Depression and Self-care in Jordanian Adults with Diabetes: The POISE Study

Rasmieh Al-Amer

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School of Nursing & Midwifery,

University of Western Sydney
Dedication

I dedicate this work to my family – who supported me admirably from afar – in particular my husband Mohamed Darwish for his support in all I do, to my son Motasem, my daughters: Maram, Tamara and my sweetheart Rima for their belief in all I do. I am truly grateful for your endless patience, love, support and encouragement. Also, I dedicate this thesis to my brothers and sisters for all memories that we have shared.

Special dedication to my parents who would swell with pride at the thought of achieving this work –if they were alive; I hope that the hands of God would touch me through their souls for I truly believe that God sets HIS mercy to me through their love.
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Statement of Authentication

The work presented in this thesis is, to the best of my knowledge and belief, original except as acknowledged in the text. I hereby declare that I have not submitted this material, either in full or in part, for a degree at this or any other institution.

(Signature)
Rasmieh Mustafa Al-Amer
10 March, 2015
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<td>BIPQ</td>
<td>Brief Illness Perception Questionnaire</td>
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<td>BMI</td>
<td>Body Mass Index</td>
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<td>BTS</td>
<td>Bartlett’s Test of Sphericity</td>
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<td>CFI</td>
<td>Comparative Fit Index</td>
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<td>CSM</td>
<td>Common Sense Model</td>
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<td>DAWN</td>
<td>Cross-National Diabetes Attitudes, Wishes and Needs Study</td>
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<td>DM</td>
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<td>HbA1c</td>
<td>Glycosylated Haemoglobin</td>
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<td>IDF</td>
<td>International Diabetes Federation</td>
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<tr>
<td>JUH</td>
<td>Jordan University Hospital</td>
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<tr>
<td>KMO</td>
<td>Kaiser-Meyer-Olkin</td>
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<tr>
<td>ML</td>
<td>Maximum likelihood</td>
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<td>NFI</td>
<td>Normed Fit Index</td>
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<td>NHMRC</td>
<td>National Health and Medical Research Council</td>
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<td>$p$</td>
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<td>$r$</td>
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<td>Religiosity and Spirituality Coping</td>
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<td>Description</td>
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<tr>
<td>SD</td>
<td>Standard Deviation</td>
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<td>SDSCA</td>
<td>Summary of Diabetes Self-Care Activities</td>
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<td>SEM</td>
<td>Structural Equation Modelling</td>
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<td>SPSS</td>
<td>Statistical Package for the Social Sciences</td>
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<td>T1DM</td>
<td>Type 1 Diabetes Mellitus</td>
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<td>T2DM</td>
<td>Type 2 Diabetes Mellitus</td>
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<td>TLI</td>
<td>Tucker-Lewis Index</td>
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<td>UKPDS</td>
<td>United Kingdom Prospective Diabetes Study</td>
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<td>UWS</td>
<td>University of Western Sydney</td>
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<td>$\chi^2$</td>
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Abstract

The global prevalence of diabetes mellitus in the developing world is reaching epidemic levels, with Type 2 Diabetes Mellitus (T2DM) being the most common form of this condition. In a developing country like Jordan, T2DM continues to escalate, with a current prevalence rate of approximately 17%. Compounding this condition is another debilitating and often co-existing problem, depression. Although the cornerstone to T2DM management is adopting a healthy lifestyle and adhering to healthcare, the day-to-day self-care of diabetes is often challenging, particularly for those with both diabetes and depression.

Using Leventhal’s Common Sense Model (CSM) which focuses on patient’s perception of illness and the associated health-related behaviour individuals use, the study examined self-care management behaviour among Jordanians with T2DM, with particular focus on psychological status, social support, religiosity and self-efficacy in order to predict health-related behaviour. Hence, the purpose of this study was to examine the prevalence of depression among patients with T2DM in Jordan and the relationship between self-care management behaviour and the following psychosocial aspects: illness perception, depression, social support, religiosity and spiritual coping, and self-efficacy. The study explored the experience of those living with T2DM, with co-existing depression. Six standardised scales translated into the Arabic language used in this study were: Brief illness perception questionnaire (BIPQ), Patients’ Health Questionnaire-9 (PHQ-9); ENRICH Social Support Instrument (ESSI); Religious and Spiritual Coping Subscale (RSC); Diabetes Management Self-Efficacy Scale (DMSES); and Summary of Diabetes Self-Care Activities (SDSCA).

Using a sequential embedded mixed methods design, 220 patients with T2DM who were attending the Endocrinology Clinic at Jordan University Hospital between 10th of June and 30th of September 2013 were recruited and completed the study survey. Of these survey respondents, 15 participants were selected and
interviewed. The selection criteria was based on their PHQ-9 scores which indicated those with mild, moderate or moderately severe depressive symptoms. In addition to descriptive and inferential statistics, Structure Equation Modelling (SEM) was performed to test the proposed conceptual model based on CSM, and to examine the relationships among these constructs with self-care management behaviour. Interviews were transcribed and translated, and textual analysis of the qualitative data was carried out using a thematic approach to elicit themes related to psychosocial factors, and self-care management behaviour.

Results of this study revealed that depressive symptoms were highly prevalent among the study population, with approximately 70% of the respondents having some form of depressive symptoms. The study also showed that depression negatively correlated with self-efficacy ($r=-0.242; p<0.001$), and self-efficacy was positively correlated with self-care management behaviour ($r=0.405; p<0.001$). Results of SEM analysis found that there was a direct relationship between self-efficacy and self-care management behaviour ($\beta=0.40; p<0.001$). Depression was indirectly related to self-care management behaviour through self-efficacy ($\beta=-0.20; p=0.003$). There was also an indirect relationship between self-care management behaviour and social support, through depression ($\beta=-0.18; p<0.001$). Qualitative data from the participants’ narrative indicated that participants with diabetes and co-existing depression believed that their religion and spirituality take the forefront role in adherence to a health plan. Integrating findings from quantitative and qualitative components showed that all psychosocial variables selected in this study were directly or indirectly related to self-care management behaviour.

The current study sheds light on the perceptions Jordanian patients with T2DM, including those with depression, have on self-care management behaviour. This study also provided information that has implications for healthcare policy and practice in Jordan, particularly aspects of patients’ self-care that require support from health professionals.
Chapter 1
Introduction

Diabetes mellitus is a serious health threat globally, the increase in psychological and social burden of this disease have influenced the mortality and morbidity rate of diabetes. In this chapter we present background on the magnitude of diabetes mellitus and its association with other psychosocial variables including, illness perception, depression, self-efficacy, social support and religiosity and spiritual coping and diabetes self-care. Further, this chapter discusses the significance of this study and explains the rationale for addressing this issue among the Jordanian population. The aims of the study are also outlined, and the structure of the thesis is described.

1.1 Background

Over the past three decades, there has been a global increase in the prevalence of diabetes mellitus (DM), commonly known as diabetes. Considered to be one of the most common chronic disorders (Shaw, Sicree, & Zimmet, 2010), diabetes has today reached epidemic proportions worldwide. According to the International Diabetes Federation (IDF) (2011), around 366 million people globally have been diagnosed with diabetes in 2011, with approximately 138 million additional cases remaining undiagnosed worldwide. By the year 2030, the number of cases globally is predicted to reach 552 million. This upsurge in the prevalence of diabetes has placed a huge financial burden on health systems around the world, with an estimated cost of $376 billion in 2010. By the end of 2030, costs worldwide
are expected to reach $490 billion (Zhang et al., 2010). Most prevalent in
developing countries (Whiting, Guariguata, Weil, & Shaw, 2011), the highest rates
of diabetes in the world can be found across the Middle East and North Africa
(Majeed et al., 2013).

In Arabic countries, the prevalence of diabetes ranges from 3.3% in Sudan, to
2.5% in Yemen, to 18.7% in the United Arab Emirates, 13.6% in Saudi Arabia (Shaw,
et al., 2010), and 9.9% in Tunisia (Bouguerra et al., 2007). In Jordan, the prevalence
of DM among adults is high at 17.1% (Ajlouni, Khader, Batieha, Ajlouni, & El-
has increased by 3.6% (Ajlouni, Jaddou, & Batieha, 1998; Ajlouni, et al., 2008).

Uncontrolled DM has been linked to numerous health complications and life-
threatening conditions. Worldwide, it is the leading cause of heart disease,
blindness, kidney failure, and lower limb amputation (International Diabetes
Federation, 2014). Diabetes can also result in mental health issues such as
depression (Anderson et al., 2007; Renn, Feliciano, & Segal, 2011; Wu et al., 2011)
and poor quality of life (Riley, McEntee, Gerson, & Dennison, 2009; Svenningsson,
Marklund, Attvall, & Gedda, 2011). Thus, diabetes care should aim to assist patients
in maintaining a good quality of life, satisfactory metabolic control and a reduction
represents the daily tasks that an individual performs to manage diabetes. It is
widely acknowledged that the psychological effects of the daily management of DM
can be overwhelming, especially for patients who are coming to terms with a recent
diagnosis (Dysch, Chung, & Fox, 2012). Behavioural changes therefore need to be
considered and systemically addressed, for example, diabetes self-management training for patients, the provision of health information, and healthcare professionals helping to foster a sense of self-determination in patients, allowing them to successfully manage their condition and its related complications. It is noteworthy in this context that care for those with diabetes is mostly provided by the patients themselves and their families (American Diabetes Association, 2013b; Funnell et al., 2009; Toobert, Hampson, & Glasgow, 2000). Self-care of diabetes needs to be personalised and to focus on adopting a healthy eating plan, regular exercise, foot care, medication adherence and smoking cessation. Healthy coping mechanisms maximise the chances of maintaining blood glucose levels within a normal range that takes into consideration the individual’s needs (American Diabetes Association, 2014).

Good self-care also entails recognising the interrelationship between the aforementioned activities, and implementing modifications to a patient’s health plan where necessary. Ideally, important self-management choices that affect a patient’s health need to be made by the patient rather than imposed by healthcare providers (American Diabetes Association, 2014). Because self-care activities are multifaceted and idiosyncratic, a subjective assessment of an individual’s levels of illness and wellness is required. Psychological conditions that frequently coexist with diabetes will significantly impact on the patient’s capacity to self-manage their condition. In particular, depression is the most debilitating psychological condition that frequently accompanies diabetes and hampers self-care management.
The coexistence of depression and diabetes has been widely acknowledged in various systematic reviews and meta-analyses (Anderson, Freedland, Clouse, & Lustman, 2001; Gonzalez et al., 2008; Lustman & Clouse, 2005; Nouwen et al., 2010). These studies revealed that depression – whether minor or major – can have serious implications for a patient’s health. Depression exacerbates problems in regulating metabolic control by reducing the vitality of patients to adhere to their health plans (Ciechanowski, Katon, & Russo, 2000; Lustman & Clouse, 2005). Additionally, patients with depression typically express negative illness beliefs and appraisals. They also exhibit decreased mental functioning; this is likely to reduce adherence to a health plan, resulting in a poor outcome (Ciechanowski, et al., 2000; Ciechanowski, Katon, Russo, & Hirsch, 2003; Paschalides et al., 2004; Stafford, Berk, & Jackson, 2009; Wu, et al., 2011; Yuniarti, Dewi, Ningrum, Widiastuti, & Asril, 2012).

Depression also results in increased morbidity, mortality and healthcare costs amongst patients with diabetes (Bogner, Morales, de Vries, & Cappola, 2012; van der Feltz-Cornelis, 2011). Psychological distress frequently affects a patient’s self-efficacy and their ability to self-manage their condition, often hindering the long-term adjustment to a diabetes health plan, thereby leading to poor diabetes control (Paschalides, et al., 2004). Whilst the link between depression and diabetes self-care management is well recognised, the underlying mechanisms are not fully understood (Pouwer et al., 2010; Riley, et al., 2009).

Knowledge of diabetes per se is an inadequate predictor of daily self-care by patients (Hurley & Shea, 1992; Shin, Chiu, Choi, Cho, & Bang, 2012; Stathopoulou,
The Common Sense Model (CSM) proposes that chronic disease management stems from the patient’s personal beliefs about their illness and treatment. In other words, a negative illness perception among patients with chronic diseases creates challenges in each phase of the treatment plan (Leventhal, Diefenbach, & Leventhal, 1992). A patient’s perception of their health condition, as a CSM of illness perception, forms the basis of their coping responses (Grace et al., 2005), which in turn impacts on their self-care activities.

Patients’ self-efficacy will influence their capacity to implement and maintain their self-care activities (Sigurðardóttir, 2005; Yuniarti, et al., 2012). Moreover, a patient’s faith in his/her capacity to execute certain tasks is a crucial determining factor in terms of being able to successfully achieve their preferred outcomes. Therefore, self-efficacy, which is part of Social Cognitive Theory (SCT), can predict behavioural performance (Bandura & Adams, 1977). Self-efficacy is a cornerstone of improving adherence to self-care activities (Hurley & Shea, 1992). Illness perception and self-efficacy can entail a cognitive process in the patient where illness representation is an indicator of self-efficacy (Lau-Walker, 2006). It could be argued, therefore, that an individual’s general idea of their illness will influence their confidence in being able to utilise specific skills or to maintain robust capabilities in terms of executing self-care activities (Gosse, 2007). Therefore, patients who are offered the support needed to cope with their health problems, are more likely to have better health outcomes (Sawicki, Sellers, & Robinson, 2011; van Dam et al., 2005). Favourable health outcomes may be manifested by good control of blood glucose levels, as monitored by serum glycosylated haemoglobin (HbA1c). Such
outcomes are essential for patient health, since reducing HbA1c to below 7% has been shown to reduce the micro-vascular and macro-vascular complications of diabetes (American Diabetes Association, 2013b).

In summary, the CSM suggests that positive illness perception results in better self-care among diabetes patients (Leventhal, Brissette, & Leventhal, 2003; Leventhal, Cameron, Leventhal, & Ozakinci, 2005; Leventhal, et al., 1992; Leventhal, Nerenz, & Steel, 1984; Leventhal, Safer, & Panagis, 1983). However, good adherence to self-care programs is a multi-factorial process, and the influence of a number of other lifestyle and cultural dimensions – such as religious belief systems – also needs to be considered (Chesla & Chun, 2005). The relevance of cultural and religious aspects will be explored in the chapters that follow.

Overall, when examining self-care in diabetes it is essential in order to identify the determinants that influence adherence to a diabetes treatment plan, and to generate an effective diabetes self-care plan that leads to positive outcomes and may prevent diabetes complications. The current study, Depression and Self-Care in Jordanian Adults with Diabetes (POISE, 2015) adopts the CSM of illness perception to examine self-care activities from the patient’s perspective.

1.2 Significance of the study

Mental health is a crucial consideration in terms of diabetes care. Fragmented or neglected mental health care can risk rendering a person vulnerable to significant increases in morbidity and mortality (Egede & Ellis, 2010b). In the Arabic community, mental health issues are considered a taboo subject; a topic that is contained within family parameters and not discussed publicly. Keeping mental
health problems only within the family is a cultural factor that has resulted in a limitation of data collected in relation to understanding the rates of depression among this population. In fact, there is only one existing study conducted in Jordan, in 2011, among patients with Type 1 Diabetes Mellitus (T1DM) and Type 2 Diabetes Mellitus (T2DM). This study reported a depression rate of 19.7% in the study group as assessed by the PHQ-8 (Al-Amer, Sobeh, Zayed, & Al-domi, 2011). However, the study was unable to elucidate the multifaceted psychosocial interaction between depression and diabetes. In other Arabic countries, there is a similar paucity of research addressing the relationship between diabetes and depression (Almawi et al., 2008). The above mentioned findings suggest that the psychological aspect of care is neither well addressed nor recognised in diabetes treatment and management plans.

The study examines the interrelationship in Jordanian patients with T2DM between the following psychosocial constructs: illness perception, depression, social support, religious and spiritual coping, self-efficacy and self-care activities. First, findings will potentially highlight the conceptualisation and integration of psychosocial factors within the context of the self-care of diabetes management. Second, the study will explicate the key determinants of health behaviour by underlining the impact of coexisting depression on self-care activities among patients with diabetes. Third, the complex interplay between social context, environment, and a person’s idiosyncratic traits, and beliefs will be identified. Fourth, the study will assist in understanding and configuring the factors that have a tangible effect on health behaviour in patients with T2DM.
Data collected in this study may also assist in promoting comprehensive nursing management for patients with comorbid diabetes and depression. Data could also be used to enhance the integration of both the psychological and the physiological aspects of care for diabetes patients, while assisting healthcare planners in creating a well-crafted support platform that utilises patients’ personal resources, and which promotes the active role of patients in managing their condition.

1.3 Rationale for addressing depression and self-care in Jordan

The prevalence of diabetes has been steadily rising in Jordan in recent years (1998 to 2008), with predictions of further increases in the coming decades (Ajlouni, et al., 2008). Moreover, the concomitant rate of depression among patients with diabetes is high (Al-Amer, et al., 2011). Diabetes and depression are individually linked to premature physical and psychological impairment. When both conditions coexist, the risk of complications increases significantly (Anderson, et al., 2001; De Groot, Anderson, Freedland, Clouse, & Lustman, 2001; Egede & Ellis, 2010b; Hsu et al., 2012).

Despite the fact that 330 million people worldwide are descended from an Arabic ethnicity (CIA, 2010; Shaalan, 2010), there is limited information available on the comorbidity of depression and diabetes in the Arab population. The numbers of Arabs in western nations are on the rise in recent decades, with 210,000 people of Arabic descent in Australia (Al-Krenawi & Graham, 2000), 1.2 million in the United States (De la Cruz, 2008), 350,000 in Canada (Statistics Canada, 2007), 2 million in
France (Al-Krenawi & Graham, 2000), and 700,000 in the United Kingdom (Miladi, 2006).

The lack of data on the effects of co-existence of diabetes and depression in Arabic populations may be attributable to the aforementioned cultural prejudices that link psychological problems with a great sense of shame and disgrace. Such cultural discourses may hinder or prevent patients from seeking the appropriate medical treatment. Furthermore, when considering that the somatic symptoms (such as loss of appetite and sleep disturbances) of diabetes and depression often overlap (Ciechanowski, et al., 2003), it is important to take into consideration the fact that Arabic patients tend to ignore psychological symptoms, or else to attribute them to physical causes, since psychological disease is seen as an indicator of moral weakness and lack of faith (Fakhr El-Islam & Abu-Dagga, 1992).

Depression among patients, in Arabic populations, with diabetes is often under-diagnosed and frequently remains untreated. This raises concerns that untreated coexisting depression among patients with diabetes may result in rising levels of frustration, thereby contributing to poor diabetes control. To optimise diabetes control, it is imperative that cases of comorbidity are detected at an early stage so that interventions and treatment can be implemented (Khuwaja et al., 2010). It is therefore vitally important that the healthcare systems of Arabic countries are aware of the prevalence of depression and its associated factors amongst people with diabetes. Existing research that addresses the relationship between self-care, depression, and diabetes has focused on patients with diabetes in western communities (Anderson, et al., 2001; De Groot, et al., 2001; Egede &
Ellis, 2010b; Hsu, et al., 2012). Factors specifically pertaining to an Arabic ethnicity and cultural background have not been considered. Existing research may or may not be applicable or generalised to Arabic patients. In order to better comprehend the multiple factors that influence self-care activities for diabetes patients in the Arabic community, a comprehensive assessment of this population is necessary.

There is also a need to provide better support to patients with diabetes and coexisting depression in order to assess and address the health risks associated with a patient experiencing the spiralling symptoms of depression. It is well recognised that depression can be reinforced by diabetes complications and vice versa (Lustman & Clouse, 2005). In Arabic-speaking communities in general, and particularly in Jordan, there are no previously documented studies where diabetes and depression are systematically investigated in relation to self-care activities among patients. Thus, the current study used a mixed method design to address and explore self-care activities in patients with diabetes and coexisting depression. The participants’ illness characteristics are interrogated in conjunction with the relevant psychosocial factors. In order to examine the important features of self-care activities among Arabic communities, a conceptual model for this study was developed and validated based on the CSM of illness perception (Leventhal, et al., 1984). The theoretical framework of this study is discussed in detail in Chapter Two.

1.4 Aims of the study

The aim of the study was to evaluate the prevalence of depression among patients with T2DM in Jordan, and to examine the relationship between self-care activities and the psychosocial aspects of illness perception, depression, social
support, religious and spiritual coping, and self-efficacy. The study explored the
experience of Jordanian patients living with T2DM and coexisting depression. One
of the study’s objectives was to examine a conceptual model of diabetes self-care
activities among an Arabic-speaking community. The study tested the association
between depression and self-care activities among adults with T2DM in Jordan from
a psychosocial perspective, while exploring the participants’ personal experiences of
living with diabetes and coexisting depression.

The aims of this mixed methods study are detailed as follows: the quantitative
phase of the study seeks to answer questions for aims 1, 2 and 3. The qualitative
phase explores participants’ experience of living with diabetes and coexisting
depression (aim 4). Both the quantitative and qualitative data sets answer the
research question in relation to aim 5.

1.4.1 Research aim 1

To identify the prevalence of depression among patients with Type 2 Diabetes
(T2DM) in Jordan.

- What is the current prevalence of depression among patients with diabetes?

1.4.2 Research aim 2

To determine the relationship between illness perceptions, depression, social
support, religious and spiritual coping, and self-care activities including: diet plan,
exercise, medication adherence, blood glucose testing, medication adherence, foot
care and smoking habits, to answer the following question:

- What is the magnitude of the relationship between the selected
  psychosocial variables and self-care activities including: diet plan, exercise,
medication adherence, blood glucose testing, foot care, and smoking habits in a population of adults with T2DM?

1.4.3 Research aim 3

To ascertain the predictors of self-care activities among patients with T2DM, and in particular to investigate the following research question:

- What are the direct and indirect predictors of self-care activities among the study-selected variables: illness perception, depression, social support, religious and spiritual coping, and self-care activities including: diet plan, exercise, blood glucose testing, medication adherence, foot care and smoking habits?

1.4.4 Research aim 4

The qualitative component of the study explored the experience of living with T2DM and depression, with a particular focus on the role of social support, religious and spiritual coping, illness perception, and self-efficacy and self-care activities.

1.4.5 Research aim 5

To integrate the quantitative data set with the qualitative data set to explicate an in-depth understanding of the behavioural patterns of patients with T2DM, and to interrogate the contextual and personal aspects that relate to the self-care activities of these patients, namely to answer the following question:

- How do factors such as the perception of illness, depression, social support, religious and spiritual coping, and self-efficacy influence self-care activities among patients with diabetes in Jordan?
1.4.6 Research aim 6

To adapt six standardised English scales for relevance and cultural appropriateness including: Brief Illness Perception Questionnaire (BIPQ), Patients’ Health Questionnaire-9 (PHQ-9); ENRICH Social Support Instrument (ESSI); Religious and Spiritual Coping Subscale (RSC); Diabetes Management Self-Efficacy Scale (DMSES); and Summary of Diabetes Self-Care Activities (SDSCA).

1.5 Chapter summary

This chapter presented background about the magnitude of diabetes on a global scale. Additionally, presented an overall review of other relevant literature which provided an overview on the epidemiological facts of diabetes in Arab countries and in particular in Jordan. Further, the link between diabetes self-care and depression has been discussed; patients with diabetes and depression often find self-care activities to be an arduous and time-consuming process. The coexistence of depression may exacerbate such feelings while hindering engagement in self-care activities; also, considered is Illness perception and self-efficacy, social support and the impact on patients with T2DM.

Self-care was highlighted as a keystone in managing diabetes in order to improve diabetes control and enhance patient’s quality of life. Further, self-efficacy was recognized as a significant factor that impacts on self-care. The theoretical framework behind this dissertation was the Common Sense Model (CSM), which involves the concept of illness perception. Evidence suggested that accurate illness perception was considered to be a crucial factor in successful diabetes care.
Also presented was the significance of the study for patients with diabetes and for health care providers, and acknowledging the following: illness perception, depression, social support, religiosity and spirituality, and self-efficacy among Jordanian’s. The study illustrated the prevalence of diabetes and depression in an Arab population is rarely addressed.

Moreover, the chapter laid out the aims of the study explicitly; in which evaluation of the depression level and the direct and indirect relationship between illness perception, depression, social support, religiosity and spirituality coping, self-efficacy and self-care was assessed. The experience of having diabetes and depression at the same time was explored in depth.

### 1.6 Structure of the thesis

This thesis consists of nine chapters.

**Chapter One:** presents an overview of the study including background, rationale for the study, significance of the study, and the aims of the study.

**Chapter Two:** presents the theoretical framework of the study, and examines the levels of adherence to self-care activities among patients with diabetes, and the impact of depression. This chapter provides a critical literature review and describes the key determinants of self-care activities. The chapter also critically appraises the available international research on self-care activities among diabetes patients with coexistent depression.

**Chapter Three:** details the methodology of the study including the study design, and examines the assumptions that underpin a mixed methods approach. The
applicability of a mixed methods design is explained. This chapter describes the survey instruments and structure of the data collection and data analysis processes. The rigour of the study is also considered.

Chapter Four: details the translation process of the study instruments, and the interview data. This chapter also describes the rigour used in the translation process.

Chapter Five: presents psychometric testing for the study survey.

Chapter Six: presents the quantitative results, through synthesis of phase one of the study.

Chapter Seven: presents the qualitative data results generated by using a thematic analysis approach. Themes that emerged from the data are presented, and each theme is discussed with examples provided to illustrate the patients’ experiences.

Chapter Eight: discusses both data sets through integration of the quantitative results with the qualitative findings.

Chapter Nine: elaborates the major findings arising from the synthesis of both data sets. The findings are discussed in light of the existing literature. New knowledge derived from this study is highlighted. The strengths and limitations of the study are addressed in the final section of this chapter, and the conclusion, recommendations, and implications for practice are presented.
Chapter 2
Literature Review

This study identifies the beliefs that may predict adherence to self-care activities, and which may suggest intervention targets among patients with Type 2 Diabetes Mellitus (T2DM) in Jordan. The study utilises the Common Sense Model (CSM) of illness perception proposed by Leventhal, Nerenz and Steel (1984). This chapter presents the theoretical framework of the study and provides a comprehensive review of the available literature. Furthermore, it discusses the relationship between the study constructs: illness perception, clinical variables including (BMI, HbA1c), social support, religious and spiritual coping, depression, self-efficacy, and self-care activities.

2.1 Common Sense Model

There is a range of existing psychosocial frameworks that have been developed to explain patient health-related actions in response to an illness (Ajzen, 1991; Bandura & Adams, 1977; Janz & Becker, 1984; Leventhal, Meyer, & Nerenz, 1980). These group of psychosocial frameworks dictate that numbers of cognitive and emotional factors are the proximal determinants of health behaviour. Furthermore, these models proposed that distal factors such as social milieu, cultural arena, and personal issues are of importance in defining a health behaviour. Additionally, they assume that the impact of distal factors is largely or completely modified by the proximal factors specified by a certain model. Of note, these health models have some limitations in term of being fully accounted for person’s cognitions and emotions that predict a person’s health related behaviour. Also
known as the self-regulation model, the CSM presents novel features in terms of predicting health behaviours. The CSM can be operationalised as an instrument or tool to predict human behaviour in regard to perceptions of illness and health (Leventhal, et al., 2003; Leventhal, et al., 2005; Leventhal, et al., 1992; Leventhal, Leventhal, & Cameron, 2001; Leventhal, et al., 1984). The CSM has also been lauded for its capacity to identify predictors of the management or self-care activities for various health conditions (Broadbent, Donkin, & Stroh, 2011; Lawton, Peel, Parry, & Douglas, 2008; Searle, Norman, Thompson, & Vedhara, 2007). The model identifies people’s beliefs about their capacity to change a situation; it also explains an individual’s ability to meet the demands and challenges faced in implementing positive change in such situations. Furthermore, the CSM can predict the health-related choices a person is most likely to make. Unfortunately, adherence to self-care activities is generally unsatisfactory, and interventions designed to promote adherence have yielded equivocal results. An initial analysis of the available literature indicates that the self-regulatory perspective of the CSM provides a deeper understanding of adherence difficulties than other models. Existing literature also indicates that the CSM as an instrument has high levels of utility in terms of its practical applicability (Leventhal, et al., 1992).

The CSM is of critical importance in understanding the relationship between illness perception and the inherent challenges of any health recommendation plan (Leventhal, et al., 1984). In particular, the CSM suggests that people dealing with a health threat will typically develop an illness representation by the dual process of: cognition and emotions. Cognitive illness representation which – accorded primacy
in the CSM refers to a person’s perception of a physical disruption to their health – a perception that arises from the somatic symptoms they are experiencing. In other words, cognitive illness representation is the objective representation of a threat. An individual’s cognitive reaction to the health threat then creates a parallel emotional illness representation process. The emotional representation is the subjective interpretation in response to the health threat (Leventhal, et al., 2003; Leventhal, et al., 1980; Leventhal, et al., 1984). These representations are important determinants of the coping strategies and behaviours that individuals adopt in response to the perceived health problem (Leventhal, et al., 2005; Leventhal, et al., 2001). Although illness representations are unique to the individual, they are also significantly shaped by a person’s cultural and social context, past experiences and beliefs about health in general. Illness representations are also inflected by a patient’s understanding of their current condition (Leventhal, et al., 2005; Leventhal, et al., 2001).

Illness representation is formulated based on three major avenues of information: i) lay information, which is the information that the individual has acquired through previous social and cultural experiences, ii) the acquisition of the information from significant others including authority figures, and iii) possession of information that is generated from previous personal experiences with the disease as well as the current experience. Illness representation is seen as the conduit through which coping mechanisms are developed. Therefore, a disease-specific somatic representation within itself is inadequate in terms of developing the motivation towards effective coping behaviour. Rather, society and culture are also

The CSM is underpinned by three principles: i) patients are dynamic individuals who are constantly seeking to understand their illness and aiming to avoid or control the illness and its related cognitive, emotional and somatic effects, ii) common sense beliefs are fundamental to strategies developed by patients to control their disease, and these beliefs are not necessarily predicated upon medical approval or reference, and iii) common sense beliefs are also affected by a number of external and internal factors including, but not limited to, social support and gender (Leventhal, et al., 2001).

What people think and believe about their illness is a critical factor in predicting their self-care activities (Lawton, et al., 2008; Searle, et al., 2007). When an individual is diagnosed with a health condition (such as diabetes mellitus), s/he generally develops a schema or a pattern of beliefs about this illness. Illness representations are idiosyncratic perceptions of symptoms and illness. Formed as a result of personal and vicarious experiences (including medical information, books, media, family and friends, culture and religion), illness representations may or may not be medically accurate, but are nonetheless fundamental in shaping one’s responses to a health condition (Hagger & Orbell, 2003; Kucukarslan, 2012).

The CSM identifies five components that construct the cognitive representation of a health threat: identity (disease label); causes (such as hereditary); consequences (such as diabetes complications); timeline (the disease
course); and contractibility (such as medication control) (Cameron & Leventhal, 2003; Diefenbach & Leventhal, 1996; Leventhal, et al., 2003; Leventhal, et al., 1992; Leventhal, et al., 2001; Leventhal, et al., 1984). It is noteworthy that the aforementioned constructs emerged across a variety of patient groups in different studies (Hampson, Glasgow, & Strycker, 2000; Meyer, Leventhal, & Gutmann, 1985). These categories or dimensions all demonstrate logical interrelationships (Weinman & Petrie, 1997). Each component can be described as follows. First, identity is the symptoms of an illness that is felt by patients as the disease’s primary identifier (Moss-Morris et al., 2002). Second, the dimension of causes designates the individual’s perception of the reasons behind the disease (Diefenbach & Leventhal, 1996; Weinman, Petrie, Moss-morris, & Horne, 1996). A meta-analysis using grouped illness representation of causation for different categories includes: biological (such as infarction), emotional (such as anxiety), environmental (such as pollutants), and psychological (such as mental issues) (Hagger & Orbell, 2003). Third, consequences are the anticipated results and perceived impacts on an individual’s life, and the perception of how the disease might affect their daily activities (Meyer, et al., 1985). Timeline refers to the duration of the disease, and finally contractibility denotes the magnitude of treatment and the healing process (Searle, et al., 2007).

The characteristics of illness representation outline and shape the coping phase and play a role in assessing coping outcomes (Leventhal, et al., 2003; Leventhal, et al., 2005; Leventhal, et al., 1992; Leventhal, et al., 2001; Leventhal, et al., 1984). The CSM is specifically concerned with certain beliefs about an illness,
and the ways in which these beliefs steer self-regulatory behaviours (Leventhal, et al., 2005; Leventhal, et al., 1992). Moreover, applying the CSM as a framework helps the researcher or health practitioner to illuminate and elucidate the underlying processes that influence adherence to self-care activities. The model also allows for a differentiation between the individual’s belief system and the medical orthodoxy in relation to a disease.

The use of coping strategies in response to illness representations underpins health-related decisions and subsequent behaviours, whether they support or oppose the medical plan (Diefenbach & Leventhal, 1996). Coping mechanisms are often developed as natural processes, to reduce the undesirable effects that could be imposed by the health threat of the disease. These mechanisms will then be subjected to an appraisal phase (Leventhal et al., 1997; Leventhal, et al., 1992). A feedback loop is thus formed, and this interplay modifies the representation of illness, either cognitively or emotionally or both. The dynamic nature of the CSM enables it to predict coping mechanisms and behaviours (Davis, Peterson, Rothschild, & Resnicow, 2011).

The CSM has three components – interpretation, coping and appraisal – and these are interconnected, which maintains equilibrium (Searle, et al., 2007). The CSM also recognises that a health threat evokes emotional reactions alongside cognitive reactions (Leventhal, et al., 1984). Emotional illness representation structurally parallels the dimensions of cognitive illness representation, and is divided into three stages: representation (interpretation), coping and appraisal (Leventhal, et al., 1984). Furthermore, emotional representations also produce
different coping strategies, such as seeking available social support, cognitive endorsement of the problem and concrete attempts to avoid the threat (Leventhal, 1990; Leventhal, et al., 2003). There is an association between the emotional status and physiological status of the body, and this is particularly salient in terms of how emotional representation impacts health coping behaviours. It is therefore plausible that emotional coping processes can influence cognitive coping processes and vice versa.

2.1.1 Development of the CSM of Illness Representation

The CSM was developed by Leventhal et al. in 1965 as an instrument that enabled an examination of people’s behavioural responses to fear media messages delivered to the public during a health education program (Leventhal, Singer, & Jones, 1965). Messages of concern were of two types in terms of seriousness: high-fear and low-fear messages. It was found that sending high or low-fear messages alone was not effective in terms of influencing people’s health behaviours. Instead, coupling either of the messages with an action plan was found to successfully influence behaviour, particularly when the action plan proposed detailed threat-lowering mechanisms (Petrie & Weinman, 1997). Therefore the fear-drive model alone was deemed to be unsustainable, since without an action plan it had little impact on health behaviour (Petrie & Weinman, 1997).

2.1.2 Summary of the Common Sense Model (CSM)

There is an abundance of literature that hypothesises that actions taken to reduce health risks and consequences are guided by the ways in which individuals construct their illness representation of a health threat (Hagger & Orbell, 2003;
Sawicki, et al., 2011; Stack et al., 2011). The self-regulation model has proven to be a reliable predictor of attitude towards wellness and illness; it represents a coping strategy that people develop after reflection and evaluation of their cognitive and emotional reactions (French, Wade, & Farmer, 2013; Hagger & Orbell, 2003; Meyer, et al., 1985). Illness perception contains core elements that are central to a patient’s experiences of illness and illness management. For instance, patients make sense of their disease from their idiosyncratic understanding of it. Illness representation is an ongoing process, formulated unconsciously, and influenced by both external factors (for example, social support, ethnicity) and internal factors (such as symptoms, distress or gender) (Leventhal, et al., 2001). When the normal path of life is disrupted by a threat or illness the individual often is compelled to restore equilibrium (Leventhal, et al., 1984). Attempts to restore equilibrium help the patient to cope with the threat of illness, on condition that they have an optimal psychological status.

2.2 Conceptual framework

The components of the CSM are conceptualised in the current study as variables that influence the adherence to self-care activities among patients with T2DM. In particular, diabetes can be seen as the health threat or the stimulus that is constructed from a person’s previous and current experiences. The variables included in this model are: illness representation, depression, social support, and religious and spiritual coping, self-efficacy, and self-care activities.

The proposed model hypothesises that illness perception, Body Mass Index (BMI) and glycosylated haemoglobin all influence self-care activities through their
various associations with depression, social support, religious and spiritual coping and self-efficacy. A schematic representation of the conceptual model is shown in Figure 2.1; page 25.
Figure 2.1  Conceptual model of the relationship between psychosocial factors and self-care activities
2.3 Research model scenario

For an adult with T2DM, the experience of having polyuria and/or polyphagia associated with polydipsia can be influenced by a contextual aspect such as education or external environment. To illustrate, in summertime, a person may attribute these symptoms to the warmer weather. Indeed, hormonal and other biological disruptions in the pituitary gland can also be attributed to such external factors. Once processing of these symptoms is activated, patients start to amass information in their quest to identify the disease that will fit their symptom profile. Thus, the primary label of having such symptoms becomes more distinct. Factors such as coherence, personal control, treatment control, timeline, consequences, emotions and identity are all personally constructed and unique. As such, these factors should be considered during the health assessment process.

2.4 Conceptual definitions

This study investigated a group of selected clinical variables: illness perception, social support, religious and spiritual coping, depression, self-efficacy, and self-care activities. These variables were defined conceptually in the current study, as discussed in the sections that follow.

2.4.1 Illness representation

In the current study, the phrases *illness representation* and *illness perception* are used interchangeably. Illness representation was defined as the person’s integrated cognitive and emotional representation of situational stimuli (in this study, diabetes); and guides the individual coping mechanism. The dimensions of a health threat are: identity, causes, consequences, medication control, personal
control, treatment control and emotions (Hagger & Orbell, 2003; Leventhal, et al., 2001; Moss-Morris, et al., 2002). The current study measures these dimensions using the Brief Illness Perception Questionnaire (BIPQ) (Broadbent, Petrie, Main, & Weinman, 2006).

### 2.4.2 Social support

Social support in the proposed conceptual model acts as a coping strategy to reduce stressors invoked by health threats. Instrumental support – the provision of physical assistance or emotional support in which a person utilises the available resources to deal with the health threat (Taylor & Friedman, 2007) – was assessed using the Enrich Social Support Instrument (ESSI) (The Enhancing Recovery in Coronary Heart Disease Investigators, 2000).

### 2.4.3 Religious and spiritual coping

Religious and spiritual coping are multidimensional mechanisms that influence various areas of human life (Koenig, King, & Verna, 2012) and are generally understood as powerful sources of hope and wellbeing (Koenig, 2009). The current study examines the influence of these dimensions, and how they are harnessed to reduce mental health illnesses such as depression (Fitchett et al., 2004; Rasic, Robinson, Bolton, Bienvenu, & Sareen, 2011). The domain was measured with a specific subscale – Religious and Spiritual Coping (RSC) – from within the Diabetes Fatalism Scale (DFS) (Egede & Ellis, 2010a). In the study, the phrase ‘religious and spiritual coping’ is used to refer to this construct.
2.4.4 Depression

Depression is defined in relation to the individual’s wellbeing. Any health threat will create a range of subjective emotional representations, such as depression and anhedonia, which are likely to adversely impact on adherence to self-care activities (Egede & Ellis, 2010b; Gask, Macdonald, & Bower, 2011; Mc Sharry, Moss-Morris, & Kendrick, 2011). Depression was measured by the nine-Patient Health Questionnaire (PHQ-9) scale (Kroenke, Spitzer, & Williams, 2001), this scale offers a categorical clustering algorithm for the diagnosis of depressive symptoms, based on the DSM-IV modified criteria for diagnosing depressive disorder (Wittkampf, Naeije, Schene, Huyser, & van Weert, 2007).

2.4.5 Self-efficacy

Self-efficacy is defined as one’s belief and confidence in one’s capacity to manage and adhere to a health plan (Bandura, 1998; Bandura & Adams, 1977). It is measured by the Diabetes Management Self-Efficacy Scale (DMSES) (Bijl, Poelgeest-Eeltink, & Shortridge-Baggett, 1999).

2.4.6 Self-care activities

The cognitive coping process centres on the strategies that are adopted by patients with diabetes in order to maintain control over their health, or to control the progression of their symptoms in response to the health threat (Leventhal, et al., 2001). This process encompasses a set of skilled behaviours undertaken to manage one’s own illness. The behaviours in this study relate to diet, physical activity, medication adherence, blood glucose measurement, foot care, and smoking behaviour (Glasgow et al., 1992; Toobert, et al., 2000). This study uses a
summated score that evaluate overall adherence to self-care activities, as previously used successfully by Ell et al. (2010).
2.5 Review of the literature

This section provides a review of the literature on the following concepts: illness representations, social support, and religious and spiritual coping, clinical variables (BMI and HbA1c), depression, self-efficacy, and self-care activities.

Researching the electronic databases for articles was guided by a wide range of defining terms including: diabetes mellitus, self-care, illness perception, depression, social support, religion and spirituality, the Arab population and culture.

2.5.1 Illness perception and self-care activities

A patient’s perception of their illness is reflected through their ‘personal model’. The CSM comprises personal beliefs, knowledge, experience and emotions in relation to their health threat (Hampson, et al., 2000; Weinman & Petrie, 1997). Patients construct their personal illness representations to help them make sense of their experience, and to provide a basis for their own coping responses (Weinman & Petrie, 1997). Examples of illness representations among individuals with diabetes contain core components of beliefs about the aetiology of their disease (for example, sweets consumption), symptoms (for example, polyuria), personal consequences of diabetes (for example, long-term and short-term complications), how long their diabetes will last (for example, forever), and the extent to which diabetes is amenable to control or cure (for example, oral hypoglycaemic agent to control/treat diabetes). It could therefore be concluded that a personal model plays an important role in determining the responses and subsequent coping behaviours of an individual to diabetes as a health threat.
Since self-care activities are considered to be a crucial factor in controlling diabetes (Chen, Creedy, Lin, & Wollin, 2012), it follows that illness perception has a significant association with diabetes outcomes. A patient’s personal beliefs about their illness are essential determinants of their coping strategies and self-care activities (Broadbent, et al., 2011; Stack, et al., 2011).

The precise nature of the components of the self-regulatory model and their interrelation (that is, the structure of personal models) often differs according to the disease. The nature of the components is also partially predicated on the relative importance of the different components for predicting disease-related behaviour (Weinman, et al., 1996). For diabetes, the components of adult personal models have been identified, replicated and demonstrated in the findings of both the concurrent and prospective studies (Ayele, Tesfa, Abebe, Tilahun, & Girma, 2012; van Esch, Nijkamp, Cornel, & Snoek, 2013; Yuniarti, et al., 2012). Some aspects of the personal model show consistent and replicable association with dietary self-care activities, patients’ beliefs concerning the seriousness (consequences) of their diabetes, and their beliefs about the effectiveness of their treatment (Abubakari et al., 2011; Kay, Davies, Gamsu, & Jarman, 2009; Stack, et al., 2011).

A systematic review of nine cross sectional studies found that stronger identity, timeline, concern, and emotional representation had a significant association with poor glycaemic control. In line with the cited study, a time series reported that treatment control significantly predicted medication adherence, and self-beliefs about personal control predicted physical activity, while perceived
timelines predicted particular self-care activities such as exercise and diet adherence (Searle, et al., 2007). On the other hand, French et al. in 2013 reported that, beliefs about one’s diabetes were not a strong predictor of any aspect of self-care activities (French, et al., 2013), rather, the beliefs about a health behaviour were strongly associated with the patient’s health behaviour.

When applying personal beliefs in the context of diabetes management, Key et al (2009), in an exploratory qualitative study among women, found that personal illness perception affects self-care activities including glycaemic control and adherence to medication regimens and healthy eating plans. When discussing medication adherence, key influencing factors need to be addressed. For example, a patient’s own illness representation model, including the benefits of diabetes-related drugs, will encourage adherence to medication. Here again, it could be argued that the beliefs in the effectiveness of diabetes related-medications enhanced the behaviour toward adherence to such treatment (French, et al., 2013).

In contrast, emotional representations such as fear of the possible side effects, or an aversion to the perceived long-term effects of the medication, might negatively impact on adherence (Horne, Weinman, & Hankins, 1999). Of note, T2DM is a chronic disease with progressive loss of beta-cell function which would increase the demands for complex medication regimen. Although, adherence to diabetes related-drugs ultimately minimises serious consequences including microvascular complications in diabetes management, it could induce hypoglycaemia (United Kingdom Prospective Diabetes Study, 1998b). Consequently, had the patients suffered from frequent hypoglycaemic attacks this would lead them to skip doses.
Understanding these nuances and specificities is of crucial importance, because adherence to medication regimens is an essential contributory factor in maintaining optimal physiological functioning.

In summary, Leventhal’s model highlighted that chronic disease management stems from a patient’s personal beliefs about their illness. These personal beliefs determine and guide a patient’s subsequent behaviour. Negative illness perception among patients with diabetes creates a challenge in each phase of the treatment plan. Therefore, under-recognition of this interplay compromises the efficacy of disease management programs. Solicitude and care for patients’ psychological status would put patients at ease, allowing them the opportunity to adopt a proactive role in their therapeutic course. According to Leventhal et al. (1984), when patients perceive positive changes in their health, this acts as a motivation to reinforce constructive health behaviours. Adoption of new positive coping mechanisms might correspondingly reduce deleterious and health-limiting behaviours (Whiting, Scammell, Gray, Schepers, & Bifulco, 2006).

A better understanding of the self-regulation model and the factors that influence the ways in which individuals, in particular depressed patients with diabetes, perceive their health threat, can lead to better predictions of adherence to self-care activities. The study’s selected psychosocial constructs – illness perception, clinical variables, social support, religious and spiritual coping, depression and self-efficacy – all need to be considered in more detail.
2.5.2 Clinical factors

Body weight and blood glucose levels, as indicated respectively by BMI and HbA1c values, are clinical factors that can aggravate a health threat. The presence of these factors can contribute to a negative illness perception, particularly when viewed by patients as evidence of personal failure and low levels of personal control (Broadbent, et al., 2011).

2.5.2.1 Body Mass Index (BMI)

As one of the major health problems in Jordan, obesity, is on the rise with rates predicted to increase significantly according to current trends (Jordanian Ministry of Health, 2011; Zindah, Belbeisi, Walke, & Mokdad, 2008). In 2011, the Jordanian Ministry of Health (MOH) implemented a behavioural surveillance program to monitor the prevalence of risk factors associated with chronic diseases including but not limited to, obesity and diabetes. This program revealed a high prevalence of obesity in Jordan, with over 80% of adults aged ≥25 classified as either overweight or obese (Jordanian Ministry of Health, 2011). Obesity is indicated by BMI >30 kg/m², a range that is highly prevalent not only throughout the Middle East but also worldwide (Prentice, 2006). However, such figures should be interpreted cautiously for various reasons, including the scarcity of available survey information, comparisons between surveys with substantially different ethnicities and cultural backgrounds, and also the variances within the sampling scheme.

Nevertheless, BMI can serve as a strong predictor of diabetes control. A review of seventeen studies has shown, a decrease in BMI is frequently
accompanied by an improvement in diabetes control (Markowitz, Gonzalez, Wilkinson, & Safren, 2011). Consistent with the review, several cross-sectional studies have reported that BMI is an important determinant of diabetes control (Ayele, et al., 2012; Bouguerra, et al., 2007; Elbagir, Eltom, Elmahadi, Kadam, & Berne, 1996; Peters, 2009; Sacco et al., 2007). One’s BMI offers indications about the extent of a person’s adherence to a health plan. Namely, obesity can impede self-care activities such as diet plan and exercise regimen, consequently adversely impacting on diabetes control (Willey & Singh, 2003).

It is reported in the literature that a high BMI is a risk factor for depression among patients with diabetes (Sacco, et al., 2007; Wayne J, 2008; Wing, Phelan, & Tate, 2002). Comorbidity in turn affects diabetes outcomes because the presence of depression impacts on self-care activities (Sacco, et al., 2007). In contrast, Ayele et al. (2012) reported that the measure of BMI has no statistical significance in terms of self-care activities.

2.5.2.2 Glycosylated Haemoglobin (HbA1c)

Effective blood glucose management is the basis of diabetes control (American Diabetes Association, 2006; United Kingdom Prospective Diabetes Study, 1998a). Both hyperglycaemia and hypoglycaemia adversely affect diabetes control. Chronic hyperglycaemia increased the risk of long-term complications of both a micro-vascular and macro-vascular nature (Lustman & Clouse, 2005; Regenold, Thapar, Marano, Gavirneni, & Kondapavulu, 2002). Hypoglycaemia, with its attendant demands of commitment to a diet and exercise regimen, is also an impediment to achieving good glycaemic control. If implemented at the time of
diagnosis, glycaemic control is associated with a significantly decreased risk of myocardial infarction and death (Holman, Paul, Bethel, Matthews, & Neil, 2008). These findings are consistent with the results of a large randomised controlled trial, undertaken in the United Kingdom Prospective Diabetes Study (UKPDS) hospitals between 1977 and 1991, which revealed that glycaemic control in patients with T2DM was associated with a reduced risk of clinically evident micro-vascular complications (United Kingdom Prospective Diabetes Study, 1998a).

Moreover, depression is strongly associated with poor HbA1c among T2DM patients. In a randomised controlled trial among eighty-six patients with Type 1 and Type 2 diabetes in the United States, the improvement in glycaemic control was linked to a reduction in depressive symptoms (Lustman, Clouse, Griffith, Carney, & Freedland, 1997). Similarly, a meta-analysis, of a total of 24 studies, undertaken by researchers in 2000 reported that depression has a significant relationship with a higher HbA1c level (Lustman et al., 2000). Others have argued, however, that the clinical treatment of depression does not necessarily lead to good control or lower HbA1c, although it still often confers benefits as it enhances quality of life (Ludman et al., 2004; Riley, et al., 2009). On the other hand, Green et al. (2012) argued that the path of causality can be inferred as the opposite direction, i.e. hypoglycaemia leading to depression.

The prevention of hyperglycaemia and hypoglycaemia has been widely found to be crucial to the maintenance of optimal health. Another study reported non-significant increases in HbA1c among depressed patients with diabetes (Ciechanowski, et al., 2003). Conversely, Gross et al. (2005) argued that there is no
global consensus regarding the relationship between depression and glycaemic control; they concluded that further investigation is warranted. It is evident that the impact of HbA\textsubscript{1c} on depression among patients with diabetes is a controversial aspect. Thus, it needs to be examined in a different context such as an Arab population which could add to the body of knowledge.

### 2.5.3 Social support

Social support is an exchange of resources between at least two persons, with the aim of increasing the wellbeing of the recipient (Shumaker & Arlene, 1984). The importance of social support has been universally documented as ‘cushioning’ people from the negative effects of psychological stressors (Li et al., 2009; Lind, Waernbaum, Berhan, & Dahlquist, 2012). Social support can also help to increase a patient’s perception of self-control (Awasthi & Mishra, 2011). The type of support whether it is instrumental or emotional is of importance, also, the support should be given in a timely manner. Excessive instrumental support, however, can have the inverse effect and actually lead to dependency and loss of control. In other words, too much or too little support may worsen diabetes outcomes (van Dam, et al., 2005). Psychological support is nevertheless overwhelmingly understood as an important factor in enhancing the self-care activities of patients with diabetes. Social support helps to ensure adherence, encourage lifestyle changes and increase personal freedom, leading to better diabetes outcomes (Adams, Bowden, Humphrey, & McAdams, 2000; van Dam, et al., 2005). Possible explanation for the positive effect of social support could be due to the fact that social network provides information that could benefit individuals to understand their disease.
Additionally, social support when offered, is expected to alter the psychological stress and physical reaction to a health threat, consequently, alleviating the suffering or the sad mood. Further, patients with diabetes tend to overlook their health plan during a stressful time, this could be lessened with good social support. In Arab population, the social support may take a logistic form, for example, assisting with the medications, above all, the whole family would support the sick person (Al-Krenawi & Graham, 2000; Aloud & Rathur, 2009).

Robust social support networks are believed to promote mental wellbeing and alleviate psychological burden including depression states and anxiety. Such support networks benefit the recipient and impact positively on their health status. It also encourages healthy behavioural patterns that enable patients to control their disease and results in altering stressful reactions to a disease, keeping in mind that social support is a double-edged sword. Some studies have reported an inverse correlation between social support and the physical and psychological symptoms of T2DM (Awasthi & Mishra, 2011; Yuniarti, et al., 2012).

In summary, social support will, in most cases, confer benefits for patients who are experiencing difficulties. Social support may alleviate negative psychological symptoms and ultimately influence overall physical health (Awasthi & Mishra, 2011).

2.5.3.1 Culture and health beliefs

This study was conducted in an Arabic country. Using the definition offered by Jabra (1971), an Arab is ‘anyone who speaks Arabic as his [or her] own language and consequently feels as an Arab (p. 174). It has been argued that culture shapes
the ways in which people perceive their diseases. Culture also determines the values ascribed to the concepts of illness and wellness (Osborn et al., 2010). Arabic culture has been described as collectivist, where social life is family-centric rather than egocentric, and loyalty to the family transcends an individual’s needs and ambitions (Nydell, 1987). It has been proposed that Arabic patients have more shared responsibility and less personal accountability in their disease management plans. Generally speaking, Arabic people prefer medical decisions to be made by the family (Gortner, Rankin, & Wolfe, 1988). It is therefore reasonable to suggest that in most cases in Arabic cultures, control over the treatment of disease is shared within a patient’s close social group. For patients, this represents a more external control over their disease. These cultural structures might explain why Arabic families exert a high level of influence over disease outcomes.

Arabic people venerate the family. Similarly, the family acts as a buffer or a safeguard against stressors. In Arabic culture, the first priority is to support family members when in need, and this plays an important role in determining health behaviours (Feghali, 1997). Despite the many benefits of these cultural structures, however, they also have their downside, and can rob people of their individual rights and personal agency (Gortner, et al., 1988). In Arabic cultures an individual’s behaviour is seen as reflective of the social values and expectations of the whole family (Furnham, 1994; Youssef & Deane, 2006). Social reputation is a vital concern that the individual works to keep intact; the family must not, under any circumstances, be disgraced or dishonoured (Wilson, 1996). When an individual in an Arabic family needs psychological help, the family will assume the role of
determining whether or not the individual should seek professional assistance. Such a decision automatically becomes a family issue rather than a personal one (Furnham, 1994; Gortner, et al., 1988). It is noteworthy that Arabic people tend to describe psychological problems through somatic symptoms, possibly because they perceive psychosocial problems as a sign of weakness and lack of faith. At times, Arabic people ascribe their disease state to supernatural powers (Ypinazar & Margolis, 2006). Despite this widespread illness attribution, literature about Arabic perceptions of illness in general, and among diabetes patients in particular, is scant.

2.5.4 Religion and health beliefs

Religion is a significant component of a person’s integrated belief system. As such, it exerts an important influence on personal illness perception (Chesla & Chun, 2005). In general, Arabs share the same religious principles, whether they are Christians or Muslims (Gortner, et al., 1988). These beliefs could act as health promoters or barriers during sickness and death (Hammoud, White, & Fetters, 2005). For instance, Muslims believe that illness and health are bestowed by God (Allah), and that He dispersed health in accordance with His divine judgement (Rezaei, Adib-Hajbaghery, Seyedfatemi, & Hoseini, 2008; Weisfeld, 1990; Ypinazar & Margolis, 2006). Obedience to Allah will bring physical, psychological and spiritual comfort (Pinelli, Herman, Brown, & Jaber, 2010). The belief in Allah has a significant effect on a Muslim’s life, especially for those with a strong religious certainty and conviction (Ypinazar & Margolis, 2006). Consequently, levels of religiosity can influence health beliefs, and this in turn might influence self-care activities.
Conversely, religion has the potential to impose a negative influence on health, for example, people who do not conform with their communities religious and cultural beliefs, suffer some form of discrimination and judgement which could foster distress that leads to depression (Williams & Sternthal, 2007).

There is little research that has addressed this point among Arabic communities, although a recent literature review of studies in non-Arabic cultures has identified the importance of religion and health beliefs (Koenig, 2009; Smith, McCullough, & Poll, 2003; Williams & Sternthal, 2007). Although religiosity and spiritual coping were studied, there is a paucity of studies that investigate potential confounders such as, the social milieu, sociodemographic variables, and ethnicity within the health system. The current study aims to add to the body of knowledge by considering the impact of Arabic culture and religion on participants’ health behaviours.

2.5.5 Effects of depression on self-care activities

Self-care activities are a central concern in the lives of patients with diabetes. Good management of self-care is a well-addressed topic in the literature, and has been identified by the American Diabetes Association (ADA) as one of the chief goals for patients with T2DM. Consideration needs to be given to an individual’s lifestyle habits, such as healthy eating, exercise, foot care, medication adherence, and strategies to keep blood glucose levels normal or near normal. Other factors that need to be considered are the multiple clinical and diagnostic tests required to monitor and identify complications resulting from diabetes; initiating treatments to control or prevent further damage; and close monitoring of complications that are
often coupled with T2DM. Attention to these factors can significantly improve health outcomes for patients with diabetes, reducing the development of diabetes-related comorbidities, and leading to maximise the quality of life (American Diabetes Association, 2013b), for the benefits outweigh the burden of self-care. A reduction in comorbidities and other complications also reduces fiscal burden on patients with diabetes and the health care system (Egede & Ellis, 2010b).

There is ample literature supporting the significant association between psychological status (and in particular depression) and adherence to self-care activities, with one group of investigators reporting that more than two-thirds of non-adherent patients will eventually meet the diagnostic criteria for depression (DiMatteo, Lepper, & Croghan, 2000; Kalsekar et al., 2006). Further evidence supports the idea that non-adherence adversely impacts treatment results (DiMatteo, et al., 2000). Depression was frequently found to exacerbate diabetes by impeding adherence to self-care activities, thus increasing disability and healthcare expenditure (Egede, Ellis, & Grubaugh, 2009; Riley, et al., 2009).

Depression was also found to impact on adherence to prescribed treatments among those with diabetes, and this too resulted in a worsened health outcome (Sacco & Bykowski, 2010; Sacco et al., 2005). Although the mechanism with which depressive symptoms impact on adherence is not well established (Sacco, et al., 2005), this relationship is very likely to be mediated by self-efficacy. The mediation role of self-efficacy may also be linked to the existence of the ‘feedback loop’ through which non-adherence stems from depression, and the former exacerbates the latter (DiMatteo, 2004).
Several empirical studies support the association between diabetes metabolic control and depression. A systematic review conducted by Lustman and Clouse (2005) reported a clinically significant relationship between depression and the level of metabolic control. A large population based study recruited 4,193 subjects with diabetes in the United States and suggested a strong association between uncontrolled blood glucose levels (as indicated by HbA1c ≥8 %) and major depression (Katon et al., 2004). It must be acknowledged, however, that a discrepancy exists between studies and findings. For instance, another population based study undertaken in Norway between 1995 and 1997 among 1,181 participants with T1DM and T2DM did not report a significant association between depression and glycaemic control (Engum, Mykletun, Midthjell, Holen, & Dahl, 2005). Some reasons behind the inconsistency among the studies could be explained by the difference in cultural, social, and economic issues.

Depression is also associated with increased levels of mortality and morbidity. It was found that diabetes and coexisting depression is significantly associated with an increased rate of mortality due to different causes. For example, compared to their counterparts, patients with this comorbidity are 2.5 times more likely to die due to heart disease. It has also been found that women with diabetes suffer higher rates of depression than men with the same condition (Anderson, et al., 2001).

A decline in self-care activities among patients with comorbid diabetes and depression has been reported in the literature. A recent meta-analysis found that depressed patients with diabetes are more likely to have fewer days of adherence to diet, exercise, and glucose monitoring and self-care activities. These patients also
demonstrated a 2.3-fold increase in omitting medication doses compared with other respondents (Egede & Ellis, 2010b). These results could be linked to the patients’ mental health status as it interacts with their self-care activities (Sigurðardóttir, 2005; Yuniarti, et al., 2012). Furthermore, major depression among patients with diabetes influences their health-related behaviours. Those diagnosed as suffering from major depression are reported to initiate behaviours such as unhealthy eating habits, low levels of physical activity, and reduced medication adherence (Lin et al., 2004). In support of these results, it was reported that depression reduces adherence to medication regimens and a healthy diet plan (Ciechanowski, et al., 2000). The presence of depression also decreases the likelihood of a patient seeking and undergoing medical treatment for diabetes (Kalsekar, et al., 2006). This lack of compliance ultimately results in poor blood glucose control (Lustman, et al., 2000).

Despite the importance of self-care activities in diabetes control, for many people the necessity of having to manage their health condition on a daily basis can be an overwhelming and challenging experience (Glasgow et al., 2002; Skinner, John, & Hampson, 2000). The coexistence of depression among patients with T2DM can add complexities to these demands, imposing heavy burdens on a patient’s capacity to self-manage their diabetes (Ciechanowski, et al., 2000; Egede & Ellis, 2010b). Furthermore, it was found that patients with diabetes who also suffered major depression were highly likely to exhibit strong psychological and behavioural reactions that can affect their glycaemic control and perpetuate resistance to change. Such comorbidity imposes substantial obstacles for initiating effective
coping mechanisms, and for maintaining productivity and positive human development (Gask, Ludman, & Schaefer, 2006).

Moreover, depression has a direct relationship to a patient’s self-efficacy. Many patients will develop overlapping patterns in the ways in which they perceive their illness. Depression will also affect a patient’s confidence in self-managing their condition. The Cross-National Diabetes Attitudes, Wishes and Needs (DAWN) study conducted among patients with diabetes and healthcare providers in 13 countries across Asia, Australia, Europe and North America, found depression to be one of the key predictors of low adherence to self-care activities (Peyrot et al., 2005). Other studies have reported similar findings (Coventry et al., 2011; Gonzalez, et al., 2008; Jonkers, Lamers, Bosma, Metsemakers, & van Eijk, 2012; Maurer, 2012; van der Feltz-Cornelis et al., 2010). In other words, self-care activities in diabetes patients with comorbid depression are negatively influenced by their depressive state (Nefs, Pouwer, Denollet, & Pop, 2012; Pouwer, et al., 2010). It is clear that depression undermines confidence, reduces self-efficacy and reinforces a negative illness perception (Riley, et al., 2009). This in turn has a deleterious effect on the self-care activities of patients with diabetes (Jonkers, et al., 2012). It can be concluded that depression adversely affects diabetes and is a burden on disease management (Coventry, et al., 2011; Egede, et al., 2009; Voelmeck, 2006), although the magnitude of the negative impact on diabetes self-care activities is not yet known.

2.5.6 Self-efficacy in context

Self-efficacy, as defined by Bandura, relates to one’s belief and confidence in the ability to accomplish a task and execute skills effectively (Bandura, 1998;
Bandura & Adams, 1977). However, self-efficacy is not merely synonymous with a person’s skill level. Rather, self-efficacy denotes a patient’s perception of this skill, and what they believe they can do with it (Bandura, 1998). The relationship between the two independent concepts – illness representation and self-efficacy – could be a theoretical sequence where illness representation can predict self-efficacy (Lau-Walker, 2006). It could be argued that an individual’s general idea of their illness might influence their confidence in their capacity to achieve specific skills, or their ability to implement better self-care activities (Lau-Walker, 2006).

Self-efficacy is assumed to not only predict behaviours but also to predict the strength of such behaviours, and the ways in which a person acts when faced with an unplanned challenge while undertaking that behaviour (Bandura & Adams, 1977). For instance, if self-efficacy is weak, the person will tend to avoid certain tasks, believing these tasks to be beyond their capabilities, or more difficult than they actually are. Eventually, avoidance will lead to anxiety. On the other hand, a person with high self-efficacy for that task will be energetic and determined, and will not be overwhelmed by a challenge (Bandura, 1998). In other words, self-efficacy defines how one views one’s own potential (Bijl, et al., 1999). Self-efficacy thus paves the road for the personal behaviour and continued perseverance to achieve certain goals. Being capable of complying with a strict treatment plan requires strong self-efficacy, as it is a task-oriented process (Glasgow, et al., 2002).

2.5.6.1 Self-efficacy and self-care activities

The literature espouses self-efficacy as a predictor of a variety of human behaviours (Kott, 2008). Many studies also validate self-efficacy in so far as it has a
positive impact on diabetes self-care activities (Hurley & Shea, 1992; Padgett, 1991). Diabetes patients who exhibit high levels of self-efficacy are expected to be committed to self-care activities such as exercise regimens, diet plans, frequent blood glucose checking, and adherence to medications (Aljasem, Peyrot, Wissow, & Rubin, 2001; Maciejewski, Rigerson, & Mazure, 2000; Sacco & Bykowsk, 2010; Sacco, et al., 2005; Shumaker & Arlene, 1984; Skelly et al., 2000). This could be explained in view of the fact that self-efficacy underpins human motivation, wellbeing and individual achievements. Studies have linked self-efficacy to adherence in terms of daily diabetes management activities. However, many patients with diabetes tend to struggle within the domain of adherence (Dysch, et al., 2012; Glasgow, et al., 2002). Factors such as a patient’s emotional status need to be kept in mind when considering how self-efficacy and illness perception interact with self-care activities (Sigurðardóttir, 2005; Yuniarti, et al., 2012).

Comorbid depression among patients with T2DM can add complexities to these demands, and impose heavy burdens on self-managing diabetes (Ciechanowski, et al., 2000; Egede & Ellis, 2010b). Depression demonstrates an overlapping pattern with the ways in which patients perceive their illness. In particular, depression impacts on a patient’s confidence levels in terms of self-managing their condition (Cherrington, Wallston, & Rothman, 2010; Kanbara et al., 2008; Sacco, et al., 2007; Sacco, et al., 2005; Sharoni & Wu, 2012).

### 2.5.7 Self-care activities and diabetes

Although adherence to self-care activities is a determining factor in controlling diabetes and its related comorbidities, such adherence is a frequently neglected
component among patients with diabetes (Fisher, Thorpe, Devellis, & Devellis, 2007; Glasgow, Toobert, & Gillette, 2001; Kent et al., 2010; Rustveld et al., 2009). In Jordan, an unsatisfactory control of diabetes has been reported in up to 54% of patients (Ajlouni, et al., 2008). This suggests a lack of adherence to self-care activities, and a reluctance on the part of the patient to implement the necessary lifestyle adjustments. In fact, in 2010, this figure escalated to 65.1% as indicated by uncontrolled blood glucose levels (Khattab, Khader, Al-Khawaldeh, & Ajlouni, 2010).

Given the chronic nature of diabetes and the fact that the patient’s day-to-day self-care activities can be challenging and demanding, it is not surprising that patients often fail over time to maintain a health recommendation plan (Griva, Myers, & Newman, 2000; Rodriguez, 2013). This failure might also depend on how patients make sense of and understand their disease, and on how successfully patients can implement continuous lifestyle changes that meet the recommended medical advice (Cameron & Leventhal, 2003; Leventhal, et al., 2003). Adherence to self-care activities is not about understanding the pathological state of the disease per se; rather, it is about integrating the standardised anthropometric factors with other potential factors that often have an overlapping effect on diabetes control, such as self-efficacy, depression, social support, religious and spiritual coping.

2.6 Chapter summary

The current study aimed to examine the relationship of selected psychosocial factors on diabetes self-care activities. Leventhal’s self-regulation model was selected as the basis for the development of a conceptual framework (Leventhal, et al., 1984) because it focuses on beliefs and emotions about diabetes, and on the
relationship between these constructs and self-care activities. In addition, Leventhal’s model takes into account the perceived threats of illness, particularly the individual’s perception of their health condition. The self-regulation model proposes that illness representation is formulated around five ‘core’ dimensions regarding the cause, control, timeline (course), consequences, and identity (perceived symptoms) of the condition (Leventhal, et al., 2003; Leventhal, et al., 2005; Leventhal, et al., 1992; Leventhal, et al., 1984). A particular benefit of this model is the inclusion of subjective and personal elements, which may or may not align with conventional medical opinion (Hagger & Orbell, 2003; Kucukarslan, 2012). Additionally, demographic variables might affect illness perception among those with diabetes, since everyone has their own illness perception model (Paterson, Moss-morris, & Butler, 1999). The flexibility of the constructs allows the model to predict self-care activities in chronic illnesses. In this study, the model provided the utility to predict adherence to diabetes self-care activities. Of paramount importance is the applicability of this model to the health-illness continuum; that is, the model can be applied both in the initial identification at diagnosis of a health condition, and to the subsequent monitoring of changes across the health-illness continuum (Leventhal, et al., 1992). A further benefit of the model is its adaptability, which enables the taking into consideration other key constructs, such as social support, religious and spiritual coping, and self-efficacy. The POISE study chose to integrate these factors with a conceptual model that uses the illness representation model as its foundation.
Chapter 3
Methodology

3.1 Introduction

Chapter 3 provides an overview and explanation of the study design, a description of the settings and sampling procedure, and a review of the ethical considerations related to the study. A discussion about the standardised scales of the study is included, with particular emphasis on the psychometric assessments. Finally, the chapter presents the data collection procedures followed by the data analysis plan.

3.2 Research paradigms

A mixed methods paradigm is today recognised as a third research paradigm for it has a defined set of methods and language that did not exist before. In addition, it was acknowledged as a natural complement to traditional qualitative and quantitative research approaches (Johnson & Onwuegbuzie, 2004). It is widely recognised that the specific dimensions of the research question need to be the central determining drivers, with the most apposite methodologies evolving out of the project’s course and concomitant requirements (Kelle, 2006; Tashakkori & Teddlie, 2010a). It is important to recognise that the research process is always an evolving one in which the overarching goal is to provide various perspectives in terms of interpreting and analysing data (Bergman, 2010). The mixed methods approach evolving as a third paradigm has received great recognition among scholars (Creswell & Plano Clark, 2011; Kelle, 2006; Tashakkori & Teddlie, 2010a). Defined as a ‘research design with philosophical assumptions as well as methods of
inquiry’ (Creswell & Plano Clark, 2007, p. 5), the mixed methods approach combines qualitative and quantitative research to explore various phenomena and address complex research questions (Creswell & Plano Clark, 2011; Tashakkori & Teddlie, 2010a). For some research questions, more than one data set is required. In such cases, combining the data sets becomes of paramount importance. A mixed methods approach draws from the strength of both qualitative and quantitative paradigms, while compensating for their respective weaknesses within a single, integrated research study (Creswell & Plano Clark, 2011). The rational for choosing mixed method design for the current study is discussed later in this chapter, section 3.3.1.

### 3.3 Study design

The study used a sequential explanatory mixed methods design as described by Creswell and Plano Clark (2007). A mixed method approach enabled the examination, incorporation and integration of quantitative and qualitative data in a single study (Creswell & Plano Clark, 2011). The main reason for mixing both methods was that neither quantitative nor qualitative approaches alone was adequate to comprehensively clarify the trends and relationships between the multifaceted elements of self-care activities and psychosocial factors examined in the current study among patients with T2DM. When combined, both quantitative and qualitative data provided a composite picture, as each data set complemented the other and provided greater insight (Tashakkori & Teddlie, 2010a, 2010b). A mixed method design is particularly useful for understanding complexities in healthcare issues and in producing findings that can make a substantive contribution to effecting reform and changing practice.
3.3.1 Rationale for using a mixed methods approach

The examination of diabetes self-care activities is a crucial factor in diabetes management planning, and is the main feature of the study. It is recognised that self-care activities are multidimensional. Accordingly, the conceptual model of this study proposes that illness perception, depression, social support, religious and spiritual coping, and self-efficacy all affect diabetes outcomes through their influence on self-care activities. The use of a mixed methods design enables the integration of quantitative and qualitative data to identify different aspects of self-care activities, and to explain this on both an individual and a group level. Such differentiation and distinctions could not be achieved by using a single method design. The quantitative data provides a general schema of the relationship between the constructs in the conceptual model and their effect on diabetes self-care activities – that is, what factors contribute to and/or impede diabetes self-care activities among patients with T2DM in Jordan. The qualitative data, on the other hand, refines and explains the statistical results through an exploration of the participants’ opinions. This integrated approach afforded a deeper insight into the phenomenon of interest.

3.3.2 Sequential explanatory mixed methods design

In order to achieve a comprehensive insight into the experience of diabetes self-care activities among patients with T2DM, the study uses a sequential explanatory mixed methods design, in which the dominant quantitative study design is complemented by a qualitative component. This ‘co-relational model’ (Creswell & Plano Clark, 2007) is organised into two phases; the initial quantitative phase was conducted using a survey to obtain descriptive and co-relational results
between diabetes self-care activities and the aforementioned psychosocial variables. In brief, the initial quantitative phase served to: i) identify a subsample for the qualitative phase; ii) describe the level of illness perception, depression, social support, religious and spiritual coping, self-efficacy, and self-care activities among patients with T2DM in Jordan; iii) identify the possibly significant association between depression and self-care activities; and iv) investigate the relationship between the psychosocial variables listed in objective ii) above, and self-care activities among patients with T2DM in Jordan.

The subsequent qualitative phase elicited in-depth data from patients in order to: i) provide insight into how patients construct their experience of living with both diabetes and depression, and ii) explain why certain variables assessed in the first phase may influence self-care activities among patients with T2DM in Jordan. Finally, the findings from both data sets were analysed separately as well as integrated into the final section of the results. Figure 3.1 on page 55 provides a schematic representation of the procedure for the sequential explanatory mixed methods design used in this study.
3.4 Participants and setting

The study was carried out at the Endocrinology Clinic, Jordan University Hospital (JUH). A total of 220 participants with T2DM were recruited from patients attending the Endocrinology Clinic. The recruitment of the participants was done by placing a poster in the clinic that advertised the study. Following recruitment for the quantitative phase, a purposeful subsample for the qualitative phase was selected from those who were enrolled in the quantitative phase and stratified according to their PHQ-9 scores, to indicate those with mild, moderate, and moderately severe depression. Patients found to be severely depressed and/or at risk of suicide (as indicated by PHQ-9 score ≥20) were referred to a psychiatrist as required in this practice setting.
3.4.1 Outline of the sampling procedure

Sampling of participants was completed over a four-month period, from June 2013 to September 2013 inclusive at the Endocrinology Clinic, JUH. Jordan University Hospital was selected as the primary setting for this study for several reasons. As a major tertiary healthcare facility that is centrally located in Amman, the capital of Jordan, the hospital admits patients from all over the country. This geographical reach helped to ensure the representativeness of the sample chosen for this study.

Recruiting participants was an important component of the research process, and a poster was designed to advertise the study. This method of recruitment allowed for participants’ full and voluntary consent to participation without undue coercion from the researcher. The recruitment posters advertising the study were placed on the walls around the Endocrinology Clinic at JUH – a clinic that is typically visited by patients with diabetes. Potential participants initiated the first contact with the researcher. The researcher was available at the Endocrinology Clinic from 9:00 a.m. to 5:00 p.m. on each day the diabetes clinic operated (Sundays, Tuesdays, and Thursdays). Estimated recruitment numbers during the four-month period are depicted in Table 3.1. The entire sampling procedure for the quantitative phase is outlined in Figure 3.2, on page 58.

Table 3.1 Estimated recruitment numbers

<table>
<thead>
<tr>
<th>Duration</th>
<th>Number of patients visiting the clinic</th>
<th>Estimated number of patients meeting the criteria</th>
<th>Estimated number of recruited participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Daily</td>
<td>30</td>
<td>20</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>Weekly</td>
<td>Monthly</td>
<td>Total</td>
</tr>
<tr>
<td>--------</td>
<td>--------</td>
<td>---------</td>
<td>-------</td>
</tr>
<tr>
<td></td>
<td>90</td>
<td>360</td>
<td>1080</td>
</tr>
<tr>
<td></td>
<td>40</td>
<td>240</td>
<td>720</td>
</tr>
<tr>
<td></td>
<td>30</td>
<td>120</td>
<td>360</td>
</tr>
</tbody>
</table>
• Posters were displayed on the walls in the Endocrinology Clinic at JUH.

• Jordanian adults (≥18 years) with T2DM attending the Endocrinology Clinic at the Jordan University Hospital were informed of the study, and directed to the study poster by the reception staff.

• Potential participants made first contact with the researcher.

• A cover letter and the patient consent form were handed to the patients who met the inclusion criteria.

• Follow-up of patients who had consented to a face-to-face interview using participants’ code or number.

• Participants’ code or number was used to link the survey to patients’ clinical, biochemical and anthropometric data. Also, to identify patients who were at risk of suicide or severe depression as indicated by PHQ-9 score (≥20) for referral to a psychiatrist as required in this practice setting.

Figure 3.2 Outline of sampling procedure

After conducting the survey, levels of depressive symptoms were determined for each participant. A purposeful subsample of participants categorised as having mild, moderate, and moderately severe depression based on PHQ-9 scores were then invited for in-depth interviews. The aim of these interviews was to further examine the phenomenon of interest in greater detail. Interviews were conducted within two weeks of the survey to ensure the capturing of the time-sensitive affective status of the participants.
3.4.1 Power calculation

For the quantitative phase of the study, a priori power calculation was performed using the power calculation software G*Power (Faul, Erdfelder, Lang, & Buchner, 2007). Criteria for power analysis were set at the standard convention of an alpha level of 0.05, and to control for Type II error, beta was set at 0.95. Effect size, the magnitude of the relationship between variables (Fitzner & Heckinger, 2010) was set at medium. A medium effect size was also set for the study, as no previous study was found that directly examined these variables among patients with diabetes in Jordan. Hence, for the path analysis with 13 independent or predictor variables in the proposed conceptual model, an anticipated medium effect size ($f^2 = 0.15$) to test the outcome variable of self-care activities in a sample size of 172 subjects was required. A total of 220 patients were recruited to allow for an estimated 20% of missing and/or incomplete data.

3.4.2 Inclusion criteria

Participants recruited for the current study met the following inclusion criteria: i) a diagnosis of T2DM, as defined by the American Diabetes Association (ADA) criteria (2013b) for $\geq 6$ months, ii) age $\geq 18$ years, iii) not cognitively impaired (as determined by medical reports and/or self-reporting), iv) able to speak and write Arabic, v) willing and able to provide written consent to participate, and vi) a patient at the Endocrinology Clinic at JUH. A sample of participants who consented to the face-to-face interviews in the quantitative phase was recruited for the qualitative phase. Stratification of participants for the qualitative interviews into mild, moderate and moderately severe depression was based on their PHQ-9 scores.
(Kroenke, et al., 2001) with the following groupings: mild (5–9), moderate (10–14), and moderately severe (15–19).

3.4.2.1 Rationale for the inclusion criteria

1) Diagnosis of T2DM not less than six months: Patients with T2DM needed to have experienced self-care activities for at least six months prior to the study, to be able to provide relevant information about their experience.

2) Age ≥ 18 years: The adult age group was studied as they are able to manage their diabetes independently.

3) Cognitive impairment: Participants needed to be able to interpret and complete the survey, and cognitive impairment may have interfered with their responses.

4) Able to speak, read and write in Arabic: The quantitative data were collected primarily through written questionnaires in Jordan, where the main language is Arabic. Participants therefore needed to be literate in the Arabic language.

5) Willing and able to provide written consent: Participation in the study was entirely voluntary, and participants needed to show an understanding of what participating in the study involved and to indicate their willingness to participate.

6) Visiting the Endocrinology Clinic at JUH: The main setting for the study was the Endocrinology Clinic, JUH; hence, participants needed to be patients attending and receiving healthcare services at the clinic. Additionally, part of the survey was related to participants’ clinical data over a period of time, and these data were obtained directly from existing medical records with patient consent.
3.4.3 Exclusion criteria

The study excluded pregnant patients with T2DM as it was not the intention of the study to research pregnant patients with DM or gestational diabetes. Patients who scored on PHQ-9 >19 or < 5 were excluded from the qualitative phase. Respondents who were recruited for the pilot study and patients with Type 1 Diabetes Mellitus (T1DM) were also excluded.

3.4.3.1 Rationale for the exclusion criteria

1) Pregnant patients: Pregnant patients with DM or gestational diabetes were beyond the scope of this study, as the physiological and/or psychological changes associated with pregnancy may have confounded the results.

2) Patients who had PHQ-9 >19 were excluded in the qualitative phase: This score signifies a severe form of depression. Engaging severely depressed participants in a research study would raise several concerns in relation to voluntary participation and consent capacity according to the National Bioethics Advisory Commission (1998). Such participants are believed to suffer cognitive limitations that impact on their ability to give informed consent (Gupta & Kharawala, 2012). Additionally, as it is commonplace in Arabic cultures for collective decisions to be made for the individual, participants could potentially be subjected to inappropriate social pressure such as coercion, manipulation or undue influence.

3) Participants in the quantitative phase who scored a PHQ-9 <5 were excluded from the qualitative phase: A score of less than five indicates that no depressive symptoms are present.
4) Participants from pilot study: To avoid contamination, results of the pilot study were excluded from the data analysed. The main objective of piloting was to assess the feasibility of the study instruments, and was not for the purposes of data collection.

5) Type 1 diabetes patients: Patients with T1DM differ from patients with T2DM in their cognitive assessments, given the different aetiologies and management of the respective diseases (Plotnikoff, 2006).

3.5 Ethical considerations

Approval for the POISE study was obtained from the University of Western Sydney (UWS) Human Research Ethics Committee and the Jordan University Hospital (JUH) Ethics Committee in accordance with the National Health and Medical Research Council (NHMRC) ethics guidelines. Participants were assured of the confidentiality of the study data through verbal explanation and a cover letter that was attached to the survey. They were also notified of their right to withdraw from the study at any time and at any stage without penalty or the need for explanation. Confidentiality was maintained through the following steps: i) direct identifiers – the names of the participants were not used in data analysis and reporting phases, ii) each subject’s file number in this study was collected and destroyed following data collection and analysis, and iii) only the principal investigator and the research team had access to the participant codes. Additionally, the principal investigator allocated each participant a pseudonym when transcribing the interviews, thus maintaining the confidentiality of patients’ responses. Potential risks for participating in the project were, that some questions
were expected to invoke some stressful emotions, and a slight time burden to complete the survey and if necessary, to participate in an interview session.

### 3.6 Data collection procedure

After obtaining ethics clearance from the University of Western Sydney Human Research Ethics Committee, followed by ethics clearance and permission from the Jordan University Hospital Ethics Committee, participant recruitment posters were placed on walls at the Endocrinology Clinic at JUH. Interested participants made first contact with the researcher; informed consent was obtained after the aims of the study were comprehensively explained to eligible patients who contacted the researcher.

#### 3.6.1 Questionnaire translation and pilot testing

In accordance with recommendations for cross-cultural studies, the methodology of forward and backward translation was used to translate the instruments in order to reduce the possibility of ambiguity, discrepancy and inequality occurring during the translation process (Maneesriwongul & Dixon, 2004; Råholm, Thorkildsen, & Löfmark, 2010; Thorsteinsson, 2012). Forward translation was conducted by two Jordanian General Practitioners with proficient English language skills, both written and spoken. Both translators had Arabic as their first language. After independent translation, a discussion between the translators took place to detect inconsistencies (Råholm, et al., 2010).

Backward translation was completed using the same approach. The instruments were translated back to English by independent translators, one of whom is an English teacher whose mother tongue is English, while the second is a
General Practitioner who is an Arabic native speaker with a competent command of the English language. Each translator was blinded to the original questionnaires. Importantly, translation was based on semantic equivalence and content equivalence (Sperber, Devellis, & Boehlecke, 1994). Discrepancies were discussed and assessed until consensus was reached. The original versions of the questionnaires and backward-translated versions were compared once again for linguistic agreement and unity. Subsequently, a pilot study among 10 patients with T2DM was conducted, bearing in mind that the participants in the pilot study were randomly selected. The survey used in the piloting included an additional attached ‘survey feedback sheet’ outlining where the participants should add their comments and/or enquiries for more information. This served to: i) verify the feasibility and adequacy of the instruments and establish the timeframe required to complete the questionnaire; and ii) establish the content validity of the instruments. To ensure that the respondents of the pilot study were broadly representative of the participants in the main survey, the pilot study was conducted among patients meeting the inclusion criteria and attending the same clinic where the actual data collection took place. The questionnaires were revised based on suggestions provided by the expert panel and the respondents of the pilot study (see Figure 3.3). Data gathered from these participants were excluded from the final report of the study.
Figure 3.3  Translation process (adapted from Råholm et al., 2010)
3.7 The quantitative phase

A cross-sectional design was chosen for this phase. As a method, a cross-sectional design can demonstrate the extent and breadth of psychosocial constructs and individual characteristics that are associated with diabetes outcomes in Jordan. Using this type of design can therefore illuminate current health practices. The descriptions generated through this quantitative phase were of paramount importance, and one of the phase’s primary merits was the way in which it shaped the content of the qualitative phase (phase two). Specifically, the researcher was able to make an informed decision regarding the approach to phase two, and to reach a better understanding of the experience of patients with comorbid diabetes and depression in terms of their self-care activities. Furthermore, via the quantitative phase, the researcher was able to formulate the question route for the face-to-face interviews. A descriptive design is the best fit to address the problem with existing practice, because it examines issues at one point in time and within a short timeframe. As such, a descriptive design provides a ‘snapshot’ of real-life situations (Burns, 2009; Grove, Gurns, & Gray, 2012). Most importantly, with the scarcity of empirical data available in Jordan, the information gained from the quantitative phase fully informed the qualitative phase. The sequencing is a common approach in a mixed methods paradigm (Creswell & Plano Clark, 2007). In this chapter, the term ‘survey’ will be used to refer to the data collection method.

The study was conducted in a clinical setting and utilised the following self-administered scales consisting of two sections. The first section comprised questions related to socio-demographic and clinical variables, while the second section centred on standardised scales that assessed the following constructs:
illness perception, depression, social support, religious and spiritual coping, self-efficacy, and self-care activities (Appendix A).

3.7.1 Quantitative phase: operational definitions

1) The diagnosis of T2DM was confirmed in accordance with the American Diabetes Association criteria (American Diabetes Association, 2013b):
   a) HbA1C ≥ 6.5%. The test should be performed in a laboratory using a method that is National Glycohemoglobin Standardization Program (NGSP)-certified and that is standardised to the Diabetes Control and Complications Trial (DCCT) assay;
   OR
   b) Fasting Plasma Glucose (FPG) ≥ 126 mg/dl (7.0 mmol/l), defined as no caloric intake for at least 8 hours;
   OR
   c) Two-hour plasma glucose ≥ 200 mg/dl (11.1 mmol/l) during an Oral Glucose Tolerance Test (OGTT). The test should be performed as prescribed by the World Health Organization, using a glucose load containing the equivalent of 75 g anhydrous glucose dissolved in water;
   OR
   d) In a patient with classic symptoms of hyperglycaemia or hyperglycaemic crisis, a random plasma glucose ≥ 200 mg/dl (11.1 mmol/l). In the absence of unequivocal hyperglycaemia, the result should be confirmed by repeat testing.
2) The term ‘sex’ was used in the study rather than ‘gender’. This standardisation was based on the accepted definition of sex as ‘the relatively unchanging biology of being male or female’ (Phillips, 2005).

3) Duration ‘in years’ was defined as six months’ time after the diagnosis had been established until the time at which the survey and/or the interview was completed.

4) HbA1c was used as an indicator of blood glucose levels and was categorised into two groups: Good glycaemic control = HbA1c <7% and Poor glycaemic status = HbA1c ≥7% (American Diabetes Association, 2013b).

5) Height and weight was measured during the patient’s visit, ensuring that they were wearing light clothes. These data were utilised to calculate Body Mass Index (BMI). According to the World Health Organization (2004), the BMI criteria is categorised as follows: BMI <18.49 kg/m² = underweight; BMI 18.5–24.9 kg/m² = normal; BMI 25–29.9 kg/m² = overweight; BMI ≥30 kg/m² = obese.

6) Self-care activities include: diet, exercise, medication adherence, blood glucose testing, foot care, and smoking habits.

7) Diabetes complications include: hypertension, diabetic retinopathy, peripheral vascular disease, cardiac disease, and cerebrovascular disease (American Diabetes Association, 2013).

3.7.2 Standardised instruments

Illness perception was measured using the Brief Illness Perception Questionnaire (BIPQ) (Broadbent, et al., 2006); depression was measured using
Patient Health Questionnaire-9 (PHQ-9) (Kroenke, et al., 2001); and social support using Enrich Social Support Instrument (ESSI) (The Enhancing Recovery in Coronary Heart Disease Investigators, 2000). The diabetes Religious and Spiritual Coping (RSC) subscale was used for assessing religious and spiritual coping (Egede & Ellis, 2010a). Diabetes management self-efficacy was measured using the Diabetes Management Self-Efficacy Scale (DMSES) (Bijl, et al., 1999); and self-care activities by Summary of Diabetes Self-Care Activities (SDSCA) (Toobert, et al., 2000).

### 3.7.2.1 Brief Illness Perception Questionnaire (BIPQ)

The BIPQ is a self-report scale that assesses patients’ cognitive and emotional representations of their illness, including consequences, timeline, personal control, treatment control, identity, coherence, causes, and emotions (emotional response and concern) (Broadbent, et al., 2006). The BIPQ features a Likert scale response format that ranges from 0 to 10. Assessment of the causal relationship took place using an open-ended response item that asks participants to list the three most important underlying factors that caused their illness. Responses to the causal item question were grouped into categories such as biological, psychological, and other categories as determined by their perception of the cause of their illness (Broadbent, et al., 2006). Assessments of the psychometric properties of the BIPQ were previously tested on centre-based heart disease patients. The structural validity, reliability, test-retest reliability, and discriminant validity were found to be within acceptable limits (Broadbent, et al., 2006).
### 3.7.2.2 Patient Health Questionnaire-9 (PHQ-9)

The PHQ is a 9-item scale and refers to a 14-day interval, whereby each item can be scored from 0 (not at all) to 1 (several days), 2 (more than half the days) and 3 (nearly every day). The total score ranges from 0 to 27 as a continuous measure. Cut-off points of total scores of 5, 10, 15, and 20 represent thresholds for mild, moderate, moderately severe, and severe depression respectively (Kroenke, et al., 2001). These scores can be used to make a provisional diagnosis of depression, as well as serving as indicators of the severity of depressive symptoms. According to the PHQ-9 developer, major depression was diagnosed if at least five of the nine criteria were present for at least more than half the days in the past two-week period, and if one of the symptoms was either a depressed mood or anhedonia. Other depression categories, including minor to moderate, were diagnosed if two, three or four depressive symptoms were present for at least more than half the days in the past two-week period, and if one of the symptoms was either a depressed mood or anhedonia (Kroenke & Spitzer, 2002). A cut-off point of 10 or greater, which is commonly recommended by researchers, was used for the diagnosis of major depression (Acee, 2010; Kroenke & Spitzer, 2002). The cut-off point of 10 yields an 88% sensitivity rate and an 88% specificity rate with a positive likelihood ratio of 7.1 (Kroenke, et al., 2001). Overall, the instrument demonstrated reliability with Cronbach’s alpha of 0.89 in the PHQ Primary Care Study and 0.86 in the PHQ Ob-Gyn Study (Kroenke, et al., 2001).

### 3.7.2.3 ENRICHD Social Support Instrument (ESSI)

The ESSI is a 7-item self-report instrument that assesses social support (The Enhancing Recovery in Coronary Heart Disease Investigators, 2000). The measure
was developed for the Enhancing Recovery in Coronary Heart Disease (ENRICHD), a multicentre randomised clinical trial that investigated the effects of psychosocial interventions that targeted depression and low social support in patients following an acute myocardial infarction (The Enhancing Recovery in Coronary Heart Disease Investigators, 2000). Cronbach’s alpha reported in the data collected in the pilot study of the ENRICHD study was 0.86 (Mitchell et al., 2003). It has a Likert scale response format with the following anchor points: 1 (none of the time); 2 (a little of the time); 3 (some of the time); 4 (most of the time); and 5 (all of the time). Item number 7 enquires about marital status, and scores with 4 and 2 for yes and no respectively. The total scale ranges from 8 to 34.

### 3.7.2.4 Diabetes Fatalism Scale – Religious and Spiritual Coping (RSC)

The Diabetes Fatalism Scale (DFS) is a 12-item scale with three subscales: emotional distress (despair), perceived self-efficacy (powerlessness), and religious and spiritual coping (hopelessness) (Egede & Ellis, 2010a). Cronbach’s alpha for the 12-item DFS scale was 0.804, indicating a high internal consistency. It is a Likert scale anchored with: 1 = strongly disagree; 2 = moderately disagree; 3 = disagree; 4 = agree; 5 = moderately agree; and 6 = strongly agree. This study used the Religious and Spiritual Coping (RSC) subscale, which is conceptualised as the linkage of diabetes outcomes to a higher power, and which results in acceptance and the adoption of healthy coping strategies. Subsequently, higher scores on the RSC subscale would indicate reduced acceptance levels, a situation that leads to greater feelings of fatalism. In the current study, religious and spiritual coping scales were used to refer to this construct.
3.7.2.5 Diabetes Management Self-Efficacy Scale (DMSES)

The scale was developed to assess the self-efficacy of patients with T2DM (Bijl, et al., 1999). It assesses the extent to which the respondents were confident to manage their blood glucose levels, diet and level of physical activity. The self-administered scale consisted of 20 items with a 5-point Likert scale response format that ranges from 1 (Yes, definitely) to 5 (No, definitely not). Distribution of scores in this scale ranged from 20 to 100, with higher scores indicating greater levels of self-efficacy. The stability of the scale was measured with a time interval of one month, and Pearson's correlation coefficient mean demonstrated an acceptable reliability of $r = 0.79$ ($p < 0.001$), and Cronbach’s alpha of 0.81.

3.7.2.6 Summary of Diabetes Self-Care Activities (SDSCA)

The Summary of Diabetes Self-Care Activities (SDSCA) tool assesses the history of the self-care activities of patients with diabetes. This brief, validated self-report instrument measures the frequency of performing self-care tasks related to diabetes management, including diet, exercise, medication, blood glucose testing, foot care, smoking habits and other self-care recommendation components based on a review of seven studies (Toobert, et al., 2000). It has a total of 26 items divided into seven subscales. The average inter-item correlations within the scales were 0.47, which represents a high correlation (Toobert, et al., 2000). According to the author, test-retest correlations tend to be moderate ($r = 0.40$). For the present study, 14 items related to dietary intake, physical activity, blood glucose measurement, medication adherence, foot care, and smoking behaviour were used. A summary of the standardised instruments for the study is depicted in the following Table 3.2.
Table 3.2 Summary of the standardised instruments

<table>
<thead>
<tr>
<th>Construct measured</th>
<th>Instrument</th>
<th>Developer of the instruments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Illness perception</td>
<td>Brief Illness Perception Questionnaire (BIPQ)</td>
<td>Broadbent et al. (2006)</td>
</tr>
<tr>
<td>Depression</td>
<td>Patient Health Questionnaire-9 (PHQ-9)</td>
<td>Kroenke et al. (2001)</td>
</tr>
<tr>
<td>Social support</td>
<td>Enrich Social Support Instrument (ESSI)</td>
<td>ENRICHD investigators (2000)</td>
</tr>
<tr>
<td>Religious and spiritual coping</td>
<td>Religious and Spiritual Coping (RSC)</td>
<td>Egede &amp; Ellis (2010a)</td>
</tr>
<tr>
<td>Self-efficacy</td>
<td>The Diabetes Management Self-Efficacy Scale (DMSES)</td>
<td>Bijl et al. (1999)</td>
</tr>
<tr>
<td>Self-care activities</td>
<td>Summary of Diabetes Self-Care Activities (SDSCA)</td>
<td>Toobert et al. (2000)</td>
</tr>
</tbody>
</table>

3.7.3 Socio-demographic and clinical characteristics data

Relevant information concerning respondents was gathered using the individual characteristics data tool. The tool consisted of two sections: i) demographic data about participants (age, sex and education), which were obtained from participants themselves; and ii) information about participants’ health status, collected from data in medical records held by the hospital. These data included HbA1c, triglyceride levels (TG), cholesterol, low-density lipoprotein (LDL), high-density lipoprotein (HDL), height, weight, duration of the diabetes, treatment modalities, and diabetes-related complications including hypertension, diabetic retinopathy, peripheral vascular disease, heart disease, and stroke. The consent forms clearly specified that data regarding clinical health markers were to be extracted directly from the patients’ files.
3.8 The qualitative phase

After analysing the survey data, participants were divided into three groups: mild depression, moderate depression and moderately severe depression. A purposeful sample was chosen from each group and asked to participate in an in-depth face-to-face interview.

3.8.1 Interviews

Interviews have been extensively used within the health and humanities disciplines as an apt method for data collection (DiCicco-Bloom & Crabtree, 2006; Kanthawongs, 2012; Opdenakker, 2006; Randall, Crooks, & Goldsmith, 2012; Westbrook, 1994). Interviews can be planned at a specific time and place and at the respondent’s convenience (Opdenakker, 2006). The most commonly used format within the qualitative paradigm is the semi-structured interview (DiCicco-Bloom & Crabtree, 2006; Opdenakker, 2006; Qu & Dumay, 2011), as it allows for deep understanding of the studied phenomenon (Kanthawongs, 2012; Randall, et al., 2012). Face-to-face interviews were therefore used as a means of gathering data that captured the experience of diabetes and self-care activities in the patients’ own words.

Face-to-face interviews facilitate synchronous communication in time and place (Opdenakker, 2006), where the researcher and the interviewee are both actively involved in the communication process and the construction of meaning (Sturges & Hanrahan, 2004). A further advantage of face-to-face interaction is the opportunity for the interviewer to observe body language and non-verbal cues of the interviewee during the interview session. Cues can often indicate the need for a
follow-up probe (Sturges & Hanrahan, 2004). Finally, exploring self-care activities among diabetes patients with depression can be a delicate issue (Nagelkerk, Reick, & Meengs, 2006; Rubin & Peyrot, 2001). The participant may exhibit high levels of emotionality, which in turn can be identified and sensitively addressed within the context of a face-to-face encounter.

The interviews in the current study were audio-recorded after obtaining the consent of the participants, in accordance with protocols suggested by Pope and Mays (2006). The main purpose of recording the interviews was to enable the researcher to present a detailed and accurate description of the emergent findings, including verbatim extracts.

### 3.8.1.1 Interview guide

The semi-structured interview guide was determined by the study’s conceptual model and the results of the statistical tests, and in particular the associations between psychosocial factors and diabetes self-care activities provided by the quantitative phase. Therefore, the interview guide was developed by the researcher and piloted randomly on three participants with T2DM selected from the same target population. The guide was subsequently adjusted in accordance with their feedback and comments. As reported earlier, the pilot study participants’ reports were excluded from the full study’s report. The same interview guide was used for all subsequent interviews (DiCicco-Bloom & Crabtree, 2006).

### 3.8.1.2 Procedure

Data were collected through face-to-face interviews, which took place following the quantitative phase. Informed consent was obtained after patients
fully understood the aim of this stage of the study. The interview guide was handed
to the patients prior to the interviews to provide a template of the type of
questions the interviewer would like to explore in greater detail. The respondents
were assured that confidentiality would be maintained and anonymity protected,
and that this would be achieved through the process of coding the interviews. The
interviews were conducted by the researcher. Twelve of the interviews were
undertaken in a private room within Jordan University Hospital (JUH), and three
were conducted in participants’ homes after they explicitly requested to be
interviewed at their residences (and at their convenience). As a ‘native Jordanian’,
the primary researcher carefully assessed each of these three interview scenarios to
identify any potential risks involved in conducting the interviews in a home
environment. Accordingly, she developed a risk management plan prior to
conducting these interviews. No discernible risks were identified from the
assessment.

Interviews followed a semi-structured format with additional prompts and/or
probes to explore participants’ experiences in relation to illness perception, social
support, religious and spiritual coping, self-efficacy and their relationship with
diabetes self-care activities. A pseudonym was assigned to replace each
participant’s authentic name during the transcription and data analysis phases. An
open-ended question such as ‘Can you tell me how life has been since the onset of
your diabetes?’ was used to initiate the interview session. This was followed by
targeted questions that remained open-ended and that centred on the constructs
of interest and relevance to this study. This approach allowed participants the
freedom and flexibility to express their experiences in their own way, while also enabling the researcher to designate follow-up probes. Interview questions included questions similar but not limited to the questions listed at Appendix B on page 281. Interviewing continued until saturation was reached and the researcher had sufficient qualitative data to enhance the quantitative findings for this mixed methods study.

3.9 Statistical analysis

A sequential data analysis approach was conducted in two steps; i) Quantitative data analysis; and ii) Qualitative data analysis.

3.9.1 Quantitative analysis

Data were checked for completeness, accuracy, and the nature of the distribution before analysis. Statistical analyses were carried out using a Statistical Package for Social Sciences (SPSS, Version 20) (IBM SPSS, Somer, NY). The analysis procedure is fully explained in the following steps.

Step 1: Psychometric testing of all six standardised scales (BIPQ, PHQ-9, ESSI, SRC, DMSES, and SDSCA) was performed. This included: a) factorial validity using Principal Component Analysis as well as internal consistency using Cronbach’s alpha; b) the relationship between two variables was assessed using a correlation coefficient.

Step 2: Descriptive statistics were obtained including frequency and a percentage table for categorical variables and the measures of central tendency for numerical data and measures of dispersion (Gerstman, 2008).
Step 3: Inferential statistics were also obtained; the total score for the survey instruments was calculated.

Step 4: Initial analysis took place to explore the null hypothesis, in which the normality and linearity of the data were assumed. A Shapiro-Wilk test was undertaken and significance level was set at \( p < 0.5 \), and the normality was also explored by a visual inspection of the study variables histograms, normal Q-Q plots and box plots.

Step 5: Correlation coefficient Pearson’s \( r \) was calculated to determine the strength of the association between the selected variables and diabetes self-care activities. The significant level was set at \( p = 0.05 \).

Step 5: The Structural Equation Modelling (SEM) with AMOS version 20 was used to test the proposed conceptual model and to examine which of the study constructs predicted self-care activities. The SEM technique is frequently used to analyse causal structure based on non-experimental data (Hayduk, Cummings, Boadu, Pazderka-Robinson, & Boulianne, 2007). The SEM tests a substantiative theory by postulating a model that exemplifies predication of the theory among reasonable domains measured with the appropriate data (Blunch, 2013; Hayduk, et al., 2007). In other words, it is a theory-driven evaluation to assess whether the hypothesised model theoretically fits (Blunch, 2013).

3.9.1.1 Rationale for using SEM

Structural Equation Modelling techniques have received popularity in testing the relationship postulated in a parsimonious model (Cheng, 2001). The SEM is
considered a powerful instrument in testing a set of relationships between the dependent and independent variables simultaneously in research that necessitates using a quantitative analysis technique (Blunch, 2013). The SEM differs from a multivariate regression analysis, in which tests are influential in testing single relationships between the dependent and independent variables. In addition, SEM has the capacity to evaluate and assess the relationship among the study constructs and use of multiple measures to represent study constructs. Unlike other general linear models, in which constructs can only be addressed by one measure and in which measurement error is not displayed, the SEM can identify the aspect of measure-specific error (Cheng, 2001).

Indeed, in a theory-driven model that predicts human behaviours, the relationships are more complicated and thus unable to fit neatly into a single relationship. To illustrate, one variable could be independent in one relationship and dependent in another. Thus, a multi-step regression model lacks the statistical mechanism that takes into account the interaction effect among the postulated path model and observed data (Cheng, 2001). From a conventional test-theory standpoint, any observed measure yields true score and error, not to mention that reliable measures have less error than unreliable measures. In other words, latent variables exhibit the essential attribute associated with the accurate score, whereas error variance is accounted in the variability not explained by the true score (Bollen, 2005). The SEM is a versatile and flexible model that enables researchers to remap the data and to adopt an equivalent or even near-equivalent fit that is able to clearly explain the same data. In addition, all estimates of the model are calculated
simultaneously, thus the goodness-of-fit is a fully informative form of analysis. The SEM was therefore chosen to test the proposed integrated self-care activities model.

The current study used SEM to evaluate the parameter estimates and model fit of the proposed conceptual model as shown in Chapter 2 Section 2.2 on page 23, in order to determine the direct and indirect relationship between the study’s selected variables and self-care activities among patients with diabetes in Jordan.

3.9.1.2 Goodness-of-fit statistics

The main objective of this phase of analysis was to statistically test whether the proposed conceptual model was consistent with the data. The process includes overall fit statistics and indices estimates (Yuan, 2005). If the goodness-of-fit indices are adequate, the model ascertains the plausibility of postulated relations among the study constructs (Kline, 2011). Conversely, if the goodness-of-fit indices do not fit the data, then the tenability for the assumed relationship among the study variables is rejected (Kline, 2011). As mentioned previously, however, SEM is able to find an equivalent or near-equivalent model. The study employed the goodness-of-fit statistics including chi-square (χ2), Root Mean Square Error of Approximation (RMSEA), Normed Fit Index (NFI), Comparative Fit Index (CFI) and Tucker-Lewis Index (TLI).

The chi-square index is the most fundamental fit statistics, and if the chi-square χ2 ≥ 0.5, the goodness-of-fit measures are regarded as acceptable. That is, the observed covariance matrix is similar to the predicted covariance matrix. The probability value that is related to χ2 indicates that the chance of obtaining χ2 value
more than the $\chi^2$ value when the null hypothesis is true. Thus, the lower the likelihood associated with $\chi^2$, the larger the fit is between the hypothesised model and the perfect fit (Blunch, 2013). Small sample size and non-normality are factors that need to be considered when performing a chi-square test. Of particular relevance, this study used an adequate sample size. Further discussion in relation to the sample size and the normality issue can be found later in this chapter. However, a review study reported that if the sample size is too small, it yields an inflated chi-square level, even when the data are normally distributed, bearing in mind that the non-normality increases as the sample size decreases (West, Finch, & Curran, 1995).

Therefore, to ensure a more rigorous assessment of the hypothesised model, the current study also used other comparative goodness-of-fit indices that take a more pragmatic approach, including Root Mean Square Error of Approximation (RMSEA), Normed Fit Index (NFI), Comparative Fit Index (CFI) and Tucker-Lewis Index (TLI). These indices are commonly reported in SEM studies, because each shows model fit from a different angle (Kline, 2011; Yuan, 2005). It has been argued that using different combinations of fit indices will generally perform better than a single index performance (Hu & Bentler, 1999).

With its 90% confidence interval, the Root Mean Square Error of Approximation (RMSEA) represents a badness-of-fit. This index also considers the error of approximation in the population, and takes into account how the model would fit the population covariance matrix were it available (Steiger, 1990). This is often exemplified by a degree of freedom; hence, this would render this index sensitive to the number of estimate parameters in the proposed conceptual model.
A value <0.5 represents a good fit, and the use of a confidence interval of 90% is crucial to reflect the precision of RMSEA estimate and enables researchers to gain more information to evaluate the model fit. Of note, a narrow confidence interval reflects a good model fit (Kline, 2011).

The goodness-of-fit indices Normed Fit Index (NFI) and Comparative Fit Index (CFI) both range from 0 to 1, and compare the fit of the proposed model with the independence model. In such a combination, the correlation between variables is not assumed. A value of more than 0.95 represents a well-fitting model (Hu & Bentler, 1999). The study also used the Tucker-Lewis Index (TLI), which is consistent with the aforementioned indices, ranging from 0 to 1, where a value of 0.95 indicates a good fit (Hu & Bentler, 1999). As previously mentioned, the study employed an adequate sample size and fulfilled the distribution requirements. It is therefore less likely that TLI and GFI would yield an underestimated fit (West, et al., 1995).

3.9.1.3 Sample size in SEM

In the SEM, sample size has an important impact on the statistical results. It has been reported that the sample size in SEM analysis could have a confounding effect on the results and is more likely to occur if the sample size is small, as this increases the ‘sampling error’ (Thompson, 1996). The SEM technique requires a sufficiently large sample in order for the results to be considered stable. Notably, a review of 93 studies conducted between 1984 and 2003 that used the - SEM, reported that a sample size of 200 was typical (Shah & Goldstein, 2006). This current study recruited 220 subjects (see Section 3.4.1).
3.9.1.4 **Data requirement and model estimation**

Illness perception constructs including illness coherence, personal control, treatment control, timeline, consequences, emotional responses and identity form the exogenous variables for depression. These were included in the model. Furthermore, social support, religious and spiritual coping were exogenous variables for depression and self-efficacy. In addition, two variables including BMI and HbA$_1c$ representing clinical characteristics were exogenous variables for illness perception and self-care activities. Depression is an exogenous factor for self-efficacy, while self-efficacy is an exogenous factor for self-care activities.

The study included continuous variables in the model, because it was reported that the ordinal variables created some methodological problems in relation to SEM analysis (Kline, 2011). Nevertheless, a number of statistical solutions have been developed to address such problems whilst still maintaining the advantages of SEM (Bollen, 1998).

Furthermore, the Maximum Likelihood (ML) estimation of parameters was employed for model fit. The ML has been acknowledged to be robust even when violation of normality assumption occurs, and when the sample is small to moderate in size (Arbuckle, 1996). This approach offers several advantages. It is consistent and efficient in a statistical sense and is asymptotically unbiased. It also yields standard error estimates to provide a method for hypothesis testing (Arbuckle, 1996). The use of ML was based on the previously highlighted assumption and because the pattern of the missing data in the study did not indicate a discrete spectrum.
3.9.2 Qualitative analysis

Data collection and analysis occurred simultaneously to enable the researcher to refine the interview questions and to develop new avenues of enquiry where necessary (Parvizy, Kiani, & Ivbijaro, 2013; Pope, Ziebland, & Mays, 2000). A thematic approach was used because it is a systematic research method for creating replicable and sound inferences from the data to their milieu which can provide knowledge, awareness, illustration of evidence and guide to action (Pope & Mays, 2006). In the current study, a thematic approach was used to elicit themes related to psychosocial factors and self-care activities, within transcripts and among groups (Thomas & Harden, 2008). Audio data were transcribed and translated into English (Al-Amer, Ramjan, Glew, Darwish, & Salamonson, 2014).

Initial broad reading identified the major issues within the data, and then line-by-line reading of the text enabled initial coding and analysis to begin. Items or codes that related to similar nuances were combined into categories, followed by the generation of overarching themes and subthemes (Miles & Huberman, 1994).

The analysis process was dynamic and continuous. Refining and developing the codes therefore continued throughout the analysis process (Corbin & Strauss, 2008). The themes and ideas were coded and added to the findings of the quantitative study to further explain the constructs in a holistic manner. Codes and the code structure were considered to be finalised at the point of theoretical saturation (Elo & Kyngäs, 2008; Stemler, 2001). The following steps were used:

Step 1: Organised the data in an excel sheet with one-row-per-participant, the identifiers were maintained.
Step 2: Sorted the responses per the levels of depression and added a column for the theme names.

Step 3: First read through the transcripts enabled for analysis of the data - understanding of what participants thought and felt at some point - in time

Step 4: Sorting the data into themes; naming the ideas that the participants’ responses appeared to represent. These themes were typed into the themes’ column. Afterwards, the data were sorted alphabetically, this helped the researcher to group the participants’ response that started with words akin to each other which in turn may reflect the same ideas. In this step, the researcher used the Find button to locate the words and the phrases that were used frequently.

Step 5: Finding themes, the researcher organised the coded data into a new column, this helped to keep the initial themes intact. The sorting out function was used in this step to group responses that indicated a single theme. Responses that fitted in more than one theme were included in the notes for each. Afterwards, sub-theme analysis took place.

Step 6: The theme analysis was simplified – Higher-order themes– based on the data (Miles & Huberman, 1994). Graphical display through the excel sheet helped in executing this process. Further, the relationships among themes were identified.

3.10 Strengths and limitations

The key tenets of thematic analysis were validation or extension of a theory, or rather of a conceptual theoretical framework (DiCicco-Bloom & Crabtree, 2006). It is also a flexible technique that may be used with qualitative or quantitative data
and it employs a wide range of analytical techniques to embed findings with context (Elo & Kyngäs, 2008; White & Marsh, 2006). However, certain limitations need to be addressed, and one obvious concern is researcher bias, which is when the researcher favours evidence supporting rather than confuting their conceptual model or theory (Adams et al., 2002). In view of this concern, an audit review was undertaken by the principal researcher of the predetermined categories was conducted before the study. This was undertaken to minimise the risks of this kind of bias (Miles & Huberman, 1994). Another concern related to the social desirability bias; that is, while probing being tracked by the researcher, some participants might answer in a certain way, or agree with the questions in order to please the researcher (Hsieh & Shannon, 2005). Some participants, for instance, may agree with suggested psychosocial variables, even though they did not experience them. Overcoming such potential bias was achieved by ensuring that participants received full explanation of the value of the research objectives, and that they were assured that confidentiality would be maintained. One final concern stems from the over-emphasis of the theory, which could obfuscate researchers to contextual aspects of the studied experience (Hsieh & Shannon, 2005). To illustrate, the level of psychosocial response to self-care activities may minimise the ability to trace contextual features that influence self-care activities.

3.11 Trustworthiness

Drawing from Lincoln and Guba (1985), four main strategies were used in this study to ensure trustworthiness or rigour in the qualitative phase: credibility, transferability, dependability, and confirmability.
Credibility was defined by Baxter and Eyles (1997) as ‘the degree to which a description of human experience is such that those having the experience would recognize it immediately and those outside the experience can understand it’ (p. 512). The qualitative phase of the study ensured credibility using the following techniques: member checking, peer debriefing and triangulation (Lincoln & Guba, 1985).

3.11.1 Member checking and Peer Debriefing

Participants in the qualitative phase of the study were provided with opportunities to formally and informally validate constructions and interpretations. Member checking enabled participants to review their interview transcript, and during interviews to informally verify the researcher’s interpretations and conclusions and correct any misinterpretations. The researcher provided participants with the opportunity to provide feedback and/or correction to the transcripts after the transcription of the interview. The researcher furthermore summarised the main ideas during and at the completion of the interview, to enable confirmation or correction from participants.

Peer debriefing was another strategy used to maintain credibility. Supervisors and peers provided constructive criticism and feedback throughout the research process, particularly during the analysis stage, to ensure that the researcher’s emotion or closeness to the project did not interfere.

3.11.2 Triangulation

Triangulation is a technique of using numerous sources of data, methods, investigators or theories to validate the data or interpretations. This study used
methods triangulation through its mixed methods design and the use of both qualitative and quantitative data to provide a rich, comprehensive understanding of the phenomenon under study, and also to elucidate the relationships and divergences in the findings. Additionally, multiple sources of data were used to increase confidence in the findings, including interviews, surveys, and medical records.

3.11.3 Transferability

Transferability is defined as the degree to which the findings of the study would fit within contexts outside the study, or to which they might be reproduced in other contexts (Krefting, 1991). The present study ensured transferability as it provided detailed descriptions of the setting, sampling technique and data collection methods, indicated as follows.

3.11.4 Setting

The qualitative phase of this study was conducted in the setting of one medical institution (JUH) within their Endocrinology Clinic. This choice of venue facilitated the inclusion of participants from different social strata and from a wide range of geographical contexts within Jordan.

3.11.5 Sampling technique

The study used a stratified purposeful sampling technique to obtain variability on depression and self-care activities among primary study participants: that is, the presence or absence of self-care activities within different levels of depression. The sample plausibly produces realistic descriptions of the phenomenon. Most
importantly, ethical selection was a key consideration; severely depressed patients were not interviewed because their consent process might not be credible.

3.11.6 Data collection methods

The study indicated that face-to-face interviews be used to collect data. Interviews ranged from 30 to 45 minutes in duration. The data were collected over a three-month period.

3.11.7 Dependability and confirmability

Lastly, dependability and confirmability were maintained. Dependability refers to maintaining a consistency over time (Guba, 1981), whilst confirmability denotes the extent to which the participants and the condition of the enquiry are the key determinants of the results, as opposed to the possibility that bias may arise from the enquirer (Guba, 1981). An ‘audit trail’ was used as a means to ensure both dependability and confirmability (Cutcliffe & McKenna, 2004)

3.11.8 Audit trail

An audit trail was maintained throughout the entire study to convey a clear research description of the research process (Richards, 2009). This included; i) instrument development information (schedule); ii) raw data (field notes, audio recordings); iii) data reduction (coding, quantitative summary); iv) reconstruction and synthesis of the data (categories, definition of the categories, the relationship between the latter and theme development); and v) analysis decisions made throughout the study were also documented.
3.12 Data integration (quantitative and qualitative)

Data from each phase (quantitative and qualitative) were analysed separately, and the data sets were collated only at the point of theoretical interpretation. The Statistical Package for the Social Sciences (SPSS) was used for the quantitative analysis, while the qualitative data analysis was undertaken manually, to retrieve qualitative data in context corresponding to the quantitative data. The integration took place by connecting and merging both data sets (Creswell & Plano Clark, 2011). Connecting the data sets entailed analysing the quantitative survey, using this data to inform the subsequent qualitative data collection, identifying participants for the interview, and integrating both data sets in the discussion section of the study. For instance, quantitative statistical results were reported first, followed by the qualitative quotations or themes that either enhanced or refuted the quantitative results.

3.13 The role of the researcher

The primary responsibility of the researcher in data collection is centred on two different roles. During the quantitative phase, the researcher’s role was to: i) establish a relationship with personnel in the data collection site, that is nurses, clinic clerks and physicians; ii) conduct the pilot study; iii) validate and check the instruments; iv) recruit the participants for the study; v) administer the survey; vi) conduct quantitative data analysis using rigorous statistical analysis techniques including co-relational and SEM; and vii) write a report to present the data.

In the subsequent qualitative phase, the researcher assumed a more participatory role as demanded by the characteristics of this phase. The
researcher’s role was to: i) pilot the interview guide; ii) interview all selected participants who had enrolled in the first phase of the study and agreed to join the second phase, as the researcher shared with the participants the same language and cultural arena; iii) establish a rapport with patients to facilitate the collection of data in this phase using in-depth interviews; iv) follow with the translation and the transcription of the interviews; v) analyse each interview in a sequential manner, in addition to reporting each step of the analysis process to the supervisory panel; vi) select participants for the purpose of member checking to comment on the plausibility of the results; vii) use assessment and review provided by the researcher’s supervisory panel to follow through the progression of events; viii) ensure data were not forced into categories simply because a code existed for them; ix) present the data by writing a report; x) maintain confidentiality by deleting patients’ identifiers from all data; and xi) validate the data and the results for both data sets

**Chapter summary**

The chapter illustrated a comprehensive review of the study design and methods, in which a discussion of the mixed method design including the quantitative and the qualitative phase was presented. The sampling technique, the setting, the power calculation, inclusion and exclusion criteria were also illustrated. Information on the ethical protection of the human subjects was outlined. The data collection procedure for the quantitative phase including the instruments that were used and the analysis technique were addressed, in addition to the detailed presentation of the interview in the qualitative phase. The chapter concluded by discussing the rigor in both phases and the limitations of the current study.
Chapter 4

Cross-cultural validation

4.1 Introduction

Cross-cultural research is an essential mode of investigation in the field of public health and is of paramount importance to studies into increasingly diverse contemporary societies. Linguistic and cultural diversity have increased in the 20th century, both within countries and across national borders (Uysal-Bozkir, Parlevliet, & de Rooij, 2013). Hence, there is a growing demand in healthcare research to address issues that are relevant to multicultural communities (Fryer, Mackintosh, Stanley, & Crichton, 2012).

In healthcare-related research, linguistic complexities must be taken into account in order to examine the quality of care. The existing literature indicates that there are racial and ethnic differences to consider when approaching the issue of languages in healthcare research. Moreover, effective translation processes are essential when investigating disparities among multicultural communities (Lopez, Figueroa, Connor, & Maliski, 2008; Temple & Young, 2004). The use of valid and reliable instruments in cross-cultural healthcare research is also of crucial importance (Lopez, et al., 2008; Sousa & Rojjanasrirat, 2011), since utilising effective and efficient instruments can build on previous knowledge.

The POISE study used six instruments with a source language of English. Of these, one was already translated into the target language, Arabic (Kroenke, et al., 2001). The translation provided the basis for the cross-cultural adaptation of six
standardised English scales: Brief Illness Perception Questionnaire (BIPQ), Patients’ Health Questionnaire-9 (PHQ-9); ENRICH Social Support Instrument (ESSI); Religious and Spiritual Coping Subscale (RSC); Diabetes Management Self-Efficacy Scale (DMSES); and Summary of Diabetes Self-Care Activities (SDSCA). These were applied using currently accepted guidelines for use with Arabic-speaking participants (Råholm, et al., 2010; Ringberg, Luna, Reihlen, & Peracchio, 2010; Sousa & Rojjanasrirat, 2011). Importantly, translation was based on conceptual and cultural equivalences rather than solely on linguistic equivalence. The psychometric evaluation of the aforementioned six adapted scales was tested among Arabic-speaking patients with T2DM in Jordan.

4.2 Background

The cross-cultural adaptation of the original English instruments into Arabic was guided using published recommendations (Beaton, Bombardier, Guillemin, & Ferraz, 2002; Råholm, et al., 2010; Sousa & Rojjanasrirat, 2011). As recommended for cross-cultural studies, this included forward and backward translations. This translation process is understood to reduce the ambiguity, discrepancy and inequality that may occur during the translation process (Råholm, et al., 2010; Sousa & Rojjanasrirat, 2011; Thorsteinsson, 2012). Forward translation was conducted by two native Arabic-speaking general practitioners who had a high level of proficiency in spoken and written English. Following independent translation of the instruments, there was a discussion between the translators and the researcher to detect any inconsistencies in the translation outcomes (Råholm, et al., 2010). Afterwards, another two independent translators took over the back translation of the instruments, one of whom was a native English speaker who is an English
teacher, and the other a bilingual General Practitioner. These independent translators were blinded to the original questionnaire. The researcher highlighted any discrepancies detected between the two backward-translated versions and the original versions of the questionnaire. The backward-translated versions of the instruments were then compared by a committee with the original versions for linguistic agreement and unity. Finally, a pilot study among 10 Jordanian patients with T2DM was conducted to establish the content validity of the instruments. The process of cross-cultural validation of the aforementioned scales consisted of several steps, each of which is documented in detail below.

4.3 Steps in cross-cultural validation of the instruments

The cross-cultural validation process recommended by Sousa and Rojjanasrirat (2011) was adapted based on six steps. These steps will be discussed in two stages. First, stage one consisted of five steps, including: i) Forward translation and synthesis; ii) Comparison of the two forward-translated versions; iii) Blind backward translation; iv) Expert Committee; and v) Test of the pre-final version. Second, stage two consisted of step six: vi) Psychometric testing which mainly discusses the psychometric evaluation of the six adapted scales and the establishment of content validity and reliability presented in Chapter Five.

The process used for the validation of the cross-cultural instrument is illustrated in Figure 4.1; Page 96.
Figure 4.1 Translation process adapted from Sousa and Rojjanasrirat (2011)
4.3.1 Stage 1: Translation of the instruments

4.3.1.1 Step 1: Forward translation

The instruments were translated from English as the source language to Arabic as the target language by two bilingual bicultural translators, whose mother tongue is the desired language of the instruments (that is, Arabic) (Sousa & Rojjanasrirat, 2011). The study used two Arabic native speakers; both were General Practitioners, each with a minimum of one year of experience in clinical practice and a sound knowledge of medical terminology. The first translator was female; she had spent two years at a high school in the United States, and had lived with an American family during an international exchange program. Given her bilingual background and use of both English and Arabic in everyday life, she had a high command of English and was proficient in Arabic. The other translator was a male who was proficient in both Arabic and English as he was raised in Jordan but educated in American schools. The translators shared the same ‘cultural arena’ as the participants, an important consideration since culture, norm and beliefs are embedded in language (Yom, 1998).

Further, the translators were instructed to maintain semantic equivalence, content equivalence and conceptual equivalence as these are essential to the translation process (Beck, Bernal, & Froman, 2003; John, Angst, Pap, Junge, & Mannion, 2007; Sousa & Rojjanasrirat, 2011). Content equivalence was employed to ensure cultural relevancy of each scale’s variables to Arabic culture, whereas semantic equivalence was utilised to ensure that each item conveyed the same meaning in English to Arabic after translation.
Anthropometric variables were also translated, including age, education, gender, HbA1c and BMI. The aim of this step was to create an Arabic version that was translated as closely as possible to the English version in relation to structure and format. This step yielded two versions of the forward-translated scales.

4.3.1.2 Step 2: Comparison of the two forward-translated versions

In cross-cultural studies, it is important that a third bilingual and bicultural translator be used to compare the forward-translated versions (Sousa & Rojjanasrirat, 2011). The researcher communicated with the translators via telephone, email and face-to-face meetings. This ensured that the content equivalence and semantic equivalence of the final forward translation remained intact, and that both versions were systematically compared in relation to discrepancies, ambiguities of words, syntax and meaning (Beaton, et al., 2002; Beck, et al., 2003; John, et al., 2007; Råholm, et al., 2010; Sousa & Rojjanasrirat, 2011).

4.3.1.3 Step 3: Blind backward translation

The initial Arabic-translated version of the instruments was translated backward from Arabic to English by other independent translators. In particular, two independent bilingual experts conducted the backward translation using the same approach. One of the translators was an English teacher of 15 years’ experience. She was also familiar with the usage of colloquial phrases, and the jargon and range of expressions commonly used in healthcare settings. The other translator was a native Arabic-speaking General Practitioner with a very good command of English, who was similarly conversant with a wide range of healthcare terms and content that was relevant to the construct of the instruments. The
characteristics of these translators met the current recommendations. They both had distinct cultural backgrounds; one of the translators was knowledgeable in health terminology and the content area of the instrument in the source language, and the other translator was knowledgeable in culture and linguistic nuance (Råholm, et al., 2010; Sousa & Rojjanasrirat, 2011; Thorsteinsson, 2012). The translators worked independently during the initial translation process, and were blinded to the original version of the instruments. The initial Arabic-translated version of the instruments was translated back to English to produce the two backward-translated versions (BETV1 and BETV2). The use of independent and blinded backward translation prevented the translators from inferring meaning from the Arabic-translated versions.

4.3.1.4 Step 4: Expert committee

The original versions of the questionnaire and backward-translated versions (BETV1 and BETV2) were compared by an expert committee in order to achieve linguistic agreement and consensus. Any discrepancies and inconsistencies in the content of the translated versions were highlighted by the researcher in preparation for the expert committee. The multidisciplinary committee consisted of the two forward translators who were involved in Step 1, the two backward translators who were involved in Step 3, the researcher as a methodologist, a clinician, and three of the supervisory panel as monolingual personnel. The committee examined the items and response format, and analysed the sentences for cohesion, differences and similarities in meaning, and also considered the grammatical structures that governed the items. In addition, the committee assessed the notes made by the researcher during the translation and consolidated these to generate a ‘pre-final’
Arabic version of the Instruments 1 (APV_1). The initial Arabic version of the instruments was reviewed by a monolingual Arabic language expert in the production of the Arabic Pre-Final Version 2 (APV_2). Table 4.1 on page 101 illustrates the resources used during this process.
<table>
<thead>
<tr>
<th>Steps of translation</th>
<th>Translator number</th>
<th>Translator name</th>
<th>Credentials</th>
</tr>
</thead>
<tbody>
<tr>
<td>Forward translation</td>
<td>Translator 1</td>
<td>Maram Darwish</td>
<td>General medical practitioner lived for two years in the United States</td>
</tr>
<tr>
<td></td>
<td>Translator 2</td>
<td>Mohammd Sako</td>
<td>General medical practitioner, educated in an American school</td>
</tr>
<tr>
<td>Synthesis of the translation</td>
<td>Researcher</td>
<td>Rasmieh Al-Amer</td>
<td>MSc in diabetes education</td>
</tr>
<tr>
<td>Backward translation</td>
<td>Backward T1</td>
<td>Mervat Sharaf</td>
<td>BSc in English literature, native English speaker</td>
</tr>
<tr>
<td></td>
<td>Backward T2</td>
<td>Dr Ayman Aref</td>
<td>General Practitioner</td>
</tr>
<tr>
<td>Expert Committee</td>
<td>Methodologist</td>
<td>Rasmieh Al-Amer</td>
<td>Doctoral Candidate and Primary Researcher</td>
</tr>
<tr>
<td></td>
<td>Clinician</td>
<td>Professor Nathir Obeidat</td>
<td>Internal Medicine Consultant (Clinician)</td>
</tr>
<tr>
<td></td>
<td>Arabic language expert</td>
<td>Abdulmajid Mustafa</td>
<td>BSc in Arabic literature</td>
</tr>
<tr>
<td></td>
<td>English language expert</td>
<td>Dr Paul Glew</td>
<td>Doctor of Education, Master of Applied Linguistics (TESOL), and Master of Nursing</td>
</tr>
<tr>
<td>Pre-testing</td>
<td>T1 T2 BT1 BT2</td>
<td>Rasmieh Al-Amer</td>
<td>Doctoral Candidate</td>
</tr>
</tbody>
</table>

T1, Translator 1; T2, Translator 2; BT1, Backward Translator 1; BT2, Backward Translator 2
4.3.1.5 Step 5: Pilot testing of the Arabic Pre-Final Version 2

A pilot test of APV_2 was conducted between the 10th and 15th of June 2013 inclusive. The pilot study provided useful feedback and insight about how participants would interpret the questionnaire, and the period of time required to complete the instruments. Ten participants were randomly recruited for the pilot study. To ensure that the respondents of the pilot study were broadly representative of the participants in the main survey, it was conducted among patients meeting the same inclusion and exclusion criteria and attending the same clinic where the data collection took place. The survey used in the pilot test included an additional survey feedback sheet where participants could add their comments and/or request further information. This sheet served to: i) verify the feasibility and adequacy of the instruments and establish the timeframe needed to complete the questionnaire; and ii) establish the content validity of the instruments.

Moreover, the instruments were also sent to two Registered Nurses, a dietitian and an endocrinologist to review and comment on the meaning and the clarity of the items. The results of this stage were taken into consideration to generate the final version of the instruments (FAV). The questionnaires were revised based on feedback collated from the expert panel and the pilot study respondents (Figure 4.1). The data gathered from these participants were excluded from the main study.
### 4.3.2 Steps in cross-cultural validation of the interview

There is a dearth of literature exploring the process of translation used in qualitative research. This is particularly the case in health-related studies where non-English speaking groups are the focus of the research (Bradby, 2002). When conducting cross-cultural qualitative research, the idiosyncratic use of language often raises specific problems in terms of translation, particularly when researchers or members of the research team do not share the same language as the participants (Bradby, 2002). Therefore, a translator must possess the ability to understand the social and physical universe of the people being surveyed. Bradby (2002) urges translators to not only consider the logical connections between words but also to think of a text in terms of linguistic devices. Translators typically read and translate from their own perspective. Because of this, it is important that researchers do not accept that there is one definitive version of a text to be agreed upon by considering solely the ‘correct’ choice of words (Al-Amer, et al., 2014).

Qualitative research in a cross-cultural context often relies on translation to fully understand the values and experiences of people (Squires, 2009). Translating from one language to another can be a complex and multifaceted process due to the subtle and variegated nuances in meaning. For instance, although some languages may be similar to English, not all words from these languages can be translated into English because of differences in meaning due to culture, the implications of the usage of jargon, or a lack of equivalent words. Consequently, according to Yom (1998), the first priority in translation is to accord primacy to the general meaning of the words, rather than to the individual lexical items and
specific linguistic structures. Cultural norms are often rooted in the language, and should be given priority. As explained by Temple, Edwards, and Alexander (2006), culture is inseparable from language and discourse. Linguistic capability is not the sole requirement for well-executed translation; rather, familiarity with the research field, and most importantly, sharing the participants’ cultural arena, are the overarching goals in the translation process (Bradby, 2002; Lopez, et al., 2008; Temple, et al., 2006). For instance, a cultural arena includes shared understandings, expectations and values; this is not defined by a single ritual or by some phrases unique to a specific group, but rather by a commonality of understandings held by a group or subgroup (Temple, 2002). A shared cultural arena includes people who have had common social experiences and/or descendants of the same history with the participants (Temple & Young, 2004).

4.3.2.1 Rationale for translation

As Jordan is a Middle Eastern nation where the official language is Arabic, there was a need to translate the qualitative data that directly related to the research topic on depression and self-care activities in Jordanian adults with diabetes. One researcher from the research team was bilingual and the other team members were monolingual. The data were collected using Arabic as the preferred language for the interviews, since this was the participants’ native language. Translation into English was subsequently conducted for all transcripts, as this was a language common to the research team.
4.3.2.2 Transcription

During the preliminary stage of the research, the team agreed that the interviews would be held in the participants’ native language, and that the main researcher would transcribe the interviews into Arabic as the source language for the following reasons; 1) the main researcher was the only bilingual person in the research team; 2) she shared the participants’ language and their cultural arena; and 3) gathering the interview data enabled the researcher to be well acquainted with the data.

The first two interviews were used as pilot interviews; the researcher transcribed the interviews into Arabic and then translated them into English. The transcription of each interview took approximately 6 to 7 hours and the translation took another 6 to 7 hours. Overall, each interview required a consolidated 12 to 14 hours for both transcription and translation. For the purposes of expediency and time-efficiency, the interviews were audiotaped; and were translated and transcribed directly from these recordings.

4.3.2.3 Selection of the translator

A translator was selected from those who participated in the translation of the instruments. This translator shared the origin, language, culture, social norm and religious convictions of the participants, as recommended in the literature (Pitchforth & Van Teijlingen, 2005). The criteria details are shown in Table 4.2 on page 106.

The translation of questionnaires is similar to translating professional English to professional Arabic, and can thus be based on well-recognised guidelines (Meyer,
Sprott, & Mannion, 2008; Råholm, et al., 2010; Sousa, Hartman, Miller, & Carroll, 2009; Sousa & Rojjanasrirat, 2011). However, there was a lack of detail in the guidelines in relation to the qualitative data translation. In translating the participants’ transcripts, the data at times yielded colloquial Arabic language that needed to be translated from Arabic to English. The participants mostly used narration to construct their experiences, and this approach promoted consistency in translation, as it emphasised conceptual congruency in the translated interview data (Bradby, 2002; Temple, et al., 2006; Twinn, 1997). For this process, only one translator was selected in order to maintain consistency (Twinn, 1997) and to enhance conceptual equivalence when translating from the source language to the target language (Larkin, Dierckx de Casterle, & Schotsmans, 2007). Moreover, the translator was a general medical practitioner and was thus able to translate the medical terminology.

<table>
<thead>
<tr>
<th>The researcher</th>
<th>The translator</th>
<th>The participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>Female</td>
<td>10 females/5 males</td>
</tr>
<tr>
<td>Age 48</td>
<td>Age 25</td>
<td>Age 36–73</td>
</tr>
<tr>
<td>Married</td>
<td>Unmarried</td>
<td>Married</td>
</tr>
<tr>
<td>Children</td>
<td>No children</td>
<td>All have children except 1</td>
</tr>
<tr>
<td>PhD student</td>
<td>General Practitioner</td>
<td>Completed minimum high school School</td>
</tr>
<tr>
<td>Jordanian</td>
<td>Jordanian</td>
<td>Jordanian</td>
</tr>
<tr>
<td>Muslim</td>
<td>Muslim</td>
<td>14 Muslim/1 Christian</td>
</tr>
<tr>
<td>No experience working with translators</td>
<td>No experience of working as translator</td>
<td>Unknown experience of research</td>
</tr>
</tbody>
</table>

Adapted from Pitchforth and van Teijlingen (2005)
4.3.3 Translation process

Semantic equivalence was given precedence in the translation process because errors may occur if word-for-word translation was given priority over the semantic equivalence (Bradby, 2002; Squires, 2009). Therefore, the use of semantic and content equivalence was prioritised over word-for-word translation, particularly if an exact meaning in English was not possible, as this would retain the context of the data. The pilot interviews were translated by the same translators after they had been transcribed by the researcher. As this was a time-consuming process, the translators were asked to translate the interviews directly from the audio recordings. There was also concern that word-for-word translation from Arabic to English may jeopardise the readability of the data. Consequently, after each interview, debriefing sessions between the translators and the researcher were convened to verify the accuracy and validity of the data (Temple, 2002; Temple, et al., 2006). In cases where there was no exact meaning or no equivalent meaning in the English language, the translator translated semantically, for the meaning of the words in their context. In addition, she concentrated on how, why and when such words were normally used in Arabic in these situations.

Differences in the grammatical structures between Arabic and English also caused some difficulties. For example, adjectives in Arabic follow the noun they qualify, which can result in word order errors during translation if using word-for-word translation even when the equivalent word is available. Moreover, the Arabic language does not use the infinitive verb ‘to be’ in the present tense, or auxiliary verbs such as ‘do’ preceding a main verb for a negative statement or question form.
Therefore, content equivalence and semantic equivalence were imperative throughout the translation phase.

**4.3.3.1 Debriefing session with the translator**

After each interview, the researcher held debriefing sessions as face-to-face meetings with the translator to determine to what extent a translator accurately conveyed the meaning of the participants’ experience. To interrogate the choices made by the translator, she was asked to give examples of when a choice was made using semantic equivalence and word meaning when a direct translation could not convey the meaning. Examples identified by the translator involved situations where she had to translate words with no direct equivalence in the English language and/or where she identified that an equivalent word in English did not convey the same meaning as in the Arabic language. Decisions were also checked about the extent to which she had to stay with the construction of the sentences that the interviewees used in their own language.

‘for example, there is a common phrase Jordanian people use to show the amount of negative change that they have gone through, but if you try to translate this phrase word for word from Arabic to English you can’t get any sense of that, the exact meaning of [the phrase] is ‘fallen from the sky’. Although there is no relevance between negativity and the sky, Jordanian people use it to show that the change was negative, huge and insurmountable, so when they say [as if I have fallen from the sky] they mean that something was so good and turned bad dramatically’.
A female participant said: ‘Before diabetes my life was much better, I was healthier, more energetic ... more enthusiastic ... even my skin was glowing ... I was much better before ... even my psychological status was better... once I got the diagnosis I felt down ... I got depressed ... I assume you understand ... I got diagnosed when I was 31, above that I was suffering from hypertension at that time ... I felt bad ... I stopped paying attention to my looks ... my outfits ... nothing ... I just lost interest ... my life has [fallen from the sky] [changed dramatically] ... I don’t have sex with my husband as I used to do before ... we sleep with each other once a month if any ... I lost my life with diabetes ...’.

Another example where semantic equivalence was chosen over word-for-word translation:

It is also quite common among Jordanian people to say ‘winter has no day hours’. People use [this phrase] to indicate that day hours go fast during winter as the geographical location of Jordan during these days dictates that the day hours are less than night hours and to show that it is very difficult to achieve many tasks during that time of the year. Therefore, when one translates this phrase from Arabic to English using the word meaning it is hard to get a sense of it. Moreover, lack of knowledge about the norm, the culture and the geographical location of Jordan, makes translation cloudy. The exact meaning is ‘winter has no day hours’ although winter has both day and night in Jordan, but Jordanian people use this phrase to say that time flies during winter.
Because especially in winter I did not have enough time ... [the winter has no day hours] [the day goes by so fast] ... kids ... responsibilities ... and by the end of a day you feel exhausted and you need to go to bed badly.

In terms of grammatical issues, the following example demonstrates how the translator chose to use the present perfect tense, as she is well aware that the Arabic language lacks the distinction between actions completed in the past with or without a connection to the present. The exact translation for this phrase is ‘if [I still had sensation]’, and as the translator was acquainted with how Arabic people linked the action to the present without using perfect tense, she decided to use the present perfect tense.

‘I keep touching my limbs ... checking if [I still have sensation] ... I wash them ... I moisturise them with a special therapeutic lotion and I raise them on a pillow when I sit or sleep ... I fear one day to end up with no limbs ... to see things around me but ... not be able to move ...!’

‘Of course ... I do not have the same sexual drive I used to have ... and [I have read many] articles about that ... it affects the relationship between couples.’

The Arabic language does not use the infinitive verb ‘to be’ in the present tense. In contrast to English verb tenses, which use simple and continuous forms, the Arabic language only uses single present tense. This lack of correlatives between the two languages can result in errors. In the example below [it is very hard to
know], the translator made informed choices and was thus able to shift her thinking between the two languages. This is a very important attribute for a translator to demonstrate in order to produce good text (Ringberg, et al., 2010).

‘[It is very hard to know] that I have to carry the insulin with me everywhere.’

4.4 Rigour

4.4.1 Rigour of the instruments’ translation

Because decisions about translation have a direct impact on the trustworthiness of research, a thorough description of the translation process is required, and problems that occur during this stage must be identified (Larkin, et al., 2007; Twinn, 1997). The cross-cultural adaptation of the English scales into Arabic was conducted in accordance with well-recognised recommendations in cross-cultural healthcare research (Råholm, et al., 2010; Sousa, et al., 2009; Sousa & Rojjanasrirat, 2011). However, in conducting the forward and backward translation of the instruments, there were some minor difficulties. For example, Item number 7 in DMSES, ‘Check my feet’, was backward translated as ‘examine my feet’, which was a direct translation of the Arabic expression. Subsequently, the committee agreed to continue using the phrase ‘قدم يفحص’ ('examine my feet'). In addition, there were some difficulties when translating the response format, as the Arabic language reads from right to left, English from left to right. The researcher kept a detailed record of the translation process and the resources used during this process (see Appendix 3).
4.4.2 Rigour of the qualitative data translation

The qualitative phase of the current study aimed to collect the participants’ experiences of self-care activities and to illuminate the meanings they accorded them. Transparency of the translation process was identified as a crucial factor in terms of illustrating the duration of translations, and the reasons behind each and every choice made during translation (Lopez, et al., 2008; Temple & Young, 2004). For the sake of consistency, only one translator was used in the translation phase. The literature indicates the benefits of having only one translator, as it is seen to maximise the reliability of the data (Al-Amer, et al., 2014; Larkin, et al., 2007). Conversely, hiring multiple translators entails compromising the validity of the data and their conceptual equivalence (Squires, 2009). Although the literature recommends the use of a professional translator as a preferable option, this can also jeopardise translation of specialised lexical items such as medical terminology (Squires, 2009). Therefore, the study used a general medical practitioner to avoid the risk of misinterpreting medical terminology (Pitchforth & Van Teijlingen, 2005). Moreover, the selected translators were fluent in both English and Arabic languages, and were also Jordanian in origin. This ensured congruence with the participants’ cultural characteristics and sociolinguistic backgrounds (Pitchforth & Van Teijlingen, 2005).

4.5 Limitations

4.5.1 Limitations of the translation process of the instruments

The guidelines by Sousa and Rojjanasrirat (2011) recommend that the forward translators be bicultural, bilingual and have distinct profiles (Råholm, et al., 2010; Sousa & Rojjanasrirat, 2011). In the first step of the translation process for
the study, the translators did not meet this criterion as both of them had medical backgrounds. They were both general medical practitioners, and as such were familiar with the medical terminology. Due to time and budgetary constraints, however, the study was unable to source a translator for data collection and translation who was familiar with the linguistic nuances of the Arabic language but was not acquainted with the medical terminology. In order to minimise any adverse impact on the validity of the translated instruments, the researcher engaged in frequent communication with the translators. Although the study did not offer the participants and the reviewer an opportunity to rate the translated instrument, they were invited to comment on the instruments. Their feedback was then used in calibrating and refining the instruments. Another limitation was encountered in step three. Only one of the backward translators, who was a general medical practitioner, shared the forward translator’s knowledge about health terminology and the content area of the instrument in the source language. This did not fully comply with the guidelines, which recommend that forward translators share the same characteristics as the backward translators of the instruments (Löfmark, Thorkildsen, Råholm, & Natvig, 2012; Råholm, et al., 2010; Sousa & Rojjanasrirat, 2011). Despite the above mentioned limitations, it is unlikely that the validity of the instruments was jeopardised, since the primary researcher and the translators kept detailed records of the translation process.

4.5.2 Limitations of the translation process of the interview data

The researchers collected the interview data in the Arabic language and translated these into English for the research team. Hence, it could be argued that
the majority of the research team was not exposed to the primary data, but rather to secondary data as produced by the translator. In this sense, the validity of the data was not likely to be threatened, because the main researcher was bilingual and shared the same cultural context as the participants. Moreover, she had access to the raw data set and the translated data set, in addition to being immersed in the interview setting at the time of data collection.

The backward translation could not be employed in this phase due to time and budgetary constraints. However, the above limitation was unlikely to affect the quality of the data given the attention devoted to using semantic equivalence and content equivalence rather than word-for-word translation. Furthermore, debriefing sessions were conducted after each interview, and the translation process was systematically rendered transparent, thus strengthening the integrity of the data.

**Chapter summary**

The chapter outlined steps in cross-cultural validation of the study instruments. In particular; translation process, pilot testing and psychometric testing for the current study tools. Additionally, a rational for the cross cultural adaptation step was discussed. Further, the transcription and the selection of the translators was reported. And the translation of the narrative along with the challenges that were encountered were also presented. Finally, the rigor and the limitation in cross-cultural adaptation of the instruments and the narrative translation were charted as well.
Chapter 5
Cross-cultural validation: Psychometric testing of the survey

5.1 Introduction
The survey data were collected from a total of 220 patients with Type 2 diabetes who participated in the current study. The survey data were also used in statistical analysis of the instruments. Psychometric testing was conducted to determine the reliability and validity of the Arabic version of the study instruments; hence, construct validity and reliability were evaluated. Construct validity was used to ensure that the instrument measured what it was supposed to measure (Kim & Mueller, 1978; Williams, Brown, & Onsman, 2012). Internal consistency was assessed to ensure that all items in a scale measured the same construct. Internal consistency is the most commonly used test to assess psychometric characteristics of a cross-culturally adopted instrument (Uysal-Bozkir, et al., 2013), and Cronbach’s alpha ≥ 0.70 is the most acceptable index to assess the reliability of the study’s instruments (DeVellis, 2011).

5.2 Survey scales
The survey used in the current study contains six standardised instruments: BIPQ, PHQ-9, ESSI, RSC, DMSES and SDSCA (see Table 5.1).
### Table 5.1 Survey instruments used and contextualised in the POISE study

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Original Scale: Patient Health Questionnaire-9 (PHQ-9)</td>
<td>Construct measured: Depression</td>
<td>Used in survey: Arabic Patient Health Questionnaire-9 (APHQ-9)</td>
<td>Construct measured: Depression among patients with T2DM in Jordan</td>
</tr>
<tr>
<td>3</td>
<td>Original Scale: Diabetes Fatalism Scale, Religious &amp; Spiritual Coping (RSC)</td>
<td>Construct measured: Religiosity and spirituality</td>
<td>Used in survey: Arabic Religious and Spiritual Coping (ARSC)</td>
<td>Construct measured: Religiosity and spirituality among patients with T2DM in Jordan</td>
</tr>
</tbody>
</table>
5.3 Statistical analysis

The data were checked for completeness, accuracy and the nature of the distribution before analysis. The study assessed the distribution of the data, and normality testing for each instrument was carried out with One-Sample Kolmogorov-Smirnov test, assuming that the data were normally distributed. A $p$ value <0.05 would reject the hypothesis, and would indicate that the data were not normally distributed. To explore the characteristics of each scale, descriptive statistics were calculated including mean, median, standard deviation and range.

Factor analysis (FA) is a multivariate statistical method applied to allocate the instrument’s items into one or more subset (Tabachnick & Fidell, 2012; Thompson, 2004). Additionally, FA provides fundamental dimensions between examined variables and the underlying construct (Cramer, 2003; Williams, et al., 2012). Factor analysis therefore assists with the formation and modification of the theory or model (Williams, et al., 2012). Factor analysis employs two approaches: Exploratory Factor Analysis (EFA) and Confirmatory Factor Analysis (CFA). The study uses the EFA approach to examine which factors ‘clump together’ in the same component without predefined criteria of the number of the component (Kim & Mueller, 1978; Williams, et al., 2012).

The study used the Five-Step Exploratory Factor Analysis Protocol Williams et al. (2012):

Step 1: The factorability or the suitability of the data for factor analysis of each instrument was examined through inspecting the correlation matrix, where a coefficient of more than 0.30 was acceptable. To ensure that the test was
significant, instruments used concurrently were the Kaiser-Meyer-Olkin (KMO) Measure of Sampling Adequacy, where values of more than 0.60 were acceptable, and Bartlett's Test of Sphericity (BTS), where a $p$ value $\leq 0.5$ was acceptable. The BTS is significant at a value of $p < .05$, and consequently suitable for factor analysis.

Step 2: The components extraction methods of the factors Principal Component Analysis (PCA) was used, as it is the most popular method favoured by researchers (Ferguson & Cox, 1993). This test includes defining the minimum number of factors that can be used to best exemplify the relationship between the items.

Step 3: Determining factor extraction. The purpose of this step was to reduce a large number of items into numbers of factors; that is, to specify the numbers of components that could be extracted. It is recommended that numerous methods be used in factor extraction, including: a) Kaiser’s criterion eigenvalue of one or more than one is retained for further investigation; b) the scree test, which involves plotting each eigenvalue of the components and studying the plot visually to determine at which point the curve changes its trend and becomes horizontal. It was recommended to retain the number of components above the break; and c) Parallel analysis was used to compare the original size of the eigenvalues with those attained from a randomly created data set of the same size. Factors were retained when actual eigenvalues exceeded randomly ordered eigenvalues. Missing values were set to ‘excluded cases list wise’.

Step 4: Factor rotation and interpretation. This step involved selection of the rotation methods. It is worth mentioning that this step yields an array of loading in
a way that is simpler to interpret, rather than altering the primary solution. For single component instruments, therefore, the study calculated an unrotated solution, whereas for the instruments with more than one component, the study used the Direct Oblimin test. Each of the items on the instrument was subsequently loaded on only one component, with each component then presented by a number of strongly loaded variables.

Step 5: This step encompasses the interpretation of the characteristics of the factors. The researcher checked for the variables that loaded strongly on each of them, and for those which did not load strongly, in order to make an informed decision as to whether they fitted any logical factor, or alternatively whether they needed to be deleted from the survey.

Because reliability was another issue of concern, the internal consistency of each scale was assessed. Internal consistency is the extent to which all items that comprise the instrument are evaluated by applying the same underlying concept. Reliability was assessed by Cronbach’s alpha coefficient, and a value of $\geq 0.70$ was accepted as significant. Before checking the internal consistency, the items in the survey that were negatively worded were revised, and a check was conducted for the number of cases in each instrument and the direction of correlation between the items (DeVellis, 2011).

5.3.1 Brief Illness Perception Questionnaire (BIPQ)

5.3.1.1 Overview of the BIPQ

Brief Illness Perception Questionnaire (BIPQ) is a 9-item self-report scale, and is a truncated version of the Illness Perception Questionnaire Revised (IPQ-R).
Assessing the patient’s cognitive and emotional representations of their illness, the BIPQ consists of nine items, five of which assess cognitive illness representation: consequences, timeline, personal control, treatment control, and identity. Of the remaining items, two assess concern and emotions (emotional representation); and one assesses illness coherence (Broadbent, et al., 2006). Causal representation is assessed by open-ended questions that require the respondents to list the most important three underlying causes for their disease. Responses for this construct can be aggregated into categories for example, genetic, susceptibility, stress), depending on the conditions that are being studied. This scale has a Likert response format that ranges from 0 to 10 (Broadbent, et al., 2006). Assessments of the psychometric properties of the BIPQ have been previously tested on centre-based heart disease patients. These tests found that the structural validity, reliability, test-retest reliability, and discriminant validity were all within acceptable limits (Broadbent, et al., 2006). Notably, the current study used the construct as reported by the original scale. The scale is not meant to be measured by Cronbach’s alpha, for it summarises all items in each subscale of IPQ-R (Moss-Morris, et al., 2002) in one question. It is worth mentioning that the truncated version (BIPQ) was used to measure the illness perception constructs. The BIPQ was deemed suitable in this context due to its brevity, which is expected to minimise the likelihood of respondent burden, and to maximise the response rate.

5.3.2 Patient Health Questionnaire-9 (PHQ-9)

5.3.2.1 Overview of the PHQ-9

Patient Health Questionnaire-9 is a depression scale adopted from the full Patient Health Questionnaire (PHQ) (Spitzer, Kroenke, Williams, & Group, 1999),
which was designed to evaluate common mental health problems. It is an incomparable scale given that it is the first scale to utilise the nine criteria cited in the Diagnostic and Statistical Manual of Mental Health Disorder Fourth edition (DMS-IV) for a major depressive episode. This questionnaire addresses the somatic domain of depression, along with the affective cognitive aspect (Kroenke, et al., 2001). Its 9-item self-reported scale is designed to screen, diagnose and assess the severity of depression symptoms during the 14 days prior to the patient completing the questionnaire. For diagnostic purposes, major depression will be diagnosed if five or more of the nine depressive symptoms were reported at least for more than half of the days over the past 14 days, and if one of these symptoms is either anhedonia or a depressed mood (Kroenke, et al., 2001). Item 9 – ‘thought that you would be better off dead or of hurting yourself in some way’ – should indicate major depression if present irrespective of the duration. In relation to the severity of depressive symptoms, the scale ranges from 0 to 27; zero indicates the absence of depressive symptoms, whereas 27 exemplifies the presence of severe depressive symptoms (Kroenke, et al., 2001). Each item in this scale is scored from 0 (not at all); 1 (several days); 2 (more than half the days); to 3 (nearly every day), and totalled to produce the given range. Depressive symptoms are classified into five groups: no depressive symptoms when PHQ-9 score is 0–4, mild depressive symptoms when PHQ-9 score is 5–9, moderate depressive symptoms when PHQ-9 score is 10–14, moderately severe depressive symptoms when PHQ-9 score is 15–19 and severe depressive symptoms when PHQ-9 score is 20–27.
Now available in 27 languages (Acee, 2010), the Patient Health Questionnaire-9 (PHQ-9) is a well-recognised instrument. It is regarded as an indispensable diagnostic measure to assess depression, and this valorisation stems from its validity, reliability, brevity, ease of scoring, and its discriminating ability in primary care settings (Kawada, 2011; Kroenke, Spitzer, Williams, & Löwe, 2010; Walker et al., 2011). The PHQ-9 generates an index of the severity of depressive symptoms and offers the ability to monitor treatment outcomes that might be significant in primary management plans. Psychometric characteristics of the PHQ-9 were further explored in the current study.

5.3.2.2 Internal consistency of the PHQ-9 among the Jordanian population

The reliability of the PHQ-9 was assessed using Cronbach’s alpha. The corrected item-total correlation value of the nine items, ranging from 0.46 to 0.65, was above the 0.3 threshold for item-total correlations. Cronbach’s alpha for nine items was 0.83, and did not increase above 0.83 if any of the nine items in the PHQ-9 were deleted, which indicated that all nine items contributed to the PHQ-9 scale (see Table 5.2).
Table 5.2  Item-total correlation and Cronbach’s alpha of PHQ-9

<table>
<thead>
<tr>
<th>Item number</th>
<th>Item</th>
<th>Corrected Item-total correlation</th>
<th>Cronbach’s alpha if item deleted</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Little interest or pleasure in doing things</td>
<td>0.53</td>
<td>0.82</td>
</tr>
<tr>
<td>2</td>
<td>Feeling down, depressed or hopeless</td>
<td>0.65</td>
<td>0.80</td>
</tr>
<tr>
<td>3</td>
<td>Trouble falling or staying asleep, or sleeping too much</td>
<td>0.59</td>
<td>0.81</td>
</tr>
<tr>
<td>4</td>
<td>Feeling tired or having little energy</td>
<td>0.65</td>
<td>0.80</td>
</tr>
<tr>
<td>5</td>
<td>Poor appetite or overeating</td>
<td>0.46</td>
<td>0.82</td>
</tr>
<tr>
<td>6</td>
<td>Feeling bad about yourself, or that you are a failure, or have let yourself or your family down</td>
<td>0.50</td>
<td>0.82</td>
</tr>
<tr>
<td>7</td>
<td>Trouble concentrating on things, such as reading the newspaper or watching television</td>
<td>0.54</td>
<td>0.82</td>
</tr>
<tr>
<td>8</td>
<td>Moving or speaking so slowly that other people could have noticed</td>
<td>0.50</td>
<td>0.82</td>
</tr>
<tr>
<td>9</td>
<td>Thoughts that you would be better off dead, or of hurting yourself in some way</td>
<td>0.47</td>
<td>0.82</td>
</tr>
</tbody>
</table>

*Cronbach’s alpha of PHQ-9 = 0.83*

PHQ-9: Patient Health Questionnaire-9
5.3.2.3 Factorial validity

The Kaiser-Meyer-Olkin (KMO) test value was 0.88, which is above the cut-off value of 0.6, indicating that the data were suitable for factor analysis (Ferguson & Cox, 1993). This was further supported by Bartlett’s Test of Sphericity (BTS) with a significant finding ($\chi^2 = 499.944, df = 36, p < 0.001$). The initial principal component analysis was conducted to determine the number of components to be extracted. The eigenvalue test showed that there was only one component that exceeded eigenvalue one. As shown in the scree plot in Figure 5.1, there was one dominant component with a sharp drop between the first and the second eigenvalues. Factor loadings for each item of the PHQ-9 are presented in Table 5.3. All nine items highly loaded to one component with a loading value from 0.57 to 0.75, which explained 43.19% of the variance. As all items were highly loaded to one component, the scale was retained, since one component and the pattern between the Jordanian PHQ-9 scale and the original scale were similar (Kroenke, et al., 2001; Kroenke, et al., 2010).

![Scree plot: PHQ-9](image)

**Figure 5.1** Scree plot: PHQ-9
Table 5.3 Component loadings for principal component analysis of the PHQ-9

<table>
<thead>
<tr>
<th>Item Number</th>
<th>Item</th>
<th>Single-component solution</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>Feeling down, depressed or hopeless</td>
<td>0.75</td>
</tr>
<tr>
<td>4</td>
<td>Feeling tired or having little energy</td>
<td>0.75</td>
</tr>
<tr>
<td>3</td>
<td>Trouble falling or staying asleep, or sleeping too much</td>
<td>0.70</td>
</tr>
<tr>
<td>7</td>
<td>Trouble concentrating on things, such as reading the newspaper or watching television</td>
<td>0.66</td>
</tr>
<tr>
<td>1</td>
<td>Little interest or pleasure in doing things</td>
<td>0.64</td>
</tr>
<tr>
<td>6</td>
<td>Feeling bad about yourself, or that you are a failure, or have let yourself or your family down</td>
<td>0.62</td>
</tr>
<tr>
<td>8</td>
<td>Moving or speaking so slowly that other people could have noticed</td>
<td>0.62</td>
</tr>
<tr>
<td>9</td>
<td>Thoughts that you would be better off dead, or of hurting yourself in some way</td>
<td>0.58</td>
</tr>
<tr>
<td>5</td>
<td>Poor appetite or overeating</td>
<td>0.57</td>
</tr>
</tbody>
</table>

PHQ-9; Patient Health Questionnaire-9

5.3.3 Enrich Social Support Instrument (ESSI)

5.3.3.1 Overview of the ESSI

The ESSI is a 7-item self-report instrument and was developed for the *Enhancing Recovery in Coronary Heart Disease* Study a multicentre randomised clinical trial that aimed to investigate the effects of psychosocial interventions that targeted depression and low social support in patients following an acute myocardial infarction (The Enhancing Recovery in Coronary Heart Disease Investigators, 2000). The ESSI assesses four defining characteristics of social support: informational, emotional, appraisal and instrumental social support.
Cronbach’s alpha reported for this scale was 0.86 (The Enhancing Recovery in Coronary Heart Disease Investigators, 2000). The response format of this scale has the following anchor points: 1 (none of the time); 2 (a little of the time); 3 (some of the time); 4 (most of the time); and 5 (all of the time). Item 7 – ‘Are you currently married or living with a partner?’ – scored four for yes and two for no. The seven items are then aggregated for a total score, with lower scores indicating lower levels of social support. This study applied factor analysis and reliability testing to further assess the psychometric characteristics of ESSI.

5.3.3.2 Internal consistency of the ESSI

The reliability of the ESSI was assessed using Cronbach’s alpha. The corrected item-total correlation value of the seven items, ranging from 0.10 to 0.76, all demonstrated correlation above the 0.3 threshold for item-total correlations except Item 7. This item – ‘Are you currently married or living with a partner?’ – showed a low correlation of 0.10 in the correlation matrix, bearing in mind that this item reflects instrumental support attributes. These results draw attention to the nature of social support – the majority of ESSI items reflect general feelings of being praised and valued rather than instrumental types of social support. It has been argued, however, that social support does not merely designate concrete assistance; rather, it also encompasses a patient’s belief that somebody is available to help if needed (Langford, Bowsher, Maloney, & Lillis, 1997). The current analysis is in line with another study reporting that Item 7 had the lowest correlation with the other items in the scale (Vaglio et al., 2004). Despite these findings, it is believed that instrumental support has intrinsic merit when needed. The decision was
therefore made to retain this item in the scale, since the Cronbach’s alpha is 0.82, indicating a high degree of internal consistency (Table 5.4).

Table 5.4 Item-total correlation and Cronbach’s alpha of the ESSI

<table>
<thead>
<tr>
<th>Item number</th>
<th>Item</th>
<th>Corrected Item-total correlation</th>
<th>Cronbach’s alpha if item deleted</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Is there someone available to you whom you can count on to listen to you when you need to talk?</td>
<td>0.67</td>
<td>0.77</td>
</tr>
<tr>
<td>2</td>
<td>Is there someone available to give you good advice about a problem?</td>
<td>0.64</td>
<td>0.78</td>
</tr>
<tr>
<td>3</td>
<td>Is there someone available to you who shows you love and affection?</td>
<td>0.63</td>
<td>0.79</td>
</tr>
<tr>
<td>4</td>
<td>Is there someone available to help you with daily chores?</td>
<td>0.37</td>
<td>0.83</td>
</tr>
<tr>
<td></td>
<td>Can you count on anyone to provide you with emotional support (talking over problems or helping you make a difficult decision)?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Do you have as much contact as you would like with someone you feel close to, someone in whom you can trust and confide?</td>
<td>0.76</td>
<td>0.76</td>
</tr>
<tr>
<td>6</td>
<td>Are you currently married or living with a partner?</td>
<td>0.10</td>
<td>0.85</td>
</tr>
</tbody>
</table>

*Cronbach’s alpha of ESSI = 0.82*

ESSI; ENRICH Social Support Inventory
5.3.3.3 Factorial validity

The Enrich Social Support Instrument was also subjected to EFA as it met the corresponding satisfactory criteria for EFA. This was supported by the Kaiser-Meyer-Olkin (KMO) test value of 0.82, which exceeded the cut-off value of 0.6, and the Bartlett’s Test of Sphericity with a significant finding ($\chi^2 = 597.577$, $df = 15$, $p < 0.001$). Initial principal component analysis was conducted to determine the number of components to be extracted. The eigenvalue test showed that there was only one component that exceeded eigenvalue one. As shown in the scree plot in Figure 5.2, there was a significant drop after one component. Component loadings for each item of the ESSI are presented in Table 5.6. All seven items highly loaded to one component with a loading value from 0.48 to 0.87, which explained 59.25% of the variance. Hence the researcher specified the scale as one component scale in accordance with the original scale criteria (Mitchell, et al., 2003).
Table 5.6  Component loadings for principal component analysis of the ESSI

<table>
<thead>
<tr>
<th>Item Number</th>
<th>Item</th>
<th>Single-component solution</th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td>Do you have as much contact as you would like with someone you feel close to, someone in whom you can trust and confide? Can you count on anyone to provide you with emotional support (talking over problems or helping you make a difficult decision)?</td>
<td>0.87</td>
</tr>
<tr>
<td>5</td>
<td>Is there someone available to give you good advice about a problem?</td>
<td>0.83</td>
</tr>
<tr>
<td>2</td>
<td>Is there someone available to you whom you can count on to listen to you when you need to talk?</td>
<td>0.80</td>
</tr>
<tr>
<td>1</td>
<td>Is there someone available to you who shows you love and affection?</td>
<td>0.78</td>
</tr>
<tr>
<td>3</td>
<td>Is there someone available to help you with daily chores?</td>
<td>0.48</td>
</tr>
</tbody>
</table>

ESSI; ENRICH Social Support Inventory

5.3.4 Religious and Spiritual Coping (RSC)

5.3.4.1: Overview of the RSC

The religiosity construct was assessed using the Religious and Spiritual Coping subscale (RSC), which is a subscale of the Diabetes Fatalism Scale (DFS) (Egede & Ellis, 2010a). The Religious and Spiritual Coping subscale is a Likert subscale anchored with: 1 = strongly disagree; 2 = moderately disagree; 3 = disagree; 4 = agree; 5 = moderately agree; and 6 = strongly agree. It encompasses four items. As recommended by the scale developer, the aforementioned items were reworded before conducting an internal consistency test (Egede & Ellis, 2010a).
5.3.4.2 Internal consistency of the RSC

The reliability of the RSC was assessed using Cronbach's alpha. The corrected item-total correlation value of the four items, ranging from 0.55 to 0.75, was above the 0.3 threshold for item-total correlations. Cronbach’s alpha for the four item subscale was 0.81 and did not increase above 0.81 if any of the four items in the RSC were deleted Table 5.7, which indicated that all four items contributed to the RSC measure.

Table 5.7  Item-total correlation and Cronbach’s alpha of RSC

<table>
<thead>
<tr>
<th>Item number</th>
<th>Item</th>
<th>Corrected Item-total correlation</th>
<th>Cronbach’s alpha if item deleted</th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td>Trusting in God has helped me better deal with my diabetes</td>
<td>0.66</td>
<td>0.74</td>
</tr>
<tr>
<td>7</td>
<td>I believe God does not give me more than I can bear</td>
<td>0.60</td>
<td>0.77</td>
</tr>
<tr>
<td>8</td>
<td>I believe God can completely cure my diabetes</td>
<td>0.75</td>
<td>0.70</td>
</tr>
<tr>
<td>9</td>
<td>I have prayed about my diabetes so I am not going to worry about it anymore</td>
<td>0.50</td>
<td>0.81</td>
</tr>
</tbody>
</table>

Cronbach’s alpha of RSC = 0.81

Table 5.7: Item-total correlation and Cronbach’s alpha of RSC

<table>
<thead>
<tr>
<th>Item number</th>
<th>Item</th>
<th>Corrected Item-total correlation</th>
<th>Cronbach’s alpha if item deleted</th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td>Trusting in God has helped me better deal with my diabetes</td>
<td>0.66</td>
<td>0.74</td>
</tr>
<tr>
<td>7</td>
<td>I believe God does not give me more than I can bear</td>
<td>0.60</td>
<td>0.77</td>
</tr>
<tr>
<td>8</td>
<td>I believe God can completely cure my diabetes</td>
<td>0.75</td>
<td>0.70</td>
</tr>
<tr>
<td>9</td>
<td>I have prayed about my diabetes so I am not going to worry about it anymore</td>
<td>0.50</td>
<td>0.81</td>
</tr>
</tbody>
</table>

RSC; Religious and Spiritual Coping Subscale

5.3.5 Diabetes Management Self-Efficacy Scale (DMSES)

5.3.5.1 Overview of the DMSES

This scale was developed to assess the self-efficacy of patients with T2DM (Bijl, et al., 1999). A robust instrument that can be used in both clinical settings and research practice (Kara, van der Bijl, Shortridge-Baggett, Asti, & Erguney, 2006), this scale consists of a 20-item summated rating scale, with a 5-point Likert-type scale.
response format that ranges from 1 (Yes, definitely) to 5 (No, definitely not), with higher scores indicating lower self-efficacy. The DMSES measures a patient’s self-confidence in executing diabetes self-care activities including physical activity, blood glucose testing and diet plan. Validity and reliability of this scale have been tested among an English and Dutch population (Bijl, et al., 1999), with the results demonstrating that DMSES has good internal consistency with Cronbach’s alpha of 0.81. Test-retest reliability of the DMSES was $r = 0.79; p < 0.001$. A validation testing for this scale identified the DMSES as a multidimensional scale with four components: nutrition specific and weight; nutrition general and weight; nutrition general and medical treatment; physical exercise and blood glucose (Bijl, et al., 1999). All four components of the DMSES are related to self-care activities that patients with diabetes carry out as part of the management of their condition: medication, exercise, diet and disease management. To date, the psychometric properties of this scale have not been reported among Arabic language speakers.

5.3.5.2 Internal consistency of the DMSES

The reliability testing of DMSES in the current study was assessed by calculating the alpha coefficient, item-total correlations, and Cronbach’s alpha if the item was deleted. The internal consistency of the total scale was satisfactory as indicated by Cronbach’s alpha of 0.89. The corrected item-total correlations ranged from 0.19 to 0.72, with Items 18 and 19 yielding values below the 0.3 threshold (Table 5.8).
Table 5.8  Item-total correlation and Cronbach’s alpha of DMSES

<table>
<thead>
<tr>
<th>Item number</th>
<th>Item</th>
<th>Corrected item-total correlation</th>
<th>Cronbach’s alpha if item deleted</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>I think I am able to check my blood sugar if necessary</td>
<td>0.45</td>
<td>0.89</td>
</tr>
<tr>
<td>2</td>
<td>I think I am able to correct my blood sugar when the blood sugar value is too high</td>
<td>0.42</td>
<td>0.89</td>
</tr>
<tr>
<td>3</td>
<td>I think I am able to correct my blood sugar when the blood sugar value is too low</td>
<td>0.28</td>
<td>0.89</td>
</tr>
<tr>
<td>4</td>
<td>I think I am able to select the right foods</td>
<td>0.45</td>
<td>0.89</td>
</tr>
<tr>
<td>5</td>
<td>I think I am able to select different foods but stay within my diabetic diet</td>
<td>0.51</td>
<td>0.89</td>
</tr>
<tr>
<td>6</td>
<td>I think I am able to keep my weight under control</td>
<td>0.42</td>
<td>0.89</td>
</tr>
<tr>
<td>7</td>
<td>I think I am able to examine my feet for skin problems</td>
<td>0.44</td>
<td>0.89</td>
</tr>
<tr>
<td>8</td>
<td>I think I am able to get sufficient physical activities, for example, taking a walk or biking</td>
<td>0.51</td>
<td>0.89</td>
</tr>
<tr>
<td>9</td>
<td>I think I am able to adjust my diet when I am ill</td>
<td>0.57</td>
<td>0.89</td>
</tr>
<tr>
<td>10</td>
<td>I think I am able to follow my diet most of the time</td>
<td>0.69</td>
<td>0.88</td>
</tr>
<tr>
<td>11</td>
<td>I think I am able to take extra physical activities, when the doctor advises me to do so</td>
<td>0.54</td>
<td>0.89</td>
</tr>
<tr>
<td>12</td>
<td>When taking extra physical activities, I think I am able to adjust my diet</td>
<td>0.63</td>
<td>0.89</td>
</tr>
<tr>
<td>13</td>
<td>I think I am able to follow my diet when I am away from home</td>
<td>0.72</td>
<td>0.88</td>
</tr>
<tr>
<td>14</td>
<td>I think I am able to adjust my diet when I am away from home</td>
<td>0.69</td>
<td>0.88</td>
</tr>
<tr>
<td>15</td>
<td>I think I am able to follow my diet when I am on vacation</td>
<td>0.72</td>
<td>0.88</td>
</tr>
<tr>
<td>16</td>
<td>I think I am able to follow my diet when I am at a reception/party</td>
<td>0.69</td>
<td>0.88</td>
</tr>
<tr>
<td>17</td>
<td>I think I am able to adjust my diet when I am under stress or tension</td>
<td>0.62</td>
<td>0.89</td>
</tr>
<tr>
<td>18</td>
<td>I think I am able to visit the doctor once a year to monitor my diabetes</td>
<td>0.19</td>
<td>0.90</td>
</tr>
<tr>
<td>19</td>
<td>I think I am able to take my medicine as prescribed</td>
<td>0.25</td>
<td>0.90</td>
</tr>
<tr>
<td>20</td>
<td>I think I am able to adjust my medication when I am ill</td>
<td>0.35</td>
<td>0.89</td>
</tr>
</tbody>
</table>

DMSES; Diabetes Management Self-Efficacy Scale

---

Chapter 5
5.3.5.3 Further examination of DMSES

The inter-item correlation matrix indicated that Item 18 (‘I think I am able to visit the doctor once a year to monitor my diabetes’) had a low inter-item correlation coefficient of 0.19, with the reliability analysis indicating that alpha would not show considerable improvement if Item 18 was deleted. Similarly, Item 19 (‘I think I am able to take my medicine as prescribed’) and Item 3 (‘I think I am able to correct my blood glucose when the blood glucose value is too low’) had low inter-item correlation of approximately 0.28. A closer examination of the content of Item 18 showed that this item had a ceiling effect as the data collection took place in a hospital-based setting where all participants visited the Endocrinology Clinic every three months, either to check on their diabetes status or to have their prescription filled. An initial decision to keep this item was made, although it might arguably be more pertinent in a community setting rather than a hospital setting. Deletion of this item, however, would significantly affect the internal consistency of this scale. Item 19 concerns adherence to medication regimens, while Item 3 deals with the management of diabetes complications. Patients with such a chronic illness have to perform these behaviours on a daily basis whether they are in the community setting or in the hospital setting. Therefore, to enable comparisons of the DMSES scores of this study with previous studies, all 20 items were retained.
5.3.5.4 Factor analysis

For further analysis, scree plot ‘Elbow creation’ as shown in Figure 5.3 was used as an aid for a more convenient fit. A three-component extraction was chosen, for this structure was parsimonious and provided the most meaningful interpretation of the diabetes self-efficacy in this study (Table 5.9). Factor analysis was carried out with Varimax rotation, with all 20 items fitting into the three-component structure of the scale and explaining 54.223% of the total variance. Items in the first component comprise themes that deal with diet management and weight control; item loading component for these items ranged from 0.41 to 0.89. This component yielded an eigenvalue of 6.931, which explains 34.654% of the total variance. The second component loading was found to aggregate items that deal only with physical activity, in which the item loading component ranged from 0.83 to 0.89; eigenvalue 2.038 explains 10.189% of the total variance. Items that deal with adherence and general adjustment loaded on component three, with item loading component ranged from 0.28 to 0.72 with eigenvalue of 1.876 explaining 9.379% of the total variance.

Cross-loading was detected in Items 5 and 9. The former (‘I think I am able to select different foods but stay within my diabetic diet’) loaded 0.56 on component one and 0.46 on component three. Item 5, was best fitted in component one (‘diet and weight control’ or the ‘diet domain’). Conversely, Item 9 (‘I think I am able to adjust my diet when I am ill’) deals with diet during the illness phase, and thus was best fitted into component three (‘adherence and general adjustment’).
Of note, Item 18 (‘I think I am able to visit the doctor once a year to monitor my diabetes’) was the only item that did not have component loading above 0.3. Upon closer examination of the content of this item, it was determined that its best fit was within component three, which deals with items related to ‘adherence and general adjustment’.

![Scree plot: DMSES](image)

**Figure 5.3** Scree plot: DMSES
Table 5.9  Component loading for principal component analysis of the DMSES

<table>
<thead>
<tr>
<th>Item No.</th>
<th>Item</th>
<th>Component</th>
<th>α</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>1</td>
<td>I think I am able to check my blood sugar if necessary</td>
<td>0.09</td>
<td>0.17</td>
</tr>
<tr>
<td>2</td>
<td>I think I am able to correct my blood sugar when the blood sugar value is too high</td>
<td>0.02</td>
<td>0.18</td>
</tr>
<tr>
<td>3</td>
<td>I think I am able to correct my blood sugar when the blood sugar value is too low</td>
<td>0.11</td>
<td>-0.04</td>
</tr>
<tr>
<td>4</td>
<td>I think I am able to select the right foods</td>
<td>0.44</td>
<td>-0.16</td>
</tr>
<tr>
<td>5</td>
<td>I think I am able to select different foods but stay within my diabetic diet</td>
<td>0.56</td>
<td>-</td>
</tr>
<tr>
<td>6</td>
<td>I think I am able to keep my weight under control</td>
<td>0.41</td>
<td>0.24</td>
</tr>
<tr>
<td>7</td>
<td>I think I am able to examine my feet for skin problems</td>
<td>0.18</td>
<td>0.08</td>
</tr>
<tr>
<td>8</td>
<td>I think I am able to get sufficient physical activities, for example, taking a walk or biking</td>
<td>0.19</td>
<td>0.83</td>
</tr>
<tr>
<td>9</td>
<td>I think I am able to adjust my diet when I am ill</td>
<td>0.15</td>
<td>0.60</td>
</tr>
<tr>
<td>10</td>
<td>I think I am able to take extra physical activities, when the doctor advises me to do so</td>
<td>0.25</td>
<td>0.89</td>
</tr>
<tr>
<td>11</td>
<td>I think I am able to take extra physical activities, when the doctor advises me to do so</td>
<td>0.25</td>
<td>0.89</td>
</tr>
<tr>
<td>12</td>
<td>I think I am able to adjust my diet when I am under stress or tension</td>
<td>0.54</td>
<td>0.25</td>
</tr>
<tr>
<td>13</td>
<td>I think I am able to follow my diet when I am away from home</td>
<td>0.88</td>
<td>0.25</td>
</tr>
<tr>
<td>14</td>
<td>I think I am able to adjust my diet when I am away from home</td>
<td>0.89</td>
<td>0.19</td>
</tr>
<tr>
<td>15</td>
<td>I think I am able to follow my diet when I am on vacation</td>
<td>0.86</td>
<td>0.18</td>
</tr>
<tr>
<td>16</td>
<td>I think I am able to follow my diet when I am at a reception/party</td>
<td>0.85</td>
<td>0.14</td>
</tr>
<tr>
<td>17</td>
<td>I think I am able to follow my diet most of the time</td>
<td>0.67</td>
<td>0.32</td>
</tr>
<tr>
<td>18</td>
<td>I think I am able to visit the doctor once a year to monitor my diabetes</td>
<td>0.09</td>
<td>0.02</td>
</tr>
<tr>
<td>19</td>
<td>I think I am able to adjust my medication when I am ill</td>
<td>0.19</td>
<td>0.13</td>
</tr>
<tr>
<td>20</td>
<td>I think I am able to adjust my medication when I am ill</td>
<td>0.19</td>
<td>0.13</td>
</tr>
</tbody>
</table>

Component 1: Diet and weight control  \textbf{0.90}

Component 2: Physical activity  \textbf{0.90}

Component 3: Adherence and general adjustment  \textbf{0.70}
5.3.6 Summary of Diabetes Self-Care Activities (SDSCA)

5.3.6.1: Overview of the SDSCA

The Summary of Diabetes Self-Care Activities, a tool that assesses self-care activities of people with diabetes, has been reported to be valid, reliable and sensitive to change (Glasgow, et al., 1992; Toobert, et al., 2000). The original scale was developed to assess five constructs of diabetes self-care activities: specific diet, general diet, medication adherence, physical activity, and blood glucose monitoring (Toobert & Glasgow, 1994). Later versions of the scale have also included other items such as smoking and foot care (Toobert, et al., 2000). The scale was revised by Toobert et al. (2000) based on a review of seven studies, and was extensively used as a measure for diabetes self-care activities. A multidimensional scale, it comprises 11 items that assess 6 basic domains: i) general diet; ii) specific type of diet; iii) physical activity; iv) monitoring blood glucose; v) foot care; and vi) smoking habits (Toobert, et al., 2000). In addition, the SDSCA provides an expanded version that contains 14 items that could be used to address a particular self-care question – adherence to medication. The scale assesses how many days over the preceding week the respondents performed different self-care activities. The choices ranged from 0 to 7, with a higher score representing better adherence to self-care activities. For the present study, 14 items related to 7 constructs of diabetes self-care activities: diet including general diet and specific diet, physical activity, blood glucose measurement, foot care, medication adherence and smoking behaviour were used.
The constructs of diabetes self-care activities are interrelated and measure common activities that patients with diabetes have to carry out to self-manage their condition. As recommended by several previous studies, a composite score that evaluates adherence to self-care activities was used in the current study to specifically assess diabetes self-care activities (Ell, et al., 2010; Glasgow, Hampson, Strycker, & Ruggiero, 1997; Wu et al., 2007). To date, no psychometric testing of an Arabic translation of this scale has been reported. Therefore, the study was the first of its kind to test the psychometric properties of the SDSCA among an Arabic community.

5.3.6.2 Internal consistency of SDSCA

To assess the internal consistency of the SDSCA among the Jordanian population, alpha coefficients were obtained for the total scale and the six subscales. Cronbach’s alpha of 0.5 was considered acceptable (Peterson, 1994) and ≥ 0.7 was considered satisfactory (Nunnally, 1978). The analysis showed that the total scale had an acceptable Cronbach’s alpha with a value of 0.68 (Table 5.10). Alpha coefficient was not calculated for the smoking subscale because it only comprises one item and Cronbach’s alpha is influenced by the number of items (Peterson, 1994). The analysis yielded weak internal consistency for the specific diet subscale. Toobert et al. (2000) reported that specific diet subscale was consistently unreliable. This could be related to the difficulties in assessing the amount of specific nutritional elements in a patient’s diet, or it may be due to recall bias.
<table>
<thead>
<tr>
<th>Item no.</th>
<th>Description</th>
<th>α</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>Overall Cronbach’s alpha</strong></td>
<td>0.68</td>
</tr>
<tr>
<td></td>
<td><strong>Subscale: General diet subscale</strong></td>
<td>0.70</td>
</tr>
<tr>
<td>1</td>
<td>How many of the last seven days have you followed a healthful eating plan?</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>On average, over the past month, how many days per week have you followed your eating plan?</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Specific diet subscale</strong></td>
<td>-0.20</td>
</tr>
<tr>
<td>3</td>
<td>On how many of the last seven days did you eat five or more servings of fruits and vegetables?</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>On how many of the last seven days did you eat high fat foods such as red meat or full-fat dairy products?</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Exercise subscale</strong></td>
<td>0.58</td>
</tr>
<tr>
<td>5</td>
<td>On how many of the last seven days did you participate in at least 30 minutes of physical activity? (Total minutes of continuous activity, including walking).</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>On how many of the last seven days did you participate in a specific exercise session (such as swimming, walking, biking) other than what you do around the house or as part of your work?</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Blood sugar subscale</strong></td>
<td>0.81</td>
</tr>
<tr>
<td>7</td>
<td>On how many of the last seven days did you test your blood sugar?</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>On how many of the last seven days did you test your blood sugar the number of times recommended by your healthcare provider?</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Foot care subscale</strong></td>
<td>0.62</td>
</tr>
<tr>
<td>9</td>
<td>On how many of the last seven days did you check your feet?</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>On how many of the last seven days did you inspect the inside of your shoes?</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Medications subscale</strong></td>
<td>0.60</td>
</tr>
<tr>
<td>11</td>
<td>On how many of the last seven days, did you take your recommended diabetes medication?</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>On how many of the last seven days did you take your recommended insulin injections?</td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>On how many of the last seven days did you take your recommended number of diabetes pills?</td>
<td></td>
</tr>
</tbody>
</table>
5.4 Chapter summary

The survey used in the POISE study consisted of six standardised scales: BIPQ, PHQ-9, ESSI, RSC, DMSES and SDSCA. These existing instruments were subjected to rigorous psychometric testing including computing factorial validity and coefficient alpha. This testing indicated that the Arabic version of these instruments has satisfactory reliability and validity, comparable to those of the English version of these scales. To date, these are the first Arabic versions of BIPQ, PHQ-9, ESSI, RSC, DMSES, and SDSCA that have been evaluated in relation to internal consistency and component structure. The PHQ-9 is used widely for clinical purposes and for its utility in research settings. Reliability of PHQ-9 in a Jordanian population is supported by satisfactory internal consistency of the instrument ($\alpha = 0.83$), and using corrected item-total correlation value, it was determined that the Cronbach’s alpha could not be improved by deleting any of the items. Additionally, it is a unidimensional scale. Similarly, reliability testing of ESSI, and RSC yielded satisfactory outcomes ($\alpha = 0.82, 0.81$ respectively), and component loading highlighted the unidimensionality of each of them.

Interestingly, the results of psychometric testing showed that two of the study instruments were multidimensional: DMSES and SDSCA. The overall reliability of DMSES was ($\alpha = 0.89$) and items of this scale loaded on three separate components: diet and weight control, physical activity, and adherence and general adjustments ($\alpha = 0.90, 0.90, \text{ and } 0.70$ respectively). The Summary of Diabetes Self-Care Activities also showed overall acceptable reliability ($\alpha = 0.68$). The six constructs that were part of SDSCA – diet (subdivided into general diet and specific diet), exercise, medication adherence, blood glucose testing and foot care – were all deemed
theoretically sound and interrelated, although they have distinct characteristics. The six subscales had coefficient alpha ranging from 0.58 to 0.81, except for the specific diet subscale, which demonstrated reliability lower than the acceptable threshold. The Arabic version of the aforementioned scales is of great significance as these scales could be used in primary and clinical settings.
Chapter 6
Quantitative Results

6.1 Introduction

The chapter presents the results from the survey, including the testing of hypothesis listed in Chapter 2 Section 2.2.

The quantitative phase of the study addressed the following research questions: i) *What is the prevalence of depression among Jordanian adults with T2DM?*; ii) *What is the magnitude of the relationship between illness perception, depression, social support, religious and spiritual coping, and self-care?*; and iii) *Based on Leventhal’s CSM, what are the clinical and psychosocial factors that are directly or indirectly associated with self-care in patients with T2DM in Jordan?*

6.2 Results

The objective of the quantitative phase was to: 1) assess the prevalence of depression among Jordanian patients; 2) assess the relationships between the study-selected variables and self-care activities; and 3) evaluate the direct and indirect relationships of the study-selected variables and self-care activities. The survey data are organised into seven sections: a) survey response rate; b) demographic and clinical characteristics; c) prevalence of depression; d) characteristics of illness representation; e) group comparison of depressed and non-depressed participants; f) magnitude of associations between the study constructs; and g) results of the SEM analysis of the proposed conceptual self-care model. This chapter concludes with a brief summary.
6.2.1 Survey response rate

Of the 270 patients invited during the study period, a total of 220 participants (81% response rate) completed the survey, which was well above the minimum threshold of 60% response rate (Polit, 2010).

At the outset, it was anticipated that the length of the survey might discourage patients from returning the questionnaire, particularly considering their chronic health condition and the limitations that this may impose. The participants’ information sheet therefore stated that the average time required to complete the survey was between 30 and 40 minutes. Another challenge was that Ramadan occurred during the data collection period. Ramadan is a period during which Muslims fast from dawn to sunset, thus in this context, a long survey may have proven too onerous. Consequently, data collection was extended by a month. Rescheduling the data collection process demonstrated understanding and respect, for it was a response to a key religious event across Muslim communities.

6.2.2 Demographic characteristics of the sample

Out of 220 subjects 52.3% were females, and 85.5% were married. A detailed demographic profile is shown in Table 6.1; Page 144.

Table 6.1  Socio-demographic profile of sample (n=220)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Description</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean (SD) year, [Range: 32–82]</td>
<td>58.2 (10.8)</td>
<td></td>
</tr>
<tr>
<td>Duration of T2DM, mean (SD) year, [Range: 0.6–35]</td>
<td>9.7 (8.0)</td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Male, \( n \) (%) & 105 (47.7) \\
Female, \( n \) (%) & 115 (52.3) \\

**Marital status** \\
Single, \( n \) (%) & 8 (3.5) \\
Married, \( n \) (%) & 188 (85.5) \\
Other, \( n \) (%) & 24 (10.9) \\

**Education level** \\
Did not complete primary school, \( n \) (%) & 17 (7.7) \\
Completed primary school, \( n \) (%) & 45 (20.5) \\
Completed some high school, \( n \) (%) & 33 (15.0) \\
Completed high school, \( n \) (%) & 38 (17.3) \\
Post high school, \( n \) (%) & 87 (39.5) \\

---

6.2.3 Description of clinical characteristics

The clinical characteristics and treatment modalities of the study respondents are summarised in Table 6.2; Page 146. Almost half (45.1%) of the study group had high triglyceride levels, and over three-quarters of the participants were overweight or obese as indicated by a BMI of \( \geq 25 \text{ kg/m}^2 \). Nearly half (47%) of the participants were smokers. More than half of the participants (61.8%) did not achieve an HbA\(_{1c}\) level of the < 7% threshold recommended by ADA guidelines (2014). A high number (83.2%) of participants were on oral hypoglycaemic agents, and 27.7% were on a combination of oral hypoglycaemic medication and insulin. Further details about the sample group’s clinical parameters are provided in Table 6.2; Page 146.

Diabetes-related complications were highly prevalent among the study participants, with the most prevalent being retinopathy (75.9%), followed by peripheral vascular disease (72.3%). Approximately one-third of the participants had at least one diabetes comorbid condition, with four or more diabetes
complications reported by 8.2% of the participants. Only 18.6% of the sample did not report any diabetes long or short-term complications (Figure 6.1; Page 148).

### Table 6.2 Clinical parameters and diabetes complications (n=220)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Clinical and health behavioural characteristics</th>
<th>Treatment modalities (n = 220)</th>
<th>Diabetes complications (n = 220)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Dyslipidaemia, n (%)</td>
<td>Insulin, n (%)</td>
<td>Retinopathy, n (%)</td>
</tr>
<tr>
<td></td>
<td>159 (72.3)</td>
<td>96 (43.6)</td>
<td>167 (75.9)</td>
</tr>
<tr>
<td></td>
<td>Triglyceride (mg/dl), ≥ 150, n (%)</td>
<td>Oral hypoglycaemic agents (OHA), n (%)</td>
<td>183 (83.2)</td>
</tr>
<tr>
<td></td>
<td>96 (45.1)</td>
<td>Yes, n (%)</td>
<td>17 (7.7)</td>
</tr>
<tr>
<td></td>
<td>Cholesterol (mg/dl), ≥ 200, n (%)</td>
<td>Insulin and OHA, n (%)</td>
<td>Peripheral vascular disease, n (%)</td>
</tr>
<tr>
<td></td>
<td>149 (67.7)</td>
<td>Yes, n (%)</td>
<td>Yes, n (%)</td>
</tr>
<tr>
<td></td>
<td>Low-density lipoprotein (mg/dl), ≥ 100, n (%)</td>
<td></td>
<td>Heart disease, n (%)</td>
</tr>
<tr>
<td></td>
<td>100 (45.5)</td>
<td></td>
<td>Yes, n (%)</td>
</tr>
<tr>
<td></td>
<td>High-density lipoprotein (mg/dl), female: &lt; 50</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>75 (65.3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>High-density lipoprotein (mg/dl), male: &lt; 40</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>40 (34.8)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>HbA1C level (most recent) mean (SD), [range:</td>
<td>HbA1C level ≥ 7, n (%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>4.5–15], 8.01 (1.8)</td>
<td>136 (61.8)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Smoking, n (%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>47 (21.4)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Body Mass Index (kg/m²), mean (SD), [range:</td>
<td>Overweight 25–29.9, n (%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>19.7–53.91], 30.44 (5.97)</td>
<td>75 (34.1)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>≥ 30 (Obese), n (%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>105 (47.7)</td>
<td></td>
</tr>
<tr>
<td>Hypertension</td>
<td>Yes, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>--------------</td>
<td>------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>156 (70.9)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

HbA1c; Glycosylated Haemoglobin
As shown in Figure 6.1 on page 148, the incidence of diabetes-related complications including hypertension, diabetic retinopathy, peripheral vascular disease, cardiac disease and cerebrovascular disease among the study participants was high. Disconcertingly, approximately three-quarters of the study sample reported some form of diabetes comorbidity.

![Bar chart showing the percentage of the study participants with comorbidity](https://example.com/chart.png)

**Figure 6.1** Percentage of the study participants with comorbidity

### 6.2.4 Prevalence of depression

The study found that the proportion of participants with a PHQ-9 score > 4 was high. The overall prevalence of depression is shown in Figure 6.2 on page 149. More than 70% of the study sample reported some form of depressive symptoms. Notably, 6% of the study sample reported having severe depressive symptoms (Figure 6.2; Page 149).
6.2.5 Characteristics of illness perception among the study participants

Illness representation is informed by patients’ beliefs about their health conditions. The mean scores of the constructs of the Brief Illness Perception Questionnaire (BIPQ) are shown in Figure 6.3, keeping in mind that all of these domains range from 0 to 10. On average, respondents reported a moderate score of consequences, identity and emotional representations. These results suggest that respondents held reasonable views about the seriousness of diabetes ($M = 4.9$, $SD = 3.2$), symptomatology ($M = 4.8$, $SD = 3.1$), and diabetes-related stress ($M = 4.8$, $SD = 3.2$). The respondents perceived diabetes to be a chronic illness ($M = 8.3$, $SD = 3.0$), albeit one that could be controlled by treatment ($M = 7.4$, $SD = 2.5$). Furthermore, many respondents exhibited a clear understanding of their diabetes ($M = 7.8$, $SD = 2.6$), and reported a good self-control over their condition ($M = 6.4$, $SD = 2.5$).

Causal beliefs were assessed by using an open-ended question as presented in Chapter 3 Section 3.7.2.1. The results of causal beliefs are shown in Figure 6.3 on page 149.
6.2.5.1 The categories of the causal beliefs

Participants’ perceptions about the possible causes of their diabetes were explored using an open-ended question: ‘Please list in rank-order the three most important factors that you believe caused your diabetes’. Throughout the study sample, five categories were identified: psychological, biological, behavioural, social and spiritual factors. Less than half of the participants (45%) cited psychological problems as the primary underlying cause of their diabetes, followed by biological and behavioural factors. Spiritual reasons were by far the least frequent causes reported (Figure 6.4; Page 151).
Figure 6.4 Categories of the causal beliefs

6.2.6 Characteristics of the standardised measures

The central tendency measures – the mean standard deviation (SD) and the range of all of the study scales including PHQ-9, ESSI, RSC, DMSES and SDSCA were obtained. The participants rated highly on their level of depression (M = 9.1, SD = 5.8, Range: 0–27), social support (M = 26.0, SD = 6.4, Range: 9–34), and self-efficacy (M = 69.6, SD = 14.6, Range: 29–99). More detail presented on table 6.3 on page 151.

Table 6.3 Characteristics of the standardised measures (n = 220)

<table>
<thead>
<tr>
<th>Standardised scales, [Range]</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Health Questionnaire-9 (PHQ-9), [Range: 0–27]</td>
<td>9.1 (5.8)</td>
</tr>
<tr>
<td>Enrich Social Support Instrument (ESSI), [Range: 9–34]</td>
<td>26.0 (6.4)</td>
</tr>
<tr>
<td>Religious and Spiritual Coping (RSC), [Range: 4–24]</td>
<td>7.13 (3.90)</td>
</tr>
<tr>
<td>Diabetes Management Self-Efficacy Scale (DMSES), [Range: 29–99]</td>
<td>69.6 (14.6)</td>
</tr>
<tr>
<td>Summary of Diabetes Self-Care Activities (SDSCA), [Range: 7–84]</td>
<td>40.5 (14.5)</td>
</tr>
</tbody>
</table>
6.2.7 Self-care activities

Table 6.4 shows the mean and SD for the subscales of the SDSCA instrument. Medication adherence was the most frequent self-care activity reported (M = 6.5, SD = 1.4), followed by foot care self-management behaviour (M = 2.4, SD = 2.5). The least frequently reported self-care activities were exercise (M = 1.8, SD = 2.0) and blood glucose testing (M = 2.3, SD = 2.4).

<table>
<thead>
<tr>
<th>Subscale, mean*, (SD)</th>
<th>Subscale items</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>General diet 2.3 (2.4)</td>
<td>Follows healthy eating plan</td>
<td>3.1 (2.6)</td>
</tr>
<tr>
<td></td>
<td>Follows unhealthy eating plan over the past month (<em>n</em> = 218)</td>
<td>2.7 (2.6)</td>
</tr>
<tr>
<td>Exercise 1.8 (2.0)</td>
<td>Participates in at least 30 minutes of physical activity per day</td>
<td>2.6 (2.7)</td>
</tr>
<tr>
<td></td>
<td>Participates in specific exercise sessions</td>
<td>1.0 (2.0)</td>
</tr>
<tr>
<td>Blood sugar testing 2.1 (2.3)</td>
<td>Tests for blood sugar</td>
<td>2.6 (2.4)</td>
</tr>
<tr>
<td></td>
<td>Tests for blood sugar as recommended by healthcare provider (<em>n</em> = 217)</td>
<td>1.7 (2.5)</td>
</tr>
<tr>
<td>Foot care 2.4 (2.5)</td>
<td>Checks feet</td>
<td>2.7 (3.0)</td>
</tr>
<tr>
<td></td>
<td>Inspects the inside of shoes</td>
<td>2.0 (2.8)</td>
</tr>
<tr>
<td>Medication 6.5 (1.4)</td>
<td>Takes diabetes medication</td>
<td>6.5 (1.5)</td>
</tr>
<tr>
<td></td>
<td>Takes insulin (<em>n</em> = 93)<em>b</em></td>
<td>6.6 (1.2)</td>
</tr>
<tr>
<td></td>
<td>Takes diabetes pills</td>
<td>6.34 (1.6)</td>
</tr>
<tr>
<td>Smoking 2.4 (0.8)</td>
<td>Smoked in past seven days (<em>n</em> = 47)<em>c</em></td>
<td>2.4 (0.8)</td>
</tr>
</tbody>
</table>

*a* Range: 0–7, *b* Subjects were on insulin; *c* Subjects stated that they were a smoker.
6.2.8 Group comparison by depression levels

As most of the participants in the current study reported some form of depression, grouping the participants by levels of depression was undertaken. A statistical test of significance was performed using Mann-Whitney $U$ test to examine the differences between participants with moderate, moderately severe and severe depressive symptoms as indicated by a PHQ-9 (≥10) scores, and participants with mild or no depressive symptoms as indicated by a PHQ-9 (<10) score. As mentioned in Chapter 3 Section 3.7.2.2, a cut-off point of ≥ 10 is the commonly recommended cut-off point used by researchers (Acee, 2010; Kroenke & Spitzer, 2002), because it yields a sensitivity of 88% and a specificity of 88% (Kroenke, et al., 2001).

There was a significant group difference in self-efficacy scores between participants with high PHQ-9 (≥10) and low PHQ-9 (<10) scores. The patients with PHQ-9 score (≥ 10) had (median of 67.0, $n = 101$) and patients with PHQ-9 (<10) had (median of 73.0, $n = 119$), $U = -2.44^*, p <0.01$. Additionally, self-efficacy, social support, illness perception consequences, identity, personal control and emotional representations all showed differences with a $p$ value of < 0.001. On the other hand, illness perception timeline and treatment control did not show significant differences between the two groups, as illustrated in Table 6.5; Page 154.
Table 6.5  Comparison between two groups by depression levels  
\((n = 220)\)

<table>
<thead>
<tr>
<th>Variables</th>
<th>PHQ-9 &lt;10 Median ((n = 119))</th>
<th>PHQ-9 (\geq 10) Median ((n = 101))</th>
<th>Mann-Whitney U</th>
</tr>
</thead>
<tbody>
<tr>
<td>Triglycerides</td>
<td>131.5</td>
<td>170.2</td>
<td>(-2.45^*)</td>
</tr>
<tr>
<td>Low-density lipoprotein Level</td>
<td>98.1</td>
<td>96.0</td>
<td>(-0.38)</td>
</tr>
<tr>
<td>High-density lipoprotein Level</td>
<td>44.1</td>
<td>40.1</td>
<td>(-2.60^*)</td>
</tr>
<tr>
<td>HbA(_1c) Level</td>
<td>7.3</td>
<td>7.6</td>
<td>(-0.79)</td>
</tr>
<tr>
<td>Summary of diabetes self-care activities</td>
<td>41.0</td>
<td>38.0</td>
<td>(-1.36)</td>
</tr>
<tr>
<td>Diabetes self-efficacy scale</td>
<td>73.0</td>
<td>67.0</td>
<td>(-2.44^*)</td>
</tr>
<tr>
<td>Enrich social support instrument</td>
<td>29.0</td>
<td>26.0</td>
<td>(-3.15^{**})</td>
</tr>
<tr>
<td>Illness perception consequences</td>
<td>4.0</td>
<td>7.0</td>
<td>(-6.69^{**})</td>
</tr>
<tr>
<td>Illness perception timeline</td>
<td>10.0</td>
<td>10.0</td>
<td>(-0.44)</td>
</tr>
<tr>
<td>Illness perception control</td>
<td>7.0</td>
<td>6.0</td>
<td>(-2.90^{**})</td>
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<tr>
<td>Illness perception treatment</td>
<td>8.0</td>
<td>8.0</td>
<td>(-1.47)</td>
</tr>
<tr>
<td>Illness perception identity</td>
<td>4.0</td>
<td>6.0</td>
<td>(-5.01^{**})</td>
</tr>
<tr>
<td>Illness perception coherence</td>
<td>9.0</td>
<td>8.0</td>
<td>(-1.42)</td>
</tr>
<tr>
<td>Illness perception emotion</td>
<td>7.0</td>
<td>14.0</td>
<td>(-7.03^{**})</td>
</tr>
<tr>
<td>Age</td>
<td>60.0</td>
<td>59.0</td>
<td>(-0.05)</td>
</tr>
<tr>
<td>Body Mass Index</td>
<td>28.6</td>
<td>30.5</td>
<td>(-1.68)</td>
</tr>
<tr>
<td>Religious and spiritual coping</td>
<td>6.0</td>
<td>5.0</td>
<td>(-0.62)</td>
</tr>
</tbody>
</table>

\(^*p < 0.01; ^{**}p < 0.001\)
6.2.9 The proposed conceptual model of diabetes self-care activities

This section presents the proposed conceptual model and explicates its importance in predicting self-care activities among patients with T2DM. In particular, it examines the direct and indirect relationship between the selected psychosocial variables: Illness perception, social support, religious and spiritual coping, depression, self-efficacy, Body Mass Index, HbA1c and self-care activities.

As described in Chapter 2 Section 2.2, the proposed conceptual model in the study was developed to examine the direct and indirect relationship between the selected psychosocial variables and self-management behaviours based on the Common Sense Model (Leventhal, et al., 1984). In brief, the CSM provides a framework for understanding the aspects that impact on the ways in which a person perceives a health threat, and the relationship between cognition and emotion. Interpretation of a health threat influences the way a person reports the symptoms of an illness, and this in turn influences their health-related behaviours (Leventhal, et al., 1980). Specifically, the study explored illness perception – that is, the cognitive and the emotional factors – that underpin an individual’s motivation to adhere to a healthcare plan that may improve their health (Cameron & Leventhal, 2003).

6.2.9.1 Fit indices reporting of SEM

The study used the goodness-of-fit indices that were highlighted in Chapter 3 Section 3.9.1.2. These include the Chi-square ($\chi^2$), degrees of freedom ($df$), and the Root of Mean Square Error of Approximation (RMSEA). In addition to the goodness-
of-fit, the study applied the Normed Fit Index (NFI), Comparative Fit Index (CFI) and Tucker-Lewis Index (TLI).

6.2.9.2 Correlation Coefficient (Bivariate Analysis)

The Pearson correlation coefficient was used to investigate the intensity and the direction of the relationship between self-care activities and the selected psychosocial constructs, as described in Chapter 3 Section 3.9.1.

The correlation matrix in Table 6.6 on page 157, shows the strengths of the relationship between the study variables. It shows that depression was negatively correlated with self-efficacy ($r = 0.242; p < 0.001$), whereas self-efficacy positively correlated with self-care activities ($r = 0.405; p < 0.001$). Additionally, social support was negatively correlated with depression levels ($r = -0.248; p < 0.001$).
<table>
<thead>
<tr>
<th>No</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
<th>12</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>PHQ-9</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>DMSES</td>
<td>-0.242**</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>SDSCA</td>
<td>-0.071</td>
<td>0.405**</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>ESSI</td>
<td>-0.248**</td>
<td>0.084</td>
<td>0.021</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>RSC</td>
<td>-0.011</td>
<td>0.014</td>
<td>-0.084</td>
<td>-0.225**</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>BIPQ – Consequences</td>
<td>0.544**</td>
<td>-0.180**</td>
<td>0.086</td>
<td>-0.065</td>
<td>-0.011</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>BIPQ – Timeline</td>
<td>0.056</td>
<td>0.015</td>
<td>0.156*</td>
<td>-0.046</td>
<td>-0.013</td>
<td>0.094</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>BIPQ – Control</td>
<td>-0.227**</td>
<td>0.284**</td>
<td>0.209**</td>
<td>0.056</td>
<td>-0.013</td>
<td>-0.265**</td>
<td>-0.034</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>BIPQ – Treatment</td>
<td>-0.115</td>
<td>0.111</td>
<td>0.098</td>
<td>0.018</td>
<td>0.025</td>
<td>-0.136*</td>
<td>-0.004</td>
<td>0.495**</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>BIPQ – Identity</td>
<td>0.428**</td>
<td>-0.243**</td>
<td>0.073</td>
<td>-0.087</td>
<td>0.012</td>
<td>0.643**</td>
<td>0.174*</td>
<td>-0.257**</td>
<td>-0.146*</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>BIPQ – Coherence</td>
<td>-0.114</td>
<td>0.317**</td>
<td>0.202**</td>
<td>0.095</td>
<td>-0.179**</td>
<td>-0.163*</td>
<td>0.127</td>
<td>0.221**</td>
<td>0.165*</td>
<td>-0.171*</td>
<td>1.000</td>
</tr>
<tr>
<td>12</td>
<td>BIPQ – Emotion</td>
<td>0.558**</td>
<td>-0.083</td>
<td>0.002</td>
<td>-0.121</td>
<td>0.060</td>
<td>0.597**</td>
<td>0.154*</td>
<td>-0.107</td>
<td>0.058</td>
<td>0.497**</td>
<td>-0.101</td>
</tr>
</tbody>
</table>

** p <0.001 level; * p <0.05 level

PHQ-9, Patient Health Questionnaire-9; DMSES, Diabetes Management Self-Efficacy Scale; SDSCA, Summary of Diabetes Self-Care Activities; ESSI, Enrich Social Support Instrument; RSC, Religious and Spiritual Coping; BIPQ, Brief Illness Perception Questionnaire

Table 6.6  Spearman rho correlation coefficient between measure of self-care activities and psychosocial constructs
6.2.9.3 Hypothesis testing

The following section of the chapter addresses the relationships within the proposed conceptual model, including the direct and indirect relationships between the various selected psychosocial constructs on the engagement of self-care among patients with T2DM. The proposed conceptual model testing was undertaken in the current study to assess the magnitude of the relationship between the study constructs: illness perception, anthropometric factors, psychological status, social and religious resources, and self-efficacy. The direct and indirect relationship of these constructs was measured in relation to self-care activities. As mentioned in Chapter 3 Section 2.2, the outcome variable in this step of the analysis is self-care activities and was operationalised as adherence to: healthy eating, exercise, medication adherence, blood glucose testing, foot care, and smoking cessation.

As a preliminary step of working a full model with SEM, the psychometric properties of all standardised instruments need to be examined (Bruton, Conway, & Holgate, 2000; Kline, 2011). These data were presented in Chapter 3. The following section presents the results of testing of the proposed conceptual model using SEM.
6.2.9.4 Testing the proposed conceptual model

The study tested the hypothesis that *illness perception, Body Mass Index and glycosylated haemoglobin* influence self-care activities, *directly and indirectly*, *through their association with depression, social support, religious and spiritual coping and self-efficacy*.

The standard path coefficients and squared multiple correlations of the proposed conceptual self-care model are shown in Figure 6.5. Of the 17 path coefficients hypothesised in the proposed conceptual self-care model, only seven were statistically significant. Three constructs of illness perception, including illness perception consequences, treatment control, emotional illness representation and social support, together explained approximately 28% of the variance ($R^2 = 0.276$) of depression. Depression was associated with self-efficacy; however, this accounted for only a small percentage of variance ($R^2 = 0.061$) in self-efficacy. In combination with HbA1c and BMI, self-efficacy explained over 21% of variance ($R^2 = 0.214$) in self-care activities (Figure 6.5; Page 160).
Figure 6.5  Hypothesised measurement model: Interrelationships among study-selected psychosocial variables and self-care activities
6.2.9.5 Model fit

Following the analysis, a review of the proposed conceptual model fit indices showed evidence of poor fit in the study model. The poor fit was indicated by the modification indices (MIs) including chi-square, which was significant at the 0.05 level ($p < 0.001$). Other indices including TLI, RMSEA, CFI and NFI were < 0.90. These findings did not show satisfactory support of the proposed conceptual model (Table 6.7).

### Table 6.7 Goodness-of-fit: Chi-square index and other fit indices of the integrated self-care activities model

<table>
<thead>
<tr>
<th>Model</th>
<th>Normed $\chi^2$ df ($p$ value)</th>
<th>NFI</th>
<th>RMSEA (CF)</th>
<th>TLI</th>
<th>CFI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hypothesised full model</td>
<td>499.453 71 (&lt;0.001)</td>
<td>0.28</td>
<td>0.17 (0.152–0.186)</td>
<td>0.08</td>
<td>0.29</td>
</tr>
</tbody>
</table>

An attempt was made to produce a more parsimonious model by adjusting indices as well as theoretical assumption (Blunch, 2013; Kline, 2011). The non-significant data paths were removed: paths from illness perception timeline, illness perception control, illness perception identity, illness perception coherence, glucose control, BMI and religious and spiritual coping to depression were deleted.
Figure 6.6  Revised measurement model: Interrelationships among study-selected psychosocial variables and self-care activities
The revised model is shown in Figure 6.6 on page 162. Perceived consequences, treatment control, emotional control and social support all had a direct and significant relationship with depression. Additionally, the impact of depression on self-efficacy and BMI were both retained in the revised model. A test was conducted to assess the direct influence of illness consequences representation, treatment control representation, emotional representation and social support on depression. In addition to that the direct effect of self-efficacy and BMI on diabetes self-care activities, and the direct effect of depression on self-efficacy were assessed (Figure 6.6; Page 162).

In the revised model shown in Figure 6.6; Page 162, the path from illness perception timeline, perceived personal control, illness perception identity, illness perception coherence, HbA1c, and religious and spiritual coping were deleted.

The analysis showed that illness perception consequences, illness perception treatment, illness perception emotion and social support accounted for nearly 40% of variance ($R^2 = 0.398$) in depression levels. There was a significant inverse relationship between depression and self-efficacy; however, depression accounted for only a small percentage of variance ($R^2 = 0.038$) in self-efficacy. In the revised model, self-efficacy together with the BMI accounted for 18% of variance ($R^2 = 0.180$) in levels of self-care activities.
Finally, the model fit indices supported fit of the model to the data, as indicated by the fit statistics (Table 6.8; Page 164) resulted in excellent fit statistics ($\chi^2 = 27.46 \ P > .05$, TLI = 0.095, CFI = 0.97, NFI = 0.92, RMSEA = 0.049).

Table 6.8 Goodness-of-fit: Chi-square index and other fit indices of the trimmed self-care activities model

<table>
<thead>
<tr>
<th>Model</th>
<th>Normed $\chi^2$ $df$ ($p$ value)</th>
<th>NFI</th>
<th>RMSEA (CF)</th>
<th>TLI</th>
<th>CFI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hypothesised full model</td>
<td>27.458 18 (0.071)</td>
<td>0.92</td>
<td>0.05 (0.000–0.084)</td>
<td>0.95</td>
<td>0.97</td>
</tr>
</tbody>
</table>

### 6.3 Chapter summary

The results of the quantitative phase were presented. In summary, both illness perception and social support were found to be related indirectly to self-care activities through depression and self-efficacy. Depression had an indirect relationship with self-efficacy levels. Self-efficacy, on the other hand, had a direct relationship with self-care activities.

The quantitative results provided a comprehensive assessment of the role of the psychosocial determinants of self-care activities using the domains of Leventhal’s CSM. By incorporating illness representation, the study contributed knowledge to self-care activities among Jordanians. Arguably, a robust model predicating self-care activities among other chronic illnesses could stem from the interplay between illness perception constructs and psychosocial variables that could directly or indirectly predict it.
Chapter 7
Qualitative Findings

7.1 Introduction

The chapter presents the qualitative findings of the mixed methods study. As described in Chapter 3 Section 3.3, the dominant study design was quantitative (Phase 1), and the purpose of the qualitative phase (Phase 2) was to enhance and clarify the quantitative findings.

The aim of the qualitative phase of the study was to explore depression and diabetes self-care activities in more depth following the data collection and analysis of the first phase of the study. The reasons for further exploration included: 1) the quantitative phase revealed that depression was highly prevalent among patients with T2DM in Jordan; and 2) depression has an indirect relationship with self-care activities through its association with self-efficacy levels. Therefore, Phase 2 aimed to explore the impact of depression on diabetes self-care activities among T2DM patients, and to obtain an insider’s view of patients’ experiences. The qualitative sample consisted of 15 participants, with a 1:2 male-to-female ratio. In terms of the severity of depression, one-third of the sample (five participants) were classed as having mild depression, one-third moderate depression, and one-third moderately severe depression.

An analysis of the qualitative interview data revealed that there were various inherent challenges in managing concomitant T2DM and depression, and that the experience for many of these participants entailed a ‘rollercoaster of emotions’ and
various transformations of their perception of ‘self’. In particular, there were feelings of loss and grieving for the past ‘self’ – a former self that was perceived as healthy. There were also descriptions of personal identity being destabilised and subverted as a result of the diagnosis of diabetes. The ‘new self’ needed to learn how to adjust to different circumstances, and to acquire skills to incorporate lifestyle modifications necessary to manage a chronic illness. While most participants reported struggling with adherence to self-care activities, their capacity to effectively manage their diabetes was primarily complicated by the severity of their depression.

Through the stories of these 15 participants, it became apparent that having a concomitant diagnosis of diabetes and depression meant that life would never be the same for these individuals. The four major themes that emerged as part of the analysis were identified as: 1) Initial reactions to the diagnosis; 2) Education empowers but cultural pressures weigh in; 3) Social pressures: The good and the bad; and 4) Understanding the consequences but struggling to adjust. In this chapter, each theme is described and supported with verbatim quotes drawn from participants’ interviews. To maintain confidentiality and anonymity, participants were assigned a pseudonym and a code to identify the level of depression experienced. The participants’ codes were their PHQ-9 score. Mild depression was classed as a PHQ-9 score of 5–9, moderate depression was classed as a PHQ-9 score of 10–14, and moderately severe depression was classed as a PHQ-9 score of 15–19. Participant profiles are shown in Table 7.1 on page 167.
<table>
<thead>
<tr>
<th>Patients</th>
<th>Gender</th>
<th>PHQ-9 score</th>
<th>Duration of diabetes</th>
<th>HbA1c</th>
<th>Diabetes complication</th>
<th>Type of treatment</th>
<th>Education level</th>
<th>Age (yrs)</th>
<th>Smoking (cigarettes/day)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Khalid</td>
<td>Male</td>
<td>14</td>
<td>6</td>
<td>6.9</td>
<td>Yes</td>
<td>OHA</td>
<td>Master</td>
<td>52</td>
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<td>Marwan</td>
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<td>1</td>
<td>6.3</td>
<td>Yes</td>
<td>Diet and exercise</td>
<td>Diploma</td>
<td>54</td>
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<td>Kareem</td>
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<td>29</td>
<td>7.5</td>
<td>Yes</td>
<td>Insulin</td>
<td>Post high school</td>
<td>69</td>
<td>No</td>
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<tr>
<td>Sama</td>
<td>Female</td>
<td>16</td>
<td>20</td>
<td>11.3</td>
<td>Yes</td>
<td>OHA+ insulin</td>
<td>Post high school</td>
<td>56</td>
<td>No</td>
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<tr>
<td>Zuhra</td>
<td>Female</td>
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<td>12</td>
<td>12</td>
<td>Yes</td>
<td>Insulin</td>
<td>High school</td>
<td>48</td>
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<tr>
<td>Feryal</td>
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<td>12</td>
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<td>Sameera</td>
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<td>9</td>
<td>2</td>
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<td>Myasar</td>
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<td>13</td>
<td>6.7</td>
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<td>Shisha*</td>
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<td>Sabah</td>
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<td>High school</td>
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<tr>
<td>Naheel</td>
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<td>8</td>
<td>5.4</td>
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<td>Female</td>
<td>5</td>
<td>18</td>
<td>9.3</td>
<td>Yes</td>
<td>OHA+ insulin</td>
<td>High school</td>
<td>48</td>
<td>No</td>
</tr>
<tr>
<td>Anood</td>
<td>Female</td>
<td>10</td>
<td>5</td>
<td>7</td>
<td>Yes</td>
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<td>Bachelor</td>
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<td>Female</td>
<td>10</td>
<td>15</td>
<td>7.9</td>
<td>Yes</td>
<td>OHA</td>
<td>Primary school</td>
<td>67</td>
<td>No</td>
</tr>
<tr>
<td>Saied</td>
<td>Male</td>
<td>15</td>
<td>2.5</td>
<td>10.1</td>
<td>Yes</td>
<td>OHA+ insulin</td>
<td>High school</td>
<td>64</td>
<td>20</td>
</tr>
</tbody>
</table>

OHA; Oral Hypoglycaemic Agent

*Shisha (or Hookah) is a flexible rubber pipe for the tobacco that attaches to a bottle filled with water in which the smoke is cooled down before it is drawn (Kandela, 2000)
7.2: Diabetes and Depression: Life will never be the same

7.2.1 Initial reactions to the diagnosis

All of the participants referred back to and reflected on where they were at the time at which they received their diagnosis, how they felt and how this turning point affected their lives. Many expressed feelings of profound sorrow, seeing their diagnosis of diabetes as a ‘death sentence’. Following their diagnoses, the participants experienced a myriad of emotional reactions, including devastation, denial and acceptance. Some participants reported experiencing two or three emotional states simultaneously.

During the interviews, participants revealed the intense feelings of suffering, sorrow, anguish and emotional pain that consumed them. Moreover, some expressed feelings of reaching the point of no return, describing a fear that pain and sorrow would overtake their lives. The diagnosis was unexpected and felt overwhelming. The first major theme – ‘Initial reactions to the diagnosis’ – is divided into four subthemes to illustrate the breadth of emotional reactions experienced upon diagnosis. The subthemes are: Devastation – ‘I felt that this is the end for me’; Mixed emotions – ‘Why me? Why this disease?’ Denial – ‘I start telling myself that I don’t have diabetes’; and Acceptance – ‘My faith helps me in accepting my disease’.

7.2.1.1 Devastation – ‘I felt that this is the end for me’

For many participants, the initial experience of being diagnosed with diabetes was very stressful; it triggered intense feelings of devastation, emotional pain and grief for a loss of past identity. At the same time, it gave rise to a sense of futility
and despondency for the future. Many felt that their diagnosis was a potential ‘death sentence’, one that signified the end of their life. Interestingly, all participants who reported the subtheme ‘devastation’ as a reaction to their diagnosis experienced moderate to moderately severe depressive symptoms.

Feryal recalled the profound effect of her diagnosis, and how she felt that there was no future for her anymore. Extreme sorrow and grief surfaced whenever Feryal spoke of her diabetes. Although she received psychological support from her doctor, her sense of devastation and despair was intense when she recounted her experiences. Much of this devastation seemingly stemmed from unresolved grief, and she was unable to discuss her diabetes without becoming emotional and teary.

[With her eyes full of tears] I was devastated...overwhelmed with emotional pain...the doctor gave me plenty of time and tried so hard to ease my pain...I was really devastated...I felt that this is the end for me...I am used to tearing up when I talk about my diabetes...I started using insulin because oral hypoglycaemic agents could not control my blood sugar levels...I started giving my insulin injections on time...alone...without even showing anyone...the injections...I got used to having diabetes...but I had bitterness in my life [She tears] ...you know...I started being over-sensitive...I felt that this is the end for me ... (Feryal, PHQ-9: 15).

Two female participants disclosed that diabetes had changed their lives dramatically, affecting them physically and psychologically. For both, there was a loss of interest in physical intimacy with their partners. Furthermore, a negative body image and a sense of lost femininity emerged, and these complications compounded their misery and devastation. It seemed that a dramatic change in their concept of self had taken place. Consequently, they lost interest in life altogether and were unable to move forward.
...mmm…you have no idea how it can devastate one’s life…I think having diabetes at first...caused me to neglect myself…I just lost interest...my life has changed dramatically…I don’t have sex with my husband as I used to do before...we sleep with each other once a month if any...I lost my life with diabetes...I mean I am only 36...but I look as if I am in my late 40s...I just stopped caring... (Naheel, PHQ-9: 15).

...I stopped feeling like a woman...I stopped having sexual desire or arousal...my psychological status is not helping as well...it is all related...I am sure that diabetes caused me this loss of desire...it devastated my life...and I don’t even feel the desire to live...I lost interest in life... (Feryal, PHQ-9: 15).

For the majority of participants, feelings of devastation were intensified by a sense of sadness and the onset of depression. Notably, with time and the help of their faith and commitment to religious beliefs, all participants were able to eventually acknowledge their health status, and to arrive at a sense of acceptance regarding their diabetes. Many subsequently accepted the need to implement lifestyle adjustments in order to adapt to this ‘threat’. These adjustments seemed to be a pragmatic response, and was thus contingent on an acceptance of the reality of their situation, and an acknowledgement that there were no other options.

Well...at the time of diagnosis...it devastated me...I felt down...sad...and literally devastated...but as time passed by...I adjusted...I had to...I accepted God’s will... (Khalid, PHQ-9: 14).

This disease is from God...and I have no reason to be mad at God...I have to adjust to this disease... (Naheel, PHQ-9: 15).

7.2.1.2 Mixed emotions – ‘Why me? Why this disease?’

Mixed emotions including feelings of ‘Why me?’ and a sense of frustration, shock, surprise, and feeling down are a common response to the experience of receiving a diagnosis of a chronic disease. In an apparent attempt to make sense of their new reality, and to absorb the ramifications, patients reported asking
themselves rhetorical questions such as – ‘Why have I been chosen to live with this challenge?’ Common emotions and themes that were articulated included:

Frustration – ‘yeah… I get frustrated… yah… I was frustrated’; Shock and surprise – ‘Mm… I was surprised… shocked’; and Feeling down – ‘I felt down… got really upset’.

Significantly, these types of reaction were evident across all participants, irrespective of the level of depression.

Participants framed diabetes as a challenge that disrupted their way of living. Many asked the question ‘Why me?’, and most were unable to find the answer to this question. This disruption to their lives made no sense to them. This mindset consolidated their belief that diabetes was a burden.

In fact sometimes I feel sad… so sad… I keep wondering: ‘Why me?… Why this disease?’ (Saied, PHQ-9: 15).

The identification, timing and diagnosis of T2DM were overwhelming for participants like Sameera who, upon receiving her diagnosis, questioned God’s will. At times, she still continues to wonder why.

To be honest at first I was mad… I was wondering ‘why me?’… ‘why now?’… I hope God forgives me over that… but I did… Sometimes I do wonder… (Sameera, PHQ-9: 9).

Naheel also expressed frustration because she felt that she had already had her fair share of challenges in life. She disclosed in her interview that she had experienced problems with infertility. The management of diabetes and its complications required a lot of effort, adding yet another burden to her life.

Yeah… I get frustrated… yah… I was frustrated… I start cursing and saying ‘why me?’… don’t I have enough already! (Naheel, PHQ-9: 15).
Saied expressed mixed feelings of frustration, shock and surprise, and was not prepared for this unforeseen medical problem that now required daily management.

*I got frustrated...I was shocked and surprised...did not see it coming...* (Saied, PHQ-9: 15).

Shock and surprise were mixed emotions that commonly emerged, particularly among those with moderate to moderately severe depression who were seeking treatment for other health conditions when they were unexpectedly diagnosed with a ‘new’ problem. In these cases, their diagnoses were totally unexpected. These feelings were best summarised by Khalid and Myasar:

...*At first I was shocked...because I was in the emergency department due to some infection or fever...and there the doctors treated my infection and informed me that my blood sugar test showed that I have diabetes...Ooh...I had a fasting blood sugar level of 134mg/dl...* (Khalid, PHQ-9: 14).

Myasar’s account reinforced this view:

*Mm...I was surprised...shocked...my blood sugar was really high! ...* (Myasar, PHQ-9: 10).

Feeling down and depressed was often manifested in a grieving for a ‘past’ self; one that was mentally and physically healthier and more robust. Many subsequently engaged in maladaptive coping strategies, experiencing ongoing difficulty in finding positive ways to move forward.

*I felt down...got really upset...I got frustrated...went to the doctor and found out that I have diabetes...felt down...I even started a food strike...* (Sabah, PHQ-9: 15).

Before diabetes my life was much better, I was healthier, more energetic...more enthusiastic...even my skin was glowing...I was much better before...even my psychological status was better...once I got the diagnosis I
felt down…I felt bad…I stopped paying attention to my looks…my outfits… (Naheel, PHQ-9: 15).

7.2.1.3 Denial – ‘I start telling myself that I don’t have diabetes’

Denial was a very common emotion, and was reported by participants with mild, moderate and moderately severe depression. Some participants convinced themselves that their symptoms were a result of other causes rather than a manifestation of diabetes. They seemingly wished to avoid the inevitable, instead choosing to believe that there were other factors affecting their health. Ruba gave the best example of how she believed tiredness and fatigue caused the diabetes. This conviction allowed her to conceptualise her diabetes as a temporary affliction.

Honestly…I swear to God…I never expected it would be diabetes…I convinced myself that these things are transient, as a result of being tired (Rub, PHQ-9: 5).

Naheel was in a similar state of denial, confessing that she occasionally skipped doses of her oral hypoglycaemic agents due to their side effects. Convincing herself that she did not have diabetes allowed her to ‘downplay’ the effects and therefore to discount the long-term implications of the illness. This tendency of Naheel’s was particularly pronounced during Ramadan (a religious period in which Muslims observe a month of fasting).

I tend to skip many of my doses…I usually do so because I hate the side effects of my diabetes medications…I can’t tolerate diarrhoea…during Ramadan, so I did not take any medication…it is very frustrating to have diarrhoea while fasting…sometimes I go into a denial phase where I start telling myself that I don’t have diabetes and no need for the medications (Naheel, PHQ-9: 15).

One participant, Marwan, described not his, but rather his family’s denial. They were convinced that he had been misdiagnosed. Marwan, however, did not
subscribe to his family’s view. Rather, he understood diabetes. Marwan’s knowledge came from reading about the condition, and he readily acknowledged that he had the condition.

They [my family] were in denial...they bought me a home-measuring kit and when my fasting blood sugar was in the normal range they argued that maybe the hospital lab was wrong...but I insisted I had diabetes...because I read that at the beginning of the disease the blood sugar level goes up and down...so I did not care what they thought (Marwan, PHQ-9: 10).

7.2.1.4 Acceptance – ‘My faith helps me in accepting my disease’

There was consensus among all the participants that their faith had assisted them to dealing with their initial reactions to the diagnosis, and the strong emotions that arose. The fact that faith played such a central role could be attributable to the emphasis that Arabic people tend to place on God and His omnipotence. In spite of the fact that they had many negative reactions to the initial diagnosis of diabetes, all participants (14 Muslims and 1 Christian) believed that their disease was ‘God’s will’. Such strong religious conviction and spiritual belief also underpinned an eventual acceptance of their disease. To some extent, their faith even helped them to thank God for the experience.

Faith was a healthy coping mechanism. The participants’ connection to and intimacy with God allowed them to manage the stress and emotional strains accompanying diabetes. Participants were able to understand and accept their situation as being ‘God’s will’, a challenge sent from God as part of their destiny. Spirituality arising from the participants’ religiosity was a significant factor that impacted their health belief systems. All participants had ultimately arrived at an
acceptance of their diabetes, and this was in part due to the strength of their faith and belief in God, and their sense of a personal relationship with Him.

...mm...In fact, when the doctor informed me that I have diabetes, I thanked God, as I have no reason to be mad at God, I said no one dies twice. He told me that I should not be pessimistic. But I replied I am not being pessimistic, on the contrary, as I said its God’s decision, and I have no reason to be mad at God... (Zuhra, PHQ-9: 8).

Some of the participants viewed diabetes as a test of their patience; a personal challenge issued by God. As such, they were willing to accept their disease. Their spiritual beliefs helped them to see the experience of being diagnosed with diabetes as a way to achieve a closer relationship with God as the Healer. Although they acknowledged that they would not recover from their diabetes, they believed that faith was a key element in fostering hope and lifting their spirits.

...Of course, my faith helps me in accepting my disease...it is a challenge from God and I have no objections to God’s decision...Thank God for everything...the good and the bad...It is important to give thanks when we go through hard times as well as blessings.....my religious rituals – reading holy Quran and praying – help me feel better...lifts my spirit (Sabah, PHQ-9: 15).

...I am Christian and I know God wants me to live healthy and eat in moderation...I think if I am religious I should be stricter in my diet...Muslims as well have ‘ablution’...this should encourage self-discipline...On the other hand religion helps in accepting the disease...I mean I keep telling myself that God would not give me something I can’t handle...so I have no reason to be mad at God...maybe He is testing my patience... (Saied, PHQ-9: 15).

7.2.2 Education empowers but cultural pressures weigh in

All participants constructed unique associations between diabetes self-care activities and their personal characteristics. Their comments illustrated that their specific demographic attribute, such as education level, age and gender, influenced their knowledge of and adherence to healthcare behaviours. For example, most participants reported that their previous formal education equipped them with the
skills and expertise to be able to access and interpret reliable information about diabetes. As such, having had an education was described as an empowering and important factor in their capacity to deal with their diabetes. From a cultural perspective, older participants expressed having completed their role in this life, so for them adherence to self-care activities was not as important. Some of the participants believed that women were more committed to their self-care activities than men because of their social role in Arabic society, where cultural expectations charged women with the preparation of food for the whole family. Although some participants believed women to be more committed, there was also a common belief among both male and female participants that men were more committed to their self-care activities because in Arabic society the family depends on the man as the head of the household. The second major theme – ‘Education empowers but cultural pressures weigh in’ – is divided into three subthemes. The subthemes are as follows: Knowledge acquisition – ‘...I always seek any written medical information...’ Cultural beliefs – ‘...Old people expect the diagnosis of chronic diseases...but young people having diabetes!' and Sociocultural roles - ‘...I am serving my family...’

7.2.2.1 Knowledge acquisition – ‘...I always seek any written medical information...’

Acquisition of knowledge through education was a key influencing factor in the participants’ self-care activities required to manage their diabetes. Many participants explained that having had an education assisted them in carrying out a range of complex activities, from adherence to medical advice, lifestyle adjustment and diet control. Considering the complex nature of diabetes self-care activities, these participants suggested that education and the ability to interpret and execute
complex care activities was imperative to implementing health-promoting behaviours. Participants with mild depression believed that education assisted them to safely modify their insulin doses, check or count calories, comply with medical advice, and more generally to adjust their lifestyle to accommodate the management of the disease. These participants seemed confident and empowered, and reported high levels of self-efficacy in handling difficult tasks. Furthermore, respondents with mild depressive symptoms often identified educated patients with diabetes as being one step ahead of their counterparts.

"...Education has its own impact on diabetes...the patient takes his medication on time and on a regular basis...and if the sugar level increases...he can deal with it...or if it decreases [he can deal with it]...uneducated people can’t do that...can’t take the exact dose...an uneducated [person] can’t perform what educated people can...for example...when the doctor tells a patient you have to take two units of insulin...he has to take exactly two units...no less, no more..." (Kareem, PHQ-9: 8).

"...when someone knows about his disease he follows the doctor’s orders better...and he knows how to modify his lifestyle to his disease" (Nadeem, PHQ-9: 5).

Even those with moderate and moderately severe depression such as Marwan and Sama believed that the knowledge acquired as a consequence of a solid education empowered and helped them to achieve simple tasks. As a result, they felt they were more informed about the disease. This in turn influenced their adherence to medical advice and also allowed them to make the necessary adjustments to their lifestyle.

"Being educated helps me differentiate right from wrong better, acknowledge the consequences more" (Sama, PHQ-9: 16).
Participants with moderate to moderately severe depression also perceived the knowledge they received through education as a source of empowerment. They identified the relationship between diabetes knowledge and engagement in positive self-care activities, and moreover linked both of these to the patient’s capacity to explore a wide variety of resources. Furthermore, higher levels of awareness and knowledge that are linked to a strong education were also correlated to an incentive to seek out further information about long-term complications, such as diabetic foot ulcers and kidney disease.

...you have to know more about your disease...ask about the consequences...read about it...log into the internet...read about diabetic foot [ulcers] and the relationship between diabetes and heart attack or stroke...search for...stuff...that is what an educated person does...on the contrary a non-educated person (Saied, PHQ-9: 15).

...I keep on reading brochures about diabetes self-care activities...about healthy diets...I keep on watching documentaries about diabetes and kidney disease...so yeah being educated matters...(Sabah, PHQ-9: 15).

Moreover, participants with moderately severe depression sought material in the form of brochures and written forms. Those with high levels of literacy found these materials informative and useful. Three participants reported that they actively sought out educational material that would benefit them in managing their diabetes. They made particular reference to print material such as brochures, as well as web-based resources.

As an educated person I tend to buy educational materials...I try to get medical brochures...I always seek any written medical information that might be of benefit to me... (Saied, PHQ-9: 15).
7.2.2.2 Cultural beliefs – ‘...Old people expect the diagnosis of chronic diseases...but young people having diabetes!’

All fifteen participants discussed the effect of age on their diabetes self-care activities. It was apparent that age had a unique significance, with participants constructing the meaning of age through the prism of their own cultural beliefs and specific social realm. Four participants linked their health behaviours to a social role, assuming that older people need not take care of themselves since they no longer had a social role in relation to their children in this life. On the other hand, the older participants assumed that younger people were often motivated and driven by their children; that is, they have a responsibility to take care of themselves, because they are primarily obliged to fulfil their social role as an active member of their family. Significantly, interviewing a sample from an Arabic culture has highlighted an important issue regarding age and cultural perspectives on and discursive constructions of elderly age groups. Often emphasised a prevailing cultural attitude that a person’s community engagement and contribution will diminish with age. The physical decline inherent in ageing excuses a person from having to make an active contribution to society. This cultural attitude could be a significant element in terms of how the elderly age group self-define and how they self-manage their conditions.

A young person would still be in his/her best years...in his/her youth...the older ones feel that their roles have been fulfilled and that they have nothing to live for...their kids are married and they are done with everything...but young people have more responsibilities...they can’t just neglect themselves... (Anood, PHQ-9: 10).

Ruba added another dimension, observing that older people were generally expected to suffer from morbidities and medical problems. She considered older
people to be more accepting of their medical challenges than the young; indeed, she saw this attitudinal shift as something that was intrinsic to the ageing process. Explaining that she would still take care of herself had she been diagnosed later in life, Ruba nonetheless understood that older people could not avoid the development of conditions such as diabetes and eye disease, since these ailments are more common with advancing age.

*I would still care for myself the same if I were diagnosed at the age of 65...maybe more...ageing exposes patients to get more complications...they get...retinal and kidney problems faster than younger patients...young people take care because they need to avoid diabetes complications...but old people...what will they do...they can’t avoid consequences as everything in their world is falling apart...young patients have to take care of themselves as their organs are still good and healthy...old people...you know for sure their eyes will be sick and their kidneys will be tired as well...so when you add to this dilemma high blood sugar...everything will be ruined. However, being young you feel that you have responsibilities to others...so you take more care of yourself...* (Ruba, PHQ-9: 5).

Naheel concurred with this view, explaining:

*I was diagnosed while I was young...this is in fact horrible...against nature...I mean old people expect the diagnosis of chronic diseases...it hurts them of course but they usually consider it as a part of ageing process...but young people having diabetes...it’s like being buried alive...* (Naheel, PHQ-9: 15).

For Feryal, who suffers from moderately severe depression, being diagnosed at a young age at least had the benefit of affording her enough time to develop good self-care activities and to incorporate these into her lifestyle. Feryal was motivated to successfully manage her diabetes in the long term, because this would maintain better health and render her less of a burden on others later in life.

*Yes of course, I am not young but I care about my diabetes self-care activities because I was diagnosed young and adjusted to this regimen...I fear that with age I will lose my ability to walk...this is what scares me the most...and I hate to be a burden on anyone ...* (Feryal, PHQ-9: 15).
Participants discussed age in terms of their chronological age. Marwan and Saied, with moderate and moderately severe depression respectively, explicitly referenced death when they discussed self-care activities. Marwan and Saied believed that older people had to accept the imminence of death and the fact that life must end one day. Because of this, they felt that older patients saw no need to manage their diabetes or to adhere to diet plans, physical activity and medical treatment. Both Marwan and Saied demonstrated a more negative attitude towards self-care activities in terms of the necessity of maintaining a healthy lifestyle:

...old people think they will die soon so no need to bother doing exercise...boring diets...medications all day long...alternatively, young ones want to live a long happy life...and above all they want to enjoy their life...so they usually try to get their diabetes under control... (Saied, PHQ-9: 15).

Three participants with mild depression revealed different perspectives on ageing in relation to body image and self-care activities. Two young women pointed out that they adhered to their diabetes self-care activities plans because they were young, physically fit and cared about their bodies and body image. It is possible that young women want to maintain their attractiveness, accordingly they were motivated to engage in self-care activities such as exercise and medication adherence.

*I am young, so I can exercise easily, I can move easily...much easier than old people...I still have enthusiasm and interest in life...* (Zuhra, PHQ-9: 8).

*I believe that the younger the patient, the better the adherence to medications...while those who are old are mostly inactive and they just eat and rest...also as a young woman, I care about my figure, I care about the way I look* (Sameera, PHQ-9: 9).

Nadeem, who had mild depressive symptoms, also considered age a motivator for better self-care activities, possibly because of his understanding of
the effects of ageing on diabetes. His knowledge of the progressive nature of diabetes, in which symptoms and complications worsen throughout the course of the condition if left untreated, underpinned Nadeem’s drive to respect and adhere to self-care activities.

People my age would worry most about their sight...especially when one is an avid reader...kidney problems [etc.]...they motivate me to stick better to my diabetes plan...I think as you age you should care more about your body... (Nadeem, PHQ-9: 5).

7.2.2.3 Sociocultural roles – ‘...I am serving my family...’

Many participants remarked that their gender identity affected their self-care activities. In Arabic society, women and men have clearly delineated and distinct sociocultural roles. Men are expected to take care of and support the family both economically and materially. Fulfilling this role dictates that they must care for their health.

The man cares more...You know as a man...I do so much work ... when I go out of my house I take care of anything my family want me to do...I am serving my family...I work as ... a delivery boy for them... (Kareem, PHQ-9: 8).

Sama supported this idea in her interview, believing men to be more adherent to self-care activities than women because of family responsibilities. Such views could be seen in light of broader sociocultural expectations of a man’s role in the Arabic community. As head of the family, a man has a corresponding responsibility to maintain his own health to safeguard the wellbeing of his family’s economic situation. Unlike western society, where gender roles and identities have undergone a radical shift in recent decades, men in Arabic culture are considered the ‘breadwinners’ while women are designated as the ‘homemakers’. Observed Sama:
Males are more adherent to self-care activities. I believe...they are responsible for the whole family, they know if they go down...the whole family will go down...so they try to manage their diabetes as strictly as they can... (Sama, PHQ-9: 16).

Gender was linked to rigidly delineated cultural roles in the Arabic community, and was also invoked by participants in relation to individual behaviours. ‘Unconscious eating’ was an expression offered by a male participant who believed that women ate unconsciously whilst preparing food for their families. The primary role of a mother as nurturer to her family was a common justification for the inattention women paid to their own health. Conversely, men were viewed as being committed to self-care activities and more organised with their eating habits due to the fact that they ate only after someone had prepared food and served it to them. These beliefs articulated by the participants underscored the status assigned to men in Arabic culture.

I believe males are more committed to self-care activities than females...because females spend a lot of time in the kitchen preparing food...and while doing so they tend to eat unconsciously...while men receive their meals prepared for them at the table so they tend to eat in a more organised way... additionally, women get carried away with their families’ needs and tend to forget themselves... (Khalid, PHQ-9: 14).

For Naheel, fear was an underlying factor that compelled men to better adhere to their self-care activities. Fear motivated men to engage in health-promoting behaviours, Naheel believed, because they feared the negative consequences of poor health. To illustrate her point, she cited her husband’s attention to the management of his hypertension:

I think males tend to be more fearful, hence, they are more adherent to self-care activities...I mean my husband for instance has hypertension, and
whenever he gets a high blood pressure recording, he freaks out...he is more committed than I...even in medications...he does not forget a pill...he always takes his medications on time...anyway... the point is that males tend to be more committed to self-care activities than females due to their fear...

(Naheel, PHQ-9: 15).

Conversely, Saied (a male participant) believed that men were typically less concerned about their disease and more willing to take risks in life:

...men tend to be more adventurous...we are willing to risk it... (Saied, PHQ-9: 15).

One-third of participants, however, asserted that women were likely to manage their health more competently than men. Specifically, these participants felt that body image and how Arabic society perceived women acted as strong driving forces towards positive self-care activities. Female participants, and mostly those who suffered a mild form of depression, reported a preoccupation with their looks and a desire to maintain their partners’ attention. This need for their partners’ approbation seemed to be the driving force that compelled them towards better self-care activities. The words used by these participants often revealed their subconscious fear of losing their husbands to other women. Of equal importance to them was their anxiety over the community’s judgement if family breakdown occurred. Notably, women with poor body image and low self-esteem arising out of their poor diabetes management had lower expectations of their husbands’ commitment and fidelity.

I fear that one day my husband might say...she got diabetes and got fat...So I care so much for the way I look...I try to stay in shape... (Zuhra, PHQ-9: 8).

I believe females take better care of their diabetes than males...because as I mentioned earlier, women care about their figure and the way they
look...also I fear if I lose my sight or I get dermatological problems, my husband would be looking at other women God forbid, my kids would be depressed and sad...even I fear my extended family noticing a bad change in my appearance God forbid...so I take care of myself better than if I was a male... (Sameera, PHQ-9: 9).

For Anood, in contrast, her sociocultural identity as a mother was what provided the means that allowed her to adhere to her self-care activities. As the self-described ‘Commander-in-chief’ in her home, Anood made the executive decisions while cooking or shopping, and this control facilitated adherence to her diet plan. Anood further indicated that her family’s welfare was the real reason behind her desire to take care of her diabetes. She worried about others having to care for her children in the event that she was unable to do so. These fears helped to reaffirm and reinforce Anood’s healthier choices in life.

...a female cooks for the whole family...she cooks the meals so she gets to control the amount of fat...when she fries something...she use moderate amount of oil...she adjusts the oil and that will not affect the family...but a male has to follow his wife’s choices...and above all when a woman shops for her family...she considers herself...so she manages everything to suit her...so females care about themselves because they care about their families...I cannot imagine having my kids raised by another woman... (Anood, PHQ-9: 10).

Sameera supported Anood’s point of view, observing:

...additionally, as women are the ones who usually cook, they tend to control the diet of the whole house...for instance, I can make my family share...the same diet [as mine]...and when they demand...something specific that is out of my diet plan I tend to avoid eating...it or I eat a very little amount... (Sameera, PHQ-9: 9).

Only one of the participants felt that sociocultural expectations for men and women in Arabic society held no significance in relation to one’s ability to cope with
diabetes and maintain self-care activities. Namely, Myasar considered diabetes to be a disease that took the same course irrespective of gender.

_We care the same...it is all the same! They both suffer the same!_ (Myasar, PHQ-9: 10).

### 7.2.3 Social pressures – The good and the bad

Family, friends and the community were all factors that impacted on self-care activity practices among participants. The family and the social context were both cited as influential in terms of diabetes control, with participants indicating that they continually sought to adjust to their new lifestyle and to adhere to their health plans. Those with diabetes would therefore be expected to turn to their families to seek help and support.

However, participants reported that it was not only their families that were influential in relation to their self-care activities. They also spoke of their community. Arabs have great respect for their community and their cultural practices, with social group satisfaction accorded a higher importance than an individual’s contentedness. Correspondingly, most participants reported experiencing difficulty in adhering to their health plans when they were visiting others or attending social functions. They cancelled their regular check-ups when they received visitors, or did not adhere to their diet plans when dining with guests. Social gatherings therefore threatened to undermine attempts to adhere to their health plans.
The third major theme – ‘Social pressures: The good and the bad’ – is divided into two subthemes: Family factors – ‘They changed their diet to suit mine...’ and Community factors – ‘...I always have people over...I feel obliged to eat with them.

7.2.3.1 Family factors – ‘They changed their diet to suit mine...’

Seven participants in the study described family support as indispensable in helping them adhere to their diabetes self-care activities. For most participants, family support was similarly valued. Many explained how family support had a positive impact on their health-related behaviours including diet plans, medication regimen, exercise, seeking general advice about their condition, and engagement in self-care activities. These sentiments are exemplified in the following accounts:

*My daughters and husband avoid everything sweet or salty to help me with my diet. They changed their diet to suit mine...again even my relatives changed their diet to fit mine when they invite me over, and I have a daughter who gives me all my insulin injections ...* (Sama, PHQ-9: 16).

Although most participants conceded the importance of dietary adherence, and some of them held the view that the diet for patients with diabetes should not differ from the same healthy eating plan that everyone should follow. Most participants expressed gratitude for their family’s support, regarding it as a key component in their self-care activities to overcome feelings of loneliness and abandonment in the participants’ battle against their disease.

*...my family was very supportive...my husband is great...he advises me...listens to me....brings me diabetic food...he asks me to measure my blood sugar level when I forget...sometimes he follows my diet plan as well...having someone so supportive makes you feel that you are not alone...* (Myasar, PHQ-9: 10).

*I used to cry day and night...but thank God...my husband helped me a lot...he used to make it easy on me...he used to tell me it is very simple...just a diet
and exercise...and he used to encourage me to walk by walking with me around 1 to 1 and a half hours each day...Thank God...I managed to reduce my weight from 83 to 70 kg...and it has been around 2.5 years now since my diagnosis and I am committed to my medications... (Sameera, PHQ-9: 9).

When participants felt overwhelmed by social pressures, family support became critical. Naheel often found herself in social situations where eating sweet food was an expectation in order to ‘fit in’. At these times, she received support either from her husband or father, who also had diabetes.

...my husband supports me a lot...he reminds me of my medications...sometimes he brings them to me with a glass of water to make sure I take all of them...when we are at a gathering and people serve sweets, he makes sure I don’t get pressured and overeat...my father tries to help...you know he has diabetes...mmm...he understands how I feel in terms of diabetes better than anyone else ... he keeps telling me about adherence and how he feared his limb being amputated so I adhere... (Naheel, PHQ-9: 15).

Instrumental social support seemed to be an important component for the management of diabetes complications, particularly when short-term complications arose. For instance, Ruba’s hypoglycaemia was difficult to manage without her family’s support. With profound sorrow, Ruba recalled suffering severe episodes of hypoglycaemia. Recounting these episodes in tones that revealed her low level of confidence in her abilities, Ruba also voiced irrational thinking patterns in relation to her hypoglycaemia. Expressing fear and lack of confidence in her ability to deal with such situations, Ruba felt she lacked the self-confidence to meet this challenge. She viewed these episodes as a series of insurmountable tasks that could not be mastered independently. Instead, Ruba relied on family support during hypoglycaemia. For example, she became extremely dependent on her children at night. Her family played a major role in her management plan, and without them Ruba felt unable to survive.
They measure my sugar level...wake me up when I get hypoglycaemia...without them ... I do not know how my life would have been ... they support me so much...my husband works as an officer at the security intelligence department, so he doesn’t sleep home every day due to his work...I ask my kids to sleep with their doors open in case I need their help at night...as they can hear my agony...I get scared if any of my kids closes his/her room door...because they might not be able to wake up when I need them...I tried using my mobile but I just couldn’t dial the number then...I lost my awareness... (Ruba, PHQ-9: 5).

Ruba’s dependency stemmed from her low levels of self-efficacy. She did not know how to predict signs of impending hypoglycaemia or to manage the episodes independently by seeking advice from her doctor regarding changes to her insulin regimen. For Ruba, hypoglycaemia was a frightening and unmanageable phenomenon. Family support was not only indispensable – she also saw it as a matter of life and death:

During hypoglycaemia...I could not open my mouth...it is out of control...everything gets out of control...they usually bring a syringe and start dripping sugary water into my mouth...and even when I need to swallow...it does not work...and they even have to move my jaw...and that’s why I have jaw pain when I wake up...my son keeps on apologising to me for giving me jaw pain...and keeps on reassuring me that they do this manoeuvre as it is the only way to get the sugary solvent into my mouth... (Ruba, PHQ-9: 5).

Overdependence on family support seemed to be a chronic issue for both Ruba and Saied. Such overdependence is considered to be counterproductive because it allows patients to spiral into a state of learned helplessness. While Saied managed his cardiac medications independently, he relied on his wife to administer his insulin injections:

...My wife is the one responsible for my insulin injections...when we fight I don’t let her give me any injections...I even don’t care about the insulin...sometimes it lasts for days...and I forget all my other medications as well...my antihypertensive medications...my cardiac medications...I forget about the whole thing...few days ago we had a fight...and when I was climbing the stairs I felt...severe chest pain...thank God I had my
nitroglycerine tablets...I sat on the stairs and two pills under my tongue...Once I felt better, I...called on my wife...told her that she can be mad at me as much as she wants...but she needs to take care of my medications...[he laughed]... (Saied, PHQ-9: 15).

Other participants candidly reported that their families had hindered their self-care activities. Three of the participants with moderately severe levels of depression remarked that their families were unsupportive, which had a negative impact on their self-care activities. Family members blamed them for the onset of the condition or discouraged their eating and/or exercise:

My husband does not care what kind of a day I had...he needs me always in a good mood. Whenever I get on the treadmill, my husband starts nagging...he asks for tea...for food...for silly stuff...he starts saying that I don’t spend much time with him...you know after I get off...it is impossible for me to get back on again... (Zuhra, PHQ-9: 8).

He [my husband] blames me for having diabetes and he keeps on telling me that it is me and my way of living that got me to this point ... whenever I eat he lectures me... (Anood, PHQ-9: 10).

Another male participant with diabetes complained about his wife’s control of his diet,

She [my wife] does not like it...if I eat sugar she objects to that...when we bring sugary stuff...she says...you have eaten too much sweets...but you know sometimes...I have to eat sugar...if I don’t eat...I will pass out...feel dizzy...faint...you know...a person has to eat...such stuff...I tell her...I need to eat... (Kareem, PHQ-9: 8).

Anood added that the support she received from her biological family was indispensable: they cared genuinely and unconditionally about her, whereas her husband’s care was questionable (as noted above). At times, Anood felt that her husband was deliberately sabotaging her diabetes self-care activities.

...family offer unconditional love ... they care a lot for you ... they constantly remind you to take care of your health...you know your biological family are
so close and they take care of you more than anyone...my sisters call very often to check on me and my diabetes...my husband blames me for having diabetes and whenever I eat he lectures me (Anood, PHQ-9: 10).

Two female participants remarked that educational sessions are paramount in relation to diabetes self-care activities. They also observed that educating a family how to give emotional and instrumental support is also a crucial issue.

*I need educational sessions about weight control...diet plans variety...calorie count ... about diabetes impact on sexual life...and I think there should be educational sessions for the family of the diabetic...I mean to teach the family members about the impact of psychological support on the patient...teach them how to support the patient in terms of diet and how to help to the patient accepting the disease...I would recommend counselling sessions...I think improving psychological status will fix everything in diabetes...once psychological status is stable and good, I think adherence won’t be a problem...I always feel in need for someone to ventilate to...* (Naheel, PHQ-9: 15).

### 7.2.3.2 Community factors - ‘...I always have people over...I feel obliged to eat with them ...’

The Arab community and cultural traditions exert a strong influence on patients with diabetes and their self-care activities in Jordan. To illustrate, Arabs are well known for their expansive generosity and hospitality. How well one treats guests is a direct measure of one’s integrity and decency. Hospitality is one of the most prized and admired virtues. Indeed, families judge themselves and each other according to their guests’ level of satisfaction. For example, families will typically serve an abundance of food during gatherings or when welcoming someone. This practice signifies reverence for the guest. The guest reciprocates by showing a healthy appetite and sampling as many dishes as possible to demonstrate their respect and gratitude. In fact, declining offers of more food is deemed unacceptable and considered a grave insult to the host or hostess.
Participants with moderately severe levels of depression chose to jeopardise their health plan in favour of ‘fitting in’ with their community. They prioritised cultural values and customs, in spite of their awareness of the deleterious effects on their health.

Saied’s personal beliefs clearly influenced his decisions about his health. Although he understood the negative influence that his culture could exert on his health, Saied nonetheless chose to ignore his self-care activities and to privilege his cultural values. While he could cognitively process the information related to the importance of exercise and medical visits, Saied was emotionally bound by the strictures of his sociocultural values. Cultural imperatives – such as demonstrating hospitality to guests – were accorded a higher priority than his health. In other words, Saied valued social approval over attending to the self-care activities that were essential to his wellbeing:

...Yeah...my culture hinders my self-care activities...I skip many of my gym sessions because I have visitors...I even once cancelled a doctor’s appointment because I had visitors...and could not tell them to postpone their visit...or...to wait for me until I finish... (Saied, PHQ-9: 15).

For patients with diabetes, adhering to diet plans requires an appreciation of the relationship between carbohydrates and blood glucose levels. The knowledge about the carbohydrates is often incompatible, however, with Arabic cultural values that uphold the importance of sharing food with others. For most participants, sharing food as a social activity seemed more important than weighing the pros and cons of such actions on one’s health. When faced with such situations, the participants compromised their health and chose to eat without any consideration to their diet plan or restrictions. Moreover, they feared others becoming aware of
their diabetes. The ways in which food is shared in a social arena are best illustrated in observations made by Sameera and Maha:

...sometimes I am having visitors to my house so I am obliged to eat with them with no restrictions or conditions especially since I did not share my diabetes with anyone...and in return, when I am visiting someone, I feel obliged to eat with them ... I can only control the amount, but again I have limited control because I fear them wondering about me not eating regularly in a gathering (Sameera, PHQ-9: 9).

Social obligations in relation to diet were also emphasized by another participant,

...I am a good cook...and I always have people over my house so...ah...I feel obliged to eat with them ... yah... (Maha, PHQ-9: 10).

For Sabah, community pressures were similarly great. Although she tried to stand her ground and explain her situation to her community, success was not always guaranteed. Conceding that she was sometimes not insistent enough, Sabah described succumbing to social pressure, pointing out that the communal partaking of meals is a cultural norm within her society. Food sharing signified hospitality and generosity, and refusal could be seen as an insult.

...You know...sometimes I feel obliged to eat things that contradict my diet plan ...because...I do not want to upset people...ah...but I do not blame anyone in this regard but myself...I mean I should be in charge of my health and explain my situation in a polite way...sometimes I succeed...sometimes I am not firm enough ... the other day I was visiting my sister in-law, she had just prepared one of her special dishes and she insisted I try some...I ate some...then she insisted again...I felt irritated and I told her that’s enough firmly...what I need to tell you is that culture obliges us to share people’s food when they ask us to ... (Sabah, PHQ-9: 15).

For Anood, the fear of inciting the community’s disapproval had a greater impact on her exercise routine than on her diet plan. She explained, the potentially judgemental attitudes of her community prevented her from exercising outdoors. She feared that people would think that the time she spent exercising was taking
away from the time that she should be spending with her husband and children. According to community values, she believed, her free time did not belong to her, but rather to her family. Recounting an occasion where she attempted to take control by going out for a walk, Anood explained that her neighbours kept offering her rides back home, thinking she was in need of help. Although she tried to challenge such cultural standards that restrict outdoor physical activity, Anood felt she could not continue exercising outdoors without attracting harsh criticism and even vilification. Therefore, she succumbed to adhering to community expectations:

Yeah … exercise is very difficult…because if I belonged to a gym’ I would get home at nine … people will start blaming me for leaving my husband this long…it is not acceptable and people start criticising you … it is not very acceptable in our community to do that … and you know it is very difficult to exercise outdoors…as people would think that I do not give my family time...[Silence]…look I will tell you a story … once I decided to walk down the street as an exercise … I had three neighbours asking me if I needed a ride back home … so I just turned around and went home … they could not believe I was exercising!!! … (Anood, PHQ-9: 10).

Conversely, nearly all patients with mild depression felt that social pressure was manageable and that it had negligible effect on self-care activities. Being able to explain diabetes to others and to articulate the reasons for not partaking in meals, was a way to be excused from social obligations without showing disrespect. This again reinforced the importance of social factors in the participant’s life. These views were best conveyed by Zuhra and Nadeem.

…sometimes I refuse to eat something at another’s…and I don’t want them to interpret that as a lack of respect or as I am questioning their food or hygiene…so I tell people my condition to be excused in such situations… (Zuhra, PHQ-9: 8).

... once my friend was travelling so he had a gathering and invited me over [for] dinner and dessert…so I took a small share…and he got mad and told
me to eat more but I told him to allow me to follow my diet plan... (Nadeem, PHQ-9: 5).

7.2.4 Understanding the consequences but struggling to adjust

Participants understood that a change in lifestyle was essential in order to control their diabetes. However, many cited high stress levels as a significant obstacle to maintaining a healthy lifestyle. The narrative indicated that the participants comprehended the consequences of diabetes in relation to both short- and long-term complications. The fear of the potential negative outcome is an incentive for participants to adhere to their self-care activities and to implement the necessary lifestyle changes. However, participants found the idea of maintaining these changes for the rest of their lives a daunting prospect. They described their changed habits as a boring way to live. Participants also recognised the importance of medication in controlling their diabetes. Yet they lamented the fact that the side effects were dreadful, and at times intolerable which led to non-adherence. The fourth major theme – ‘Understanding the consequences but struggling to adjust’ – is divided into four subthemes: Stress – ‘...but this is very hard...daily stresses are huge...’ Fear – ‘this fear motivates me to adhere better to my diet plan...’ Chronicity – ‘it is kind of boring to watch your diet all your life...’ and Medication – ‘... I hate the medication ...’.

7.2.4.1 Stress – ‘...but this is very hard...daily stressors are huge...’

Most of the participants identified their psychological status as the main factor affecting their day-to-day self-care activities. Essentially, they held their emergent circumstances, events and family issues responsible for their evolving
psychological status. Adherence to diabetes self-care activities seemed to be constantly challenged by everyday emotional fluctuations, and avoiding stressors seemed to be the only way out.

_Without any doubt...the most important thing to manage diabetes is the psychological status..._ (Zuhra, PHQ-9: 8).

Another participant emphasized that the stressors may be an issue that should be dealt with for patients to cope with diabetes, however, Marwan saw stressors as a perplexing issue that is difficult to control.

_To cope with my plans...I should prevent stressors...but this is very hard...daily stressors are huge..._ (Marwan, PHQ-9: 10).

Most participants reported that stress significantly affected their diabetes self-care activities, particularly in terms of adherence to their exercise and diet plan. Stress impacted on their ability to cope with their disease, and diminished their capacity to take charge of their health. In other words, participants experienced a loss of control over their diabetes self-care activities because of stress which in turn led to feelings of sadness and depression. The ways in which participants experienced the impact of stress on their diabetes are encapsulated in the words of Khalid and Sama.

...well...a bad temper hinders me from exercising...when I am in a bad mood I don’t exercise at all...sometimes I skip dinner... (Khalid, PHQ-9: 14).

...my mood will start affecting my disease...as when I am angry I get high blood sugar levels regardless of how strict I am...sometimes I will not be able to control my blood sugar levels through diet modifications...even if I try my best! ... So I got down and depressed! ... (Sama, PHQ-9: 16).

Two female participants explained how day-to-day stress affected their diabetes self-care activities. Not only did these women cite the burden of being
dependent on their husbands as one of the main barriers to undertaking their diabetes self-care activities, but they also explicitly attributed their high stress levels to their husbands.

*It is very hard indeed to manage diabetes... In order to do that I need to have a good psychological wellbeing... [Laughing out loud]... I need to be independent of my husband... In fact my husband is the main thing that causes me distress... [Laughing again]...* (Zuhra, PHQ-9: 8).

For Feryal, the pain she had been holding onto for more than a year, along with her tendency to constantly ruminate on past events, created constant stress in her life. This adversely affected her self-care activities. Feeling that she had trapped herself in a loop of continuous stress and negative thoughts about her life, Feryal’s past cast a shadow on the present and created a consistently low mood that in turn fed into negative perceptions about her illness.

*I think I over-worry... I keep thinking of my problems... this causes me continuous stress... and as I told you before... my husband can be nasty... so this adds up... he only considers himself and doesn’t consider my health... If only I can forget all my problems... If only I can erase things from the past... I think nothing can improve my control... it totally depends on my psychological status... and my psychological status is down because of all what I have been through... [She becomes teary]... it hurts so bad... [Crying]...* (Feryal, PHQ-9: 15)

Another woman described how she failed to undertake the necessary self-care when she was stressed, even though she still tended to the needs of others during these periods. Neglecting the care needed to manage her own diabetes, Zuhra accorded primacy to looking after others. Although she recognised the negative impact of stress on her, she chose to jeopardise her health in favour of caring for her family:
Yes, of course... When I am mad... or just frustrated... I don’t care if my blood sugar level stabilised or not... I don’t care if I slept or not... any tiny problem occupies my mind and I keep on talking about it and discussing it for days... even my kids tell me that I don’t let go easily... (Zuhra, PHQ-9: 8).

- Can you recall a story about that?

...yes... a few days ago, my daughter hurt me unintentionally... maybe she did not mean to hurt me... but I did not take any insulin injection in two days... I did not eat anything... I got tired... went to the hospital... and my doctor said I had severe hypoglycaemia... and I should never do that again to myself... (Zuhra, PHQ-9: 8).

When probing into how participants coped with stress, idiosyncratic patterns and practices were revealed. For example, two participants, each with moderate to moderately severe depression, chose unhealthy habits to cope with their stress. For Anood, who was moderately depressed, ‘uncontrolled’ eating was a coping mechanism when her mood was low. Junk food and chocolate, confessed Anood, were the main foods she consumed when stressed. During stressful situations, Anood’s engagement in destructive health behaviours seemingly mirrored her tendency to engage in wishful thinking. Furthermore, the wishful thinking might be construed as a reflection of her low self-efficacy in controlling her eating habits during stressful situations.

... Stress... definitely... that’s my major issue... I do not watch my diet when I feel down... I forget myself... and no matter how much I eat then I never feel full... I keep craving food... I do not eat salad or vegetables... I do not care when I feel sad or when I am stressed... I need to eat just to reduce my hunger... I wish I ate healthy food then... this happens on a subconscious level subconscious level... I have no control over it... (Anood, PHQ-9: 10).
Saied, who has moderately severe depression, chose smoking as his maladaptive coping mechanism. He experienced smoking as a stress-relieving practice, and described as a positive experience.

...after all I smoke to ventilate from life stressors...I feel it relaxes me...it even clears my mind...I think better after I smoke [he laughed]... (Saied, PHQ-9: 15).

7.2.4.2 Fear – ‘this fear motivates me to adhere better to my diet plan...’

Fear of developing diabetes complications also influenced participants’ adherence to their self-care activities. Eight of the participants explicitly spoke of how these fears acted as an incentive to adhere to their health plan. Feryal feared physical changes would happen in her body as a result of her illness. To allay her fears, Feryal saw adherence to medication, diet and exercise as a risk management strategy.

Oh...I fear to ending up handicapped...I keep on taking my meds and insulin...I try to adhere to my diet as much as possible...I don’t exercise...but I try to move around and visit my daughters...I really fear being a burden...I fear body mutilation...I fear one day I might lose a limb...[at this point the patient starts crying]...my legs are always numb at night...I feel one day I might lose them...[She cries heavily]... (Feryal, PHQ-9: 15).

And here again Saied feared amputation,

I think my biggest motivation to adhere to health plan is fear...I fear when I see people with diabetes experiencing complications like amputations (Saied, PHQ-9: 15).

For Sameera, her fear response to external experiences similarly inspired an adherence to her health plan as a way of mitigating her own risk factors.

Well...I witnessed both my mother and my mother-in-law experiencing nail problems...they used to turn black and ugly...they also both had surgeries in
their eyes...my mom had a cataract in her eyes, and my mother-in-law had three operations done on her eyes...I really fear ending up the same way...but it motivates me...this fear motivates me to adhere better to my diet plan... (Sameera, PHQ-9: 9)

Other participants similarly explained how fear motivated them to adhere to self-care activities.

*It motivates me...I start paying more attention to my diabetes self-care activities...I start worrying about me ending up the same way God forbid ... It makes me more adherent to my regimen...* (Sabah, PHQ-9: 15).

Participants perceived diabetes as a disease with serious outcomes which in turn was a serous motive for adhering to their health plan.

*Honestly, when I experience such fears I feel down...I get depressed...I start thinking about my kids...I start thinking ‘what if I ended up blind?’... ‘what if I ended up with a limb amputation?’...but as I told you this fear motivates me* (Sameera, PHQ-9: 9).

Naheel thought dying would be easier than living with the loss of a limb, thus she is trying to adhere to her health plan.

*They motivate me...I’d rather die than have my limb amputated...when I get these fears I try to commit to my diabetes regimen* (Naheel, PHQ-9: 15).

Also Feryal reinforced here adherence to foot care is encouraged by the fear of loss of limb,

*I keep touching my limbs...checking if I still have sensation...I wash them...I moist them with a special therapeutic lotion and I raise them on a pillow when I sit or sleep...I fear one day to end up with no limbs...to see things around me but not be able to move...* (Feryal, PHQ-9: 15).

Fear was not a motivating factor for all participants, however. After being exposed to a negative experience, Zuhra’s adherence to her care plan was only temporary. Although the experience had affected her and invoked fear, she made it clear that the resultant motivation was short-lived.
Once I was going to a trip with my friends and one of my friends had her brother-in-law with her on the trip ...I wondered about that...then she told me that he is blind due to his diabetes ...at that time I got scared and I tried to adhere more strictly to diabetes regimen...but it did not last long...as I told you...I forgot about the whole story so quickly...but at that time I was very strict about my diet...my medication doses and timing...my exercise... (Zuhra, PHQ-9: 8).

7.2.4.3 Chronicity – ‘it is kind of boring to watch your diet all your life...’

For chronic disease such as diabetes, achieving a cure is not the goal. Patients with chronic conditions are required to manage their disease on a daily basis for life. The chronicity of diabetes imposed demands on the participants, who were required to change their habits and lifestyle with no possibility of a cure for their condition. Two female participants with moderately severe levels of depression perceived the diagnosis of diabetes as a life-changing event that would entail suffering for the rest of their life. They felt that diabetes would cause a lifelong deprivation of many things. On the other hand, they found that their faith fostered a sense of acceptance.

Nothing special, I told them I got diagnosed with diabetes, and considered it as a God given challenge...told them now I will be suffering my whole life...and will deprive myself of many things... (Sama, PHQ-9: 16).

This disease is for life...and there is no cure for it...It is my fate....It frustrates me when I remember it is for life... (Sabah, PHQ-9: 15).

Although Zuhra recognized the importance of maintaining an exercise regimen, she lost interest easily, this may be attributable to the chronicity of debilitation inherent in diabetes.

I have a lot of exercise machines...I have a treadmill...I have a bicycle...I even have steps...but I don’t commit...I get bored easily... (Zuhra, PHQ-9: 8).
Saied felt that having to adjust his lifestyle was a burden in itself. The diet plan, the medication and the daily exercise seemed like boring and fruitless activities to Saied, who found it hard to cope with the ongoing demands of managing his diabetes.

*It is so frustrating to know it is a chronic disease and it will not be cured...it is kind of boring to watch your diet all your life...or to take medications for life...to exercise for life...people get sick...* (Saied, PHQ-9: 15).

Likewise, Sama came to realize that the management of a chronic disease was a demanding process. Even adherence to her health plan, she felt, would not reduce the hardship of managing her disease. Sama also speculated that the diabetes’ chronicity might adversely affect her cognitive capacity.

*I got disturbed...started thinking this disease is for life...and I will be suffering throughout my life even if I adhered strictly to my regimen...I am sure you understand...I started thinking this will also affect my thinking...* (Sama, PHQ-9: 16).

The participants saw their disease imposing a huge burden upon their daily life. Their efforts to adhere to management plans and other necessary adjustments proved a daunting and at times dispiriting endeavor. One of the participants used displacement as a coping mechanism; Saied vented his anger on his family, demanding that they must understand him. His anger was displaced, since what actually frustrated Saied was the condition that had taken over his life.

*Yeah, a lot of times I get angry at myself because of my diabetes...I feel angry that I have to deal with all these meds and diets to manage it...then something silly happens and I start yelling to ventilate my anger on diabetes not the silly thing...but again no one understands that I am mad at my diabetes...and they start accusing me of being hot-tempered or moody* (Saied, PHQ-9: 15).
The participants felt that diabetes had invaded their lives. It was difficult for them to contemplate dealing with a lifetime of disease. They reported that the management of diabetes was a boring and onerous process, and consequently they predicted adherence to be unattainable.

Yes of course, that’s if I can commit...but you know I get bored...I lose interest and motivation so I stop taking it at times (Anood, PHQ-9: 15).

Two of the participants who had mild depression viewed lifestyle changes as exhausting and difficult to maintain.

I exercise once weekly for 30–60 minutes with my daughter...she calculates the time for me. I cannot exercise more because sometimes I am too tired to do so...my body is so weak... (Ruba, PHQ-9: 5).

I stuck to this plan strictly for 3–4 months...then I got tired of it... (Nadeem, PHQ-9: 5).

### 7.2.4.4 Medication – ‘...I hate the medication...’

For the participants of the study, the potential side effects from diabetes medications were perceived as overwhelming and restrictive. Participants with moderately severe depression reported fear of nausea, stomach problems and intestinal disturbances. Such anxieties in turn cast doubt on the overall benefits of the medication. Some of the adverse effects of hypoglycemic agents were also cited as points of concern, with many participants disclosing feelings of dread about the possibility of being put on insulin regimens. Participants described the hardship of enduring existing side effects and expressed their fear of needing further medications down the track.

I will tell you something; the side effects of the medications I take are so many ... I hate the medication ... it is not comfortable...I feel nausea all the
time as a side effect of my medication...as long as you are sick you have to take your medication...but by the end your stomach will get affected...but still better than having to take an insulin injection daily...I can’t accept the prospect of having to take an insulin injection...it is not acceptable to me...I can’t imagine myself taking insulin injection. I hate injections, they are very painful... (Anood, PHQ-9: 10).

While I tend to skip many of my doses...I usually do so because I hate the side effects of my diabetes medications...I can’t tolerate diarrhea (Naheel, PHQ-9: 15).

No, sometimes I forget to take my medication...just like today...the medication gives me abdominal pain as well...so I do not like it... (Maha, PHQ-9: 10).

Yes of course, but sometimes I omit one meal to omit a dose...because I know that even if these medications are good, they also have side effects...so I omit a meal to omit a dose...but I don’t omit doses haphazardly...I really fear the complications... (Khalid, PHQ-9: 14).

Reappraisal of short-term complications such as hypoglycaemia shaped Ruba’s adherence to her medication regimen. Her hypoglycaemic episodes were the underlying cause of non-compliance to oral hypoglycaemic agents or insulin. These hypoglycaemic episodes became the foundation for re-evaluation of her medication. Ruba consequently skipped one dose of her insulin regimen, as she thought she was able to manage and control hypoglycaemic episodes this way. For Ruba, this was a self-protective mechanism that could reduce side effects of such episodes. In other words, Ruba experienced tangible restrictions to her treatment plan as a result of hypoglycaemia. This in turn diminished her sense of autonomy and rendered her incapable of adhering to her medication plan. It appeared that concrete personal experience conferred a puzzling effect. Ruba was cognitively able to process the fact that insulin doses were important in maintaining a normal level of HbA1c. At the same time, however, she voluntarily chose to skip doses of the medication in response to the rebound hypoglycaemia she would consequently
suffer. It seemed that Ruba reappraised her choices through solid measurable outcomes such as HbA1c.

Blood sugar...I do that frequently... it doesn’t really affect me much...you know it measures the sugar for the past three months...as you know most of the time I have my blood sugar low...so I do not worry about the HbA1c...When my HbA1c increases I know the reason, as I sometimes skip one dose of my medication to avoid hypoglycaemia...I skip the third dose but I do not eat to compensate for that...sometimes when I feel hungry I eat salad so I can skip the does without any guilt...in general it is around 7 to 7.5...and you know HbA1c should be 6.2 or around...I know if I need to keep it less than 7 I have to take the third does of insulin and I do not want to take it...I can’t take it...I do not want to take my sugar down any more as I do not want to get more hypoglycaemic attacks...however, when I check on HbA1c and I find it low...I get nervous...I start thinking out loud... “Why has this happened”? ...as you know I try to adjust my medication and my diet as well... (Ruba, PHQ-9: 5).

7.3 Chapter summary

Despite the fact that adherence to self-care activities was identified as a key issue in managing diabetes, the data indicated that patients with diabetes and coexisting depression experienced significant challenges in implementing and maintaining the necessary lifestyle adjustments. This difficulty could be linked to the emotional responses elicited by a health threat, the chronic nature of the disease or the individual’s social milieu. Participants’ descriptions suggest that their experiences were labile with a volatile pattern of ups and downs. They reported experiencing a ‘roller coaster of emotions’. However, religiosity and spirituality, which formed a component of their health beliefs, had enabled the participants to accept their disease and consequently to deal with their emotions.

Diabetes is a chronic disease for which achieving a cure is not a goal. Rather, the management and control of symptoms is the ultimate objective. Participants in this study had to deal with daily problems as a result of living with diabetes. These
challenges, combined with the participants’ emotional responses, often disrupted self-care activities. Moreover, participants felt that diabetes had derailed the ‘normal’ trajectory of their life. Following diagnosis, they must accommodate a new identity, with their lives being changed forever thereafter.

The social milieu of participants had also heavily influenced their self-care activities. The collectivist nature of Arabic culture, in which the family and the common good transcend an individual’s interests, presented both advantages and obstacles in terms of adherence to their health plans. For example, while participants understood the adjustments that were needed in order to manage their diabetes, these adjustments also acted as a constant reminder of their loss. Despite their fear of complications, most participants failed to fully adhere to their recommended health plans.
Chapter 8
Integrated results

The aim of this mixed methods study was to examine factors that influence diabetes self-care activities among Jordanian patients with T2DM by integrating the findings from the study’s quantitative and qualitative components. An explanatory sequential mixed methods study design was used to explore selected elements of self-care activities (hereafter also referred to as self-care). A dominant quantitative phase was complemented by a subsequent qualitative phase.

As illustrated in Figure 3.1 on page 55, Chapter 3 Section 3.3.2, the quantitative phase was used to assess the direct and indirect influences of self-care. The results of this phase, using SEM, showed that self-efficacy and BMI directly influenced self-care. Additionally, illness perception and social support indirectly influenced self-care through depression and self-efficacy. The subsequent qualitative phase explored the perceptions of patients with diabetes and coexisting depression stratified according to the PHQ-9 score: mild depression (PHQ-9 = 5–9), moderate depression (PHQ-9 = 10–14) and moderately severe depression (PHQ-9 = 15–19). The overarching finding of this phase of the study was that patients with depression often believed that T2DM had changed their life forever. Furthermore, emotional reactions to diabetes, personal attributes, cultural stereotypes, social pressure, and psychological status frequently influenced the participants’ approach to self-care. This chapter integrated data from both components. A schematic representation of the data integration is represented in Figure 8.1; page 207.
Figure 8.1  A schematic representation of the data integration
8.1 Data integration: Quantitative and Qualitative findings

As previously discussed in Chapter 2 Section 2.2, it was postulated that illness perception, BMI and glycosylated haemoglobin influenced self-care through their association with depression, social support, religious and spiritual coping, and self-efficacy. The quantitative phase yielded information about the predictors of self-care. The qualitative component provided data that underscored the importance of depression, psychological status, social support, religiosity and spirituality and their relationship with self-care. It could be concluded that the composite model as illustrated at Chapter 2 Figure 2.1 on page 28 was parsimonious, specifically in the context of the clinical setting in Jordan.

The integrated findings from both the quantitative and qualitative components are illustrated in Figure 8.1 on page 208 some constructs such as religious and spiritual coping are subjective and culturally conditioned. These were explained by the qualitative data. Other constructs that related to cognitive processes around the presentation of a threat were captured only by the quantitative data. The chapter discusses the outcomes of the study.

8.1.1 Self-care activities of patients with T2DM in Jordan

The current study demonstrated the mean (SD) score of self-care activities (M = 40.49, SD = 14.47), with a range of 7 to 84 (Potential range: 7–92), with higher scores indicating higher levels of adherence to self-care activities (Toobert, et al., 2000). These data demonstrate a modest level of self-care activities among the study sample. Of the 220 respondents, only approximately 15% had high levels of self-care adherence as measured by one standard deviation above the mean SDSCA
This suggests that the majority of respondents found it difficult to adhere to their healthcare plan. Interview data confirmed that none of the participants fully adhered to their health plan, suggesting that complete control over diabetes management was frequently challenging.

### 8.1.2 Self-care activities and self-efficacy

The results from the quantitative component demonstrated that self-efficacy was the cornerstone of self-care activities for patients with T2DM. This finding was corroborated in the qualitative findings, and also provided an explanation of how the participants’ levels of self-efficacy influenced their self-care.

Explanatory factors for self-efficacy were explicated in the qualitative interview findings. To illustrate, factors relating to the theme of *Education empowers but cultural pressures weigh in, which* were organised into three subthemes: *Knowledge acquisition, Cultural beliefs and sociocultural roles*, showed that self-efficacy was a vital issue in self-care. Participants observed that various personal attributes influenced their capacity to self-manage their health condition. For example, some participants reported that their previous formal education had assisted them in feeling competent in accessing and interpreting reliable information about diabetes. A good education was thus seen as empowering. Participants similarly found that having an active social role was a key motivator for adherence to a healthcare plan. Correspondingly, many reported experiences and beliefs suggesting that ageism could hinder self-care activities.

Other variables such as BMI and glycaemic control also impacted on diabetes-related self-care.
8.1.3 Self-care activities and Body Mass Index (BMI)

More than 50% of the study participants were classified as obese (BMI ≥ 30 kg/m²). In the SEM analysis, BMI had a significant correlation (β = −0.184; p < 0.01) with self-care. However, an indirect relationship with self-care activities through depression and self-efficacy was not shown in the quantitative component.

The direct and indirect link between BMI and self-care activities emerged even more emphatically in the qualitative data. A high BMI was linked not only to fatigue, excessive sleepiness and low levels of physical activity, but also to negative emotions and depression.

_The higher the Body Mass Index one has, the less the activity he performs...and this in turn increases sleepiness, fatigue, and depression..._ (Khalid, PHQ-9: 14).

_When I gain weight... it affects all my body systems...and it affects my activity indoors and outside...I feel heavy and sleepy all the time..._ (Sama, PHQ-9: 16).

8.1.4 Self-care activities and blood glucose control

Blood glucose level control was assessed by Glycosylated haemoglobin (HbA₁c). Data showed that 62% of the study population demonstrated an HbA₁c ≥ 7%, suggesting poor long-term glycaemic control (American Diabetes Association, 2013b). The SEM analysis found neither a direct nor indirect relationship between HbA₁c and self-care. Findings from the qualitative component of the study, however, provided a different insight, with participants’ narratives revealing their understanding of the relationship between HbA₁c levels and their psychological
status. Several participants discussed their adherence to self-care activities and how this related to their HbA\textsubscript{1c} levels.

\begin{quote}
When I measure my blood sugar level and find it within normal I feel extremely happy! (Myasar, PHQ-9: 10)
\end{quote}

### 8.1.5 Self-care activities and depression

Depression was highly prevalent in the study sample, with approximately 40% of participants reporting moderate to moderately severe forms of depression as indicated by their PHQ-9 scores ($\geq 10$). The SEM analysis showed that depression had an indirect relationship to self-care, through self-efficacy.

Despite the absence of a significant direct relationship between depression and self-care activities in the quantitative results, 10 participants interviewed across all depression spectrums discussed the influence of their psychological status on self-care. Participants viewed the psychological stressors engendered by their diagnosis as obstacles to managing their health condition. As discussed in Chapter 7 Section 7.2.1.1, participants described their diagnosis as a turning point in life, or even a ‘death sentence’. The first theme that emerged from the qualitative data was \textit{Initial reactions to the diagnosis}. Thus, the qualitative findings provided insights into the potentially overwhelming and challenging issues relating to the emotional impact of diabetes.

Some participants emphasised the importance of psychological-based counselling sessions for individuals with diabetes and their families. Such services, they asserted, would help Jordanians with diabetes to cope with their condition. These participants believed that counselling services should be implemented as
standard practice in all diabetes health management plans. They further asserted that counselling sessions would empower patients to more effectively draw on available social resources to assist them in coping with diabetes.

In summary, although the quantitative data did not show a direct relationship between depression and self-care activities, the qualitative data explicated this relationship, highlighting the importance of health-enhancing psychosocial factors such as social support.

**8.1.6 Self-care activities and social support**

Quantitative data in this study supported the indirect relationship between social support and self-care activities ($\beta = -175; p < 0.001$). Overall, participants reported good levels of social support as indicated by the ESSI score ($M = 26.00; SD = 6.4$, Range: 8–34).

Although quantitative data did not reveal a direct relationship between social support and self-care activities, narratives from the qualitative interviews endorsed this relationship, unveiling both its positive and to some extent negative impacts on self-care activities. Overall, a positive value was accredited to support received from family members. This was not consistent across all interviews, however, with some participants reporting negative social pressures that they attributed to the community. Others spoke of rigid cultural expectations having a deleterious effect on their self-care.

The qualitative findings were able to explicate social support as a concept, and to elucidate the particular attributes of this support by contextualising it within
Arabic culture. The negative aspects of social expectation within Arabic cultural traditions were also identified as potential barriers to self-care. For example, the imperative of sharing food as a social activity seemed to be privileged over weighing up the pros and cons of such actions on the participants’ health. In order to fit in with their community, respondents reported typically compromising their health by choosing to eat when in company without any consideration to their diet plan. This conformist approach prevailed despite participants possessing the knowledge about their necessary dietary restrictions. Essentially, participants felt bound by their sociocultural values to blend in with the crowd.

8.1.7 Self-care activities and religious and spiritual coping

In the quantitative component of the study, religious and spiritual coping were evaluated using a Religious and Spiritual Coping (RSC) subscale. In the SEM analysis, it was hypothesized that those with higher levels of religiosity would be more likely to engage in self-care activities. It was found that RSC was not significantly related to self-care, directly or indirectly. However, the narratives emerging from the interviews clearly indicated a strong relationship between religiosity/spirituality and self-care, with all 15 participants alluding to their religious conviction in the context of their adherence to self-care activities.

All participants (14 Muslims and 1 Christian) believed that their health condition was ‘God’s will’, and these beliefs facilitated an ultimate acceptance of their diabetes. Clearly, faith, spirituality and religious views strongly informed their attitudes towards their health status. Subscribing to the belief that their condition
was the ‘will of God’ proved to be a crucial factor in the participants’ acceptance of their T2DM.

8.1.8 Self-care activities and illness perception

8.1.8.1 Consequences

The present study hypothesised that the level of depression is expected to be high when the perceived consequences of diabetes are high. In the SEM analysis, a significant relationship between illness perception, consequences and depression levels was found ($\beta = 0.293; p < 0.001$). This was corroborated by the qualitative data findings, with Stress and Fear emerging as subthemes under the theme Understanding the consequences but struggling to adjust. Participants noted that stress and fear stemmed from diabetes risk perception. The presence of these emotions, they explained, hindered their self-care activities. Although fear of diabetes-related complications was acknowledged as a motivator to implement self-care activities, participants also noted that such motivation was typically short-lived.

Data in the qualitative phase also captured comments from participants regarding the impact of diabetes that evoked distress rather than depression per se. In dealing with the consequences of diabetes, it is not unexpected that participants would develop a wide range of emotional representations that either facilitated or hindered self-care.

8.1.8.2 Emotional representation

The participants of the study rated their emotional representation within the mid-range ($M = 4.8, SD = 3.2, \text{Range: } 0–10$). In the SEM analysis, emotional illness
perception was found to have a positive and direct relationship with depression ($\beta = 0.362; p < 0.001$). These results were corroborated by the qualitative findings whereby participants repeatedly confessed that their emotional reactions hindered their self-care. They cited occasions when they used emotional representations such as denial as reasons for skipping doses of diabetes medication.

During the interviews, participants also elaborated on the issue of stress, linking it to different aspects of their lives such as emergent circumstances, events and family issues. Participants described daily challenges and stressors as representing an obstacle to their self-care activities. For many participants, solace was found in maladaptive and health-damaging behaviours such as smoking and eating high glycaemic index foods.

### 8.1.8.3 Treatment control

Another component of illness representation – the perception of treatment control – was rated highly ($M = 7.4, SD = 2.5, \text{Range: 0–10}$). In the SEM analysis, treatment control had a negative and direct relationship with depression ($\beta = 0.109; p < 0.05$).

The association between treatment control and depression was confirmed in the qualitative findings. Participants described their inability to control the potential side effects of diabetes medication (nausea, stomach problems and intestinal disturbances) as overwhelming and insurmountable. Feelings of helplessness represented a barrier to self-care. Similarly, insulin-based treatment was reported as a dreaded option for diabetes control, and the anxieties around their treatment
led some participants to skip insulin doses. Participants attributed their aversion to insulin treatment to the route of medication administration (injection).

**8.1.8.4 Identity-illness representation**

The identity representations score yielded ($M = 4.8, SD = 3.1, \text{Range: } 0–10$). However, the SEM analysis failed to show a significant association between depression and identity in the path analysis model ($\beta = 0.017; p > 0.05$).

The qualitative data analysis provided a range of views. The subtheme, *Chronicity*, which was related to the fourth theme, *Understanding the consequences but struggling to adjust*, revealed hypoglycaemic symptoms to be the underlying cause for non-compliance with a treatment plan. Participants described how hypoglycaemic episodes became a source of stress, anxiety and fear. This emotional response diminished their freedom and also impeded their adherence to the required medication plan.

Notably, the average duration of T2DM was ($M = 9.7, SD = 8.0$) years, and a lack of awareness of diabetes-related symptoms could occur as a result of the long duration of T2DM. Additionally, depression-related symptoms could have mitigated diabetes-related symptoms; for example, the side effects of diabetes medications could have masked the effects of diabetes symptoms.

**8.1.8.5 Timeline perception**

Timeline perceptions represent participants’ beliefs about the acuteness versus chronicity of diabetes. Although participants understood diabetes to be a chronic condition ($M = 8.3, SD = 3.0, \text{Range: } 0–10$), the SEM analysis did not show a
significant relationship between the diabetes timeline and depression ($\beta = 0.014; p > 0.05$).

The interview data refuted the quantitative results in this respect, with respondents seemingly linking the chronicity of their condition to their psychological distress. Chronicity of diabetes, which is a subtheme of the fourth theme, *Understanding the consequences but struggling to adjust*, had an impact on shaping the participants’ psychological status.

The participants spoke of their biological and psychological restrictions, and described the hardships inherent in the day-to-day management of their health. Living with diabetes for the rest of their life was a difficult concept to accept, they explained, and this struggle often limited their self-care behaviors. In some cases, the chronicity of diabetes engendered boredom that in turn hindered self-care activities. The realization that diabetes is for life, and that management of a chronic disease was a very demanding process, caused some participants to be consumed by a sense of hopelessness and futility. The knowledge that even full adherence to a health plan would not effect a cure was in some cases a disincentive for maintaining a self-care plan. Participants described the process of adhering to a management plan as a tedious and pointless endeavor. Moreover, they anticipated adherence to be unattainable.

In theory, the chronicity of diabetes should result in better personal control over diabetes, when patients engage in their self-care activities for a long time, they become familiar with such activities, thus, they gain experience that enables them
to practice some control over their condition. However, this was not found to be the case among the study participants.

8.1.8.6 Personal control

Participants gave a high rating to their personal control over diabetes (M = 6.4, SD = 2.5, Range: 0–10), although no direct relationship could be established between personal control and depression in the SEM analysis.

However, the qualitative data showed a different trend, where participants who claimed less personal control over their health condition were also more likely to report depression. Participants described a decline in their psychological status as occurring in conjunction with their sense of lack of agency over their health condition.

_When I can’t control my disease ... I feel so bad and depressed..._ (Myasar, PHQ-9: 10).

8.1.8.7 Illness coherence

The term illness coherence refers to the participants’ understanding of their condition. The participants considered their understanding of T2DM to be high (M = 7.8, SD = 2.6, Range: 0–10). Although there was no direct relationship between illness coherence and depression in the SEM analysis, the narratives revealed that the patients did have some understanding of diabetes-related comorbidities. This in turn influenced their psychological status as well as their daily self-care activities.

_I feel that I understand it enough to explain it to others ... I know diabetes and I know its treatment ..._ (Ruba, PHQ-9: 5)
When my HbA1c increases I know the reason, as I sometimes skip one dose of my medication to avoid hypoglycemia… I skip the third dose but I do not eat to compensate for that… sometimes when I feel hungry I eat salad so I can skip the medication without any guilt… (Ruba, PHQ-9: 5)

8.2 Chapter summary

The integration of findings from both the quantitative and qualitative components of this study confirms the direct and indirect relationships of the composite model proposed in Chapter 2 Figure 2.1 on page 55. The interplay between the study outcomes, self-care, and the psychosocial constructs examined in this study was validated.

The findings give credence to the importance of using a mixed methods design in studying a multifaceted phenomenon. Conducting a sequential two-phase study, quantitative followed by qualitative, and using a mixed methods approach, enabled a comprehensive exploration of the experience of self-care activities among patients with T2DM in a tertiary outpatient setting in a Jordanian hospital.
Chapter 9: Discussion and conclusion

9.1 Introduction

The final chapter discussed the major findings that emerged from the study, with reference to the existing literature on self-care activities and their relationship with the study-selected psychosocial variables. The chapter also addresses how these findings might contribute to achieving adherence to a health plan, which in turn can lead to better health outcomes. Implications and relevance to healthcare practice and health education programs will be considered. This will be followed by a discussion of the strengths and limitations of the study, and finally by a general conclusion.

The main findings of the POISE were: i) depression is highly prevalent among patients with T2DM in Jordan; ii) illness perception, depression and social support have an indirect relationship with self-care activities; iii) self-efficacy and Body Mass Index have a direct relationship with self-care activities; iv) religiosity is an important aspect in self-care activities; and 5) day-to-day self-care activities are often challenging, with the participants’ psychological status frequently compromising adherence.

9.2 Sample Characteristics

Of the 220 adult participants diagnosed with T2DM and recruited for this study, all were Arabs, with 52.3% of the study respondents being female and 47.7% male. This result is consistent with a recent study among the same population, in
which no significant disparity between women and men in the prevalence of diabetes was reported (Ajlouni, et al., 2008).

The participants in the study were relatively young with an average age (Mean = 58.2, SD = 10.8) years. These results are in line with an earlier project that drew numerical projections for the incidence of diabetes globally, and that reported the average age of people diagnosed with T2DM in developing countries to be between 45 and 64 years, with the majority being younger than 64 years (King, Aubert, & Herman, 1998). The early onset of T2DM among the respondents in the current study provided a snapshot illustration of the widespread burden of T2DM among Jordanians (Stayoussef et al., 2009). These demographic attributes revealed challenges to diabetes self-care. The prevalence of diabetes in the Jordanian population also reflected the impact of environmental, cultural and behavioural changes such as urbanisation, the prevalence of an increasingly sedentary lifestyle, the consumption of high-calorie foods and the increasing rates of obesity (Alhyas, Nielsen, Dawoud, & Majeed, 2013; Jordanian Ministry of Health, 2011). These aspects of modern life were reflected in the BMI results, with more than 80% of the study respondents falling within the overweight or obese category. This result is consistent with the BMI range reported in an official Jordanian health publication (Jordanian Ministry of Health, 2011). Overweight and obesity among Jordanians could be a precursor to increasing the burden of diabetes, for example, increasing dyslipidaemia which in turn could result in cardiovascular-related disorders and disability.
Lipid profile results revealed that most of the respondents had dyslipidaemia, as evidenced by their high levels of LDLs, triglycerides and total cholesterol, and low levels of HDLs. These results are consistent with previous studies undertaken in Jordan, indicating a high prevalence of dyslipidaemia among Jordanian patients with diabetes (Khader, Batieha, Ajlouni, El-Khateeb, & Ajlouni, 2008; Khattab, et al., 2010). Fortunately, the majority of the respondents had been prescribed lipid-lowering medications, which is in line with the ADA recommendations (2014). The participant’s lipid profile could indicate the lack of a specific adjustments of their diet.

The average duration of T2DM in participants was 9.7 years ($SD = 8.0$, Range: 0.6–35 years). This study yielded comparable findings to a study undertaken amongst Jordanians that reported a high prevalence of diabetes among the 50–59 year age group (Ajlouni, et al., 2008). According to an ADA report (2014), the duration of T2DM is a risk factor for micro-vascular complications among patients. Moreover, long duration is a risk factor with a greater effect at a younger age. Diabetes-related complications were highly prevalent among the current study population, with the majority of the participants demonstrating at least one diabetes-related comorbidity such as diabetic retinopathy, peripheral vascular disease, cardiac disease, cerebrovascular disease and hypertension. These macro and micro-vascular complications are reported to be common amongst patients with diabetes (American Diabetes Association, 2014).

Although a substantial body of clinical trials has found that tight glycaemic control is of key importance in reducing diabetes-related comorbidities (Control &
Group, 1995; Ohkubo et al., 1995; UK Prospective Diabetes Study Group, 1998), the majority of the participants had uncontrolled blood glucose, as indicated by HbA1c ≥ 7% (American Diabetes Association, 2014). This is consistent with the findings of a recent cross-sectional study undertaken in Jordan on a group of patients with T2DM (Khattab, et al., 2010). In the current study, poor glycaemic control could be explained by the long duration of T2DM among the study participants, combined with a low level of adherence to diet plans and physical activity, which in turn will be reflected in high diabetes-related morbidity.

9.3 Major findings

9.3.1 Depression is highly prevalent among patients with T2DM in Jordan

The current study revealed a high rate of depression (76%) among patients with T2DM in Jordan. This is higher than previously reported (Al-Amer, et al., 2011). This disparity in results could be attributable to several factors: a) the previous study used PHQ-8, an earlier iteration of PHQ-9 with slight differences in diagnostic criteria; b) the author only used a forward-translation method to translate the English version of PHQ-8 to an Arabic version; and c) the previous study only reported the prevalence of major depression, and did not report the prevalence of mild and moderate levels of depression. In contrast, the current study reported all levels of depression as recommended by the PHQ-9 developer (Kroenke & Spitzer, 2002). This is also the first study that used the PHQ-9, and also translated using a forward-backward translation method to evaluate the depression levels of Jordanian patients with T2DM.
In relation to depression prevalence, the results of this study are comparable to other published findings of T2DM prevalence in countries within the same region. For example, a study conducted in Bahrain reported a high prevalence of mild to moderate and even severe depression among patients with T2DM (Almawi, et al., 2008). Similarly, a study undertaken in Iran reported a depression rate of 71.8% among patients with T2DM (Khamseh, Baradaran, & Rajabali, 2007). Globally, depression prevalence among patients with diabetes seems to be a common phenomenon. An oft-cited meta-analysis study found that patients with diabetes have double the odds of developing depression in comparison to their counterparts without diabetes (Anderson, et al., 2001).

In the current study, women with T2DM were more likely to develop depression than their male counterparts. Moderate to severe depression was found to be more prevalent among women than men, with rates of 31.3% and 21% respectively. This corroborated international data that indicate a higher rate of depression among women with diabetes in comparison to their male counterparts (Ali, Stone, Peters, Davies, & Khunti, 2006; Anderson, et al., 2001). These results were consistent with other studies across the Arab region. For instance, in Bahrain, depression was found to be more common in Arabic women with T2DM in comparison to their male counterparts (Almawi, et al., 2008). It could be argued that a higher prevalence of depression among women stems from the differences in coping strategies between the genders, in which depression levels are intricately linked to a sense of self-confidence and feelings of mastery for men or that women might be more proactive in seeking medical help and/or openly acknowledging
mental health issues (Cherrington, et al., 2010). In general, men in Arabic communities display higher levels of confidence, which is not surprising in a patriarchal society in which a man is considered the head of the family and is accorded the highest authority and status. Women, conversely, typically occupy subordinate positions in society, with their role restricted to supporting their husbands, raising children and running the household (Al-Krenawi, Graham, Dean, & Eltaiba, 2004).

Overall, the high rate of depression among patients with diabetes in Jordan suggests a lack of a societal recognition and/or awareness of depression among those with T2DM. In some cases, the existence of depression may be denied or concealed due to fear of stigma, shame and marginalisation from the community. As discussed earlier, in Arabic culture, health issues are typically handled as private family matters (Aloud & Rathur, 2009; Youssef & Deane, 2006), and this frequently leads to delays in seeking medical treatment.

9.3.2 Direct and indirect factors influencing self-care activities

This section discusses the findings that illness perception, depression, and social support all have an indirect relationship with self-care activities. Self-efficacy and BMI, conversely, are seen to have a direct relationship with self-care activities.

9.3.2.1 Indirect factors influencing self-care activities

9.3.2.1.1 Illness perception

The CSM would propose that accurate and positive illness representation would lead to greater self-care. Using the CSM, a sound argument can be advanced in relation to the current results. That is, the illness perception of T2DM forms part
of a person’s beliefs or ‘idiosyncratic illness model’. The illness perception model demonstrated by participants in the study is in line with a broader cultural discourse in Jordan that reflects Arabic cultural-normative beliefs in relation to health. The collectivist nature of Arabic culture, where people respect and comply with cultural norms in order to be accepted socially (Feghali, 1997; Nydell, 1987) shapes the way people perceive their diseases, and the values they ascribe to the states and concepts of illness and wellness. It is therefore reasonable to suggest that illness perception can be seen at once as an individual model, and also one that is strongly affected by cultural background and ethnicity. Many other studies have reported the impact of cultural background on illness perception models in response to a health threat (García, 2011; Jayne & Rankin, 2001; Kucukarslan, 2012; Pinelli, et al., 2010; Yamakawa & Makimoto, 2008; Ypinazar & Margolis, 2006).

9.3.2.1.1 Consequences

The consequences of T2DM demonstrated a significant relationship with the depressive symptoms, yet, some participants reported that diabetes related complications motivated them to self-manage their diabetes. The importance of the awareness of diabetes complications among patients with T2DM is seen. Those who acknowledged a high sense of consequences of T2DM exhibited a high level of depressive symptoms. Realization that diabetes carries some related consequences could be used as a crucial factor in a more personal adherence to a health plan. On the other hand, having conscious about the diabetes complications among Arabs, could lead to fatalistic thinking which could lead to poor diabetes self-care. A previous meta-analysis study reported that the seriousness of a health threat is linked negatively to psychological wellbeing (Hagger & Orbell, 2003). Likewise, as
identified in the literature, the level of intensity of the consequences of diabetes is directly linked to the nature of the emotional reaction that a person expresses in response to a health threat (Abubakari et al., 2012; Lawson, Bundy, Belcher, & Harvey, 2010; Yuniarti, et al., 2012).

**9.3.2.1.1 2 Emotional representation**

The emotional illness representation revealed that the participants reported having moderate negative feelings in relation to their diabetes ($M = 4.8$, $SD = 3.2$). However, a higher score in emotional representation predicted higher depressive symptoms. This created a cycle in which depression would arise, adversely impact on self-efficacy, and in turn negatively affect self-care activities. Thus, it is plausible that the emotional state of the participants would lend support to the driving power of their mental health status relating to diabetes care. Consistently, literature reported the motivating power of worries about diabetes impacting on the disease outcome (Vollmann et al., 2010; Yuniarti, et al., 2012).

**9.3.2.1.1 3 Cure/ Control**

The POISE study found that treatment controls had a significant association with depression. In contrast to low dietary and exercise adherence, the participants were highly adherent to oral hypoglycaemic agents and/or insulin. These results suggest that participants might consider medications to be a ‘quick fix’, unlike diet therapy or exercise, both of which require an ongoing commitment. These patterns reflect what is already known: as reported in a review study, if prescribed treatments are unable to control the symptoms of chronic disease, emotional responses such as distress and depression are likely to emerge (Kucukarslan, 2012). However, it was
found that chronic pain led to poor diabetes outcome, and present symptom relief took precedence over a long self-care plan. Lack or ambiguity of diabetes symptoms meant no proximal threat and adherence to self-care declined (Stack, et al., 2011).

9.3.2.1.1 4 Identity

Identity construct refers to the number of somatic symptoms that patients had as a result of their diabetes and it was a central factor in the participants’ illness perception model. The ways in which participants labelled their condition and dealt with the symptoms were central contributing factors to their emotional response. Where the symptoms of an illness were frequent and experienced as serious, they were likely to be perceived grimly, thus escalating the negative cognitive and emotional reactions to a health threat. Most reported was fatigue; less extent to fatigue was hypoglycaemia and upset stomach. It is widely acknowledged that many oral antidiabetic drugs have gastrointestinal effects which in turn could explain these findings. The results of the study revealed that participants linked these symptoms to diabetes. Hence, it is evident that participants had an accurate identity for T2DM which is most likely to produce the aforementioned symptoms. However, for T2DM to result in a few symptoms is challenging for patients. To illustrate, the lack of symptomatology would reduce the motivation for diabetes self-care. A review study by Hagger and Orbell (2003) reported a predictable relationship between illness symptoms and coping behaviours.
9.3.2.1.1 5 Timeline

The chronicity of diabetes is largely understood by the participants; keep in mind that the chronic timeline of diabetes is mostly linked to diabetes complications. The participants viewed the chronicity of T2DM as connected to higher levels of complications and potential disability. Whenever they heard stories concerning the potential long-term complications of diabetes, they experienced an increase of stressful emotions. In turn, these emotions influenced their self-care activities. Thus, chronic timeline of diabetes could be seen as a barrier for self-care because once people perceived their disease as a chronic health problem they were more likely to doubt the effectiveness of self-management. Consistently, a systematic review study reported that chronic timeline of diabetes is linked to more concern of diabetes with greater emotion representation which led to poor diabetes outcome (Mc Sharry, et al., 2011). However, a study by (Yuniarti, et al., 2012) reported that the chronic timeline for diabetes led to more understanding of the disease and led to more confidence in the treatment plan ((Yuniarti, et al., 2012). Thus, it is important that nursing professionals assist individuals with T2DM to prioritize their treatment plan to not only consider acute symptoms, but also to observe late developing symptoms.

9.3.2.1.1 6 Personal control

This construct revealed the participants’ beliefs in a person’s action. The participants reported a good level of personal control over diabetes ($M = 6.4$, $SD = 2.5$). These results could signify a greater sense of confidence in managing diabetes. However, evidence of good self-management is lacking in this group. These results
could be explained in view of different aspects such as social aspect, in which participants had to conform to the culture in terms of dietary habits and lack of physical activities. Hence, even though participants perceived high self-control over diabetes the social desirability and conformity were seen as necessity more that adhering to a health plan.

9.3.2.1.1 Illness coherence

The item referred to this construct, suggested that participants had a clear sense of diabetes understanding. This item yielded \( M = 7.8, SD = 2.6 \). This is could be another paradox within the participant’s views, to which, this understanding did not add to their self-care. Nevertheless, there is a room for improving diabetes related management, for this construct correlated negatively with diabetes symptoms which were seen as a physical and social limitation, consequently reducing self-care.

9.3.2.1.2 Depression and self-care activities

The POISE study found that depression had an indirect relationship with self-care activities through its association with self-efficacy, and that this in turn had a direct relationship with self-care activities among patients with T2DM. These results could be linked to the fact that most of the study sample reported some form of depressive symptoms (such as fatigue, hopelessness and apathy), and that these symptoms might impair cognitive ability to execute self-care activities. As a result, confidence levels would be adversely affected as participants start to question their ability to manage their condition of T2DM. The study found that participants felt more competent in adhering to self-care activities when they showed acceptance of
their condition. Conversely, participants who experienced low mood and felt depressed described a failure to adhere to self-care activities. They reported maladaptive coping mechanisms such as smoking or consuming junk food when they were feeling depressed.

The study also found that patients experiencing depression were more likely to indulge in a negative perception of their world, including a spectrum of negative self-perceptions. For example, depressed participants perceived T2DM as a devastating illness with dire consequences that were frequently near impossible to control. This often created a feedback loop that led participants to believe that controlling T2DM was an insurmountable hardship. The outcome was a reduced confidence in their ability to self-manage their condition. Additionally, participants viewed their future performance pessimistically, and they feared the possibility of being dependent on others for life. The findings of this study supported earlier literature that reported that patients with positive thoughts about their diabetes are more likely to maintain confidence in their ability to commit to their health plan (Aljasem, et al., 2001; Maciejewski, et al., 2000; Shumaker & Arlene, 1984; Skelly, et al., 2000). Other studies claimed that the relationship between depression and self-care activities is mediated by self-efficacy (Bisschop, Kriegsman, Beekman, & Deeg, 2004; DiMatteo, 2004; Sacco, et al., 2005). It is well-established that factors such as emotional status, self-efficacy and illness perception interact with and impact upon self-management activities (Rodriguez, 2013; Sigurðardóttir, 2005; Yuniarti, et al., 2012). Furthermore, the level of confidence that patients have in their ability to
perform self-care activities is directly linked to the levels of stress and depression experienced when facing a threat (Bandura, 1994).

9.3.2.1.3 Social support and self-care activities

Social support played a pivotal role in promoting self-care activities among patients with T2DM in Jordan. In trying to make sense of their health conditions, patients were inevitably influenced by their social milieu. Participants reported that family support often enhanced mental wellbeing and reduced psychological burden. To clarify, patients received both instrumental and emotional support from their families, and this helped them manage certain aspects of their health condition. Social life in Arab countries is family-centric rather than egocentric, and loyalty to the family is more important than an individual’s needs and ambitions. An advantage of such cultural values is that the family will actively support its members during times of need (Nydell, 1987). Arab people who have a chronic illness will often view the family members as their primary source of support. In other words, the family plays a pivotal role in supporting its members and helping to build resilience and foster a sense of confidence – these are indispensable attributes for those facing a health threat.

These results were comparable to a previous review that reported the buffering effect of social support, and the ways in which it mitigates the negative consequences of psychological stressors (Brown et al., 2004). Social support has also been shown to have a positive impact on psychological and mental health (Berkman, Glass, Brissette, & Seeman, 2000; Brown, et al., 2004; Li, et al., 2009; Lind, et al., 2012). A review from the United States reported that patients with
diabetes who rarely received social support had double the risk of developing depression, compared with their counterparts who received regular social support (Li, Ford, Strine, & Mokdad, 2008). Social support is therefore inversely correlated with the severity of both the physical and psychological influence of diabetes (Awasthi & Mishra, 2011; Yuniarti, et al., 2012).

The study also revealed the negative consequences of social support on self-care activities. Some participants reported delegating medical duties (such as administering insulin injections or monitoring medications) to a family member. Surrendering one’s autonomy in this way serves to increase dependence on the family unit, and thus further diminishes the patient’s confidence in their capacity to execute self-care activities. These findings are consistent with other studies, which also reported that not all types of social support are helpful. For example, excessive instrumental support, where a family member monitors glucose levels for a patient, may lead to dependency and loss of control. This in turn may worsen diabetes outcomes (van Dam, et al., 2005; Vollmann, et al., 2010). Additionally, social support had negative consequences when family members blamed a patient for his/her lifestyle habits which led to feelings of frustration and guilt, generating higher levels of depression. The fact that some patients viewed social support in a negative light could be a symptom of their depression. Patients experiencing a depressed mood will inevitably hold negative views about the world, and such an outlook can lead to avoidance behaviours.
9.3.2.2 Direct factors influencing self-care activities

9.3.2.2.1 Self-efficacy and self-care activities

The study found that self-efficacy had a direct relationship with self-care activities. Many of the participants reported that their confidence levels impacted on their ability to undertake self-care activities. For respondents, gaining mastery over their health habits, adhering to a diet plan, exercising regularly and monitoring weight control were all regarded as hardships. This pervasive negativity was intricately linked to their low confidence levels. Previous studies reported that perceived high levels of self-efficacy are associated with better adherence to a health plan, in particular diet, treatment and physical activity (Broadbent, et al., 2006). In general, studies that assessed the relationship between self-efficacy and self-care activities reported that self-efficacy impacted significantly on self-reported adherence to a health plan (Aljasem, et al., 2001; Bandura, 2004; Broadbent, et al., 2006; Maciejewski, et al., 2000; Nouwen, Urquhart Law, Hussain, McGovern, & Napier, 2009; Sacco & Bykowski, 2010; Sacco, et al., 2005; Wu, et al., 2007).

The study has added to the growing body of evidence that self-efficacy is a universal and pivotal issue in self-care activities among patients with diabetes. However, Arabic ethnicity is limited in the existing literature. This study has helped to fill this gap by exploring self-care practices among Arab patients with diabetes.

9.3.2.2.2 Body Mass Index (BMI) and self-care activities

The study found a direct and negative association between BMI and self-care activities. In a community where overweight and obesity are prevalent, there could be a number of reasons for the association (Jordanian Ministry of Health, 2011;
Zindah, et al., 2008). A high BMI is more likely to be contingent upon lower adherence to health prescriptions. In particular, a high BMI is connected to a failure to adopt and maintain positive dietary and exercise habits. This could be partially attributable to the fact that the Arabic culture is not particularly pro-physical activity (Badran & Laher, 2012). Additionally, Arabic people generally prefer to share food socially, even when it could prove deleterious to their health. A recent study held in the Gulf area in the United Arab Emirates (UAE) among women with diabetes found that Arabic sociocultural norms impeded a healthy lifestyle – for example, rendering it difficult for women to engage in outdoor physical activities (Habiba, Baynouna, & Bernsen, 2010).

### 9.3.3 Religious and spiritual coping and self-care activities

Although the SEM results did not show a relationship between religious/spiritual coping and self-care activities in this study, the qualitative data provided evidence that religious orientation influenced the severity of depression, and that this in turn affected self-care activities.

Participants in the study believed that their faith in God, made it easier for them to accept their diagnosis of T2DM and to deal with their symptoms. Additionally, this study provided evidence that faith helped patients to harness an inner strength. Through their connection to and intimacy with God, patients were able to manage the negative emotions that accompanied a diagnosis of T2DM. These results are consistent with other studies that found religious convictions to be an important factor in a person’s belief system. Religion and spirituality exerted a considerable influence on personal illness perception and mental wellbeing (King,
Speck, & Thomas, 1994; Koenig, et al., 2012; Rezaei, et al., 2008; Storch et al., 2004). A review study found that, despite the fact that religious orientations could be important in fostering a sense of hope and acceptance, religion was also frequently associated with psychological difficulties (Koenig, 2009). Although the latter study shed light on the impact of religiosity/spirituality on the mental health issue and identified religion as a powerful source of hope and meaning, the study only reviewed recent studies and did not use a systematic selection criteria. As such, these findings should be regarded with caution (Koenig, 2009). Existing research does however stress the importance of religion and health beliefs (Koenig, 2009; Nabolsi & Carson, 2011; Ypinazar & Margolis, 2006; Yuniarti, et al., 2012).

### 9.3.4 Day-to-day self-care activities are often challenging

Overall, the majority of participants reported moderate adherence levels to their self-care activities (Mean = 40.5, SD = 14.5, Range: 7–84). Despite the benefits of exercise in controlling blood glucose, improving metabolic problems and reducing obesity (American Diabetes Association, 2014), exercise was the health behaviour with the lowest level of participation among survey respondents in this study. These findings are in accord with a report released by the Jordanian Ministry of Health in 2011, indicating that approximately 80% of adult Jordanians were physically inactive. This report also found physical inactivity to be a worsening trend among Jordanians (Jordanian Ministry of Health, 2011). The current study similarly found low adherence levels to a diet plan.

Lack of compliance to dietary and exercise regimens could be attributable to the fact that adherence to diabetes self-care activities is a complex and
multifaceted process – and one that requires identifying the individual’s perception and beliefs about diabetes within the client’s psychosocial milieu that impacts on their coping behaviour. Moreover, adherence to blood glucose testing was (M=2.1, SD =2.3), which means that participants had a low level of adherence to blood glucose testing. However, it also indicated that participants were willing to perform health behaviour that was instantly rewarding. Of note, the ADA (2014) reported that blood glucose testing on a daily basis is of low importance in controlling T2DM, never the less, testing blood glucose twice a week or when necessary is of benefit.

Foot care is another aspect that is considered of importance in diabetes care, to prevent complications of lower extremities. The score of the subscale concerning foot care in the study group was (M= 2.4, SD=2.5). These results showed that the participants performed foot care; however, not at a satisfactory level according to the guidelines recommended by ADA (2014). However, the participants of the study could have been driven by fear to perform foot self-care. Thus, it is plausible that the risk perception may have worked as a motivator. There is room for health education that enhances the understanding and comprehensibility of diabetes, which in turn helps patients to adapt foot self-care that is more evidence based. Consistently, the literature reported that patients with diabetes are more likely to undertake foot-care when they perceive their own personal risk (Scollan-Koliopoulos, Walker, & Bleich, 2010; Searle et al., 2008).

Whilst the implementation of self-care activities requires sound cognition, it is noteworthy that a participant’s psychological status also influenced their capacity to execute such skills. Participants reported a loss of self-confidence when faced with a
stressful condition. It seemed the lack of confidence in their capacity to perform self-care activities was a central contributing factor to the low levels of adherence to a health plan. The lack of confidence sat alongside other psychological factors that impeded their ability to implement and maintain a self-care plan. Consequently, there is a difference between “knowing” and “doing”. Thus, healthcare providers are responsible for educating patients how to incorporate their knowledge into personal diabetes management to ensure a holistic approach to care.

9.4 Implications

The current research has important implications for healthcare practice and the development of healthcare policies to better manage patients with T2DM, particularly in Arabic countries.

9.4.1 Implications for healthcare practice

The study is significant because it evaluated the pivotal issue of self-care activities among patients with T2DM and coexisting depression, and also explored the influence of the psychosocial context. It revealed that self-efficacy and psychological status both play an important role in self-care activities and also provided empirical data on the prevalence of depression among patients with T2DM.

The implications of the study are multifaceted. Specifically, the study: i) provided further evidence of the incidence of depression among patients with diabetes; ii) used a mixed methods design to maximise the benefits of self-care activities in patients with T2DM and coexisting depression in Jordan. The mixed
methods design allowed the study to include a group of psychosocial variables within the patients’ milieu to assess self-care activities among Jordanian patients with T2DM; iii) provided evidence about the important role played by translation in cross-cultural research in health disciplines; and iv) revealed factors that are interrelated with the healthcare behaviour among T2DM patients in Jordan, and thus provided evidence to healthcare providers of the importance of tailoring an individualised health plan that meet a patient’s needs.

The study provides a snapshot of the prevalence of depression among patients with T2DM in Jordan. Depression was found to be highly prevalent (76%) among the study population. These data draw attention to the need for health prevention programs in conjunction with existing treatment programs. This information could be valuable to healthcare policy makers and regulators. The study’s findings also indicate the potential extent of the burden of depression among patients with T2DM in Jordan. Therefore, the study provides evidence for the need for future larger scale studies involving participants with diverse characteristics drawn from a broader demographic. The results of this study could be used as a baseline for future studies. Subsequent studies of broader populations of Jordanians, for instance, would enable a comparison of the depression prevalence across time. As such, the study’s findings may contribute to longitudinally tracking trends in the incidence of depression comorbidity in T2DM patients in Jordan.

The study also is important because it used the strengths of a mixed methods design to enhance our understanding of the selected psychosocial variables and
their relationship with self-care activities. To summarise, in existing literature there was a lack of empirical evidence of the magnitude of depression burden among patients with T2DM in Arabic communities. In order to address this gap, this study used a survey method to provide evidence-based data on the prevalence of depression. The study examined the association between T2DM and selected psychosocial constructs: illness perception, depression, social support, religious and spiritual coping, and self-efficacy. The analysis of data found depression to be highly prevalent among T2DM patients in Jordan. Building on these results, the study sought to understand how patients with T2DM and coexisting depression describe their experience with self-care activities. To achieve this, qualitative data were collected. The qualitative data established that Arabic individuals are strongly bound by their cultural and religious beliefs, and that these dogmas permeated the ways in which they viewed their illness and wellness. While the quantitative data uncovered the factors that have a significant relationship with self-care activities, the qualitative data complemented this by revealing how the participants’ beliefs shaped their levels of adherence to a health plan.

The assumption identified in the study’s conceptual model turned out to be correct and applicable to Jordanian patients with T2DM. Namely, participants in this study executed their self-care activities based on their cultural beliefs. These findings are consistent with those in existing literature, in which cultural background was recognised as a central factor in self-care adherence. This knowledge will enable healthcare providers to customise individual health plans to
meet personal needs (García, 2011; Jayne & Rankin, 2001; Kucukarslan, 2012; Pinelli, et al., 2010; Yamakawa & Makimoto, 2008; Ypinazar & Margolis, 2006).

Moreover, the POISE study is significant because the survey instruments were translated from the English language to the Arabic language. These instruments were subjected to rigorous psychometric testing, including computing factorial validity and coefficient alpha. These checks indicated that the Arabic version of these instruments had satisfactory reliability and validity, comparable to those of the English version of these scales. This study demonstrated a sound approach to translations of the study survey, with the translation being a multistage process that was based on well-recognised guidelines (Beaton, et al., 2002; Råholm, et al., 2010; Sousa & Rojjanasrirat, 2011). This study provided strong support for the validity and reliability of the Arabic version of the instruments. However, prospective studies to assess the impact of using this instrument on T2DM outcomes should be undertaken.

The instruments in the survey could be used to monitor changes in the psychosocial status of patients, and also to monitor patients’ adherence to self-care activities. Monitoring of self-care activities is likely to result in improving the adherence rates in diabetes-related health, and could also promote consistency in self-care activities. In summary, these instruments are valid and reliable and may be useful for further studies in which the populations are Arabs with T2DM.

The current study is one of only a few that translated the entire narratives. Narrative translation was based on the principles of semantic equivalence and context equivalence rather than verbatim translation. The study also evaluated the
influence of translation on the trustworthiness of findings. The translation was approached using a methodology based on the current literature (Al-Amer, et al., 2014). The study used only one translator to translate the narrative – a bilingual person whose first language is Arabic. Restricting the translation to one person is a strategy that ensures consistency across all interviewees’ accounts. Existing literature validates this approach to translation as best practice (Al-Amer, et al., 2014; Wu, et al., 2007). In this current cross-cultural research, the translation process provided an avenue for exploring how a multilingual team of researchers were able to manage the data within the Arabic context.

Further, the study presented evidence of the relationship between self-care activities and the selected psychosocial variables. It found that all the study-selected variables are of crucial value in predicting self-care activities among the study population. However, self-efficacy was the most influential factor in relation to adherence to self-care activities. These findings could provide evidence to healthcare professionals of the need to individualise a health plan that meets the needs of each patient, taking into consideration their specific psychosocial milieu. Such a customised approach would assist in increasing a patient’s confidence in their ability to incorporate self-care activities as part of their health plan.

9.4.2 Policy and practice

The Jordanian Government would ideally incorporate self-efficacy and mental health-enhancing interventions in programs promoting self-care activities. Among the study’s population, the incidence of depression was found to be over 70%. Because it impacts on a patient’s confidence and belief in their capacity to adhere
to a health plan, depression indirectly influences self-care activities. Self-efficacy was found to have a direct correlation with self-care activities. The possession of self-confidence in executing prescribed self-care activities is an important determinant in a patient’s capacity to cope with T2DM. Thus health education programs should focus on boosting the confidence levels of patients. Such a strategy, if incorporated into education and counselling contexts, could optimise diabetes management outcomes. Improvements to self-efficacy levels could lead to higher rates of adherence to self-care activities, and this in turn would lead to better diabetes outcomes.

The study found that cultural beliefs play a significant role in influencing self-care activities. It is therefore important for health education practitioners to stay informed regarding the role played by cultural and religious practice among Jordanian patients with T2DM. Such awareness would help them to deliver sensitive ethnocultural health services. Religious and spiritual coping were also found to be important predictors of a patient’s capacity to deal with T2DM. Healthcare programs that incorporate these factors should be made accessible to patients with T2DM. Such programs could be delivered in a number of environments, including hospital settings, community settings, workplaces, residential settings and remote areas.

It is important to implement health education programs that are led by trained diabetes educators who are practised at counselling patients with diabetes, and who are aware of the correlation between self-efficacy, depression and self-care activities. Importantly, such programs need to focus on fostering a sense of
self-confidence in patients in terms of their ability to self-manage their condition. This study found a positive relationship between the level of depression and a patient’s confidence in executing positive health behaviours.

The high incidence of depression found in the participants in this study indicates that the depressive symptoms may have been underestimated among patients with T2DM in Jordan. Thus, there is a need for the government to develop policies so healthcare practitioners can implement strategies aimed at the early detection of depression among patients with diabetes. Evidence-based guidelines propose psychological wellbeing as a fundamental issue in diabetes care. Furthermore, guidelines emphasise the importance of addressing psychosocial issues (American Diabetes Association, 2014). These objectives could be achieved by using a self-reporting questionnaire that is brief and easily scored, such as the Arabic version of PHQ-9. Maintaining psychological wellbeing amongst a T2DM population requires early detection of mental health issues. Training programs focusing on the early identification and effective management of depression among individuals with diabetes would prove invaluable. Such courses could deliver training to healthcare providers, covering issues such as professional communication, counselling skills and interview methods and strategies.

Special education initiatives need to be established to help people with comorbid depression and T2DM to manage their diabetes. Diabetes management plans could be personalised to correspond to the patient’s idiosyncratic profile. In order to help patients manage their disease more effectively, treatment plans need to consider a patient’s specific physiological, social and psychosocial reality
(American Diabetes Association, 2014). Importantly, educators in diabetes education programs and interventions need to focus on fostering the patient’s sense of self-confidence.

It would be beneficial for the Jordanian Government to prioritise funding for new educational programs that promote a healthy lifestyle. In this study, 47.7% of participants were found to obese and a further 34.1% were overweight. Correspondingly, the least frequently reported self-care management behaviour was engaging in a regular exercise routine. Notably, the ADA guidelines recommend that nutrition therapy be provided to all patients with diabetes and that this therapy be incorporated into their health plan. The Jordanian Government could therefore offer funding for nutrition therapy for patients with diabetes. In conjunction, programs that promote physical activities could be funded, using the media as an instrument to educate the target and broader population about the importance of exercise. Campaigns that use public figures are often effective, as are partnerships between community health service providers and workplaces, the latter of which could deliver programs for patients with diabetes aimed at increasing their physical activity.

9.4.3 Healthcare providers

The current study has shown that patients’ confidence in their ability to manage their health condition is influenced by their psychological status. The study also demonstrated that a lack of psychological wellbeing is a factor that can compromise adherence to self-care activities. It is therefore important that
healthcare providers draw on participants’ resources such as their social milieu to empower them to be able to adhere to their health plans.

The study showed participants with depression had inherent challenges in self-managing their diabetes. Depression in Arabic culture is considered a family issue, and one not to be discussed outside the family. There is a widespread cultural anxiety that disclosure of mental health issues could lead to stigma and ostracism from the community. Therefore, diabetes educators could place a greater emphasis on early intervention, including uncovering the symptoms of depression at an earlier stage, as well as educating patients with T2DM about depression. The ADA-recommended guidelines emphasise that diabetes educators should provide psychosocial education to patients with diabetes. It would be beneficial if health education sessions on the management of diabetes also incorporated educational material about depression. Notably, any educational interventions need to be based on culturally and religiously acceptable beliefs. Incorporating educational material about depression within a routine education session, for example, could reduce the stigma of depression, specifically when family members are included in these sessions.

The study found low levels of adherence to diet and physical activity regimens amongst the participants. Therefore, educators need to place a greater emphasis on the provision of material that promotes weight control and physical activity. Although diabetes educators in the Jordanian healthcare system –already provide nutrition therapy education in line with ADA guidelines (American Diabetes Association, 2013a), they could supplement this with the counselling of patients, as
well as a more rigorous approach to personalising nutrition therapy in order to achieve better outcomes. Furthermore, educators could advise their patients that at least thirty minutes of daily exercise will increase their wellbeing and optimise disease management outcomes (American Diabetes Association, 2014). Different yet complementary strategies could also be implemented to encourage patients to successfully manage their condition. These could include the delivery of educational resources during regular health visits, such as brochures, leaflets, flyers and audiovisual material that provide further detail about self-care activities. Patients with diabetes also need to be kept informed about online materials that are relevant to their condition, and that align with their cultural and religious beliefs.

This study found that social support is a vital factor that influences levels of adherence to self-care activities. Diabetes educators could therefore draw on patients’ resources, and also encourage the participation of family members in regular health education sessions.

### 9.4.4 Future studies

Future studies are needed to assess the progressive nature of diabetes as well as the frequently attendant depressive symptoms. Keeping in mind that Arabic people are unlikely to disclose mental health problems outside the family, culturally appropriate approaches need to be considered when designing future studies such as employing research assistants who share the same cultural arena with the research participants.

The study found that depression has an indirect relationship with self-care activities. However, the study could not infer causality. Thus further studies are
warranted in order to clarify whether this relationship is unidirectional or bidirectional among Jordanians with T2DM.

Further studies in the Arabic countries to investigate the interaction between depression, social support, religious and spiritual coping and self-efficacy with self-care activities are also warranted. These studies should be undertaken using a larger and more diverse sample group.

Although the CSM explained a significant variance in self-care activities, other models may be able to assess different perspectives of this issue, or may provide different views in relation to adherence to a health plan. Thus, comparison between this study model and different conceptual models is crucial. The comparison would highlight the most practical and effective theoretical framework to be employed among patients with diabetes and depression in order to produce the most favourable outcomes.

9.5 Limitations

The findings of the study were based on a sample from a single site – that is, from one hospital in Jordan. As Jordan University Hospital is a tertiary referral hospital, respondents recruited from that site were more likely to have acute or serious T2DM. The study only recruited participants who demonstrated good literacy levels. This criterion for the sample might limit the generalisability of this study, as it disallowed a voice for illiterate people. It is worth noting that the illiterate sector of the population is more vulnerable to depression, low self-efficacy, and poor self-care activities. As such, illiteracy could be linked to levels of
dependability. Illiteracy is also likely to limit one’s ability to access and utilise existing healthcare services.

Patients who were severely depressed as assessed by PHQ-9 score > 19 were excluded from the qualitative phase of the study. Thus, the study did not assess the impact of severe depression on self-care activities. We do, however, acknowledge that participants with severe depression should be given a platform from which to express their thoughts, ideas and concerns.

The empirical data of this study were collected using self-reporting instruments. Although this is accepted as a practical and expedient method for collecting data during a specified timeframe and from a large cohort of participants, this method does nonetheless generate data that demonstrate some bias (McCrae & Costa, 1983). For example, social desirability bias, in which respondents often portray themselves in a socially acceptable light, is a common phenomenon associated with this method of data collection.

The study used Summary of Diabetes Self-Care Activities (SDSCA) scales to measure the outcome variables. Although a well-recognised scale used by various studies, the reliability and validity of the SDSCA are limited. Furthermore, Brief Illness Perception Questionnaire (BIPQ) is a new instrument that has not been used widely among patients with diabetes, although it does show reliable psychometric properties.
9.6 Strengths

To date, this is the first study to address the relationship of self-care activities with a group of psychosocial factors that could predict adherence to a health plan among patients with T2DM in Jordan. This study could provide a framework through which strategies might be implemented to increase adherence to self-care activities within the Jordanian T2DM population.

Recruiting participants for the quantitative phase with the use of a poster allowed for full and voluntary participation without undue coercion from the researcher. In the qualitative phase, the study also excluded participants with severe levels of depression PHQ-9 >19 in order to ensure voluntary participation. Patients with severe depression often have diminished ability to give valid consent (National Bioethics Advisory Commission (NBAC), 1998). As discussed earlier, in Arabic culture, the family exerts a strong influence. Therefore, participants with severe depression could also be subjected to inappropriate social pressure such as coercion, manipulation or undue influence. In this study, it was anticipated that respondents with severe levels of depression could not necessarily give voluntary informed consent in this specific social context. As such, this cohort was excluded from the study.

The clinical data, including HbA1c, lipid profile and diabetes complications, were all collected from the patients’ medical records. This has further strengthened the reliability of the results due to the fact that data have already been subjected to protocols that have been checked for integrity.
The study used a sequential mixed methods design as devised by Creswell and Plano Clark (2007). This approach was deemed the most appropriate for this study as it draws on Leventhal’s CSM. This model asserts that human behaviour manifests in two elements in response to a health threat: the objective constructs (cognition) and the subjective constructs (emotions). A mixed methods design enabled the study’s research questions to be most comprehensively addressed.

9.7 Chapter summary

The POISE study is the first research to address self-care activities by taking into account psychosocial constructs within a population of T2DM participants in Jordan. The study established a conceptual model of self-care activities among patients with diabetes. This model is parsimonious in adult Jordanians with T2DM as a measure to evaluate the direct and indirect relationship between the study constructs: illness perception, depression, social support, religious and spiritual coping, self-efficacy and self-care activities. The study makes a primary contribution to theory and has application in a clinical-based practice setting. The study’s conceptual model is validated and can be applied by healthcare providers. The measures in this model were translated into the Arabic language and proved to be valid and reliable. It is noteworthy that any of the survey instruments can be used – either discretely or clustered – to investigate relevant psychosocial health beliefs among Arabic patients with diabetes. These instruments could be used by clinicians and diabetes educators to identify dysfunctional health beliefs that may inhibit self-care activities among patients with T2DM.
As part of the delivery of a robust health service, providers need to possess the capacity and knowledge to assess beyond the mere physical aspects of diabetes. Psychological and social dimensions of diabetes patients must also be taken into account, with attention focussed on cognitive processes and emotional factors that impact on a patient’s adjustment to diabetes.

Overall, the findings presented in this study could lead to improvements in self-care activities among adult Jordanians with T2DM, eventually effecting a reduction in disease burden nationally.
References


Kroenke, K., Spitzer, L., & Williams, J. (2001). The PHQ-9: Validity of a brief depression severity measure. Journal of General Internal Medicine, 16(9), 606-613.


References


References


References


Toobert, D. J., Hampson, S. E., & Glasgow, R. E. (2000). The Summary of Diabetes Self-Care Activities Measure: Results from 7 studies and a revised scale. *Diabetes Care, 23*(7), 943-950. doi: 10.2337/diacare.23.7.943


Appendix A: Ethics Approval (UWS)

Locked Bag 1797
Penrith NSW 2751 Australia

Office of Research Services

Our Reference: 13/000882 | H10014

HUMAN RESEARCH ETHICS COMMITTEE

8 March 2013

Associate Professor Yenna Salamonson
School of Nursing and Midwifery

Dear Yenna

I wish to formally advise you that the Human Research Ethics Committee has approved your research proposal H10014 "Depression and Self-Care in Jordanian Adults with Diabetes", until 27 February 2015 with the provision of a progress report annually and a final report on completion.

Please quote the registration number and title as indicated above in the subject line on all future correspondence related to this project.

This protocol covers the following researchers:
Yenna Salamonson, Paul Glew, Lucie Ramjan, Rasmieh Al-Amer

Yours sincerely

[Signature]

Associate Professor Anne Abraham
Chair, Human Researcher Ethics Committee
Appendix B: Ethics Approval (Jordan University Hospital)
Appendix C: Patient Information Sheet (English)

Human Research Ethics Committee
Office of Research Services

University of Western Sydney

Participant Information Sheet (General)

Project Title: Depression and Self-Care in Jordanian Adults with Diabetes: The POISE study

Who is carrying out the study?
You are being asked to join a research study conducted by Mrs. Rasmieh Al-Amer, an HDR (Doctoral) candidate at the University of Western Sydney, Australia.

The study will form the basis for the degree of Doctor of Philosophy - Nursing and Midwifery at the University of Western Sydney, Australia under the supervision of Associate Professor Yenena Salamonson, Dr. Lucie Ramjan, and Dr. Paul Glew.

What is the study about?
This study is about diabetes self-care management behaviors among patients with type 2 Diabetes Mellitus (T2DM) in Jordan, it aims to examine the relationship between depression, social support, religiosity, self-efficacy, illness perception, and self-care management behaviors among adults with T2DM in Jordan, and to assess the prevalence of depression among the studied group, in addition to exploring the experience of living with both T2DM and depression.

What does the study involve?
The study involves participants filling out questionnaires assessing their depression state, social support, religiosity, self-efficacy, illness perception, and self-care management behaviors. Among those, some will be asked to join an in-depth interview to talk about more detailed self-care management behaviors and diabetes experience.

How much time will the study take?
Completing the questionnaires will take around 40 minutes. The interviews will take 30-45 minutes.

Will the study benefit me?
This study does not benefit you directly. However, your contribution will help researchers to understand the experience of managing diabetes within psychosocial concepts, and the opportunity to talk about self-care management in diabetes with psychosocial variables may be of benefit in integrating this aspect with diabetes management plans. This might help you and other diabetes patients in the future.

Will the study involve any discomfort for me?
The study is not expected to involve any discomfort, however as experiences around your experiences of
managing your health condition are personal and not always positive, there is the potential for some participants to become distressed. If you do become upset during the interview, you will be given the option of stopping the interview and/or withdrawing from the study. Prior to the interview, you will be provided with a list of free counseling services should you require support.

How is this study being paid for?
The researcher is studying under the International Postgraduate Research Scholarship (IPRS) with Australian Postgraduate Award (APA). Otherwise, this research is unfunded.

Will anyone else know the results? How will the results be disseminated?
Participants will be contacted with their real name for interview, and pseudonym will be provided to the participants during transcription of interviews and the data analysis part of this study and confidentiality of the results will be maintained throughout the study. A report of the study may be submitted for publication, but individual participants will not be identifiable in such a report. Participants will be notified of the results by providing them a thesis report if they wish.

Can I withdraw from the study?
Participation is entirely voluntary; you are not obliged to be involved and if you do participate, you can withdraw at any time without giving any reason and without any consequences.

Can I tell other people about the study?
Yes, you can tell other people about the study by providing them with the chief investigator's contact details. They can contact the chief investigator to discuss their participation in the research project and obtain an information sheet.

What if I require further information?
Once you have read and understood this information, Mrs. Rasmieh Al-Amer will explain the research study and your part in the study in detail and will also answer all your questions in regards to the study. If at any stage you have a question, please call the principal investigator Mrs. Rasmieh Al-Amer at +962 (79) 6523279 or +61(04) 06176879. If you cannot reach the principal investigator or wish to talk to someone else, you can call the head of the Internal Medicine Department at Jordan University Hospital Dr. Nathir Obeidat at +962 (79) 7637647.

What if I have a complaint?
This study has been approved by the University of Western Sydney Human Research Ethics Committee. The Approval number is [enter approval number]

If you have any complaints or reservations about the ethical conduct of this research, you may contact the Ethics Committee through the Office of Research Services on Tel +61 2 4736 0229 Fax +61 2 4736 0013 or email humanehtics@uws.edu.au.

Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

If you agree to participate in this study, you may be asked to sign the Participant Consent Form.
Appendix D: Patient Information Sheet (Arabic)

ورقة معلومات للمشاركين

عنوان المشروع: الأنتفاخ والرعاية الذاتية عند الأردنيين البالغين الذين يعانون من مرض السكري

من الذي يجري الدراسة؟

لقد تم الاعتراف بالأنتفاخ في دراسة بحثية تجربيا ريسمية الأعرس، وهي طالبة دراسات عليا (دكتوراه) في جامعة HDR غرب سيني، أستراليا.

الدراسة سوف تكون الأساس للحصول على ر-twadrktjqrj شوري والمتبقي في جامعة غرب سيني، أستراليا.

أين تجرى الدراسة؟

هذا الدراسة تجري حول السلوكيات المتعلقة بمرض السكري، والرعاية الذاتية بين المرضى الذين يعانون من مرض السكري من النوع الثاني في الأردن. وتهدف إلى دراسة علاقة بين (الاكتتاب والدعم الاجتماعي، القيادة الذاتية والإدراك) والسلوكية المتصلة بالرعاية الذاتية بين المرضى الذين يعانون من مرض السكري في الأردن. تم تطبيق هذه الدراسة تقييم مدى إنتاج الانخراط بين المرضى الذين يعانون من مرض السكري، بالإضافة إلى استكشاف تجربة الممارسة لكي من مرض السكري والإكتتاب.

ماذا تتضمن هذه الدراسة؟

تشمل الدراسة، المشاركون، استدلالات، الانتفاخ والدعم الاجتماعي، وتشتمل، القيادة الذاتية والإدراك المرضي، والسلوكية أو علاج السكر. كما سوف يتضمن بعض المشاركون انتفاخ لتمثيل حالة للذين يعانون من سلوك الذاتية للاعتصام أو الرعاية الذاتية مع مرض السكري. فما أن يكون المتضمنة المتصلة بالرعاية الذاتية وساعة لوج وسكتا.

كم من الوقت يستغرق الدراسة؟

سوف يستغرق هذه الدراسة حوالي 40 دقيقة. و المقابلات سوف تستغرق 30-45 دقيقة.

هل سافدت من هذه الدراسة؟

هذا الدراسة لا تتقدم مباشرة. ولكن سابحت سوف تستفيد من البيانات، والتي ستدخل تجربة إجابة مرض السكري ضمن المواقف النفسية والاجتماعية، وانعكاس الرسالة للبحث عن الرعاية الذاتية في إدارة مرض السكري مع التغييرات النفسية والاجتماعية، قد تكون ذات فائدة في وجه خطاب إدارة مرض السكري. وهذا قد يساعد في تجربة من مرضى السكري في المستقبل.

هل ستكون الدراسة إجابة بالنسبة لي؟

ليس من المتوقع أن يكون في الإ涉ارك في هذه الدراسة أي إجابة، ولكن يمكن أن تكون هناك عدة نتائج التي قد تكون ذات صلة. وسوف تكون هذه النتائج متاحة للوضوع والمشاركة. وسوف تكون هناك اجابة على سؤال ما إذا تم التنبؤ بالنتائج. وسوف تكون النتائج متاحة للوضوع والمشاركة.

كيف سيتم تداول هذه الدراسة؟

هذا البحث غير مقبول.
فقط الباحثون سيكونون من الحصول على المعلومات التي تم جمعها عن هذا المشروع. ويمكن تقديم تقرير عن الدراسة للمشاركين، ولكن البيانات الشخصية للمشاركين لن تكون محددة في مثل هذا التقرير. سيتم إبلاغ اسم المشاركين برقاقة خاصة بعد الانتهاء من الدراسة، والتي سيتم استخدامها أثناء السماح، وتحقيق الهدف، ومرحلة الباحث. سيتم إخطار المشاركين في الافتتاح من خلال توزيعهم تقرير عن الأطروحة إذا رغوا في ذلك.

هل يمكنني الإسحاب من الدراسة؟

المشاركة طوعية تمامًا. لا تتحمل أن تشارك وإذا قررت أن تشارك، يمكنك الإسحاب في أي وقت دون إبداء أي سبب ودون أي عرفة.

هل يستطيع أي شخص آخر أن يشارك؟

نعم، يمكنك أن تخبر من تشاء عن الدراسة من خلال توزيعهم بارقام الاتصال الباشة الرئيسي. يمكنك الاتصال لمناقشة مشاركتهم في مشروع البحث والحصول على ورقة المعلومات.

ما إذا كنت تحتاج إلى المزيد من المعلومات؟

بمجرد الانتهاء من قراءة هذه المعلومات، سوف تقوم البدء في الدراسة. يشرح الدراسة المهمة والجزء الخاص بك في الدراسة بالتفاصيل، وسيتم أيضًا الإجابة على جميع الأسئلة الخاصة بك في ما يخص الدراسة. إذا في أي مرحلة كان لديك أسئلة، فسيكون الاتصال بالباحث الرئيسي البداية رسمية الاعتراف على 07965237279. إذا لم تتمكن من الوصول إلى الباحث الرئيسي أو ترغب في التحدث مع شخص آخر، يمكنك الاتصال على رقم تابع للإدارات الداخلية في منشأة الجامعة الأوروبية الدكتور نور عبيدات.
Appendix E: Patient Consent Form (English)

Participant Consent Form

Project Title: Depression and Self-Care in Jordanian Adults with Diabetes: The POISE study

I, ____________________________, consent to participate in the research study titled Depression and Self-Care in Jordanian Adults with Diabetes: The POISE study.

I acknowledge that:

I have read the consent form and understood its terms and have had all my questions regarding my participation in this study satisfactorily answered.

The researcher has also fully explained to me all the procedures for this study and the time needed for completion.

By signing the consent form, I thereby consent to fully answer the questionnaires.

I understand that the data I provide for this study as well as my participation in it will remain confidential, and if this study is to be published at any time, no personal information that could be used to identify me will be mentioned.

I understand that my participation in this study is voluntary, hence I can disengage and withdraw from it at any time without affecting my treatment plan or jeopardizing my medical care services at Jordan University Hospital (JUH) now or in the future.

Signed: ____________________________

Name: ____________________________

Date: ____________________________

Return Address:

Mrs Rasmieh Al-Amer MSc, HDR (Doctoral) Candidate
University of Western Sydney, School of Nursing & Midwifery
Locked Bag 1797, Penrith 2751
New South Wales, Australia
Phone: ++61 (02) 4820 3335 M: ++61 (79) 652 3279/+61 (04) 06176879
Fax: ++61 (02) 4820 3161
Email: R.Al-Amer@uws.edu.au, 37335977@studentuws.edu.au
This study has been approved by the University of Western Sydney Human Research Ethics Committee.

The Approval number is: [enter approval number]

If you have any complaints or reservations about the ethical conduct of this research, you may contact the Ethics Committee through the Office of Research Services on Tel +61 2 4736 0228 Fax +61 2 4736 0013 or email humanethics@uws.edu.au. Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.
Appendix F: Patient Consent Form (Arabic)

استمارة الموافقة للمشاركين

عنوان المشروع: الاكتساب والرعاية الذاتية عند الأرامل البالغين الذين يعاونون من مرضى السكري

أوافق أن أشارك في دراسة تحليلية حول الاكتساب والرعاية الذاتية عند الأرامل البالغين الذين يعاونون من مرضى السكري.

لقد قمت وفهمت استمارة الموافقة ومضمونها وقد تم الإفصاح عن كل ما يتعلن من أنشطة يتضمنها المشاركون في هذه الدراسة بصورة مفصلة.

لقد أوضح الباحث في المقابلة الإجابة على هذه الدراسة والموافقنة لاستكمالها.

أوافق على المشاركة في فعالية التي تتضمن تسجيل صوتي، ووعي أن أقدم تفاصيل الاتصال الخاصة على الامتناع.

أعطي الباحث الثقة في الوصول إلى السجلات الطبية الخاصة في جميع البيانات الخاصة في التعليم، والกายماهة، والفيزياءات وغيرها لأغراض هذه الدراسة.

أعلم أن البيانات و المعلومات التي تقدمها لهذه الدراسة وكذلك مشتارك في هذه الدراسة سوف تظل سريًا، وإذا تم نشر هذه الدراسة في أي وقت، لن يتم الإفصاح عن أي معلومات تتعلق بما يمكن من حفظها التعرف عليه.

أعلم أن مشاركي في هذه الدراسة هو طوعي، واصطلاح الانسحاب منها في أي وقت دون أن يؤثر ذلك على الخدمات والرعاية الطبية المقدمة في مستشفى الجامعة الأردنية الآن أو في المستقبل.

اسم:

التوقيع:

تاريخ:
Appendix G: Participant Survey

Please answer all questions. Most questions require you to tick a box(es) to indicate your answer. Choose the box(es) that best matches your answer.

<table>
<thead>
<tr>
<th>Section A: General information about yourself</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Year of birth/ سنة الولادة</td>
</tr>
<tr>
<td>2. Marital status/ الحالة الاجتماعية</td>
</tr>
<tr>
<td>3. Sex/ الجنس</td>
</tr>
</tbody>
</table>
### Section B: Clinical Variables

**التاريخ الصحي (يرجى وضع حالة على ما ينطبق)**

1. **Health history** *(Please tick all that apply)*
   - (a) High blood pressure *(mmHg)*
   - (b) Diabetic retinopathy
   - (c) Stroke / Cerebrovascular accident
   - (d) Heart (coronary) problems
   - (e) Peripheral vascular disease
   - (f) High blood Cholesterol *(mg/dL)*

2. **Health history**
   - (g) Triglycerides level in the blood *(mg/dL)*
   - (h) Low density lipoproteins level in the blood *(mg/dL)*
   - (i) High density lipoproteins level in the blood *(mg/dL)*
### Section C: Treatment modalities

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>5. Oral hypoglycemic agent(s)</td>
<td>No/☐ ☑ Yes/☐ ☑ Other/☐ ☑</td>
</tr>
<tr>
<td>6. Insulin injections</td>
<td>No/☐ ☑ Yes/☐ ☑ Other/☐ ☑</td>
</tr>
<tr>
<td>7. Other treatments <em>(Please specify)</em></td>
<td></td>
</tr>
</tbody>
</table>

---

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>(j) HbA1c level in the blood (%)</td>
<td>☐ ☑</td>
</tr>
<tr>
<td>(k) Duration of diabetes (years)</td>
<td>☐ ☑</td>
</tr>
<tr>
<td>(l) Height (cm)</td>
<td>☐ ☑</td>
</tr>
<tr>
<td>(m) Weight (kg)</td>
<td>☐ ☑</td>
</tr>
<tr>
<td>(n) Others <em>(Please specify)</em></td>
<td>☐ ☑</td>
</tr>
</tbody>
</table>
### Section D: Please indicate your response by circling the corresponding number

**القسم D: الرجاء وضع دائرة حول الرقم ال있는 في الجوانب**

**Instructions:** Please indicate how true each statement is of you.

*Patient Health Questionnaire 9 (PHQ-9)*

أعطي درجة تعبيرية تشير إلى مدى صحة كل ضعفي بالنص من خلال وضع دائرة حول الرقم المناسب لإجابةك.

**How often during the past 2 weeks were you bothered by any of the following problems?**

خلال الأسبوعين الماضيين، كم مرة عانت من أي من المشاكل التالية؟

<table>
<thead>
<tr>
<th>Problems</th>
<th>Not at all</th>
<th>Several days</th>
<th>More than half the days</th>
<th>Nearly everyday</th>
</tr>
</thead>
<tbody>
<tr>
<td>Little interest or pleasure in doing things</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeling down, depressed or hopeless</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trouble falling or staying asleep, or sleeping too much</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeling tired or having little energy</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor appetite or overeating</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeling bad about yourself, or that you are a failure, or have let yourself or your family down</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trouble concentrating on things, such as reading the newspaper or watching television</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moving or speaking so slowly that other people could have noticed or the opposite — being so fidgety or restless that you have been moving around a lot more than usual</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Thoughts that you would be better off dead, or of hurting yourself in some way</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Appendix E: | 4

Appendices
## Social support (ENRICH) (دعم الاجتماعي)

<table>
<thead>
<tr>
<th>Items</th>
<th>None of the time</th>
<th>A little of the time</th>
<th>Some of the time</th>
<th>Most of the time</th>
<th>All of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is there someone available to whom you can count on to listen to you when you need to talk?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Is there someone available to give you good advice about a problem?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Is there someone available to you who shows you love and affection?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Is there someone available to help you with daily chores?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Can you count on anyone to provide you with emotional support (talking over problems or helping you make a difficult decision)?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Do you have as much contact as you would like with someone in whom you can trust and confide?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Are you currently married or living with a partner?</td>
<td>No 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix G- | 6

Appendices

Page | 286

**Instructions:** Please indicate how true each statement is of you by circling the number corresponding to your response.

شاملات: برخي بيان مدى سمحة كل جمعة بالنسبة لك وذلك بوضع سنة حول الرقم المقابل لإظهار

The questions below ask about diabetes self-care activities during the past 7 days

ملخص النشطة الرعاية الذاتية لمرض السكري (SDSCA)

<table>
<thead>
<tr>
<th>Items / عدد الأيام</th>
<th>Number of Days</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>10.1</strong> How many of the last seven days have you followed a healthful eating plan?</td>
<td></td>
</tr>
<tr>
<td><strong>10.2</strong> On average, over the past month, how many days per week have you followed your eating plan?</td>
<td></td>
</tr>
<tr>
<td><strong>10.3</strong> On how many of the last seven days did you eat five or more servings of fruits and vegetables?</td>
<td></td>
</tr>
<tr>
<td><strong>10.4</strong> On how many of the last seven days did you eat high fat foods such as red meat or full-fat dairy products?</td>
<td></td>
</tr>
<tr>
<td><strong>10.5</strong> On how many of the last seven days did you participate in at least 30 minutes of physical activity? (Total minutes of continuous activity, including walking)</td>
<td></td>
</tr>
<tr>
<td><strong>10.6</strong> On how many of the last seven days did you participate in a specific exercise session (such as swimming, walking, biking) other than what you do around the house or as part of your work?</td>
<td></td>
</tr>
<tr>
<td><strong>10.7</strong> On how many of the last seven days did you test your blood sugar?</td>
<td></td>
</tr>
<tr>
<td>Question</td>
<td>Options</td>
</tr>
<tr>
<td>--------------------------------------------------------------------------</td>
<td>---------</td>
</tr>
<tr>
<td>How many of the last seven days did you test your blood sugar the number of times recommended by your health care provider?</td>
<td>0 1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>How many of the last seven days did you inspect the inside of your shoes?</td>
<td>0 1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>How many of the last seven days did you take your recommended diabetes medication?</td>
<td>0 1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>How many of the last seven days did you take your recommended insulin injections?</td>
<td>0 1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>How many of the last seven days did you take your recommended number of diabetes pills?</td>
<td>0 1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>Have you smoked a cigarette—even one puff—during the last seven days?</td>
<td>No ☐ Yes ☐</td>
</tr>
<tr>
<td>If Yes, how many cigarettes did you smoke on an average day?</td>
<td></td>
</tr>
<tr>
<td>Number of cigarettes:</td>
<td></td>
</tr>
</tbody>
</table>

Appendix G: | 7

Appendices
For the following questions, please circle the number that best corresponds to your views:

Brief Illness Perception Questionnaire (BIP-Q)

11.1. How much does your illness affect your life?

11.2. How long do you think your illness will continue?

11.3. How much control do you feel you have over your illness?

11.4. How much do you think your treatment can help your illness?

11.5. How much do you experience symptoms from your illness?

11.6. How concerned are you about your illness?
11.7. How well do you feel you understand your illness?

Don't understand at all

Not very well

Understand very clearly

Understand very clearly


11.8. How much does your illness affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?)

Not at all affected emotionally

A little affected

Extremely affected emotionally


Please list in rank-order the three most important factors that you believe caused your illness. The most important causes for me:

1. 

2. 

3. 

The most important causes for me: 

اليأحد ووزير مشكك علما عاطفياً؟ ( على سبيل المثال هل يجعلك عاطفاً مفتوحاً أو مختطاً؟)
Instructions: Please answer each question by selecting the answer that describes how convinced you are in managing your diabetes.

**Diabetes Management Self Efficacy Scale (DSES)**

<table>
<thead>
<tr>
<th>Items/السؤال</th>
<th>Definitely Yes بالتأكيد</th>
<th>Probably Yes أرجح</th>
<th>Maybe No ربما</th>
<th>Probably No ربما</th>
<th>Definitely No بالتأكيد</th>
</tr>
</thead>
<tbody>
<tr>
<td>12.1 I think I am able to check my blood sugar if necessary أعفت أنني قادر على التحقق من نسبة السكر في مي إذا أزم الأمر</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>12.2 I think I am able to correct my blood sugar when the blood sugar value is too high أعفت أنني قادر على تعديل نسبة السكر في مي عندما تكون نسبة السكر في الدم عالية جداً</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>12.3 I think I am able to correct my blood sugar when the blood sugar value is too low أعفت أنني قادر على تعديل نسبة السكر في مي عندما تكون نسبة السكر في الدم منخفضة جداً</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>12.4 I think I am able to select the right foods أعفت أنني قادر على اختيار الأطعمة الصحيحة</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>12.5 I think I am able to select different foods but stay within my diabetic diet أعفت أنني قادر على اختيار الأطعمة المختلفة ضمن الحمية السكرية المتوازنة</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>12.6 I think I am able to keep my weight under control أعفت أنني قادر على الحفاظ على وزني ضمن الحد السمنوي</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>12.7 I think I am able to examine my feet for skin problems أعفت أنني قادر على فحص قدمي في ما يمكن من ملء الثقوب والتشنجات</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>12.8 I think I am able to get sufficient physical activities, for example, taking a walk or biking أعفت أنني قادر على ممارسة الأنشطة البدنية بما يكفي على سبيل المثال المشي أو دروب الفوائد</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>12.9</td>
<td>I think I am able to adjust my diet when I am ill</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>12.10</td>
<td>I think I am able to follow my diet most of the time</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>12.11</td>
<td>I think I am able to take extra physical activities, when the doctor advises me to do so</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>12.12</td>
<td>When taking extra physical activities, I think I am able to adjust my diet</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>12.13</td>
<td>I think I am able to follow my diet when I am away from home</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>12.14</td>
<td>I think I am able to adjust my diet when I am away from home</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>12.15</td>
<td>I think I am able to follow my diet when I am on vacation</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>12.16</td>
<td>I think I am able to follow my diet when I am at a reception/party</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>12.17</td>
<td>I think I am able to adjust my diet when I am under stress or tension</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>12.18</td>
<td>I think I am able to visit the doctor once a year to monitor my diabetes</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>12.19</td>
<td>I think I am able to take my medicine as prescribed</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
</tbody>
</table>
### Religious and Spirituality Coping (RSC)

<table>
<thead>
<tr>
<th>Items</th>
<th>Strongly Disagree</th>
<th>Moderately Disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13.6</td>
<td>Trusting in God has helped me better deal with my diabetes</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>13.7</td>
<td>I believe God does not give me more than I can bear</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>13.8</td>
<td>I believe God can completely cure my diabetes</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>13.9</td>
<td>I have prayed about my diabetes so I am not going to worry about it anymore</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

15.1 هل ترغب في المشاركة بجودة للاقتذائية الشخصية؟

☐ لا
☐ هي، برجي تقديم تقديرات الاتصال بكل

االاسم

(a)

Appendix G | 12

Appendices
Thank you for participating in this survey

شكراً لك على المشاركة بهذا الاستقصاء.
Appendix H: Patient Interview Schedule

Appendix-B

Interview Schedule

--------------------------------------------------------------------------------------------------------
Depression and Self-Care in Jordanian Adults with Diabetes: The POISE study
--------------------------------------------------------------------------------------------------------

Participant’s No: ________________

Date of Interview: ________________

Interview Room: ________________

Time of Interview: ________________

General questions

• What has life been like since the onset of your diabetes?

• Can you describe what being healthy means to you?

• What has helped you to cope with your diabetes?

• What barriers or obstacles have you faced with diabetes?

Thank you for talking to me about this issue.
## Appendix I: Glossary

<table>
<thead>
<tr>
<th><strong>Glossary Term</strong></th>
<th><strong>Definition</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Adherence</td>
<td>The extent to which a person’s behaviour – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider.</td>
</tr>
<tr>
<td>Arab</td>
<td>Anyone who speaks Arabic as his [or her] own language and consequently feels as an Arab.</td>
</tr>
<tr>
<td>Backward translation</td>
<td>Translation from a ‘target language ‘to a ‘source’ language.</td>
</tr>
<tr>
<td>Body mass index</td>
<td>A measure of human body size and proportion. It is defined as the weight in kilograms divided by the square of height in meter. Various levels of BMI are used as guidelines for healthy targets.</td>
</tr>
<tr>
<td>Body Mass Index</td>
<td>Approximate measure of the body fat, calculated by dividing their weight in kilograms by the square of their height in metres.</td>
</tr>
<tr>
<td>Brief Illness Perception Questionnaire</td>
<td>It is a 9 item self-report instrument developed to evaluate five components of thinking.</td>
</tr>
<tr>
<td>Categorical Data/Variables</td>
<td>Statistical data type that can be sorted into categories. The data is of equal value with no category holding a value greater than another. Every value can be allocated to only one category (e.g. gender).</td>
</tr>
<tr>
<td>Chi-Square Test ((x^2))</td>
<td>Chi-square is a statistical hypothesis test used to compare observed data with data that is expect to be obtained according to a specific hypothesis.</td>
</tr>
<tr>
<td>Cronbach’s Alpha Coefficient</td>
<td>A value indicative of the degree of reliability of a psychometric test score.</td>
</tr>
<tr>
<td>Chronic diseases</td>
<td>Diseases which have one or more of the following characteristics: they are permanent, leave residual disability, are caused by no reversible pathological alteration, require special training of the patient for rehabilitation, or may be expected to require a long period of supervision, observation or care.</td>
</tr>
<tr>
<td>Common Sense Model</td>
<td>A theoretical model that has addressed how cognitive and emotion factors influence individuals’ health related decisions.</td>
</tr>
<tr>
<td>Confidence interval</td>
<td>A range of values (interval) that act as an estimate of the unknown population parameter used to indicate the reliability of an estimate; represent the range of effect sizes and statistical accuracy for interpreting results.</td>
</tr>
<tr>
<td>Continuous Data/Variables</td>
<td>Statistical data type that holds a value with a finite or infinite interval. Continuous data can be arranged in numerical order (e.g. height, weight, temperature).</td>
</tr>
<tr>
<td><strong>Cramer’s V</strong></td>
<td>Is a statistical term to describe the measure of association between two nominal variables, giving a value between 0 and +1 (inclusive).</td>
</tr>
<tr>
<td><strong>Credibility</strong></td>
<td>The degree to which a description of human experience is such that those having the experience would recognize it immediately and those outside the experience can understand it.</td>
</tr>
<tr>
<td><strong>Dependent Variable</strong></td>
<td>The variable being measured in a study that is affected by the independent variables.</td>
</tr>
<tr>
<td><strong>Depression</strong></td>
<td>A mood disorder characterized by sadness, inactivity, difficulty with thinking and concentration, significant increase or decrease in appetite and time spent sleeping, feelings of dejection and hopelessness, and, sometimes, suicidal thoughts or an attempt to commit suicide.</td>
</tr>
<tr>
<td><strong>Diabetes complications</strong></td>
<td>Diabetes complications are acute and chronic adverse consequences for health caused by diabetes. Chronic complications include retinopathy (eye disease), nephropathy (kidney disease), neuropathy (nerve disease), cardiovascular disease (disease of the circulatory system), foot ulceration and amputation, and acute complications include hypoglycaemia and hyperglycaemia.</td>
</tr>
<tr>
<td><strong>Diabetes complications</strong></td>
<td>A secondary disease or condition aggravating already existing diabetes: hypertension, diabetic retinopathy, peripheral vascular disease, cardiac disease, and cerebrovascular disease.</td>
</tr>
<tr>
<td><strong>Diabetes Management Self Efficacy Scale</strong></td>
<td>It is a self-administered scale consisting of 20 Items, it measures self-efficacy among patients with T2DM. It assesses the extent to which respondents are confident in managing their blood sugar levels, diet and physical activity regimen.</td>
</tr>
<tr>
<td><strong>Diabetes mellitus</strong></td>
<td>Diabetes mellitus is a chronic condition that arises when the pancreas does not produce enough insulin or when the body cannot effectively use the insulin produced. There are two basic forms of diabetes: type 1 and type 2.</td>
</tr>
<tr>
<td><strong>Effect Size</strong></td>
<td>A measure of the magnitude to which two variables correlate in a statistical population.</td>
</tr>
<tr>
<td><strong>Enrich Social Support Instrument</strong></td>
<td>Is a 7-item self-report instrument to assess the impact of social support on certain conditions.</td>
</tr>
<tr>
<td><strong>Exogenous variables</strong></td>
<td>Independent variable that affects a model without being affected.</td>
</tr>
<tr>
<td><strong>Forward translation</strong></td>
<td>Translation from a ‘source language ‘to a ‘target language’.</td>
</tr>
<tr>
<td>Glossary Term</td>
<td>Definition</td>
</tr>
<tr>
<td>-----------------------------------</td>
<td>-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Gestational diabetes</td>
<td>A carbohydrate intolerance of varying degrees of severity with onset or first recognition during pregnancy. Gestational diabetes develops during some cases of pregnancy, but usually disappears when pregnancy is over. However, women who have had gestational diabetes are at greater risk of developing type 2 diabetes at a later stage in their lives.</td>
</tr>
<tr>
<td>Glucose</td>
<td>The main sugar the body produces from proteins, fats and carbohydrates. Glucose is the major source of energy for living cells and is carried to each cell through the bloodstream. However, the cells cannot use glucose without the help of insulin.</td>
</tr>
<tr>
<td>Glycated haemoglobin</td>
<td>A form of haemoglobin that is measured mainly to identify the average plasma glucose concentration over prolonged periods of time.</td>
</tr>
<tr>
<td>Glycosylated haemoglobin (HbA1c)</td>
<td>Glycohaemoglobin; often referred to as HbA1c or A1c – is a haemoglobin molecule bound with glucose. HbA1c levels are determined by a blood test that determines the proportion of glycohaemoglobin in the blood. Typically, approximately 4% to 6% of haemoglobin in the blood has glucose bound to it, but individuals with diabetes usually have higher blood levels of glycohaemoglobin.</td>
</tr>
<tr>
<td>Human Research Ethics Committee (HREC)</td>
<td>A committee of members who review research proposals for ethical considerations when proposed research involves humans.</td>
</tr>
<tr>
<td>Hyperglycaemia</td>
<td>A raised level of glucose in the blood; a sign that diabetes is out of control. It occurs when the body does not have enough insulin or cannot use the insulin it does have to turn glucose into energy. Signs of hyperglycaemia are thirst, dry mouth and frequent to urination.</td>
</tr>
<tr>
<td>Hypoglycaemia</td>
<td>Too low a level of glucose in the blood. This occurs when a person with diabetes has injected too much insulin, eaten too little food, or has exercised without extra food. A person with hypoglycaemia may feel nervous, unsteady, weak, or sweaty, and have a headache, blurred vision and hunger.</td>
</tr>
<tr>
<td>Illness perception</td>
<td>Patients’ personal beliefs about their illness and treatment. It is formulated around five ‘core’ dimensions regarding the cause, control, timeline (course), consequences, and identity (perceived symptoms) of the condition.</td>
</tr>
<tr>
<td>Independent Variable</td>
<td>A statistical term to describe a variable that is manipulated during a study to observe the effects upon the dependent variable.</td>
</tr>
<tr>
<td>Insulin</td>
<td>A hormone secreted by beta cells in the pancreas that enables the cells of the body to absorb glucose from the bloodstream and use it as an energy source.</td>
</tr>
<tr>
<td>Internal Consistency</td>
<td>Correlation statistic to determine whether individual items of an instrument all measure the same construct, usually represented as a Cronbach’s alpha coefficient (α).</td>
</tr>
<tr>
<td><strong>Interval variable</strong></td>
<td>Is a statistical term to describe a measurement where the difference between two values is meaningful. The difference between a temperature of 100 degrees and 90 degrees is the same difference as between 90 degrees and 80 degrees.</td>
</tr>
<tr>
<td>-----------------------</td>
<td>------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Logistic Regression</strong></td>
<td>A type of regression analysis used for predicting the outcome of a variable that can only be assigned to certain categories based on one or more predictor variables.</td>
</tr>
<tr>
<td><strong>Macro-vascular disease</strong></td>
<td>Disease of the large blood vessels that may occur in people who have had diabetes for a long time. Fat and blood clots build up in the large blood vessels and stick to the vessel walls. The three kinds of macro-vascular disease are: coronary heart disease, cerebro-vascular disease and peripheral vascular disease.</td>
</tr>
<tr>
<td><strong>Micro-vascular disease</strong></td>
<td>Disease of the smallest blood vessels that may occur in people who have had diabetes for a long time. The walls of the vessels become abnormally thick but weak. Therefore, they bleed, leak protein and slow the flow of blood through the body.</td>
</tr>
<tr>
<td><strong>Mixed methods design</strong></td>
<td>Mixed methods design it is an approach or methodology focusing on research questions that call for real-life contextual understandings, multi-level perspectives, and cultural influences. Employing quantitative approach assessing magnitude and frequency of constructs and qualitative approach exploring the meaning and understanding of constructs, and integrating these methods to draw a final conclusion.</td>
</tr>
<tr>
<td><strong>Morbidity</strong></td>
<td>Any departure, subjective or objective, from a state of physiological or psychological wellbeing.</td>
</tr>
<tr>
<td><strong>Participant/respondents</strong></td>
<td>An individual who participate in a research.</td>
</tr>
<tr>
<td><strong>Pearson’s r</strong></td>
<td>Is a measure of the strength and direction of the linear relationship between two variables that is defined in terms of the (sample) covariance of the variables divided by their (sample) standard deviations, and it is influenced by the distribution of the independent variable in the sample.</td>
</tr>
<tr>
<td><strong>PHQ-9</strong></td>
<td>Is the depression module [of the PRIME-MD diagnostic instrument for common mental disorders], which scores each of the 9 DSM-IV criteria as “0” (not at all) to “3” (nearly every day). In addition to making criteria-based diagnoses of depressive disorders, the PHQ-9 is also a reliable and valid measure of depression severity. These characteristics plus its brevity make the PHQ-9 a useful clinical and research tool.</td>
</tr>
<tr>
<td><strong>Power</strong></td>
<td>The probability of avoiding a type II error, thus rejecting a false null hypothesis.</td>
</tr>
<tr>
<td><strong>Power Analysis</strong></td>
<td>A statistical test used to calculate the minimum sample and effect size required in a study.</td>
</tr>
<tr>
<td>Term</td>
<td>Definition</td>
</tr>
<tr>
<td>-------------------------------------------</td>
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</tr>
<tr>
<td>Prevalence</td>
<td>The proportion of individuals in a population who at a particular time (be it a point in time or time period) have a disease or condition. Prevalence is a proportion and not a rate.</td>
</tr>
<tr>
<td>Prevalence rate</td>
<td>The proportion of individuals that are affected by a disease or a risk factor at a given point in time.</td>
</tr>
<tr>
<td>Principal Component Analysis (PCA)</td>
<td>Statistical method with the purpose of examining patterns of interrelationships among observed variables reducing the large number of variables to a small number of closely linked components.</td>
</tr>
<tr>
<td>Psychometric</td>
<td>The technique of psychological measurement using a quantitative instrument.</td>
</tr>
<tr>
<td>P-Value</td>
<td>The calculated probability of rejecting the null hypothesis when the hypothesis is true; with a value ranging from zero to one.</td>
</tr>
<tr>
<td>Ratio variables</td>
<td>A statistical term to describe a variable with the features of interval variable and, whose any two values have meaningful ratio, making the operations of multiplication and division meaningful.</td>
</tr>
<tr>
<td>Reliability</td>
<td>The degree to which an instrument measures a construct yielding consistent and dependable results within similar circumstances.</td>
</tr>
<tr>
<td>Religion</td>
<td>The feelings, acts, and experiences of individual men in their solitude, so far as they apprehend themselves to stand in relation to whatever they may consider the divine. By the term &quot;divine&quot; it means any object that is godlike, whether it is a concrete deity or not to which the individual feels impelled to respond with solemnity and gravity.</td>
</tr>
<tr>
<td>Self-efficacy</td>
<td>Is related to one’s belief and confidence in their abilities to accomplish a task and execute skills effectively.</td>
</tr>
<tr>
<td>Sequential embedded mixed methods designs</td>
<td>Design which use quantitative and qualitative approaches in tandem and embed qualitative data set in the quantitative data set as the design is quantitative dominant.</td>
</tr>
<tr>
<td>Sex</td>
<td>The biological and physiological characteristics that define men and women.</td>
</tr>
<tr>
<td>Social support</td>
<td>An exchange of resources between at least two persons, aimed at increasing the well-being of the recipient.</td>
</tr>
<tr>
<td>Spearman rho coefficient</td>
<td>Is a non-parametric measure of statistical dependence between two variables. It assesses how well the relationship between two variables can be described using a monotonic function.</td>
</tr>
<tr>
<td>Spirituality</td>
<td>Spirituality as an integral aspect of religious experience aspects of life and human experience which go beyond a purely materialist view of the world without necessarily accepting belief in a supernatural reality or divine being.</td>
</tr>
<tr>
<td>Term</td>
<td>Definition</td>
</tr>
<tr>
<td>-------------------------------------------</td>
<td>----------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Standard Deviation (SD)</td>
<td>Indicates the portion of variation that exists from the mean; low SD indicates that values are within close proximity to the mean, whereas high SD indicates that values lie further from the mean.</td>
</tr>
<tr>
<td>Statistical Package for the Social Sciences (SPSS)</td>
<td>Software designed for statistical calculations and analysis.</td>
</tr>
<tr>
<td>Summary of Diabetes Self-Care Activities (SDSCA)</td>
<td>Is a brief valid self-reporting instrument which measures the frequency of performing diabetes self-care tasks, including diet, exercise, medication, blood glucose testing, foot care and smoking habits.</td>
</tr>
<tr>
<td>Triangulation</td>
<td>Using numerous sources of data, methods, investigators or theories to validate the data or interpretations.</td>
</tr>
<tr>
<td>Type 1 Diabetes Mellitus (T1DM)</td>
<td>An autoimmune disease in which the body's immune system attacks and destroys the insulin-producing cells of the pancreas.</td>
</tr>
<tr>
<td>Type 2 Diabetes Mellitus (T2DM)</td>
<td>A metabolic disorder that occurs when the pancreas does not produce enough insulin and/or when the body does not properly use the insulin it makes.</td>
</tr>
<tr>
<td>Validity</td>
<td>The extent to which an instrument measures the underlying construct it is intended to measure.</td>
</tr>
<tr>
<td>α Error (type I error)</td>
<td>Otherwise referred to as alpha (α), refers to a conclusion that statistical significance is present when in actuality it is not. This is colloquially known as a false positive in which the null hypothesis is rejected when in fact it is true.</td>
</tr>
<tr>
<td>β Error (type II error)</td>
<td>Statistically known as beta (β), may be regarded as a false negative where statistical significance is disregarded instead of being acknowledged. This is caused when the null hypothesis is considered to be true when it is false.</td>
</tr>
</tbody>
</table>