took the initiative to monitor their own blood-glucose levels increased from 21.1% to 44.2% (AlHayek et al, 2012).

The last two scales of the PACIC-5As "Decision Support" and "Advice" were mapped under the health information system in the ICCC framework. Although approximately half of diabetic participants in this study reported low levels for all the PACIC-5As scores, the health information items had higher mean scores. Earlier international studies of the same kind had reported a higher level for providing and sharing information with patients (Glasgow et al, 2005a; Schmittdiel, et al, 2008; Frei et al 2014). Sharing information with the patients required good linguistic and
communication skills which might be a challenge for the KSA healthcare system as there was a lack of qualified local medical staff and because the majority of the nurses were non-Arabs (Al-Shahrani, et al. 2012). According to the result of this thesis, the proportion of diabetic patients who did not receive enough advice was higher than in other Saudi studies. For example, Al-Khaldi and Khan (2000) reported that 20% of diabetic patients did not receive healthcare education. However, the researchers applied a different pre-designed checklist to collect the data, and consequently, the estimated percentage of participants in this study did not give any indication about the quality information provided.

In conclusion, several factors related to the healthcare service organization as community support, patient self-management, and the information system had an impact on the level of patient-centeredness and most of the Saudi respondents in this thesis felt that they were helped to discover and develop the inherent capacity to be responsible for one's own condition. Coordinated care and multidisciplinary team approach are critical to success in diabetes care and complications prevention. Encouraging patients to ask questions was found to be the only method of seeking information, but it was also a mechanism for patient participation in the clinical dialogue which was positively associated with patients' satisfaction and health outcomes. Likewise, encouraging the exchange of information between the health care provider and the patient is the main purpose of medical communication which is also considered as a facilitating mechanism for a patient-centered approach (Nolte and McKee, 2008; Gugiu et al, 2013; Beran, 2015). The PACIC-5As findings revealed that the micro level of KSA health system was characterized by a lack of community partnership with more of the physicians' dominance and less of a consideration for the patients’ concerns and expectations as well as their role in their own T2DM self-
management. However, organizational, cultural, and technical factors were identified in the macro and meso levels of the KSA healthcare system. This included, among other things, a lack of local qualified clinical staff that caused an increased in the workload pressure in the clinics. Additionally, the short time allotted for each visit might have limited the effectiveness of the healthcare provided.

7.6. The Strengths and Limitations of the Study

This thesis has provided the first healthcare system analysis of KSA based on a multi-method approach combining documentary analysis, workers’ interviews, and a patients’ survey. What matters, therefore, for such research is its contribution to knowledge and the transferability of its findings to other similar settings. This section provides the main strengths and limitations of the study.

7.6.1 The Strengths of the Study

This study possesses several strengths with the first one being the adoption of the ICCC as a theoretical framework for the thesis and which constituted an effective and novel approach to assessing the efficacy of the Saudi healthcare system. Although previous studies in KSA had reported similar inadequacies in T2DM management, the use of this model has revealed that the previous literature was very limited in the scope of the research. This is so because the study presents the perspective of both the providers and the patients and identified the hindrances at the political, sectorial, and individual levels by drawing on the ICCC framework for examining the healthcare system’s response to T2DM. It was a multi-method approach using iterative and reflexive methods for the collection and analysis of the primary and secondary data that were rigorous, yet pragmatic.
Secondly, the PACIC-5As was found to be a valuable tool in assessing care delivered to patients with chronic diseases, including diabetes (Glasgow et al., 2005a; Aragones et al., 2008; Koley et al., 2015). In this thesis, the PACIC-5As was used as a micro level assessment of the ICCC framework. Given the increase in the number of T2DM patients in the Arab countries (Fatani et al., 1987; Al-Baghli et al., 2010; Alharbi et al, 2014), there is a pressing need for using the ICCC to guide the healthcare system changes in these countries and to establish the validity of the PACIC-5As for evaluating the healthcare system in Arab-speaking nations. I believe that the Arabic version of the questionnaire will help to fill that void. This version may be an important tool for Arab health systems to use in assessing and improving the quality of chronic disease care.

Thirdly, an important benefit accruing from this research is the dissemination of the study results through the publication of two important papers of in peer-reviewed, international journals. The first paper was a systematic review and meta-analysis done to estimate the current and future prevalence of T2DM in KSA and this paper was considered as a rationale for selecting T2DM as a lens through which to explore the KSA healthcare system (Al-Harbi et al, 2014). In addition, a second paper on the significance of analysing healthcare policy documents with regard to T2DM management in KSA was presented (Al-Harbi et al, 2016). These two studies are also the first of their kind to deal exclusively with Saudi Arabia. Their contents can potentially help to persuade healthcare planners, decision-makers and healthcare providers to consider the plethora of factors shaping T2DM self-management outcomes.

Fourthly, although this study was country specific, the results can be generalized for other developing regions, particularly GCC countries, where their
MOHs are burdened by huge healthcare expenses. This becomes even more important because Arabian gulf countries are quite similar in terms of their economic growth, culture, norms, and health behaviors which, in turn, makes diabetes prevalence in four of GCC countries among top 10 countries worldwide (IDF, 2013).

7.6.2 The Limitations of the Study

This study applied different methods, and the limitations to each method must be taken into consideration when reading the findings. The first limitation related to the documentary analysis. In order to assess the KSA healthcare system, it was crucial to carefully analyse the policy documents to ensure alignment between the policy objectives and the intended outcomes. In this stage, the researcher decided to conduct a documents analysis because documents are a more accessible source of information than conducting interviews with hard-to-reach, time-limited, policy makers. However, there was a limited number of national official documents, which made it necessary for the researcher to include regional surveys and gray literature. Due to this, it was not easy to demonstrate performance of the KSA National Diabetes plan at the general level. The objective of this thesis was not to demonstrate direct links between healthcare policy and its implementation regarding health outcomes. Instead, the aim was to explore how various aspects of healthcare policy, namely, actor, content, process, and context influenced the healthcare system.

Secondly, there were limitations regarding the qualitative study. Although a wide range of stakeholders were enrolled to participate in this study, GPs from PHC centers were not included. Therefore these eligibility criteria meant that their views were not represented. Furthermore, questions were asked regarding support systems which, as this research indicates, do not exist in Saudi Arabia. Due to the lack of
existence of such systems, most of the questions were answered based on perception rather than on more objective data or experience.

Finally, limitations related to the patients’ survey. As a female researcher, it was impossible to get access to the male patients’ waiting area to recruit these participants. Additionally, patients were selected from tertiary care centers which are considered a referral site, run by endocrinologists. It has been shown that T2DM patients who are treated in specialised healthcare settings have higher PACIC-5As score than those treated in PHC centers (Glasgow et al., 2005a; Aragones et al., 2008; Koley et al., 2016). However, the PACIC-5As questionnaire was a useful tool to obtain general information about the quality of patient-providers and the community interactions.

7.7. Recommendations for Policy

T2DM remains a significant global healthcare challenge of this century. However, the following recommendations may assist the KSA healthcare system with establishing a foundation for successfully managing this chronic disease now and in the future.

1- The dramatic increase of chronic diseases in KSA demands innovative restructuring of services and a shift from reactive to proactive care that puts people with T2DM at the heart of their management. At present, the healthcare system is organised around an acute episodic model of care which no longer meets the needs of many patients with chronic conditions (Wagner, 1998; Bodenheimer et al., 2007; Coleman et al., 2009; Nutting et al., 2007). If policymakers were to take action regarding plans, policies, healthcare service organisations and the community to reduce the threats of the chronic conditions facing the population,
the healthcare system and the economy. These could then be used to inform the
decision-makers, thereby significantly improving the treatment of chronic diseases
in the county (WHO, 2002; Epping-Jordan et al., 2004). A notable
recommendation from this study is that the ICCC framework could be used as a
guide for updating the KSA healthcare systems to include explicit consideration of
Saudi culture when implementing treatment order to better meet the needs of
chronic conditions like diabetes.

2- The most important recommendation identified by KSA policymakers brought out
in this thesis was the need to establish integrated care. The evidence reviewed in
this study has demonstrated that integrated and coordinated care yields better
quality outcomes and lower service utilization (Nolte and McKee, 2008; Gugiu et
al., 2013; Beran, 2015). Thus, an integrated healthcare system could be a major
solution to the challenges of sustaining the KSA healthcare system and optimising
coordination and continuity in healthcare over time and in different settings.
Furthermore, it would also help to foster a culture of communication (Leutz, 1999;
Woods, 2001; Kodner & Spreeuwenberg, 2002). Indeed, this investigation has
shown that a better quality information system would benefit healthcare in KSA
greatly. Therefore, it would be valuable to extend the coverage of the current
diabetes registry in order to improve coordination and develop information sharing
strategies across all healthcare settings.

3- One of the key findings of this study is the lack of local, qualified, medical staff in
KSA. In this case, the implementation of multi-sectorial links with other
government departments and the private sector, especially the Ministry of
Education, would promote basic diabetes management skills and education for
PHC workers, as well as the re-allocation of training resources in favor of the need for chronic disease management.

4- Most chronic diseases, including T2DM, are preventable, as are the complications arising from these conditions, but the combined commitment and action of healthcare organisations, the community, and other government sectors are crucial for the successful promotion of disease prevention (WHO, 2002; Epping-Jordan et al., 2004; Epping-Jordan et al. 2005). As such, policymakers in KSA could consider developing and implementing preventive measures for every kind of health interaction. The PHC, in particular, could be strengthened to better prevent and manage chronic conditions. Most importantly, prevention efforts could be tailored to fit within Saudi social and cultural contexts; for example, consideration could be given to utilizing the powerful voices of "religious leaders" to spread messages about healthy lifestyle behaviors.

5- This investigation has demonstrated that women have an influential role in the management and control of diabetes because they usually make lifestyle choices on behalf of their families. However, the study has also shown that male domination is the cultural norm and gender-based subordination is deep-rooted in the consciousness of the Saudi community. This is worrisome because community norms influence women more than men (Midhet, 2010; Mobaraki, 2010). However, there is an opportunity for KSA policy makers to use woman as a vehicle to promote a healthy lifestyle. For example, sports classes could be introduced to girls’ schools, open spaces dedicated to female physical activities could be created, and dietary health messages could be promoted via social media. As the evidence in this paper has indicated, such measures would not only enhance the health of Saudi women, but would also extend to include the entire family.
7.8. Call for further research

This study can be extended in two major ways. Further research needs to be done to investigate and understand the socio-cultural contexts that affect diabetes management as viewed by patients and their families. For example, a qualitative study could be done involving more than one researcher (ideally one man and one woman) who can collect data through field studies undertaken throughout all the regions of Saudi Arabia to see if discrepancies exist across regions and which strategies might work for different population groups in KSA. Secondly, research is also required to collect primary data about the quality of healthcare provided by the primary healthcare services. The research should further evaluate the appropriateness and comprehensiveness of this care from the PHC workers’ prospective. Thirdly, since several effective preventative strategies are known internationally for T2DM, then to reduce its negative impact, it is worth exploring the possibility of employing some of these strategies in the Saudi context.

7.9. Conclusion

This research project explored the current KSA healthcare system’s response to T2DM management from a variety of stockholder’s perspective. From the combined discussion of the documentary analysis, the practitioner interviews and the patient surveys, major critical points were identified. The problem with managing T2DM in KSA is that despite its increasing prevalence, not all diabetic cases are detected and the healthcare system is not well-equipped to take care of identified cases. In addition, the preventive and promotional strategies used by the healthcare system are not integrated. Consequently, there is an ever increasing load on the system, resulting in poor care (Alharbi et al, 2014; Alharbi et al, 2016b).
Generally speaking, reforms in the healthcare system are usually implemented without any attempt to assess to what extent these systems respond to patient needs, especially in developing countries (Mills et al, 2006; Atun et al, 2013; Beran, 2015). In this thesis, the assessment of the healthcare system has been considered within the Saudi context. The KSA was chosen for this study because it has been undergoing major demographical, social and economic changes which have caused an increase in the prevalence of chronic diseases like diabetes (Alharbi et al, 2014; MOH, 2015). Consequently, these changes in the country are posing considerable challenges to the healthcare system. In order to explore the management of chronic diseases, T2DM was chosen as a lens through which to assess the overall healthcare system. The ICCC framework was the road map for this thesis (WHO, 2002; Epping-Jordan et al., 2004).

At the center of this model was the patients’ interaction with healthcare providers and the community within the environment of the healthcare organizations and their policies (WHO, 2002; Epping-Jordan et al., 2004; Epping-Jordan et al. 2005). Working from this perspective has highlighted the significance of the Saudi socio-cultural factors that influence patients’ behavior and substantially affect healthcare provisions and the general healthcare system. Within this framework, it was observed that the ICCC did not significantly recognize community sensitivity, particularly, the community culture, religion, norms, and beliefs (WHO, 2002; Epping-Jordan et al., 2004). Nevertheless, both community support and the health information system emerged as intersecting elements that needed to be integrated into all the ICCC levels in the KSA healthcare system. Furthermore, considering the socio-cultural factors that affect patient-providers’ interactions at the micro level can help the policymakers in tailoring preventive programs and initiatives based on the community needs. Regardless of this gap, the ICCC framework provides a
comprehensive means of identifying the challenges in the current KSA health system. The adjusted KSA’s ICCC framework in managing T2DM is presented in Figure 17.

![Figure 17: The adjusted KSA’s ICCC framework in managing T2DM](image)

As the KSA has a stable economy and shows huge economic growth, the Saudi MOH intends to pay attention to the supply side of healthcare. This includes the healthcare budget as well as the number of PHCs, diabetes units and centers (MOH, 2015, Alharbi et al, 2016b). This approach is inherited from the biomedical model of healthcare. The Saudi healthcare policy documents which were analyzed using the Walt and Gilson's policy triangle model, state that public policies should be formed bearing in mind the impact of the context (Walt and Gilson, 1994; Gilson, 2013). According to this research, another key problem in the case of the Saudi Arabian government's policies towards the management of T2DM is that it ignores the KSA context. Economic and socio-cultural factors influence the healthcare system in
various ways in KSA. The MOH has a narrow view when it comes to equity regarding the social aspects that affect patients’ access in that the KSA has interpreted the health plan solely on the basis of the biomedical model. The National Executive Plan for Diabetes Control (2010-2020) did not address the need for sensitivity to the Saudi’s culture, even though WHO “Health For All Strategy” advocates for social equity as a means of promoting health (WHO, 1998).

This study provides a rich cases example of culture dissonance. Clearly, religious belief, gender issues, traditional values and the presence of a large workforce comprised of foreign nurses are all important culture issues as highlighted by this thesis (Al-Saeedi et al, 2003; Al Quaiz & Tayel, 2009; Al-Hazzaa et al, 2011; Aldossary et al, 2102). Islamic principles affect almost all aspects of Saudi lifestyle. The same goes for gender which creates obstacles for women who are not allowed to carry out physical activities or communicate with the opposite sex. Reliance on traditional treatment also proved to be another challenging issue at both the level of the patient as well as that of the healthcare system. This is further compounded by the difficulty of arising from non-Arabic nurses’ inability to communicate effectively with patients which, in turn, can affect interpersonal relationships between the two. This lack of cultural sensitivity can have a significant negative impact on the quality of healthcare delivered. Comparing the identified KSA healthcare system components with the Donabedian system-based framework (1980), the process used by the KSA system is likely to be influenced by religious and social norms since the Saudi society has different values from those of western society. The cultural dissonance found within the society certainly has serious implications for the healthcare system and adopting a healthcare model from different culture can result in less favorable health
outcomes. Therefore, in order to achieve the desirable outcomes, the MOH must also consider the psycho-social element of health.

Exploring the Saudi healthcare system through primary and secondary data revealed the following important finding. Despite the availability of specialised healthcare services, the system is fragmented and still organized around an acute and episodic model of care that no longer meets the needs of patients with chronic conditions. In KSA, there is an increasing ageing population and a decrease in communicable diseases have produced this incongruity between health problems and healthcare where non-communicable diseases, including T2DM, are on the rise (MOH, 2015). However, this situation in the country matches closely the findings of many other national healthcare systems across Middle Eastern countries. Even though this thesis was undertaken in a completely different healthcare system, the findings are remarkably similar to those from elsewhere, indicating a broader relevance (Kilic et al, 2014; Ahmad et al, 2015; Ben Romdhane et al, 2015; Faraji et al, 2015).

Patients, healthcare providers, and most importantly, policymakers, should be aware that managing T2DM requires a different type of healthcare provision.

The process of working through the ICCC has revealed a lack of integration across sectors, settings, providers and time. There is also the lack of integration emerging as a common weakness of the KSA’s healthcare system based on the documentary analysis and further highlighted by the interviews. This was evident from the low PACIC-5As scores, particularly for "Follow up and Coordination" and "Arrange". The most important lesson from this was that the KSA healthcare system needed to guard against the fragmentation of its services. The kind of healthcare needed for T2DM must be integrated to ensure information is shared across different levels of the service, among the various healthcare teams, and across time (i.e., from
first patient contact and onwards). Most of the interviewees in this thesis stated that diabetes management in KSA would benefit from employing the integrated approach.

Effective communication and information sharing among members of the healthcare team, also known as "horizontal integration", is the heart of a multi-disciplinary health team approach. This is in keeping with the ICCC’s support for an integrated, patient-centered, team-based and community-oriented approach. However, the establishment of partnerships and the employment of qualified medical staff are needed to ensure the effectiveness of the integration (WHO, 2002; Epping-Jordan et al., 2004; Epping-Jordan et al. 2005; Atun et al, 2009). All of this should result in savings in the cost of health (Russell et al, 2009). On the other hand, better integration between PHC and the specialized diabetes clinics, also known as "vertical integration", was shown to be improve the continuity of care. However, without an infrastructural framework, the integration of the system will be stifled.

Comprehensive care for T2DM extends beyond the MOH, therefore, partnerships are crucial for the effective use of resources and to reduce the isolation of the different facilities and sectors. Thus, improved collaboration between all these players becomes important. Unfortunately, the MOH has not offered any strategy to develop collaboration as a means of ensuring effective linkages between the various ministries (MOH, 2013c; MOH, 2015). Therefore, in order to facilitate multi-sectorial collaboration in KSA, logistic adjustments are needed. For example, there could be, among other things, the provision of a financially pooled budget across several budget lines; the establishment of financial incentives to motivate coordination between different organizations; and the promotion of the use of evaluation techniques to monitor multi-sectorial actions (Mendis & Chestnove, 2013). Furthermore, before establishing legislation for organizational evaluation, an adequate surveillance and
monitoring systems across all relevant departments is needed to provide information for policy reforms and for tracking progress as well (Mendis & Chestnove, 2013).

Although the MOH has initiated a PHC health information strategy as a part of the National e-Health Plan, nevertheless, the strategy remains a work in progress as most of PHC still used paper-based medical records. Generally, the information system, including that used for appointments, is not firmly established in KSA and this is likely to impede the provision of continued care for patients (MOH, 2016). The interviewees recommended that a robust and integrated HIS would be beneficial for technological health interventions such. In the long run, it could help to promote the use of EMR that could also assist in evidence-based treatment decisions (Alharbi et al, 2016a). Improving the HIS would not only enhance integration, but it would also facilitate planning, auditing and improving the diabetes plan (Atun et al, 2009; Alharbi et al, 2016a). The case of KSA is similar to that in other countries as the WHO report indicated that in the majority of developing countries, the national health information system had a limited capacity. However, few countries had implemented a standardized registry for tracking T2DM epidemic, including disease risk factors and information on the social determinants which would allow them to routinely collect data to monitor the implementation and outcomes of their healthcare plans (WHO, 2011).

There do presently exist a number of successful integrated experiences from which the KSA policymakers can learn. For example, in Scotland, policy initiatives have sought to encourage a greater integration of healthcare and community services for the elderly and disabled. In order to arrive at this kind of integration, the Scottish government has set key requirements, such as, a model for the integration; a listing of the scope of the functions and services that are to be delegated to each sector; and
provisions for financial and operational management. Each of the integrated sector, for example, health and social services, participated in the strategic planning to bring together the primary and community health services with a range of specialist services. This integration had a positive impact on both of the providers and the patients. As for the workers, they felt more engaged in carrying out their responsibilities and were more committed to continually improve the information, support, care, and treatment they provided. One positive outcome from this was the patients being able to manage themselves more effectively (Woods, 2001). Therefore, in order to establish an integrated system of T2DM management, the KSA government should provide leadership through the alignment of the government sectors with the community.

Another fundamental challenge affecting the KSA`s healthcare system is the shortage of local qualified staff. While it is good that the number of medical education institutions has been increased recently in the country, however, as mentioned earlier, the training facilities in the area of diabetes are few and the number of specialized healthcare professionals is low as there is only one diabetes educational course provided at a university hospital (KSAU, 2017). In the country, diabetes education is not included in the general course curriculum, therefore, policymakers in the Ministry of Education need to update the curriculum and also include effective teaching methods in the area of health promotion. It has been shown that increasing the professionalism of the physicians can lead to an improvement in the quality of the programs. For example, the adoption of the case study technique to teach diabetes to nursing students has enabled them to develop a clearer understanding of the disease (Sandstrom, 2006). Furthermore, the development of a continuing education program
is also very important as it would allow for various courses on diabetes to be provided inside and outside the health institutions.

In addition, the interviewees indicated that there was little knowledge among them about the diabetes clinical guidelines which meant the practitioners in the clinics and PHC facilities were working on their own to manage T2DM, rather than as part of a multidisciplinary team. This could result in a fragmentation of the service with healthcare providers trying to educate or treat the patients on an isolated basis with no continuity of care for the patient or any form of collaboration between these providers and the clinical staff. These factors point to a gap in the implementation of the PHC approach with the services they provide lacking continuity and comprehensiveness (De Maeseneer et al, 2003; De Maeseneer et al, 2008). However, a regular process of auditing and obtaining feedback can improve the chances of the physicians following the clinical guidelines as was made evident from a local study done by Al-Hussein (2008).

Nurses have a major role in diabetes management, however, in KSA; nursing composes a challenge for the healthcare system for the following reasons. Firstly, the number of non-Arab nurses in the healthcare services is quite large. In addition, those nurses deal with a sizable sector of consumers who speak mainly the Arabic language with a variety of accents. Secondly, not much orientation is given to the nurses on local traditions and the prevalent health-related beliefs and culture (Aldossary et al, 2102). This situation creates a complex environment for provider-patient interaction which has been evident in the PACIC-5As results in this thesis. In this regard, there is a need to increase the proportion of local nurses so that culturally appropriate holistic care can be delivered. Without shared culture and language, it will be difficult to deliver effective health care to T2DM patients (Aldossary et al., 2008). In addition,
training the existing local nurses can shift some tasks form the physicians. For example, the first experience of upgrading nurses, known as "nurse-led", was in Sweden in 1990 where the nurses were enabled to work independently in these clinics after receiving special education and training. The immense benefit from this experience has spread the concept to many other countries (Strömberg et al., 1998). In light of the current medical staff shortage in KSA, this strategy could be applied to gradually reduce the gap in the number of persons in the present workforce.

As previously mentioned, partnership between the MOH and the Ministry of Education is needed to help overcome the lack of local qualified medical staff. A good example of how this could possibly be done can be seen in the experience of the Estonian government. This country has successfully implemented a number of reforms which have enhanced the effectiveness of PHC system. These include specialist training for family practitioners and introducing diabetes evidence-based-guidelines. The key achievements of these reforms were the increased professionalism at the PHC level and enhancing the role of physicians and nurses which substantially increased the number of diabetes consultation in PHC clinics. There, consultations grew between 2000 and 2003 by almost 62% with reduced hospital referrals rates. The Estonian MOH recognized that partnership between the health and educational sectors, strong leadership, and good coordination among the healthcare system levels were needed to successful implement the healthcare policy (Atun et al, 2006).

Beyond the aforementioned factors cited as hindering the KSA’s healthcare system, the review of the policy documents indicated a gap in the preventive strategies in the governmental plan. T2DM, like most chronic conditions, is preventable. Additionally, many of its complications can be prevented (Huang et al, 2009; IDF, 2013). Implementing prevention programs has been found not only to
reduce the rate of diabetes complications, but also to help to lessen the rate of patient’s visits and hospitalization and the related direct and indirect costs (Kuo et al, 2011). In analyzing the KSA National Diabetes Plan documents, there was also a weakness in the early detection and the prevention strategies regarding such as increasing physical activity, and the limiting prolonged, unhealthy nutrition habits (Al-Saeedi et al, 2003; Al Quaiz & Tayel, 2009; Al-Hazzaa et al, 2011).

Improving access to the PHC was paramount for providing chronic disease services through the continuum ranging from care to health promotion and prevention, early detection, and responding to acute episodes of diseases. Access to early detection of T2DM is also a key requirement. However, in KSA, like most developing countries, the PHC is poorly resourced (Al-Khaldi et al, 2002; Alfi, 2004; Khan et al, 2010). Subsequently, patients are usually diagnosed after they have already developed complications like foot or kidney problems. At this disease stage, tertiary health care becomes essential and usually increases the burden on the healthcare system budgets and worsens the health outcomes as was confirmed by the medical indicators obtained from the PACIC-5As results.

The community and social sectors are critical to the care of T2DM patients. They can fill the gap in the services or resources provided by the healthcare centers (De Maeseneer et al, 2003). Unfortunately, such a community support system does not exist in KSA as there was only one community charity association available in Riyadh city. In addition, no formal links exist between healthcare organizations and the community resources in KSA. The interviews and surveys indicated little or no collaboration between the healthcare facilities and the SCAD that provided on-going health educational programs. The literature suggests that strong links between clinical and community-based services is an important element in a successful chronic disease
healthcare system (De Maeseneer et al, 2003; De Maeseneer et al, 2008; Gardner et al, 2011). However, the PACIC-5As results revealed that most of diabetic patients were not being referred to any community groups, thereby, adding to the clinical-based facilities patient load which the community-based facilities were usually designed to relieve. Public awareness in KSA may be a key to further improvements to diabetes management and prevention. This thesis provided primary and secondary data based on interviews and documentary analysis, respectively, and identified a lack of awareness about diabetes by the Saudi at both the macro and meso levels (Sharaf et al, 2013; Al Shahrani, & Baraja, 2014; Alsunni, Albaker & Badar 2014; Bani, 2015). These findings were also confirmed at the micro level where PACIC-5As instruments produced a low mean for the self-management aspects and showed that the majority of the Saudi patients were unaware of their exact measure of their HbA1c. For these reasons, it can be seen that a lack of public awareness was an important challenge for the healthcare system. Unfortunately, the KSA healthcare system seems ill-prepared to offer educational interventions to improve public awareness regarding negative lifestyle behaviors that contribute to so many chronic diseases. In addition, there is a lack in the self-management interventions inside the healthcare institutions. In this thesis, healthcare providers also indicated that they were too pressured in terms of time to address the educational deficits and the psycho-social needs of patients and families. Sadly, intensive group health education for diabetic patients was not undertaken, resulting in an overload of the secondary and tertiary healthcare facilities in KSA. However, as supported by a local study, group education could surely be one of the time and cost-saving measures that should be adopted (Al Hussain, 2008).

Social and religious beliefs are two important factors that shape Saudis health behaviors (Al-Saeedi et al, 2003; Aljoudi & Taha, 2009; Bakhotmah & Alzahrani,
Therefore, the Saudi healthcare system needs to work towards adopting diabetes interventions that include cultural considerations. There is a growing global interest in the possibility that culturally adjusted interventions could play an important role within the biomedical system (Mbeh et al, 2010; Boateng et al, 2016). For example, in Cameroon, just like in the KSA, traditional healers frequently act as a first port of call for diabetics seeking treatment. In order to include the healers in the fight against diabetes, the Cameroon MOH started a pilot intervention program to train them in a range of topics and practices relating to diabetes. These included risk factors, the symptoms and complications of diabetes, and health lifestyle strategies. This project showed that healers could learn diabetes prevention methods relatively quickly and use their communication skills to teach others and distribute educational materials (Mbeh et al, 2010). A similar method could be adopted in KSA as the traditional healers tend also to be mainly religious leaders, even as one of the interviewees, an endocrinology consultant, suggested that ‘there should been educational speech made in the mosque during the Friday sermon, I think people here would listen to an Imam more than a doctor’.

It seems that the biomedical model is dominant in the KSA healthcare system and unless the model is changed, at least in primary health-care settings, it is unlikely that efforts to manage T2DM will be very successful. The fact that only 17% of the PACIC-5As participants had a controlled glycemic level was very good evidence that medications alone was not the comprehensive answer to effective T2DM management (Engel, 1997; Donabrdian, 1980). It is imperative for health planners in KSA to follow the international trend and adapt a chronic care model that fits into the Saudi context. The community specificity of the Saudi population and the HIT are shown to be very complex in the way that they intersect with and are interrelated to the various
elements of the ICCC from the macro through to the meso level. Tackling cultural determinants in developing a diabetes healthcare policy is extremely important when creating and implementing diabetes health policies.

Despite the level of recognition of the epidemic in T2DM (MOH, 2009; Alharbi et al., 2014; MOH, 2013c) and the investment in medical care facilities, the KSA healthcare system still lacks integration and has a problem with cultural dissonance. The KSA healthcare system should be integrated for many reasons as it should seek to have each level of the healthcare system – the macro, meso, and micro - working together and sharing the same goal of optimizing the care for patients with T2DM. The boundaries among the levels of the system should be removed or lessened to allow for a true integration of healthcare organizations and the community as well as the policies and the treatment of patients. Coordination, integration, collaboration and continuity should occur across time and healthcare settings, including primary health care, and the specialized diabetes settings. Care should be integrated across all elements of chronic diseases, moving beyond the traditional biomedical model of care.
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Appendix A

Availability of resources of diabetic care in primary health care settings in Aseer region, Saudi Arabia

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ABSTRACT

Objective: The objective of this study is to evaluate the availability of resources of diabetes care in primary health care settings in Aseer region, Southwest, Kingdom of Saudi Arabia.

Methods: This study was conducted during September 2001 by distributing a questionnaire to all technical directors of primary health care centers (PHCCs) in Aseer region. The questionnaire, designed by the authors, contained 6 sections that dealt with the necessary structures of diabetic care in the region in addition to the data base of PHCC such as served population, distance from the hospital, and total working physicians and nurses at the PHCC. The data from the questionnaire was entered and analyzed using Statistical Package for Social Sciences.

Results: Two hundred and forty-two PHCC technical directors responded to the questionnaire. Total served population by PHCC was 970,306 individuals. Total working physicians were 391 and nurses were 902.

Diabetics represented 2.7% of the total served population. More than 90% of PHCCs have diabetic files, registers, appointment system and protocol for diagnosis and treatment of diabetics. Oral hypoglycemic agents were always available at 55% of PHCCs while metformin was not available at 52% of PHCCs. Diabetic identification cards were available in 80.4% of PHCCs while the health education means were less available, except for health education programs was available at 97.5% of PHCCs. At least, 40% of PHCCs were provided financially or by different means of health education through community health committees.

Conclusion: This study revealed that resource items for diabetic care are adequate in particular drugs and laboratory facilities. Establishment of a diabetes committee in Aseer region is a priority in order to manage such shortages and to plan, supervise and coordinate the diabetic care in the region.

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Diabetes mellitus (DM) is one of the most common metabolic disorders in the Kingdom of Saudi Arabia (KSA). According to some national epidemiological studies, the prevalence of DM is increasing dramatically.1-2 In the Southern region, the prevalence of DM ranged from 3.8-10.8%.1,2 Despite the fact that DM is an increasing and a major health problem in Aseer region, the introduced care to the diabetics is still below the expected national targets as reported by some studies during the past 5 years.3-4 Most of these reports and studies blamed the health system as one of the barriers that was unable to provide the minimum infrastructures for diabetic care which resulted in poor processes and outcomes among diabetics. Other studies from Aseer region found that many procedures including laboratory investigations were less than the national targets due to lack of coordination between the Primary health care centers (PHCCs) and the district hospitals.5-6 However, most of the previous studies were

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conducted in a few practices which made generalization of these findings difficult to accept. The objective of this study is to evaluate the availability of the essential diabetic resources in primary health care (PHC) setting in Aseer Region, Southwest of KSA.

**Methods.** Aseer is one of the administrative regions of KSA with a total population of 1.2 million. The health services in this region are provided through a network of PHCCs, general hospitals and one central hospital. In order to make health services accessible to every one, the region is divided into 14 health sectors. Each sector consists of a group of PHCCs and one general hospital. These patients who need secondary care are referred from PHCCs to general hospitals through formal referral forms to the concerned specialists. Diabetic care in Aseer region, as other health care services are provided by the governmental agencies (Ministry of Health [MOH], Ministry of Defense and Aviation [MODA], Ministry of Interior [MOI] and some private hospitals and polyclinics). To achieve the objective of this study, the investigators designed a questionnaire based on the quality assurance and mini-clinics manual of the Directorate General of Primary Health Care. The questionnaire consisted of 6 main sections. The 1st section dealt with essential data regarding PHCCs, namely, total served population, distance from the nearest general hospital, type of road, number of served diabetics at each PHCC, number of working physicians and nurses; the 2nd section was related to the presence of the diabetic mini-clinic, diabetes health educator or trained nurse to conduct health education for diabetics, appointment system, recall system, diabetic files, diabetic registers, referral registers for diabetics, protocol for diagnosis and management of DM, attending diabetes training coordination between the PHCC and the referred general hospital. The 3rd section was concerned with the availability of the essential drugs for diabetes. The 4th section was related to the degree of availability of the essential items of laboratory services (glucose meter, refractometer, dipstick, patient list, honored list, step test, portable glucometers, hypoglycemic agents (OHAs), blood analysis (HbA1c)). The 5th section was regarding the availability of available laboratory tests related to diabetes. This part was assessed by using 2 point scales (0=not available, 1=available). The last section was about the patterns of participation of the community and the health committees in supporting diabetes at PHCC. This part consisted of 5 items: (financial donation, providing PHCC with glucometer, providing PHCC with glucometer, printing health education materials, provision of audiovisual aids, prepare or build venues for health education programs). The questionnaire was delivered by mail during September 2001 to the working technical directors at all sectors who distributed it to all PHCCs in their sectors, collected the response and returned it within 4 weeks to the technical directorate of PHC in Health Affairs of Aseer Region. In order to obtain reliable data, the name, the signature of the technical director of PHCC and the stamp of the PHCC were asked to be put in the front page. The data of the questionnaire were entered and analyzed by using Statistical Package for Social Sciences (SPSS).

**Results.** Two hundred and forty-two out of 245 PHCCs (98.8%) in Aseer region responded to the questionnaire. Three PHCCs did not respond as the technical directors were on annual vacation. Table 1 summarizes the profile of PHCCs in Aseer region. These PHCCs served more than 970,000 individuals. The mean distance between PHCCs and the hospitals is 34.3 kilometers, most of the roads between these PHCCs and hospitals are paved. The total number of the working physicians was 391 and nurses was 902. The total served diabetics was 26,313, more than 56% of them were males. Table 2 shows the availability of essential infrastructures in PHCCs in Aseer Region. Approximately, three fourths of the PHCCs served diabetics; however, only 24% had recall system. Diabetic registers, diabetic referral records, protocol for diagnosis, treatment and follow up of diabetes. On the other hand, a recall system was available in 82% of PHCCs, health educators were present in 8% of PHCCs. These attending diabetes training courses was 18% and ability to perform fundoscopy was 16.4%. Table 3 depicts the degree of availability of essential drugs and laboratory tools. Most PHCCs were available in more than one third of PHCCs. Oral hypoglycemic agents (OHAs) and aspirin were always available in more than 50% of PHCCs while metformin and insulin were only frequently available in more than one quarter of PHCCs. On the other hand, the quality of laboratory related items such as glucometers, sticks of testing for glucose and urine protein were always available in more than two thirds of PHCCs. Regarding the availability of health education means for diabetes, it was found that health education programs on diabetes were available in 97.5% of PHCCs. The presence of diabetes identification cards and posters was 74.4% and pamphlets was 55.5%, booklets was 44%; and videotapes was 11% of PHCCs. Concerning community participation in diabetic care, it was found that 40% of PHCCs received financial...
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Process: staff shortage

Process: staff shortage

Process: staff qualification

Content: coordination

Process: resources availability

Content: community support

Content: participation

Process: staff qualification

Process: referral system

supplies, 38% of PHCCs were provided with

Discussion. Successful process and good diabetic outcomes are based on providing adequate infrastructure items. Previous studies from Aser region revealed that poor process and outcomes could be contributed significantly to lacking of adequate and essential infrastructures for diabetic care. All those studies were conducted in few practices which made their generalizations questionable. In this study, which involved almost all PHCCs in Aser region, a clear picture regarding the diabetic infrastructure items has become obvious. More than 970,000 citizens are served by 242 PHCCs at which 391 physicians and 902 nurses work. As a result, the nurse to population ratio was 1:1076 and the physician to population ratio was 1:1670. The report was issued by the MOH in 1996 and 1998. The percentage of registered diabetics in Aser region according to the report was 8.7 – 9.8%. Aser region is a very poor region. The government has been trying to improve the situation. However, the situation is not yet significantly improved. This high figure could be attributed to the regular impact of health care on diabetic care was evaluated. In the current study, among the diabetes education programs, 30% attended diabetes training course and the ability of carrying fundoscopy by PHCCs physicians were less satisfactory. In order to introduce good quality care for diabetics, it is necessary to conduct fundoscopy. Different diabetic drugs are essential if diet therapy fails to achieve good metabolic diabetic control. Our findings revealed that oral hypoglycemic agents such as glibenclamide were available at all time in 55% of PHCCs while metformin and insulin were rarely available. On the other hand, glucoseimeters, glucometers and sticks of testing urine for protein were not available adequately in 20% of PHCCs. Previous studies from Aser region revealed that lack and shortage of drugs and inability of PHCCs to carry out blood and urine analysis for sugar were contributed significantly to poor compliance to the medical advice increasing defaulters among diabetics. To overcome this shortage, the medical supply in cooperation with the PHC department at each sector should distribute the drugs and laboratory requirements according to the number and the actual needs of diabetics at each PHCC. Our daily observations in practice revealed that providing diabetics with drug refill cards give a good impact on rationalization of drugs presencting and improvement in appointment compliance among diabetics. The need of each PHC. Health education is considered the cornerstone of successful diabetes management. In a study conducted in a large PHCC in Aser region, it was found that absence of health educator and inadequate health education materials stand behind poor health education program in that PHCC. In this study, only 8% of PHCCs have health educators and 45.4% trained nurses who can conduct health education. On the other hand, availability of health education materials and means were inadequate except for health education program at PHCCs. To achieve high quality health education for diabetics, it is essential to train all nurses who run diabetic clinics in order to manage the shortage in health educators in the region, provide all PHCCs with adequate health education materials in coordination with health education department in the region.

Community participation is an important element of PHCC. Community can support PHC settings through the local health committees. In this study, many patterns of community participation were present. Financial donation and providing PHCCs with laboratory and health education means and material were the major types of community participation in the region. In order to facilitate community participation in this regard, it is vital to involve the teachers, religious leaders and the other community leaders in planning, implementing and evaluating the local diabetic program at the PHCCs level. Diabetic care needs coordination from district hospital in order to perform some periodic examinations such as fundoscopy, kidney function test and lipid profile. Approximately 35% of PHCCs in Aser region lack of coordination with their referred hospitals. In previous studies, it was reported that referral system in Aser region which is poorly structured and managed. There is a need for better coordination and cooperation between PHCCs and the local health committees. Another factor that affects the success of health education is the local dictorian program. In this study, only 8% of PHCCs have health educators and 45.4% trained nurses who can conduct health education. On the other hand, availability of health education materials and means were inadequate except for health education program at PHCCs. To achieve high quality health education for diabetics, it is essential to train all nurses who run diabetic clinics in order to manage the shortage in health educators in the region, provide all PHCCs with adequate health education materials in coordination with health education department in the region. Community participation is an important element of PHCC. Community can support PHC settings through the local health committees. In this study, many patterns of community participation were present. Financial donation and providing PHCCs with laboratory and health education means and material were the major types of community participation in the region. In order to facilitate community participation in this regard, it is vital to involve the teachers, religious leaders and the other community leaders in planning, implementing and evaluating the local diabetic program at the PHCCs level. Diabetic care needs coordination from district hospital in order to perform some periodic examinations such as fundoscopy, kidney function test and lipid profile. Approximately 35% of PHCCs in Aser region lack of coordination with their referred hospitals. In previous studies, it was reported that referral system in Aser region which is poorly structured and managed. There is a need for better coordination and cooperation between PHCCs and the local health committees. Another factor that affects the success of health education is the local dictorian program. In this study, only 8% of PHCCs have health educators and 45.4% trained nurses who can conduct health education. On the other hand, availability of health education materials and means were inadequate except for health education program at PHCCs. To achieve high quality health education for diabetics, it is essential to train all nurses who run diabetic clinics in order to manage the shortage in health educators in the region, provide all PHCCs with adequate health education materials in coordination with health education department in the region. Community participation is an important element of PHCC. Community can support PHC settings through the local health committees. In this study, many patterns of community participation were present. Financial donation and providing PHCCs with laboratory and health education means and material were the major types of community participation in the region. In order to facilitate community participation in this regard, it is vital to involve the teachers, religious leaders and the other community leaders in planning, implementing and evaluating the local diabetic program at the PHCCs level. Diabetic care needs coordination from district hospital in order to perform some periodic examinations such as fundoscopy, kidney function test and lipid profile. Approximately 35% of PHCCs in Aser region lack of coordination with their referred hospitals. In previous studies, it was reported that referral system in Aser region which is poorly structured and managed. There is a need for better coordination and cooperation between PHCCs and the local health committees. Another factor that affects the success of health education is the local dictorian program.
optimize the referral and coordination processes for diabetics, it is mandatory to implement the recommendations issued by MOH.7,8

Recommendations. In order to introduce good diabetic care in Aseer region we suggest the following recommendations: 1) All PHCCs should be provided with adequate diabetes related resources according to their actual needs. 2) Conducting regular training courses on diabetes for PHC physicians and nurses. 3) Improving the referral system between PHCCs and hospitals through providing the hospitals with coordination offices, essential resources and qualified coordinators. 4) Involving the community leaders in planning and evaluation of diabetes program at PHCCs in order to activate their roles in diabetes management. 5) Establishing a diabetic committee in Aseer Region to plan, supervise and coordinate diabetic related care in the region.

In conclusion, this study revealed that some important items of infrastructures diabetic care in Aseer region are not adequately available particularly drugs, laboratory facilities and health education materials. Establishment a Regional Diabetic Committee (RDC) can overcome such shortage through regular supervision of diabetic care and coordination with the other relevant diabetic care affairs.

References

## Appendix B

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<tr>
<th>Questions</th>
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<td>2. What does health mean to you? Why?</td>
<td>How do you think something can affect someone psychologically/physically?</td>
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<td>What does health mean to someone with diabetes?</td>
<td>How do you think something can affect someone psychologically/physically?</td>
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<td>How do you think something can affect someone psychologically/physically?</td>
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<td>5. Can you give me an example of a patient who is able to do this?</td>
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<td>6. Can you see any similarities between self-management and diabetes?</td>
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<td>22. Can you see any similarities between self-management and diabetes?</td>
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<tr>
<td>23. Can you see any similarities between self-management and diabetes?</td>
<td>Can you give me an example of a patient who is able to do this?</td>
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Appendix C

الحفاظ على الصحة قد يكون أمر صعب عندما تعاني من مرض مزمن، نود ان نتعرف على أنواع المساعدات التي تلقاها من قبل الفريق الطبي المعالج والمتعلقة بمرضك المزمن. هذه المساعدة قد تشمل طبيبك المعالج، الممرض الخاص به أو مساعد الطبيب المسؤول عن علاج مرض السكر.

فكر في الرعاية الصحية التي تلقيتها لعلاج مرضك السكر خلال السنتين الماضيتين (إذا كنت اخر مقابلة لك مع طبيبك المعالج أو المرضعة مضى عليها أكثر من ستة أشهر، استرجع اخر زيارة صحية قمت بها خلال الأشهر السنتين الماضيتين. عندما تلقيت الرعاية الصحية لمرض السكر كنت:

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في الرعاية الصحية التي تلقيتها لعلاج مرضك السكر خلال الأشهر الماضية، استرجع أخر زيارة صحية قمت بها:

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<tr>
<td>20</td>
<td>أسأل كيف كانت مراجعاتي مع باقي الأطباء</td>
<td></td>
</tr>
<tr>
<td>21</td>
<td>أسأل عن الأمور التي لا أو مشكلات في مرضي خلال زياراتي للراحة</td>
<td></td>
</tr>
<tr>
<td>22</td>
<td>أسأل عن تأثير مرضي على عملي، أسرتي أو فرصي الاجتماعية</td>
<td></td>
</tr>
<tr>
<td>23</td>
<td>أخذ في وضع خطط للاستعداد من الإسعاف، أسرتي، أو مجتمعي</td>
<td></td>
</tr>
<tr>
<td>24</td>
<td>أسأل عن أهمية الممارسات التي قومنا لها للرعاية الصحية (مثل ممارسة الرياضة)</td>
<td></td>
</tr>
<tr>
<td>25</td>
<td>أخذ هدف للممارسات التي يمكن أن أقوم بها لرعاية حياتي مع فريقي الطبي</td>
<td></td>
</tr>
<tr>
<td>26</td>
<td>أعطي سجل تدريب وتوثيق مدى تطور حالتي الصحية</td>
<td></td>
</tr>
</tbody>
</table>

البقاء بصحة جيدة أمر صعب عندما تعاني من مرض مزمن، نود من معرفة نوعية المساعدات التي تلتقاها من قبل الفريق الطبي المعالج والمتعلقة بمرضك المزمن. هذه المساعدة قد تشمل طبيبك المعالج، المرضي الخاص به، مساعد الطبيب المسؤول عن علاج مرض السكر. إجابتك سوف تعامل بسربية تامة ولن نشاركها مع أي شخص ما.
فكر في الرعاية الصحية التي تلقيتها لعلاج مرض السكر خلال 6 أشهر الماضية (وإذا كانت آخر زيارة لك مع الطبيب أو الممرض مضى عليها أكثر من 6 أشهر، استرجع آخر زيارة صحية قمت بها خلال 6 أشهر الماضية، عندما تلقيت الرعاية الصحية لمرض السكر:

<table>
<thead>
<tr>
<th>1</th>
<th>تم سؤالي عن إفكارك عندما وضعنا خطة العلاج.</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>تم تزويدني بخيارات العلاج المتاحة لأفكار بها.</td>
</tr>
<tr>
<td>3</td>
<td>طلب مني الأفصاح عن أي مشاكل متعلقة بالدواء أو تأثيراته الجانبية.</td>
</tr>
<tr>
<td>4</td>
<td>تم تزويدني بقائمة مكونات العلاج التي يجب على القيام بها من أجل تحسين صحتي.</td>
</tr>
<tr>
<td>5</td>
<td>راضي عن رعايتي الصحية المتواصلة.</td>
</tr>
<tr>
<td>6</td>
<td>تم إيضاح ما يجب على فه على الاهتمام بالعراض الصحي المترتب على حالي.</td>
</tr>
<tr>
<td>7</td>
<td>طلب مني أن أتحدث عن المشاكل أو اضطرابات المرض المزمن.</td>
</tr>
<tr>
<td>8</td>
<td>تم مساعدتي في تحديد أهداف لتحسن نظامي الغذائي أو نمائي البدني.</td>
</tr>
<tr>
<td>9</td>
<td>تم تزويدني بنسخة من خطة العلاج.</td>
</tr>
<tr>
<td>10</td>
<td>تم توجيه أسئلة، سواء مباشرة أو عبر استمارة، في كيفية عاداتي الصحية.</td>
</tr>
<tr>
<td>11</td>
<td>وقت بأن طبيبي أو المرضي كانوا مراقبين لديهم وعائدون عادة عند توصيتي لقبول العلاج.</td>
</tr>
<tr>
<td>12</td>
<td>تم مساعدتي في وضع خطة علاج قابلة لتنفيذ بشكل يومي.</td>
</tr>
<tr>
<td>13</td>
<td>تم مساعدتي على وضع خطة مستقبلية للاستمرار بالتحسن حتى في الأوقات الحرجة.</td>
</tr>
<tr>
<td>14</td>
<td>تم مساعدتي في وضع خطة مستقبلية للاستمرار بالتحسن حتى في الأوقات الحرجة.</td>
</tr>
<tr>
<td>15</td>
<td>تم التواصل معي بعد زيارتي للعامة لتذكيرني من أن كل شيء على ما يرام.</td>
</tr>
<tr>
<td>16</td>
<td>تم تحفيزي على الانضمام للبرامج التي يقدمها المجتمعات والتي من شأنها أن تساعدني.</td>
</tr>
<tr>
<td>17</td>
<td>تم إعدادني إلى استراتيجيتي لعلاج السكر والتفصيل الصحي والأنشطة.</td>
</tr>
<tr>
<td>18</td>
<td>تم إخباري بأن مراجعاتي مع دكتور الأطباء كطبيبي العون أو الجراح ساعدت في علاجي.</td>
</tr>
<tr>
<td>19</td>
<td>تم سؤالي عن مزامناتي مع دكتور الأطباء كطبيبي العون أو الجراح ساعدت في علاجي.</td>
</tr>
<tr>
<td>20</td>
<td>تم توجيه أسئلة، سواء مباشرة أو عبر استمارة، في كيفية عاداتي الصحية.</td>
</tr>
<tr>
<td>21</td>
<td>وقت بأن طبيبي أو المرضي كانوا مراقبين لديهم وعائدون عادة عند توصيتي لقبول العلاج.</td>
</tr>
<tr>
<td>22</td>
<td>تم مساعدتي في وضع خطة مستقبلية للاستمرار بالتحسن حتى في الأوقات الحرجة.</td>
</tr>
<tr>
<td>23</td>
<td>تم مساعدتي في وضع خطة مستقبلية للاستمرار بالتحسن حتى في الأوقات الحرجة.</td>
</tr>
<tr>
<td>24</td>
<td>تم مساعدتي في وضع خطة مستقبلية للاستمرار بالتحسن حتى في الأوقات الحرجة.</td>
</tr>
<tr>
<td>25</td>
<td>تم توجيه أسئلة، سواء مباشرة أو عبر استمارة، في كيفية عاداتي الصحية.</td>
</tr>
<tr>
<td>26</td>
<td>وقت بأن طبيبي أو المرضي كانوا مراقبين لديهم وعائدون عادة عند توصيتي لقبول العلاج.</td>
</tr>
</tbody>
</table>

Appendix E

البقاء بصحة جيدة يعد أمرًا صعبًا عندما تعاني من مرض مزمن. نود أن نعرف على نوعية المساعدة المتعلقة بحالةك، والتي تتعلقها من قبل الفريق الطبي المعالج. هذه التقييم تشمل طبيبك المعالج، المرضي الخاص به أو مساعد الطبيب المسؤول عن علاج مرض السكر. اجابة سوف تعامل بسرية تامة ولن نشاركها مع أي شخص آخر.
Appendix F

Living with good health is a difficult matter especially when you suffer from chronic disease. We would like to know the types of support and help you received from the treating medical team and related to your chronic disease. This help may include your treating physician, your nurse or assistant doctor in charge of treating sugar disease. Your response will be confidential and not shared by any individual.

Think in the health care received as a treatment of your Diabetes during last six months (and if the last meeting with your treating physician or your nurse was from six months, remind your last health visit).

During the last six months, when you received the health care related to Diabetes, you were:

<table>
<thead>
<tr>
<th>No</th>
<th>Description</th>
<th>No</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Always</th>
<th>Usually</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>I was asked for my opinion when we set up the treatment's plan</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>2</td>
<td>I gave options related to the treatment to think about</td>
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<td>3</td>
<td>I was asked for any problems related to my medicine and its side effects</td>
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<td>4</td>
<td>I was given a written list of things I shall do for improving my health</td>
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<td>5</td>
<td>I was satisfied for my well organized health care</td>
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<tr>
<td>6</td>
<td>I was aware of how to take care with health assumptions influencing on my health</td>
<td></td>
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<tr>
<td>7</td>
<td>I was asking for my opinions about the objectives of treatment's plan</td>
<td></td>
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<tr>
<td>8</td>
<td>I was receiving the support to determine my objective to develop my diet and physical activity</td>
<td></td>
<td></td>
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<tr>
<td>9</td>
<td>I was taking a copy of treatment's plan</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>10</td>
<td>I was motivated for participating with customized groups and activities for educating me about how to treat with my health condition</td>
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<tr>
<td>11</td>
<td>I was asked by questions whether directly or by presenting a questionnaire related to my health habits and traditions.</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>12</td>
<td>I was confident that my physician or nurse take care my values and traditions when recommend me any treatment and medicine.</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>13</td>
<td>I was helped for preparing a treatment's plan which I can execute daily.</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>14</td>
<td>I was helped to plan by self since I can take care my condition specially in critical situations.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>I was asked for the impacts and effects of my chronic disease on my life.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>I was communicated by the clinic after the visit to be sure that every is all right.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>I was supported to attend the programs helping me in the society.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>18</td>
<td>I was transferred to dietician or health education or consultant.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>19</td>
<td>I was asked for my revisions and followings with remaining physicians such as ophthalmologist or surgeon.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>20</td>
<td>I was asked for how was my following with remaining physicians.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>21</td>
<td>I was asked about the matters which I would like to discuss about my disease during my visits to clinic.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>22</td>
<td>I was asked about the effects of my disease on my work, family or social life.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>23</td>
<td>I was participating in setting plans to receive support from my friends, family or society.</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>24</td>
<td>I was asked for the importance of the practices I do for taking care my health (such as practicing exercises, and sports).</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>25</td>
<td>I was determining the objective of the practices that I may do for taking care my condition under the control of my treating.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>medical team</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>--------------</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>26 I was giving a record for registering and documenting the development level of my health condition.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix G

Miss Nouf Al-Herbi  
Department of Health Care Management and Policy  
FBEL

29 October 2014

Dear Miss Al-Herbi

UEC ref: EC/2014/14/FBEL  
Study Title: Evaluation of Electronic Health Technologies to Support People with Type 2 Diabetes Mellitus in Saudi Arabia

On behalf of the Ethics Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the submitted protocol and supporting documentation.

Date of confirmation of ethical opinion: 29 October 2014

The final list of documents reviewed by the Committee is as follows:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Covering letter from researcher addressing further comments from the Committee, sent 07 Oct 2014</td>
<td></td>
<td>20 Oct 2014</td>
</tr>
<tr>
<td>Research Insurance Proforma</td>
<td>Sub.</td>
<td>20 Oct 2014</td>
</tr>
<tr>
<td>Interview guide for physicians and health care providers (tracked copy)</td>
<td>Sub.</td>
<td>23 Sep 2014</td>
</tr>
<tr>
<td>Interview guide for physicians and health care providers (clean copy)</td>
<td>Sub.</td>
<td>23 Sep 2014</td>
</tr>
<tr>
<td>Interview guide for health care managers</td>
<td>Sub.</td>
<td>23 Sep 2014</td>
</tr>
<tr>
<td>Interview guide for IT technicians / Data analyst / Public health analysts</td>
<td>Sub.</td>
<td>23 Sep 2014</td>
</tr>
<tr>
<td>Interview guide for Saudi Society for Diabetes members</td>
<td>Sub.</td>
<td>23 Sep 2014</td>
</tr>
<tr>
<td>Participant Information Sheet</td>
<td>v.4</td>
<td>Sub. 23 Sep 2014</td>
</tr>
<tr>
<td>Consent Form (tracked copy)</td>
<td>v.2</td>
<td>20 Oct 2014</td>
</tr>
<tr>
<td>Consent Form (clean copy)</td>
<td>v.2</td>
<td>20 Oct 2014</td>
</tr>
<tr>
<td>Covering letter from researcher addressing comments from the Committee, sent 23 June 2014</td>
<td>v.2</td>
<td>23 June 2014</td>
</tr>
<tr>
<td>Protocol Cover Sheet (tracked copy)</td>
<td>Sub.</td>
<td>18 Aug 2014</td>
</tr>
<tr>
<td>Protocol Cover Sheet (clean copy)</td>
<td>Sub.</td>
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<td>Sub.</td>
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<tr>
<td>Protocol (clean copy)</td>
<td>Sub.</td>
<td>18 Aug 2014</td>
</tr>
<tr>
<td>Covering letter from researcher addressing comments from the</td>
<td></td>
<td>23 May 2014</td>
</tr>
</tbody>
</table>
PUBLICATIONS
Trends in the prevalence of type 2 diabetes mellitus and obesity in the Arabian Gulf States: Systematic review and meta-analysis

Nouf Sahal Alharbi a,b, Reem Almutari c, Simon Jones a, Nasser Al-Daghir d, Kamlesh Khunti e, Simon de Lusignan a,*

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c Department of Public Health, King Saud bin Abdulaziz University for Health Sciences, Riyadh, Saudi Arabia
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ARTICLE INFO

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Obesity

ABSTRACT

We report trends in type 2 diabetes mellitus and obesity in adults residing in the Arabian Gulf States. Among the Saudi population, the prevalence of diabetes increased from 10.6% in 1989 to 32.1% in 2009. Prevalence of the disease increased faster among Saudi men than women, with growth rates of 0.8% and 0.6% per year, respectively.

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The prevalence of type 2 diabetes mellitus (T2DM) has increased rapidly in Arabic countries over the past 30 years. According to the International Diabetes Federation (IDF), three of the Arabian Gulf countries have the highest prevalence of T2DM anywhere in the world [1]. Obesity is one of the main factors affecting the prevalence of T2DM, which has also reached epidemic proportions in the Arabian Gulf States [2]. However, exact figures relating to the increasing prevalence of these diseases have yet to be collected, compared and analyzed for the region [3–5]. We report how the prevalence of T2DM and obesity had changed over the last 30 years among adults residing in the Arabian Gulf States.

1. Methods

We conducted a comprehensive literature search for studies of T2DM and obesity using Medline and Embase. In addition, we reviewed the reference lists from retrieved articles in order to identify additional relevant papers. We included publications dating from 1st January 1979 to 31st December 2011 and focussed specifically on studies describing the prevalence of diabetes and obesity according to the WHO criteria, or the equivalent, explicit, blood glucose-level criteria for the diagnosis of diabetes. We included studies that considered

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http://dx.doi.org/10.1016/j.diabres.2014.08.019
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both type 1 and type 2 diabetes, because T2DM accounts for over 90% of all diabetes cases [6].

Two reviewers (N. H. and R. M.) independently reviewed the title, the abstract, and the article. Discrepancies were resolved by consensus or determined by other reviewers (K. K. and S. de L.). Meta-analysis was performed to estimate pooled prevalence rates using a random-effects model which gives an average estimate across studies weighted by sample size. In addition, we used meta-analysis to assess the prevalence trends by year for both sexes.

2. Results

A total of 34 papers (36 studies) met our inclusion criteria: 21 assessed the prevalence of T2DM, and 12 reported the prevalence of obesity, while a further 3 assessed the prevalence of both diabetes and obesity. The prevalence of diabetes varied between the countries. The current estimated prevalence of T2DM among the Arabian Gulf population ranged from 5.9% in the United Arab Emirates [7] to 32.1% in Saudi Arabia [8], while the recorded prevalence of obesity ranged from 20.3% in Saudi Arabia [9] to 56% in Kuwait [10]. Details of individual prevalence studies are reported in Appendix 1.

Although the overall estimate of the prevalence of T2DM was 14.9% we used a random-effects model to identify differences among the collected data. This heterogeneity arose from differences in the countries, and the year of publication. We could not apply the heterogeneity test to the obesity studies because there was too small a number of studies included and most of them were conducted in Saudi Arabia.

The prevalence of diabetes among the Saudi population increased over time from 12.4% in 1987 [11] to 27.7% in 2011 [12]. Using a simple statistical analysis (t-test), it appeared that there was no significant difference in the prevalence of T2DM between genders. However, there was a significant difference in the rate of increase between males and females with T2DM. Our results showed that the prevalence of T2DM was estimated to increase by about 0.8% in males and 0.6% in females each year (p < 0.0001). There were insufficient data on the prevalence of obesity in adults to observe a clear trend occurring over time (see Fig. 1).

3. Discussion

Consistent with the findings of other studies is our observation that T2DM and obesity have a higher prevalence in Arabian
Gulf States than most other countries. These findings fit with a non-systematic review of a smaller number of studies published between 1982 and 2004, which estimated that diabetes prevalence increased from 2.5% to 23.7%, for both genders and all age groups in Saudi Arabia [13]. The prevalence estimate of T2DM among Saudi adults is similar to increases reported in Bangladesh and Iran [14,15]. We also found, however, that there is a steeper increase rate of prevalence of T2DM among men than among women, a finding which has previously not been detected in earlier studies.

The IDF reports that the prevalence of diabetes in Saudi Arabia for both sexes in 2012 was 23.38% [16]. Our review estimates the prevalence to be higher, however, putting the figures at 25% for men and 31% for women (see Fig. 1). These figures are likely to be more accurate estimates than the IDF’s estimation because in the Middle East and North African regions over half of all cases of diabetes are undiagnosed (53%) [16].

Physical inactivity, poor eating habits, and increasingly sedentary lifestyles are probably responsible for the T2DM epidemic among Saudi citizens: for example, people now make greater use of cars than they used to in the country and tend to begin meetings with sweet tea and snacks [17]. Obesity and being overweight are major factors contributing to the onset of T2DM [12]. In this review, we found more limited evidence relating to the prevalence of obesity. Further research is needed to ascertain the prevalence of ongoing trends in obesity and to identify any other factors that compound the risk of T2DM onset. The quality of T2DM management in Arabic Gulf States is ranked as “poor” [18]. The Gulf States need to plan interventions to reverse this trend. Preventative interventions have been shown to reduce obesity and influence outcomes in terms of diabetes onset. Such interventions like the Diabetes Prevention Program (DPP) in the United States of America [19] and the national prevention program in Finland [20] have shown that T2DM can be prevented or delayed in persons at high risk of developing diabetes.

There have been previous systematic reviews of diabetes studies in the Arabian Gulf States, but none have focused on the difference in prevalence rates of T2DM according to gender [4,5,13]. The limitations of these reviews are as follows: the majority of the studies reviewed did not distinguish between type 1 and type 2 diabetes, and the studies reviewed displayed heterogeneity of methods, sample size, and age range.

In conclusion, this systematic review reports an increase in the prevalence of T2DM and obesity among Arabian Gulf citizens, as well as identifying a higher prevalence rate among men than women. These trends require urgent intervention such as the implementation of prevention, health promotion, and improved diabetes management systems.

Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at http://dx.doi.org/10.1016/j.diabres.2014.08.019.

REFERENCES


Conflict of interest

There are no conflicts of interest. This research was carried out independently.

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An Analysis of Health Policies Designed to Control and Prevent Diabetes in Saudi Arabia

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Abstract

A trend analysis of the prevalence of diabetes in Saudi Arabia revealed a steep increase in diagnosis rates for the disease between the years 1989 and 2009. Between these years, the percentage of the population suffering from diabetes rose from 10.6% to 32.1% of the adult population, and the diagnosis rate is likely to increase in the future. The controlling and prevention of diabetes in the future, therefore, would potentially benefit from a scholarly review of current policies and programmes designed to contain the disease. The current study examines such policies and programmes, specifically those existing in Saudi Arabia and which are currently in operation in 2016. It employs the thematic-content-analysis technique to review key literature, and also uses Walt and Gibson’s policy triangle framework to facilitate the analysis. Searches of PubMed and Medline databases were conducted to locate sources and sources were manually screened by the authors before inclusion in the study. The study concludes that prime obstacles to the successful implementation of diabetes programmes are: insufficient training of practitioners for the treatment of diabetes; lack of remuneration for the work of diabetes educators and no existing evaluation of their outputs; and a lack of training and appropriate modes of qualifying professionally for diabetes educators. The authors recommend that the Saudi government award a greater proportion of resources to programmes designed to treat diabetes sufferers, as well as educational programmes related to disease for the wider public.

Keywords: diabetes, document analysis, Saudi Arabia, policy analysis

1. Introduction

Diabetes is one of the most pressing health concerns facing the global population today. Both the illness itself and complications resulting from it affect millions of people living in the Gulf Cooperation Council (GCC) countries every year (Alharbi et al., 2014). It is indeed recognised by global institutions such as the World Health Organisation as the key healthcare challenge of twenty-first century. For patients and their family members, as well as for the government, the disease generates huge social and economic costs (International Diabetes Federation [IDF], 2013); see Table 1.

Table 1. Saudi Arabia at a glance (IDF Diabetes Atlas, 2013)

<table>
<thead>
<tr>
<th>Category</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult population (aged 20–70)</td>
<td>18 056 840</td>
</tr>
<tr>
<td>Diabetes cases (aged 20–79)</td>
<td>3 650 890</td>
</tr>
<tr>
<td>Diabetes raw national prevalence (%)</td>
<td>20%</td>
</tr>
<tr>
<td>Diabetes expenditure per diabetes patient (USD)</td>
<td>943</td>
</tr>
<tr>
<td>Diabetes related deaths (aged 20–79)</td>
<td>22 113</td>
</tr>
<tr>
<td>Number of people with undiagnosed diabetes (aged 20-79)</td>
<td>1 485 910</td>
</tr>
</tbody>
</table>
Understandably, then, the prevention of diabetes is fast becoming one of the key objectives of healthcare policy makers around the world (Alharbi et al., 2014). While clinical treatments of diabetes are standardised around the world, however, preventive measures need to be shaped according to localised cultures. Since societal characteristics differ widely it is thus essential to develop policies and strategies which will be effective in the context of the values and practices of the society in which they are intended to be implemented (Majeed et al., 2013).

Based on the latest Ministry of health (MOH) (2008) report, there were 1,803,435 registered people who have diabetes (7.5% of the population) in Saudi Arabia. Chronic diseases, especially diabetes, pose a significant challenge to the Saudi Ministry of Health’s efforts to improve health outcomes (Khoja, 2010). While the Saudi government has developed and implemented several policies designed to manage diabetes, the effectiveness of these policies has not yet been evaluated. It is therefore fitting to assess the sensitivity of these policies to the socio-cultural environment, which, as past researchers have suggested, plays a vital role in affecting the prevalence of diabetes in Saudi society. It is also important to find out if the current policies advocate the soft approach, i.e. health education and awareness, which is likely to have a more significant impact on managing diabetes than post-illness clinical care. This paper evaluates the Saudi government’s policies and strategies for prevention of diabetes in Saudi society.

2. Method

2.1 Study Design

The study used Walt and Gilson’s policy triangle framework, which is designed especially for analysing data produced in scientific research on health, and identifies four dimensions of understanding processes of political and cultural implementation of health policies (Figure 1) (Walt et al., 2008). The available policy papers regarding the chosen study topic were analysed using the triangle framework.

![Model for Health Policy Analysis](Figure 1. Model for Health Policy Analysis (Adopted from Walt and Gilson (1994))

2.2 Search Strategy

In conformance with qualitative methods, a combination of theory-based, convenience, and purposeful sampling strategies were adopted (Miles & Huberman, 1994). Existing research papers on topics related to diabetes and healthcare policy were accessed. The search was limited to papers relating to GCC nations. In order to ensure reliability of secondary data, the researchers limited their scope to information provided by globally recognised institutions (such as International Monetary Fund, World Bank, United Nations Conference on Trade and Development, International Diabetes Federation, etc.) and government websites (especially GCC governments’
To find the required literature, several reputable online journal databases such as PubMed, Science direct, Emerald Insight, Social Science Research Network, etc. were used. In order to search for online information relevant keywords such as “healthcare policy”, “diabetes policy”, “diabetes management”, “diabetes control program”, “diabetes control policy”, “diabetes management strategy”, “diabetes prevention policy”, “diabetes control program”, etc. were used. In order to source the most relevant information, only articles and information published in the last five years were used in this study.

The search strategy was implemented in five key stages: condensing of topic description into a single, precise sentence; highlighting keywords and phrases in the sentence; identifying synonyms and variant spelling for the keywords; linking the keywords and phrases using a Boolean search (AND/OR/NOT); and locating the information/results. This search strategy was considered appropriate for its ability to locate relevant research and allow for use of explicit methods to identify what can reliably be said on the basis of those studies. The search strategy was also seen as effective in identifying, appraising, and selecting qualified research evidence, particularly in healthcare research (Bowling, 2014).

2.3 Data Analysis

The main aim of qualitative data analysis is to appropriately categorize it and identify dominant themes within it. In order to obtain accurate analyses, the researcher should adopt a neutral stance to the data and prevent personal views from affecting judgement. “Bracketing” is a technique which involves putting aside one’s own beliefs, not making judgments about what one has observed or heard and remaining open to the data as it is revealed (Bernard and Ryan, 2010). Bracketing was used to analyse the papers.

Following the principles of thematic content analysis, the researchers classified, described and analysed relevant studies. Studies were ordered chronologically and were consulted on multiple occasions by the research team. The researchers then conducted a primary coding of all studies. The primary researcher then assigned initial codes to main themes according to each study’s conceptual framework. Following this, the researchers agreed on an appropriate data analysis process after which the coding instruction was produced. This then allowed all documents to be coded and for themes to be re-classified according to the coding instruction. The codes were then reviewed again by the team and a final consensus was ascertained as to what constituted the final codes and themes.

3. Results and Discussion

3.1 Content

The Ministry of Health sought to implement objective healthcare methods in all fields of health services provision, designed to both prevent and treat patients and to rehabilitate patients. It aimed to do so by establishing a network of integrated facilities. This was with the aim of securing a decent standard of health for all. Thus, it established 20 specialized centres for treating diabetics, and the construction of eight more centres is underway across Saudi Arabia's regions and governorates. The Ministry of Health approved a ten-year national executive plan (2010–2020) for controlling diabetes and initiating future preventions (MOH, 2012).

The main, noticeable health problems in Saudi Arabia have been identified by the World Health Organisation (WHO) (2013) as an increase in non-communicable diseases (NCDs) and its modifiable behavioural risk factors. These include: tobacco use, physical inactivity and unhealthy diet. The prevalence of NCDs, diabetes, hypertension, obesity and coronary artery disease is on the rise in recent years (WHO, 2010).

The Saudi MOH and WHO both created The Cooperation Strategy for 2006–2011 (WHO, 2013) with the aim of addressing these problems. The strategy recommended that the Saudi health system should prioritize the promotion of a healthy lifestyle, especially among young people. The strategy also suggested providing an integrated health education and research project that would be commensurate with Saudi culture. WHO (2006) identified yet another increase in diagnosis rates for chronic diseases, however, thus demonstrating that the intended aims of The Cooperation Strategy for 2006–2011 were not achieved. The same report suggested that the explanation for the failure of the initiative was a continued increase in sedentary lifestyles.

A second initiative was developed by the MOH focusing primarily on the promotion of a healthy lifestyle within the specific context of Saudi values and practices, thus creating a strategy that was similarly preventative in approach (WHO, 2013). It recommended an updating of all polices to ensure a more substantial implementing of health education. Several international publications (Midhet, Almohaimed, & Sharaf, 2010; Aldossary, Barriball, & While, 2012; WHO, 2010; MOH, 2011) had previously argued that most major Saudi health problems are attributable to behaviour; the perceived solution, therefore, was to increase as health promotion and
health education. It is not clear why the MOH created a similar strategy in light of the failure of the first initiative; it is plausible, however, that, given a high turnover of health ministers, there was little consideration of how earlier initiatives could be improved. It is certainly the case that successive ministers have simply cancelled existing initiatives.

Over the last few years, the MOH has started several initiatives to control chronic diseases and the diabetes epidemic, including a national awareness programme for diabetes (MOH, 2013). These initiatives may have led to a decline in diabetes prevalence over the last eight years. Also, in September 2012, the Saudi MOH, in collaboration with the World Health Organization’s Eastern Mediterranean Regional Office (EMRO), organized an international conference that aimed to address the topic of NCDs in the area (WHO Regional Office for the Eastern Mediterranean, 2012). The conference resulted in the Riyadh Declaration that included ten recommendations to combat NCDs at the regional level (WHO EMRO 2012). The MOH worked with EMRO, and the declaration was adopted by EMRO during the regional committee meeting in October 2012. This step will amount to a major impact on health in Kingdom of Saudi Arabia and the region. Indeed, the Gulf countries have similar habits and health profiles (Mokdad, Jaber, Aziz, AlBuhairan, & AlGhaithi, 2014).

3.2 Actors

The Ministry of Health is the government agency responsible for healthcare policies, supervision and planning in Saudi Arabia. At the population level, the Saudi MOH is in charge of health promotion, early detection, and disease treatment of Saudis, and is a free healthcare system. In addition to the MOH, there are several governmental bodies that provide health services, including the Ministry of Defence and Aviation (the second-largest health services provider), the Ministry of Interior and the National Guards. Government bodies, especially the MOH, provide 80% of health services in the Kingdom (Alkhamsi, 2012).

Since its establishment in 1951, the MOH has developed in three main stages (Regional Health Systems Observatory, 2004): during the 1970s the Ministry primarily focussed on the provision of acute care services by hospitals and tertiary health centres, and thus supported primary healthcare to a lesser extent. The second stage roughly correlates with the decade 1980–1990, which, saw WHO encourage the adoption of a ‘Health for All’ movement. This movement increased attention on, and recognition of, the importance of primary health care in managing health on a national basis. Therefore, early attention toward primary health services, including diabetes care, was derived from international recommendations rather than Saudi health planners’ beliefs that primary care plays an essential role in improving health outcomes. In the third stage, a royal decree was issued in 2002 emphasising that health services should be provided in an equitable and affordable manner for all persons.

Actors involved with diabetes management and care in Saudi Arabia are not well placed or trained to effectively contain the disease. To best utilize its human and financial resources, Saudi MOH needs accurate and timely data to allocate the appropriate resources for treatment by disease or disability, but current national data on diabetes in Kingdom of Saudi Arabia are non-existent, with the most recent estimates dating from 2005 (Ministry of Health, Kingdom of Saudi Arabia, in collaboration with WHO, 2005). The data does support a number of concerns, however, one of which is a lack of human resources in the country. Saudi Arabia heavily relies on non-Arabian healthcare professionals, which make up 40 to 80 percent of the total healthcare workforce (Informa, 2012). Education on T2DM in Saudi Arabia is thus conducted by physicians alone, particularly in primary healthcare centres where there are no diabetes educators (Al-Hussein, 2008). According to a study that examined a diabetes education programme in the Asir region of Saudi Arabia, 27% of people with diabetes received no health education and of the remaining 73% of patients who received education, only 26% of them reported receiving instructions about exercise for the managing of diabetes (Al-Khaldi & Khan, 2000). Overall, diabetes education in Saudi Arabia does not comply with WHO’s recommendations that emphasise the need for active collaboration between educators and programme recipients (Al-Khaldi & Khan, 2000; Al-Hussein, 2008).

A study conducted in the eastern province of Saudi Arabia reported that less than half of all primary care centres attendees knew about the risk of diabetes and how to prevent it (Aljoudi & Taha, 2009). In these centres, health education services are expected to be performed by nurses (Jradi, Zaidan, & Al Shehri, 2012). Recent studies however show that most nurses in Saudi Arabia are expatriates from non-Arabic speaking countries and are thus unable to communicate effectively with patients (Jradi et al., 2012).

Moreover, these nurses, and even healthcare professionals speaking Arabic as their first language, were not trained in public health or health promotion (Jradi et al., 2012). In addition to the lower level of health education services, healthcare providers in Saudi Arabia do not seem to be properly advocating the measures necessary for prevention of the disease. One study was conducted to measure the effort applied by primary care physicians in Riyadh City to educate their patients in the importance of physical activity. Only 24% of physicians were
satisfactorily engaged in such educational activity and only 45% of the physicians were properly exercising themselves. These reports together suggest a lack of a proper, public educational effort to raise awareness of diabetes (Rademeyer, 2014).

3.3 Processes

The Saudi public health system mainly executes diabetes healthcare through its primary healthcare service. Patients normally attend primary healthcare services before receiving referrals to specialist diabetes centres. The first stage of diabetes care is registration in a primary healthcare clinic, where patients are provided with a diabetes card. Patients are diagnosed via a medical examination and through laboratory tests on samples. Patients also receive guidance as to how to self-manage their condition, usually through use of the Diabetes Patient’s Education Checklist. The goal of this first stage is to establish a diagnosis and prevent early-stage complications. The role of the diabetes centre is then to manage care and, if needed, refer patients to specialised care units, for example cardiological or surgical department. Diabetes patients are also referred by these centres for yearly physical examinations.

Treatment and control of type 2 diabetes in the Arab Gulf States was found to be suboptimal in a recent systematic review. The study based its conclusion on the three prime intermediate outcome measures (lipid control, bloody pressure and glycaemic indicators). Clinical outcome targets were met by less than 50% of sufferers (Alhyas, McKay, Balasanthiran, & Majeed 2011). Al-Ahmadi and Roland found that primary care centres repeatedly fail to provide a sufficient standard of care, especially with regard to accurate diagnoses and referrals (Al-ahmadi, 2005). Although there is a high rate of diabetic retinopathy in Saudi Arabia, only 40–68% of people with diabetes in the country have been referred to eye clinics. There are many reasons for this sub-optimal management of diabetes: apart from a lack of funding, primary care physicians are employed that are inadequately trained to treat diabetes; diabetes educators are rarely remunerated for their efforts or evaluated according to their professional outputs; and the same educators do not receive sufficient training and qualification. These shortcomings will be exacerbated greatly in the near future. A study by McKinsey predicted a 32% increase in demand for diabetes treatment in GCC countries by the year 2025 (Mourshed, Hediger, & Lamb, 2008).

There are very few papers evaluating organisational response to diabetes management and care. According to an IDF report (2014), “there is a national diabetes plan in development but no NCD plans or policies. No Ministries apart from Health are discussing the response to the diabetes challenge.” Diabetes is discussed in the context of several other, categorised health issues: for example, in nutrition documents issued by Ministry of Health which emphasize the need for adequate nutrition as a means of reducing the likelihood of non-communicable diseases. Saudi Arabia has not adopted the Global Monitoring Framework for diabetes. In fact the latest IDF (2014) report suggests that the Saudi MOH does not use any framework for the monitoring and surveillance of diabetes. According to IDF report, “the health system provides services for early diagnosis and treatment, although not universally. Less than 50% of the costs are covered and no services exist for diabetes prevention. Specialised services are provided for women but availability of self-education management is limited.”

3.4 Context

Saudi Arabia is distinct from Western societies in several ways and consequently requires policies which are in line with the local socio-cultural environment. The Kingdom of Saudi Arabia has witnessed a demographic shift over the last 20 years, accompanied by behavioural changes such as an increase in calories, fat and carbohydrate intake with a reduction in physical activity (Al-Hazzaa, Abahussain, & Al-Sobayel, 2011; Ng, Zaghoul, & Ali, 2011). In 2010, the country had a high proportion of years lost to disability (YLDs) caused diabetes: about 8%, compared to ischemic heart disease, which possesses a YLDs percentage of 0.81%. Alhyas, McKay, Balasanthiran and Majeed (2011) have characterised recent changes in Saudi culture as “rapid economic development and urbanisation; changes in lifestyle that have led to reduced levels of physical activity, increased intake of refined carbohydrates, and a rise in obesity” (Majeed et al., 2013).

Whereas WHO defines health according to personal wellbeing, sociability and productivity, Saudis tend to define it according to religious and cultural laws and traditions. In 1984, WHO defined health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”. Laverack (2007) states that the WHO’s definition and concept of health is the most commonly used official interpretation for health promotion and health education practice. The framework considers multiple dimensions of well-being, including physical, social and mental well-being, as well as the absence of illness. Physical well-being means the healthy function of the human body, biological normality, and physical fitness and capacities to perform tasks. Social well-being incorporates a wide scope of social responsibilities and issues such as marital satisfaction,
employability, and interpersonal relationships. Mental well-being includes self-efficacy, subjectivity well-being, social inclusion, and the abilities of individuals to adapt to their environment and their societies. Such a comprehensive definition of health would be foreign to most Saudi citizens, however, who primarily view health and wellbeing as arising from following cultural ‘rules’ and family traditions, and shunning technology and innovation. To be healthy is to follow the law according to Allah and illness is sent by Him; new technology has no place at present in this ancient culture. Similarly, Abdoli et al. showed that Iranian Muslims believed diabetes to be God’s Will, but they also believed the body was a gift from God; therefore they had a responsibility to take care of God’s gift. This study hopes to contribute to a change in beliefs using the accepted cultural norms so that the whole population of KSA can benefit from new medical knowledge and technology and thus hopefully some of the older, more dangerous practices can be eliminated.

Social and cultural practices in Saudi Arabia have a particularly direct influence in the form of traditional healing practices. Traditional medicinal practices are common in Saudi Arabia, especially among old and poorly educated Saudis in both rural and urban areas of the Kingdom (Al-Shahri, 2002). These include: herbal medicine, cauterizing, dietary treatments, chiropractic, fracture reduction, cupping, and spiritual healing (Aldosari, 2007). A study conducted by Al-Saeedi, Elzubier, Bahmassi and Al-Dawood, (2003) indicated that 15.6% of Saudis with diabetes believe that traditional herbal medicine is safe and effective for treating diabetes; 25.85 % believe that traditional healers are beneficial, and 30% of patients have actually used a medicine traditionally used to treat diabetes. Al-Saeedi et al. (2003) indicate that the popularity of traditional medical practices among a large number of Saudis is very high as most of the participants have used it based on the recommendation of their friends or family members, a finding that constitutes further evidence of a widespread confidence in traditional medicine. The finding also highlights a tendency in Saudi culture for individuals to seek help from non-qualified individuals in their social circle.

A further example of confidence in traditional health practices is that Saudi girls are not allowed to play sports as it is believed that they may lose their virginity by tearing their hymens (Human Rights Watch, 2012). Even apart from this, the cultural barriers limiting even visual contact between males and females affect the ability of females in engaging in sports activities. In fact, Saudi cultural practices negatively affect women’s health more generally: several studies (Al-Nozha et al., 2004; Al Quaiz & Tayel, 2009; Sharaf, 2010) investigated Saudi women’s physical activities and concluded that cultural beliefs not only create health problems arising from a lack of physical activity but also make them at risk of developing other health problems. Community support in encouraging all-round healthy lifestyles is this essential for facilitating diabetes management in Saudi Arabia.

Switching the focus to the so-called ‘modern’ aspects of contemporary Saudi life, there are also aspects of its current political set-up which hamper effective diabetes management. A lack of administrative stability has had a detrimental effect on the realization of government-initiated goals designed to manage diabetes. Since 2013, 6 different people have assumed the position of Minister of Health, and thus given the lack of sustained leadership from any one figure it is difficult for any one initiative to be extensively implemented.

4. Conclusion

In 2010, diabetes ranked fifth among leading causes of death in the Arab World, an increase from the 11th cause, as reported for 1990 (Mokdad et al., 2014). Having reviewed existing literature regarding diabetes in KSA, the study found state healthcare provisions in the country to be lacking. Primary care services are particularly underdeveloped, specifically in terms of their making accurate diagnoses and referrals. Furthermore, primary-care physicians lack adequate training regarding the disease. Diabetes educators lack specialized training and formal qualification, are rarely reimbursed for their efforts, and the results of their efforts is not monitored. The state health service is also understaffed, with a high proportion of practitioners coming from overseas. Current understanding of the disease is lacking: for example, there are no national databases focussing on diabetes. Further research on the disease is required to assist in successful containment of diabetes in the future: the Saudi MOH needs accurate data to allocate the appropriate resources for treatment. Becherouai et al. (2015) reported low utilization of free health services for preventative care, which calls for a major effort to inform the public of the value of prevention. In addition to regular physical checkups and screenings, programmes to improve diet and increase physical activity are urgently needed.

Such programmes should take into account the culture and environment in Saudi Arabia. Implementing such measures is particularly difficult in Saudi Arabia, however, where a persistent trust in cultural and religious values and practices tends to override an embracing of progressive reforms advocated by global health organisations, and where a lack of indoor spaces or amenities provided in a hot climate deters people from engaging in physical activity. Creative methods will need to be adopted to increase physical activity in a very hot
environment. In many places in the world, outdoor activities are encouraged, but in Saudi Arabia indoor activities have to be established and made available to the public and communities, perhaps using Saudi Arabia’s large indoor infrastructure, which includes malls and public spaces.

There are governmental mechanisms in place in Saudi Arabia which are currently addressing the problem of ineffective policy implementation caused by administrative instability (as previously noted, the Minister for Health has been replaced six times in the past two years). The National Authority for Combating Corruption investigates the failure of successive ministers to responsibly manage policies established by their predecessors. It aims to identify those responsible for creating delays in implementing projects and attempts to issue sanctions, with the ultimate aim of enabling citizens across Saudi Arabia to directly benefit from initiatives at the pragmatic health level.

**Limitations of the Study**

A lack of available data made it difficult to evaluate the extent to which interventions in diabetes cases in GCC countries are effective. Additionally, the data and findings covered by the study are not extensive or exhaustive owing to its primary focus on qualitative as opposed to quantitative studies.

**Ethical Considerations**

The authors have fully taken into account relevant ethical issues, including plagiarism and appropriate response to instances of data duplication or double submission of articles.

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**Conflict of Interest Statement**

The authors declare that there is no conflict of interest

**References**


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Challenges associated with treating children with diabetes in Saudi Arabia

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ABSTRACT

Background: Type 1 Diabetes Mellitus (T1DM) patients among the children have been increasing rapidly in the recent years in Saudi Arabia, as a result there is a need for extensive research in this area. Various suggestions were kept forward including m-health technologies, telemedicine etc. However, very little research has been conducted in understanding the T1DM among the children, measures being taken to control, and the feasible policies and procedures that could be adopted for managing T1DM among child population.

Objective: The primary aim of this study is to investigate and identify the challenges being faced in T1DM among the children in Saudi Arabia.

Methods: A questionnaire based survey is conducted with the child participants including the parents of the children with T1DM. The questionnaire has a multiple choice answers which need to be selected according to the participants views.

Results: Lack of initiatives taken by the health ministry in creating awareness about T1DM and its complications, and also in providing the effective infrastructure in healthcare centres; the role of schools in providing additional care for the children with T1DM is limited; the children are completely unaware of the T1DM self-management techniques, and feel nervous and embarrassed about the disease management process; and they are completely dependent on their parents for managing the disease.

Conclusion: Though there are few aspects where the care is delivered through parents, the need for self-management techniques is necessary and highlighted as the children spend most of their time in schools away from the parents.

1. Introduction

T1DM is one of the most chronic diseases in children (<15 years) worldwide. This disease accounts for 80-90% of diabetes in children and adolescents [1,2]. According to the International Diabetes Federation (IDF) the overall annual increase of T1DM is estimated to be 3% with 79,000 children worldwide are expected to develop T1DM every year [2]. T1DM is an autoimmune disease by insulin deficiency due to destruction of pancreatic islet beta cells. Children who have T1DM can also have several acute complications like hypoglycemia, and diabetes ketoacidosis (DKA) and...
long-term complications like retinopathy, nephropathy, dyslipidemia and other complications [5,6]. The impact of T1DM on children, parents and other family members can be significant because of the invasive, complex, and relentless nature of diabetes management [7]. The ultimate goal in T1DM management is to control the level of hemoglobin (HbA1c), to the recommended levels and to prevent T1DM complications [8]. The National Institute for Clinical Excellence (NICE) recommends a glycosylated hemoglobin target of 7.5% (58 mmol/mol) or less [9]. According to the American Diabetes Association (ADA) it is important to devise an insulin regimen that is tailored to the individual’s changing development and lifestyle, particularly in children and adolescents [10].

Children with T1DM are at very complex and challenging condition; they require more attention from their family, schools, and the health care centers. In addition the children are required to deal with a daily complex and demanding treatment regime through self-management techniques [11]. It is very much essential for the children to be fully integrated into school activities and learning opportunities while remaining medically safe. According to the ADA, it is recommended that children with T1DM must achieve the same level of disease management in school as they do outside of this environment [12]. As the T1DM among children is increasing worldwide, the complexities associated with it are also increasing, and this may seriously affect the health of the children in future, as they grow [13]. There is a need for effective T1DM self-management system, which must consider the changing lifestyles, attitudes and behavior of the children in managing T1DM, as the lifestyle changes are unavoidable. However, the studies in this aspect of T1DM management among the children are limited.

According to IDF Saudi Arabia is one among the different countries with high prevalence of T1DM among children, and the recent studies showed that the incidence was estimated at 27.5 per 100,000 with 17% annual increase; while the prevalence was estimated at 159 per 100,000 and is expected to increase as child gets older [3,4]. However the data on T1DM challenges among children in the recent past in Saudi Arabia is limited. Therefore in this study we aim to understand and explore the challenges patients encounter in managing T1DM at home, school, and in the health care facility.

2. Methodology

2.1. Study setting and participants

In order to explore the challenges of managing T1DM among the children in Saudi Arabia (KSA), a preliminary study on the current children T1DM management was carried out in KSA. The study was carried out through a follow up questionnaire designed to understand and identify the key challenges of T1DM management from four different perspectives: health sectors in KSA, Home, schools, and self-management. The patients with T1DM were recruited by clinical staff during the office visits in different health care centres, by sending SMS messages, emails and Twitter’s hashtag. Out of the total 241 people consulted, 239 of them participated in the survey. Two of the participants did not participate in the survey and the reasons were unknown.

2.2. Research tools

2.2.1. Study survey

The questionnaire was designed to answer the key questions about daily T1DM management among the children in different places which are usually visited as the part of their regular or daily routine like home, school, health care centers. In addition, the aspect of self-management at all these places is considered in designing the questionnaire. Accordingly, the questionnaire contained 23 questions which were grouped under five sections, which include: the basic information of the participants, their health care centers, home, schools and the aspect of their self-management techniques. Furthermore, the questionnaire was translated into Arabic. A sample snapshot of the online questionnaire structure is shown in Fig. 1. The questionnaire was based on multiple choice answers, which need to be selected by the parents of the child with T1DM by taking into the considerations of the child opinions. The responses were filled by the parents/guardians of all the patients (children with T1DM), and no child has directly participated in answering the survey questions. The data collection through survey process was conducted for 8 weeks, and the results were analysed.

The questionnaire was published and posted online using Google forms. The questionnaire was forwarded online using a link through twitter, and the responses were received from different regions of Saudi Arabia. The participants click on the link which would redirect to the online survey questionnaire, where they can submit their responses. The responses are saved in the google database and can be accessed anytime. The parents or guardians were briefed about the purpose of the study, and assured that the given information would be kept secure and confidential. The survey link was online and distributed from 04/10/2015 to 10/11/2015.

2.2.2. Inclusion & exclusion criteria

Both male and female patients from all ethnic backgrounds, aged between 2 and 14 years, who were diagnosed with T1DM are included in the study. Patients condition is verified and determined by self-reporting and verified according to

Fig. 1 – Snapshot of the used online questionnaire in Arabic version.
the 1997, American Diabetes Association criteria (fasting glucose > 126 mg/dl, symptoms of hyperglycaemia with casual plasma glucose > 200 mg/dl or two-hour plasma glucose > 200 mg/dl after a 75 g oral glucose load). The patients HbA1c levels must be less than or equal to 11% (97 mmol/mol), and must be taking insulin injections. All participants must be willing to participate in the study and follow the procedures as explained during the study. Participants, who do not fulfill the above conditions, are excluded from the study.

3. Results

3.1. Children with T1DM demographics

Table 1 presents the demographic information of the children participated in the study. Among the total children with T1DM participated (N = 239) there was almost equal number of males and females with 56% of males (n = 134), and 44% of females (n = 105). Most of the participants were between the ages 9 and 14 (n = 123, 51%, mean = 11.8, Std Dev = 1.7), followed by those older than 6 years and younger than 9 years (n = 65, 27%, mean = 7.3, Std Dev = 1.21), those older than 3 years and younger than 6 years (n = 50, 21%, mean = 4.3, Std Dev = 1.16), and those younger than 3 years (n = 1, 0.4%).

The mean HbA1C level of the 239 participants was found to be 8.9 (74 mmol/mol), with STDEV of 1.39. The mean HbA1c level shows that patients were above the recommended values [27] which put them at a higher risk for complications.

3.2. Children management challenges

The study found the following results in the aspect of challenges being faced in T1DM management among the children:

i. Majority of the participants, 52% of them (n = 124) stated that there are no special children T1DM management centres in their city or villages.

ii. 42% of the participants (n = 100) stated that they sometimes find difficulties in communicating the health problems with the doctors; 25.2% (n = 60) stated that they don’t communicate with their doctors regarding their health concerns, when they visit clinics; 16.8% (n = 40) stated that they rarely find difficulties in communicating the health problems with the doctors; and 16% (n = 39) of them stated that they always find difficulties in communicating the health problems with the doctors.

iii. Regarding the T1DM care services offered by the healthcare centers, and the follow-up services, majority of the participants, 51.5% (n = 123) stated that they are not satisfied and happy; while very few participants, 12.6% (n = 30) of them stated that they are satisfied.

iv. Majority of the participants (65%) stated that the health ministry in KSA hasn’t taken any initiative and launched children T1DM educational programs or activities in their areas.

v. Majority of the participants (62%) stated that they check their children’s blood glucose levels at home; however the frequency of the checks varied among them with 16% of them always, 24% of them sometimes, and seven percent rarely check the blood glucose levels. 53% of the participants stated they do not monitor blood glucose levels of their children at home. Lack of knowledge and awareness and inability to afford monitoring devices were found to be the major reasons for not monitoring the blood glucose levels at home.

vi. Supporting the fact that there are no initiatives being taken by the health ministry regarding the T1DM management among the children, the majority of the participants, 78.2% (n = 187) of them stated that they didn’t join any T1DM management program for children.

vii. Regarding the care received from the school management front, only 26% of the participants stated that the schools always provide additional care for the children with T1DM, while 43% of them stated that schools sometimes provide additional care, and 13% of them stated that schools rarely provide additional care. 18% of the participants stated that the schools do not provide any additional care for the children with T1DM.

viii. Majority of the participants, nearly 65.5% (n = 155) of them stated that there are no educational programs regarding T1DM management are launched by the schools for children, while 34.5% of them stated schools sometimes undertake such programs.

ix. 80% (n = 191, n = 1 for <3 years old, n = 50 for 3–6 years old, n = 65 for 6–9 years old, n = 75 for 9–15 years old) of the participants stated that their children are not aware and doesn’t know any self-management techniques for T1DM. The children have to be supported by their parents for T1DM management.

<table>
<thead>
<tr>
<th>Table 1 – Participants demographic data.</th>
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<tbody>
<tr>
<td>General characteristic</td>
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<tr>
<td>Gender</td>
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<td>Male</td>
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<td>Female</td>
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<tr>
<td>Age Group</td>
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<td>More than 3 years less than 6 years</td>
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<td>More than 9 years</td>
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</tbody>
</table>
x. Regarding the nervousness while taking insulin injections, 37.2% (n = 89) of the participants stated that their children always feel nervous; 41.8% (n = 100) of them stated that their children sometimes get nervous, and 17.1% (n = 41) of them stated that their children rarely get nervous while taking the insulin injections. Only nine (.03%) participants stated that their children don’t get nervous in the process of insulin injections. There were no participants who relied on pumps.

xi. Majority of the participants, nearly 68.2% (n = 163) of them stated that their children always feel embarrassed while taking insulin in the presence of their classmates, while 18.8% of them stated that their children sometimes feels embarrassed, and 12.9% (n = 31) of them stated that their children rarely feels embarrassed in such instances.

4. Discussion and conclusion

Various studies have shown poor infrastructure, lack of specific standards of practice and healthcare delivery, and irregularities in managing T1DM in the country [15–21]. The diabetic care earlier delivered in secondary and tertiary care centres is now being delivered through primary care centres, with very few dedicated centres for diabetic care [14]. However, studies have found that primary care clinics did not adhere to the standards guidelines of ADA (American Diabetes Association) with inadequate laboratory facilities and training programs [15,17]. Studies have shown that the majority (93.7%) of healthcare expenditure is borne by the government with minimum expenditures by patients or insurance companies (6–7%). The rising population with diabetes and poor infrastructure in the delivery of care would increase the financial burden on the government as there is resource deficiency [19,21].

A recent study has showcased the large set of irregularities in managing the T1DM in Saudi Arabia [22]. The demographic information of only 65.08% of female patients and 34.9% of male populations was found with the hospitals. 49.2% of the insulin prescriptions were unclear and 59% of the prescriptions were mentioned without ‘unit’. 56.1% of the insulin regimen used was premixed insulin followed by combination of Regular with NPH insulin (32.1%). Among the oral hypoglycemic drug prescribed with insulin, Also Metformin with 34.9% stood first. The study also found that the majority of the patients’ blood glucose levels exceeded the levels prescribed in the international standards [22]. Another study [23] focusing on incidence trends in childhood T1DM has found that the T1DM among the Children has increased at alarming levels. Another study has found that the prevalence of T1DM among the Saudi Arabian children to be 109.5 per 100,000 [24]. The study also identified that the insulin intake is administered by the parents of the children and the educational background and awareness of T1DM management knowledge of the parents is limited and needs improvement [25]. Another recent study has outlined the need for the health education classes for both teachers and parents through primary care centres, and also routine school health check-ups to ensure the proper healthcare management of school children [26].

Unlike the healthcare management in USA [27,28] where there are specific guidelines outlined for the management of T1DM among children by involving parents, children, teachers and primary care team, there are no Saudi Arabia specific guidelines formulated. There is an active involvement of independent organizations and also the government healthcare provider NHS in specifying the guideline among children with T1DM and in increasing the awareness among the parents, children and teachers [29,30].

Considering the findings in the above sections, the results of the survey can be discussed from four perspectives. Firstly, it is clear from the reports that the T1DM among the children in KSA has been increasing. Complications associated with T1DM can affect the children with diabetes may be severely affected as they grow old. Therefore proper care and effective self-management techniques for T1DM among the children is very much necessary. The healthcare centres are also less effective in creating awareness about the T1DM and its effects, and also the importance of self-management among the children with T1DM and their parents. The results from the survey indicate that there is less or no initiatives are being taken by the health ministry to control the situation. There is a need for health ministry/government to take initiatives developing and implementing effective strategies for diabetes management.

The communication strategy adopted by the healthcare centres has to be improved as most of the participants find it difficult to express their health related problems. The collaboration of health ministry and education ministry would be a good approach in launching initiatives and educational programs for creating awareness about T1DM and its complications, and the need for T1DM self-management. In addition, the healthcare activity in the remote areas has to be increased. An active involvement of parents, children and teachers along with primary care centres is necessary to effectively manage T1DM among the children. Mobile health technologies can be a useful approach in delivering the healthcare services in remote areas where the access to healthcare is limited. Adopting standardised guidelines formulated by international organizations like ADA, and by involving the research organizations, the Saudi government can formulate an effective healthcare strategy and standard guidelines of practice.

Secondly, the role of schools in T1DM management is very limited in KSA. As children spend most of their time in schools, it is very much essential that the school management has to take initiatives in providing additional care for children with complex health conditions. T1DM, being a chronic disease requires effective care for managing the blood glucose levels, managing food habits, lifestyles and physical activities. Therefore, there is a need for additional care in schools for the children with T1DM, where they may not only receive care but also learn T1DM self-management techniques, and also receive emotional support. However, the role of schools in KSA, as per the survey results is very limited. There is less or no additional care being delivered by the schools in KSA and there are no educational programmes being conducted by the school management in order to create
awareness among the children and the parents regarding the T1DM and its complications. The situation can be improved by increasing the awareness among the teachers, children and parents, by involving primary care centres as it is followed in USA and UK [27,29]. In addition, there is no proper medium of communication between schools and the parents regarding the health management of the children. This aspect has to be improved in order to ensure an effective communication channel between home and schools not just to maintain the educational activity of the children but also their health conditions.

Thirdly, the efforts of the parents in managing the condition of their children must be effective. Children usually are sensitive and need emotional and motivational support from the parents, friends and family in dealing with complex health conditions like T1DM. The results from the study indicate that the role of parents in managing T1DM is satisfactory. Though most of the parents stated that their children are not aware of T1DM self-management techniques and they involve in tasks like measuring blood glucose levels, injecting insulin etc., it is clear from the results that children do feel embarrassed and nervous in this process. Therefore there is a need for emotional and motivational support from the parents and their active involvement in making their children to adopt self-management techniques.

Lastly, it is clear from the results that there are no initiatives or very less initiatives are being taken in the promotion of T1DM self-management. T1DM is a very complex condition which requires regular care, and healthy diet, along with physical exercise. The children usually undergo different emotional and behavioural changes as they grow. Therefore, there is a need for adopting these changes accordingly so that the diabetes management process in not affected. In such cases, the T1DM self-management techniques can be an effective approach. The children must be taught the need for T1DM self-management, and they must be supported in adopting it. Eventually, children can adopt these techniques according to their changing lifestyles. These techniques can be reviewed regularly with doctors and updated according to the changing needs. As per the survey results are considered, there is less or no initiative being taken by the health ministry or schools or parents in managing the T1DM among the children in KSA using self-management techniques.

4.2. Conclusion

As the study focuses on the T1DM management among the children in KSA from different perspectives, it can be concluded that there are many drawbacks in these areas. The drawbacks are investigated and found using the questionnaire based survey, and the results highlight the need for the government/health ministry involvement in managing T1DM among the children, and similarly the need for increasing the role of schools, friends, and family in providing emotional and motivational support to the children and educating them with the T1DM self-management techniques. The results indicate that there is a need for many improvements in the healthcare sector in KSA and also with the diabetic health management among children involving schools, parents, friend and family.

Conflict of interest

The authors have no conflicts of interest to declare.

REFERENCES


Impact of Information Technology–Based Interventions for Type 2 Diabetes Mellitus on Glycemic Control: A Systematic Review and Meta-Analysis

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Abstract

Background: Information technology–based interventions are increasingly being used to manage health care. However, there is conflicting evidence regarding whether these interventions improve outcomes in people with type 2 diabetes.

Objective: The objective of this study was to conduct a systematic review and meta-analysis of clinical trials, assessing the impact of information technology on changes in the levels of hemoglobin A1c (HbA1c) and mapping the interventions with chronic care model (CCM) elements.

Methods: Electronic databases PubMed and EMBASE were searched to identify relevant studies that were published up until July 2016, a method that was supplemented by identifying articles from the references of the articles already selected using the electronic search tools. The study search and selection were performed by independent reviewers. Of the 1082 articles retrieved, 32 trials (focusing on a total of 40,454 patients) were included. A random-effects model was applied to estimate the pooled results.

Results: Information technology–based interventions were associated with a statistically significant reduction in HbA1c levels (mean difference −0.33%, 95% CI −0.40 to −0.26, \( P < .001 \)). Studies focusing on electronic self-management systems demonstrated the largest reduction in HbA1c (0.50%), followed by those with electronic medical records (0.17%), an electronic decision support system (0.15%), and a diabetes registry (0.05%). In addition, the more CCM-incorporated the information technology–based interventions were, the more improvements there were in HbA1c levels.

Conclusions: Information technology strategies combined with the other elements of chronic care models are associated with improved glycemic control in people with diabetes. No clinically relevant impact was observed on low-density lipoprotein levels and blood pressure, but there was evidence that the cost of care was lower.


KEYWORDS
diabetes mellitus; medical informatics applications; technology

Introduction

Chronic diseases such as diabetes can be managed better by implementing system-wide practices such as the chronic care model (CCM). This model identifies 6 components as essential for chronic disease management: health system organization, delivery system design, self-management support, community resources, decision support, and clinical information systems [1]. The CCM is globally applied to support system changes in
diabetes management and places particular emphasis on the use of information technology [2]. Advanced information technologies enhance communication among and between health care providers and patients [3] and improve chronic disease management [4]. Various information technology applications are currently available, including electronic patient registers, electronic decision support systems, electronic medical records (EMRs), telemedicine, videoconferencing, and electronic self-management systems [5]. Advanced informatics technology can aid the monitoring of hemoglobin levels, improve clinical practices, and help eliminate the health problems caused by diabetes [6].

Several systematic reviews evaluated the potential benefits of information technology–based diabetes management interventions, and all concluded that information technology–based interventions could improve diabetes management for adult care [7-11]. However, they did not extend their focus to consider blood glucose measurements using meta-analysis techniques or map interventions incorporating CCM elements. Therefore, this systematic review aimed to determine the effect of information technology–based elements of the CCM on glycemic control in people with type 2 diabetes mellitus (T2DM).

**Methods**

**Search Strategy**

A comprehensive literature search was conducted using PubMed and EMBASE for articles focusing on information technology–based diabetes interventions, which were published up until July 2016. A search strategy that combined keywords and Medical Subject Headings (MeSH) using the terms “diabetes,” “diabetes mellitus,” “non-insulin-dependent,” “diabetes type 2,” and “informatics” was used. In addition, international journals were searched manually and the reference lists from retrieved articles were reviewed in order to identify additional, relevant papers (Table 1).

**Inclusion and Exclusion Criteria**

Titles and abstracts of all studies identified were independently reviewed by 2 reviewers (NSA and NA) from February to July 2016. Any discrepancies between the choices of the 2 reviewers were resolved by another reviewer (SDL). The inclusion and exclusion criteria for the study are presented in the Textboxes 1 and Textboxes 2, respectively.

Table 1. Search strategies.

<table>
<thead>
<tr>
<th>Database</th>
<th>Search terms</th>
<th>Number of studies</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2: “Medical Informatics Applications”[Mesh]</td>
<td>37,851</td>
</tr>
<tr>
<td></td>
<td>1 and 2</td>
<td>425</td>
</tr>
<tr>
<td>EMBASE</td>
<td>2: ‘diabetes’/exp AND ‘mellitus’/exp</td>
<td>537,195</td>
</tr>
<tr>
<td></td>
<td>1: ‘information’/exp AND ‘technology’/exp</td>
<td>28,774</td>
</tr>
<tr>
<td></td>
<td>1 and 2</td>
<td>557</td>
</tr>
</tbody>
</table>

Textbox 1. Inclusion criteria for the study.

- The study design specifically evaluated the use of information technology–based interventions for the management of diabetes mellitus or T2DM, but the authors also included studies where information technology was part of a comprehensive intervention in which the impact of the information technology element was reported separately
- The study focused on T2DM or both type 1 and type 2 diabetes mellitus, because T2DM accounts for more than 90% of all diabetes cases [12]
- The study reported glycated hemoglobin (hemoglobin A\textsubscript{1c} or HbA\textsubscript{1c}) as an outcome measure
- The study had one of the following study designs: randomized controlled trial, nonrandomized controlled trial, and before-after trial

Textbox 2. Exclusion criteria for the study.

- Reviews lacking original study data
- Studies that evaluated information technology–based interventions in other chronic diseases
- Studies published in languages other than English or Arabic
- Studies of children with diabetes, as very few have T2DM, or studies of pregnant women with gestational diabetes, as this is not T2DM (even though people with gestational diabetes are at an increased risk)
- Papers using the same data as those already selected for use in the review
Data Extraction and Quality Assessment

Two reviewers (NH-NS) independently reviewed the title, the abstract, and the article. Discrepancies were resolved by consensus or determined by other reviewers (SDL). Information was taken from each study using a predesigned collection form: authors, date of the study, technology type, country, study site, duration of the intervention, type of diabetes, study design, communication type, main user, number of participants, and outcome measures. Relevant missing data were obtained from authors. A qualitative review was performed to extract information about the clinical and process outcome measures: body weight, systolic blood pressure, diastolic blood pressure, low-density lipoprotein (LDL) cholesterol, high-density lipoprotein, process of care, cost of care, patients’ satisfaction, smoking levels, and medication adherence. As part of data collection, quality assessment for each included study was conducted using PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines [13]. The studies were assigned a quality score ranging from 0 to 7 based on certain criteria (each item scored 1 point; the total score was 7), as depicted in Textbox 3.

Textbox 3. Criteria for assigning the quality score.

- Whether the study design was randomized
- Whether the study described criteria for selection of participant
- Whether both groups had similar baseline
- Whether the study described the intervention methods
- Whether the study evaluated the interventions after 6 months or more
- Whether the study used intention-to-treat analysis
- Whether the study reported method of blinding

Data Analysis

The outcome measure was the changes in HbA1c levels from baseline to follow-up. HbA1c is recognized as a significant indicator of information technology–based intervention effectiveness in patients with T2DM because it reflects average glycemia over 8 weeks and is strongly associated with diabetes complications [14,15]. A heterogeneity test (random-effects model) was used to evaluate variation between the studies. In addition, meta-analysis was used to assess the effectiveness of information technology–based interventions according to the type of technology used. All analyses were performed using the R Project for Statistical Computing program (AT&T Labs) [16]. HbA1c is recognized as a valuable indicator of treatment effectiveness in patient with T2DM, because it reflects average glycemia over several months, unaffected by self-report bias, and strongly associated with T2DM complications [17].

Results

Study Selection and Characteristics

The data search produced 982 studies and a further 100 studies were identified by manual searching and from the references of included articles, giving a total of 1082 studies. A flow diagram of the search and selection process is shown in Figure 1. The data search identified 1082 relevant studies, but 682 studies were excluded after title or abstract analysis. Therefore, 400 full-text studies were assessed for eligibility after excluding 34 duplicates (as well as 648 studies that did not address the topic under consideration). At the final stage of eligibility assessment, 369 articles were excluded, and the remaining 32 studies were included in this review.

All 32 studies selected for the review were published in English. Included studies had a total of 40,454 patients, more than half of them with both type 1 diabetes mellitus (T1DM) and T2DM, the others suffering from T2DM alone. Most of the included studies were conducted in the United States, while the 5 remaining studies were carried out in the United Kingdom [18], Korea [19], Germany [20], the Netherlands [21], and Canada [22], with the majority published after 2005. Study duration ranged from 3 months to 36 months; the main characteristics of the included studies are summarized in Multimedia Appendix 1. The intervention was targeted at monitoring diabetes care. As our meta-analysis was designed to specify, all studies included different types of technologies. The interventions had varying degrees of complexity. Information technology–based intervention strategies included different combinations of transmission of data, reminders, and data storage: 4 studies used a diabetes registry [18,23-25], 3 studies used EMRs [26-28], 18 articles used electronic patient self-management technology [19,29-45], and the other studies used electronic decision support systems (7 studies) [20-22,46-49].
Applications of Technologies

Four types of technological applications were identified as constituting the information technology–based intervention: electronic self-management system, electronic decision support system, diabetes registry, and EMRs. In some studies a combination of 2 technologies was identified. However, we categorized the types based on the main technology used in such cases.

Electronic Self-Management System

Out of 32 articles, 18 used electronic self-management tools [19,29-45]. These studies have applied several tools designed for electronic self-management systems, and the technologies have all shown to be successful. In this category, patients made use of the Internet, mobile phones, telemedicine, or other technologies to enhance their self-management, essentially to access diabetes health education programs or to communicate with clinicians.

In this group, the best weighted mean change in HbA1c level, −1.86%, was reported in the study by Smith et al [37]. To elaborate, the baseline HbA1c level was 10.83% (intervention group) and 11.08% (control group; P<.001). HbA1c level in intervention and control groups at 9 months was 7.68% and 10.83%, respectively (P=.02). In this study, patients used the MyCareTeam system, which gives people with diabetes the opportunity to log in and receive information about their condition, provides a portal for patients to log their blood glucose readings, and creates a space in which patients can discuss their condition with physicians and exchange information related to diabetes management. This technology was found to improve long-term glycemic control where a 1% decrease in HbA1c levels is associated with a 35% decrease in nerve damage, vision loss, and kidney disease, a 22% decline in peripheral vascular disease, an 18% reduction in the likelihood of suffering a heart attack, and a 25% reduction in diabetes-related deaths of all types [37].

Decision Support System

Out of 32 articles, 7 used a decision support system [20-22,46-49]. Tools belonging to this system were used to process data and provide recommendations and alerts to providers and their patients. Studies in this category utilized advanced forms of technology such as telemedicine, touch screen, computer-aided assessment, and Web-based diabetes trackers. In this group 71% of studies showed improvements in glycemic levels. The best improvement in HbA1c level in this group was observed in a study by Augstein et al [20] (−0.34% in the intervention group vs 0.27% in the control group; P<.011). This randomized trial enrolled adult patients with T1DM or T2DM and who were recruited from 5 outpatient centers. The decision support system tool that was used is the Karlsburg Diabetes Management System (KADIS). This system is an interactive, computerized, personalized decision support system.
for T1DM and T2DM. It allows for visualization of the current, characteristic daily HbA\textsubscript{1c} profile, identification of individual weak points, and interactive simulation procedures to predict outcomes of therapeutic strategies and lifestyle changes in HbA\textsubscript{1c} profiles [20].

### Diabetes Registry

Diabetes registry was the primary intervention in 12% (4/32) of the included studies [18,23-25]. The impact of diabetes registries on improving care was difficult to quantify because the registries performed many different functions. Although several studies have demonstrated improvements in the process of care delivery, the mechanism that accounts for this improvement is far from clear. Any improvement in the HbA\textsubscript{1c} level was modest [18,23-25], and strict entry criteria in another study left very little scope for improvement.

In one study, a pragmatic, cluster randomized controlled trial was conducted over a period of 15 months, with 3608 adult patients with T2DM, older than 35 years, and clients of 58 general practices from 3 localities in England. The intervention was a computerized diabetes register that incorporated the diabetes recall and management system. The registries were based on structured datasets completed on paper forms and laboratory reports. The results revealed that the intervention group demonstrated a decline in the mean level of HbA\textsubscript{1c} down to 7.32%. In addition to the improvement of the clinical outcome, the study also demonstrated improvements in the clinical process, including foot examinations, 67.3% (P<.05); dietary advice, 46.3% (P<.05); and blood pressure monitoring, 71.4% (P<.05) [18].

Among the studies, 2 randomized controlled trials did not show a significant improvement in the levels of HbA\textsubscript{1c} [24,25]. However, the first of these evaluated the effects of a registry-generated audit for diabetes, as well as feedback and patient reminder interventions on diabetes care, for 483 diabetic patients [24]. The registry was integrated electronically with other clinical information systems, automatically queried clinical databases, and reported summaries. After 12 months of evaluation, the study demonstrated that the hemoglobin levels were not different for either the intervention group or the control group.

### Electronic Medical Record

Only 3 out of 32 studies utilized EMR as the primary technological equipment [26-28]. The EMR was used as a decision support system or was integrated with Web-based personal health records. Out of the 3 articles in this group, 2 showed improvement in clinical outcomes, with O’Connor et al highlighting the best improvements in HbA\textsubscript{1c} levels. In this study the impact of EMR was evaluated over 12 months, in 11 clinics, and involving 2556 diabetic patients. The implementation of the EMR was associated with significant improvements in HbA\textsubscript{1c} level (8.5%-7.9%, P<.011) and systolic blood pressure control but no improvement in LDL cholesterol levels [26].

### Types of Technology Used

This systematic review has identified 4 broad categories of T2DM management technologies. Electronic self-management technologies were a major component of studies targeting patients. These technologies may be placed broadly into 4 categories. The first category is the Web-based intervention that is based on interactive websites. Patients upload their data and receive feedback at a time most convenient for them and are not limited to clinic office hours [29-32,36,38,45]. The second category is the telephone-based system, where patients regularly submit data about their conditions and they receive instructions and feedback through telephone calls performed by diabetes clinicians for follow-up or drug adjustment [34,39,40]. The third category is a mobile phone–based system, where patients use their mobile phone to upload their data manually or by connected glucometer, and then all data stored can be transmitted directly to their clinicians [19,42]. The last category is the telemedicine, which is a useful technology for consulting [41].

EMRs and disease registries facilitate care providers to conduct clinical audits, provide them with reports for analyzing a patient’s key diabetes-related measures, and assist in tracking the patient’s progress. Registries are a central component of the CCM within both the public and private health sectors. Previous studies have suggested that their use correlates with improved outcomes for patients with diabetes [50]. The use of a diabetes registry can improve clinical outcomes, including HbA\textsubscript{1c} levels [18,23,24]. Also, information technology has been used as a decision support system based on several tools such as clinical guidelines, condition-specific order sets, or reminders that linked to specific patient data such as blood pressure, cholesterol level, hemoglobin control, and annual eye and foot screenings, with the advice given to the physicians based on evidence-based guidelines.

### The Effects of Information Technology–Based Interventions on HbA\textsubscript{1c}

The overall effect of different information technology–based interventions on the mean reduction in HbA\textsubscript{1c} level was 0.33% (95% CI −0.40 to −0.26, P<.001; Figure 2). For the 4 information technology–based interventions, studies focusing on electronic self-management systems demonstrated the largest reduction in HbA\textsubscript{1c} level (0.50%), followed by those with EMRs (0.17%), an electronic decision support system (0.15%), and a diabetes registry (0.05%).
Discussion

Principal Findings

This study reviewed clinical trials that assessed the effect of information technology on glycemic control of patients with T2DM. This systematic review (32 studies, 40,454 patients) shows that information technologies achieved a significant reduction in glycated hemoglobin in patients with T2DM. Significant positive effects on HbA1c levels were found in 30 studies. The subgroup analysis demonstrated that electronic self-management technology had the greatest impact on the health of patients with T2DM, while the diabetes registry had the least effect.

The impact of diabetes registries on improving care was difficult to quantify because the registries performed many different functions: it was unclear if the improvements had been driven by the functioning of the basic diabetes registry or other interventions. In the same way, being certain about the effectiveness of electronic health record systems is challenging because there cannot be a certain relationship with any presumed dependent variable; there is at best an association between technology use and quality and satisfaction [51]. Although some studies have demonstrated improvements in the process of care delivery, demonstrating improvements in HbA1c levels has proved to be more challenging [18,23,24]. In addition, the baseline hemoglobin level in one study was 7.7% in both control and intervention groups [28]. Information technology diabetes interventions may need to be introduced to patients with a baseline HbA1c level equal to or higher than 8.0% in order to effect changes, as was the case in 12 studies reported. This analysis further demonstrated a greater reduction in HbA1c level in patients with a poor HbA1c level as compared with a moderate one (−0.58% vs −0.20%).

These days, information technologies are advancing rapidly and are ubiquitously available worldwide. There is widespread belief that information technology may reduce care costs for patients with diabetes. However, relatively few studies have evaluated the effect of information technology on costs. The secondary outcome measures were summarized qualitatively because they were measured with various instruments. We found that a
number of information technology studies reported improvements in the process of care and patient satisfaction, which suggests that information technology may be an effective strategy for changing patient behaviors. Additionally, our review demonstrates that there was no clinically relevant effect on LDL and no effect on blood pressure. This finding confirms those from a previous systematic review [7].

For diabetes care to be successfully supported by information technology–based interventions, their use should be embedded in the CCM. This review was able to map these technologies onto the CCM. It found that the most common CCM components used in trials besides the clinical information system were self-management support, delivery system design, and decision support. Health care organization and community resources were not reported. Most of the studies reported using multiple components in their interventions. It was difficult to determine which elements of the CCM benefit diabetic patients the most. However, interventions using self-management support reported the largest improvements in HbA1c levels. Four components of the CCM have a stronger effect on HbA1c levels than do 2 or 3 elements.

**Comparison With Prior Work**

Several systematic reviews related to health information technology have been undertaken, but they have limited their scope to specific systems such as telemedicine [52], clinical decision support system [53], mobile phone [54], and EMRs [55,56]. No study to date has reviewed a broad range of health information technologies. In addition, previous systematic reviews with less methodological rigor have not performed meta-analysis or have failed to detect significant differences between different types of technological interventions [8,10]. The findings confirm the findings of meta-analyses that stated that changes must be made in multiple areas of CCM elements in order to considerably improve the quality and outcomes of diabetes care [57].

There is evidence to suggest that electronic self-management systems may improve glycemic control in patients with T2DM: this meta-analysis indicated that this type of technology significantly reduced HbA1c levels compared with the control group (pooled mean difference 0.50%, P<.001). These results support the conclusion previously reported in 2012 [51]. It appears that clinical outcomes improve more when several CCM components are utilized simultaneously. In a review of 69 studies of diabetes care systems that used a variety of CCM components, the results demonstrated that utilizing all CCM elements may reduce the HbA1c level by 0.46%, which is quite similar to our findings (−0.50%).

**Limitations**

This review and meta-analysis has several advantages over most, previous systematic reviews of the impact of information technology on diabetes care. We reviewed a large body of literature, assessed the quality of included trials, and contacted authors of some studies to collect missing data. To our knowledge, this systematic review presents the first pooled analysis results of varied information technology types on HbA1c levels among patients with T2DM. Nevertheless, this review also has limitations. We used HbA1c level as the primary outcome measure because of its long-established association with adverse cardiovascular outcomes in diabetes [58]. However, we recognize that an appropriate process of care, as described in the CCM, may be more important in improving health outcomes. In addition, there is the possibility of publication bias as people are more likely to publish positive findings. Selection bias also consists of an exclusive focus on English- or Arabic-language studies, to the exclusion of studies in other languages. Although searches were carefully conducted using major databases and a cross-referencing method, there is the possibility that some publications were not included in the study because of the inclusion criteria. Most of the studies were conducted in the United States, with only a few conducted elsewhere. Considering that many European countries have implemented information technology interventions, it was surprising to note the lack of evaluation of these systems in diabetes care. Inevitably in this study, only HIT that was operational and part of a health system was included in our review. We know that may HIT implementations fail, and that a socio-technical approach and provide insights into why and when HIT can improve the care of patients with T2DM [59,60]. Further research needs to include how and why some implementations succeed and potentially improve health while others fail.

**Conclusions**

The findings of this review suggest that, in general, information technology interventions improve glycemic control. Patient self-management support appears most promising; EMRs and clinical decision support system appear to confer benefits, but disease registries by themselves do not appear to improve quality. In addition, the results conform to presumptions surrounding the CCM that changes must be made in multiple areas in order to considerably improve the outcomes of diabetes care. However, further investigation is still required to increase our understanding of how, why, and when information technology can improve the care of patients with T2DM. This includes a cost-benefit analysis of using information technology and the other secondary outcomes.

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**Conflicts of Interest**

None declared.
Multimedia Appendix 1

Summary of information technology–based interventions for type 2 diabetes.

[PDF File (Adobe PDF File), 54KB - jmir_v18i11e310_app1.pdf ]

References


Abbreviations

CCM: chronic care model
EMR: electronic medical record
HbaA1c: hemoglobin A1c
LDL: low-density lipoprotein
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
T1DM: type 1 diabetes mellitus
T2DM: type 2 diabetes mellitus