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Preferences for shared medical decision-making: Cross-cultural perspectives

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**RESEARCH
DEGREES
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Preferences for shared medical decision-making: Cross-cultural perspectives

by

Fatimah Sayer Alharbi

A thesis submitted to Plymouth University
in partial fulfilment of the degree of

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Author's declaration

At no time during the registration for the degree of Doctor of Philosophy has the author been registered for any other University award without prior agreement of the Graduate Sub-Committee.

Work submitted for this research degree at the Plymouth University has not formed part of any other degree either at Plymouth University or at another establishment.

All the studies carried out in this thesis were conducted by myself, including literature review, developing tools, selecting of stimuli, designing of experiments, data collection, analysis, and discussion of results.

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Abstract

The goal of this thesis project was to investigate cross-cultural differences in preferences for shared medical decision-making (SDM) by studying adults from the UK and Saudi Arabia. The aim of Study 1 was to gauge preferences for SDM in non-clinical samples from the UK and Saudi Arabia. Results show that there were indeed differences in SDM between Saudi and UK participants. Saudi participants tended to prefer stronger involvement from their doctor, whereas UK participants preferred to make choices themselves. The aim of Study 2 was to investigate in how far Saudi patients with Type 1 diabetes would be interested to be involved in medical decision. The results of this qualitative study showed that, in general, physicians were reported to often have poor communication skills, which makes patients feel uncomfortable. Participants reported that their physician gave them medication without any discussion over the reasoning behind the prescription provided. Study 3 investigated parents' preferences regarding their involvement in medical decisions when making decisions for themselves or their child, to record parents' emotional reaction to shared medical decision-making, and to identify cultural differences on these topics in parents from Saudi Arabia and the UK. The results showed that parents were more likely to take an active role in the decision-making process when making the decision for themselves rather than their child. Decision confidence was higher in the non-informed choice condition. Emotional reaction and decision confidence was higher in the informed choice condition. A number of important recommendations for policy and practice that aim to increase shared decision-making and highlight the importance of culture. While European health-care professionals are increasingly encouraged to involve patients in decisions about their care, this study indicates that preferences for such shared medical decision making vary by culture and the recipient of the decision.

This should be taken into account when health care professional involve patients in medical decisions.

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Chapter 1: Introduction

Historically, care and compassion were at the core of the “treatment” options offered by physicians to patients suffering from acute and/or chronic illnesses (Barry & Edgman-Levitan, 2012). There has, however, been a drastic shift over the course of time along with the advances in medical science expanding the range of active treatment options that deliver positive outcomes, which have inadvertently distanced physicians from their patients (Barry & Edgman-Levitan, 2012).

Good quality health care is described as one which is safe, effective, patient-centred, timely, efficient, and equitable (Barry & Edgman-Levitan, 2012). Over the years there has been a growing concern that health systems are failing to provide patients with consistent, evidence-based medical care to match their clinical needs (Kon, 2010). These failings include lapses in patient safety, disjointed care delivery systems, and inappropriate use of services (Lee & Emanuel, 2013). Given the risks and consequences that are associated with these shortcomings, the Institute of Medicine (IOM) in the U.S is making attempts to encourage health care providers to redesign health care systems to improve the quality of care being delivered (Barry & Edgman-Levitan, 2012).

As part of this drive to improve quality of care, there has been an increasing demand for physicians to involve their patients more in the process of making clinical decisions of a patient’s diagnosis, prognosis and treatment of disease. According to Barry (1999), this type of shared decision-making (SDM) is particularly essential when a patient has a preferred outcome from a number of alternatives offered. It is therefore

very likely that the optimal health management strategy for different patients with similar diagnostic test results will differ based on their preference.

Shared decision making approaches have been shown to be patient-centred and more effective in the treatment of patients in comparison to more traditional physician-led decision-making. The current research will focus on the psychological processes that relate to the patient-centeredness and equitability of health care from a cross-cultural perspective, and the impact of culture on the shared decision making process. Social and cultural factors play a crucial role for patients as they impact on their understanding of health conditions, thus it is crucial for health care providers to identify and explore patients' understanding of their health problems.

1.1 What is shared medical decision making?

1.1.1 Definitions

Shared-decision making (SDM) is defined as a collaborative process that involves the patient and their physician, when they are reviewing the best available evidence and outcomes to make health care decisions which take into account patient preferences (Elwyn, et al., 2012). As such, SDM is closely related to concepts such as patient-centred care, patient empowerment, and evidence-based patient choice. Similarly, Lee and Emanuel (2013) state that SDM is a method which requires physicians and patients to work together in selecting the best medical treatments, management procedures and support packages. It is a process that empowers patients to engage and become active participants in the management of their healthcare. Consequently, it delivers the best outcome for patients as there is effective interaction, and communication from physicians and patients are kept well informed about their health conditions through the provision of relevant information (Elwyn et

al., 2012). A SDM process thus helps the patient to choose the most acceptable health care option in accordance with their preferences and suitability (Kon, 2010; Légaré et al, 2008). According to Lee and Emanuel (2013), SDM is a preference-sensitive approach in which mutual decisions are made by focusing on the best medical treatment for the patients. There are, however, concerns that physicians do not have sufficient time to engage with the SDM approach. This is particularly relevant in the current era of managed care, in which most office-based physicians feel pressured to see an increasing number of patients in the same amount of time, thus limiting the time spent on each consultation (Barry, 1999).

SDM often arises in situations where there is uncertainty about the medical outcome and there is more than one medically supported solution for the treatment of the disease. This approach goes much further than traditional informed consent which involves setting out the risks, benefits, and alternatives. It involves physicians and patients making healthcare decisions from a range of options (e.g. elective surgery, choice of diagnostic test, reliance on a long term medication regime, etc.) depending upon the severity of the disease and the patient's desired outcome. It means that this approach is more effective than traditional procedures as it incorporates the patient's acceptance of the option and a more robust discussion of all alternative options in decision-making that may quickly improve the health of patients. Traditional informed consent is often inadequate, particularly with high risk medical procedures where patients are not involved in the decision-making process. Rather, physicians directly inform or take consent about the operation without any detailed discussion of the circumstances of the surgical procedure with their patient. This can have quite adverse consequences for patient health care, as patients are poorly informed about any side-effects especially those that have a long term impact on their daily lives. Hence, the

SDM process enables the early identification of individual patient ideas, beliefs, values and risk preferences for a particular medical course of action out of a number of probable options (Légaré et al, 2008).

1.1.2 Models for Medical Decision Making

Whitney et al. (2003) proposed a conceptual model that categorises medical decisions into four types based on degrees of risk and certainty. They define uncertainty as being present when there are two or more medically reasonable choices to address a medical problem. These types of medical decisions include decisions involving high risk and high certainty situations, for example, laparotomy for gunshot wound of abdomen; decisions involving low risk and high certainty situations, for example, lower diuretic for patients with low serum potassium level, decisions involving high risk and low certainty situations for example, mastectomy or lumpectomy plus radiation for early breast cancer; and decisions involving low risk and low certainty situations, for example, lifestyle change. The model set out by Whitney et al. (2003) suggests that SDM is independent of the risk level and will only be present in situations where low certainty is associated with a medical decision.

The model of SDM has four main characteristics. These include (1) mutual active participation by the patient and the physician; (2) information is freely and openly exchanged between patient and physician; (3) there is a positive attempt by both sides to build a consensus around a favoured course of treatment; and (4) both sides come to an agreement to implement a particular course of treatment (Stevenson et al., 2000). For SDM to be effective, patients must be willing and ready to participate in the process and also take responsibility to be open and honest in their disclosure of predilections, asking questions, consideration and assessment of treatment options

and verbalising a preference Stevenson et al. (2000) describes the key elements of SDM as information exchange, deliberation about treatment options and deciding on the treatment to implement. Communication is a vital component of any SDM process between the physician and the patient.

According to Saba et al. (2006) more research is required to fully understand the relationship between SDM and the subjective experience of patients in the health care system. Zoppi and Epstein (2002) suggests that patient-physician communication can best be understood through communication behaviours and participants' subjective experiences of the interaction. They argue that the communication behaviour of SDM is related to patients' and physicians' subjective experience of partnership. According to Saba (2006) there are three domains of behaviours normally associated with the SDM process. These include exchanging feelings and beliefs; exchanging information about the disease, its diagnosis, and its treatment; and reaching closure. Saba and his colleagues designed a coding framework for SDM which comprise of five components of understanding communication behaviour (2006). These include offering beliefs, eliciting beliefs, offering information, eliciting information, and reaching closure. There are two key perspectives to communication within the patient-physician relationship. The first perspective regards communication as a set of skills and behaviours that can be objectively observed, whilst the second considers communication to be a reflection of the subjective experience of the patient-physician relationship (Saba et al, 2006).

1.1.3 Shared decision making and decision aids

Clinical guidelines are intended to support decision-making by providing a summary analysis of the best available evidence with respect to resolving a given

clinical problem(s). These guidelines are typically set up to support clinicians and in order for SDM to be effective, patients need reliable, simple unbiased, understandable non-technical information about their condition as well as treatment options communicated to them (Coulter & Collins, 2011). Tools such as patient decision aids are analogous to clinical guidelines, as they are based on evidence based research and facilitate informed preference by presenting the information in such a manner that enables patients to comprehend the different options and possible consequences (Coulter & Collins 2011).

Decision aids are distinct from traditional information given to patients, in that they do not provide directive and instructional information but rather outline facts about the pros and cons of a series of treatment or screening options to help patients make measured decisions about a preferred option. Decision aids usually contain the following (adapted from Coulter & Collins, 2011; p. 5):

- *A description of the condition and symptoms*
- *The likely prognosis with and without treatment*
- *The treatment and self-management support options and outcome probabilities*
- *What's known from the evidence and not known (uncertainties)*
- *Illustrations to help people understand what it would be like to experience some of the most frequent side-effects or complications of the treatment options (often using patient interviews)*
- *A means of helping people clarify their preferences*

- *References and sources of further information*
- *The authors' credentials, funding source and declarations of conflict of interest*

Research into the impact of SDM on patient experience underline the importance of specific methods or techniques, such as decision aids and organized checklists, in enabling effective interaction and exchange between patients and health consultants thereby supporting the decision making process (Kon, 2010). According to Hoffman et al. (2014) there has been increasing attempts to integrate the teaching and study of how guidelines can be modified to facilitate SDM with research and resource tools that recognise both approaches. There are emerging examples of research programmes and priority setting taking place in patient-physician partnerships, which support the provision of relevant evidence for decision making and the development of a new evidence criterion (Hoffman *et al.*, 2014). In some situations, SDM procedures involve the use of decisions aids (such as computer programmes or applications) by healthcare providers to help structure and guide the decision making process. Technology mediated decision aids are not intended to act as a substitute to the physician's input, but rather supplement their consulting skills. Physicians still have to contribute to the decision making process by sharing their medical knowledge of a condition, likely outcomes, and healthcare options. Thus, decision aids are intended to help reinforce SDM by increasing the scope of patient engagement and acknowledging the significance of their values (Joosten et al, 2008).

Barry & Edgman-Levitan (2012) suggest that in clinical situations that warrant SDM (i.e., there are multiple feasible treatment or screening options), physicians can support the process by providing decision aids that raise the patient's awareness and

understanding of treatment options and possible outcomes. Decision aids that can be delivered across multiple media (i.e., online, paper, video, audio, etc) are a useful resource for patients as they can facilitate the understanding of clinical evidence, support the development and communication of informed preferences, particularly where there is no prior experience of likely outcomes (Barry & Edgman-Levitan, 2012)

There have been a growing number of randomised trials of SDM supported by patient decision aids. A review by O'Connor et al., (2009, as cited in Barry & Edgman-Levitan, 2012) looked at evidence emerging from 55 published trials, which focused on the use of patient decision aids for a range of preference-sensitive decisions. The review concluded that there is growing evidence that patient decision aids can lead to increased knowledge about certain conditions, better and a more accurate perception of risks and greater consistency between decisions and patients' values. It can also result in reduced levels of conflict between the patient's viewpoint and internal decisions, and patient passivity and indecision.

Barry & Edgman-Levitan (2012) are of the opinion that decision aids in SDM programmes have been resulted in the emergence of prostate-specific-antigen tests as the preferred patient choice for prostate-cancer screening, as well as patient antipathy for major elective surgery. Thus underlines the importance of SDM as a useful tool for managing problems associated with over diagnosis and overtreatment.

Coulter and Collins (2011) take the view that notwithstanding the extensive interest in SDM, decision aids have been used only sparingly and inconsistently in the United Kingdom. They argue that the reason for this might be that the decision aids available (most of which have been produced outside the UK) are unsuitable for use in the UK as they have not been produced or modified to suit the UK population and

setting. It could also be linked to fact that decision aids have been poorly shared across healthcare systems, clinical teams have been ignorant or sceptic of their existence and there has been ambiguity surrounding the evidence base for decision aids and their applicability in a UK context (Coulter & Collins, 2011).

1.2 Positive Effects of Shared Decision Making

However, despite the lack of use in the UK, SDM as a process and policy, is becoming popular around the globe. One reason for the increased popularity of SDM in the medical and healthcare sectors is that research seems to indicate that SDM leads to more positive health outcomes compared to more traditional medical decision-making processes. There are a number of benefits associated with SDM. The process enables patients to be more involved in the management of their health care and it is one of the best ways to convince patients to engage with procedures that may have adverse outcomes (e.g., a painful surgery). SDM provides a platform for creating awareness about the benefits and risks associated with different medical treatment protocols and can help eliminate or mitigate against the stress associated with the negative consequences of a procedure (Joosten et al, 2008). According to Légaré et al., (2010) health-policy researchers suggest that SDM may reduce over-diagnosis and over-treatment of conditions, thereby decreasing overall healthcare costs. It improves the quality of the health care leading to increased patient satisfaction and better and more rapidly improving health (Kon, 2010; Légaré, et al., 2010). SDM also increases patient engagement and trust, because SDM is focused on patients' personal preferences of the management of their health care (Barry and Edgman-Levitan 2012; Joosten et al, 2008; Kon, 2010). SDM might also help establish and sustain trust in the healthcare provider as it decreases the occurrence of

inconsistencies in the provision of healthcare and reduces complaints from patients (Kon, 2010)

1.2.1. Impact on Patient-Centred Experience

One of the possible outcomes of the SDM model is that patients who are given adequate and useful information about their health problems and participate in the decision making process with respect to choices about the management of their care will be more satisfied with their care givers. The rationale behind this reasoning is that patients feel more satisfied when they are informed about all available healthcare options and they have played a role in choosing the best evidence-based healthcare that suits their needs (Légaré et al, 2008). According to McKinstry (2000) a number of research studies have shown that SDM increases patient satisfaction with health services provided and with their involvement in managing their care. Similarly, research by Veroff et al. (2014) examined the views of 108 analysts on the importance of SDM; they reported that SDM was associated with improved patient satisfaction and had more impact than gender, education or the number of healthcare visits. Katz and Hawley (2014) observed that SDM improved patient satisfaction amongst patients suffering from major depression and that increase in patient satisfaction led to rapid improvement in the quality of personal health. Similarly, Elwyn et al. (2012) is of the view that patients and their healthcare providers are more satisfied with medical treatments, such as surgery leading to the treatment of particular disease or replacement of human body part damaged after an accident, when SDM had been implemented. Approaches that involve the patient's family members and other interested parties (e.g., psychologists or social workers) in decision-making often leads to improved patient satisfaction (Hoffmann et al., 2014).

Légaré et al., (2010) have argued that patient decision support tools make it easier to discuss the importance of a surgical procedure with patients, particularly those procedures that appear to be risky. Many patients are often reluctant and scared of undergoing surgical operations and of the possible side effects. Thus, these tools assist the SDM process but also increase patients' satisfaction as they are made aware of the future benefits of procedures.

Lee and Emanuel (2013) developed a computerised decision support system for cancer patients, where patients can communicate their symptoms and receive real-time feedback on the range of evidence-based medical care available. This system can lead to rapid improvements in patients' satisfaction resulting in better health outcomes (Barry & Edgman-Levitan, 2012). At the core of patient-centred medicine is the understanding of relevant social and psychological factors that can have an impact on patients' health including their experiences of illness (Stevenson, et al. 2000). SDM therefore requires physicians and other health professionals to have very good communication and listening skills in order to encourage patients to express their opinions, ideas, and preferences, in order to understand their points of view and expectations. Health professionals also have to work closely with their patients in finding a consensus with respect to their healthcare management needs (Stevenson et al., 2000).

1.2.2. Patient Preference for Shared Decision Making

There are a number of clinical and healthcare situations where there is clarity about the course of treatment and patient preferences play little or no role, for example a fractured shoulder, acute appendicitis, or bacterial staphylococcus infection. However, for some medical conditions, such as therapy for early stage breast or

prostate cancer or genetic and cancer screening tests, there is often more than one possible treatment pathway, including the option to do nothing. The various medical options often involve multiple combinations of possible medically beneficial effects and side effects. Given the uncertainty associated with such medical cases, engaging patients in the decision making about the course of action adds significant value and benefit to the process (Barry & Edgman-Levitan 2012).

The concept of SDM is predicated on patients' taking an active role in the process. However, it is appreciated that the extent of individual patient's involvement may vary significantly. Stevenson et al (2000) is of the view that there will be patients who will not want to assume full responsibility for their medical care. Nonetheless it is vital that any concerns, needs and ideas that they may have is integrated into eventual decisions about their care.

Charles et al. (1997) suggested that patients should disclose treatment preferences and these should be discussed together with the physician's preferences. It is also crucial that the physician's preferences are expressed and juxtaposed with that of the patients for SDM to be effective (Stevenson et al, 2000).

Makoul et al. (1995) pointed to a dearth of discussion of patients' opinions about medicines, although such information may be relevant for making decisions about the necessity of a given prescription. In a study by Stevenson et al. (2000), general practitioners (GPs) expressed surprise when asked about patients' opinions of medicine and could only guess or assume as to what those views were. Similarly, patients expressed a hesitation to share their choices. It was observed that out of the patients who reported that they did not want a prescription, only four raised the issue with their GP (Stevenson et al, 2000). Another study by Saba et al. (2006) examined

the relationship between SDM and the different experiences of patient-physician partnerships in primary care. It showed that effective communication did not guarantee collaborative experience and a positive but partial experience of partnership was not always the result of effective communication. These studies indicate that often patients' knowledge and preferences are not known or deemed relevant in the medical decision-making process. Even if they are known, for patients' preferences to feature in the decision-making process requires extra effort and attention.

Medical ethics includes self-determination of one's own body as an appropriate and fundamental principle. In terms of ethics, patients or clients are considered best suited for deciding the implementation of a treatment as they are the ones suffering potential (negative) consequences and side effects. As discussed previously, patients experience healthier outcomes when information and choices are provided to them (Jared, 2007). Different studies have showed that when decisions are made in a shared way this decreases the eagerness to implement expensive and doubtful therapies, thus making SDM cost effective (Dennis et al., 1997). SDM also increases patient's satisfaction, facilitates the adherence of treatment, and in most of the cases decreases the burden of symptoms.

Patients anticipate healthcare decisions more than anybody else does, as treatment alternatives become at times difficult to manage and handle. Therefore, the time spent in a consultation with a physician is critical because patients may need time to get involved in their own health through SDM (Légaré & Witteman., 2013). In the past, physicians mainly engaged in decision-making in which the consent or point of view of patients was rarely considered.

According to Stevenson et al (2000) patients think differently about any specific treatments. Similarly, individuals vary in terms of how empowered they feel to be involved in their treatments. Empirical evidence has indicated that there is a large numbers of patients who do not prefer to participate in the process of shared decision-making.

Preferences of whether to be involved in the medical decision-making process vary with the characteristics of a patient. A number of studies, mostly conducted in western societies, tried to investigate whether demographic or other characteristics influence preferences for SDM. Arora and McHorney (2000) showed that the majority (69%) of the patients in the UK had a preference of leaving the medical decisions to their physicians. Preference for taking an active role in the decision-making process declined with age, and females were more active in SDM than males. Arora and McHorney (2000) also demonstrated differences in SDM among patients suffering from different diseases. In comparison to patients who were suffering from minor hypertension, those suffering from severe heart diseases and diabetes did not prefer to contribute to decision-making. On the other hand, patients with severe mental illness were more likely to be active to contribute in decision-making (Adams, 2007).

Arora and McHorney (2000) found that patients who had active coping strategies were highly active compared to the ones who coped passively. Coping strategies are particular efforts that are made through both psychological and behavioural approaches. Coping strategies are used for mastering, minimising, tolerating or reducing stressful events. Active coping strategies include both behavioural and psychological efforts to lessen stressful circumstances. Passive coping strategies assist in avoiding the stressful circumstance. Passive coping strategies lead to a feeling of helplessness and a dependency on others (Arora & McHorney, 2000).

Likewise, a study conducted by Adams (2007) showed that many severely mentally ill clients were likely to express a preference for SDM.

Frosch and Kaplan (1999) studied the degree of involvement of cancer patients in the decision of treatment with diverse diagnoses. They showed that participants were in favour of shared decision making, however preferences differed with age. Specifically, 87% of patients between the ages of 20 and 39 years and 62% of 40 to 59 year olds preferred to contribute to SDM. This preference gradually declined to 51% for patients aged of 60 years and above. Similarly, differences in terms of education were also observed with higher education attainment relating to more active participation in shared decision making.

Another important factor, which affects the shared decision making process is the relationship of patient with the physician and the extent of their interaction. It is still unclear if the decision-making style of the physician affects the preference or if the patients work better with the ones who have a decision-making style similar to the preference (Simon, 2003). Furthermore, patients of low socio-economic status do not prefer a shared medical decision compared to patients of high socioeconomic status (Say and Thomson, 2006).

In summary, in western societies, such as the UK, patients' preference for SDM varies with the experiences of patients, their age, gender, education, and socioeconomic status. In addition, patients' satisfaction with their involvement impacts on the probability of engagement in SMD in the future (Say and Thomson, 2006)

To deal with these kinds of problems, UK health researchers have suggested different policies to engage patients more in their health and SDM (Stevenson et al., 2000). For involving patients in the process of decision-making, physicians of the UK

adopt different strategies. For instance, they do a cost-benefit analysis with patients by conceptualising the processes of considering risks and benefits of specific treatments. To complete this step, physicians' first priority is to ask patients about their experiences, which does not only help them in sharing information, but also empowers patients to be involved in the discussion. In the UK physicians also include the treatment recommendations in the SDM process with patients. A majority of physicians prefer to share such information with their patients, and they think this is the responsibility of physicians. However, physicians in the UK also prefer to make decisions for evaluating alternative treatments (Stevenson et al., 2000).

Research on SDM and patients' preferences for SDM in non-western cultural contexts is scarce. One goal of this dissertation is to gauge (preferences for) SDM in Saudi Arabia. Historically, physicians in Saudi Arabia had poor communication strategies with their patients and preferred not to share or disclose information in front of others. Therefore, participants' involvement in taking (alternative) decisions was very low (Mobeireek et al., 2008). More recently, physicians' attitude towards patients and their social networks has changed, and one major reason behind this is the focus on religious factors, as it is considered a moral stigma if the family is not involved in the decision (Mobeireek et al., 2008). Physicians prefer to favour the patient's autonomy by supporting a more Western model of disclosure. However, physicians' preferences for SDM are less than those of patients, which might be a cause for conflict and weaken the physician-patient relationship (Mobeireek et al., 2008).

In Saudi Arabia all the patients are well aware about health matters, therefore, expectations of public involvement is comparatively high. Study has shown that 70% of patients prefer to share their information with their physicians as well as family members of all other patients (Mobeireek et al., 2008). This percentage increases with

the severity of the disease, such as HIV infection. Saudi patients share information with other relatives and physicians about prolonging therapy and becoming a part in decision-making process (Mobeireek et al., 2008).

As compared to the UK, physicians of Saudi Arabia assume that patients and other relatives have the right to know details about patients' disease. Therefore, they prefer to share knowledge with patients and families at about 56 percent in less severe diseases (Mobeireek et al., 2008). Conversely, if HIV and other severe or complex disease are observed, then 81 percent of physicians prefer to share information with others and involve their patients in the decision-making process. Empirical evidence reflects that the major concern of physicians in Saudi Arabia is to provide information to all the patients about their life expectancy (Mobeireek et al., 2008).

Even though Saudi patients are now more aware of health matters compared to the past, people have different reasons for experiencing frustration and dissatisfaction with their care. Patients are dissatisfied and frustrated with their care because they feel they are not provided with adequate information and may not be involved in health decisions which are then made by clinicians (Mobeireek et al., 2008). One reason for such problems is the lack of knowledge that patients might have regarding their treatment to make an informed decision. In particular, some patients do not comprehend the evidence that is used to make or recommend certain decisions (Mobeireek et al., 2008).

In summary, patients' preferences for SDM when making their treatment plans is popular in the UK and is starting to be preferred by physicians in Saudi Arabia. Even though Saudi physicians had not been utilising this method of sharing, practices are changing and they prefer to value patient's autonomy by supporting the Western

model of disclosure. On the other hand, the UK physician has been involved in shared decision making for many years. This preference of following the shared decision-making method is observed in physicians as well.

1.3 Cultural Factors in Shared Decision-Making

It has been suggested that shared decision making in clinical situations is best achieved when both physicians and patients openly discuss their motivations and reservations about the medical options under consideration (Stevenson et al., 2000). Stevenson and her colleagues argue that physicians should share their technical knowledge about the pros and cons of all options that could possibly resolve a medical issue(s), whilst patients should be free to express their reservations about the options proposed, which may stem from their personal experiences (2000). Kleinman and Geest (2009) have also suggested that physicians should make every attempt to provide full and reasonable answers to questions raised by patients, even if it means consulting other physicians and health professionals. It has equally been suggested that better healthcare outcomes can be achieved when physicians recognise and/or consider illnesses as one component of a social ailment (Kleinman and Geest 2009).

The physician-patient interaction in SDM should focus on reconciling patient concerns about their well-being and therapeutic choices. These may be underpinned by patients' and health care providers' culture and ethnicity (Kleinman and Geest 2009). According to Barry and Pandey (2011), cross-cultural psychology offers a useful explanatory framework for understanding patient anxieties, choices and engagement with the medical decision making process. Important cultural elements, such as values, practices, behaviour domains, position, capacities, styles and scope,

can help health care providers to better understand the patient's point of view and, therefore, help with SDM processes and outcomes (Barry & Pandey, 2011). An understanding of cross-cultural factors is vital for the recognition of culture-specific patterns and differences in beliefs and expectations about diseases and their treatment (Barry & Pandey, 2011; Harkness & Keefer, 2000).

There are two important aspects of culture which may influence patient interaction with physicians, one of which is the cause and effect relationship between culture and behaviour, whilst the other is the expression of culturally distinctive phenomena, for example language, values, norms, perceptions etc. (Barry & Pandey, 2011). It can therefore be argued that research in cross-cultural psychology provides important information for health care providers in developing their knowledge on cultural variability and diverse manifestations of social representations, as well as developing new theoretical frameworks for understanding how culture influences attitudes and behaviour towards healthcare provision (Harkness & Keefer, 2000).

Cultural factors are likely to play an important part in health care and behaviour (Beaton et al., 2000) particularly concerning the interactions between patients, physicians, and other health-care professionals. Cross-cultural research on health care and behaviour can identify potential cultural barriers, which, if not realised and addressed, can lead to miscommunication between the patient and physician. Therefore, cross-cultural research can help remove cultural barriers and can potentially improve health care and outcomes. This could lead to development of more cultural competence in health care professionals, that is, understanding that patients' beliefs and norms are influenced by culture. Healthcare providers need to respect the viewpoint of patients as these strongly influence health and sickness (Betancourt et al., 2003). Because cultural factors can influence patients' health behaviour in general

and preferences for SDM specifically, the next section will discuss cross-cultural psychological approaches in more detail.

1.3.1 What is cross- cultural psychology?

The main focus of cross-cultural psychology is the identification of cultural factors in human behaviour. That is, cross-cultural psychology examines the impacts and consequences of culture on human behaviour (Berry, 2002). This branch of psychology investigates cross-cultural effects in child development, personality, social attitudes, verbal communication attainments, and others. The basic function and objective of cross-cultural psychology is to explore and identify which human behaviours are universal as well as culture-specific behavioural patterns and attributes (Triandis, 2000).

There are two main theoretical and methodological approaches in cross-cultural psychology. One is related to the etic approach in which special consideration is given to similarities across and within cultures (Berry, 2000). This etic approach feeds into the universalist notion of human psychology that human psychological processes are the same or largely similar across different cultures. The etic approach to culture focuses on differences across cultures and on what makes cultural groups or units unique (Berry, 2000). Consequently, etic approaches to culture are relativistic in nature, acknowledging that culture strongly shapes human psychology and focuses on what makes human experiences unique within a specific cultural group.

1.3.2 Individualism and Collectivism (IC): theory, method, and application

One of the most important of the models on how culture can influence individuals' cognitions, emotions, and behaviour is the eco-cultural theory, which reflects emerging

knowledge from cross-cultural research as well as evidence from the field of psychology and ecology (Harkness & Keefer, 2000). This theory assumes that individual behaviours, attitudes, and orientations of individuals are learned through interactions with other individuals and the environment (Ozer, 2015). Thus, the eco-cultural model hypothesises that thought and behaviour is socially constructed (Weisner, 1984). The model comprises a number of important concepts, such as family action and accommodation, which underscores the importance of family in the development and modification of practical every day activities and schedules in response to societal, economic and ecologic variables as well as new situations within the family (Harkness & Keefer, 2000; Ozer, 2015). The eco-cultural model also provides a means of identifying, explaining and predicting cultural contrasts through the theoretical lens of Individualism-collectivism (IC).

The focus on individualism and collectivism (IC) in the cross-cultural psychological literature increased dramatically after the publication of Hofstede's (1980) highly influential analysis of the dimensions underlying cultural differences in attitudes and values (Oyesrman, et al., 2002). According to Fischer et al. (2009), IC facilitates the understanding of human behaviour, and provides a hypothetical framework of cultural similarities and contrasts. The IC framework is based on the idea of individuals' psychology and behaviour as thoughts and practices that are produced as a result of long term regular interaction with social groups as well as the individual's inherent psychological and physical mechanisms for understanding the physical and social world (Berry et al., 2011).

1.3.3 Definition of Individualism and Collectivism

The IC framework places emphasis on whether and how individuals perceive themselves to be connected or distinct from others in their social groups (Fischer, et al. 2009). The concept of individualism suggests that individuals should think of and perceive themselves and others as independent, autonomous entities. Cultures or individuals prescribing to an individualistic point of view regard human beings as having separate identities and being able to independently think about aspects of their social world (Wagner et al., 2012). Therefore, persons or cultures high in individualism show a preference for individual rights, autonomy and autonomous decision-making. In other words, the basic assumption of an individualistic mind-set is that one's own goals and happiness have priority over those of the group.

Individualism is very much related to concepts of taking responsibility for oneself, self-independence, and self-initiative (Wagner et al., 2012). In an individualistic culture, the individual is defined by distinct characteristics that set them apart from others as well as having objectives that are different from their wider social (in-) group (Wagner et al., 2012). Whilst Hofstede (1980) defined individualism as a focus on individuals' rights over duties to others, care for an individual and one's own family, Wagner et al. (2012) define individualism as emphasising one's personal autonomy and self-fulfilment, developing self-identity and pride in personal accomplishments.

Individualism is regarded as an ethical concept that identifies morals of an individual in the fields of both psychology and political science. A central tenet of individualism is that people have separate identities based on autonomy and, potentially, different preferences and needs. Therefore, the sovereignty of individuals'

minds need to be respected and valued (Wagner et al., 2012). In the context of political ethics (Schwartz, 1990), individualism supports the superiority of individual rights over other concerns. The basic political structure and model of individualism stands on the principle that one's moral obligation is to pursue one's own happiness. Individualists have personal goals that might not overlap with those of their in-groups. If there are differences between group goals and individual goals, individualists believe that their personal goals should have priority over the group goals (Schwartz, 1990).

In contrast to individualistic societies, in collectivistic cultures relationships and the needs of people's in-groups (e.g., families, religious groups) usually have priority over individual needs. Thus, collectivism can be understood as practices that focus on the well-being of a person's (primary) in-groups rather than personal or individual well-being (Borkowski, 2015), and that collective actions and practices should be applied. Collectivism requires that groups must be given more importance and significance as compared to individuals (Gorodnichenko & Roland, 2012). In a collective culture individuals possess a number of shared traits, values and objectives that are common to their in-group group or community. Individual–group relations include trade-offs between personal and group thoughts and convictions that are based on communal values and philosophies (Ozer, 2015). The supremacy of the group has a moral value in collectivistic societies and individuals (Gorodnichenko and Roland, 2012).

According to Hofstede (1980), when conceptualising individualism and collectivism, it is essential to assess how interdependence between people is conceptualised in a society. In individualistic societies people are supposed to look after themselves and their direct family only. In collectivist society's people belong to 'in groups' that take care of each other in exchange for loyalty. These differing views give rise to construing one's identity in different ways: Whereas people with an

interdependent/collectivistic self define themselves as part of a group, people with an independent/individualist self focus on self-identity and autonomy from groups (Markus & Kitayama, 1991).

The concept of individualism-collectivism has been transformed and changed in subsequent research. Of particular importance for the current research is the addition of a horizontal-vertical dimension by Triandis and colleagues (Triandis & Gelfand, 1998). They argued that individualism and collectivism could be either horizontal (i.e., emphasising equality between people) or vertical (i.e. emphasising hierarchy between people). According to Singelis et al (1995), individuals high on vertical collectivism perceive the self as part of a collective, but accept inequalities within these collectives. People high in horizontal collectivism perceive the self as part of the collective, but consider all the members of the collective as the same stressing equality. People high in individualism conceptualise the self as independent from others. People high in vertical individualism perceive (independent) individuals as unequal, people high in horizontal individualism perceive independent individuals as similar and equal. These conceptions of horizontal and vertical individualism and collectivism have been based both on theoretical considerations and empirical research (Singelis et al., 1995; Triandis & Gelfand, 1998).

1.3.4 Individualism-collectivism in Saudi Arabia and UK

According to Hofstede (1980; <http://geert-hofstede.com/>) the UK is amongst the highest-scoring countries in terms of individualism, only out-scored by countries such as Australia and the U.S.A. The British are a highly individualist and private society. Children are taught from an early age to think for themselves and to find out what their unique purpose in life is and how they can contribute to society in a unique

way Hofstede (1980; <http://geert-hofstede.com/>). The route to happiness is through the fulfilment of personal desires and goals. As the affluence of Britain has increased throughout the last few decades, a much discussed phenomenon is the rise of what has been seen as rampant consumerism and a strengthening of the 'ME' culture.

According to Hofstede (Hofstede, 2001; <http://geert-hofstede.com>) Saudi Arabia is considered a strongly collectivistic society. Based on the definitions of individualism and collectivism, this means that people in Saudi Arabia show close long-term commitments to their in-groups, for example their families, extended families, or other important relationships. Loyalty to one's in-group(s) is really important, more important than most other societal rules and regulations. Offending one's in-group and in-group members leads to shame and loss of face (Hofstede, 2001; <http://geert-hofstede.com>). Al-Rwaita (2008) compared individualism/collectivism in a sample of 142 Egyptian and 157 Saudi males and a sample of 139 Saudi males and 123 Saudi females. The results reinforced that the Saudi society was more collectivistic than individualist, and that females were more collectivistic than males. In contrast, Egyptian males were more individualistic than Saudis.

Bjerke and Al-Meer (1993) examined cultural orientations in Saudi Arabia by drawing on Hofstede's (1980) four dimensions of individualism-collectivism, power distance, uncertainty avoidance, and masculinity-femininity. Their analysis was based on a survey with Saudi MBA students and their co-workers. Bjerke and Al-Meer (1993) found that on the one hand Saudi Arabia is a typical Muslim country and holds a high score in terms of power distance. On the other hand (business) relationships with the western world and the booming oil industry lead to some individualistic features with

effective management behaviour, organizational structures, intuition as well as the application of the management theories (Bjerke and Al-Meer ,1993).

Ali and Krishnan (1997) studied the relationship between individualism-collectivism and decision-making styles among 307 managers working in Kuwait. Participants were from government, private or some mixed organisations. The study involved measures of collectivism, individualism, and decision style. Participants of the study showed a high propensity to collectivism and weak commitment to individualism as well as a strong preference for counselling colleagues and participative styles of decision-making (Ali and Krishnan, 1997). According to participants, a participative approach was the most efficient style of decision-making, especially in business settings. However, most of them thought that their respective supervisors were pseudo-consultative, that is they did not really follow this preferred style of decision-making (Ali and Krishnan,1997). Overall, one can draw two important conclusions from this study: First, on average Kuwaitis, like Saudis, show a stronger commitment to collectivism than individualism; second, that individuals in a collectivistic society, such as Kuwait, prefer a collaborative and participative decision-making style.

Al-Zahrani and Kaplowitz (1993) studied the decision-making processes, particularly attributional biases, and health behaviours in Saudi and American adults. They found that Saudi participants were more collectivistic whereas American participants were more individualistic. Saudis were more likely to use internal attribution style and perform tasks in a group-serving style that is supposed to benefit the family as well as national groups. In other words, Saudi participants showed less self-serving bias. On the other hand, these aspects were not found in Americans, as they wanted to work in an environment which supported individualistic values. In terms of health behaviour, Saudi participants' health behaviour improved when different

psychological perspectives (e.g., by family members) were considered. However, the health behaviours of Americans were not affected by their degree of individualism.

In sum, these studies indicate that people from Saudi Arabia are higher in collectivism and lower in individualism than people from the UK and the US. In addition, there is some indication that Saudi adults score higher on the dimension of power-distance than people from western societies.

Al-Rwaita (2002) has examined locus of control and its impact on Saudi psychology from the perspective of Rotter (1976). Individual's behaviour and its consequences can be interpreted based on the causal attributions people make. People are said to adopt an internal locus of control when they attribute behaviour and its consequences to ability or effort. People exhibit an external locus of control, when they attribute actions to luck, fate, accident, etc. Wallston (1978) argued that in matter of locus of control in the health domain destiny must be dissociated from luck and chance (Al-Rwaita ,2002)

Al-Rwaita's (2002) findings indicate that destiny is a unique factor than can be regarded as an external health determiner independent of luck and accident. With this in mind and given the Islamic orientation of Saudi society destiny means the will of god in everything is not associated with luck and chance. This highlights the influence of the concept of the point of control variables as well as cultural and religious separations of lucks and destiny in some cultures. Saudis might adopt an attitude such as "I am responsible for my health care but according to the will of god", which mixes internal and external locus of control (Al-Rwaita,2002).

Fischer et al. (2009) developed and validated an instrument for quantifying the norms and values associated with individualism-collectivism (IC). They examined IC

norms as a shared-culture construct at both the individual and cultural level. The tool was based on the premise that IC norms are framed by individual inclinations, idiosyncrasies and position as well as by the interrelationship between individuals within a group. Fischer et al. (2009) investigated several conceptual elements of individualism-collectivism (IC) norms and values across eleven countries including Saudi Arabia and the United Kingdom. Specifically, they studied the extent of intercultural agreement and divergence about the IC standards and the degree to which IC standards are invariant over individual and cultural levels.

The study identified a distinction between individual-level and institutional collectivism. Pride in personal achievements and devotion to one's group were identified as key to individual-level collectivism, whilst the degree a group and its leaders promote and enforce loyalty and responsibility was identified as key to institutional collectivism and dissociated from individual-level collectivism (Fischer et al., 2009).

It has been suggested by Fischer et al. (2009) that the conduct and behaviour of an individual can be anticipated by both self-report IC and subjective IC norms. In order to better understand culturally mediated behaviour, an appreciation of individual differences in cultural expression and viewpoints can provide useful insights. Based on their research, Fischer et al. (2009) warn that when individual orientation is not taken into consideration, then the IC construct does not predict individual behaviour well. For example, college students who have reported that they regard the prioritisation of personal goals over family goals as acceptable (individualism) have shown to be more disposed to helping friends and nonfamily-related peers. This is believed to be driven by instrumental motivations, because of the high level of interdependence required to succeed in an university setting. Similarly, individuals who

prioritise family goals above personal goals (collectivism) are also inclined to support their friends, but as a result of normative. This suggest that norms that are confined to a particular group can have diverse and contradictory consequences across groups and that other in-group norms can become prominent in particular contexts. Consequently, Fischer et al. (2009) has suggested that the interaction between different groups, related norms and values, the target of the behaviour and the implications of specific behaviours for the groups involved are key factors in the cultural mediation of individual and group behaviour. As a consequence for the present research, individual-level commitments for individualism-collectivism will be measured.

1.3.5 Health Care Provision and Behaviour in Saudi Arabia and the United Kingdom

Cultural orientation can be described as a way of learning to think, feel or work in a culturally grounded manner. The Arab cultural orientation needs to be considered in the health care domain as it is likely to affect health care provision and behaviour (Purnell, 2014). Here, we first examine research on the relationship between patients and health care providers. This relationship can be heavily influenced by miscommunication and misunderstandings of cultural values and factors. The communication styles of Arab patients and their practitioners affect their relationship (Moran et al., 2014). Analysing cultural orientation is of critical importance as Arab people have different ethnicities but share common values and norms. Arab people emphasise and assign importance to their family and associations (Moran et al., 2014). However, other cultural aspects can be considered equally important and are manifested in people's interaction style, health behaviours and responses to illness (Moran et al., 2014).

Consequently, cultural orientations can influence the health care domain. These orientations can result in different issues and concerns for practitioners. In Arab countries, physicians commonly come from different countries and have different origins (Gielen et al., 2012). So, language barriers and other cultural factors can become obstacles to effective communication between patients and practitioners. Patients' beliefs might also conflict with those of their health care providers, negatively affecting health care provision (Gielen et al., 2012). Arab people have been observed to act in very authoritarian ways to these individuals. This behaviour is discouraging to physicians and other practitioners from different cultures and origins. In addition, Arab people do not understand many other languages and prefer to use their native language. Practitioners have to make efforts to support and enhance health care provision (Gielen et al., 2012)

In Arab countries, other cultural factors can influence health care provision. Among the dominant Arab cultural factors is the process of negotiation and bargaining (Pérez & Luquis, 2013). Issues and concerns might not be discussed in detail as Arab people exhibit strong body language and gestures when angry (Pérez & Luquis, 2013). Consequently, practitioners avoid arguing and responding to patients whose families do not understand the viewpoint of their physicians and other practitioners (Pérez & Luquis, 2013). On the other hand, Arab families show a unique caring behaviour, which can help bridge (communication) gaps in health care provision in Arab countries. Overall, there is a need for close collaboration and investigation of health-related issues so that the communication gaps and relationship issues affecting the Arab community and health care system can be minimised (Kulwicki et al., 2000).

The UK cultural orientation in the health care domain is different as it includes aspects related to the differences in interpersonal relationships and self-identity (Scott

et al., 2003). Interpersonal relationships between patients and practitioners are seen as important in the patient-oriented approach (Scott et al., 2003). As described above, the UK health care system emphasises the provision of treatments and promotes shared decision-making to boost patient autonomy. Patients and practitioners make decisions after patients are provided with adequate information and knowledge about their illness and diseases. The UK National Health Service (NHS) safeguards patients and their rights by the implementation of shared decision-making. This practice empowers patients and increases their autonomy as they have clear information about their care and health care providers. Practitioners also receive support and assistance to improve or sustain the balance in patients' and practitioners' relationship (Grosios et al., 2010).

Other cultural attributes, such as individualism and collectivism, also affect cross-cultural relations in the health care domain. The attributes of individualism and collectivism are related to patients' health behaviours and influence the shared decision-making process. Other assumptions and concepts have emerged recently as cross-cultural health care provision and shared medical decision making have been applied in different ways in various cultures. However, most of this research has not been conducted in a Middle Eastern context.

McLaughlin and Braun (1998) investigated health care decision making in Asian and Pacific Islanders examining how cultural values affect these decisions. This study explored the importance of traditional values in the decision-making process. For instance, the Asian and Pacific Islanders have different cultures, which allow them to make decisions in accordance with their feasibility the health procedure.

According to the individuals of these regions, they are successful because of making collective decisions. Furthermore, the health care professionals (who were working in Hawaii) identified that the individuals (specifically the patients and physicians) of these regions want effective treatments and thus, they focus on collectivism. On the other hand, it is a common perception of Asian and Pacific Islanders that individual decision-making may cause harmful results in terms of ineffective treatments, which may hinder the quality of life as well as growth of the economies. Essentially, participants believed that collectivism is better than individualism for encouraging health behaviours (McLaughlin & Braun, 1998)

Kim and colleagues (1999) investigated medical decision-making and self-construal in Chinese patients, that is, to what extent the preferences for medical decision-making process are affected by patients' cultural orientations. For this study, patients in Hong Kong and Beijing were selected. It was found that self-construal was correlated with individualism. However, both collectivism and individualism both impact on the health behaviour of Chinese patients and professionals. Overall, Chinese patients preferred to make decisions about their medical care themselves. However, in terms of actual medical decision-making, patients' take decisions with the help of their families. Thus, Chinese patients are not making decisions individually. Therefore, the residents of Hong Kong and Beijing are favouring collectivism rather than the individualism in their actual decision-making. Subsequently, this collectivism has improved the health behaviours within these regions. Similarly, the findings of the study shows the use of shared decision-making process in these regions is collectivistic.

The results of the study (Kim et al., 1999) also show that there are some patients, who do not want the involvement of others. Their major focus is on the

independent self-construal and they make choices themselves without the interference of family members and doctor, which is called individualism. Such patients face several negative impacts of their decisions due to their ineffective preferences. For instance, without the interference of doctors, a patient cannot make right decisions about their treatment. One reason of this dual nature of patients is associated with cultural differences. For instance, the patients in Hong Kong were more likely to use individualistic decision-making styles, as the diversity in this region and western influences are greater. On the other hand, Beijing patients favour collectivism, which is increasingly significant for medical departments and hospitals in Beijing.

Moazam (2000) investigated the role of families, patients, and physicians in medical decision-making in Pakistan. The major focus of this study was to assess whether shared decision-making exists in a collectivistic country. Moazam (2000) identified Pakistan as a collectivistic country, which is also propagated by the government. However, most of the physicians are being educated in the West. Thus, both traditional collectivistic and individualistic attitudes could affect medical decision-making in Pakistan.

The Pakistani culture requires a traditional approach to make a striking balance between preserving its indigenous cultural-values and patients and/or professionals' participation. Muslim culture focuses on both individuals' and social roles to lead a successful life. It influences the performance of every person, specifically family members and physicians from the period of birth to the death. Therefore, both individualism and collectivism affect the health behaviours in this country through shared decision-making process (Moazam, 2000). The study showed that most of the decisions about patients' health care were made by the family and/or the physicians, an indication of a more collectivist decision-making style.

A study by Rochelle and Marks (2011) examined the relationship between cultural and health beliefs within the Chinese community in the UK. The results showed that acculturation was a key factor in the use of Traditional Chinese Medicine (TCM) by Chinese respondents living in the UK. The study showed that individuals born overseas but with Chinese as a first language were more inclined to use TCM compared to those born in the United Kingdom with English as a first language. Additionally, other factors such as a sense of cultural superiority, observance of traditional rites and rituals, and making linkages between cultural values, religious beliefs and health behaviours were significantly associated with the use of TCM. However, given that the majority of individuals sampled had resided in the host country for a considerable number of years and routinely used western medicine (WM), this indicated a more bicultural health-seeking orientation of the sampled respondents. The results suggest that whilst most of the respondents used western medicine, it was used simultaneously with traditional Chinese medicines.

A similar study by Levesque and Li (2014) investigated cultural differences in health beliefs and practices amongst a sample of 60 respondents drawn from three different cultural groups in Canada. The results of the study indicated that there were cultural variations in health conceptions and practice and concluded that culture had a significant influence on the health beliefs and as a consequence on people's health practices.

1.4 Overview of this thesis

The aspiration of this chapter was to assist the researchers to analyse the shared decision making approach. Shared decision making involves the effective communication between the patients, their providers and the health consultants.

Shared decision making offers positive effects through increasing the patient's satisfaction and self-confidence. This approach is perceived to be successful in rapidly improving the health of the patients. Vignette studies indicate that young patients prefer to be involved in shared decision making whereas older patients rely on their doctor's decisions. The aspect of cross-cultural in health is very much influenced and endorsed through the help of notions or concepts related to cultural competence and cross-cultural understanding. This is an important and significant aspect when it comes to attaining patient success (e.g., patient satisfaction, protection, enhanced and better health deliverables or results). For understanding the reasons behind their patients' illness and disease as well as their recovery and well-being, health care providers should pay attention to and realise the importance and significance of social and cultural factors. Cultural factors are also likely to impact on shared decision making preferences and processes.

Chapter 2 will discuss how people's (shared) medical decision making preferences are influenced by their cultural orientations (i.e., individualism-collectivism) as well as by different types of motivations that likely differ between cultures, that have been shown to affect people's health behaviour (at least in western societies), and that, consequently, could also influence people's preferences for shared medical decision making

Chapter 3 will discuss the qualitative study involving patients with Type 1 diabetes in Saudi Arabia, investigating how far patients with Type 1 diabetes would be interested to be involved in medical decision that effect on their preferences.

The following chapter 4 will examine research on parental surrogate decision-making for children and factors affecting this. I will then discuss basic and applied research on whether it makes a difference when people make a decision for

themselves versus others. The last chapter will provide a general discussion for the whole thesis.

Chapter 2

Study 1: Preferences for shared medical decision-making: Influences of cultural and psychological variables

The main objective of this study was to gauge preferences for (shared) medical decision making in non-clinical samples from the UK and Saudi-Arabia. As discussed in Chapter 1, while shared medical decision making has developed into an ideal standard for medical decision making and has received increased research interest in North-American and European countries, very little is known about practices of shared medical decision making in non-western societies. Given the positive outcomes associated with shared medical decision-making reported for western patients, it seems warranted to investigate this practice further in non-western countries. This study presents a first step in this direction. I was interested in investigating how people's (shared) medical decision making preferences are influenced by their cultural orientations (i.e., individualism-collectivism) as well as by different types of motivations that are likely to differ between cultures, that have been shown to affect people's health behaviour (at least in western societies), and that, consequently, could also influence people's preferences for shared medical decision making. In the following sections, I will discuss these theories of human motivation and action in more detail, drawing particularly on self-determination theory.

2.1 Self-Determination Theory

While a number of theories of human motivation exist, self-determination theory (SDT) has emerged as the macro-theory of well-being, personality development and human motivation. SDT's main focus is on self-determined or volitional behaviour and the cultural and social conditions that advance it (Ryan, 2009). It offers empirically informed principles and guidelines for motivating individuals to explore events and experiences to enable them to implement adaptive changes in relationships, behaviours, and goals. SDT is representative of broad motivational behaviour theory that is based upon experimentally tested principles and constructs at both macro and micro levels (Ryan & Deci, 2008). The explanations of SDT focus on the psychological level rather than the physiological or social levels, thereby focusing on human needs, emotions, cognitions, and perceptions as predictors of behavioural, and regulatory outcomes (Deci & Ryan, 2015).

SDT postulates that there are three fundamental and universal psychological needs that operate across development, namely the needs for relatedness, autonomy, and competence (Ryan et al, 2009), "Autonomy refers to the need to feel that one's behaviour and resulting outcomes are self-determined, or self-caused, as opposed to being influenced or controlled by outside forces" (Johnston & Finney, 2010, p280). (i.e. behaviour is performed to achieve an outcome independent from the behaviour itself) (Donnachie et al 2017). "Competence refers to the need to feel effective and capable of performing tasks at varying levels of difficulty" (Johnston & Finney, 2010,280). (i.e. behaviour is motivated not only by its valued outcomes but also because it has been assimilated with one's beliefs and values) (Donnachie et al 2017). "Relatedness refers to the need to feel connected to, supported by, or cared for by other people" (Johnston

& Finney, 2010,280). (i.e. behaviour is performed in response to external pressure, such as rewards or to avoid punishment) (Donnachie et al 2017). As a theory of motivation, SDT differentiates between intrinsic motivation and extrinsic motivation. Intrinsic motivation manifests when individuals act to fulfil an internal reward. Conversely, extrinsic motivation necessitates some form of instrumentality between an act and some distinct consequences, for instance tangible or verbal rewards. The satisfaction emanates from extrinsic effects produced by the act (Leal et al, 2012). Additionally, SDT conceptualizes autonomous motivation and controlled motivation. Autonomous motivation is the extent to which an individual perceives his/her actions as self-endorsed and executed with a sense of free choice, self-reflection, and willingness. Controlled motivation is the degree to which an individual feels external coercion or pressure to undertake a behaviour. The SDT holds that the quality of motivation depends on the support for innate needs (competence, autonomy and relatedness) in a given social environment or setting. Satisfaction of these needs, especially through intrinsically and autonomous motivation, results in greater psychological development, self-motivation, and well-being (Donnachie et al, 2017).

2.2 Applications of the Self-determination Theory

SDT has been applied in various healthcare domains, including weight management, smoking cessation, and diabetes management. Physical inactivity is often cited as one of the most common causes of mortality globally, and is linked to various diseases, including obesity and type 2 diabetes mellitus (Donnachie et al., 2017). Recent years have seen an increase in SDT-based research on physical activity and exercise, and long-term weight control. SDT provides a theoretical framework that can be used to understand motivations that underpin physical activity. It is hypothesised that underpinning health care interventions with SDT can improve

the effectiveness of the interventions (Teixeira, et al, 2012). Increasing evidence suggests that greater autonomous motivation is linked to long-term increase in exercise/physical activity behaviour and successful control of weight. Studies have investigated the motivational dynamics linked to long-term physical activity behaviour underpinned in the SDT framework and demonstrated that internalisation and self-worth of motivations were vital for physical activity maintenance (Donnachie et al., 2017). Teixeira and colleagues explored the effects of motivation and self-determination on long-term weight management and related behaviours. They found out that if people fully embrace weight loss-related behavioural goals and were autonomous as well as competent about attaining them, as suggested by SDT, there was a high likelihood that their efforts were associated with long-term weight control (Teixeira et al., 2012). Similarly, Mahmoodabad and colleagues (2017) conducted a randomised controlled clinical trial to explore the effect of a motivational interviewing (MI)-based intervention using SDT on physical activity promotion in reproductive age women (N=70) in Iran. Their study revealed that MI-based intervention using SDT successfully promoted physical activity in this population (Mahmodabad, et al, 2017). In another randomised controlled trial, Friederichs and colleagues (2015) examined the long-term effects (12-months) of SDT in a web-based physical activity intervention (I Move). Their study revealed that the I Move intervention effectively increased weekly minutes for moderate-vigorous physical activity. They concluded that it would be best for web-based computer directed physical activity interventions to incorporate SDT elements (Friederichs et al, 2015). Equally, Klain and colleagues (2015) analysed the validity of SDT hypothesised relations in predicting physical exercise adherence among personal training subjects (N=588) and

concluded that SDT can promote exercise adherence through identification of mediators and moderators responsible for the behaviour (Klain et al, 2015).

Tobacco use is also a major health problem and a leading cause of mortality in developed countries. Smoking cessation has been linked to a longer lifespan and better quality of life (Williams et al, 2016). Researchers have explored the effectiveness of SDT-based interventions in promoting smoking cessation. Williams and colleagues (2016) evaluated the effectiveness of SDT-based intensive tobacco-dependence intervention designed to support autonomy and found out that such interventions were efficient especially among subjects who completed the whole intervention (Williams et al., 2016). In a randomised controlled clinical trial, Pesis-Katz and colleagues (2013) explored the cost-effectiveness of tobacco dependence intervention based on SDT in adult smokers and found that such an intervention was successful in promoting tobacco abstinence and was cost-effective relative to other medical and tobacco dependence interventions (Pesis-Katz, et al, 2013). Similarly, Williams and colleagues conducted a randomised cessation-induction trial to explore the effectiveness of a SDT-based intensive tobacco-dependence intervention meant to support perceived competence and autonomy in promoting long-term tobacco abstinence in adult smokers. This study also revealed that the intervention successfully promoted long-term abstinence from tobacco in the studied population (Williams, et al, 2009).

In addition, researchers have applied SDT to explore motivation across different cultures. Existing studies have demonstrated the effectiveness of SDT in explaining cross-cultural variations in health behaviour. For instance, Vlachopoulos and colleagues (2013) applied a cross-sectional research design to explore cross-cultural invariance of the Basic Psychological Needs in Exercise Scale (BPNES) across

Turkish (n=686), Portuguese (n=989), Spanish (518), and Greek (n=504) samples using the SDT as the conceptual framework. Their study revealed largely invariant BPNES scores across the different cultures. They concluded that their study was supportive of valid cross-cultural variance comparisons at the level of relatedness, competence, and autonomy constructs using the BPNES (Vlachopoulos et al., 2013). In another study, Church and colleagues (2013) tested the SDT hypothesis that relatedness, competence, and autonomy needs satisfaction is a universal psychological well-being requirement in a cross-cultural study drawing on college students from Japan, China, Malaysia, the Philippines, Venezuela, Mexico, Australia, and the United States. Their study showed that perceived need satisfaction was predictive of similar overall well-being in all the cultures. They concluded that their study supported the universal importance of satisfaction of SDT needs in various cultures (Church et al, 2013).

2.3The present study

The present research aimed to investigate and compare Saudi and British adults' (from a non-clinical sample) preferences for (shared) medical decision-making. This study measured two types of preferences for shared medical decision-making: a general preference for shared medical decision making (overall, across medical situation), and a specific preference for shared medical decision-making in a hypothetical scenario where participants were presented with two different treatment options for diabetes.

In addition, I was interested in how preferences for shared medical decision making was affected by demographic and psychological variables. First, participants' levels of horizontal/vertical individualism and collectivism were measured. I decided to

differentiate between horizontal/vertical individualism and collectivism, because adults from the Middle East have been shown to differ on both dimensions from adults in western societies. Besides individualism-collectivism two types of motivations were measured that have been shown to influence health decision-making in western samples and are likely to differ between Saudi and UK participants. The first concept was to measure participants' basic psychological needs. According to self-determination theory (SDT, Deci & Ryan, 2000) there are three basic psychological needs that are innate and universal: the need for competence, autonomy, and relatedness. According to SDT, a balance of these psychological needs is associated with human well-being and happiness. In the healthcare domain, a host of studies have shown that supporting patients' basic needs leads to a number of positive mental and physical health outcomes (see Ng et al., 2012 for an overview). Yet, cross cultural research (e.g., Markus & Kitayama, 1991) indicates that the desire to fulfil some needs might be higher in some cultures than others. For example, the need to feel autonomous, viewing ourselves as the author and agents of our own destinies and actions, might be higher in individualistic than collectivistic societies (see Rudy et al., 2007). I therefore explored whether participants from Saudi Arabia and the UK differed in their degree of basic psychological needs and whether these influenced their preference for shared medical decision-making.

As discussed above, SDT has been applied to the health-care domain (see Ng et al., 2012). The theory suggests that people who engage in health-related behaviours to support their autonomy needs achieve better health outcomes compared to those who engage in these behaviour for "external" reasons, such as other people's reactions. So far, most of this research has been conducted in western (i.e., North American, European) societies. It is an open question whether autonomous regulation

in the health domain is (a) a preferred modus operandi in non-western societies; and (b) whether preferences for autonomous or controlled regulation affect participants' preferences for SDM.

Specifically, the study investigated the following research questions and hypotheses:

1) Do adults' SDM preferences differ between Saudi Arabia and the UK?

I expected, based on research on individualism and collectivism, that participants in the UK should show higher preferences for themselves being involved in their medical decisions. In contrast, participants in Saudi Arabia should be more likely to prefer the doctor making the decision for them. This should be true for both the general medical decision-making preferences as well as the specific medical decision-making preferences. Based on previous research in western societies, I also expected that younger participants and females would like to take a more active role in medical decision making, at least among UK participants. These questions are explored in the Saudi sample.

2) Are there differences in psychological needs and regulation in Saudi Arabia and the UK?

While SDT assumes that the needs for autonomy, competence, and relatedness are universal, cross-cultural research has suggested that there should be differences particularly in the need for autonomy and relatedness in individualistic and collectivistic societies. Based on previous research, I thus expected that Saudi participants would show a higher need for relatedness, whereas UK participants should show higher needs for autonomy. Furthermore, UK participants should show higher desire for autonomous regulation in the health care domain.

- 3) Does autonomous regulation affect preferences for shared medical decision-making in both societies?

SDT research suggests that autonomous regulation leads to better health outcomes. However, this question was mainly studied in western societies so far. I explored whether autonomous regulation was associated with more autonomous medical decision-making in both societies.

Methods

2.2.1 Participants

A total of 204 participants were recruited from non-clinical populations in the United Kingdom (UK) and Saudi-Arabia. Recruitment was via convenience sampling; the inclusion criteria were that participants needed to be 18 years or older and either be residents of the UK or Saudi Arabia. There were 116 Saudi participants (M-Age = 26.74 years, SD = 6.98, 56 females, 44 males) and 102 UK participants (M-Age = 26.22 years, SD = 10.11, 60 females, 42 males). Only 16 of the participants of Saudi sample did not complete all the sections of the questionnaire and 2 participants from the UK sample not complete all sections of questionnaire. Demographic information of the sample is shown in Table 2.1.

2.2.2 Procedure

Participants were sent a link to complete an online survey in English or Arabic which they could fill out at their convenience. The first page provided participants with information regarding the study, assured anonymity of their data and informed them of their right to withdraw. Once participants clicked on the box providing their consent to take part they were guided through the questionnaire online. After completing all the questions, participants were presented with a debrief sheet Completion of the

questionnaire, including reading through the information and debriefing, took a total of 20 minutes.

Table 2.1. Demographic information of participants

| Variables | Saudi | UK |
|------------------------------------|-------|----|
| Gender | | |
| Female | 56 | 42 |
| Male | 44 | 60 |
| Health insurance | | |
| Yes | 40 | 39 |
| No | 60 | 61 |
| Someone come with you | | |
| Partner | 65 | 28 |
| Family member | 2 | 5 |
| Friends | 33 | 67 |
| One of family have diabetes | | |
| Yes | 34 | 20 |
| No | 66 | 80 |

2.2.3 Measures

2.2.3.1 Demographics and background information. Participants were asked to report their date of birth, gender, and country of residence. Furthermore, they were asked whether they had health insurance, whether they or one of their family members have diabetes and, if they answered yes, for how long, when they last saw a physician

or other health professional, and whether somebody else came to the physician's appointment with them.

2.2.3.2 General Preferences for Medical Decision Making. I utilised one of the most frequently used SDM measures, the Control Preference Scale (Degner et al., 1997) to gauge participants' general preferences for shared medical decision making. In this one-item scale, participants have to indicate one out of five statements that best indicate their preference for how they would like to be involved in decisions concerning their health care and medical treatment decisions. Answer options were: (1) I prefer to make the final selection about which treatment I will receive; (2) I prefer to make the final selection of my treatment after seriously considering my doctor's opinion; (3) I prefer that my doctor and I share responsibility for deciding which treatment is best for me; (4) I prefer that my doctor make the final decision about which treatment but seriously consider my opinion; (5) I prefer to leave all decisions regarding treatment to my doctor.

2.2.3.3 Specific Preferences for Medical Decision Making. Participants were asked to imagine that they were patients suffering from Type 1 Diabetes. The symptoms, causes, and treatment of Type 1 Diabetes were briefly explained to them (see Appendix 180). Participants were then presented with two treatment options for Type 1 Diabetes, namely daily injections versus insulin pumps, as well the advantages and disadvantages of these treatment options. They were then asked their preferences for who should make the treatment decision utilising the Control Preference Scale. Answer options were: (1) I prefer to make the final selection about which treatment I will receive; (2) I prefer to make the final selection of my treatment after seriously considering my doctor's opinion; (3) I prefer that my doctor and I share responsibility for deciding which treatment is best for me; (4) I prefer that my doctor

make the final decision about which treatment but seriously consider my opinion; (5) I prefer to leave all decisions regarding treatment to my doctor.

2.2.3.4 Horizontal and Vertical Individualism and Collectivism Scale (Triandis & Gelfand, 1998). This 16-item scale assesses horizontal and vertical individualism and collectivism orientations. The scale has been widely used in cross-cultural research. Items include “I’d rather depend on myself than others” (horizontal individualism) and “If a co-worker gets a prize, I would feel proud” (horizontal collectivism). Each dimension consisted of four statements; participants were asked to rate the extent to which the statement represented their opinion on a 9 point Likert-scale (1 = never; 9 = always). All statements were randomised to avoid ordering effects. Four scores were derived: Horizontal collectivism ($\alpha=0.74$), vertical collectivism ($\alpha=0.75$), horizontal individualism ($\alpha=0.62$), and vertical individualism ($\alpha=0.63$).

2.2.3.5 Basic Psychological Needs Scale (Deci & Ryan, 2000). The scale consists of 21 items which are answered on a 7-point Likert scale (1 = not at all true; 7 = very true). This scale assesses people’s general satisfaction with the fulfilment of the psychological needs for competence, autonomy, and relatedness in their lives. Items include “I really like the people I interact with” and “I feel pressured in my life”. Three scores were derived: Autonomy ($\alpha=0.49$), competence ($\alpha=0.43$) and relatedness ($\alpha=0.41$)

2.2.3.6 Treatment Self-Regulation Questionnaire (Williams et al., 1998). This questionnaire measures why people engage in healthy behaviours or certain treatment options. We used a scale that has been specifically developed to gauge people’s motivation to control their glucose level. For this scale there were two general

questions (“I take my medications for diabetes and/or check my glucose because:” and “The reason I follow my diet and exercise regularly is that:”) Each question is followed by 8 answer options/reasons. For each reason, participants have to indicate on a 7-point Likert scale how true this reason is for their motivation (1 = not true at all, 7 = very true). Two scores were derived: Autonomous regulation ($\alpha=0.76$) and controlled regulation ($\alpha=0.76$).

Results

2.3.1 Descriptive statistics

Table 2.2 presents the means and standard deviations of the main study variables by participants’ country of residence. A series of independent-samples t-test were conducted to compare the UK and Saudi samples in the main variables. Participants from the UK scored higher in Horizontal Individualism, $t(200) = -3.456$, $p = .001$, and Horizontal Collectivism, $t(200) = -2.626$, $p = .009$, than participants from Saudi Arabia. However, participants from Saudi Arabia scored higher in Vertical Individualism than participants from the UK, $t(200) = 3.459$, $p = .001$. However, there was no significant country differences in Vertical collectivism, $t(200) = 1.392$, $p = .166$.

Participants from the UK showed significantly higher Autonomous Regulation than participants from Saudi Arabia, $t(200) = -7.552$, $p = .000$, although there was no significant cultural differences in Controlled Regulation, $t(200) = 1.144$, $p = .254$. Need for Autonomy and Competence did not differ between the two cultural samples (Autonomy: $t(200) = -.118$, $p = .906$; Competence: $t(200) = -.271$, $p = .787$), but participants from the UK showed higher need for Relatedness than participants from Saudi Arabia, $t(200) = -3.007$, $p = .003$.

To determine the convergence of the various variables, the nine scales described above were inter-correlated. As shown in **Table 2.2** most variables were

highly or very highly positively correlated with each other. However, Vertical Individualism did not correlate with Autonomous Regulation, and Horizontal Individualism did not correlate with Controlled Regulation.

Table 2. 3. Means and standard deviations of the main study variables by culture

| Variables | Saudi Arabia (N = 100) | | United Kingdom (N = 100) | |
|--------------------------|---------------------------|-----------|-----------------------------|-----------|
| | <i>M</i> | <i>SD</i> | <i>M</i> | <i>SD</i> |
| Horizontal Individualism | 6.17 | 1.74 | 6.89 | 1.13 |
| Vertical Individualism | 5.45 | 1.65 | 4.66 | 1.56 |
| Horizontal Collectivism | 6.33 | 1.86 | 6.89 | 1.12 |
| Vertical Collectivism | 7.06 | 1.92 | 6.74 | 1.25 |
| Autonomous Regulation | 3.98 | 1.33 | 5.17 | .85 |
| Controlled Regulation | 4.35 | .92 | 4.18 | 1.19 |
| Autonomy | 4.49 | .95 | 4.50 | .62 |
| Competence | 4.28 | .96 | 4.32 | .67 |
| Relatedness | 4.45 | .94 | 4.79 | .63 |

Table 2. 4. Correlation between the study variables

| Variables | HI | VI | HC | VC | AR | CR | A | C | R |
|-------------------------------|-----------|-----------|-----------|-----------|-----------|-----------|----------|----------|----------|
| Horizontal Individualism (HI) | 1 | | | | | | | | |

| | | | | | | | | | |
|-----------------------------|--------|--------|--------|--------|--------|--------|--------|--------|---|
| Vertical Individualism (VI) | .259** | | 1 | | | | | | |
| Horizontal Collectivism(HC) | .445** | .270** | 1 | | | | | | |
| Vertical Collectivism(VC) | .535** | .360** | .600** | 1 | | | | | |
| Autonomous Regulation (AR) | .239** | .034 | .233** | .140* | 1 | | | | |
| Controlled Regulation(CR) | .077 | .216** | .250** | .243** | .473** | 1 | | | |
| Autonomy(A) | .294** | .300** | .262** | .326** | .236** | .275** | 1 | | |
| Competence(c) | .236** | .264** | .217** | .268** | .293** | .246** | .665** | 1 | |
| Relatedness(R) | .303** | .197** | .285** | .223** | .312** | .212** | .599** | .614** | 1 |

** indicates significance level at $p < 0.01$

* indicates significance level at $p < 0.05$

2.3.2 Main analysis

Table 2.4 shows participants' general medical preferences for involvement in medical decisions in Saudi Arabia and the United Kingdom. A chi-square test was performed to find out whether there was any impact of culture on the general preferences for involvement in medical decision-making. The results were significant, $\chi^2(4) = 30.51, p < .001$. As shown in **table 2.4**. Participants from the UK preferred being more strongly involved in the medical decision (options A, B, and C), whereas participants from Saudi Arabia preferred their doctor to make medical decisions (options D, E).

Similar results were found for participants' preferences to be involved when making medical decisions in a specific scenario (**see** Error! Reference source not found.2.5). A significant chi-square result, $\chi^2(4) = 39.58$, $p < .001$, indicated that participants from the UK rather preferred to make the choices themselves (Options A, B) whereas participants from Saudi Arabia preferred a stronger involvement from their doctor (Options C, D, E)

Table 2. 5. Frequencies (%) for general preferences for involvement in medical decision making by culture

| | Saudi Arabia (N = 100) | | United Kingdom (N = 100) | |
|---|---------------------------|----|-----------------------------|----|
| | Frequency | % | Frequency | % |
| A) I prefer to make the final selection about which treatment I will receive. | 4 | 4 | 10 | 10 |
| B) I prefer to make the final selection of my treatment after seriously considering my doctor's opinion | 20 | 20 | 36 | 35 |
| C) I prefer that my doctor and I share responsibility for deciding which treatment is best for me. | 25 | 25 | 40 | 39 |
| D) I prefer that my doctor make the final decision about which treatment but seriously consider my opinion. | 31 | 31 | 13 | 13 |
| E) I prefer to leave all decisions regarding treatment to my doctor | 20 | 20 | 3 | 3 |

Table 2. 6. Frequency's (%) for specific preferences for involvement in medical decision making by culture

| | Saudi Arabia (n = 100) | United Kingdom (n = 100) |
|--|---------------------------|-----------------------------|
|--|---------------------------|-----------------------------|

| | Frequency | % | Frequency | % |
|---|-----------|----|-----------|----|
| A) I prefer to make the final selection about which treatment I will receive. | 10 | 10 | 18 | 18 |
| B) I prefer to make the final selection of my treatment after seriously considering my doctor's opinion | 19 | 19 | 52 | 51 |
| C) I prefer that my doctor and I share responsibility for deciding which treatment is best for me. | 28 | 28 | 22 | 22 |
| D) I prefer that my doctor make the final decision about which treatment but seriously consider my opinion. | 22 | 22 | 7 | 7 |
| E) I prefer to leave all decisions regarding treatment to my doctor | 21 | 21 | 3 | 3 |

A two step-wise multiple logistic regression analyses were performed for general preferences and two step-wise multiple regression analyses were performed for general and specific preferences for medical decision-making, respectively. To allow logistic regression on binary responses, step 1 involved limiting participant's responses to three options; namely, active, collaborative, and passive ones, with culture, gender, and age being entered as predictors. Culture, gender, and age were entered as predictors. At Step 2, basic psychological needs and regulation were additionally entered as predictive variables. Because autonomous regulation differed by culture, the interaction of autonomous regulation x culture was additionally entered as a predictor at Step 3.

As can be seen in Table 2.6, culture significantly predicted general preferences for shared medical decision-making, with participants from Saudi Arabia being more likely to prefer their doctor to make the decisions and participants from the UK tending to prefer to make the decision independently or with input from the doctor. None of the psychological needs and regulation variables nor the interaction were significant predictors of general preferences for shared medical decision making.

Culture also significantly predicted specific preferences for shared medical decision-making (see Table 2.7) with participants from Saudi Arabia being more likely to prefer their doctor to make the decisions and participants from the UK tending to prefer to make the decision independently or with input from the doctor, $F(3, 195) = 14.67$, $p < .000$, $R^2 = .184$. None of the psychological needs and regulation variables nor the interaction were significant predictors of specific preferences for shared medical decision making for participants' specific preferences for medical decision-making, respectively.

Table 2. 7. Multiple Regression Analysis predicting general preferences for shared medical decision-making

| Independent variables | | General preference for shared medical decision-making | | | | | |
|---------------------------------|-----------------------|---|--------------|------------|-----------|------------|-----|
| | | β | ΔR^2 | ΔF | <i>df</i> | Δp | |
| Step 1 | Age | .01 | .13 | 10.06 | 3,195 | .00 | |
| | Gender | .02 | | | | | |
| | Culture | -.37** | | | | | |
| Step 2 | Age | -.00 | .01 | .51 | 5,190 | .77 | |
| | Gender | .02 | | | | | |
| | Culture | -.42** | | | | | |
| | Autonomous Regulation | .04 | | | | | |
| | Controlled Regulation | -.03 | | | | | |
| | Autonomous | -.03 | | | | | |
| | Competence | -.09 | | | | | |
| | Relatedness | .14 | | | | | |
| | Step 3 | Age | -.02 | .01 | 1.12 | 1,189 | .29 |
| | | Gender | .02 | | | | |
| Culture | | .05 | | | | | |
| Autonomous Regulation | | .04 | | | | | |
| Controlled Regulation | | -.02 | | | | | |
| Autonomous | | .19 | | | | | |
| Competence | | -.10 | | | | | |
| Relatedness | | .13 | | | | | |
| Autonomous regulation x culture | | -.51 | | | | | |

**p < .01

Table 2. 8. Multiple Regression Analysis predicting specific preferences for shared medical decision-making

| Independent variables | | General preference for shared medical decision-making | | | | | |
|---------------------------------|-----------------------|---|--------------|------------|-----------|------------|-----|
| | | β | ΔR^2 | ΔF | <i>df</i> | Δp | |
| Step 1 | Age | -.00 | .18 | 14.68 | 3,195 | .00 | |
| | Gender | -.02 | | | | | |
| | Culture | -.43** | | | | | |
| Step 2 | Age | -.02 | .01 | .34 | 5,190 | .89 | |
| | Gender | -.02 | | | | | |
| | Culture | -.43 | | | | | |
| | Autonomous Regulation | -.00 | | | | | |
| | Controlled Regulation | .06 | | | | | |
| | Autonomous Regulation | -.07 | | | | | |
| | Competence | -.05 | | | | | |
| | Relatedness | .05 | | | | | |
| | Step 3 | Age | -.02 | .00 | .14 | 1,189 | .71 |
| | | Gender | -.02 | | | | |
| Culture | | -.59** | | | | | |
| Autonomous Regulation | | .00 | | | | | |
| Controlled Regulation | | .06 | | | | | |
| Autonomous Regulation | | -.14 | | | | | |
| Competence | | -.05 | | | | | |
| Relatedness | | .05 | | | | | |
| Autonomous regulation x culture | | .18 | | | | | |

**p < .01

Discussion

The primary objective of this study was to explore differences in preferences for shared medical decision-making among participants from the UK and Saudi Arabia and whether those preferences were influenced by psychological motivations and needs. Specifically, based on previous cross-cultural research, I expected that participants from the UK would show higher SMD preferences and needs for autonomy but Saudi participants would show higher need for relatedness.

Overall, participants of this study did indeed express a substantial difference in preferences for shared medical decision-making (SMD) based on their country of residence. I found that both concerning their general preference for shared SMD (i.e., how much they generally want to be involved in SMD) and specific SMD in a concrete scenario on decision-making of diabetes treatment, most participants in Saudi Arabia showed a stronger tendency to leave the decision partly or entirely to their doctor. Similarly, the largest part of participants from the UK confirmed that they preferred shared decision-making whereby a joint decision is made after discussion between them and their physician. It is possible that with changing cultural mores, younger people in Saudi Arabia would become more similar to UK participants. Thus, future research might focus on specific strata of the population to determine preferences for shared medical decision-making. The cross-cultural survey indicated that there are differences between UK and SA participants in terms of their preference for taking responsibility in making decisions about their healthcare.

Furthermore, decision preferences in the general and specific scenario were strikingly similar between the Saudi Arabian and UK participants. The results are consistent with earlier studies reporting that the decision-making domain (specific vs.

general health issue) did not significantly affect preferences for involvement in decision-making (Adams, 2007; Hanoch et al., 2015). In other words, participants were more likely to state the same preference as to who they would like to have more involvement in medical decision-making whether in the general or specific domains. On the other hand, the UK respondents seemed to opt for more participation in decisions about a particular condition, with 51% choosing the shared decision-making approach when it comes to decisions about their medical conditions in general, with 39% preferring the decision to be made exclusively by themselves. One interpretation is that when their condition is a general health condition, the patient may be able to delegate their involvement in decision-making. However, in specific or severe medical conditions, they have to make the final decision about their care preference. Patients consider the need to take specific conditions seriously due to their unique nature, in which case health care providers need to inform the patient about their options. The process might involve multiple decisions to be made and frequently reviewed (Hanoch et al., 2015). One can also interpret this in light of the experience of illness that could be linked to preferences for involvement with patient with diabetes (Gerfield et al., 2007). These findings are consistent with previous research efforts by Adams (2007) and Gerfield et al. (2007), which indicated that patients need to be involved in the decision-making stage in life-threatening medical conditions as compared to general health conditions. It is important that future research attempt to identify other factors that are linked to preferences for involvement in the treatment of certain health conditions.

The results confirm results from previous studies showing individual differences on patient preferences on who will be involved in medical decisions related to their health issues (Adams, 2007). Interestingly, in the only study on medical decision-

making conducted in Saudi Arabia, Moberriek (2008) showed that Saudi patients also showed a strong preference to engage their families in the decision making process. Potentially, then, it is not that Saudi participants prefer a “traditional” model of medical decision making, in which the health care professional makes the decision, but they like to integrate many of their important (in group) members as possible. This interpretation, that Saudi participants potentially prefer an interdependent decision-making style, should be explored in future studies.

The regression analyses indicated that participants’ cultural background was the main variable that consistently predicted differences in preferences for SMD. Other variables were considered such as demographic (e.g., age, gender) and psychological and motivational variables (e.g., competence, autonomy, relatedness, autonomy and controlled regulation) which previous research has linked to individuals’ health behaviour and decisions (e.g., Broeck, et al 2013; Deci & Ryan 2011; Ng et al, 2012). Unlike previous research that has shown that females and younger patients are more likely to prefer to be involved in medical choices that affect them (e.g., Arora & Machorny, 2000; Say et al, 2006), age and gender did not affect preferences for medical decision-making in the present study. The methodology used may explain the differences found in SDM preferences among the participants of the study. It is possible that the participants of the study, a non-clinical convenience sample, had little experience being involved in medical decision-making. Another explanation for the aforementioned reverse relationship among participations regarding preferences SDM utilisation may be found in the absence or availability of health awareness. Finally, the reverse relationship may be explained by the non-random sampling and the non-inclusion of other relevant factors in the selection of participants. Empirical studies have demonstrated that income and education levels are associated with a preference

for either a shared or passive decision-making style. Hence, in explaining why Saudi participants were more inclined to rely on their physician in medical decisions, it is possible that low education levels, low income, and ethnicity may have resulted to this preference (Say et al., 2006; Frosch & Kaplan, 1999). Therefore, with respect to the first research question, Hypothesis 1 is accepted while Hypothesis 2 is rejected.

I considered a number of psychological and motivational variables that might influence preferences for SMD, including psychological needs (competence, autonomous and relatedness) and motivation (autonomous vs. controlled regulation). Autonomy and relatedness are core competencies in the context of SMD on the presupposition that all human beings are not entirely self-governing agents and need to make decisions with the assistance of their interpersonal relationships in what authors call “relational autonomy” (Mackenzie, 2008) or “collaborative autonomy” (Rubin, 2013). Self-determination theory explains that competence (wanting to act proficiently in one’s own environment), autonomy (perceiving that one has a choice in all decisions), and relatedness (the need to feel connection and support from other people) are important needs in the shared decision-making process (Ryan & Deci, 2000). On the other hand, motivational variables give patients consideration to promote an enhanced well-being and therefore render them more effective with regard to the medical decisions. SDM contributes to positive motivation in the form of increased patient satisfaction and self-confidence. Moreover, Teixeira et al. (2012) found that the fulfilment of competence, relatedness and autonomy were significantly related to levels of activity, life satisfaction, subjective imperativeness and positive affect.

Previous research has demonstrated how SDM contributes to life satisfaction since patients who participate in the decision-making process are empowered and

become more satisfied with their decisions (Hoffman et al., 2014; Van den Broeck, Vansteenkiste & De Witte, 2013). Furthermore, studies have also shown that decision-making approaches which involve family members and other relational dependencies also enhanced patient satisfaction. A collaborative approach in decision-making that involves family members fulfils the needs for autonomy, competence and relatedness, thereby improving the patients' emotional well-being. With respect to motivational variables such as autonomous versus controlled regulation, Deci and Ryan (2011) emphasised that support for self-sufficiency exerted by physicians and other health professionals is positively related to a patient's autonomous inspiration which then produces well-being and conducts change.

Previous research then points to the significance of psychological and motivational variables in influencing patients' preference in involvement regarding medical decisions which affect them. Thus, I expected that Saudi participants would report higher relatedness needs whereas UK participants would report higher autonomy needs. In addition, I expected that UK participants would show a higher preference for autonomous regulation in both the general and specific health care domain. Finally, I reasoned that autonomous regulation would be positively correlated with autonomous decision-making in both samples. While past research has investigated the relationship between decision roles and patient life satisfaction, I have no knowledge of a study which factored in the psychological needs and motivation in preferences of SMD plays within this context.

The results from the present study did not, however, reveal any effect of psychological and motivational factors for preferences in SMD in both cultures. A number of factors could help explain this departure from previous findings and my expectations. First, there is a difference in the variables considered in our study

compared with past research. Previous studies focused on a comparison of patients and non-patients in related to a serious illness, however in this study, I utilised a non-homogeneous and non-clinical sample. The selected sample population in this study was more diverse and subject to different contextual variables which may explain the difference in results. Unlike previous studies, this research relied on the general population as a sample instead of patients with a specific illness. Second, the research design I employed might explain the divergent results. In this study, participants were first asked of their involvement in medical decision-making in general then subsequently, were asked of their preference in involvement using a hypothetical medical scenario involving Type 1 diabetes. Thus, one important contribution future research could make would be to repeat this study in a clinical sample.

In interpreting these results, the cultural context must be taken into consideration (Hofstede, 1980). Culture significantly influences decision-making because family and organisational life is heavily influenced by either collectivism or individualism. Hence, the cultural differences among the samples of the previous studies and the present study offers a viable explanation on the differences in the results. Most studies on SMD preferences were conducted in Western contexts where individualism is highly valued while there is a paucity of research conducted in the Arab context where collectivism is more highly valued (Ali et al, 1997; Moberriek, 2008). Since Arab communities are similar in terms of traditions and customs, they are classified as collectivistic societies according to Hofstede (1980). It can be argued that based on Hofstede's theory, Arab communities and participants would be more inclined towards collective decision-making processes, putting importance on the opinions of their family and relatives.

My findings indicate that classifying Saudi Arabia as collectivistic and the UK as individualistic might be too simplistic. In fact, the degree of verticalism versus horizontalism, that is whether relationships are regarded as largely equal or hierarchical, seems to better describe differences in Saudi and UK participants' cultural orientation. In fact, it is possible that the cultural differences in SMD I found in this study could also be due to the fact that health professionals, as authority figures, are awarded more respect, knowledge, and trust in Saudi Arabia than in the UK. Thus, the hierarchical relationship between health professional and patient might make Saudi participants less likely to wanting to be involved in SMD. This aspect is explored in more detail in the qualitative analyses in the next chapter.

In general, the results reflect the need for a deeper analysis of how culture affects decision-making methods and outcomes. In this light, the study design and heterogeneous sampling would account for the divergent outcome which is inconsistent with established literature. Still, it can also be argued that culture may no longer be strongly correlated with how people make medical decisions as literature has previously asserted. It may be further argued that the significant association of culture to specific variables may not be generalisable across all contexts. However, it can also be argued that the design of the study limits a sufficient investigation of the role of culture in decision-making. Previous studies on culture have utilised different methods of analysis including direct assessment, Hofstede's model, and the model of Triandis and Gelfand (1998). While studies seem to be unanimous in arguing that culture is a correlate of decision-making processes, similar methods may produce variant effects. Clearly, these conflicting findings merit further investigation.

As discussed, the study has several limitations. The findings cannot be generalised to a large population due to the small sample size. Moreover, the study

also had sampling limitations and an equal ratio of participation with respect to cultural group was not achieved as expected. The study design, which was purely quantitative, could also be improved. A mixed method research design would have provided a more complex and broader perspective/answer on the topic. Despite these limitations however, the study is unique in that with a few exceptions, culture has been a relatively neglected topic in the literature focusing on the development of conceptual models of treatment decision-making, empirical studies of treatment decision-making, and the development and use of applied tools such as decision aids to facilitate patient participation in treatment decision-making. This study contributes additionally to the scarcity of such studies. However, acknowledging such limitations exist, more research is thus needed in these areas.

Chapter 3

Study 2: Preferences for shared medical decision making in Saudi Arabia: A qualitative study with Diabetes Patients

Until recently, the subject of medical decision-making in Saudi Arabia received very little attention. Previous research has showed that there was poor communication between physicians in Saudi Arabia and their patients (Mobeireek et al., 2008). Study 1 also showed that non-clinical participants from Saudi Arabia had lower preferences to be involved in medical decision-making than UK participants. While Study 1 was one of the first to explore preferences for shared medical decision making in a Middle Eastern culture, it had two major drawbacks. First, it relied on non-patient samples. While all of Study 1's participants had experience in dealing with physicians and other health professionals, the specific scenario used in Study 1, treatment options for diabetes, was hypothetical to the majority of participants. In the current study I drew in a sample of Saudi adults who suffered from Diabetes Type 1 and examined their preferences for shared medical decision focusing on the treatment of diabetes. Second, Study 1 used a quantitative methodology to assess participants' preferences for shared medical decision-making. In the current study, I used a qualitative interview approach to further delve into the reasons as to why patients with Diabetes Type 1 might or might not prefer to be involved in shared medical decision-making. In the following, I will first review literature on various aspects of diabetes in Saudi Arabia and other countries in the Middle East. I will then focus on the case of treatment for Diabetes Type 1 because different treatment options could be made through SMD.

3.1 Diabetes in the Middle East

Shared-decision making (SDM) is defined as a collaborative process that involves the patient and their physician, when they are reviewing the best available evidence and outcomes to make health care decisions which take into account patient preferences (Elwyn, et al., 2012). As the healthcare services change from traditional patient care to the patient-centered care (where physicians have realized the importance of patients' preferences and values in making a choice about the right approach to managing health condition which includes management of diabetes) SDM has grown in importance (Agoritsas et al., 2015).

Al-Nozha et al. (2004) studied Diabetes Mellitus (DM) and its prevalence based on gender, age, and place of residence (urban, rural) in Saudi Arabia. The study used a community-based epidemiological health survey on people aged between 30-70 years among selected households over a duration of 5 years from 1995 to 2000. Data on the history of infection, amount of fasting plasma regulation, and body mass index (BMI) was collected. The data used the 1997 American Diabetes Association criteria to classify the individuals as diabetic, reduced fasting glucose¹ and normal. Out of the 17,232 participants, 23% were diagnosed with DM, and the prevalence was 21.5% among males and 26.2% among females. There was a high prevalence rate among the urban population at 25.5% compared to 19.5% among the rural population. In comparison, in 2013 there were 3 million people who had a diagnosis of diabetes type 1 in the UK (Diabetes UK, 2015). Irrespective of the existence of healthcare facilities, there was a high rate of unawareness of having DM at a rate of 27.9% among Saudi

¹ New diagnostic criteria of DM include fasting plasma glucose in contrast to the old criteria, which are based upon an oral glucose tolerance test (OGTT). Using the new diagnostic criterion allows better classification of individuals and leads to fewer therapeutic misjudgements

participants. The authors recommended that a national prevention program should be put in place at the community level to address the diabetes problems of those categorised as high-risk groups (i.e. females, urban population) of patients.

Bani (2015) examined the prevalence and risks associated with diabetes mellitus among patients in Saudi Arabia. The study was motivated by the fact that DM has contributed to increased health problems for patients in Saudi Arabia, which has resulted in the country being ranked 7th highly affected by diabetes in the world. The study was conducted with the objective of estimating the rate of occurrence, and the resulting risks of DM among patients in the Jazan region in Saudi Arabia. The study adopted an observational cross-sectional approach among participants who were aged approximately 15 years and over, and who were patients at eight Primary Health Care Centres. The results indicated that the general incidences of DM (type1 and type 2) among those who took part in the study were 12.3%. The prevalence rate based on gender indicated that there was a comparatively higher prevalence among women at 19% compared with men at 9.8%. There was a high relationship between the participants' body mass index, age, the existence of diabetic condition in the family, exercise, and presence of DM. It was concluded that due to an increased prevalence of diabetes, there is a need to implement health promotional programs directed towards prevention, and therefore reducing the resulting burden from the disease.

Mohieldein, Alzohairy and Hasan (2011) studied the level of understanding of diabetes among adults who were not affected by the disease in the AlQassim region in Saudi Arabia. The study was motivated by the fact that the ability to understand the extent of public awareness regarding a disease is important in formulating future plans and programs. Similarly, as discussed above, a large proportion of potentially at-risk adults were unaware or had low knowledge of diabetes (Al-Nozha et al., 2004). The

study used a cross-sectional survey composed of a number of questions regarding the participants' demographic characteristics and their sources of information about diabetes. All participants (100%) had heard about diabetes mellitus, and 31% knew that diabetes mellitus was an incurable disease. Male respondents were twice likely to have knowledge about DM compared with females. The main sources of information about DM included the media (47.1%) and healthcare professionals (19.1%). The authors concluded that there was a relatively high level of understanding of diabetes mellitus among residents of Al-Qassim area due to their ability to identify symptoms and risk factors. However, participants did not possess knowledge regarding secondary complications from diabetes (e.g., eye problem, high blood pressure). The study recommended measures to increase awareness of diabetes especially with regards to these secondary complications.

In contrast, Al-Dahan et al. (2013) who sought to determine the knowledge of diabetes among Saudi patients, came to different conclusions. The objective of their study was to evaluate the understanding of diabetes among attendees of basic health care services in Riyadh, the capital of Saudi Arabia, and to use the outcomes in setting the strategy for future health education on diabetes. A questionnaire on participants' knowledge of diabetes and management practices was administered to a total of 467 male participants (aged 18 years or older). Sixty percent of participants had knowledge of diabetes mellitus, and 78% had knowledge of treatment options. Twenty-eight percent knew how diabetes was diagnosed. The main sources of knowledge for diabetes were reported to be education and media. Overall, the authors concluded that there was a rather substantial lack of awareness of DM among participating patients. Authors recommended to introduce more efficient health education programmes that focus on creating public awareness on misconceptions

about DM, and motivating the development of healthy lifestyles and early prevention of diabetes mellitus.

Al-Maskari et al. (2013) studied the knowledge of diabetes mellitus among patients in the United Arab Emirates (UAE), and the practices they implemented to manage the disease. Similar to the study by Al-Dahan et al. (2013), 31% of the patients demonstrated poor understanding of diabetes. Fifty-seven percent had hemoglobin (HbA_{1c}) levels that reflected poor glycemic control. Seventeen percent of participants had adequate amount of control over their blood sugar while 10% stated that they did not comply with any medication procedures. While the level of diabetes awareness and management of the condition was low, patients exhibited positive attitudes towards the significance of DM care and effectiveness of management of diabetes in the UAE. It was recommended that there is a need to incorporate programmes focusing on increasing understanding of the role of compliance in managing diabetes, including the development of healthy lifestyles and early prevention of diabetes mellitus.

Alasiri and Bafaraj (2016) studied whether Saudi patients with diabetes were aware of the concept of diabetic retinopathy, a serious secondary complication, and associated risk factors. The findings showed that out of the 357 diabetic patients who participated in the study, 61% had awareness of diabetic retinopathy. The study found that only 38% of the participants had awareness that retinal examinations focus on reduction of diabetic retinopathy, and 70% were not aware of the type of treatment that needed for diabetic retinopathy. Only 50% of patients who were affected by diabetic retinopathy sought check-ups. It was concluded that despite the existence of a large number of diabetics in Saudi Arabia, most patients did not have the knowledge

of the associated risk factors and the methods that could be used to prevent the disease.

Abu Sabbah and Al Shehri (2014) studied the practices of self-management as a method of preventing diabetes among patients in Saudi Arabia. The study was conducted with the aim of understanding self-management practices used by patients in order to manage diabetes, and to examine the demographic characteristics associated with self-management practices. Participants were interviewed to determine their practices on self-management, and possible factors affecting practices by the use of Summary of Diabetes Self-Care Activities (SDSCA) questionnaire. A total of 386 patients with a mean age of 40.03 years were interviewed. Around 40% of participants understood the nature of diabetes they were suffering from. The majority of participants complied with their medication; however, a substantial proportion (22%) were least involved in the practice of glucose testing. Around half of the respondents followed a specific diet for management of diabetes, and were involved in physical activities and foot protection measures. Overall, the authors concluded that participants displayed inadequate diabetic management plans specifically among the non-pharmacological aspect of managing the disease. Patients preferred to fulfil medication recommendations rather than changing their lifestyle through diet and physical exercise.

Al-Shahrani et al. (2012) conducted a study which examined the impacts of educating patients on their metabolic control and the ability to manage their diabetic condition among diabetes type 2 patients in Saudi Arabia. A sample of 438 diabetes type 2 patients (158 males and 280 females) was selected. All the participants underwent a 5-day diabetes education programme. Data relating to each individual before they attended the programme, and three months after completion of the

program was collected. It was found that most metabolic parameters, such as weight, systolic blood pressure, diastolic pressure, and low density lipoprotein (but not high density lipoprotein), underwent significant improvements. Thus, an intensive education programme enabled the healthcare team to address the needs of diabetes type 2 patients.

Jarab et al. (2012) conducted a randomised controlled trial that focused on clinical pharmacy practices for diabetes type 2 among outpatient population in Jordan. This was aimed at reducing the rate of complications resulting from increased incidences of diabetes in Jordan. The study sought to determine the effect of outpatient practices patients used in order to manage the disease on glycemic control, pressure, amounts of lipids, adherence to self-reported medications, and personal care activities among diabetes type 2 patients. A test group of 156 patients with diabetes type 2 in outpatient clinics was selected, and categorised into an intervention group (77 patients) and usual care group (79 patients). At baseline, the intervention group received face-to-face objective education from a clinical pharmacist about type 2 diabetes, prescription medications, and necessary lifestyle changes, followed by 8 weekly telephone follow-up calls to discuss and review the prescribed treatment plan and to resolve any patient concerns. It was found that there was a higher decrease in glycemic control among the intervention than the control group. It was concluded that diabetes type 2 patients who were provided with additional outpatient care services such as those led by pharmacists experienced improvements in their metabolic parameters in comparison to those who underwent usual care procedures.

In sum, previous research on various aspects of diabetes in Saudi Arabia and other countries in the Middle East shows an increased prevalence of diabetes in these countries. At the same time, there is high rate of unawareness of having DM or low

knowledge of diabetes, its diagnosis, complications, and treatment. Education programmes have been shown to be successful in addressing some of these shortcomings and to help patients manage their disease.

Patients suffering from diabetes have several problems which require consideration of the values, context, and preferences of patients. This might improve offering treatments which do not fit the needs and values of patients. Shared decision making helps to fill this medical gap (Shay & Lafata, 2015). Shared decision making promotes emphatic conversation between the patient and physician which integrates best evidence-based care with context, preferences, and values of the patient. SDM increases the knowledge of the diabetes patient about their conditions as well as becoming aware of possible treatments and choices that they have (Shay & Lafata, 2015). This helps to promote recovery and build a stage for the provision of quality and value-based care to the patient.

3.2 Diabetes management in Saudi Arabia

Generally, most individuals in Saudi Arabia can access primary care directly, where diabetes mellitus including other chronic diseases are managed. The cost incurred for prescriptions has been found to be around 30 to 40 percent of the total direct cost of diabetes. In Saudi Arabia, a significant increase in the cost of the treatment of diabetes is related to an increase in the use of cardiovascular medications, new anti-diabetic, and utilisation of evidence-based guidelines (Algothamy et al., 2014).

The Al Maatouq Manual of Diabetes Practice (2010) indicates that the therapeutic prescription for DM includes, insulin, oral antidiabetic agents, or the integration of both. For type 2 diabetes, the initial recommended drug is Metformin. Glycosylated hemoglobin A1C is the most widely used test to assess of blood glucose

(ALHreashy & Mobierek, 2014). In Saudi Arabia DM is usually associated with risk factors for cardiovascular disease. Here, the standard diabetes care includes drug therapy for control of dyslipidemia, blood pressure, as well as antiplatelet therapy assessment. According to statistics, about 60 percent of individuals who suffer from DM Type 2 are affected by hypertension (ALHreashy & Mobierek, 2014).

In Saudi Arabia, the use of alternative and complementary medications is practiced for chronic diseases; this is done either to prevent their complications, to slow down its progression, or to cure them (Alqurashi et al 2011). Diabetes mellitus is a chronic disease, and Saudi health-care management usually tries to prevent the complications and progression of the disease. It has also been found that most diabetic patients in Saudi Arabia use herbs in addition to conventional treatment (Alqurashi, et al, 2011). These patients use herbs not to alleviate the side effects associated with prescribed DM medication, but because herbs can create (the illusion of) a fast relief of symptoms and because of cultural reasons related to preventing the progression of the disease. The most commonly used herbs include cinnamon, black seed (nigella), garlic, and fenugreek (ALHreashy & Mobierek, 2014). The use of herbs in diabetes has also been used in other countries. According to Turkish research, the most commonly utilised herbs were pomegranate syrup and garden thyme, in addition to cinnamon (ALHreashy & Mobierek, 2014). Ginseng was also used in combination with Chinese herbs according to research done in Taiwan (ALHreashy & Mobierek, 2014). These herbs are perceived by the patients to decrease insulin resistance. According to other studies (conducted in Palestine and Saudi Arabia), Aloe and Myrrh were also mentioned as herbs used by people to treat or manage diabetes. (ALHreashy & Mobierek, 2014)

In a study conducted by Algothamy et al (2014) in Saudi Arabia, 228 individuals who suffered from diabetes were interviewed. From these, 24.6 percent were using herbs, revealing the rise in the use of herb among diabetics within the past decade in Saudi Arabia. Furthermore, this indicates that diabetic patients are now using herbs as a second line therapy for regulating their blood sugar. Approximately 33.9 percent of the surveyed patients were illiterate, and about 57.1 percent of the interviewed diabetics revealed that they were suffering from type 2 diabetes, and about half of them stated that they had a history of DM in their family (Algothamy et al., 2014).

On some occasions, because of the costs, the delayed response, and known side effects of the common DM medications, many diabetic patients in Saudi Arabia resort to the herbal remedies. Initially, the herbal remedies were mislabelled by sellers or by the public as safe from side effects; patients assumed that the herbs were natural and fairly effective in treating and managing diabetes (ALHreashy & Mobierek, 2014). According to research, the safe label associated with herbal medicine by diabetic patients could be false, but there is no scientific prove regarding their efficacy or their safety (Alqurashi, et al, 2011).

Other ways to treat and manage diabetes in Saudi Arabia are through weight management which is now a routine practice in Saudi Arabia (Algothamy et al., 2014). Obesity is among the risk factors for diabetics, and it has been found to be prevalent in many patients in many studies conducted (Algothamy et al., 2014). Weight gain by many diabetic patients may have been due to Insulin and pioglitazone therapies. Apart from these medications, another common treatment for diabetes in Saudi Arabia is DDP-4 inhibitor treatment; this works by increasing the hormones which make the pancreas to supply more insulin (Hassan, 2017). The insulin then stimulates the liver to produce lower volumes of glucose. This medication offers Saudi physicians an

effective and safe treatment approach that effectively controls blood sugar and has minimal negative effects on vital organs such as the heart and kidney. This new therapy is proving to be an effective modern way to improve the quality of life of patients and also to manage diabetes in Saudi Arabia (Hassan, 2017). Victoza (Liraglutide) is another medication commonly used in Saudi Arabia. This drug is to be taken daily at certain fixed periods, irrespective of meals, and prescribed by a specialist (Rasooldeen, 2017). The medication is known to change the course of diabetes for the better, and it is sold by stores throughout Saudi Arabia. This is a significant treatment option for those suffering from type 2 diabetes. Shared decision making encourages the patients to be more active in the decision making. It leads to better healthcare outcomes and lower costs. Research indicates that patients who actively engage with their health care providers in making the decision are better informed and are more aware of the health care options that are available for their conditions (Agoritsas et al., 2015). This means that a diabetic patient involved in decision making about their health tend to make better decisions about their own care, choosing options that they are more likely to adhere to. Integration of increased treatment compliance along with informed choices has been shown to minimize costs for managing diabetes and improve the quality of care.

3.3 Shared decision making in diabetes management in Saudi Arabia

As discussed in previous chapters, shared decision-making refers to a collaborative process where clinicians and patients collaborate through a deliberative dialogue. The dialogue is conducted to identify reasonable management options that suit and addresses the patient's unique situation (Tamhane et al., 2015). Shared decision-making ensures that patient-centered research is put into practice and it is

appropriate for diabetes care as diabetes care usually requires scrutiny of management options which are different in ways that matter to the diabetic patients (Tamhane et al., 2015). Shared decision making helps patients with diabetes to be more active in the decision making. This encourages them to provide more information about their condition, preferences, and values and in turn, they are more informed about different stages of their condition and the best way that can be used to manage the situation and risks attached in each method. Shared decision making creates a platform for a structured approach towards reviewing feedbacks and outcomes of the health care provided to the patient. Healthcare feedback is important to the physicians, and the healthcare center in helping to improve on their areas of weaknesses and build on their areas of strengths which ultimately leads to the development high-quality health care (Shay & Lafata, 2015).

Over the past decade, the concept of shared decision-making has proven useful and feasible for involving patients in decision making and sharing evidence with clinicians. Today most clinical and health care policies advocate for shared decision-making, and this might be a useful concept in treating and managing diabetes (Tamhane et al., 2015). For Saudi Arabia, shared decision-making might be useful (ALHreashy & Mobierek, 2014). For instance, it might contribute to high-quality healthcare through encouraging a patient-centered approach. Also, the involvement of the diabetic patients in picking the components of diabetes medication that best suits their preferences and values can improve medication adherence and outcomes. As of yet, however, there has been very little research on shared medical decision-making in Saudi Arabia. In this study I explored (1) whether shared medical decision making is practiced when treating and managing DM among Saudi patients; and (2)

whether Saudi diabetes patients would prefer a shared decision-making approach to managing their condition.

3.4 Research questions

While there is a high prevalence rate of diabetes in Saudi Arabia, problems in its management and treatment have emerged in previous research. Shared medical decision making might be one way to help patients manage their disease better. However, as of yet, it is not known whether Saudi patients would like to be involved in such a shared medical decision-making process. Following this the present study aimed to explore this question. Specifically, I aimed to answer the following questions:

- (1) How do Saudi patients with diabetes receive and understand their diagnosis?
- (2) What treatment options do physician provide?
- (3) At what level do patients wish to be involved in decision about the management of their illness?

Based on previous research showing that many patients are unaware of their diabetes diagnosis or secondary complication relating to the disease (Alzohairy & Hasan, 2011; Alnozha et al., 2004), I expected that many patients (in this study) would not possess knowledge about diabetes and the secondary complications. Second, I expected that it would not be common for physicians to offer a range of treatment options. Third, most patient would want a degree of involvement in their treatment.

Method

3.2.1 Participants

Thirty patients of Sheikh Abdul Malik bin Ibrahim Centre for Diabetes took part in this study. These thirty participants were recruited using a convenience sampling approach from the out-patients department's clinical sample and volunteered to take part. The inclusion criteria were that participants needed to be 18 years or older, be residents of Saudi Arabia, and must have had a diagnosis of Type 1 Diabetes. Hospital authorities invited patients to participate in the study. Patients had a mean age of 47 years (SD = 13.33), and age ranged between 18 – 72 years. The sample included 15 females and 15 males.

3.2.2 Materials

The interview covered the main content area of participation of patients in medical decision-making. I used the interview script developed by Belcher et al. (2006) as a starting point to investigate whether and how patients want to be involved in medical decisions. The interview was divided into three sections (diagnosis, treatment offered by doctor and participate decision). The interviewer (myself) asked participants three main questions about their interaction with physician, with nine follow-up questions, which could be expanded on if it was felt that important information could be gained, and questions could be reworded.. Table 3,1 contains the main interview questions.

Table 3. 1. Main open-ended interview questions (adapted from Belcher et al., 2006)

| Questions number | Main interview questions |
|------------------|---|
| 1 | How do you talk to your doctor about medicine? |
| 2 | What things can you think of that might help people be a part of making decisions about their medicine? |
| 3 | What things keep people from being a part of making decisions about medicine with their doctor? |

Moreover, at the end of the interview participants were given a questionnaire measuring preferences for involvement in medical decision-making. I utilised one of the most frequently used SDM measures, the Control Preference Scale (Degner et al., 1997; adapted by Garfield, et al., 2007). In this one-item scale, participants had to indicate one out of four statements that best indicated their preference for how they would like to be involved in decisions concerning their medicine and medical treatment decisions. Answer options are: (1) you alone; (2) mostly you; (3) doctor or other healthcare professional and you equally; (4) doctor or other health care professional alone. Then, demographic questions on participants' date of birth, gender, and country of residence were collected. Furthermore, they were asked how long they had a diagnosis of Type 1 diabetes; whether they had more than one physician in the last year; and whether they received more information from some physician than others, what type of information, and whether information differed between physicians.

3.2.3 Design and Procedure

This study employed a mixed-method design. Participants were presented with an information sheet detailing the aims of the study, anonymity of their data, their right

to withdraw, etc. After giving consent, participants were assigned a personal identification code. The interview began with a brief introduction to the interviewer and a short explanation of what would happen: “,I introduce myself as the researcher Fatima. First, thank you for agreeing to participate in this study. I will give a brief explanation about the study. This study is concerning views on how to participate in medical decision-making. Your answers to the questions in this study will remain unknown to anyone else and do not affect your medical treatment in any case. In addition, I would like your permission to record the interview in order to save the information only. Before starting the interview, here is an approval form. Please go through it and, if acceptable, sign at the bottom of the page”

Participants were asked to take part in a semi-structured, one-to-one interview with open-ended questions. After the interview, they were given them a questionnaire. All interviews and the questionnaires were conducted in Arabic. The whole sessions lasted between 30-60 minutes.

The interviews were audio-recorded during interview with a digital recorder. All participants were then thanked and debriefed.

3.2.4 Data coding

The coding in this study covered three main themes, which is (1) understanding diagnosis; (2) treatment options; (3) involvement in decision. The “subtheme codes” included trust physician, discussion option and family sharing. NVivo software was used to organise the data which was analysed using thematic content analysis. The transcripts were read and were coded according to themes. Themes were modified as further data was collected and analysed. Identification of the themes came from the

data and was influenced by a literature review conducted prior to the study. Ethical approval for the study was granted by Plymouth University

Analyses

3.3.1 Quantitative Results

Table 3.2 presents participants' demographic characteristics. Their ages ranged from 18 to 72 years with a mean of 47.40 years. There was an equal distribution of males and females in the study. Over half of the patients had a diagnosis of Type 1 diabetes for more than three years (53.3%).

Table 3. 2: Demographic information of participants

| Characteristic | |
|--|-----------------------|
| Gender | |
| Male | 15 |
| Female | 15 |
| Age (years) | M = 47.40, SD = 13.33 |
| Age range | 18 – 72 years |
| Length of diagnosis | |
| Less than 1 year | 5 |
| 2 years | 5 |
| 3 years | 4 |
| More than 3 years | 16 |
| Information about whether they saw another doctor? | 10 |

Patients' preferences for involvement in decision making for medication are presented in Table 3.3. The majority of patients preferred to equally share the responsibility of making a decision about new medication or the amount of medication needed with their doctor. However, when it came to stopping medication most preferred to leave this to the doctor alone.

Table 3. 3: Frequencies (%) of patients' preferences for thinking about involvement in decision making for medication

| Preference for involvement in medical decision-making | | | |
|---|--------------|--------------------|-------------------|
| | New medicine | Amount of medicine | Stopping medicine |
| A) you alone | 6(6%) | 9(9%) | 6(6%) |
| B) mostly you | 4(4%) | 2(2%) | 5(5%) |
| D) Doctor or other healthcare professional and you equally. | 13(13%) | 12(12%) | 8(8%) |
| E) Doctor or other health care professional alone | 7(7%) | 7(7%) | 11(11%) |

3.3.2 Qualitative Results

The themes that emerged from the analysis were organised into the following four headings: (1) getting information from physicians; (2) understanding diagnosis; (3) treatment options; (4) involvement in decision. The main theme that emerged was the agreement in participants' perceptions of the possibility of patients playing any role in medication decision making. The other major themes included physicians' attitudes or behaviours, and factors that could either impede or facilitate patient participation in decision-making. The themes and subthemes that emerged from the interviews are

listed in Table 3.4 and reflect the research of Belcher et al. (2006). The following sections will discuss the main themes and subthemes in turn.

Table 3. 4: Qualitative themes

| Main themes | Subthemes |
|-------------------------------------|--|
| Getting information from physicians | - Patient goes to several physicians, finding different information, no further information needed |
| Understanding diagnosis | - Patient does not understand diagnosis first time round |
| Treatment options | - offer treatment - treatment choice - management of illness - advantage and disadvantage of medication - trust in the physician |
| Involvement in decision | - Information about treatment - discussion option - responsibility of chosen treatment - shared discussion |

3.3.2.1 Getting information from physicians

In order to explore participants' view of their health care providers and what they class as important information about their health care, they were asked if they had visited more than one physician to obtain more information about their health care. Participants recalled discrepancies in the information received from different physicians. The completed analysis yielded an interesting account of what participants believed to be the main antecedents, attributes and consequences of different information.

Different information

The analysis of patient interviews revealed that patients receive different information from different physicians, this was demonstrated by a male participant:

"I'm uneducated (illiterate) and the conflict of opinions between the doctors pushed me to look for a third doctor to determine to me the insulin dose I need. But I couldn't find sufficient information from all the doctors. I wish to know more and I think some doctors give unsuitable medication". P4, 54 years old, Male

This is an interesting quote as the participant has compared the information provided from a number of physicians. The conflict of opinion between physicians was also mentioned by another male respondent who explained his experience of communication and the consulting style of a physician:

"I visited more than one doctor until I knew I had diabetes and I got different information according to your comfortability with the doctor and good relationship you feel that you accept information. Some doctors do not talk much (less information). I saw an excellent doctor but unfortunately did not continue with him because he was

moved to another area. Some doctors simplify to you the information and make you accept it and some do not. Of course, they differ in the way they communicate with patient and the amount of information. Of course, there is a difference. Some doctors are useful to me and some aren't". P18, 58 year old, male

The different types of information received was connected to physician`s qualification and level of experience. The more qualified and experienced a physician was the more high-quality the information patients received. This is emphasised by the following quote by a female patient comparing physicians in different medical centres:

"There are big differences between doctors. In medical centres they aren't qualified and don't have experience and the doctors in King Salman Centre provided me with all the information that I need. Even in an emergency they are always available. It depends on your comfortability with the doctor. Some of them like to speak and explain and simplify information and some of them do not reply to your questions. Even in medication, there is a difference". P28, 44 year old, female

Same information

The analysis revealed that a third of participants receive the same information from different physicians:

"I saw more than one doctor and went to more than one hospital. The information I got was sufficient. I was satisfied by the information I got from the first doctor as he explained to me the nature of diabetes and type of medication. When I visited more than one doctor, it was not just to look for information about diabetes but also to verify the correctness of the medication prescribed to me. I trusted the first

doctor and I, thanks to Allah, feel satisfied and accept my illness". P2,61 year old, female.

Another patient noted that there is no difference in diagnosis and medication.

"I didn't notice any difference. I visited three doctors and approximately the same information I got on diabetes in the diagnosis method and medication. I was looking for a doctor to give me a regulator rather than insulin injections and all of them refused and agreed on the insulin injections as being necessary to me". P10,48 years old, male

No further information needed

Participants commented on the absence of wanting to have any information about their illness, due to sufficient information obtained from the experiences of their family member(s).

"I have a brother with type 2 diabetes. I used to accompany him to the appointments sometimes and I give him his medications and look for any information he needs. Therefore, I have enough information. I just visit the doctor for prescription and repeat medication. The information is always repeated by every doctor". P15, 51 year old, male

"I didn't visit any doctors other than my own doctor. I do not need any more information about diabetes. I have 9 brothers who all have diabetes, so I have all the information I need". P16, 50 year old, male

"I never visited more than one doctor, same medical Centre where I follow but there is a different doctor in each appointment. As far as I know their words are similar with no difference, same information and diagnosis, because patients in general are aware of

some information about diabetes, which is considered the disease of our modern age and all have some information about it" P19, 55 year old, male

Overall, some of the main issues emerging from this theme revolve around communication. For example, medical terminology and the inability of some physicians to explain diagnoses and treatment in a language that their patients can understand which emerged repeatedly. In general, physicians are often reported to have poor communication skills which makes patients feel uncomfortable. This results is consistent with other studies (e.g., Mobeireek et al., 2008) which reported poor communication between physicians and patients in Saudi Arabia. It is also consistent with other studies (Davey et el, 2013) which reported that some GPs are not perceived to take young adults' (18-25) health care concern seriously to explain things clearly. Poor communication can affect patients' care, trust and satisfaction and could potentially lead to inaccurate diagnosis and an inappropriate treatment plan. While a number of patients sought second opinions from other physicians, they also reported that the diagnosis and medication was consistent across physicians, in line with what other studies have found (Saba et al, 2006; Stevenson et al, 2000; Kon, 2010; Joosten et al, 2008). Receiving the same information from different physicians led to positive health outcomes and trust, and patients considered their physicians as being good at communication skills. Thus, these findings highlight the importance of communication style for patients, their trust in the physicians, and, ultimately, their trust in their diagnosis and suggested treatment.

3.3.2.2 Understanding the diagnosis

One major theme that emerged from the interviews was that there is a lack of understanding around the diagnosis of diabetes. Participants reported that their

physicians give them medication without any discussion over the reasoning behind the prescription provided, as demonstrated in the quotes below:

“The doctor never explained the nature of the disease. However, s/he explained to me how to use insulin and then referred me to the health education specialist, and the role of this specialist is to explain to me the nature of the disease, diet and the followed diet program. This was already done. P1, 18 years old, Female

The same patient repeated twice: *“I did not know what insulin Lantus (a type of insulin). Now I have knowledge about it. I used to take it twice but now I take it once. Nevertheless, I do not know why the second doctor reduced the insulin quantity for me. Then I knew that insulin was a happiness for me. Frankly, I was tired looking for a skilled doctor because one of them, as I mentioned before, was the cause of my coma, until I found the second doctor who was very specialized and referred me to the health education specialist for more information.” P1, 18 years old, Female*

“The doctor didn't explain the cause of diabetes nor its symptoms but told me about its complications and to pay attention to high blood sugar. Now it has been three years and I don't know how to deal with diabetes or control it (sometimes high and sometimes low).” P4, 56 year old, Male

Although the consensus was that patients generally do not understand the causes and diagnosis of diabetes the first time they are diagnosed, several statements by the interviewees suggested that there are some patients who understand their diagnosis (18 out of 30 patients). A number of patients talked about their physicians referring them to specialist doctors or health education specialists to explain their diet, sport, and provide patients with more information:

“He told me how to manage the disease and explained to me the complications of diabetes” P6,55 year old, male

“The doctor explained to me that it is dysfunction in the pancreas and the factors of aging have a potential for infection. He explained to me the causes of diabetes in general and explained the appropriate food and told me to stay away from unhealthy food. The doctor was very helpful and explained to me from my point of view most of the information about diabetes and also provided me with publications about the disease and told me if there is a query in the next appointment we will discuss it with each other and also explained to me the possible disadvantages of diabetes that it may affect the general functions of the body such as bones, kidney, and it has the advantage of regulating healthy food.” P10, 48 year old, male

Understanding their diagnosis is probably the most important aspect of the whole process for the patients. In line with other studies (Al-Dahan et al., 2013; Al-Nozha et al., 2004; Bani, 2015; Mohiedein et al, 2011) I found that a sizeable proportion of participants did not have good knowledge of their diagnosis or only after seeing a specialist health educator. This lack of understand may lead to an increased number of complications over the next years especially due to a lack in general changes in behaviour patterns and lifestyles. Another finding from this study is the conflicting information provided by physicians (and health educators) which can play a part in the increased lack of understanding of diabetes. Moreover, the lack of understanding of the diagnosis, found in this study, was based on the different information sought by patients and the communication between patients and physicians. Another finding was the lack of knowledge of the risk factors and symptoms of diabetes, which is consistent with Mohiedein et al (2011), where only one patient reported knowledge of such risk factors. Overall, the current study indicates

that the Saudi health care system needs some improvement in how the diagnosis of diabetes and associated risk factors are communicated to a range of different patients by physicians.

Knowledge about side effects of diabetes medication is also important, however results from this study show a lack of knowledge about side effects, and a difficulty in understanding information related to side effects for patients. This difficulty in understanding side effects may affect patient's preferences in treatment options (Alasiri and Bafaraj 2016). Despite this lack of knowledge and understanding, it is apparent that patients in this study are managing their illness, which is consistent with findings from other studies (Thorn and Paterson, 2000; Abu- sabah and Shehri 2014). These studies reported the importance of patients developing their expertise in making decisions about diabetes self- management. This might explain why patient's preferences to involve may increase over time. The length of time a patient has diabetes might have an effect on their level of involvement in decision- making.

3.3.2.3 Treatment Options

The analysis revealed the following representative comments about treatment options, and how they were discussed between health care providers and patients.

Treatment offer

There were only two options for treatment offered to the participant which were insulin injection or insulin pen. This sub theme refers to the discussions between a patient and physician about what would facilitate more patient engagement in decision making over a treatment plan involving medication. Although many participants did not report wanting to be involved in decision making about their medication, they

described situations where it would have been helpful. Some described how the physician never provided them with treatment options, and just prescribed (repeated) medication, determining the dosage required without discussing it with the patient:

“The doctor never gave me any treatment options. He just gives me the medication and determines the required dose” P1, 18 years old, female

“He did not give me any options. He wrote me a prescription for medication (insulin injections) only. He was directing me about the amount of doses I needed because the overdose made me tired a lot and if I cut it, my sugar would drop”

P10, 48 years old, Male

“Now it has been three years the same medication is repeated. He didn't suggest anything, just the medications” P16, 50 years old, Male

Few respondents (3 out of 30) were offered several options for treatment:

“Frankly, the doctor offered me two choices of medication; insulin injection and insulin pen, and explained to me that the injection are a bit old and more painful whereas the insulin pen is a better choice and involves very slight pain, and said these are the options available in King Salman Centre” P13, 18 years old, female

“...the doctor suggest to me that he could give me regulator pills or insulin injections” P 20, 38 years old, female

In some cases (5 out of 30), the physician made the decision for treatment for the patient. When a patient requested a particular type of medication, this was overruled by the doctor:

“...insulin only and I asked the doctor to give me pills better and she told me only the injections are suitable” P26, 45 years old, female

In some cases (6 out of 30), the physicians suggested a different option, but still made the final decision:

“He didn't suggest any medication. Every three months he changed medications in terms of its quantity by increasing or decreasing, he usually suggests to me alternatives and said there are options take this or this based on the analysis , if my condition improved he would decrease the insulin dose or increase and he gave me medication according to the options available in the pharmacy . Most often he suggest and says there are options or choices what do you think suits you. Sometimes no he decides what suits me without asking me” P14, 62 years old, male

Treatment choice

Three participants were offered more than one option for the medication type and dosage, allowing participants to express a preference when they had one

"The doctor gave me two choices; the pump and insulin but I refused the pump and he left the decision to me. I like the doctor to involve me in decision" P22, 20 years old, female

Some respondents suggested that their doctors appeared to lack knowledge of all or recent treatments.

“She didn't give me a choice. She prescribed the medication as available in the pharmacy and well-known to all diabetics” P23,42 years old, female

A commonly mentioned reason for not being able to participate related to the perception of the physician's experience and knowledge. One individual described this phenomenon.

"Said the same treatment they gave to my brothers before, there is nothing new" P16, 50 years old, male.

Despite the high importance of treatment choice for the patients, a number of interviewees indicated a preference when given a choice. However, the majority of physicians did not seem to give this choice to participate.

Management of illness

Participants can be taught how to effectively manage their illness by being referred to health education specialists to inform them about their diet and exercise, with an individually tailored food programme to follow. They could also be provided with additional information, such as a booklet and pamphlets specifically for diabetics:

"He referred me to health education, and I got diet program and healthy food program and sports. In each appointment the doctor reminds me of diet and the importance of sports" P 11, 38 years old, female

"The health education specialist explained to me about sports, diet, food program and alternatives and gave me a booklet and pamphlets to read" P3, 51 years old, female

Those patients (n=5), who did not receive such information mentioned the need for additional information to manage their illness better as they were left to their own devices:

“I wish to get more information or alternatives that can help me to control the disease” P9, 57 years old, female

“He only mentioned sports and how it helps improve sugar decline. He did not give me options and we did not discuss on this. I tried to make myself a diet and food program but it did not help me improve my diabetes. Because I worked out this diet by myself and I don't know if it was healthy or not. I was hoping that he would help me in the diet issue so I can control the high sugar. Even then he did not transfer me, like the rest of the patients, to a health education specialist” P16, 50 years old, male

Some participants (n = 9) mentioned the lack of information provided at the initial appointment. However, when referred to another centre they received sufficient information to manage their illness:

“In the first appointment, the doctor explained to me about the diet, food program and exercise like walking. I was initially in a health centre but they did not give me all the information about diet and sports until I was referred to the King Salman Centre and got enough information” P10,48 years old, male

Participants who were confident enough to self-educate themselves on their illness and how to manage it did so without the help of their physician:

“I am well informed and I like to read books and booklets of diabetes and I educate myself on everything relating to diabetes. My experience is built through dealing with a number of doctors but some doctors aren't very useful in this respect” P18, 56 years old, male

One participant expressed slight frustration about the lack of options provided by their physician around their regime with reference to exercise:

“The doctor does not give alternatives for example of exercise if you are busy or how to help yourself by going up the stairs more than once” P19, 55 years old, male

According to the participants physicians did not give them enough information or choice about managing their illness. However, this was subsequently provided by other health professionals.

Advantages and disadvantages of medication

Five patients understood what the advantages and disadvantages of taking their medication were:

“The doctor always explains to me and he convinced me to take syringes and explained to me sufficiently and I was always in discussion with him, and he convinced me (if the insulin dose increases and if sugar rises above 200 it affects the kidneys). My own doctor has the advantage of persuading me always” P8, 58 years old, male

“He gave me all information about the pump and insulin injections. I prefer insulin injections as I feel it is easier for me. He strongly recommended the pump but I refused” P22, 20 years old, female.

It is apparent from the lack of explanation from the physicians about the medication that the majority of participants did not understand the advantages and disadvantages of taking their medication:

“She doesn't explain if I told her it doesn't suit me she changes it” P 25 , 54 years old, female

“He usually doesn't explain medication complications, sometimes he says this is alternative for this. I read the prescription in the medication pack, sometimes the

pharmacist tells me about its complications says there is a better alternative tell the doctor to prescribe it to you” P 14, 62 years old,male

“As I said before, the doctor does not talk about medicines until the next appointment, tests are done if appropriate or not. Always if I need any information I can search by myself online or read the prescription in the medicine box” P7, 58 years old, male

Trust in the physician

Trust emerged as a complex subtheme with both the presence and absence of trust in the doctor acting as a barrier and a facilitator to patient participation. Some participants felt that trust was necessary for involvement in decision-making, but that this depended on community, skills, and communication with doctors:

“I don't have any choice better than the doctor I have to trust him otherwise I will not accept medication” P 24, 39 years old, male

“I trust him largely. But it depends on the doctor experience and his presentation of information sometimes you get out from the doctor and you are not convinced by the information he told you and you go and look for alternatives” P14, 62 years old, male

In addition, about 50% of participants trusted their physicians because they thought that physicians generally have more knowledge and experience to guide them to better choices:

“I trust the doctor since he has knowledge and experience.” P10, 48 years old, male

“Surely the doctor looks for his patient's interest and offers as best as he can”

P20, 38 years old, female

This study attempted to explore the factors that might encourage patient involvement in decision making. Findings suggest that the physicians did not provide patients with treatment options, which may affect patient's preferences to interact with health care providers. This is consistent with a study by Moberiak et al (2008), where they reported poor communication, which might be a cause of conflicts and therefore weakens the physician- patient's relationship (Moberiak et al, 2008). However, this is not consistent with other studies suggesting a working alliance between physicians and patients to select the best treatment delivering the best outcome for patients due to this effective interaction. (Elwyn et al., 2012; Lee and Emanuel 2013).

3.3.2.4 Involvement in decisions

All participants were asked to describe their views on what kept people from being a part of making decisions (about medicine) with their physicians. This was a direct attempt to better understand their views and preferences to be involved in decisions. Participants expressed a lack of wanting to participate in decision-making. Several participants felt that not all patients wanted to participate in medical decisions, rather preferred the physician to tell them what to do. The fear and anxiety participants felt about their illnesses, and the fact that participants considered disease and illness overwhelming were reasons cited by patients for not wanting to participate in medical decision making.

In relation to this, the information about the treatment, discussion of options, responsibility of chosen treatments and shared discussions were subthemes that emerged from the analysis.

Information about treatment

Trying to locate appropriate information for their information about treatment can be a difficult process. However, there are some resources to help with this process, for example, the internet, TV programmes about diabetes, and leaflets. Finding correct guidance can be difficult especially when using the internet. Patients who do not receive sufficient information from their physician seek alternative sources of information, with some experiencing devastating consequences through misinformation:

“ I was given medications without explaining to me about them and why I should take them or the benefit from them, such as what happened to me when I had a coma caused by overdose and medical error. I think that it'd be better that the doctor always should seek to involve the patient in the decision so that the patient feels comfortable and understands his/her health and not be unaware” P1, 18 years old, female

“I got a lot of information by searching the internet and when mother was ill I used to take care of her. Now I am a diabetic and it is only natural and supposed that I have more information about the disease and new medications in this field so as to help myself. It is not necessary that I rely on the doctor.” P10, 48 years old, male

“Certainly I wish to get more information because the doctor doesn't explain treatment steps or talks with me about new medications” P20, 38 years old, female

“I want to obtain a lot of information and I search the internet and newspapers, programs, and the doctor usually doesn't provide the patient with more options. For example, in the appointment I put forward all the choices to the doctor and discuss them with him, and choose the one suitable to me provided it doesn't involve any

harms, but the doctor usually doesn't provide a lot of information" P30, 34 years old, male

However, reading the information from alternate sources is not as good as face to face interaction with a physician:

"I wish she provide me with more information because reading a book or booklet is not the same as discussing with the doctor and there should be medication choices in a better way so that the patient can choose" P 26,45 years old, female

"I am satisfied with the information I get from the doctor" P4, 56 years old, male

"I am satisfied by the information I got from the doctor because he is experienced in his field of specialization only. It is supposed he provides the patient with any information about medications that will help the patient" P6, 55 years old, male

"I don't need more information because I'm satisfied with the information I get from the doctor (since he is more informed about my health condition) I don't want to know even about medications. Sometimes I listen to my daughters' advice on medications if there is something suitable" P11, 38 years old, female

With regard to information about treatment, relevant information should come from the physicians. Patients, however, did not seem to receive sufficient information from their physician, and sought out other source of information. The danger is they may find it difficult to locate correct guidance. Consequently, there may be adverse consequences through misinformation.

Discussing options

Eight patients did not want their physician to discuss options with them, as they preferred their physician to make a decision for them:

“I don't wish to discuss options I prefer leave it to the doctor as he is well informed on diseases and the medications” P 20, 38 years old, female

“I only wish he would listen to my opinion as consultation or let me know why he prescribed this medication and what its effects on my health are” P16, 50 years old, male

However, the remainder of the participants preferred to be involved in the decision making process or at least be able to discuss options with their physician:

“I hope the doctor will share with me and ask me whether I am satisfied or not. Some doctors never ask for my opinion” P1 18 years old, female

“The discussion is very important. I am supposed to suggest to the doctor a group of medications and the doctor advises. I completely reject the doctor make decision alone” P12, 72 years old, male

“I sometimes give choices to the doctor and discuss with him and guides me if the choices are useful to my health, and if he gives me two alternatives I choose the one suitable to me” P22, 20 years old, female

The majority of respondents preferred to discuss options with their physician. Thus, physicians should offer patients the opportunity to decide if they wish to be involved in SDM about their treatment.

Responsibility of chosen treatment

Some participants who felt patients could, and should, participate in medical decision-making focused primarily on patients' responsibility to know about their medications and conditions, and how they should be responsible for their decision. Some participants felt they were responsible for being informed about all information of treatment:

"After the doctor explains to me the advantages of medication such as some drugs cause dizziness. After that, I choose the one which suits me and I take responsibility for the decision and choose the best and the easiest and of course after discussion with the doctor" P7, 58 years old, male

"Surely I can bear responsibility for the option I chose on condition that I have obtained sufficient information of the medication and there is no harm. This is my choice" P13, 18 years old, female

"I bear responsibility if I chose the medication and agreed to it and when informed and know all information why not if the doctor explained to me then he bears no responsibility and I bear full responsibility. But if he asked me to bear responsibility for options I don't have sufficient information for {the doctor did not explain}, in this case I refuse to bear responsibility. The doctor should bear responsibility." P14, 62 years old, male

" Conditional that the doctor gives sufficient information so that one will not harm himself by choosing something and later on doesn't suit him and the doctor bears part of responsibility because he provides available choices to the patient" P26, 45 years old, female

"It depends on the treating doctor. If I see him as trustworthy then I bear responsibility for choice of suggested medication. It is better for the patient to make his own decision"

P23, 42 years old, female

Twelve patients wanted physicians to be more responsible for treatment decisions:

"I wouldn't take risks and bear responsibility. I will choose if the doctor says take it. I measure the rate of risk and if it is high I wouldn't take it I will leave it for the doctor. It is she who decides if advantages are high and disadvantages lower I would take it but if the opposite I will leave it to the doctor, whether pills, injections or pump and surely the doctor takes the best choices for me" P25, 54 years old, female

"I don't like to bear responsibility. The doctor should be responsible because the decision is really difficult and it is his function and role. He gives options and then he chooses the most suitable one to me and take my opinion into consideration like when he gives you a sheet of paper and you execute what it contains, for example diet" P 17, 46 years old, female

"I don't want to bear responsibility for any decision relating to my health. I like to leave it to the doctor who is supposed to bear responsibility" P 20, 38 years old, female

"It is the doctor who should bear responsibility since I have no experience and I don't know what is good for me or suits me well" P28, 43 years old, female

The question of personal responsibility in one's treatment choices seems to be a tricky issue. On the one hand, participants who want to feel responsible and be involved in medical decisions also discussed that in order to do so, patients need to be informed about treatment choices, for example. On the other hand, as discussed above, physicians seem to rarely provide information and choices (this might be done

by other health professionals, though). Thus, in order to make patients comfortable with and willing to engage in shared medical decision making and to reap the benefits from this process, physicians need to provide critical information and choices from the start.

Shared discussions

There were only three participants who wanted to independently take a final decision:

“Me alone because it is difficult to accept other people's opinions and be convinced. We do not trust nor convinced of every doctor” P18, 56 years old, male

“I like to make decisions relating to my health by myself after consulting the doctor” P19, 55 years old, male

The majority, though, preferred to leave the final decision to their physician or share the responsibility with a member of their family (e.g.daughter, husband or sister):

“From my experience in life the decision is always to the doctor, and I did not notice any difference in treatment, so I leave the decision to the doctor. I prefer to consult my children because they are doctors and pharmacists “ P 2, 61 years old, female

“I usually consult and ask people in the hospital waiting room who have already had the same disease. Sometimes I am satisfied with the doctor's opinion or friends if they have the same symptoms and medications. I would leave the decision to the doctor alone” P4, 56 years old, male

“I like to involve my sister in most decisions. After each appointment, I always take care to contact with her and take her opinion” P12, 72 years old, male

The main aim of study attempted to discover what information patients with diabetes receive, how they understand their diagnosis and their level of involvement in SDM. This study revealed several themes relating to patients with diabetes type 1 to be involved in SDM. There was variability in perceptions on whether it was possible or desirable for patients to participate to involve in SDM. While some participants expressed that they only would discuss treatment options with their physician or deferring decisions completely to the physician, some considered it possible for patients to participate if known more details about all available option and advantage or disadvantage for possible options. A few patients expressed the desire to include family members into the discussion because they could not trust their physician or their own opinion alone. The desire to widen the decision making process to family members has already been discussed in Chapter 2 (Study 1). It might be an important feature of (medical) decision-making in Saudi Arabia or family-oriented societies generally, but has not really been discussed in the literature on SDM in western societies. It might be interesting to explore the involvement of trusted family members in the decision making process and its benefits in future research on medical decision-making.

For some interviewees, involvement was limited to the physician providing information to the patient, which a necessary step is not the same as sharing decisions. Others expressed the idea that shared decision making should be based on individual patients' health preferences. Generally, patients do not want to be involved, rather they prefer to share information with their physician. This finding is consistent with previous research (Garfield et al, 2007; Levinsion et al, 2005), where it was found that not all patients wanted to participate in the treatment of their condition.

The possible explanation could be that people's involvement is dependent on their clinical condition (Moberiak et al, 2008) and the information they have available.

Many of our findings are consistent with previous studies addressing decision-making related to other health care decision making. Prior investigations have shown, in western societies for example, that some patients do not want to be involved in decision making(Arora, McHorney 2000; Degner et al; 1992) Of those who do want to be involved, the spectrum of involvement ranges from sharing information to active participation in the final decision (Charles et al,1997; Charles et al, 1999; Levinson et al., 2005). Many of the views and issues mentioned by our participant's consideration of communication between them and health care providers and providers enough information for treatment options. One such unexpected theme in the present study was that both presence and absence of different information between physicians could serve to either facilitate or impede participation. This complex relationship between trust and patient involvement requires further exploration and hints at the difficulties to start a shared decision-making process. In general, participants argued that involvement in decision-making might be approached in different ways by physicians. Patients appeared to prefer to get more information about their treatment, consistent with the study by Mohiedein et al (2011) where they found that the main resource of information about DM was from the media (47%) and only 19% was sought from health care providers. This provides a possible explanation for the association between physician and patient preferring more passive or collaborative involvement in decision- making.

Limitations future research

This study focused on patients with type 1 diabetes. While this is an increasing health problem in Saudi Arabia, the conclusions drawn from this research can, of course, not be generalised to patients suffering from other illnesses. This study did not investigate any gender or age effects. The patient's age range was quite wide (18-72 years old), and it is possible that there are differences in the preferences for SDM between older and younger patients, as has been shown by research in western societies.

This study provided a foundation in the understanding of patient decision making in Saudi for diabetic patients. Further research should focus on the communication between physician and patients, and continue to develop our understanding of the factors that might affect decision-making in both physicians and patients.

Conclusion

This is the first study demonstrating patient's preferences in Saudi diabetic patients. Interviews showed that participants had enough knowledge to understand their diagnosis in general, however their understanding of treatment options was limited. It is clear that health care providers do not encourage patients to make their own decision or at least have a discussion regarding treatment options with their patients. This impedes shared medical decision-making even among patients who would, in principle, like to participate in this process. Therefore, our study suggests that more effort should be made to increase patients' involvement of decision-making. One first step would be to encourage physicians to provide patients with appropriate information. Given that a number of participants indicated that they would also like to

involve their family members in the process, this could be a way to better include patients in their treatment decisions as well. In general, it might be worth investigating whether including family members in the medical decision-making process would be beneficial for patients' health outcomes.

Chapter 4

Study 3: Saudi and British Parents' Preferences for Shared Medical Decision Making

In Chapter 1, some of the positive effects of shared medical decision-making (SDM) for individual patients were reviewed. SDM may be helpful when families have to make decisions on the disadvantages and advantages of more than one treatment (O'Brien et al., 2011). There has been a movement to involve minors in medical decisions affecting them (Ruggeri et al., 2014). This movement starts with the idea that children should be involved in making decisions about issues that concern them. However, parents are still called upon to make medical decisions on behalf of minors (i.e., children and adolescents under the age of 18).

The study reported in this chapter was concerned with the level at which parents are interested in being involved in medical decisions that affect their children. It also considered whether their preferred level of involvement differed when they make medical decisions for their children or for themselves. The focus was on SDM concerning the choice on how to treat Diabetes Type 1, because diabetes is a debilitating disease, which is increasingly affecting minors (Acton, 2013). Furthermore, there are different treatment options available, and the choice for these treatments could be made through SMD. Whilst there are clear benefits in involving minors in medical decisions that affect them, this is not possible in some instances, for example with very young children. In these cases, parents may act as surrogates making decisions on behalf of their children. Surrogates should be treated as if they were the patient for whom they are deciding (Rhodes & Holzman 2004).

The following literature review will examine research on parental surrogate decision-making for children and factors affecting this. I will then discuss basic and applied research on whether it makes a difference when people make a decision for themselves versus others before I formulate my research questions for the current study

4.1 Surrogate medical decision making

Surrogates have a duty to execute to the wishes of those for whom they are acting. According to Tunney and Ziegler (2015), the decision-making pattern of the surrogate can be based on the psychological traits of the surrogates. Before making any decisions, various interests may be discerned by the surrogate such as the patient, his/her family, the healthcare institution (finance and legal implications) and society (religious perspective and availability of resources or treatment to manage the patient's disease). Based on these considerations, various patterns of surrogate decision-making can be established. Tunney and Ziegler (2015) postulate that a surrogate decision can be classified under four key categories with respect to the intention and the ability of the surrogate to infer the concerns or wishes of the recipient. These categories are egocentric, simulated, projected and benevolent. An egocentric surrogate fails to model the recipient's wishes and makes a decision that maximises their own interest. In the simulated model, the surrogate attempts to model the desires and wishes of the recipient. The accuracy of this model depends on the extent to which the decision matches or reflects the recipient's wishes. Third is the projected model whereby the surrogate decides what action to take as if it was them in that situation. Finally the benevolent perspective, when the surrogate reflects on the best interests of the recipient regardless of the recipient's actual desires. In addition, Tunney and Ziegler (2015) also point to the significant role that emotions and confidence play in

the decision-making process. Through emotions as well as perspective-taking and knowledge, surrogates are able to get the confidence to make decisions concerning the recipients.

4.2 Outcomes of surrogate decision-making. Shalowitz et al. (2006) investigated the accuracy of surrogate decision-making. The authors emphasised that clinicians depend on the next-of-kin and patient-designated surrogate to make decisions in the best interests of patients who cannot make decisions for themselves. The surrogate's judgment is used to direct the decision by the clinicians on the appropriate medical procedure that the patient would have selected. However, the accuracy of the choice of the various decisions with regard to patient care has been a key area of concern. According to Shalowitz et al. (2006), an accurate choice or surrogate's decision refers to an action or procedure that the recipient would have chosen or desired if s/he was not incapacitated.

The research involved a systematic review of the PubMed and Cochrane databases as well as the manuscript references. Only 16 out of 151 studies were eligible for the analysis of the accuracy of the surrogate's decisions. The review established that surrogates lie within a 68% accuracy level. Neither prior discussion nor the current predicted health status (i.e., situations involving the patient's current health) influenced the surrogate's accuracy (Shalowitz et al., 2006). Though the data presents compelling argument on the accuracy of surrogate's decision, a third of surrogates failed to correctly identify the recipient's wishes. Other methods have to be established to identify the wishes or needs of the patient in order to make accurate decisions.

In certain circumstances, doctors make decisions on behalf of their patients and need to predict patients' preferences. Garcia-Retamero and Galesic (2012), investigated whether these decisions concur with those of the patient. They established three critical factors that affect doctors' decisions: doctors' risk preferences for their patients and for themselves, patients' risk preferences for themselves, and self-other discrepancy in decisions. Garcia-Retamero and Galesic (2012) found that doctors' decisions tended to be conservative, favouring safer options, when they were making surrogate decisions for their patients. Physicians were not aware of such discrepancies between the decisions they would make for themselves versus their patients.

Sometimes parents are required to make serious life-or-death decisions when confronted with the reality that their infants may be too weak for resuscitation to take place in the delivery ward, for example. If the infant survives, the parents may be asked to consider the withdrawal of life-sustaining medical treatment, for example ventilation. This is usually done shortly after birth. Generally, in such scenarios, most parents wish to take part in making any life-support decision relating to their children. Most parents prefer health care providers to address their parental concerns and wishes and provide them with as much information as possible regarding their baby before and immediately after delivery. Health care providers play a crucial role in aiding parents' decision-making by offering emotional support and helping them to understand the information provided (Moro et al. 2011).

Meert et al. (2000) explored parents' perceptions on decisions made to withdraw or limit life-support from seriously ill children. They evaluated parents' views in cases of a child's death in the Pediatric Intensive Care Unit (PICU), and their satisfaction with the medical care provided. Seventy-eight parents whose children had

died in the PICU between 1995 and 1998 were interviewed. Forty-one of the parents remembered discussing the withdrawal or limitation of life-support from their children with a clinician. Of these, 31 felt that they had sufficient authority to make such critical decisions for their children. These parents identified various factors that were important in their decision-making process including the degree of pain and suffering, diagnosis, recommendations by the physician, and expected neurologic recovery. The researchers concluded that the recommendations made by physicians, expected neurologic and nature of illness are essential to parents when making decisions about life-support limitation or termination. Additionally, the formation of trust between medical practitioners and parents was found to be important in directing parents through the decision-making process. The study demonstrated that parental presence during a child's death, provision of sufficient information, and the availability of a sympathetic environment bring about a healthy grief response in parents.

Sullivan et al. (2015) investigated whether parents should be key decision-makers for their children in the case of life-threatening clinical matters. Twenty-five parents in life-support decision-making situations for their children were interviewed. Three decision-making responsibilities were identified: guided, self-determined (vigorous decision-making) and consenting (passive decision-making). The authors found that most parents were active decision-makers and that they perceived themselves as the final decision-makers. Parents in guided and self-determined sets reported no undesirable consequences from their involvement in end-of-life decision-making. Most parents stated that they should always be the end-of-life decision-makers for their children. The findings support the parents' desire to be the end-of-life decision-makers for their children, unless the decision is not in the best interest of the child.

Caeymaex et al. (2011) aimed to obtain a qualitative account of end-of-life decision-making as described by parents who have lost their children in the Neonatal Intensive Care Unit (NICU). To achieve this objective, the researchers conducted face-to-face and telephone interviews with 164 parents, three years after losing their children in four NICUs in France. Interviews were carried out to find out how parents perceive their responsibilities in the decision-making process. The study used a detailed examination of perceived parents' responsibility in making end-of-life decision and that parents perceive it as important to express their views in the end-of-life decision-making process when it comes to the lives of their children. Nonetheless, they require continuous emotional support and a clear understanding of their role in end-of-life decision-making. As participation preferences can vary, real shared decision-making should allow parents to decide what role they want to play in this critical situation. According to Caeymaex et al. (2011) in these tragic decisions, parents' future coping ability would be aided by clinicians' recommendations that the parents should not take a full responsibility for such decisions. Consideration of the best interests of the ill child may help in putting these decisions in a clearer context.

4.3 Surrogate decision confidence and emotions. As pointed out by Tunney and Ziegler (2015), psychological variables, such as confidence and emotions, can affect the surrogate decision-making process. Majesko and White (2012) proposed that a timely and better-quality communication between the physician and the surrogate provides a strong basis for higher levels of confidence. A low level of confidence is a key challenge to overcome as it has negative consequences on the surrogate decision-making process. Creating high levels of confidence and managing emotions are crucial to the success of the process. Meeker (2004) investigated the decision-making process amongst Japanese-American families. Using interpretivist

methodology, the researcher interviewed 16 families. The participants described their encounters with the death of 22 family members. Meeker (2004) established four key dimensions concerning surrogate decision-making: Awareness of the seriousness of the problem; decision-making concerning the treatment; willingness to accept death; and the dying process. Nurses, as well as key healthcare providers, played an important role in understanding these dimensions and improved the experience of the surrogate.

Wendler and Rid (2011) conducted a review of the literature searched within databases including MEDLINE, PsychINFO, and EMBASE to assess negative emotions associated with surrogate's decision-making. Of the 40 studies included, 29 used qualitative methods and 11 used quantitative methods. At least a third of respondents reported a negative effect or an emotional burden as a result of surrogate decision-making. Effects lasted from two months to several years. Not all experiences were negative as some surrogates played a crucial role in motivating or supporting the patient. Also, a treatment that adhered to the preferences of the patient was a key factor in reducing negative feelings.

Carnevale et al. (2007) examined whether parents or physicians assume decision-making responsibility for the treatment of ill babies and how those responsibilities relate to parental feelings. In Anglo-American settings, parents are responsible for end-of-life decisions while in France, physicians are regarded as the final decision-makers. Carnevale et al. (2007) interviewed 31 parents of seriously ill children, 13 nurses, and nine physicians who were attending these children in two French PICUs and two Canadian PICUs. They found that in France, physicians are considered to be the decision-makers whilst in Canada, the authority to make such a decision was shared by parents and physicians. French parents were found to be more

concerned with their relationship and communication with physicians than Canadian parents. Again, parents in France were more concerned with the quality of communication rather than the decisional authority. The study demonstrated that some degree of medical paternalism is inevitable, regardless of the ethical and legal norms in place. This study also highlights potential cultural differences in the parents' desire to be involved in the medical decision-making for their children.

Similarly, Orfali (2004) explored cultural differences in the role of parents in making critical medical decisions for their children in France and the USA. In both countries, parents were minimally involved in decisions regarding withdrawal of care. In America, only 10% of the parents made the decision for the withdrawal of healthcare for their baby. In America, the law plays a crucial role in what physicians do. For instance, one of the mothers insisted on having her baby provided with care to survive, but the weight of the baby (680g) made this impossible even though it had lived for 11 days. Thus, the ability of parents to make decisions on behalf of their children must be guided by the law, and physicians must act without contravening the law or medical ethics. In contrast, in France, it is the physicians who made most of the decisions regarding withdrawal of medical care for babies, whilst providing parents with information that helped parents understand the decisions made. French physicians objectively informed the parents about the condition of the babies that prevented their survival while their American counterparts did not offer the suggestion of withdrawing medical care. This study brings to light how the legal and social-conventional setting of a culture can influence parents' decision-making for their children.

Botti et al (2009) carried out a study to establish how making such highly-consequential decisions was related to parents' emotions and desires for autonomy in France and the USA. The researchers found that when parents had to make a choice

as to whether to continue life-support for a terminally-ill child, making a decision by oneself rather than the doctor making the decision, elicited more negative feelings. Nevertheless, participants were equally against making decisions on their own or for letting someone else decide for them. Findings with the French parents accentuated the need for physicians to provide objective information regarding risky or potentially tragic medical decisions. This approach made the involved parents more comfortable in making a decision on the withdrawal of medical support for less-than-one-month-old infants with life-threatening conditions. Physicians in America informed the parents about the consequences and issues around removing medical support, but they left the decision with the parents. This led to confusion and the inability to make the right choice. Botti et al. (2009) conclude that making tragic decisions alone may lead to more feelings of regret than having an external person make the decision. If a parent decides to have the life-support of his or her child withdrawn and the child dies, the parents are more likely to regret the decision than if someone else suggests and executes the withdrawal. This study supports other studies that highlight the dilemma of making treatment choices; it is not always that rationale individuals make a choice that they find satisfactory. Simply presenting a set of choices does not guarantee happiness.

Overall, these studies indicate that parents might want to be involved or even have the final say in making decisions on behalf of their children. However, making such decisions can have negative emotional consequences. Support and good communication by health care professionals and objective information can increase decision confidence in parents. Previous research has also started to address cultural differences in parental decision-making. However, most of the research reviewed above investigated parental surrogate decisions for serious and tragic choices, for

example on behalf of seriously sick children. These studies did not investigate whether and how parents would like to be involved in making less serious medical choices for their children, for example when deciding on a treatment option for their child. I explored this question in the case of parents' preferences for being involved in a hypothetical decision on their child's treatment for diabetes.

4.5 Diabetes Treatment

Statistics showed in that in 2013, there were 3 million people who have been diagnosed with diabetes type 1 in the UK (Diabetes UK, 2015). In Saudi Arabia reports showed a high prevalence of diabetes of 13.4%, but estimates indicate that 43.6% of sufferers have been undiagnosed (Al-Mendalawi & Al-Herbish 2009). There are several types of diabetes; I will particularly focus on type 1 diabetes mellitus (T1DM) and discuss the current (shared) medical decision-making approach applied to its treatment.

Normally, when it comes to treating T1DM, there are many approaches available. Following diagnosis, patients may be advised on the functions of each treatment approach. The differing functions might potentially affect the treatment recommended by the physician. They might also affect the way the patient perceives and complies with the treatment. A patient with type 1 diabetes must inject insulin several times daily and maintain a strict diet. Patients are offered the choice to either inject insulin multiple times a day with a needle or use an insulin pump(Ly, et al,2013) Although physicians typically advise patients with T1DM to follow a certain treatment plan, it is still the patient who accepts the treatment and physicians are mandated to comply with the patient's decision. Physicians can only offer advice on the positives and negatives of each approach. Hence, patients should carefully consider each

treatment approach (Kattan, 2009). When it comes to controlling or treating chronic conditions such as T1DM, sharing decision-making with the patient is a very effective approach (Porta 2005). Porta (2005) claimed that it makes sense to consider shared decision-making when it comes to treating T1DM, for which there are several options available to help reduce complications of the disease. Shared decision-making often entails individualised decision analyses which are based on a personalised assessment conducted by physicians upon their patients so that both parties will have better understanding of the current state of their chronic condition, as well as any possible treatment or advice that can be taken (Porta 2005). The most important contribution of this approach is that it psychologically influences the patient to be aware of the significant values and importance of such an approach, as well as the harms and dangers that are also attributed to it (Fogel & Greenberg 2015).

Medical decisions relating to the management of insulin-dependent diabetes are a particularly apt example concerning the involvement of children in their medical care, because diabetes requires a life-long commitment to having injections, taking blood tests, and eating healthy. This commitment necessitates that children affected by diabetes are involved on a daily basis (Alderson et al., 2006). Interviews with diabetic children showed that children understand what diabetes, hypoglycaemia and hyperglycaemia are, as well as what happens to their bodies when they have low or high blood sugar. They know when they require injections or other medications, and they are cognisant of what to do in case blood sugar falls or rises above normal levels (Alderson et al., 2006).

4.6 The Present Research

The focus of this study is to identify the preferences of parents when making choices in medical decision-making for themselves or on behalf of their children. Additionally, I wanted to discover if information about medical decisions affect parents' preferences for medical decision-making for themselves and their children in UK and Saudi Arabia and to identify emotional consequences and decision confidence. The following hypotheses were put forward:

H1: Parents will show a higher preference for being involved in SDM for themselves, but will prefer a physician to make decisions regarding their child.

H2: Full disclosure of information will impact upon parents' preferences and confidence regarding SDM for themselves and their child.

Previous research by Botti and McGill (2006) indicated that despite the popular view that individuals who are left to make personal choices are happy with their decisions, this may not be the case for those people who cannot access the required information. Individuals may either regret or be satisfied by the preferred choice. Random choosers may either blame themselves if they find that their chosen alternative does not have the expected benefits or give themselves credit if their preference gives them the expected benefit. Furthermore, Botti et al. (2009) showed that French parents making a tragic choice for their children were more comfortable with their choice when objective information was presented by the physician.

H3: There will be positive and negative emotional consequences for SDM as shown by Botti and McGill (2006).

This hypothesis follows up the results from the study by Botti et al. (2009) who investigated preference for autonomy and emotional reactions to parents' tragic medical decisions. In two studies, the authors examined whether parents who have to make a "tragic choice", that is a decision leading to highly consequential, highly undesirable outcomes (i.e., discontinue an infants' life support) want to be involved in this decision and parents' emotional reactions to these decisions. While participants had strongly negative emotional reactions when they (rather than their doctor) had to make this tragic choice, they nevertheless strongly valued being able to make this choice (i.e., their autonomy).

H4: There will be cultural differences between parents in the UK and Saudi Arabia in their choices regarding SDM and the emotional impact of those decisions.

My previous research (Study 1, Chapter 2) indicated that UK participants preferred making a medical choice themselves whereas Saudi participants preferred their doctor to make the choice. This is in line with Botti et al. (2009) who also found cultural differences: US parents showed a higher preference for making this tragic choice themselves than French parents, but also experienced more negative emotions.

Methods

4.2.1 Participants

A total of 199 participants were recruited from non-clinical samples in the United Kingdom (UK) and Saudi Arabia. Recruitment was via convenience sampling; the inclusion criteria were that participants needed to be 18 years or older, either a residents of the UK or Saudi Arabia, and had to be parents. In the UK respondents were selected from (a) parents attending a Plymouth baby lab and (b) parents from

Mount Street primary school in Plymouth. In Saudi Arabia, parents from different schools were invited to participate in the study following a letter of explanation from the head teacher(s). There were 99 Saudi participants (M-Age = 32.30 years, SD = 7.80, 84 females, 15 males) and 100 UK participants (M-Age = 33.34 years, SD = 7.22, 88 females, 12 males).

4.2.2 Procedure

The study was approved by the University of Plymouth Ethics Committee. A questionnaire was presented to participants on paper to complete. The first page was a brief summary about the study, including information about the anonymity of participants' data as well as their right to withdraw, and how to create their personal identification code. Once they consented to participate, participants filled out the remainder of the questionnaire.

Participants were tested in two conditions, using a between-subject design. In Condition 1 (Informed choice), participants were asked to imagine being a parent making a medical decision on behalf of their child suffering from Type 1 diabetes. Participants were asked whether and how much they would like to be involved in making a decision as to whether their child should have insulin administered using an insulin pump or injections. Advantages and disadvantages of both administration methods were presented before participants indicated their preference for shared medical decision with regard to the treatment of their child (*Choice-Child*) using the Control Preference Scale (Degner et al., 1997). Using the same scale, participants were also asked about their preferences for shared medical decision making, if they had to decide on a treatment for their own Type 1 diabetes (*Choice-Self*). The order of Choice-Child and Choice-Self was counterbalanced among participants.

Condition 2 (Non-informed choice) was analogous to Condition 1, but participants were not presented with information about the advantages or disadvantages of insulin injections versus insulin pumps. Participants in both conditions had to rate their emotions and confidence after indicating their preference for shared medical decision-making for their child (Choice-Child) and for themselves (Choice-Self).

All participants answered the Horizontal and Vertical Individualism and Collectivism Scale. After completing all of the questions, participants were debriefed. The whole study took no longer than 20 minutes.

4.2.3 Measures

4.2.3.1 Demographics and background information. Participants were asked to report their date of birth, gender, and country of residence. Furthermore, they were asked whether they had health insurance, whether they or one of their family members had diabetes and, if yes, for how long, when they last saw a doctor or other health professional, and whether somebody else came to the doctor's appointment with them. Participants were also asked about how many children they had and the age of their youngest child.

4.2.3.2 The Control Preference Scale (Degner et al., 1997) gauges participants' preferences for shared medical decision making. For the current study, participants were asked how much they wanted to be involved in making the treatment choice for their child (Choice-Child). Answer options on the survey were (1) I prefer to make the final selection about which treatment my child will receive; (2) I prefer to make the final selection of my child's treatment after seriously considering the doctor's opinion; (3) I prefer that the doctor and I share responsibility for deciding which treatment is best for my child; (4) I prefer that the doctor makes the final decision about

which treatment my child receives while seriously considering my opinion; and (5) I prefer to leave all decisions regarding treatment to the doctor. They were also asked about how much they wanted to be involved in the treatment choice, if the treatment was for themselves (Choice-Self). Answer options were (1) I prefer to make the final selection about which treatment I will receive; (2) I prefer to make the final selection of my treatment after seriously considering my doctor's opinion; (3) I prefer that my doctor and I share responsibility for deciding which treatment is best for me; (4) I prefer that my doctor make the final decision about my treatment while seriously considering my opinion; and (5) I prefer to leave all decisions regarding treatment to my doctor.

4.2.3.3 Emotion and confidence ratings. Participants rated their emotions using the Positive and Negative Affect Schedule (PANAS; Watson et al., 1988). This is a 20-item questionnaire which assesses participants' positive (e.g., excited, enthusiastic) and negative affect (e.g., distressed, upset) on a 5-point Likert scale (1=not at all to 5= extremely). For each choice (Child, Self), mean negative and positive affect scores were derived. Cronbach's alpha for Negative effect Choice-Child was $\alpha=0.80$, for positive effect Choice-Child it was $\alpha=0.82$. Cronbach's alpha for Negative effect Choice-Self was $\alpha=0.80$, for positive effect Choice-Self it was $\alpha=0.90$.

After each choice, participants had to indicate their confidence about their treatment choice on a 7-point Likert scale (not at all confident; very confident).

4.2.3.4 Horizontal and Vertical Individualism and Collectivism Scale (Triandis & Gelfand, 1998). This 16-item scale assesses horizontal and vertical individualism and collectivism orientations. The scale has been widely used in cross-cultural research (reference). Items include "I'd rather depend on myself than others" (horizontal individualism) and "If a co-worker gets a prize, I would feel proud" (horizontal

collectivism). Each dimension consisted of four statements; participants were asked to rate the extent to which the statement represented their opinion on a 9 point Likert-scale (1 = never; 9 = always). All statements were randomised to avoid ordering effects. Four scores were derived: Horizontal collectivism ($\alpha=0.24$), vertical collectivism ($\alpha=0.49$), horizontal individualism ($\alpha=0.69$), and vertical individualism ($\alpha=0.37$).

Results

4.3.1 Sample characteristics

Table 4.1 shows the demographic characteristics of the participants as well as potentially statistically significant differences between the two groups. Saudi and UK participants did not differ regarding their age, gender, and age of youngest child. However, Saudi participants were significantly more likely than UK participants to be diagnosed with diabetes. Furthermore, Saudi participants had significantly more children.

Table 4. 1. Sample characteristics

| Variables | Saudi Arabia (N=99) | United Kingdom (N=100) | Significance tests |
|-----------|---------------------------|---------------------------|-------------------------------|
| Age | M = 32 years SD = 7.80 | M = 33 years SD = 7.02 | $t(199) = -.98, p = .33$ |
| Gender | 15 Males 84 Females | 12 Males 88 Females | $\chi^2(1) = .42, p = .52$ |
| Diabetes | 45 (45%) | 18 (18%) | $\chi^2(1) = 17.78, p < .000$ |

| | | | |
|-----------------------------|------------------------------|---------------------------------|------------------------------|
| Number of children | $M = 2.00$ $SD = 1.19$ | $M = 1.66$ $SD = .80$ | $t(199) = 5.08, p < .000$ |
| Age of youngest child | $M = 2$ years $SD = 1.10$ | $M = 1.81$ years $SD = 1.00$ | $t(199) = 1.81, p = .071$ |
| Age range of youngest child | | | |
| 0 – 1 year | 39 (39%) | 49 (49%) | $\chi^2(3) = 4.72, p < .194$ |
| 2-4 years | 30 (30%) | 33 (33%) | |
| 4-6 years | 13 (13%) | 6 (6%) | |
| More than 6 years | 17 (17%) | 10 (10%) | |

4.3.2 Individualism-collectivism

Table 4.2 presents the means and standard deviations for the four individualism-collectivism variables by culture. Saudi participants scored significantly higher in Horizontal Individualism and Vertical Individualism than participants from the UK, but there were no significant country differences in Vertical and Horizontal Collectivism.

Table 4. 2: Means and standard deviation of individualism-collectivism dimensions by culture

| Variables | Saudi Arabia (N = 99) | | United Kingdom (N = 100) | | t-test |
|--------------------------|--------------------------|-----------|-----------------------------|-----------|---------------------------|
| | <i>M</i> | <i>SD</i> | <i>M</i> | <i>SD</i> | |
| Horizontal Individualism | 7.27 | 1.53 | 6.37 | 1.19 | $t(199) = 4.62, p = .000$ |

| | | | | | |
|-------------------------|------|------|------|------|--------------------------------|
| Vertical Individualism | 6.24 | 2.79 | 4.11 | 1.43 | $t(199) = 6.77,$ $p = .000$ |
| Horizontal Collectivism | 7.21 | 2.53 | 6.96 | 1.08 | $t(199) = .922,$ $p = .357$ |
| Vertical Collectivism | 7.62 | 1.24 | 7.38 | 1.04 | $t(199) = 1.51,$ $p = .132$ |

4.3.3 Main analysis

4.3.3.1 Informed choice condition. Table 4.3 presents parents' preferences to be involved in medical decision when they have to make a medical choice for their child or themselves in the informed choice condition. Saudi participants preferred the doctor to make medical decisions for their children (options D, E). However, UK participants preferred being more involved in the medical decision (options A, B, and C) for their children. The results were significant, $\chi^2(4) = 16.11, p < .003$. Similar cultural difference were obtained when participants' were asked about SMD preferences when making the treatment for themselves, $\chi^2(4) = 9.91, p < .042$ (Table 4.3).

Table 4.4 displays the positive and negative affect as well as the confidence associated with participants' medical decisions for their child or themselves in the informed choice condition. A series of independent-sample t-tests were conducted. Only one significant effect emerged: Participants in Saudi Arabia reported significantly higher positive affect in the Choice-Child condition than UK participants.

Table 4. 3: Informed choice condition: Frequencies (%) of preferences for involvement in medical decision making by culture

| | Choice-Child | | Choice-Self | |
|---|-----------------------------|-----------------|-----------------------------|-----------------|
| | Saudi Arabia (n = 99) | UK (n = 100) | Saudi Arabia (n = 99) | UK (n = 100) |
| Preference for involvement in medical decision-making | | | | |
| A) I prefer to make the final selection about which treatment I will receive. | 2 (2%) | 2(2%) | 4(4%) | 2(2%) |
| B) I prefer to make the final selection of my treatment after seriously considering my doctor's opinion | 12 (12%) | 29(29%) | 17(17%) | 26(26%) |
| C) I prefer that my doctor and I share responsibility for deciding which treatment is best for me. | 16(16%) | 13 (13%) | 13(13%) | 17(17%) |
| D) I prefer that my doctor make the final decision about which treatment but seriously consider my opinion. | 14(14%) | 5(5%) | 11(11%) | 4(4%) |
| E) I prefer to leave all decisions regarding treatment to my doctor | 7(7%) | 1(1%) | 6(6%) | 1(1%) |

Table 4. 4: Informed choice condition: Means (and standard deviations) for emotional responses and decision confidence ratings by cultures

| Choice-Child | Choice-Self |
|---------------------|--------------------|
|---------------------|--------------------|

| | Saudi (n = 99) | UK (n = 100) | t-test | Saudi (n = 99) | UK (n = 100) | t-test |
|-----------------|-------------------|-----------------|---------------------------|-------------------|-----------------|---------------------------|
| Positive affect | 3.14 (.85) | 2.74 (.89) | $t(199) = 2.30, p = .02$ | 2.80 (1.02) | 2.53 (1.00) | $t(199) = 1.34, p = .18$ |
| Negative affect | 2.30 (.84) | 2.00 (.84) | $t(199) = 1.82, p = .07$ | 2.24 (.99) | 1.97 (.79) | $t(199) = 1.51, p = .132$ |
| Confidence | 5.21 (1.25) | 5.24 (1.11) | $t(199) = -.10, p = .918$ | 5.05 (1.25) | 5.28 (1.21) | $t(199) = -.90, p = .370$ |

4.3.3.2 Non-informed choice. Table 4.5 presents participants' preferences for being involved in the medical decision for their child or themselves by culture. Concerning Choice-Child, participants from the UK tended to prefer to make the choices for their children (Options A, B) whereas participants from Saudi Arabia tended to prefer their doctor to make the choice (Options C, D, E), $\chi^2(4) = 25.80, p < .001$. Similar cultural differences were found when participants made their choice for themselves, $\chi^2(4) = 18.12, p < .001$

Table 4. 5: Non-informed choice condition: Frequencies (%) of preferences for involvement in medical decision making by culture

| | Choice-Child | Choice-Self |
|--|--------------|-------------|
|--|--------------|-------------|

| | Saudi Arabia (n = 99) | UK (n = 100) | Saudi Arabia (n = 99) | UK (n = 100) |
|---|-----------------------------|-----------------|-----------------------------|-----------------|
| A) I prefer to make the final selection about which treatment I will receive. | 0(0%) | 2(2%) | 6(6%) | 3(3%) |
| B) I prefer to make the final selection of my treatment after seriously considering my doctor's opinion | 8(8%) | 27(28%) | 10(10%) | 27(28%) |
| C) I prefer that my doctor and I share responsibility for deciding which treatment is best for me. | 13(13%) | 15 (15%) | 14(14%) | 16(16%) |
| D) I prefer that my doctor make the final decision about which treatment but seriously consider my opinion. | 17(17%) | 4(4%) | 10(10%) | 3(3%) |
| E) I prefer to leave all decisions regarding treatment to my doctor | 10(10%) | 2(2%) | 8(8%) | 1(1%) |

Table 4.6 shows parents' emotional responses and decision confidence ratings in the non-informed choice. A series of independent-samples t-tests were conducted to compare these variables across cultures. Saudi participants indicated higher positive affect than UK participants in the Choice-Self condition. Saudi participants rated their positive and negative affect in both conditions marginally higher than British participants. There were no cultural differences regarding confidence ratings.

Table 4. 6: Non-informed choice condition: Means (and standard deviations) for emotional responses and decision confidence ratings by cultures

| | Choice-Child | | | Choice-Self | | |
|-----------------|----------------|---------------|--------------------------|----------------|----------------|--------------------------|
| | Saudi | UK | t-test | Saudi | UK | t-test |
| | (n = 99) | (n = 100) | | (n = 99) | (n = 100) | |
| Positive affect | 3.38 (.81) | 2.95 (.87) | $t(199) = 2.49, p = .08$ | 3.29 (1.15) | 2.42 (.88) | $t(199) = 4.19, p < .01$ |
| Negative affect | 2.30 (.84) | 1.99 (.88) | $t(199) = 1.75, p = .08$ | 2.34 (1.10) | 1.96 (.94) | $t(199) = 1.84, p = .06$ |
| Confidence | 5.62 (1.48) | 5.70 (.81) | $t(199) = .31, p = .76$ | 5.70 (1.48) | 5.34 (1.31) | $t(199) = 1.29, p = .20$ |

4.3.3.3 Predicting preferences for shared medical decision-making. Generalised Estimating Equations (GEE) with an ordinal logistic link function were conducted to assess the influence of culture (Saudi Arabia, UK), condition (informed, non-informed) and recipient (child, self) on preferences for shared medical decision making. Table 4.7 displays the (significant) main and interaction effects. Across cultures, Choice A (preferring to make the oneself) was picked significantly less often than expected, whereas Choices C and D (preferring the doctor to make the decision) were significantly more often than expected. Participants showed a higher preference for the doctor to make the decision when they were deciding for treatment for the child rather than themselves.

I further conducted a GEE with a identity link function to assess the effects of culture, condition, recipient, and shared decision making preference on decision confidence. This analysis indicated a significant effect of condition, Wald $\chi^2 (1) = 5.74$, $p = .02$. Participants in the informed choice condition were significantly more confident in their decision than participants in the non-informed choice condition (see Table 4.8 for parameter estimates). No other significant main or interaction effects emerged.

A GEE with identity link function assessed the effects of culture, condition, recipient, and shared decision-making preference on reported negative affect. Only the intercept was significant; none of the independent variables predicted negative affect (see parameter estimates in Table 4.9). Concerning positive affect, a GEE with identity link function revealed the significant main effects of country, Wald $\chi^2 (1) = 6.56$, $p = .01$, recipient, Wald $\chi^2 (1) = 42.67$, $p < .001$, and a marginally significant effect of condition, Wald $\chi^2 (1) = 2.96$, $p = .09$. Participants from Saudi Arabia reported higher positive affect. When making the decision for their child, participants reported higher positive affect. Participants in the non-informed condition tended to report higher positive affect (see Table 4.10 for parameter estimates).

Table 4. 7: Generalized estimating equations predicting preferences for shared medical decision making.

| <i>Preferences for shared medical decision-making</i> | | |
|---|------------------------------|------------------------------|
| Predictors | <i>B</i> (standard error) | 95% Wald confidence interval |
| Threshold/Intercept | | |
| Choice = A | -3.09 (.38)** | [-3.83, -2.35] |

| | | |
|-----------------------------|--------------|--------------|
| Choice = B | -.33 (.27) | [-.86, .19] |
| Choice = C | 1.08 (.28)** | [.53, 1.62] |
| Choice = D | 2.41 (.34)** | [1.75, 3.07] |
| Country | | |
| Saudi Arabia | -.67 (.36) | [-1.37, .04] |
| UK | | |
| Recipient | | |
| Child | .61 (.19)** | [.24, .98] |
| Parent/self | | |
| Condition | | |
| Non-informed | .42 (.33) | [-.22, 1.06] |
| Informed | | |
| Country x Condition | | |
| Saudi Arabia x Non-informed | -.44 (.45) | [-1.32, .44] |
| Country x Recipient | | |
| Saudi Arabia x Child | -.49 (.34) | [-1.15, .17] |

Table 4. 8: Generalized estimating equations predicting decision confidence

| Predictors | Preferences for shared medical decision-making | |
|-------------------------------|--|------------------------------|
| | <i>B</i> (standard error) | 95% Wald confidence interval |
| Intercept | 4.99 (.30)** | [4.42, 5.58] |
| Country | | |
| Saudi Arabia (v. UK) | -.18 (.44) | [-1.03, .68] |
| Recipient | | |
| Child (v. Parent/Self) | .02 (.11) | [-.19, .23] |
| Condition | | |
| Non-informed (v. Informed) | .52 (.26)* | [1.02, 4.08] |
| SDM preference | .04 (.08) | [-.11, .19] |
| Country x Condition | | |
| Saudi Arabia x Non-informed | -. (.33) | [-.90, .38] |
| Country x Recipient | | |
| Saudi Arabia x Child | .13 (.15) | [-.15, .42] |
| Country x SDM preference | | |
| Saudi Arabia x SDM preference | .10 (.14) | [-.16, .37] |
| QIC | 633.93 | |
| QICC | 631.12 | |

Table 4. 9: Generalized estimating equations predicting negative affect

| Predictors | Preferences for shared medical decision-making | |
|-------------------------------|--|------------------------------|
| | <i>B</i> (standard error) | 95% Wald confidence interval |
| Intercept | 2.17 (.20)** | [1.78, 2.57] |
| Country | | |
| Saudi Arabia (v. UK) | -.26 (.26) | [-.29, .37] |
| Recipient | | |
| Child (v. Parent/Self) | -.00 (.09) | [-.18, .18] |
| Condition | | |
| Non-informed (v. Informed) | .04 (.17) | [-.29, .37] |
| SDM preference | .03 (.05) | [-.07, .14] |
| Country x Condition | | |
| Saudi Arabia x Non-informed | -.05 (.23) | [-.51, .41] |
| Country x Recipient | | |
| Saudi Arabia x Child | .03 (.12) | [-.18, .25] |
| Country x SDM preference | | |
| Saudi Arabia x SDM preference | -.01 (.07) | [-.16, .14] |
| QIC | 338.73 | |
| QICC | 337.30 | |

Table 4. 10: Generalized estimating equations predicting positive affect

| Predictors | Preferences for shared medical decision-making | |
|-------------------------------|--|------------------------------|
| | <i>B</i> (standard error) | 95% Wald confidence interval |
| Intercept | 3.06 (.19)** | [2.68, 3.44] |
| Country | | |
| Saudi Arabia (v. UK) | -.63 (.31)* | [-1.25, -.02] |
| Recipient | | |
| Child (v. Parent/Self) | 2.47 (.08)** | [.09, .40] |
| Condition | | |
| Non-informed (v. Informed) | .38 (.18)* | [.03, .73] |
| SDM preference | -.07 (.05) | [-.17, .03] |
| Country x Condition | | |
| Saudi Arabia x Non-informed | -.33 (.25) | [-.82, .16] |
| Country x Recipient | | |
| Saudi Arabia x Child | .13 (.09) | [-.06, .31] |
| Country x SDM preference | | |
| Saudi Arabia x SDM preference | .08 (.10) | [-.11, .26] |
| QIC | 368.80 | |
| QICC | 366.27 | |

Discussion

The main aim of this study was to investigate parents' preferences for shared medical decision-making when they had to make a choice regarding the treatment of their child. I contrasted preferences in this decision situation to one where parents' had to make a choice about their own treatment. I was further interested in the role of information and culture in parents' SDM preferences as well as the relationship between SDM preferences and emotions and confidence. While previous research has investigated parents' surrogate decision-making for their children, this was often based on investigating parents' decisions in "tragic" medical situations, often involving life-or-death decisions. However, the current study investigated parents' preferences for SDM concerning different treatment options for children's Type 1 Diabetes. The following sections present this study interpretation and discussion of the data collected, and how the above aims have been addressed.

Overall, parents were more likely to prefer the doctor making the decision concerning the treatment of their child than concerning their own treatment. This finding is in line with previous research on surrogate decision-making generally and surrogate decision making in parents specifically. For example, Garcia-Retamero and Galesic (2012) found that doctors were more conservative (i.e., risk-averse) when making surrogate decisions for their patients than when making decisions for themselves. A number of studies on parents' tragic choices (e.g., Caeymaex et al., 2011; Meert et al., 2000) showed that the communication and input from doctors and other health professionals was very valued and essential to parents' surrogate decision making in these situations. Thus, while parents might prefer more autonomy when it comes to their own treatment and believe that they should have the final say about the treatment of their children in tragic medical situations (e.g., Carnevale et al.,

2007), at least in some cultures, they might still prefer a stronger input from the doctor for decisions that concern their children. This study did not ask parents about the reasons for their differing preferences. Future research might explore these reasons in a more qualitative way. For example, previous studies have shown that the legal context plays a big role in parents' surrogate decision-making (e.g., Orfali, 2004). Other factors that might affect parents' SDM preferences might be how much they view their doctor or health care professional as an authority figure.

In line with Study 1 (Chapter 2) and previous research (Bottley et al., 2009; Carnevale et al., 2007), I found some cultural differences in parents' preferences for shared medical decision making. Saudi parents were more inclined to have the doctor make the treatment decision, whereas British parents tended to want to make the decision themselves. In addition, Saudi participants recorded higher positive affect when they left a doctor to make a decision for themselves. Overall, this research highlights that cultural factors are important considerations for healthcare professionals to take into account when they guide patients in their decision-making. However, overall, culture did not affect the majority of study variables. This might indicate that while there is a potential cultural bias regarding preferences for SDM, the psychological variables potentially associated with these preferences (e.g., emotions, confidence) operate similarly across cultures.

As pointed out by Tunney and Ziegler (2015), emotions and decision confidence play a big role in surrogate decision making. Indeed, previous research has indicated that surrogate decisions are often perceived as an emotional burden and thus associated with negative emotions (e.g., Wendler & Rid, 2011). However, as pointed out above, many of the studies on parental surrogate decision-making has focused on tragic situations. The results from this study indicates that participants

overall reported medium ranges of negative affect and that none of the other study variables predicted negative affect. Concerning positive affect, participants from Saudi Arabia showed more positive affect across conditions. Furthermore, participants reported more positive affect when they made the decision for the child rather than themselves. This is a surprising finding, given previous research on emotions in surrogate decision making. As reported above, when making decisions for their children, participants were more likely to prefer the doctor making the choice rather than themselves. Thus, participants might be happier when the doctor makes the choice rather than themselves. This mirrors the findings from Botti et al. (2009) that while parents might want to have the autonomy to make (tragic) medical decisions for their children, they are more unhappy when they practice this autonomy. Intriguingly, participants also reported more positive affect in the non-informed choice condition, and they were also more confident in their decisions. This seems to run counter to previous findings that when faced with tragic choices parents are more content and confident when doctors communicate information clearly (e.g., Botti et al., 2009; Meeker, 2004). As pointed out repeatedly, many of the previous studies on parental surrogate decisions focused on tragic medical choices, whereas this study looked at treatment choices. It is possible that pointing out the various advantages and disadvantages of the treatment options decreased participants' confidence that the "right" choice was made. Investigating the role of positive and negative emotions and confidence in surrogates' non-tragic medical choices should therefore be continued to be investigated in future research.

Limitations and Recommendations

While participants in this study were all parents, they were not necessarily parents of a child with diabetes. Thus, the scenario presented to participants was

largely hypothetical. Nevertheless, parents routinely make medical decisions on behalf of their children, mostly non-tragic ones, for example, whether or what medication to give to their children when they have a cold (see Hanoch et al.,2010).Thus, future studies should ideally examine clinical samples of children and their parents, but should also continue to investigate parents' preferences for SDM in more everyday medical situations affecting their children. Furthermore, future research might want to directly focus children's and adolescents' desire to be actively involved in their health decision making. Ruggeri et al. (2014) found that Italian adolescents preferred to be involved in a tragic medical choice affecting them, whereas children showed less autonomy in the medical choices. It is an open question whether similar effects could be found for Saudi children and adolescents or whether we would see the preferences for having the doctor make the decision in Saudi patients across age groups.

This study plays a critical role in adding to our understanding of parental preferences of being involved in shared medical decision making in different cultures. It puts emphasis on the need to continue with offering shared medical decision making opportunities and with supporting medical practitioners with making sure that patients are well informed about the different medical procedure to be performed on them. Future research can also be derived from the research gaps that can be identified from this research. Such research could focus on the following areas, for example On the application of counselling on the issue of surrogate decision making to help parents and other surrogates in making informed choices. Furthermore, other methods can be utilized to improve confidence and emotional stability in making decisions in healthcare. Good communication may provide the information surrogates need to make decisions and the support to face the emotional impact of their decisions.

Conclusion

Parents continue to play a fundamental role in making decisions for their child as themselves and provide information they need. Children cannot be left to make decisions on matters of their health since their understanding is limited. The sample of this study is limited by the ethical requirement of being as self-selected voluntary sample also the sample has imaging medical context. However, the limitations cannot be avoided. Cultural differences remain a key factor that impacts decision making for many people across the world. Some present limitations to their own decisions while others promote the capacity to make decisions regarding their health.

Chapter 5: General Discussion

As stated in the opening chapter of this thesis, the main objective of this thesis was to investigate cross-cultural differences in preferences for SDM by studying adults from the UK and Saudi Arabia and examining preferences for SDM in normal and clinical populations. To establish this objective, this chapter will begin with a discussion of the main findings and conclude with recommendations for practice as well as suggestions for further research.

5.1 The Main Findings

The first aim of this thesis was to investigate how people's medical decision-making preferences were influenced by their cultural orientations as well as by different types of motivations that likely differ between cultures. Also, the thesis included an investigation on how basic psychological needs for competence, autonomy and relatedness are related to people's medical decision-making preferences. The data from the first study showed that there were indeed differences in SDM between Saudi and UK participants. Saudi participants tended to prefer stronger involvement from their physician, whereas UK participants preferred to make choices themselves. The results also support previous studies showing individual differences in patient preferences on who will be involved in medical decisions related to his or her health issues (Adams, 2007). Interestingly, in the only study on medical decision-making conducted in Saudi Arabia, Moberriek (2008) showed that Saudi patients also showed a strong preference to engage their families in the decision-making process. Potentially, then, it is not that Saudi participants prefer a 'traditional' model of medical decision-making in which the health-care professional makes decisions, but they like to integrate as many of their important (in group) members as

possible. Other demographics were considered in my studies, like gender and age. Unlike previous research that has shown that females and younger patients are more likely to prefer to be involved in medical choices that affect them (e.g., Arora & Machorny, 2000; Say et al., 2006), age and gender did not affect preferences for medical decision-making in the present study.

The results also showed participants from the UK scored higher in Horizontal Individualism and Horizontal Collectivism, and participants from Saudi Arabia scored higher in Vertical Individualism. However, there was no significant difference by country with regard to Vertical Collectivism. Culture significantly influences decision-making because family and organisational life is heavily influenced by either collectivism or individualism. Hence, the cultural differences among the samples of the previous studies and the present study offers a viable explanation on the differences in the results. Most studies on SMD preferences were conducted in Western contexts where individualism is highly valued while there is a paucity of research conducted in the Arabic context where collectivism is more highly valued (Ali et al., 1997; Moberriek, 2008). Since Arab communities are similar in terms of traditions and customs, they are classified as collectivistic societies according to Hofstede (1980). It can be argued that, based on Hofstede's theory, Arab communities and participants would be more inclined towards collective decision-making processes and placing greater importance on the opinions of their family and relatives.

Nevertheless, participants from the UK showed significantly higher Autonomous Regulation, but there was no significant cultural difference in Controlled Regulation. Need for Autonomy and Competence did not differ between the two cultural samples, but participants from the UK showed a higher need for Relatedness than participants from Saudi Arabia. Previous research points to the significance of

psychological and motivational variables in influencing patients' preferences in involvement regarding medical decisions that affect them (Hoffman et al., 2014; Van den Broeck, et al, 2013; Ryan & Deci, 2000). Overall, these findings imply that the model of autonomy in the Saudi community is still weak, as there are some collectivist communities that do not support the desire of autonomy of patients in making decisions.

The implication of this study's findings is that it is clear that many Western countries lean towards models of independency for the patient to achieve the patient's desires and better outcomes, whereas the model of autonomy in the Saudi community is still weak, as there are some collectivist communities that do not support the desire of autonomy of patients in making decisions. According to the data collected, there is a difference in the priority and importance of independent decision-making, especially concerning issues such as patients' rights and community interests. While in Saudi Arabia there is some recognition of the desire in patients for independence, most Saudi participants still attach an important role to the family in the field of health care. There is a vital need to conduct more studies on the role of family in shared medical decision-making and clinical practice to further support the results from this study. Health care providers need to learn more effective communication skills and develop methods for the decision-making process. Moreover, future research should concentrate on the effectiveness of these interventions. Additionally, future efforts may need to focus on the education of health-care providers.

Study 2 aimed to investigate whether and how patients with type 1 diabetes would be interested in being involved in medical decisions and the effect it had on their preferences. Another aim was to identify the patients' understanding of the original diagnosis and to discover, if patients were offered options for treatment by the doctor,

to discover if patients were advised of the advantages and possible disadvantages of each treatment options. This was imperative to discovering if patients preferred to let the doctor make decisions about their treatment and if patients would like to be involved in choices about treatment. The analysis of qualitative patient interviews revealed the following four major themes: (1) getting information from physicians; (2) understanding diagnosis; (3) treatment options; and (4) involvement in decision.

Overall, some of the main issues emerging from the data revolved around communication. For example, medical terminology and the inability of some physicians to explain diagnoses and treatment in a language that their patients can understand emerged repeatedly. In general, physicians were reported to often have poor communication skills, which makes patients feel uncomfortable. These results are consistent with other studies (e.g., Mobeireek et al., 2008), which reported poor communication between physicians and patients in Saudi Arabia. It is also consistent with other studies (Davey et al., 2013) that reported that some of general practitioners are not perceived to take young adults' (18–25) health-care concerns seriously or explain things clearly. Poor communication can affect patients' care, trust and satisfaction and could potentially lead to inaccurate diagnosis and an inappropriate treatment plan. While a number of patients sought second opinions from other doctors, they also reported that the diagnosis and medication was consistent across physicians, which was in line with what other studies have found (Saba et al., 2006; Stevenson et al., 2000; Kon, 2010; Joosten et al., 2008). Receiving the same information from different physicians leads to positive health outcomes and trust, and patients considered their physicians as being good at communication skills. Thus, these findings highlight the importance of communication style for patients, their trust in the physicians and, ultimately, their trust in their diagnosis and suggested treatment.

Understanding their diagnosis is probably the most important aspect of the whole process for the patients. In line with other studies (Al-Dahan et al., 2013; Al-Nozha et al., 2004; Bani, 2015; Mohiedein et al., 2011), I found that a sizeable proportion of participants did not have good knowledge of their diagnosis or only acquired such knowledge after seeing a specialist health educator. Another finding from this study is the conflicting information provided by physicians (and health educators), which can play a part in the increased lack of understanding of diabetes. Moreover, the lack of understanding of the diagnosis, found in our study, was based on the different information sought by patients and the communication between patients and physicians. Another finding was the lack of knowledge of the risk factors and symptoms of diabetes, which is consistent with Mohiedein et al. (2011) where only one patient reported knowledge of such risk factors. Overall, the current study indicates that the Saudi health-care system needs some improvement in how the diagnosis of diabetes and associated risk factors are communicated to a range of different patients by physicians.

Knowledge about side effects of diabetes medication is also important, however, results from this study show a lack of knowledge about side effects and a difficulty in understanding information related to side effects for patients. This difficulty in understanding side effects may affect patients' preferences in treatment options (Alasiri & Bafaraj, 2016). Despite this lack of knowledge and understanding, it is apparent that patients in this study are managing their illness, which is consistent with findings from other studies (Thorn & Paterson, 2000; Abu-sabah & Shehri, 2014). These studies reported the importance of patients developing their expertise in making decisions about diabetes self-management. This offers possible explanations for why patients' preferences be involved may increase with managing their disease. The

length of time a patient has diabetes might have an effect on their level of involvement in decision-making.

This study attempted to explore the factors that might encourage patient involvement in decision-making. Findings suggest that the physicians did not provide patients with treatment options, which may affect patient's preferences to interact with health-care providers. This is consistent with a study by Moberiak et al. (2008) where they reported poor communication, which might cause conflict and, therefore, weaken the physician–patient relationship (Moberiak et al., 2008). However, this is not consistent with other studies suggesting a working alliance between physicians and patients to select the best treatment delivering the best outcome for patients was due to this effective interaction (Elwyn et al., 2012; Lee & Emanuel 2013).

The results suggest that patient's satisfaction will enormously help increase better health outcomes. Thus, comprehensive awareness is needed to involve patients in decision-making. In considering the high prevalence of diabetes mellitus in Saudi Arabia, this study showed that there was a significant number of the Saudi population who lack awareness and knowledge about diabetes. This finding supports the need for shared decision-making programmes focussing on health-care providers, improving community skills and encouraging a healthy lifestyle. It also showed that health education should be done through the decision-making approach where mass media and printed media are important sources of public information.

The aim of Study 3 was to investigate parents' preferences regarding their involvement in medical decisions when making decisions for themselves or their child, to record parents' emotional reaction to shared medical decision-making and to identify cultural differences on these topics in parents from Saudi Arabia and the UK.

In summary, the findings showed UK participants were significantly more likely than Saudi participants to prefer being more actively involved in the decision process. Participants were more likely to take an active role in the decision-making process when making the decision for themselves rather than their child. Decision confidence was higher in the non-informed choice condition and were positive emotional reactions. The findings above are consistent with findings from a previous study by Polman and Vohs (2016), which revealed that when people are making choices for themselves, they exercise more self-control rather than when making them for others. According to Tafarodi et al. (2002), individuals' confidence clearly differs in their approach to such issues. Faith is said to determine the confidence levels people attach to decisions and their reactions are based on the confidence level that makes them go through the consequences of their decisions.

According to Botti et al. (2009), when people make medically superior decisions without knowing, they are more emotionally affected, especially if the decisions end up being catastrophic. However, the emotional reaction is quite different for the other group of people whose results may turn out to be catastrophic but did not make the decision themselves. Our data further suggests that the emotional reaction and decision confidence was higher in the noninformed choice condition. In addition, Saudi participants recorded a higher positive affect when they left a physician to make a decision for themselves. The above findings contradicted with previous studies, such as Majesko and White (2012), which revealed that surrogate decisions were attributed to a low level of confidence, as it usually related to the paucity of information or experience. However, in the current study, informed-choice is assisted with a higher level of confidence and positive emotional responses towards their decision. This also agreed with the study by Wendler and Rid (2011) which revealed that the desire for a

surrogate decision is undertaken as a decision with lower negative emotions and confidence. In addition, not every surrogate decision was negative; some of what the surrogate did supported the patient. However, the implications attached to consenting to certain decisions affect the emotions resulting from that decision. The results of our study also revealed that Saudi participants were significantly higher in Vertical and Horizontal Individualism than participants from the UK, but there were no differences between these two countries in Vertical and Horizontal Collectivism. This finding is surprisingly positive and is consistent with our first study, and there appears to be a need for cultural groups to continue replacing the traditional. These findings highlight the psychological and practical consequences if parents fulfil these parts of their role.

The implications of these findings is that, while European health-care professionals are increasingly encouraged to involve patients in decisions about their care, preferences for such shared medical decision-making vary by culture and the recipient of the decision. This should be taken into account when health-care professionals involve patients in medical decisions. This study could be replicated in order to identify differences in other cultures.

5.2 Limitations and Future Directions

There are a number of important study limitations that are important to consider in these studies. Perhaps the most important limitation was that, at least for Studies 1 and 3, general population and student data was collected that was not necessarily representative and, therefore, was lacking in generalisability. In addition, the sample size was not large enough to allow for generalisability. Sampling limitations and an equal ratio of participation between the cultural groups was not achieved.

Despite these limitations, however, the studies are unique in that with a few exceptions, culture has been a relatively neglected topic in the literature focusing on the development of conceptual models of treatment decision-making, empirical studies of treatment decision-making and the development and use of applied tools, such as decision aids to facilitate patient participation in treatment decision-making. These studies contribute to the scarcity of such studies. However, acknowledging the existing limitations, more research is, thus, needed in these areas. The focus of this thesis was on type 1 diabetes. The patients were 18- to 72-years-old and did not include children. In the qualitative study the majority of respondents had been diagnosed for more than two years, and were of Saudi nationality only; we did not investigate other cultures. Also, participants were only selected themselves from one hospital. Because of time constraints, this study was conducted by only one researcher as part of PhD programme. In this study, we did not investigate if preferences for involvement was associated with gender, ethnic group, health status or quality of life. Further studies need to investigate additional factors, such as education, age and clinical conditions. Parents continue playing a fundamental role in making decisions for their child and provide the information they need. Children cannot be left to make decisions on matters of their health since their understanding is limited. The sample of this study is limited by the ethical requirement of being a self-selected voluntary sample; also, the sample has imaging medical context. However, these limitations could not be avoided. Cultural differences remain a key factor that impact decision-making for many people across the world. Some present limitations to their own decisions while others promote the capacity to make decisions regarding their health.

5.3 Future Research

The research presented in this thesis will offer a basis to better understand patient preferences in shared decision-making from a cross-cultural perspective. With its focus on Middle Eastern participants, my research contributes to the improving health-care and health outcomes for this very under-studied community.

My research mainly focused on comparing residents of the UK and Saudi Arabia. However, in our mobile a multi-cultural societies, different ethnic communities co-exist and interact. An important avenue for future research would be to investigate preferences for shared medical decision making and its relationship to health outcomes in different ethnic communities in western and Middle-Eastern societies. Cross-cultural research (e.g., Berry, 2003) has shown how acculturation processes affect changes in people's behaviours, preferences, and values and lead to successful and unsuccessful adaptation. Thus, exploring the health-care preferences of different ethnic groups in societies can help physicians in tailoring communication and health care to different patients and lead to better health outcomes.

This research mainly investigated preferences for shared medical decision making from the perspective of the patient. However, my studies have shown that others play an important role in this context. Thus future research should investigate these roles in more detail. Concerning the role of health-care providers, the focus should be on the level of rapport between physician and patients and on the development of a better understanding of the factors impacting on decision-making for both patients and practitioners. There should also be emphasis on the use of counselling on the surrogate decision-making aspect to improve the process of making informed choices. In addition, future research should adopt methods to enhance

confidence and emotional stability in making decisions in healthcare settings. Similarly, further research should be particularly focused on investigating involvement of health-care practitioners and looking at health-care providers' perspectives when it comes to allowing their patients to take part in decision-making. Another area of research might look particularly at the role of family members in the shared medical decision making process, as my research has revealed that the family is an important resource especially in Saudi Arabia. This might lead towards a more culture-sensitive conceptualisation of preferences for SMDM, as in the current study I mainly applied a western model of shared decision making to the Middle Eastern context.

5.4 Conclusion

This study investigated cross-cultural differences in preferences for SDM by studying adults from the UK and Saudi Arabia. It also marks the first attempt to examine preferences in shared medical decision-making of Saudi Arabia. Further, it provides a multi-method in-depth examination employing quantitative and qualitative measures to SDM in normal and clinical populations. The findings perhaps most critically highlight the importance of culture in determining and understanding attitudes towards preferences for shared medical decision. As such, these findings and their implications should be considered by health care providers to encourage patients' SDM in the UK and Saudi Arabia.

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Appendices

Appendices (1)

Decision Making in Medical Situations

Thank you for agreeing to take part in this study. Your views about how decisions in the medical area can and should be made are important to us. Your answers will be kept anonymous and will not affect your own medical treatment in anyway.

Some information about yourself:

1) **Date of Birth:** ____ ____ / ____ ____ / ____ ____ ____
D D M M Y Y Y Y

2) **Sex: (please tick)** ____ **Male** ____ **Female**

3) **Which country to you live in:** _____
Since when? ____ ____ ____ (year)

4) **Do you have health insurance (please tick):** ____ **yes** ____ **no**

5) **Do you or one of your family members have Diabetes?**
____ **Yes.** Since when? ____ ____ ____ (year)
____ **No**

6) **When was the last time you saw a doctor/ other health professional?**
____ ____ / ____ ____ / ____ ____ ____
D D M M Y Y Y Y

If someone came with you to your last doctor's appointment what is your relationship to them?
(e. g. partner, daughter, friend)

Section 1 – Preferences about your health care

When thinking about the interactions with their doctor, patients have different opinions about who should make treatment decisions.

Please select one of the following five statements that best reflect your preference for how you would like to be involved in decisions concerning your health care and medical treatment decisions. Please tick only one option.

- (a) I prefer to make the final selection about which treatment I will receive.
- (b) I prefer to make the final selection of my treatment after seriously considering my doctor's opinion.
- (c) I prefer that my doctor and I share responsibility for deciding which treatment is best for me.
- (d) I prefer that my doctor make the final decision about which treatment but seriously consider my opinion.
- (e) I prefer to leave all decisions regarding treatment to my doctor.

In the following, we would like you to imagine that you are a person suffering from Type 1 diabetes.

Type 1 diabetes develops when the insulin-producing cells in the body have been destroyed and the body is unable to produce any insulin. Insulin is a hormone that helps to use glucose in your blood to give you energy. In Type 1 diabetes the body is unable to produce insulin, so cannot process the glucose in your blood. Therefore, glucose builds up in your blood. About 10% of all adults with diabetes suffer from Type 1 diabetes.

Type 1 diabetes is commonly treated by injecting insulin. Some people with Type 1 diabetes will be offered the choice to either inject insulin multiple times a day with a needle or use an insulin pump. Both methods have benefits and disadvantages:

| Benefits of insulin pumps vs. Drawbacks of injections | |
|--|---|
| Cannulas are put into the skin every few days | Injections are needed several times a day. |
| Press button to deliver a dose at each meal or snack | Need to inject for each meal and some snacks |
| Basal insulin can be turned off or reduced during or after sports | Any changes to basal insulin need to be done several hours in advance. |
| Basal insulin is constantly delivered | Need to remember to reject background insulin at specific times of the day. |
| Pumps can be programmed at certain times a day, even when asleep, if required. | Any increase in insulin must be injected manually. |

| Benefits of injections vs. Drawbacks of insulin pumps | |
|---|---|
| Need only appear when an injection is needed | Can only be disconnected for short periods of time. |
| Can suffer from air bubbles, but this is generally less of a problem than with insulin pumps. | Can occasionally have issues, such as air bubbles, which can adversely affect blood glucose levels. |
| No tubing | Tubing can sometimes get caught in objects such as door handles, if tubing is not kept covered. |
| Less complicated to learn to use and maintain. | Initially, it takes longer to learn how to adjust to using and care for a pump. |

Please imagine that you are a person suffering from Type 1 diabetes. You have to decide whether to deliver insulin via injections or an insulin pump. Please select one of the following five statements that best reflects your preference for being involved into the decision of whether to use insulin injections or an insulin pump. Please tick only one option.

___ (a) I prefer to make the final selection about which treatment I will receive.

___ (b) I prefer to make the final selection of my treatment after seriously considering my doctor's opinion.

___ (c) I prefer that my doctor and I share responsibility for deciding which treatment is best for me.

___ (d) I prefer that my doctor make the final decision about which treatment but seriously consider my opinion.

___ (e) I prefer to leave all decisions regarding treatment to my doctor.

Information about Type 1 diabetes and its treatment has been taken from: diabetes.co.uk and diabetes.org.uk

SECTION 2 – Questionnaire 1

Please read through the following list of statements. Please circle the response that best represents your opinion.

| | Never | | | | Some- times | | | | Always |
|---|--------------|---|---|---|------------------------|---|---|---|---------------|
| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| 1. I'd rather depend on myself than others. | | | | | | | | | |
| 2. It is my duty to take care of my family, even when I have to sacrifice what I want | | | | | | | | | |
| 3. To me, pleasure is spending time with others. | | | | | | | | | |
| 4. It is important to me that I respect the decisions made by my group. | | | | | | | | | |
| 5. I feel good when I cooperate with others. | | | | | | | | | |
| 6. I rely on myself most of the time; I rarely rely on others | | | | | | | | | |
| 7. The well-being of my co-workers is important to me | | | | | | | | | |
| 8. My personal identity, independent of others, is very important to me | | | | | | | | | |
| 9. Competition is the law of nature. | | | | | | | | | |

| | | | | | | | | | |
|---|--|--|--|--|--|--|--|--|--|
| 10. If a co-workers gets a prize, I would feel proud. | | | | | | | | | |
| 11. Winning is everything. | | | | | | | | | |
| 12. Family members should stick together, no matter what sacrifice are required | | | | | | | | | |
| 13. Parents and children must stay together as much as possible. | | | | | | | | | |
| 14. When another person does better than I do, I get tense and aroused. | | | | | | | | | |
| 15. I often do “my own thing” | | | | | | | | | |
| 16. It is important that I do my job better than others. | | | | | | | | | |

Questionnaire 2

There are a variety of reasons why diabetes patients take their medications, check their glucose, follow their diet, or exercise regularly. Please imagine that you are a diabetes patient. Consider the following behaviors and indicate how true each of these reasons would be for you, if you were a diabetes patient.

I'd take my medications for diabetes and/or check my glucose because:

| | Not at all true | | | Some-what true | | | Very true |
|--|------------------------|---|---|-----------------------|---|---|------------------|
| | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 1. Other people would be mad at me if I didn't. | | | | | | | |
| 2. I'd find it a personal challenge to do so. | | | | | | | |
| 3. I would personally believe that controlling my diabetes will improve my health. | | | | | | | |
| 4. I would feel guilty if I didn't do what my doctor said. | | | | | | | |
| 5. I would want my doctor to think I'm a good patient. | | | | | | | |
| 6. I would feel bad about myself if I didn't. | | | | | | | |
| 7. It would be exciting to try to keep my glucose in a healthy range. | | | | | | | |
| 8. I would not want other people to be disappointed in me. | | | | | | | |

The reason I'd follow my diet and exercise regularly is that

| | Not at all true | | | Some-what true | | | Very true |
|--|------------------------|---|---|-----------------------|---|---|------------------|
| | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 1. Other people would be upset with me if I didn't. | | | | | | | |
| 2. I'd personally believe that that these are important in remaining healthy. | | | | | | | |
| 3. I would be ashamed of myself if I didn't. | | | | | | | |
| 4. It would be easier to do what I'm told than to think about it. | | | | | | | |
| 5. I would have carefully thought about my diet and exercising and believe it's the right thing to do. | | | | | | | |
| 6. I wanted others to see that I can follow my diet and stay fit. | | | | | | | |
| 7. I would just do it because my doctor said to. | | | | | | | |
| 8. I'd feel personally that watching my diet and exercising are the best thing for me. | | | | | | | |
| 9. I'd feel guilty if I didn't watch my diet and exercise. | | | | | | | |
| 10. Exercising regularly and | | | | | | | |

| | | | | | | | |
|---|--|--|--|--|--|--|--|
| following my diet would be choices I really wanted to make. | | | | | | | |
| 11. It would be a challenge to learn how to live with diabetes. | | | | | | | |

Questionnaire 3

Please read each of the following items carefully, thinking about how it relates to your life, and then indicate how true it is for you.

| | Not at all true | | | Some-what true | | | Very true |
|--|------------------------|---|---|-----------------------|---|---|------------------|
| | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 1. I feel like I am free to decide for myself how to live my life. | | | | | | | |
| 2. I really like the people I interact with. | | | | | | | |
| 3. Often, I do not feel very competent. | | | | | | | |
| 4. I feel pressured in my life. | | | | | | | |
| 5. People I know tell me I am good at what I do. | | | | | | | |
| 6. I get along with people I come into contact with. | | | | | | | |
| 7. I pretty much keep to myself and don't have a lot of social contacts. | | | | | | | |
| 8. I generally feel free to express my idea and opinions. | | | | | | | |
| 9. I consider the people I regularly interact with to be my friends. | | | | | | | |
| 10. I have been able to learn interesting new skills recently. | | | | | | | |

| | | | | | | | |
|--|--|--|--|--|--|--|--|
| 11. In my daily life, I frequently have to do what I am told. | | | | | | | |
| 12. People in my life care about me. | | | | | | | |
| 13. Most days I feel a sense of accomplishment from what I do. | | | | | | | |
| 14. People I interact with on a daily basis tend to take my feelings into consideration. | | | | | | | |
| 15. In my life I do not get much of a chance to show how capable I am. | | | | | | | |
| 16. There are not many people that I am close to. | | | | | | | |
| 17. I feel like I can pretty much be myself in my daily situations. | | | | | | | |
| 18. The people I interact with regularly do not seem to like me much. | | | | | | | |
| 19. I often do not feel very capable. | | | | | | | |
| 20. There is not much opportunity for me to decide for myself how to do things in my daily life. | | | | | | | |
| 21. People are generally pretty friendly towards me. | | | | | | | |

Preferences for shared medical decision making

Participants must be 18 years or older. They must be either residents of the United Kingdom or Saudi Arabia.

Principal Investigator: Fatimah Alharbi, fatimah.alharbi@plymouth.ac.uk

Supervisor: Dr. Michaela Gummerum, michaela.gummerum@plymouth.ac.uk

Purpose of the Study: In this study we are interested in people's preferences for medical decision-making. This means that we want to find out what kind of interactions you prefer with your doctor or other health professional. We are also interested in whether cultural orientations and how much people value autonomy affect preferences for medical decision-making.

Description of the Study: To take part in this study you must be 18 years or older and you must be a resident of the United Kingdom or Saudi Arabia. We expect 200 participants to take part in the study. You will be asked to read a consent form and give your consent (3 minutes), answer some demographic questions (3 mins), and complete series of questions regarding your general medical decision-making preferences, your medical decision-making preferences if you were a patient with Type 1 Diabetes, and a number of questions about your endorsement of different activities related to autonomy, cultural values, and health care (15 minutes). At the end of the study, you can review more information about the purpose of the study (2 minutes).

This research conforms to each clause of Plymouth University's Principles for Research Involving Human Participants and has been approved by the Plymouth University's Health and Human Sciences Ethics Committee.

Risks and Discomforts: There are no risks in taking part in this study. You will be giving us your time, which some may see as a disadvantage.

Benefits of the Study: There may be no direct benefits to participants; however, the proposed research may benefit participants and patients in the long term. Research, mainly in western societies, has indicated that patients' preferences for medical decision-making procedures are important for their health outcomes. We would like to investigate this in different cultural settings.

Confidentiality: All information collected during this study will be anonymous because no identifying information (e.g., participants' name) will be collected. The data from this study will be stored on a password protected computer to which only the investigators will have access. Complete data from each participant will be kept for 10 years after which it will be destroyed.

Voluntary Nature of Participation: Participation in this study is voluntary. If you decide to participate, you are free to withdraw your consent and to stop your participation at any time without penalty. If you wish to stop your participation or withdraw from the study, simply exit the survey at any time (you will also have the option of re-consenting at the end of the study). You have the option to not answer any question by leaving it blank. Withdrawing at any point from the survey will result in an automatic removal and deletion of your data. Data from participants who indicate at the end of the survey that they do not consent to have their responses included will also be deleted and not included in analyses.

Questions: If you have any questions about the research please contact the researchers. Their information is available at the top of this form.

If you having any questions regarding your rights as a research participant in this study, you may contact the Plymouth University Faculty of Health and Human Sciences Human Ethics Committee; Ms Sarah Jones, sarah.c.jones@plymouth.ac.uk

Agreement: Clicking the “I consent to participate in this research” indicates that you have read the information in this agreement and have had a chance to ask any questions you have about the study (by emailing the researcher). Your consent also indicates that you agree to be in the study and have been told that you can change your mind and withdraw your consent to participate at any time. If you wish to keep a copy of this agreement, please save or print this page.

By clicking “I consent” you are not giving up any of your legal rights.

Preferences for shared medical decision making

Debriefing

Thank you very much for participating in this study.

Now we would like to inform you in more detail about the study.

In this study we are interested in how people's preferences for medical decision making. That is, we are interested in what kind of interactions with their doctor or health professional people prefer, and whether these preferences are influenced by cultural orientations and preferences for autonomy. To that end you were presented with a question about your general preferences for medical decision-making as well as a specific scenario where you had to imagine to make a decision as a patient with Type 1 Diabetes. We also gave you three questionnaires measuring your cultural orientation and preference for autonomy.

Previous research indicates that patients' preferences for medical decision-making influences can influence their health outcomes. Research has also shown that demographic variables, such as age and gender, can affect preferences for medical decision-making. Most of this research has been conducted in western societies. With this research we would like to investigate whether there is a cultural dimension to people's medical preferences.

If you have any questions concerning this research please contact the principle investigator, [Fatimah Alharbi, fatimah.alharbi@plymouth.ac.uk](mailto:fatimah.alharbi@plymouth.ac.uk). If you are dissatisfied with the way the research is conducted, please contact the principal investigator in the first instance. If you feel the problem has not been resolved please contact the secretary to the Faculty of Health and Human Sciences Ethics Committee, Ms Sarah Jones, sarah.c.jones@plymouth.ac.uk.

Thank you again for your participation and have a nice day.

Appendices (2)

interview schedule for third study:

Thank you for agreeing to take part in this study. Your views about how decisions in the medical area can and should be made are important to us. Your answers will be kept anonymous and will not affect your own medical treatment in anyway. We would like to tap recorded the interview will be anonymous.

Can you read this consent form before you agree to complete interview?

1) demographics about yourself

1) **Date of Birth:** ___ ___ / ___ ___ / ___ ___ ___ ___

D D M M Y Y Y Y

2) **Sex:** (please tick **Male** **Female**)

3) **Which country to you live in:** _____

Since when? ___ ___ ___ ___ (year)

5) **How long since diagnosis with type 1 diabetes?**

6) **Have you seen more than one physician in the las year, did you get more information from some physician than others. What information did you get? Was anything different between physician?**

There are some opened questions help to start with patients, there are three main questions and we prepared with follow- up questions if initially get short responses or don't understand. It might take time to elicit from patients.

Questions for interview:

(1) How do you talk to your doctor about medicine? Possible follow-ups:

- what happened when the doctor first time met you?
- Do you remember first meeting with a doctor?
- Do you remember when with you first diagnosis?
- what was your diagnosis?
- Did your doctor explain your illness to you?

(2) What things can you think of that might help people be a part of making decisions about their medicine?

Possible prompts:

- what treatment did your doctor offer to you?
- did your doctor give you a choice of treatment?
- did your doctor give your information how to manage illness?
- did your doctor tell you about advantage and disadvantage of treatment?
- did you trust your doctor to advise on the best treatment?

(3) What things keep people from being a part of making decisions about medicine with their doctor?

Possible follow-ups:

- would you have like it more information about the treatment available?
- would you have like it to discuss the options with your doctors before a decisions were made?
- would you like to take responsibility for chosen treatment options?
- is there anyone else that you feel could be involved in deciding a treatment options?

after that we will give you a structured questionnaire:

when thinking about starting a new medicine, if the doctor or health professional has told you about its benefits and risk, who should finally decide about your treatment?

- you alone

- mostly you
- doctor or other healthcare professional and you equally
- doctor or other health care professional alone

when thinking about changing the amount of a medicine that you are already taking, if the doctor or other health care professional has told you about the risk and benefits of doing so, who should finally decide about your treatment?

- you alone
- mostly you
- doctor or other healthcare professional and you equally
- doctor or other health care professional alone

when thinking about stopping a medication, assuming that the doctor or health care professional has told you about the risk and benefits of doing so, who should finally decide about your treatment?

- you alone
- mostly you
- doctor or other healthcare professional and you equally
- doctor or other health care professional alone

UNIVERSITY OF PLYMOUTH

FACULTY OF HEALTH AND HUMAN SCIENCES

Human Ethics Committee Consent Form

CONSENT TO PARTICIPATE IN RESEARCH PROJECT

Principal Investigator: Fatimah Alharbi, fatimah.alharbi@plymouth.ac.uk

Supervisor: Dr. Michaela Gummerum, michaela.gummerum@plymouth.ac.uk

Parents' preferences for shared medical decision making

Purpose of the Study: In this study we would like to investigate whether patients are interested to be involved in medical decision that affect them (e.g., choosing a treatment option for Diabetes Type 1). We also want to identify whether patients understanding their diagnosis and whether they were offered options for treatment by the doctor. We are also interested in whether patients prefer to let the doctor make the decision about the treatment.

Description of the Study: To take part in this study you must be 18 years or older and you must be a resident of Saudi Arabia. You must have been diagnosed with type 1 diabetes for at least 1 year. We expect 30 participants to take part in the study. You will be asked to read a consent form and give your consent (3 minutes), answer some demographic questions (3 minutes), and take part in an interview (30 minutes). The interview will focus on your preferences for being involved in medical decision-making. Finally, we will ask you three questions about your preferences of treatment and medicine (5 minutes). At the end of the study, you can review more information about the purpose of the study (2 minutes).

This research conforms to each clause of Plymouth University's Principles for Research Involving Human Participants and has been approved by the Plymouth University's Health and Human Sciences Ethics Committee.

Please note that this study is independent of and does not in any way affect your care at King Fahad hospital.

Risks and Discomforts: There are no risks in taking part in this study.

Benefits of the Study: There may be no direct benefits to participants; however, the proposed research may benefit participants and patients in the long term. Research, mainly in western societies, has

indicated that patients' preferences for medical decision-making procedures are important for their health outcomes. We would like to investigate this in different cultural settings.

Confidentiality: All information collected during this study will be anonymous because no identifying information (e.g., participants' name) will be collected. Any information about you will have a number on it instead of your name. We will not be sharing information about you to anyone outside of the research team. We will tape-record the interview with you. This tape recordings will be saved in a secured password-protected computer to which only the research team has access. Complete data from each participant will be kept for 10 years after which it will be destroyed.

Voluntary Nature of Participation: Participation in this study is entirely voluntary. It is your choice whether to participate or not. If you decide to participate, you are free to withdraw your consent and to stop your participation at any time without penalty. Withdrawing at any point from the study will result in an automatic removal and deletion of your data. Data from participants who indicate at the end of the study that they do not consent to have their responses included will also be deleted and not included in analyses.

Questions: If you have any questions about the research please contact the researchers. Their information is available at the top of this form.

If you having any questions regarding your rights as a research participant in this study, you may contact the Plymouth University Faculty of Health and Human Sciences Human Ethics Committee; Ms Sarah Jones, sarah.c.jones@plymouth.ac.uk

patients' preferences for shared medical decision making

Debriefing

Thank you very much for participating in this study.

Now we would like to inform you in more detail about the study.

In this study we would like to investigate how far patients interested to be involved in medical decision that effect on their preferences. Also to identify the patients understanding of the original diagnosis, additionally, to discover if patients offered options for treatment by the doctor, to discover if patients were advised of the advantages and possible disadvantages of each treatment options. To discover if patients preferred to let the doctor make the decision about the treatment for them. Finally, to discover if patients would like to be involved in choices about treatment.

Previous research indicates that patients' preferences for medical decision-making influences their health outcomes. Research has also shown that demographic variables, such as age and gender, can affect preferences for medical decision-making. Most of this research has been conducted in western societies. With this research we would like to investigate whether there are patient's preferences. This is why we conduct this research Saudi Arabia. We predict that Saudi participant`s will be more likely to prefer their doctor to make medical decisions for themselves. In this study we would like to find out the reasons for this.

If you have any questions concerning this research please contact the principle investigator, Fatimah Alharbi, fatimah.alharbi@plymouth.ac.uk. If you are dissatisfied with the way the research is conducted, please contact the principal investigator in the first instance. If you feel the problem has not been resolved please contact the secretary to the Faculty of Health and Human Sciences Ethics Committee, Ms Sarah Jones, sarah.c.jones@plymouth.ac.uk.

Thank you again for your participation and have a nice day.

Appendices (3)

Decision Making in Medical Situations

Thank you for agreeing to take part in this study. Your views about how decisions in the medical area can and should be made are important to us. Your answers will be kept anonymous and will not affect your own medical treatment in anyway.

Please create your personal identification code:

Some information about yourself:

1) **Date of Birth:** ____ ____ / ____ ____ / ____ ____ ____
D D M M Y Y Y Y

2) **Sex: (please tick)** _____ **Male** _____ **Female**

3) **Which country to you live in:** _____
Since when? ____ ____ ____ ____ (year)

4) **Do you have health insurance (please tick):** _____ **yes** _____ **no**

5) **Do you or one of your family members have Diabetes?**

____ Yes. Since when? ____ ____ ____ ____ (year)

____ No

6) **When was the last time you saw a doctor/ other health professional?**

____ ____ / ____ ____ / ____ ____ ____ ____
D D M M Y Y Y Y

If someone came with you to your last doctor's appointment what is your relationship to them?
(e. g. partner, daughter, friend)

7) **How many children do you have?**

8) **What is the age of your youngest child?**

Condition 1: Informed choice

As parents you are often asked to make medical choices on behalf of your child. We are interested in your thoughts and feelings in these medical decision-making situations. We will give you a hypothetical scenario and ask you to imagine that you are a parent making a choice for your child in this situation.

In the following, we would like you to imagine that your child is suffering from Type 1 diabetes.

Type 1 diabetes develops when the insulin-producing cells in the body have been destroyed and the body is unable to produce any insulin. Insulin is a hormone that helps to use glucose in our blood to give us energy. In Type 1 diabetes the body is unable to produce insulin, so cannot process the glucose in our blood. Therefore, glucose builds up in our blood. About 345,000 people are living with Type 1 diabetes in the UK, from young children to adults.

Type 1 diabetes is commonly treated by injecting insulin. Some people with Type 1 diabetes will be offered the choice to either inject insulin multiple times a day with a needle or use an insulin pump. Both methods have benefits and disadvantages:

| Benefits of insulin pumps vs. Drawbacks of injections | |
|--|---|
| Cannulas are put into the skin every few days | Injections are needed several times a day. |
| Press button to deliver a dose at each meal or snack | Need to inject for each meal and some snacks |
| Basal insulin can be turned off or reduced during or after sports | Any changes to basal insulin need to be done several hours in advance. |
| Basal insulin is constantly delivered | Need to remember to reject background insulin at specific times of the day. |
| Pumps can be programmed at certain times a day, even when asleep, if required. | Any increase in insulin must be injected manually. |

| Benefits of injections vs. Drawbacks of insulin pumps | |
|---|---|
| Need only appear when an injection is needed | Can only be disconnected for short periods of time. |
| Can suffer from air bubbles, but this is generally less of a problem than with insulin pumps. | Can occasionally have issues, such as air bubbles, which can adversely affect blood glucose levels. |
| No tubing | Tubing can sometimes get caught in objects such as door handles, if tubing is not kept covered. |
| Less complicated to learn to use and maintain. | Initially, it takes longer to learn how to adjust to using and care for a pump. |

Please imagine that your child is suffering from Type 1 diabetes and meets the criteria for both insulin injections and an insulin pump. There is a choice as to whether insulin is administered to your child through an insulin pump or through injection. Please select one of the following five statements that best reflects your preference for being involved into the decision as to whether insulin should be delivered to your child through insulin injections or an insulin pump. Please tick only one option.

- (a) I prefer to make the final selection about which treatment my child will receive.
- (b) I prefer to make the final selection of my child's treatment after seriously considering the doctor's opinion.
- (c) I prefer that the doctor and I share responsibility for deciding which treatment is best for my child.
- (d) I prefer that the doctor makes the final decision about which treatment my child receives but seriously considers my opinion.
- (e) I prefer to leave all decisions regarding treatment to the doctor.

How well does each of these emotional states describe your mood as a consequence of your treatment preference?

| | Very slightly | | | | Very much |
|--------------|---------------|---|---|---|-----------|
| Distressed | 1 | 2 | 3 | 4 | 5 |
| Upset | 1 | 2 | 3 | 4 | 5 |
| Guilty | 1 | 2 | 3 | 4 | 5 |
| Ashamed | 1 | 2 | 3 | 4 | 5 |
| Hostile | 1 | 2 | 3 | 4 | 5 |
| Irritable | 1 | 2 | 3 | 4 | 5 |
| Nervous | 1 | 2 | 3 | 4 | 5 |
| Jittery | 1 | 2 | 3 | 4 | 5 |
| Scared | 1 | 2 | 3 | 4 | 5 |
| Afraid | 1 | 2 | 3 | 4 | 5 |
| Interested | 1 | 2 | 3 | 4 | 5 |
| Alert | 1 | 2 | 3 | 4 | 5 |
| Attentive | 1 | 2 | 3 | 4 | 5 |
| Excited | 1 | 2 | 3 | 4 | 5 |
| Enthusiastic | 1 | 2 | 3 | 4 | 5 |
| Inspired | 1 | 2 | 3 | 4 | 5 |
| Proud | 1 | 2 | 3 | 4 | 5 |
| Determined | 1 | 2 | 3 | 4 | 5 |
| Strong | 1 | 2 | 3 | 4 | 5 |
| Active | 1 | 2 | 3 | 4 | 5 |

How well does each of these emotional states describe your mood as a consequence of your treatment preference?

| | Very slightly | | | | Very much |
|--------------|---------------|---|---|---|-----------|
| Distressed | 1 | 2 | 3 | 4 | 5 |
| Upset | 1 | 2 | 3 | 4 | 5 |
| Guilty | 1 | 2 | 3 | 4 | 5 |
| Ashamed | 1 | 2 | 3 | 4 | 5 |
| Hostile | 1 | 2 | 3 | 4 | 5 |
| Irritable | 1 | 2 | 3 | 4 | 5 |
| Nervous | 1 | 2 | 3 | 4 | 5 |
| Jittery | 1 | 2 | 3 | 4 | 5 |
| Scared | 1 | 2 | 3 | 4 | 5 |
| Afraid | 1 | 2 | 3 | 4 | 5 |
| Interested | 1 | 2 | 3 | 4 | 5 |
| Alert | 1 | 2 | 3 | 4 | 5 |
| Attentive | 1 | 2 | 3 | 4 | 5 |
| Excited | 1 | 2 | 3 | 4 | 5 |
| Enthusiastic | 1 | 2 | 3 | 4 | 5 |
| Inspired | 1 | 2 | 3 | 4 | 5 |
| Proud | 1 | 2 | 3 | 4 | 5 |
| Determined | 1 | 2 | 3 | 4 | 5 |
| Strong | 1 | 2 | 3 | 4 | 5 |
| Active | 1 | 2 | 3 | 4 | 5 |

| | | | | | | | | | |
|---|--|--|--|--|--|--|--|--|--|
| 6. I rely on myself most of the time; I rarely rely on others | | | | | | | | | |
| 7. The well-being of my co-workers is important to me | | | | | | | | | |
| 8. My personal identity, independent of others, is very important to me | | | | | | | | | |
| 9. Competition is the law of nature. | | | | | | | | | |
| 10. If a co-workers gets a prize, I would feel proud. | | | | | | | | | |
| 11. Winning is everything. | | | | | | | | | |
| 12. Family members should stick together, no matter what sacrifice are required | | | | | | | | | |
| 13. Parents and children must stay together as much as possible. | | | | | | | | | |
| 14. When another person does better than I do, I get tense and aroused. | | | | | | | | | |
| 15. I often do “my own thing” | | | | | | | | | |
| 16. It is important that I do my job better than others. | | | | | | | | | |

Decision Making in Medical Situations

Thank you for agreeing to take part in this study. Your views about how decisions in the medical area can and should be made are important to us. Your answers will be kept anonymous and will not affect your own medical treatment in anyway.

Please create your personal identification code:

Some information about yourself:

1) **Date of Birth:** ____/____/____
D D M M Y Y Y Y

2) **Sex: (please tick)** _____Male _____Female

3) **Which country to you live in:** _____
Since when? ____ ____ (year)

4) **Do you have health insurance (please tick):** _____ yes _____ no

5) **Do you or one of your family members have Diabetes?**

____ Yes. Since when? ____ ____ (year)

____ No

6) **When was the last time you saw a doctor/ other health professional?**

____/____/____
D D M M Y Y Y Y

If someone came with you to your last doctor's appointment what is your relationship to them?
(e. g. partner, daughter, friend)

7) **How many children do you have?**

8) **What is the age of your youngest child?**

Condition 1: Non-informed choice

As parents you are often asked to make medical choices on behalf of your child. We are interested in your thoughts and feelings in these medical decision-making situations. We will give you a hypothetical scenario and ask you to imagine that you are a parent making a choice for your child in this situation.

In the following, we would like you to imagine that your child is suffering from Type 1 diabetes.

Type 1 diabetes develops when the insulin-producing cells in the body have been destroyed and the body is unable to produce any insulin. Insulin is a hormone that helps to use glucose in our blood to give us energy. In Type 1 diabetes the body is unable to produce insulin, so cannot process the glucose in our blood. Therefore, glucose builds up in our blood. About 345,000 people are living with Type 1 diabetes in the UK, from young children to adults.

Type 1 diabetes is commonly treated by injecting insulin. Some people with Type 1 diabetes will be offered the choice to either inject insulin multiple times a day with a needle or use an insulin pump. Both methods have benefits and disadvantages.

Please imagine that your child is suffering from Type 1 diabetes and meets the criteria for both insulin injections and an insulin pump. There is a choice as to whether insulin is administered to your child through an insulin pump or through injection. Please select one of the following five statements that best reflects your preference for being involved into the decision as to whether insulin should be delivered to your child through insulin injections or an insulin pump. Please tick only one option.

- (a) I prefer to make the final selection about which treatment my child will receive.
- (b) I prefer to make the final selection of my child's treatment after seriously considering the doctor's opinion.
- (c) I prefer that the doctor and I share responsibility for deciding which treatment is best for my child.
- (d) I prefer that the doctor makes the final decision about which treatment my child receives but seriously considers my opinion.
- (e) I prefer to leave all decisions regarding treatment to the doctor.

How well does each of these emotional states describe your mood as a consequence of your treatment preference?

| | Very slightly | | | | Very much |
|--------------|---------------|---|---|---|-----------|
| Distressed | 1 | 2 | 3 | 4 | 5 |
| Upset | 1 | 2 | 3 | 4 | 5 |
| Guilty | 1 | 2 | 3 | 4 | 5 |
| Ashamed | 1 | 2 | 3 | 4 | 5 |
| Hostile | 1 | 2 | 3 | 4 | 5 |
| Irritable | 1 | 2 | 3 | 4 | 5 |
| Nervous | 1 | 2 | 3 | 4 | 5 |
| Jittery | 1 | 2 | 3 | 4 | 5 |
| Scared | 1 | 2 | 3 | 4 | 5 |
| Afraid | 1 | 2 | 3 | 4 | 5 |
| Interested | 1 | 2 | 3 | 4 | 5 |
| Alert | 1 | 2 | 3 | 4 | 5 |
| Attentive | 1 | 2 | 3 | 4 | 5 |
| Excited | 1 | 2 | 3 | 4 | 5 |
| Enthusiastic | 1 | 2 | 3 | 4 | 5 |
| Inspired | 1 | 2 | 3 | 4 | 5 |
| Proud | 1 | 2 | 3 | 4 | 5 |
| Determined | 1 | 2 | 3 | 4 | 5 |
| Strong | 1 | 2 | 3 | 4 | 5 |
| Active | 1 | 2 | 3 | 4 | 5 |

How well does each of these emotional states describe your mood as a consequence of your treatment preference?

| | Very slightly | | | | Very much |
|--------------|---------------|---|---|---|-----------|
| Distressed | 1 | 2 | 3 | 4 | 5 |
| Upset | 1 | 2 | 3 | 4 | 5 |
| Guilty | 1 | 2 | 3 | 4 | 5 |
| Ashamed | 1 | 2 | 3 | 4 | 5 |
| Hostile | 1 | 2 | 3 | 4 | 5 |
| Irritable | 1 | 2 | 3 | 4 | 5 |
| Nervous | 1 | 2 | 3 | 4 | 5 |
| Jittery | 1 | 2 | 3 | 4 | 5 |
| Scared | 1 | 2 | 3 | 4 | 5 |
| Afraid | 1 | 2 | 3 | 4 | 5 |
| Interested | 1 | 2 | 3 | 4 | 5 |
| Alert | 1 | 2 | 3 | 4 | 5 |
| Attentive | 1 | 2 | 3 | 4 | 5 |
| Excited | 1 | 2 | 3 | 4 | 5 |
| Enthusiastic | 1 | 2 | 3 | 4 | 5 |
| Inspired | 1 | 2 | 3 | 4 | 5 |
| Proud | 1 | 2 | 3 | 4 | 5 |
| Determined | 1 | 2 | 3 | 4 | 5 |
| Strong | 1 | 2 | 3 | 4 | 5 |
| Active | 1 | 2 | 3 | 4 | 5 |

| | | | | | | | | | |
|---|--|--|--|--|--|--|--|--|--|
| 6. I rely on myself most of the time; I rarely rely on others | | | | | | | | | |
| 7. The well-being of my co-workers is important to me | | | | | | | | | |
| 8. My personal identity, independent of others, is very important to me | | | | | | | | | |
| 9. Competition is the law of nature. | | | | | | | | | |
| 10. If a co-workers gets a prize, I would feel proud. | | | | | | | | | |
| 11. Winning is everything. | | | | | | | | | |
| 12. Family members should stick together, no matter what sacrifice are required | | | | | | | | | |
| 13. Parents and children must stay together as much as possible. | | | | | | | | | |
| 14. When another person does better than I do, I get tense and aroused. | | | | | | | | | |
| 15. I often do “my own thing” | | | | | | | | | |
| 16. It is important that I do my job better than others. | | | | | | | | | |

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UNIVERSITY OF PLYMOUTH

FACULTY OF HEALTH AND HUMAN SCIENCES

Human Ethics Committee Consent Form

CONSENT TO PARTICIPATE IN RESEARCH PROJECT

Principal Investigator: Fatimah Alharbi, fatimah.alharbi@plymouth.ac.uk

Supervisor: Dr. Michaela Gummerum, michaela.gummerum@plymouth.ac.uk

Parents' preferences for shared medical decision making

Purpose of the Study: In this study we are interested in parent's preferences to be involved in a hypothetical medical decision when they have to make a choice for themselves or for their child (choosing a treatment option for Diabetes Type 1). We are also interested in parents' emotional reactions towards shared medical decision making and how cultural orientations affect preferences for medical decision-making.

Description of the Study: To take part in this study you must be 18 years or older and you must be a resident of the United Kingdom or Saudi Arabia also you must be parents. We expect 200 participants to take part in the study. You will be asked to read a consent form and give your consent (3 minutes), answer some demographic questions (3 mins), and complete a series of questions regarding parent's preferences for being involved in medical decision-making when they have to make a choice for themselves or for their kids (choosing a treatment option for Diabetes Type 1), and a number of questions about your endorsement of different activities related to emotions and cultural values (10 minutes). At the end of the study, you can review more information about the purpose of the study (2 minutes).

This research conforms to each clause of Plymouth University's Principles for Research Involving Human Participants and has been approved by the Plymouth University's Health and Human Sciences Ethics Committee.

Risks and Discomforts: There are no risks in taking part in this study.

Benefits of the Study: There may be no direct benefits to participants; however, the proposed research may benefit participants and patients in the long term. Research, mainly in western societies, has indicated that patients' preferences for medical decision-making procedures are important for their health outcomes. We would like to investigate this in different cultural settings.

Confidentiality: All information collected during this study will be anonymous because no identifying information (e.g., participants' name) will be collected. Any information about you will have a number on it instead of your name. We will not be sharing information about you to anyone outside of the research team. Complete data from each participant will be kept for 10 years after which it will be destroyed.

Voluntary Nature of Participation: Participation in this study is entirely voluntary. It is your choice whether to participate or not. If you decide to participate, you are free to withdraw your consent and to stop your participation at any time without penalty. Withdrawing at any point from the study will result in an automatic removal and deletion of your data. Data from participants who indicate at the end of the questionnaire that they do not consent to have their responses included will also be deleted and not included in analyses.

Questions: If you have any questions about the research please contact the researchers. Their information is available at the top of this form.

If you having any questions regarding your rights as a research participant in this study, you may contact the Plymouth University Faculty of Health and Human Sciences Human Ethics Committee; Ms Sarah Jones, sarah.c.jones@plymouth.ac.uk

Parents' preferences for shared medical decision making

Debriefing

Thank you very much for participating in this study.

Now we would like to inform you in more detail about the study.

In this study we are interested in parents' preference to be involved in a medical decision affecting their child, namely choosing a treatment option for Diabetes Type 1. We compare participants' preference for being involved in shared medical decision-making when they have to make the choice for themselves versus their child and predict that participants are more likely to engage in shared medical decision-making when they decide for themselves.

Previous research indicates that patients' preferences for medical decision-making influences can influence their health outcomes. Research has also shown that demographic variables, such as age and gender, can affect preferences for medical decision-making. Most of this research has been conducted in western societies. With this research we would like to investigate whether there is a cultural dimension to people's medical preferences. This is why we conduct this research both in the UK and Saudi Arabia. We predict that UK parents will be more likely to prefer being involved in medical decisions for themselves than participants in Saudi Arabia. However, we predict no cultural differences when it comes to parents' decisions regarding their children.

If you have any questions concerning this research please contact the principle investigator, Fatimah Alharbi, fatimah.alharbi@plymouth.ac.uk. If you are dissatisfied with the way the research is conducted, please contact the principal investigator in the first instance. If you feel the problem has not been resolved please contact the secretary to the Faculty of Health and Human Sciences Ethics Committee, Ms Sarah Jones, sarah.c.jones@plymouth.ac.uk.

Thank you again for your participation and have a nice day.

Name of Researcher: F

Patient's Code: 1

| Question | | |
|----------|---|---|
| | | I introduce myself as the researcher Fatima. First, thank you for agreeing to participate in this study. I will give a brief explanation about the study. This study is concerning views on how to participate in medical decision-making, its importance for patients as well as your opinion on the same. Your answers to the questions in this study will remain unknown to anyone else and do not affect your medical treatment in any case. Also, I would like your permission to record the interview in order to save the information only and will not reach anyone else other than the researcher. Before starting the interview, here is an approval form. Please go through it and, if acceptable, sign at the bottom of the page |
| | 1 | I do not mind, OK to interview me |
| | F | Are you ready to start the interview? First there are demographic about yourself? |
| | 1 | Ok |
| 1 | F | Date of Birth? |
| | 1 | 14.6.1419H |
| 2 | F | Sex |
| | 1 | Female |
| 3 | F | Which country to you live in? since when? |
| | 1 | Riyadh, since I was born |
| 4 | F | How long since diagnosis with type 1 diabetes? |
| | 1 | A year ago approximately, but I don't know which type I have |
| | F | What type of medication have you been taking? |
| | 1 | Insulin injections |
| 5 | F | Have you seen more than one physician in the last year,? Did you get more information from some of the doctors than from others and what information did you get? Was there anything different between the doctors? |
| | 1 | Yes, I visited more than one doctor. |
| | F | Why? |
| | 1 | I noticed some symptoms such as thirst, frequent urination and lethargy. The treating doctor conducted Medical analysis and found out that I suffer from diabetes |
| | F | Why did you see several doctors? |
| | 1 | Just to be sure I had diabetes |
| | F | Did you get more information from some of the doctors than from others? and what information did you get? Was there anything different between the doctors? |
| | 1 | Yes, there were differences between them. Some of the doctors did diabetes tests and gave me injections. One doctor referred me to a diabetes specialist hospital (Military Hospital in Riyadh) and explained to me a lot of information which I had to know about diabetes because when I first knew I had diabetes I was shocked and didn't accept the matter. I discovered I had diabetes after the final tests and I I guess the most likely reason is tension and examinations pressure. |

| | | |
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| 6 | F | How do you speak to your doctor about the medications? |
| | 1 | Sorry, I didn't understand your question |
| 6.1 | F | Do you remember the first appointment with the doctor? |
| | 1 | He told me it was necessary to start with insulin |
| 6.2 | F | Did the doctor explain to you the nature of the disease? |
| | 1 | No, the first doctor did not explain the nature of the disease. (The patient stopped then went on to say) I even didn't know what diabetes was and I was very scared and was admitted to the Intensive Care because of the doctor's fault. After that I was referred to another hospital and saw another doctor who explained to me the nature of the disease and that the first doctor made a mistake by overdosing insulin. He changed the dose and referred me to a specialist doctor (who really explained to me and I felt relaxed with this medication). Before I saw the second doctor I didn't know for three months the benefit from insulin and when I was referred to a Health Education Specialist I was given insulin Lantus |
| | F | When you changed the doctor, did the second doctor explain to you the nature of the disease? |
| | 1 | The doctor never explained the nature of the disease. But explained to me how to use insulin and then referred me to the health education specialist, and the role of this specialist is to explain to me the nature of the disease, diet and the followed diet program. This was already done. The patient repeated twice (previously, previously) I did not know what insulin Lantus (a type of insulin). Now I have knowledge about it. I used to take it twice but now I take it once. But I do not know why the second doctor reduced the insulin quantity for me. Then I knew that insulin was a happiness for me. Frankly, I was tired looking for a skilled doctor because one of them, as I mentioned before, was the cause of my coma, until I found the second doctor who was very specialized and referred me to the health education specialist for more information. |
| 7.1 | F | What was the medication suggested by the doctor for you? |
| | 1 | The doctor never gave me any treatment options. He just gives me the medication and determines the required dose. |
| 7.2 | F | Did your doctor give you treatment options? |
| | 1 | According to my case, the doctor explained to me about the insulin pump only and said after adjusting the cumulative sugar we will think of giving it to you. The patient stopped and then said, "I prefer the pump." The doctor gave me two options either the syringes or the pump. Then he told me that the pump should be changed every three days. Like I said the doctor explained to me that it does not suit me. |
| 7.3 | F | Did he explain to you why it doesn't suit you? |
| | 1 | Yes, because the rate of cumulative sugar is very high |
| | F | This means that the doctor gave you treatment options? |
| | 1 | Yes, he gave me options but after a long time, and not all doctors give options |
| 7.4 | F | Did your doctor explain the advantages and disadvantages of treatment? |
| | 1 | I did not understand the question |

| | | |
|-----|---|--|
| | F | Advantages and disadvantages of insulin, for example, or pump? |
| | 1 | It was the last doctor who explained to me the advantages of the two and told me what was best for me, and after I was referred to her the health education specialist explained to me and I understood what diabetes is. But I didn't feel comfortable with the first and second doctors. |
| 7.5 | F | Did the doctor give you specific information about how to manage your illness? |
| | 1 | Of course, the education specialist explained to me about diet, diet program and sports |
| 7.6 | F | Do you trust that your doctor offers you the best advice on treatment? |
| | 1 | It depends on my psychological comfort with the doctor |
| | F | How? |
| | 1 | For example, some doctors are anxious and provide all the information and give you options and some do not, like what happened to me with my former doctor. |
| 8.1 | F | Do you wish to get more information about available medicines? |
| | 1 | Yes, for example, I was given medications without explaining to me about them and why I should take them or the benefit from them, such as what happened to me when I had a coma caused by overdose and medical error. |
| 8.2 | F | Do you wish to discuss options with your doctor before making decisions? |
| | 1 | I hope the doctor will share with me and ask me whether I am satisfied or not. Some doctors never ask for my opinion. |
| 8.3 | F | Do you want to take responsibility for the treatment options chosen? |
| | 1 | Sometimes the doctor gives me medicine and I do not take it |
| | F | Why not? |
| | 1 | Because I take this responsibility as I do not trust doctors and at the beginning of my illness, I did not care about the disease because the doctors I saw did not explain to me. |
| | F | Now you've become more knowledgeable and have got better understanding about medicines and diabetes.? |
| | 1 | Because for months I have been dealing with this disease and I feel that I am better now to take responsibility for my own health. |
| 8.4 | F | Is there anyone you feel can participate in determining the treatment options? |
| | 1 | Me and the doctor. |
| 8.5 | F | Do you have any information you would like to add before the end of the interview? |
| | 1 | I think that it'd be better that the doctor always should seek to involve the patient in the decision so that the patient feels comfortable and understands his/her health and not be unaware. |
| | F | Before the end of the interview there are three questions related to the same subject. Please answer them? |
| | 1 | Ok. |
| | F | Thanks once again for participating in this study and here is a copy of the study summary you can keep with you. |

Name of Researcher: F

Patient's Code: 2

| | |
|---|--|
| | <p>I introduce myself as the researcher Fatima. First, thank you for agreeing to participate in this study. I will give a brief explanation about the study. This study is concerning views on how to participate in medical decision-making, its importance for patients as well as your opinion on the same.</p> <p>Your answers to the questions in this study will remain unknown to anyone else and do not affect your medical treatment in any case. Also, I would like your permission to record the interview in order to save the information only and will not reach anyone else other than the researcher. Before starting the interview, here is an approval form. Please go through it and, if acceptable, sign at the bottom of the page</p> |
| 2 | I don't mind |
| F | Are you ready to start the interview? First there are general questions to answer. |
| 2 | Ok |
| F | Date of Birth? |
| 2 | 1.1.1964 |
| F | Sex |
| 2 | Female |
| F | Place & date of residence? |
| 2 | Riyadh, since I was born |
| F | When was Diabetes type 1 diagnosed? |
| 2 | I think I have the second type |
| F | What type of medication have you been taking? |
| 2 | Insulin injections |
| F | When was Diabetes type 1 diagnosed? |
| | A year ago, approximately. |
| F | Have you seen more than one doctor during this year? Did you get more information from some of the doctors than from others and what information did you get? Was there anything different between the doctors? |
| 2 | Yes, I saw more than one doctor and went to more than one hospital. |
| F | Did you get more information from some of the doctors than from others? and what information did you get? |
| 2 | The information I got was sufficient |
| F | Was there anything different between the doctors? |
| 2 | I was satisfied by the information I got from the first doctor as he explained to me the nature of diabetes and type of medication |
| F | Was there anything different between the doctors? |
| 2 | When I visited more than one doctor it was not just to look for information about diabetes but to verify the correctness of the medication prescribed to me. I trusted the first doctor and I, thanks to Allah, feel satisfied and accept my illness. |
| F | How do you speak to your doctor about the medications? |
| 2 | I didn't understand the question. Can you reword the question? |
| F | Did the doctor explain to you the nature of the disease? |

| | |
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| 2 | Yes, he explained to me the nature of the disease and type of medication that I should use and type of food and to keep away from nervousness. |
| F | Do you remember how the doctor explained to you the nature of the disease? |
| 2 | I remember when the doctor first told me it was a shock, but, the doctor reassured me that diabetes is the disease of modern age and infects both adults and children, and thank God as much as I have this disease and I am at this age. He also explained to me about the type of disease and said, "diabetes has complications" and I continued to regulate diabetes. Five years later I was given injections. |
| F | What was the medication suggested by the doctor for you? |
| 2 | The first time I visited him the doctor did not prescribe any medicines. He just instructed me to follow a diet for one month. After a month he noticed that sugar level was very high and gave me a regulator which I used for five years and after that I started insulin injections. |
| F | Did your doctor give you treatment options? |
| 2 | There are conflicting opinions of doctors because some of them say there is no need for injections, just the tablets are sufficient while another doctor says injections are necessary |
| F | Did you believe any doctor? |
| 2 | More than one doctor persuaded me to take the injections, thanks to Allah I feel comfortable with this. |
| F | Did your doctor explain the advantages and disadvantages of treatment? |
| 2 | Yes, because the rate of cumulative sugar is very high |
| F | This means that the doctor gave you treatment options? |
| 2 | One year did not change and my mother is similar to my case and uses the same medicine, therefore I don't think there are options. The doctor's role is to prescribe medication without discussing with patient. |
| F | Advantages and disadvantages of insulin or pump for example? |
| 2 | The first time I hear this information. The doctor has never discussed it with me. |
| F | Did the doctor give you specific information about how to manage your illness? |
| 2 | Yes, he explained to me how to control sugar if it rises such as sports, diet and in cases of fainting. |
| F | Do you trust that your doctor offers you the best advice on treatment? |
| 2 | Not always, I trust that doctors offer advice but sometimes there is a conflict of opinion and type of medicines. |
| F | Do you wish to get more information about available medicines? |
| 2 | Yes, I want to get more information. My daughter is a pharmacist and I always take information about medicines and make sure. But diabetes drugs are known and there is nothing new. Patients have been living with this disease for a long time. |
| F | Do you wish to discuss options with your doctor before making decisions? |
| 2 | It is supposed to be the doctor's decision because he is more aware of the disease than me. Yes, I would like if there is a new |

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| | and possible treatment that helps me away from the old routine of taking injections on a daily basis. |
| F | In such case who makes the decision? |
| 2 | The doctor, but I think it is better to involve me and give me information |
| F | If the doctor told you the advantages and disadvantages of the medicine and leave the decision to you only, what would you decide? |
| 2 | From my experience in life the decision is always to the doctor, and I did not notice any difference in treatment, so I leave the decision to the doctor |
| F | Do you want to take responsibility for the treatment options chosen? |
| 2 | I do not take responsibility, it is the doctor who bears responsibility because he is the one who proposes it to me. Sometimes I take responsibility, for example if I'm tired of it I leave it without consulting a doctor, and sometimes the doctor gives options if it has complications by leaving |
| F | Is there anyone you feel can participate in determining the treatment options? |
| 2 | I prefer to consult my children because they are doctors and pharmacists |
| F | Do you have any information you would like to add before the end of the interview? |
| 2 | The patient recounted a story (when I traveled abroad - America specifically - I met a GP. He explained to me the relationship between food and diabetes, the diagnosis is the same diagnosis, but the treatment is different, for example in America the doctor asks about general symptoms and suggests any appropriate treatment and gives me options. The situation in Saudi Arabia is quite different. The doctor does not inform you or tell you, just gives you medicine as available in the hospital's pharmacy. |
| F | Before the end of the interview there are three questions related to the same subject. Please answer them? |
| 2 | Ok. |
| F | Thanks once again for participating in this study and here is a copy of the study summary you can keep with you. |

Name of Researcher: F

Patient's Code: 3

| | |
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| | <p>I introduce myself as the researcher Fatima. First, thank you for agreeing to participate in this study. I will give a brief explanation about the study. This study is concerning views on how to participate in medical decision-making, its importance for patients as well as your opinion on the same.</p> <p>Your answers to the questions in this study will remain unknown to anyone else and do not affect your medical treatment in any case. Also, I would like your permission to record the interview in order to save the information only and will not reach anyone else other than the researcher. Before starting the interview, here is an approval form. Please go through it and, if acceptable, sign at the bottom of the page</p> |
| 3 | I don't mind |
| F | Are you ready to start the interview? First there are general questions to answer. |
| 3 | Ok |
| F | Date of Birth? |
| 3 | 1.7.1385H |
| F | Sex |
| 3 | Female |
| F | Place & date of residence? |
| 3 | Riyadh, since I was born |
| F | When was Diabetes type 1 diagnosed? |
| 3 | A year approximately, what is meant by type 1? |
| F | What type of medication have you been taking? |
| 3 | Insulin injections with regulator. The doctor didn't explain to me which type. I thought diabetes is one type only. |
| F | Have you seen more than one doctor during this year? Did you get more information from some of the doctors than from others and what information did you get? Was there anything different between the doctors? |
| 3 | No, the doctor did not explain anything to me and told me I need injections and he gave them to me. This is the first time I hear from you that there are types of diabetes. In fact I have not visited more than one doctor because I naturally do not care about diseases and I guess diabetes is a normal and common disease and infects everyone and it is not my nature to ask a doctor |
| F | How do you speak to your doctor about the medications? |
| 3 | I didn't understand the question. Could you repeat the question? |
| F | Did the doctor explain to you the nature of the disease? |
| 3 | The doctor only informed me I had diabetes this is what I can remember. After that the patient continued and said the doctor explained to me in general about the symptoms of diabetes and its complications and described the treatment I need by a small percentage. |
| F | How did he diagnose your condition? |

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| 3 | <p>The doctor relied on the tests through comprehensive tests and then transferred me to the department of Family Medicine. He did not explain to me and I remember that he said it was necessary that I should pay attention to myself and he explained to me why he took cumulative so as to know blood sugar within three months.</p> <p>I had previously refused to take insulin because I was afraid of injections and I have become used to over time. Now I have inflammation of the nerves and to this moment the doctor did not explain to me the cause of inflammation or even prescribe the appropriate medication.</p> |
| F | What was the medication suggested by the doctor for you? |
| 3 | The doctor did not suggest any treatment and then the patient said (to the extent that if the medication ran out I would buy from the pharmacy without a doctor's prescription This happened a lot). |
| F | Did your doctor give you treatment options? (insulin pump or insulin syringes) |
| 3 | No. The doctor told me that there was only one treatment of diabetes that is insulin injections. He explained to me how to use the syringe and appropriate dosage. In the beginning I had a problem that the dose did not suit me but now, thanks to Allah, all things are fine. Even I've never heard of insulin pump and the doctor has never given me any choices. |
| F | Did your doctor explain the advantages and disadvantages of treatment? |
| 3 | No, the doctor is the person who decides and gives medication without asking the patient. For example, I preferred a certain type of sugar regulator which was really suitable for me. The doctor changed the medication without informing me or even check if I agree to change or not, which meant he didn't give me choices. In brief, if ask him he answers and if I don't he explains nothing. He usually gives me the medication and says if there are no complications, continue to use it but if there are complications he changes it. |
| F | Did the doctor give you specific information about how to manage your illness? |
| 3 | Of course, he referred me to the health education specialist and family medicine and in case of any questions they help m. The health education specialist explained to me about sports, diet, food program and alternatives and gave me a booklet and pamphlets to read. |
| F | Do you trust that your doctor offers you the best advice on treatment? |
| 3 | Sometimes I trust in some of them in respect of feeling of relaxation and their manner of communication with the patient and communicating information and try their best to persuade you. Some doctors you never feel relaxed with. The issue of trust depends on doctors and their way of communicating with patients. Then the patient added: The doctor asks and consults on medication, in this case I trust and rely on him. Sometimes, I have sufficient information and once get in to the doctor I explain |

| | |
|---|---|
| | my condition and suggest a medication to him until he writes down a prescription. |
| F | Do you wish to get more information about available medicines? |
| 3 | Sure, I want to get more information and hope to know the best options of medications available to diabetes sufferers. |
| F | Do you wish to discuss options with your doctor before making decisions? |
| 3 | <p>If my situation of diabetes developed, I wish to obtain more information such as amount of medication, but now my situation is stable, thanks to Allah.</p> <p>When I get in to the doctor, I prefer he discusses and explains and gives me choices for medication and complications and side effects of each medication and all that suits my case and finally decide together the best choice of medication.</p> <p>Then the patient added: A truth must be told ~(You rarely find a doctor who consults with you and takes your opinion for a suitable medication) and that is what we lack with doctors; consulting and involvement to decide medication</p> |
| F | Do you want to take responsibility for the treatment options chosen? |
| 3 | It is the doctor who bears responsibility because he is informed about medicines and I believe the best is the choice with the least complications and most benefits. |
| F | Is there anyone you feel can participate in determining the treatment options? |
| 3 | I don't like to consult anyone I'm satisfied with the doctor's opinion. This is something related to my situation and the doctor is informed of the diagnosis. |
| F | Do you have any information you would like to add before the end of the interview? |
| 3 | The issue of taking medications returns to the patient himself/herself and I think we cannot do without the doctor on that. If the doctor doesn't give sufficient information, I have to look for medicines' information by myself. |
| F | Before the end of the interview there are three questions related to the same subject. Please answer them? |
| 3 | Ok. |
| F | Thanks once again for participating in this study and here is a copy of the study summary you can keep with you. |

Name of Researcher: F

Patient's Code: 4

| Question# | | |
|-----------|---|---|
| | | I introduce myself as the researcher Fatima. First, thank you for agreeing to participate in this study. I will give a brief explanation about the study. This study is concerning views on how to participate in medical decision-making, its importance for patients as well as your opinion on the same. Your answers to the questions in this study will remain unknown to anyone else and do not affect your medical treatment in any case. Also, I would like your permission to record the interview in order to save the information only and will not reach anyone else other than the researcher. Before starting the interview, here is an approval form. Please go through it and, if acceptable, sign at the bottom of the page |
| | 4 | I don't mind |
| | F | Are you ready to start the interview? First there are general questions to answer. |
| | 4 | Ok |
| 1 | F | Date of Birth? |
| | 4 | 14.5.1380 |
| 2 | F | Sex |
| | 4 | Male |
| 3 | F | Place & date of residence? |
| | 4 | Riyadh, since I was born |
| 4 | F | When was Diabetes type 1 diagnosed? |
| | 4 | Three years ago. but I don't know which type I have. I just take insulin |
| 5 | F | Have you seen more than one doctor during this year? Did you get more information from some of the doctors than from others and what information did you get? Was there anything different between the doctors? |
| | 4 | Yes, I visited three doctors. |
| | F | Did you get more information from some of the doctors than from others? and what information did you get? |
| | 4 | I'm uneducated (illiterate) and the conflict of opinions between the doctors pushed me to look for a third doctor to determine to me the insulin dose I need. But I couldn't find sufficient information from all the doctors. I wish to know more and some doctors give unsuitable medication. Note: the patient is trying to explain his suffering with doctors and the search for information and appropriate diagnosis. |
| 6.1 | F | Did the doctor explain to you the nature of the disease? |
| | 4 | The doctor didn't explain the cause of diabetes nor its symptoms but told me about its complications and to pay attention to high |

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| | | blood sugar. Now it has been three years and I don't know how to deal with diabetes or control it (sometimes high and sometimes low). |
| 7.1 | F | What was the medication suggested by the doctor for you? |
| | 4 | He didn't suggest anything. He just wrote the prescription and specified the suitable insulin dose. |
| 7.2 | F | Did your doctor give you treatment options? |
| | 4 | No, The doctor said there is only one cure for diabetes |
| | F | For example, did he give you choices of pump or syringes? |
| | 4 | No, I never heard about that. |
| 7.3 | F | Did your doctor explain the advantages and disadvantages of treatment? |
| | 4 | No, he never explained to me. One of my sons helps me in reading medicine prescription. Once I ate the diabetes regulator and it caused me a lot of fatigue and I called my children to read my prescription for the possibility of something wrong. Sometimes, I ask the pharmacist about some medicines. |
| 7.4 | F | Did the doctor give you specific information about how to manage your illness? |
| | 4 | He explained to me about diet, sports and their alternatives. |
| 7.5 | F | Do you trust that your doctor offers you the best advice on treatment? |
| | 4 | No, sometimes my trust in the doctor depends on the consultation he offers to me. I usually follow the prescription. I don't prefer changing or discussing about medication |
| 8.1 | F | Do you wish to get more information about available medicines? |
| | 4 | I definitely have a wish if that is useful to me. I am satisfied with the information I get from the doctor. |
| 8.2 | F | Do you wish to discuss options with your doctor before making decisions? |
| | 4 | No, I don't prefer to discuss with the doctor. No, I do not like talking with your doctor. I prefer the doctor to make the decision alone |
| | F | Why did you visit more than one doctor since you trust the doctor that he would give you the best advice? |
| | 4 | I was sick of doctors in determining the appropriate dose, and at the beginning of my illness I was shocked and did not know how to deal with my illness. If the dose fits me, then I leave the decision to the doctor alone |
| | F | If your doctor told you the advantages and disadvantages of treatment then left the decision to you. What would you decide? |
| | 4 | I would leave the decision to the doctor alone. |
| 8.3 | F | Do you want to take responsibility for the treatment options chosen? |
| | 4 | The doctor bears responsibility because he well knows medicines and their benefits. |
| 8.4 | F | Is there anyone you feel can participate in determining the treatment options? |
| | 4 | I usually consult and ask people in the hospital waiting room who have already had the same disease. Sometimes I am satisfied with the doctor's opinion or friends if they have the same symptoms and medications |

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| 8.5 | F | Do you have any information you would like to add before the end of the interview? |
| | 4 | Thanks |
| | F | Before the end of the interview there are three questions related to the same subject. Please answer them? |
| | 4 | Ok. |
| | F | Thanks once again for participating in this study and here is a copy of the study summary you can keep with you. |

Name of Researcher: F

Patient's Code: 5

| Question# | | |
|-----------|---|---|
| | | I introduce myself as the researcher Fatima. First, thank you for agreeing to participate in this study. I will give a brief explanation about the study. This study is concerning views on how to participate in medical decision-making, its importance for patients as well as your opinion on the same. Your answers to the questions in this study will remain unknown to anyone else and do not affect your medical treatment in any case. Also, I would like your permission to record the interview in order to save the information only and will not reach anyone else other than the researcher. Before starting the interview, here is an approval form. Please go through it and, if acceptable, sign at the bottom of the page |
| | 5 | I don't mind |
| | F | Are you ready to start the interview? First there are general questions to answer. |
| | 5 | Ok |
| 1 | F | Date of Birth? |
| | 5 | 1/5/1440 |
| 2 | F | Sex |
| | 5 | Male |
| 3 | F | Place & date of residence? |
| | 5 | Riyadh, since I was born |
| 4 | F | When was Diabetes type 1 diagnosed? |
| | 5 | I don't know what type 1 is. |
| | F | What kinds of medication are you taking? |
| | 5 | Injections |
| | F | When was diabetes type 1 diagnosed? |
| | 5 | Since 15 years. |
| 5 | F | Have you seen more than one doctor during this year? Did you get more information from some of the doctors than from others and what information did you get? Was there anything different between the doctors? |
| | 5 | No, I have been infected with this disease for a long time and have only been satisfied with my private doctor |
| 6.1 | F | How do you speak with your doctor about medications? |

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| | 5 | I can't remember. He just gives me medicines and follows up with me and I use a regulator with insulin injections |
| 6.2 | F | Did the doctor explain to you the nature of the disease? |
| | 5 | He didn't explain to me the nature of the disease. I have got along with this disease and become accustomed to it and I only have information about the complications of diabetes and how I can keep it low |
| | F | Do you remember how he explained to you the nature of the disease? |
| | 5 | Yes, he referred me to a nutritional specialist and set up a food program that I follow and how to take the injections and drugs punctually. |
| 7.1 | F | What was the medication suggested by the doctor for you? |
| | 5 | I have been using injections for 15 years, and that is the only cure for diabetes and there aren't any suggestions. |
| 7.2 | F | Did your doctor give you treatment options? |
| | 5 | There aren't any choices. Each visit we discuss about the tests to determine the dose and continue with it |
| 7.3 | F | Did your doctor explain the advantages and disadvantages of treatment? |
| | 5 | No, usually the doctor does not explain the complications of medications. He says in the case of any medication causing fatigue, we look for an alternative or reduce the dose. Disposal of medicines is based on what is available in the pharmacy. |
| | F | Advantages and disadvantages of insulin or pump for example? |
| | 5 | I don't have any information about advantages of insulin or pump. I only know that insulin helps to adjust sugar and I don't have any other information. |
| 7.4 | F | Did the doctor give you specific information about how to manage your illness? |
| | 5 | Yes, surely, he explained to me about diet and sports to relieve diabetes and gave me a schedule that I've followed for years in walking and food. |
| 7.5 | F | Do you trust that your doctor offers you the best advice on treatment? |
| | 5 | Yes, I trust the doctor because he is more aware of the decisions that help me |
| | F | How do you trust the doctor while you say he does not consult with you? |
| | 5 | Usually I do not ask the doctor, but if I ask he would respond. Note: The doctor has an initiative in counseling, but it is according to the patient's wish does not take the initiative (for example the patient says I do not ask the doctor on anything) |
| 8.1 | F | Do you wish to get more information about available medicines? |
| | 5 | Yes certainly, but the doctor usually does not talk about medicines. I wish to learn and know about the complications of medication. Based on my experience, I have been following with the doctor for a long time and I trust the doctor. |
| 8.2 | F | Do you wish to discuss options with your doctor before making decisions? |
| | 5 | I prefer to leave options to the doctor as he is informed more than me and I don't know how to discuss with him or take part in |

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| | | the decision, I've never done that before. The doctor always diagnose the case and write a prescription and certainly he knows better than I do. |
| 8.3 | F | Do you want to take responsibility for the treatment options chosen? |
| | 5 | I don't wish to bear responsibility. I prefer to leave decision to the doctor and I don't have any experience in that. |
| 8.4 | F | Is there anyone you feel can participate in determining the treatment options? |
| | 5 | No. only the doctor. |
| 8.5 | F | Do you have any information you would like to add before the end of the interview? |
| | 5 | No. |
| | F | Before the end of the interview there are three questions related to the same subject. Please answer them? |
| | 5 | Ok. |
| | F | Thanks once again for participating in this study and here is a copy of the study summary you can keep with you. |

Note: The patient tends to keep silent most of the time. In addition, he is old aged.

Name of Researcher: F

Patient's Code: 6

| Question# | | |
|-----------|---|---|
| | | I introduce myself as the researcher Fatima. First, thank you for agreeing to participate in this study. I will give a brief explanation about the study. This study is concerning views on how to participate in medical decision-making, its importance for patients as well as your opinion on the same. Your answers to the questions in this study will remain unknown to anyone else and do not affect your medical treatment in any case. Also, I would like your permission to record the interview in order to save the information only and will not reach anyone else other than the researcher. Before starting the interview, here is an approval form. Please go through it and, if acceptable, sign at the bottom of the page |
| | 6 | I don't mind |
| | F | Are you ready to start the interview? First there are general questions to answer. |
| | 6 | Ok |
| 1 | F | Date of Birth? |
| | 6 | 1/7/1381 |
| 2 | F | Sex |
| | 6 | Male |
| 3 | F | Place & date of residence? |
| | 6 | Riyadh, since I was born |
| 4 | F | When was Diabetes type 1 diagnosed? |
| | 6 | Two years ago. What does type 1 mean? |
| | F | What kinds of medication are you taking? |
| | 6 | Insulin injections with regulator |

| | | |
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| 5 | F | Have you seen more than one doctor during this year? Did you get more information from some of the doctors than from others and what information did you get? Was there anything different between the doctors? |
| | 6 | Yes, it was a check with the doctor. |
| | F | Did you get more information from some of the doctors than from others and what information did you get? |
| | | Same information from all doctors even in specifying dose and medication, no difference at all. |
| 6.1 | F | How do you speak with your doctor about medications? |
| | 6 | I didn't understand your question. |
| 6.2 | F | Did the doctor explain to you the nature of the disease? |
| | 6 | Yes, he told me about diabetes and the use of insulin and thanks to Allah, steady with me. But the doctor didn't say which type of diabetes I have. The doctor asked me to refrain from eating fats, to commit to sports and walking, and warned me against anger. This is the information I can remember. |
| | F | Do you remember how the doctor explained to you the nature of the disease? |
| | 6 | he told me how to manage the disease and explained to me the complications of diabetes |
| 7.1 | F | What was the medication suggested by the doctor for you? |
| | 6 | He didn't suggest any medication. He told me diabetes cure is only one and didn't talk to me about anything related to medications or how to use them. I always ask the pharmacist who sometimes explains to me and sometimes says: ask your doctor. |
| 7.2 | F | Did your doctor give you treatment options? |
| | 6 | The doctor doesn't talk with me about medications rather than give me choices. If there is any question, I should ask the pharmacist or read the medicine information in the pack. In fact it is the first time I have heard of the pump. No one ever told me about it. |
| 7.3 | F | Did your doctor explain the advantages and disadvantages of treatment? |
| | 6 | No, I search by myself, and like I explained before I ask the pharmacist or ask the doctor during the following appointment. |
| 7.4 | F | Did the doctor give you specific information about how to manage your illness? |
| | 6 | Yes, he told me about diet and sports |
| 7.5 | F | Do you trust that your doctor offers you the best advice on treatment? |
| | 6 | I consider him trustworthy because I trusted God and then the doctor |
| | F | Why do you trust him? |
| | 6 | Because he has more knowledge and experience than me |
| 8.1 | F | Do you wish to get more information about available medicines? |
| | 6 | Yes, if information is available why not benefit from it. Surely I wish to obtain such information. |
| | 6 | The patient asked the researcher: do you have any information about medicines that can help me? |

| | | |
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| | F | It is supposed you ask your doctor such question in order to explain to you sufficient information such as insulin pump or insulin injections and you have free choice. Then the patient added: I remember the doctor warned me against anger. I am satisfied by the information I got from the doctor because he is experienced in his field of specialization only. It is supposed he provides the patient with any information about medications that will help the patient |
| 8.2 | F | Do you wish to discuss options with your doctor before making decisions? |
| | 6 | I trust the doctor. He has the right to choose the right decision for me only. I would prefer to be better informed about medications |
| 8.3 | F | Do you want to take responsibility for the treatment options chosen? |
| | 6 | No, I leave it to the doctor since he is expert in his field of specialization. |
| 8.4 | F | Is there anyone you feel can participate in determining the treatment options? |
| | 6 | No. I prefer only the doctor to share the opinion and convince me |
| 8.5 | F | Do you have any information you would like to add before the end of the interview? |
| | 6 | No. thanks. |
| | F | Before the end of the interview there are three questions related to the same subject. Please answer them? |
| | 6 | Ok. |
| | F | Thanks once again for participating in this study and here is a copy of the study summary you can keep with you. |

Name of Researcher: F

Patient's Code: 7

| Question# | | |
|-----------|---|---|
| | | I introduce myself as the researcher Fatima. First, thank you for agreeing to participate in this study. I will give a brief explanation about the study. This study is concerning views on how to participate in medical decision-making, its importance for patients as well as your opinion on the same. Your answers to the questions in this study will remain unknown to anyone else and do not affect your medical treatment in any case. Also, I would like your permission to record the interview in order to save the information only and will not reach anyone else other than the researcher. Before starting the interview, here is an approval form. Please go through it and, if acceptable, sign at the bottom of the page |
| | 7 | I don't mind |
| | F | Are you ready to start the interview? First there are general questions to answer. |
| | 7 | Ok |
| 1 | F | Date of Birth? |
| | 7 | 1/7/1378 |

| | | |
|-----|---|--|
| 2 | F | Sex |
| | 7 | Male |
| 3 | F | Place & date of residence? |
| | 7 | Riyadh, since I was born |
| 4 | F | When was Diabetes type 1 diagnosed? |
| | 7 | Two years approximately |
| | F | How did you know you had type 1 diabetes? Note: I asked this question because you are the first patient I interviewed who knows the type of disease |
| | 7 | During the first four years I was taking type 2 diabetes pills. Then it developed. For two years I have been taking insulin injections. Of course it was the doctor who told me the type of disease |
| 5 | F | Have you seen more than one doctor during this year? Did you get more information from some of the doctors than from others and what information did you get? Was there anything different between the doctors? |
| | 7 | No, I check with my doctor. |
| 6.1 | F | How do you speak with your doctor about medications? |
| | 7 | I started taking type 1 medications two years ago |
| 6.2 | F | Did the doctor explain to you the nature of the disease? |
| | 7 | Yes, and he gave me a diet and a system for treatment and advised me to practice sports and follow a diet. He started by pills and moved gradually to insulin injections |
| | F | Do you remember how the doctor explained to you the nature of the disease? |
| | 7 | Yes, at the beginning of the disease explained to me the symptoms of the disease and how I organize and told me to stay away from things that raise sugar and help balance and explained the causes and complications of the disease, thank God I felt that I understood the nature of the disease and explained to me that it is a chronic disease and will continue with me to the end of my life. The doctor explained to me how to manage the disease such as diet and sports, and to get away from anger and that diabetes should be your friend in life and you should know how to coexist with it. As for the treatment, the doctor said that the available treatment is injections and replace the long type by insulin pen, which is a small pen. The doctor also referred me to a nutritionist for further guidance and said it was necessary for the patient to adapt to diabetes. Note: The patient is aware of the nature of his illness and the type of medication he is taking. |
| 7.1 | F | What was the medication suggested by the doctor for you? |
| | 7 | The patient or diabetics usually intervene in the treatment and the doctor gives suggestions according to the treatment available to them and dispense the medicine accordingly. The doctor mentioned the diet and gave me options and how to follow it and get used to it, but did not give the any options regarding treatment or decision on it |
| 7.2 | F | Did your doctor give you treatment options? |
| | 7 | The doctor never discusses with me about medications or choices. The doctor dispenses the medication and after three |

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| | | months sets out an appointment and follows the treatment plan if it is appropriate for me or if there are any changes he will reduce or increase the dose. Unfortunately I do not have any background on medication options. The doctor before dispensing the medication does not give any options and dispenses medication as he understands the situation, especially doctors in government hospitals never consult patients in treatment options |
| 7.3 | F | Did your doctor explain the advantages and disadvantages of treatment? |
| | 7 | No, as I said before, the doctor does not talk about medicines until the next appointment, tests are done if appropriate or not. Always if I need any information I can search by myself online or read the prescription in the medicine box. The patient was silent and then said: I remember once when the doctor changed the needles of insulin to Insulin pen he advised and encouraged me to use it and told me all its advantages |
| 7.4 | F | Did the doctor give you specific information about how to manage your illness? |
| | 7 | Yes, this happened in several appointments with the health education specialist at the beginning of my disease such as diet and sport. |
| 7.5 | F | Do you trust that your doctor offers you the best advice on treatment? |
| | 7 | The problem is that the difference between doctors is obvious. One doctor tries to simplify the information and make you accept it, while others do not. I review the same case and every time the doctor is different from the first, I notice a big difference. Some doctors do not speak with the patient, just write down the prescription and never discuss. Just say "go to the pharmacy". Sometimes I ask the doctor about the results of the analysis, and unfortunately does not respond and just say "fine". It is my right to know over the past three months how the results were, how much they were, and why they were performed. It is my right to know how the results of sugar are calculated and it is my right to know every analysis and its purpose. Doctors do not explain. They Just try to finish checking the largest number of patients in the least time. I expect this is one of the reasons not to give each patient their right and the doctor is now writing medication on the computer linked to the pharmacy directly and when I arrive at the pharmacy I find the medication was prepared without knowing the type of the medication given to me not even an explanation of the medications and how to use or even the appropriate options for me. |
| 8.1 | F | Do you wish to get more information about available medicines? |
| | 7 | Yes, I'm always aware of information such as reading medicine prescription of insulin and how to use it and sometimes use the internet before I see the doctor so as to be aware of medications as I can't discuss with the doctor. |
| 8.2 | F | Do you wish to discuss options with your doctor before making decisions? |
| | 7 | I wish this and I think it is useful. I care for my health more than a doctor does and I follow up the drugs and know their functions |

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| | | and whether the dose is useful if increased or harmful if decreased. I must be aware, such as whether taking the medicine before or after eating is useful or harmful, because the doctor does not explain such points. Note: The patient was dissatisfied with the type of medication and the unwillingness of the doctor to discuss it with him |
| 8.3 | F | Do you want to take responsibility for the treatment options chosen? |
| | 7 | I prefer to choose, but after the doctor explains to me the advantages of medication such as some drugs cause dizziness. After that I choose the one which suits me and I take responsibility for the decision and choose the best and the easiest and of course after discussion with the doctor |
| 8.4 | F | Is there anyone you feel can participate in determining the treatment options? |
| | 7 | I always look for someone who has already used the same medication to take their opinion about the complications or benefits of the medication. For example, when the doctor explained to me about the insulin pen, I searched and found someone who used it and advised me to use it. Or if the doctor explained to me in an excellent manner, I become satisfied with his opinion |
| 8.5 | F | Do you have any information you would like to add before the end of the interview? |
| | 7 | No. thanks. |
| | F | Before the end of the interview there are three questions related to the same subject. Please answer them? |
| | 7 | Ok. |
| | F | Thanks once again for participating in this study and here is a copy of the study summary you can keep with you. |

Name of Researcher: F

Patient's Code: 8

| Question# | | |
|-----------|---|---|
| | | I introduce myself as the researcher Fatima. First, thank you for agreeing to participate in this study. I will give a brief explanation about the study. This study is concerning views on how to participate in medical decision-making, its importance for patients as well as your opinion on the same. Your answers to the questions in this study will remain unknown to anyone else and do not affect your medical treatment in any case. Also, I would like your permission to record the interview in order to save the information only and will not reach anyone else other than the researcher. Before starting the interview, here is an approval form. Please go through it and, if acceptable, sign at the bottom of the page |
| | 8 | I don't mind |
| | F | Are you ready to start the interview? First there are general questions to answer. |

| | | |
|-----|---|--|
| | 8 | Ok |
| 1 | F | Date of Birth? |
| | 8 | 20/8/1378 |
| 2 | F | Sex |
| | 8 | Male |
| 3 | F | Place & date of residence? |
| | 8 | Riyadh, since I was born |
| 4 | F | When was Diabetes type 1 diagnosed? |
| | 8 | Five years approximately |
| 5 | F | Have you seen more than one doctor during this year? Did you get more information from some of the doctors than from others and what information did you get? Was there anything different between the doctors? |
| | 8 | No, I didn't see more than one doctor because I think their information about diabetes is the same. When I was fatigued and had a fainting episode, I was transferred from my workplace to the King Abdul Aziz Diabetes Center and when it turned out to be a sugar coma I was transferred to the King Salman Diabetes Center as it is specialized in diabetes only. |
| 6.1 | F | What was the diagnosis of your case? |
| | 8 | I was surprised when I knew I had diabetes and I did not know before. I was at work when I fainted and from the initial diagnosis I knew I had this disease |
| 6.2 | F | Did the doctor explain to you the nature of the disease? |
| | 8 | Yes the doctor explained to me about the disease and told me that I can control it and live with it, and frankly he reassured me and relieved me on this calamity and simplified to me the idea about diabetes. At first I was very scared and unhappy but thanks to Allah the doctor calmed me and reassured me and explained the symptoms of the disease and how I can know when my sugar is high. Every time I visit the doctor, he tests and examines me and reassures me until I feel comfortable and not afraid of this disease. The doctor gave me a booklet on diabetes and I read it fully and I have experience in diabetes as my older brothers are all diabetics. Finally, thanks to Allah, the doctor explained to me in details about this disease. I also think that now the public know the whole meaning of diabetes and its medication. I do not expect anything new to be added. Most diabetics have a great awareness of this disease. |
| 7.1 | F | What was the medication suggested by the doctor for you? |
| | 8 | He gave me insulin injections and sugar regulator |
| 7.2 | F | Did your doctor give you treatment options? For example insulin pump or syringes? |
| | 8 | No, only one type insulin needles are available in the hospital. There was no choice. I expect if there are options the doctor would have explained to me, or at least presented to me, but unfortunately diabetes has no medication options. |
| 7.3 | F | Did your doctor explain the advantages and disadvantages of medication? |
| | 8 | Yes, the doctor always explains to me and he convinced me to take syringes and explained to me sufficiently and I was always |

| | | |
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| | | in discussion with him, and he convinced me (if the insulin dose increases and if sugar rises above 200 it affects the kidneys). My own doctor has the advantage of persuading me always. |
| 7.4 | F | Did the doctor give you specific information about how to manage your illness? |
| | 8 | Yes, sports, diet and much focus on diet. "If I continue on diet, I will not need to increase insulin doses," he said. But the problem is I do not keep up the sport. I remember when I joined a sports club the sugar dropped automatically |
| 7.5 | F | Do you trust that your doctor offers you the best advice on treatment? |
| | 8 | Yes, I trust him very much |
| 8.1 | F | Do you wish to get more information about available medicines? |
| | 8 | Yes, I am familiar with information through the Internet and small publications that are distributed in associations such as the market. I am familiar with the complications of the medication and its side effects and then I discuss with the doctor about it. Honestly, the doctor was open and helpful with me. |
| 8.2 | F | Do you wish to discuss options with your doctor before making decisions? |
| | 8 | Yes, certainly, once one of my friends uses a new medication I brought the medication with me to the clinic and the doctor looked at it so as to advise me if it was suitable for me or not. My doctor is always familiar with diabetes research and explains to me if there is anything new |
| 8.3 | F | Do you want to take responsibility for the treatment options chosen? |
| | 8 | No, my doctor is responsible because he has experience about the harm and benefit of the medication. Unless the doctor gives me two alternatives and explains on both to me, in this case I take responsibility for my choice. |
| 8.4 | F | Is there anyone you feel can participate in determining the treatment options? |
| | 8 | The doctor always makes the decision alone because it is he who diagnoses the case and knows the nature of the disease. I may have information but not like the doctor's information. |
| 8.5 | F | Do you have any information you would like to add before the end of the interview? |
| | 8 | No. thanks. |
| | F | Before the end of the interview there are three questions related to the same subject. Please answer them? |
| | 8 | Ok. |
| | F | Thanks once again for participating in this study and here is a copy of the study summary you can keep with you. |

Name of Researcher: F

Patient's Code: 9

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| Question# | | |
| | | I introduce myself as the researcher Fatima. First, thank you for agreeing to participate in this study. I will give a brief explanation about the study. This study is concerning views on how to |

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| | | participate in medical decision-making, its importance for patients as well as your opinion on the same. Your answers to the questions in this study will remain unknown to anyone else and do not affect your medical treatment in any case. Also, I would like your permission to record the interview in order to save the information only and will not reach anyone else other than the researcher. Before starting the interview, here is an approval form. Please go through it and, if acceptable, sign at the bottom of the page |
| | 9 | I don't mind |
| | F | Are you ready to start the interview? First there are general questions to answer. |
| | 9 | Ok |
| 1 | F | Date of Birth? |
| | 9 | 1/7/1379 |
| 2 | F | Sex |
| | 9 | Female |
| 3 | F | Place & date of residence? |
| | 9 | Riyadh, since I was born |
| 4 | F | When was Diabetes type 1 diagnosed? |
| | 9 | 4 years ago, but I don't know which type. |
| 5 | F | Have you seen more than one doctor during this year? Did you get more information from some of the doctors than from others and what information did you get? Was there anything different between the doctors? |
| | 9 | No, I didn't see more than one doctor, I was satisfied with my own doctor since he knows my health condition. |
| 6.1 | F | How do you speak with your doctor about medications? |
| | 9 | Sorry. I didn't understand the question. |
| 6.1.1 | F | What was the diagnosis of your case? |
| | 9 | Diabetes, and the doctor gave me insulin injections |
| 6.2 | F | Did the doctor explain to you the nature of the disease? |
| | 9 | Yes, the doctor explained to me the nature of the disease and asked me to stay away from things that could raise sugar like anger and emotion. At first he gave me insulin injections but I do not know what kind. I continued to use it for one year. Now the doctor gave me a second type of injection a little lighter than the first and increased the dose of insulin and asked me to do some analysis periodically every three months. He also explained to me the complications of the disease in general. Note: The patient has a satisfaction that her doctor has explained everything to her. |
| 7.1 | F | What was the medication suggested by the doctor for you? |
| | 9 | He didn't suggest anything, just gave me the suitable medication by a prescription and gave me a regulator with syringes and in each visit he determines the dose according to the analysis. |
| 7.2 | F | Did your doctor give you treatment options? For example insulin pump or syringes? |
| | 9 | He didn't suggest any option. |
| 7.3 | F | Did your doctor explain the advantages and disadvantages of medication? |

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| | 9 | A doctor usually doesn't explain, he just write down the prescription (and says take this and don't take this) and I don't ask the doctor. Why not? Because I remember he explained to me at the beginning the use of syringes. |
| | F | Advantages and disadvantages of insulin or pump for example? |
| | 9 | I don't remember the doctor said anything about advantages or disadvantages, but I remember he said insulin is important in rebalancing sugar. |
| 7.4 | F | Did the doctor give you specific information about how to manage your illness? |
| | 9 | Patient asked the researcher: I'm supposed to ask you how to control and overcome diabetes |
| | F | In other words, did the doctor give you any advice to overcome the disease such as diet? |
| | 9 | Yes, at the beginning he explained to me about diet and sports and that they are important. I wish to get more information or alternatives that can help me to control the disease |
| 7.5 | F | Do you trust that your doctor offers you the best advice on treatment? |
| | 9 | I, by nature, do not ask questions. The doctor does not provide me with all the information I need and he does not speak to me unless I ask him about my health. He does not propose any treatment plan and tells me what suits me and does not explain the next step or why he gave me this medication. |
| 8.1 | F | Do you wish to get more information about available medicines? |
| | 9 | Yes, I have a strong wish. I want to be aware of diagnosis, reasons, medication and any suggestions on medication in the future. |
| 8.2 | F | Do you wish to discuss options with your doctor before making decisions? |
| | 9 | Yes, of course I wish to ask the doctor about medication and take my opinion and I prefer to get information from the doctor rather than from the internet or people who had the disease before because cases differ from one person to the other. I prefer to ask the doctor and finally share decision and suitable medication. |
| 8.3 | F | Do you want to take responsibility for the treatment options chosen? |
| | 9 | Yes if the doctor consults me and explains information and there is no risk. I hope the doctor would consult me in every step of medication. |
| 8.4 | F | Is there anyone you feel can participate in determining the treatment options? |
| | 9 | No, the doctor only. |
| 8.5 | F | Do you have any information you would like to add before the end of the interview? |
| | 9 | No. thanks. |
| | F | Before the end of the interview there are three questions related to the same subject. Please answer them? |
| | 9 | Ok. |
| | F | Thanks once again for participating in this study and here is a copy of the study summary you can keep with you. |

Name of Researcher: F

Patient's Code: 10

| Question# | | |
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| | | I introduce myself as the researcher Fatima. First, thank you for agreeing to participate in this study. I will give a brief explanation about the study. This study is concerning views on how to participate in medical decision-making, its importance for patients as well as your opinion on the same. Your answers to the questions in this study will remain unknown to anyone else and do not affect your medical treatment in any case. Also, I would like your permission to record the interview in order to save the information only and will not reach anyone else other than the researcher. Before starting the interview, here is an approval form. Please go through it and, if acceptable, sign at the bottom of the page |
| | 10 | I don't mind |
| | F | Are you ready to start the interview? First there are general questions to answer. |
| | 10 | Ok |
| 1 | F | Date of Birth? |
| | 10 | 24/5/1388 |
| 2 | F | Sex? |
| | 10 | Male |
| 3 | F | Place & date of residence? |
| | 10 | Riyadh, since I was born |
| 4 | F | When was Diabetes type 1 diagnosed? |
| | 10 | One month ago approximately |
| 5 | F | Have you seen more than one doctor during this year? Did you get more information from some of the doctors than from others and what information did you get? Was there anything different between the doctors? |
| | 10 | Yes, I visited the district health center. He was then transferred to King Salman Diabetes Center |
| | F | Did you get more information from some of the doctors than from others and what information did you get? |
| | 10 | No. the difference between the doctors is only on diet. The diabetes center did some program and guidance on diet more than the local (district) center. |
| | F | Was there anything different between the doctors? |
| | 10 | I didn't notice any difference. I visited three doctors and approximately the same information I got on diabetes in the diagnosis method and medication. I was looking for a doctor to give me a regulator rather than insulin injections and all of them refused and agreed on the insulin injections as being necessary to me. |

| | | |
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| 6.1 | F | How do you speak with your doctor about medications? |
| | 10 | I didn't understand the question. |
| 6.2 | F | Did the doctor explain to you the nature of the disease? |
| | 10 | The doctor explained to me that it is dysfunction in the pancreas and the factors of aging have a potential for infection. He explained to me the causes of diabetes in general and explained the appropriate food and told me to stay away from unhealthy food. The doctor was very helpful and explained to me from my point of view most of the information about diabetes and also provided me with publications about the disease and told me (if there is a query in the next appointment we will discuss it with each other) and also explained to me the possible disadvantages of diabetes that it may affect the general functions of the body such as bones, kidney, and it has the advantage of regulating healthy food) |
| 7.1 | F | What was the medication suggested by the doctor for you? |
| | 10 | He did not give me any options. He wrote me a prescription for medication (insulin injections) only. He was directing me about the amount of doses I needed because the overdose made me tired a lot and if I cut it, my sugar would drop. |
| 7.2 | F | Did your doctor give you treatment options? For example insulin pump or syringes? |
| | 10 | No, never. Just insulin injections the only available medication. |
| 7.3 | F | Did your doctor explain the advantages and disadvantages of medication? |
| | 10 | Of course he changed some medications and explained to me that in the past period it caused my health to deteriorate and gave me injections and vitamins to help me. The doctor was helpful with me. Every three months he performs tests and, based on the tests, he changes the amount of drugs. But the doctor did not explain the advantages and complications of treatment. I read it from the prescription in the medication box or ask the pharmacist and the doctor after the analysis explains what to do and what not to do. |
| | F | Advantages and disadvantages of insulin or pump for example? |
| | 10 | No, I don't remember the doctor talked to me about this. |
| 7.4 | F | Did the doctor give you specific information about how to manage your illness? |
| | 10 | Yes at the beginning. In the first appointment the doctor explained to me about the diet, food program and exercise like walking. I was initially in a health center but they did not give me all the information about diet and sports until I was referred to the King Salman Center and got enough information. The doctor who treated me at this center changed the treatment but did not take my opinion. He just said we changed the treatment for your benefit and the injections should be taken instead of the regulator. I have not been referred to health education to get more information like other diabetics. Only I am from my own experience with the diabetic mother and I do not need education because I have enough experience and information. |

| | | |
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| 7.5 | F | Do you trust that your doctor offers you the best advice on treatment? |
| | 10 | Yes, after God's Will I trust the doctor since he has knowledge and experience. |
| 8.1 | F | Do you wish to get more information about available medicines? |
| | 10 | I have a lot of information by searching the internet and when mother was ill I used to take care of her. Now I am a diabetic and it is only natural and supposed that I have more information about the disease and new medications in this field so as to help myself. It is not necessary that I rely on the doctor. Then she added (We cannot do without doctors) |
| 8.2 | F | Do you wish to discuss options with your doctor before making decisions? |
| | 10 | Yes sure . For example, my doctor offered to increase the dose of insulin and I told him no. I prefer to be the same dose because it is suitable for me and because the period of low sugar tired me a lot, especially after breakfast until noon. I like to share options with the doctor because the person knows what suits his/her condition, if the doctor gives him/her the option |
| | F | In such case who make decision? |
| | 10 | I leave decision to the doctor finally. Discussion is necessary because he has more information and experience. I just prefer discussion and the final decision is up to the doctor. |
| | F | If the doctor informs you the advantages and disadvantages of medication and leaves decision to you alone, what would you decide? |
| | 10 | I leave decision to the doctor. |
| 8.3 | F | Do you want to take responsibility for the treatment options chosen? |
| | 10 | If I choose the presented option, then yes I bear responsibility. |
| 8.4 | F | Is there anyone you feel can participate in determining the treatment options? |
| | 10 | I often involve my colleagues and take their opinions about drugs and especially my close colleague. He is very highly enlightened on health matters and feel more comfortable with him. I discuss medical options with him if suggested by the doctor. |
| 8.5 | F | Do you have any information you would like to add before the end of the interview? |
| | 10 | Nothing currently. I hope that the doctor builds a relationship with the patient through (exchanging ideas to reach the result) to get more information and feel comfortable during the discussion |
| | F | Before the end of the interview there are three questions related to the same subject. Please answer them? |
| | 10 | Ok. |
| | F | Thanks once again for participating in this study and here is a copy of the study summary you can keep with you. |

Name of Researcher: F
Patient's Code: 11

| | | |
|-----------|----|--|
| Question# | | |
| | | <p>I introduce myself as the researcher Fatima. First, thank you for agreeing to participate in this study. I will give a brief explanation about the study. This study is concerning views on how to participate in medical decision-making, its importance for patients as well as your opinion on the same.</p> <p>Your answers to the questions in this study will remain unknown to anyone else and do not affect your medical treatment in any case. Also, I would like your permission to record the interview in order to save the information only and will not reach anyone else other than the researcher. Before starting the interview, here is an approval form. Please go through it and, if acceptable, sign at the bottom of the page</p> |
| | 11 | I don't mind |
| | F | Are you ready to start the interview? First there are general questions to answer. |
| | 11 | Ok |
| 1 | F | Date of Birth? |
| | 11 | 21/5/1398 |
| 2 | F | Sex? |
| | 11 | Female |
| 3 | F | Place & date of residence? |
| | 11 | Riyadh, since I was born |
| 4 | F | When was Diabetes type 1 diagnosed? |
| | 11 | One year ago, but I don't know which type |
| | F | What type of medication are you taking? |
| | 11 | Insulin injections |
| 5 | F | Have you seen more than one doctor during this year? Did you get more information from some of the doctors than from others and what information did you get? Was there anything different between the doctors? |
| | 11 | No, just the Diabetes Centre. |
| 6.1 | F | Did the doctor explain to you the nature of the disease? |
| | 11 | <p>I had symptoms like thirst and frequent urination. I asked the doctor about the symptoms and he did tests for me and I discovered that I had diabetes. Now thank God after my first visit it has been stable with me. Of course the doctor was a cooperative and explained to me all about the complications of diabetes and its causes and how to avoid high sugar) and I remember he gave me a paper containing all the information about diabetes and the doctor always responded if I asked him. I followed with him every three months. The doctor referred me to health education to get a diet and food program. I remember the doctor told me (what helps you in this disease is your own concern of yourself).</p> |
| 7.1 | F | What was the medication suggested by the doctor for you? |
| | 11 | He gave me injections I take one before breakfast and one before dinner and before sleep I take regulator. |
| 7.2 | F | Did your doctor give you treatment options? For example insulin pump or syringes? |

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| | 11 | No, he didn't explain any choice. He Just gave me the suitable medication. I've never heard of pump before except from you (researcher) and the insulin injections are suitable to me. |
| 7.3 | F | Did your doctor explain the advantages and disadvantages of medication? |
| | 11 | I do not remember. The doctor said if do not be organized in the treatment it will cause complications and she mentioned the importance of insulin in the control of blood sugar only |
| 7.4 | F | Did the doctor give you specific information about how to manage your illness? |
| | 11 | Yes he referred me to health education and got diet program and healthy food program and sports. In each appointment the doctor reminds me of diet and the importance of sports. |
| 7.5 | F | Do you trust that your doctor offers you the best advice on treatment? |
| | 11 | Yes, I trust because he helps people and has knowledge and experience. |
| 8.1 | F | Do you wish to get more information about available medicines? |
| | 11 | I don't need more information because I'm satisfied with the information I get from the doctor (since he is more informed about my health condition) I don't want to know even about medications . sometimes I listen to my daughters' advice on medications if there is something suitable. |
| 8.2 | F | Do you wish to discuss options with your doctor before making decisions? |
| | 11 | I am satisfied with the doctor's opinion, I don't wish to discuss because my experience is incomparable with his |
| | F | If the doctor informs you the advantages and disadvantages of medication and leaves decision to you alone, what would you decide? |
| | 11 | I don't prefer to make a decision relating to my health |
| | F | In such case who shall decide? |
| | 11 | The doctor alone |
| 8.3 | F | Do you want to take responsibility for the treatment options chosen? |
| | 11 | I do not like it. I prefer that the doctor bears responsibility for his decision because he is aware and knowledgeable and knows my health. I trust the doctor will give me the most appropriate and the best. |
| 8.4 | F | Is there anyone you feel can participate in determining the treatment options? |
| | 11 | Only the doctor shall choose the most suitable and most proper |
| 8.5 | F | Do you have any information you would like to add before the end of the interview? |
| | 11 | No, thanks |
| | F | Before the end of the interview there are three questions related to the same subject. Please answer them? |
| | 11 | Ok. |
| | F | Thanks once again for participating in this study and here is a copy of the study summary you can keep with you. |

Name of Researcher: F

Patient's Code: 12

| Question# | | |
|-----------|----|---|
| | | I introduce myself as the researcher Fatima. First, thank you for agreeing to participate in this study. I will give a brief explanation about the study. This study is concerning views on how to participate in medical decision-making, its importance for patients as well as your opinion on the same. Your answers to the questions in this study will remain unknown to anyone else and do not affect your medical treatment in any case. Also, I would like your permission to record the interview in order to save the information only and will not reach anyone else other than the researcher. Before starting the interview, here is an approval form. Please go through it and, if acceptable, sign at the bottom of the page |
| | 12 | I don't mind |
| | F | Are you ready to start the interview? First there are general questions to answer. |
| | 12 | Ok |
| 1 | F | Date of Birth? |
| | 12 | 16/10/1494 |
| 2 | F | Sex? |
| | 12 | Male |
| 3 | F | Place & date of residence? |
| | 12 | Riyadh, since I was born |
| 4 | F | When was Diabetes type 1 diagnosed? |
| | 12 | Three months ago. Note: the patient is aware of diabetes type. |
| 5 | F | Have you seen more than one doctor during this year? Did you get more information from some of the doctors than from others and what information did you get? Was there anything different between the doctors? |
| | 12 | No, this is my second visit after it was found out I had diabetes. |
| 6.1 | F | What was the diagnosis of your case? |
| | 12 | The patient said confidently (I am better than the doctor and I explain to the doctor all the information that I have. I don't need any further information) |
| | F | How? |
| | 12 | Father and mother have diabetes. I'm satisfied with the information I have. Doctors do not have anything new about diabetes. |
| 6.2 | F | Regardless of the information you have, did the doctor take initiative to explain to you the nature of the disease? |

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| | 12 | Of course he talked at the beginning about the nature of food. The problem I have is weight and he talked about relationship of diabetes with obesity. Frankly through my getting along with the disease with father and mother I don't care too much on sugar issue. Also the doctor didn't discuss with me any information about diabetes may be because I already have information. The doctor asked me whether I knew diabetes and I said yes. |
| 7.1 | F | What was the medication suggested by the doctor for you? |
| | 12 | He prescribed insulin injections as the only cure for diabetes. |
| 7.2 | F | Did your doctor give you treatment options? |
| | 12 | No, unfortunately he didn't inform me of any choice. He wrote the prescription and repeated it. He only explained to me how to use the injections and where to insert the injection in the body |
| 7.3 | F | Did your doctor explain the advantages and disadvantages of medication? |
| | 12 | No, we never discussed about medications, he just gave me insulin injections. |
| | F | Advantages and disadvantages of insulin or pumps for example? |
| | 12 | He didn't explain anything about that and didn't give me any choices. |
| 7.4 | F | Did the doctor provide you any special information about how to manage your illness? |
| | 12 | I already know about it. He transferred me to the health education specialist to obtain more information and he gave me brief information about diet and sports and how to lose weight. |
| 7.5 | F | Do you trust that your doctor offers you the best advice on treatment? |
| | 12 | This is my second visit and if I don't benefit from the medication, I will certainly look for another doctor. In fact I didn't feel comfortable with this doctor because he does not discuss a lot with me. |
| 8.1 | F | Do you wish to get more information about available medicines? |
| | 12 | Yes, I hope to know about the best available medications (I wish to know about the medication, its type and advantage) and I hope the doctor would discuss on medications and improve information rather than just repeating information in every visit. For example, if the medication is useful for diabetes it might be harmful in other things. That is what I hope doctors would discuss with their patients. I would like to know such information instead of what my doctor says (this medication is better) and then keeps silent. I want choices and discuss them. |
| 8.2 | F | Do you wish to discuss options with your doctor before making decisions? |
| | 12 | Of course this is necessary. I would like it if this mechanism be followed. For example, in the first appointment to collect all information about me and conduct analysis and testing and discussion. In the second appointment we can discuss the options and choose the medicine and the best option. Then the patient said: The discussion is very important. I am supposed to suggest to the doctor a group of medications and the doctor advises. I completely reject the doctor make decision alone. As for my appointment today with the doctor, I am dissatisfied |

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| | | with it because I have not yet understood the alternative options I can do or the options that I might not do. If you forget to use insulin injections, what could be the alternative option, and also if you feel tired from needle pricking on a daily basis what could be the alternative? |
| | F | If the doctor informs you the advantages and disadvantages of medication and leaves decision to you alone, what would you decide? |
| | 12 | I decide that. |
| 8.3 | F | Do you want to take responsibility for the treatment options chosen? |
| | 12 | I do not take responsibility because it was the doctor who gave me the options. If I am sure and confident that the option is harmless to my health, I will take responsibility. For example, if the doctor leaves to me determining the dose of insulin whether by increase or decrease provided that in both cases there will be no harm, I assume responsibility. But if the doctor does not explain all the possibilities to me, in this case he shall be responsible. |
| 8.4 | F | Is there anyone you feel can participate in determining the treatment options? |
| | 12 | I like to involve my sister in most decisions. after each appointment I always take care to contact with her and take her opinion |
| 8.5 | F | Do you have any information you would like to add before the end of the interview? |
| | 12 | I have a lot of inquiries. Sometimes doctors do not give the patient any bit of their time to inquire and be satisfied of treatment and reassured about the disease and living with it. For example, I want to know a lot about diabetes. The doctor did not add anything new. The information I want to share with my father and mother. Even in the medication it is always the same thing I take the medication and use it without knowing anything except when to use it. The only one question I asked and the doctor reassured me was if diabetes was a dangerous disease and he replied 'no'. |
| | F | Why didn't you ask the doctor all these queries? |
| | 12 | Sometimes I do not feel comfortable with the doctor and the doctor continues in writing all the time and do not listen to me carefully and it isn't easy to ask him all the questions the first time I visit him. Sometimes I forget and do not remember anything during the appointment. |
| | F | Before the end of the interview there are three questions related to the same subject. Please answer them? |
| | 11 | Ok. |
| | F | Thanks once again for participating in this study and here is a copy of the study summary you can keep with you. |

Name of Researcher: F

Patient's Code: 13

| Question# | | |
|-----------|----|--|
| | | I introduce myself as the researcher Fatima. First, thank you for agreeing to participate in this study. I will give a brief explanation about the study. This study is concerning views on how to participate in medical decision-making, its importance for patients as well as your opinion on the same. Your answers to the questions in this study will remain unknown to anyone else and do not affect your medical treatment in any case. Also, I would like your permission to record the interview in order to save the information only and will not reach anyone else other than the researcher. Before starting the interview, here is an approval form. Please go through it and, if acceptable, sign at the bottom of the page |
| | 13 | I do not mind. |
| | F | Are you ready to start the interview? First there are general questions to answer. |
| | 13 | Ok |
| 1 | F | Date of Birth? |
| | 13 | 8/4/1420 |
| 2 | F | Sex |
| | 13 | Female |
| 3 | F | Place & date of residence? |
| | 13 | Riyadh, since I was born |
| 4 | F | When was Diabetes type1 diagnosed? |
| | 13 | Nine months ago approximately Note: patient is aware of the type of diabetes |
| 5 | F | Have you seen more than one doctor during this year? Did you get more information from some of the doctors than from others and what information did you get? Was there anything different between the doctors? |
| | 13 | Yes, I visited more than one clinic (not for purpose of checkingI had diabetes but so as to obtain sufficient information to feel content about my healthconditionand live with the disease and obtain suitable medication to continue with.. |
| | F | Did you get more information from some doctors than from others? What information did you get? |
| | 13 | I visited a doctor but didn't explain to me sufficient information. He told me about diet and sports and said that the cure of diabetes is the same and there are no choices. After that I looked for another doctor who was younger than the first doctor and was newly graduated and gave me sufficient information about diabetes. |
| 6.1 | F | What was the diagnosis of your case? |
| | 13 | Diabetes type 1 |
| 6.2 | F | How do you speak with your doctor about medications? |

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| | 13 | He never discusses with me about medications. He just speaks about diagnosis.. |
| 6.3 | F | Did the doctor explain to you the nature of the disease? |
| | 13 | Not all doctors explain about medications. Only the second doctor I visited explained to me about the disease fully, its causes, symptoms and ways of prevention from the disease and the medications that can help me, and thanks to Allah after my visit to the doctor I was very relaxed and helped me how to adapt with diabetes and now it has been 9 months and I never had a diabetes coma or faint |
| 6.4 | F | What are the things you can thank about to help people to be involved in making decision related to their medication? |
| | 13 | I hope there will be suggestions on medication so that we can choose from both, |
| 7.1 | F | What was the medication suggested by the doctor for you? |
| | 13 | Frankly, the doctor offered me two choices of medication; insulin injection and insulin pen, and explained to me that the injection are a bit old and more painful whereas the insulin pen is a better choice and involves very slight pain, and said these are the options available in King Salman Center. |
| 7.2 | F | Did your doctor give you treatment options? |
| | 13 | No, the doctor didn't give me any alternatives. |
| 7.3 | F | Did your doctor explain the advantages and disadvantages of the? |
| | 13 | Yes, when he explained to me about two types of insulin (injections and pen) and as well for the regulator he gave me two options and said both options he recommended this one and he instructed me to the suitable medication and left the choice to me and I chose the medication based on his recommendation and when I felt tired from the regulator and involved complications I asked him to change it in the next appointment. |
| 7.4 | F | Did the doctor give you specific information about how to manage your illness? |
| | 13 | Yes, he explained how to follow the diet and sports and change lifestyle. He gave me a lot of options for diet and advised me to change my lifestyle and also explained to me what to do if sugar rises or drops. Thanks to Allah I'm happy with the doctor. |
| 7.5 | F | Do you trust that your doctor offers you the best advice on treatment? |
| | 13 | I don't want to rely on myself to obtain information. Sometimes I am not convinced by what the doctor says, except if not taking the medication involves risk, but if there are options certainly I will choose the best for me. My trust in the doctor depends on the extent of my communication with him, feeling content and the amount of information he offers to me and my reliance on the accuracy of such information. I usually search the internet to verify the information. |
| 8.1 | F | Do you wish to get more information about available medicines? |
| | 13 | Yes, for example if I heard about a new medication I ask the doctor about it whether it suits me or not even there are some programs present advice to diabetics in the following appointment I ask the doctor about the program and know his instructions if it is suitable or not. For example once I heard of some home remedies that help to cure diabetes and I talked about it with my doctor and he told me to keep away from them. I expect the doctor if there is anything new he will certainly inform his patients. It is well known that diabetics rely on insulin and regulators |

| | | |
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| 8.2 | F | Do you wish to discuss options with your doctor before making decisions? |
| | 13 | I hope the doctor will give more options. |
| | F | Like what? |
| | 13 | I hope the doctor gives options such as insulin pump and diet I heard a lot that there is a diet that replaces the insulin injection I hope the doctor would present such options unfortunately he told me the pump isn't available with us |
| | F | In this case who takes the decision? |
| | 13 | Me if there is no harm |
| 8.3 | F | Do you want to take responsibility for the treatment options chosen? |
| | 1 | Yes surely I can bear responsibility of the option I chose on condition that I have obtained sufficient information of the medication and is no harm . This is my choice. |
| 8.4 | F | Is there anyone you feel can participate in determining the treatment options? |
| | 13 | Yes, my family sometimes such as my mother and sisters I ask them on some decisions relating to my health and type of medication |
| 8.5 | F | Do you have any information you would like to add before the end of the interview? |
| | 13 1 | I hope there would be choices for insulin such as the pump ,or diet or insulin once a month. |
| | F | Before the end of the interview there are three questions related to the same subject. Please answer them? |
| | 13 | Ok. |
| | F | Thanks once again for participating in this study and here is a copy of the study summary you can keep with you. |

Name of Researcher: F

Patient's Code: 14

| Question# | |
|-----------|--|
| | <p>I introduce myself as the researcher Fatima. First, thank you for agreeing to participate in this study. I will give a brief explanation about the study. This study is concerning views on how to participate in medical decision-making, its importance for patients as well as your opinion on the same.</p> <p>Your answers to the questions in this study will remain unknown to anyone else and do not affect your medical treatment in any case. Also, I would like your permission to record the interview in order to save the information only and will not reach anyone else other than the researcher. Before starting the interview, here is an approval form. Please go through it and, if acceptable, sign at the bottom of the page</p> |

| | | |
|-----|----|---|
| | 14 | I do not mind. |
| | F | Are you ready to start the interview? First there are general questions to answer. |
| | 14 | Ok |
| 1 | F | Date of Birth? |
| | 14 | 1/7/1374 |
| 2 | F | Sex |
| | 14 | Male |
| 3 | F | Place & date of residence? |
| | 14 | Riyadh, since I was born |
| 4 | F | When was Diabetes type1diagnosed? |
| | 14 | Probably a year ago, but I don't know which type. |
| | F | What type of medication are you taking? |
| | 14 | Insulin injections |
| 5 | F | Have you seen more than one doctor during this year? Did you get more information from some of the doctors than from others and what information did you get? Was there anything different between the doctors? |
| | 14 | No, just my own doctor in King Salman Diabetes Center, and the system here (King Salman Center) is that each visit we see a different doctor. I have known diabetes for a long time because in the past I used to follow a diet and a year ago I took insulin injections and afterwards I knew I had diabetes. |
| | F | Did you get more information from some doctors than from others? What information did you get? |
| | 14 | I didn't notice any differences between the doctors. |
| 6.1 | F | How do you speak with your doctor about medications? |
| | 14 | He told me sugar level is very high and it is necessary to take insulin and gave me a diet to follow so as not to experience fatigue and tiredness. |
| 6.2 | F | Did the doctor explain to you the nature of diabetes? |
| | 14 | Yes, he did. |
| | F | Do you remember how the doctor explained the nature of disease? |
| | 14 | <p>He informed me its symptoms and prevention ways such as walking, following a daily program in eating and healthy food. He referred me to a health education specialist who gave me somebooklets containing all information relating to diabetes and wrote down for me a food program to follow, gave me medication. I followed the doctor's program and then I felt tired and he changed the medication once again and gave extra vitamins..</p> <p>Of course the doctor told me about the complications of diabetes, such as eye harm, kidneys and he was explaining to me any analysis why (he explained tests and results) satisfied fromthe doctor by his method of diabetes diagnosis and in fact</p> |

| | | |
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| | | he explained every step he did or anything we would do in the future relating to medication. |
| 7.1 | F | What was the medication suggested by the doctor for you? |
| | 14 | He didn't suggest any medication. Every three months he changed medications in terms of its quantity by increasing or decreasing, he usually suggests to me alternatives and said there are options take this or this based on the analysis , if my condition improved he would decrease the insulin dose or increase and he gave me medication according to the options available in the pharmacy . most often he suggest and says there are options or choices what do you think suits you. Sometimes no he decides what suits me without asking me |
| 7.2 | F | Did your doctor give you treatment options insulin or pump? |
| | 14 | No, if there are alternatives then he suggest {for example I discussed with him about regulator medication given with insulin he told me it wasn't available before but now I will give it because it's now available}I think the doctor gives choices based on what available in the pharmacy and gives medication without asking if it is suitable or not. |
| 7.3 | F | Did your doctor explain the advantages and disadvantages of the medication? |
| | 13 | No, he usually doesn't explain medication complications sometimes he says this is alternative for this .i read the prescription in the medication pack sometimes the pharmacist tells me about its complications {says there is a better alternative tell the doctor to prescribe it to you} |
| | F | Advantages and disadvantages of insulin or pump |
| | 14 | No I never discussed with the doctor on this |
| 7.4 | F | Did the doctor give you specific information about how to manage your illness? |
| | 14 | Yes by means of health education and diet and food program |
| 7.5 | F | Do you trust that your doctor offers you the best advice on treatment? |
| | 14 | Yes, I trust him largely. But it depends on the doctor experience and his presentation of information {sometimes you get out from the doctor and you are not convinced by the information he told you and you go and look for alternatives} |
| 8.1 | F | Do you wish to get more information about available medicines? |
| | 14 | Yes I have big desire it's good that one search for information and reads I always used to read prescriptions in the medicine box so as to know complications but the doctor should inform the patient about available medication options and complications so that the patient can decide if the medicine is without prescription the pharmacist or doctor should explain how to use it or it's complications but unfortunately usually they don't explain |
| 8.2 | F | Do you wish to discuss options with your doctor before making decisions? |
| | 14 | I decide if the doctor gave me advantages and disadvantages of medication if complications are less and advantages are more sometimes I decide provided I get sufficient information |

| | | |
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| | F | If the doctor informs you the advantages and disadvantages of medication and leave the decision to you what would you decide? |
| | 14 | Me |
| 8.3 | F | Do you want to take responsibility for the treatment options chosen? |
| | 14 | Yes I bear responsibility if I chose the medication and agreed to it and when informed and know all information why not if the doctor explained to me then he bears no responsibility and I bear full responsibility but if he asked me to bear responsibility for options I don't have sufficient information of {the doctor did not explain} in this case I refuse to pay responsibility the doctor should pay responsibility |
| 8.4 | F | Is there anyone you feel can participate in determining the treatment options? |
| | 14 | I always would like to involve my doctor only because it is better than involving others {sometimes you get experience from others and it hurts you } I rely on myself or the doctor or any medical information such as a book or the internet if there is trust and truthfulness between me and the doctor certainly I will rely on that |
| 8.5 | F | Do you have any information you would like to add before the end of the interview? |
| | 14 | Request from all doctors to take part in the decision and tell the patient of all choices or alternative he has and finally taking part in making decision so as to achieve better results in treatment and if he gives me all available choices the decision should be shared among the doctor and patient |
| | F | Before the end of the interview there are three questions related to the same subject. Please answer them? |
| | 14 | Ok. |
| | F | Thanks once again for participating in this study and here is a copy of the study summary you can keep with you. |

Name of Researcher: F

Patient's Code: 15

| Question# | |
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| | <p>I introduce myself as the researcher Fatima. First, thank you for agreeing to participate in this study. I will give a brief explanation about the study. This study is concerning views on how to participate in medical decision-making, its importance for patients as well as your opinion on the same.</p> <p>Your answers to the questions in this study will remain unknown to anyone else and do not affect your medical treatment in any case. Also, I would like your permission to record the interview in</p> |

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| | | order to save the information only and will not reach anyone else other than the researcher. Before starting the interview, here is an approval form. Please go through it and, if acceptable, sign at the bottom of the page |
| | 15 | I do not mind. |
| | F | Are you ready to start the interview? First there are general questions to answer. |
| | 15 | Ok |
| 1 | F | Date of Birth? |
| | 15 | 1/4/1385 |
| 2 | F | Sex |
| | 15 | Male |
| 3 | F | Place & date of residence? |
| | 15 | Riyadh, since I was born |
| 4 | F | When was Diabetes type1 diagnosed? |
| | 15 | Four years ago. (the patient is aware of type 1) |
| 5 | F | Have you seen more than one doctor during this year? Did you get more information from some of the doctors than from others and what information did you get? Was there anything different between the doctors? |
| | 15 | I have a brother with type 2 diabetes. I used to accompany him to the appointments sometimes and I give him his medications and look for any information he needs. So I have enough information. I just visit the doctor for prescription and repeat medication. The information is always repeated by every doctor |
| 6.1 | F | What was the diagnosis of your case? |
| | 15 | Of course I had pressure and I was doing pressure analysis and discovered I was diabetic. Then the doctor suggested to me initially a diet and food program that I should follow. And I actually followed the proposed plan and then it wasn't as the situation worsened and the doctor prescribed to me insulin. |
| 6.2 | F | Did the doctor explain to you the nature of diabetes? |
| | 15 | Yes, he gave me a sheet of nutrition and pamphlets. But as I said, I do not need all this information because I know it in advance through my experience with my brother and my exposure to newspapers and health issues in general. So I did not care about the doctor's words and I was not interested in asking for more information from the doctor. (When the doctor asked me, did you have information about diabetes, I said yes) |
| 7.1 | F | What was the medication suggested by the doctor for you? |
| | 15 | The doctor recommended the sugar regulator (Clofage), but the doctor was concentrating with me on dieting in addition to exercising, and the more sweet food I avoided, the better. He gave me a way to change my diet and to rely on healthy food. The doctor referred me to a nutritionist to help me choose the right diet for diabetics |
| 7.2 | F | Did your doctor give you treatment options? |
| | 15 | No, the doctor did not give me options, only disposable insulin needles and Clofage regulator. The doctor at each visit only updates the data and prescribes the repeat treatment. I remember when I was following up with my brother for 20 years |

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| | | there was nothing new. The doctor always determines the medication as available in the pharmacy. It is the doctor who determines the dosages without asking about the times when the dose is taken, or whether it suits me or not according to my health. I remember once the doctor told me he would increase the dose, I told him I am comfortable now and the dose is appropriate for me, but the doctor does not offer options or treatment procedures such as diet, dosage or regulator. Usually he says 'this fits you and if it causes any complications we will change it for you' |
| 7.3 | F | Did your doctor explain the advantages and disadvantages of the medication? |
| | 15 | No, usually the doctor does not explain. If there is something I look for it by myself and I ask the doctor if I want to make sure of the information |
| | F | Advantages and disadvantages of insulin or pump |
| | 15 | No, he never explained it to me. |
| 7.4 | F | Did the doctor give you specific information about how to manage your illness? |
| | 15 | Yes of course like I said before. |
| 7.5 | F | Do you trust that your doctor offers you the best advice on treatment? |
| | 15 | Yes trust exists. I have a perception that diabetes is a disease that everyone knows and knows how to treat it because there is a difference between diabetes and the disease of pressure, which I still suffer from and I find no information or diagnosis or things that help me |
| 8.1 | F | Do you wish to get more information about available medicines? |
| | 15 | Yes I have a desire and I hope to know more information about the medicines available to us in the future. I have heard about a new treatment but so far they say it has not proved effective, and I asked the doctor about it and he told me 'it never fits'. Sometimes I ask a pharmacist colleague. |
| 8.2 | F | Do you wish to discuss options with your doctor before making decisions? |
| | 15 | Yes, I am sure I have a desire if there are options better than continue on a medication that will be prescribed all the time. But the doctor does not discuss the options. The doctor only prescribes medication as available and rarely talks about the disadvantages or benefits of medication. The same routine even for treatment options and this has become well known to us |
| 8.3 | F | Do you want to take responsibility for the treatment options chosen? |
| | 15 | No, it is essential that the doctor involves my decision and tells me about the available treatment and then tells me which is best for me. For example, say this is appropriate and this is also appropriate and I suggest this is the most appropriate. Then he said (here I consider it a joint decision between me and him because he involved me in the choices) |
| 8.4 | F | Is there anyone you feel can participate in determining the treatment options? |

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| | 15 | I always like to listen to multiple opinions, but in the end I take the doctor's opinion |
| 8.5 | F | Do you have any information you would like to add before the end of the interview? |
| | 15 | I hope for better options in treatment, for example the insulin pump that I have heard about a lot and is considered comfortable and a second option. I expect it is a German company. But unfortunately it is not available. Some doctors use the command formula in the treatment options and say "Take this" |
| | F | Before the end of the interview there are three questions related to the same subject. Please answer them? |
| | 15 | Ok. |
| | F | Thanks once again for participating in this study and here is a copy of the study summary you can keep with you. |

Name of Researcher: F

Patient's Code: 16

| Question# | | |
|-----------|----|---|
| | | I introduce myself as the researcher Fatima. First, thank you for agreeing to participate in this study. I will give a brief explanation about the study. This study is concerning views on how to participate in medical decision-making, its importance for patients as well as your opinion on the same. Your answers to the questions in this study will remain unknown to anyone else and do not affect your medical treatment in any case. Also, I would like your permission to record the interview in order to save the information only and will not reach anyone else other than the researcher. Before starting the interview, here is an approval form. Please go through it and, if acceptable, sign at the bottom of the page |
| | 16 | I do not mind. |
| | F | Are you ready to start the interview? First there are general questions to answer. |
| | 16 | Ok |
| 1 | F | Date of Birth? |
| | 16 | 1/7/1386 |
| 2 | F | Sex |
| | 16 | Male |
| 3 | F | Place & date of residence? |
| | 16 | Riyadh, since I was born |
| 4 | F | When was Diabetes type1diagnosed? |
| | 16 | Three years ago approximately. But what is meant by type one? |
| | F | What types of medication have you been taking? |
| | 16 | Insulin injections |

| | | |
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| 5 | F | Have you seen more than one doctor during this year? Did you get more information from some of the doctors than from others and what information did you get? Was there anything different between the doctors? |
| | 16 | I didn't visit any doctors other than my own doctor. I don't need any more information about diabetes. I have 9 brothers who all have diabetes, so I have all the information I need. |
| 6.1 | F | What was the diagnosis of your case? |
| | 16 | They told me that I have diabetes. |
| 6.2 | F | Did the doctor explain to you the nature of diabetes? |
| | 16 | No, he just gave me the medication and he did not tell me anything else. He mentioned to me the negatives of diabetes such as renal failure, poor vision and liver. I remember the doctor did not give me or recommend to me any diet. But I remember the doctor saying I should walk and I was scared because every appointment he prescribed a different type of regulator and the injections were fixed. Sugar is still not stable. The doctor did not explain to me many thing. I feel that there is numbness in the feet. The doctor did some analysis and told me it was normal. Most of the information I know has been taken from my nine brothers who have diabetes. |
| 7.1 | F | What was the medication suggested by the doctor for you? |
| | 16 | Now it has been three years the same medication is repeated. He didn't suggest anything, just the medications. |
| 7.2 | F | Did your doctor give you treatment options? |
| | 16 | No, the doctor was repeating the same treatment. So the patient was silent and said the same treatment they gave to my brothers before, there is nothing new. |
| | F | Did the doctor give you choices of insulin and insulin pump? |
| | 16 | No, this is the first time I hear about the insulin pump |
| 7.3 | F | Did your doctor explain the advantages and disadvantages of the medication? |
| | 16 | Yes, usually when he prescribes medication he tells me how to use but he usually doesn't talk about complications. He just says if it does not suit you we will change it the following appointment. For example, once I experienced a situation and the doctor gave me the neuro (nerves) therapy and told me how to use it with insulin injections and told me that it has no effect on the injections |
| | F | Advantages and disadvantages of insulin or pump |
| | 16 | No, I don't remember he said anything about this. |
| 7.4 | F | Did the doctor give you specific information about how to manage your illness? |
| | 16 | He only mentioned sports and how it helps improve sugar decline. He did not give me options and we did not discuss on this. I tried to make myself a diet and food program but it did not help me improve my diabetes. Because I worked out this diet by myself and I don't know if it was healthy or not. I was hoping that he would help me in the diet issue so I can control the high sugar. Even he did not transfer me, like the rest of the patients, to an a health education specialist. |

| | | |
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| 7.5 | F | Do you trust that your doctor offers you the best advice on treatment? |
| | 16 | Yes, if I hadn't trusted him, I wouldn't have continued with him for three years. |
| 8.1 | F | Do you wish to get more information about available medicines? |
| | 16 | I hope, especially since I have meals to eat at the right time or sugar will decrease. I always ask my colleagues and people with diabetes if there is any new information about medicines and everyone gives a prescription and everyone gives something that looks like home remedies that reduces diabetes. But the doctor does not explain to me or give me any time and if there is something new he repeats the same medication. |
| 8.2 | F | Do you wish to discuss options with your doctor before making decisions? |
| | 16 | No, I'd rather leave it to the doctor to decide. However, I only wish he would listen to my opinion as consultation or let me know why he prescribed this medication and what are its effects on my health. |
| 8.3 | F | Do you want to take responsibility for the treatment options chosen? |
| | 16 | No, it is the doctor who bears responsibility because he prescribes the medication and he has knowledge and experience in medications and has been following up the case and he is responsible to determine medication |
| 8.4 | F | Is there anyone you feel can participate in determining the treatment options? |
| | 16 | Only the doctor. Sometimes I ask my colleagues or people who have diabetes before if there is any new medication I try to get their opinions before I take any step. |
| 8.5 | F | Do you have any information you would like to add before the end of the interview? |
| | 16 | No, thanks. |
| | F | Before the end of the interview there are three questions related to the same subject. Please answer them? |
| | 16 | Ok. |
| | F | Thanks once again for participating in this study and here is a copy of the study summary you can keep with you. |

Name of Researcher: F

Patient's Code: 17

| Question# | |
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| | <p>I introduce myself as the researcher Fatima. First, thank you for agreeing to participate in this study. I will give a brief explanation about the study. This study is concerning views on how to participate in medical decision-making, its importance for patients as well as your opinion on the same.</p> <p>Your answers to the questions in this study will remain unknown to anyone else and do not affect your medical treatment in any case. Also, I would like your permission to record the interview in order to save the information only and will not reach anyone else other than the researcher. Before starting the interview, here is</p> |

| | | |
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| | | an approval form. Please go through it and, if acceptable, sign at the bottom of the page |
| | 17 | I do not mind. |
| | F | Are you ready to start the interview? First there are general questions to answer. |
| | 17 | Ok |
| 1 | F | Date of Birth? |
| | 17 | 1/7/1970 |
| 2 | F | Sex |
| | 17 | Female |
| 3 | F | Place & date of residence? |
| | 17 | Riyadh, since I was born |
| 4 | F | When was Diabetes type1diagnosed? |
| | 17 | I don't know the type |
| | F | What types of medication have you been taking? |
| | 17 | Injections with regulator |
| | F | When was Diabetes type1diagnosed? |
| | 17 | A year ago approximately |
| 5 | F | Have you seen more than one doctor during this year? Did you get more information from some of the doctors than from others and what information did you get? Was there anything different between the doctors? |
| | 17 | No, I visited only my doctor in King Salman Diabetes Center |
| 6.1 | F | What was the diagnosis of your case? |
| | 17 | The patient asked if diabetes is associated with glands |
| | F | You can ask your doctor about this to provide you with more accurate information |
| 6.2 | F | Did the doctor explain to you the nature of diabetes? |
| | 17 | He told me that sugar is very high and told me to take care and it is necessary to follow a diet and it is necessary to exercise. But she did not explain anything else to me |
| | F | Do you remember your first appointment with the doctor? |
| | 17 | I don't know, I don't remember anything, just she gave me a medication. |
| | F | Did she explain the disease complications and causes? |
| | 17 | No, she told me to take the medication and use it at the specified time. I do not have enough information (I want someone to explain to me what diabetes is ... I want to know if diabetes affects the glands.) a lot of information in my mind. A year ago I asked them to conduct comprehensive tests for me but no one answered me. She didn't explain to me anything about diabetes. |
| | F | Does that mean the doctor didn't tell you about the nature of disease? |
| | 17 | I know that diabetes is destruction. She just told me that it has a lot of bad symptoms such as blood pressure and renal failure. She also said I have to walk a lot |
| 7.1 | F | What was the medication suggested by the doctor for you? |
| | 17 | I only use injections and regulator pills at night. |
| 7.2 | F | Did your doctor give you treatment options? |
| | 17 | She told me you have so and so and you need so and so but did not tell me which type of pills or the insulin quantity that I need,. |

| | | |
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| 7.3 | F | Did your doctor explain the advantages and disadvantages of the medication? |
| | 17 | No, he usually prescribes medications , Sometimes if he prescribes regulator he tells me it might cause me fatigue or acidity in the stomach but this is normal and will clear away in a few days. Sometimes in some appointments he just prescribe medications and asks me if there are any complications |
| | F | Advantages and disadvantages of insulin or pump |
| | 17 | yes, she told me about walking and diet and its importance to reduce sugar. She gave me substitute plans for hot weather to do at home and she advised me to buy a gym (sports) apparatus and use at home. I think the doctor is cooperative when I ask he answers my questions |
| 7.4 | F | Did the doctor give you specific information about how to manage your illness? |
| | 17 | yes, she told me about walking and diet and its importance to reduce sugar. She gave me substitute plans for hot weather to do at home and she advised me to buy a gym (sports) apparatus and use at home. I think the doctor is cooperative when I ask he answers my questions |
| 7.5 | F | Do you trust that your doctor offers you the best advice on treatment? |
| | 17 | Yes, I trust him, but I wish to look for information by myself and know about advantages or disadvantages of medication. Any new medication prescribed by the doctor I discuss with him during the following appointment |
| 8.1 | F | Do you wish to get more information about available medicines? |
| | 17 | Yes, I do, but the doctor usually doesn't explain any new thing, I tell the doctor about a new medication I hear of and ask for the doctor's opinion and sometimes he tells me to leave it because it is useless |
| 8.2 | F | Do you wish to discuss options with your doctor before making decisions? |
| | 17 | I hope there is some flexibility and discussion. I prefer the doctor would consult with me and let me know all information relating to my health. The doctor usually doesn't give me choices and never speaks just two or three words |
| 8.3 | F | Do you want to take responsibility for the treatment options chosen? |
| | 17 | I don't like to bear responsibility. The doctor should be responsible because the decision is really difficult and it is his function and role, he makes options and the he chooses the most suitable one to me and take my opinion into consideration like when he gives you a sheet of paper and you execute what it contains, for example diet |
| 8.4 | F | Is there anyone you feel can participate in determining the treatment options? |
| | 17 | I like to know more and read about diabetes but responsibility for decision and choices refer to the doctor |
| | F | Where did you get the information from? |

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| | 17 | My mother through experience in managing the disease |
| 8.5 | F | Do you have any information to add? |
| | 17 | I hope they would guide us more about the disease and how to avoid mistakes in dealing with the disease |
| | F | Before ending the interview there are three questions for you to answer |
| | 17 | Ok |
| | F | Thanks once again for participating in this study and here is a copy of the study summary you can keep with you. |

Name of Researcher: F

Patient's Code: 18

| Question# | | |
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| | | I introduce myself as the researcher Fatima. First, thank you for agreeing to participate in this study. I will give a brief explanation about the study. This study is concerning views on how to participate in medical decision-making, its importance for patients as well as your opinion on the same. Your answers to the questions in this study will remain unknown to anyone else and do not affect your medical treatment in any case. Also, I would like your permission to record the interview in order to save the information only and will not reach anyone else other than the researcher. Before starting the interview, here is an approval form. Please go through it and, if acceptable, sign at the bottom of the page |
| | 18 | I do not mind. |
| | F | Are you ready to start the interview? First there are general questions to answer. |
| | 18 | Ok |
| 1 | F | Date of Birth? |
| | 18 | 1/7/1380 |
| 2 | F | Sex |
| | 18 | Male |
| 3 | F | Place & date of residence? |
| | 18 | Riyadh, since I was born |
| 4 | F | When was Diabetes type1 diagnosed? |
| | 18 | I don't know the type |
| | F | What types of medication have you been taking? |
| | 18 | Injections |
| | F | When was Diabetes type1 diagnosed? |
| | 18 | 6 year ago approximately |

| | | |
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| 5 | F | Have you seen more than one doctor during this year? Did you get more information from some of the doctors than from others and what information did you get? Was there anything different between the doctors? |
| | 18 | Yes, I visited more than one doctor until I knew I had diabetes |
| | F | Did you get more information from some of the doctors than from others and what information did you get? Was there anything different between the doctors? |
| | 18 | yES, I got different information according to your comfortability with the doctor and good relationship you feel that you accept information. Some doctors do not talk much (less information). I saw an excellent doctor but unfortunately did not continue with him because he was moved to another area. Some doctors simplify to you the information and make you accept it and some don't. Of course they differ in the way they communicate with patient and amount of information. |
| | F | Was there anything different between the doctors? |
| | 18 | Yes of course there is difference. Some doctors are useful to me and some aren't |
| 6.1 | F | What was the diagnosis of your case? |
| | 18 | Diabetes after he did some tests |
| 6.2 | F | Did the doctor explain to you the nature of diabetes? |
| | 18 | Yes, he explained about diabetes in full and told me about diet and sportd, He warned me about shoes not to be very tight because it affects the feet of diabetics |
| | F | Do you remember your first appointment with the doctor? |
| | 18 | Yes, I remember everything and I accepted it complacently |
| 7.1 | F | What was the medication suggested by the doctor for you? |
| | 18 | Just prescribed insulin |
| 7.2 | F | Did your doctor give you treatment options? |
| | 18 | Yes, he gave me two options; insulin pump under the skin and insulin syringes. But he chose to me the pump as better for me and advised and instructed me to use it |
| 7.3 | F | Did your doctor explain the advantages and disadvantages of the medication? |
| | 18 | Yes, he explained the insulin and pump and provided me information of both and persuaded me to use the pump and he was very cooperative |
| 7.4 | F | Did the doctor give you specific information about how to manage your illness? |
| | 18 | Of course he explained this at the beginning during the first appointment about the pills, sport and diet and gave me options if I felt tired or sugar decreases and I should keep away from nervousness, Sometimes he says I am better than him on information |

| | | |
|-----|---------|---|
| | F 18 | How do you have experience in diabetes information? I am well informed and I like to read books and booklets of diabetes and I educate myself on everything relating to diabetes. My experience is built through dealing with a number of doctors but some doctors aren't very useful in this respect |
| 7.5 | F | Do you trust that your doctor offers you the best advice on treatment? |
| | 18 | It depends on whether I'm convinced by his words. Sometime I believe his words and sometimes not. I trust and believe the doctor who gives me information and persuades me. I followed with a doctor before I had diabetes and he prescribed the pump to me. I am very convinced of him and I have good relationship with him, call him on his mobile and talk to him if sugar increases. I think the patient's trust in a doctor depends on the relationship |
| 8.1 | F | Do you wish to get more information about available medicines? |
| | 18 | Sometimes I get the medications such as vitamins or sugar regulator but not use them. I read books and newspapers and sometimes I ask the doctor |
| 8.2 | F | Do you wish to discuss options with your doctor before making decisions? |
| | 18 | It depends on my my psychological comfort with the doctor if I can discuss with him the choices and usually it is the doctor who decides but should tell me what he would do. I wish to choose the medication that suits me |
| 8.3 | F | Do you want to take responsibility for the treatment options chosen? |
| | 18 | Yes of course I bear responsibility if I choose it |
| 8.4 | F | Is there anyone you feel can participate in determining the treatment options? |
| | 18 | Me alone because it is difficult to accept other people's opinions and be convinced . We do not trust nor convinced of every doctor |
| 8.5 | F | Do you have any information to add? |
| | 18 | I would like to add that I hope all doctors in general would consult and give more information to help in making decision with the patient and I hope to pass my experience I get from the doctor to other people with the same disease so as to benefit from. |
| | F | Before ending the interview there are three questions for you to answer |
| | 18 | Ok |
| | F | Thanks once again for participating in this study and here is a copy of the study summary you can keep with you. |

Name of Researcher: F

Patient's Code: 19

| | | |
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| Question# | | I introduce myself as the researcher Fatima. First, thank you for agreeing to participate in this study. I will give a brief explanation about the study. This study is concerning views on how to participate in medical decision-making, its importance for patients as well as your opinion on the same. Your answers to the questions in this study will remain unknown to anyone else and do not affect your medical treatment in any case. Also, I would like your permission to record the interview in order to save the information only and will not reach anyone else other than the researcher. Before starting the interview, here is an approval form. Please go through it and, if acceptable, sign at the bottom of the page |
| | 19 | I do not mind. |
| | F | Are you ready to start the interview? First there are general questions to answer. |
| | 19 | Ok |
| 1 | F | Date of Birth? |
| | 19 | 1/6/1381 |
| 2 | F | Sex |
| | 19 | Male |
| 3 | F | Place & date of residence? |
| | 19 | Riyadh, since I was born |
| 4 | F | When was Diabetes type1diagnosed? |
| | 19 | Two years approximately |
| 5 | F | Have you seen more than one doctor during this year? Did you get more information from some of the doctors than from others and what information did you get? Was there anything different between the doctors? |
| | 19 | No, I never visited more than one doctor, same medical center where I follow but there is a different doctor in each appointment. As far as I knowtheir words are similar with no difference, same information and diagnosis, because patients in general are aware of some information about diabetes, which is considered the disease of our modern age and all have some information about it |
| 6.1 | F | What was the diagnosis of your case? |
| | 19 | I did some tests and I found out I had diabetes |
| 6.2 | F | Did the doctor explain to you the nature of diabetes? |
| | 19 | He didn't give me much information since I have previous background about diabetes from my brother and father and I didn't need more information. The doctor asked if I knew diabetes and I said yes. |
| | F | Do you remember he explained to you the symptoms? |

| | | |
|-----|----|---|
| | 19 | Yes, he explained without details as I have information that some doctor try to look attentive which depends on profit issue since you pay money for diagnosis , but doctors in government centers say the same thing with no difference |
| 7.1 | F | What was the medication suggested by the doctor for you? |
| | 19 | Just prescribed insulin |
| 7.2 | F | Did your doctor give you treatment options? |
| | 19 | no, he didn't give any options since the available medication is insulin injections and the regulator will be given as available in the pharmacy and does not give suggestions |
| 7.3 | F | Did your doctor explain the advantages and disadvantages of the medication? |
| | 19 | No he didn't explain |
| 7.4 | F | Did the doctor give you specific information about how to manage your illness? |
| | 19 | Yes, because it is natural that the doctor explains such things since they help reduce high sugar such as sports, diet but does not give alternatives if you are busy or how to help yourself by going up the stairs more than once |
| 7.5 | F | Do you trust that your doctor offers you the best advice on treatment? |
| | 19 | Yes but it depends on the information I get from him. while most doctors do not have time to speak to every patient for half an hour since he has too many patients. He just wants to finish with all of them. I don't even know if the info I get from the doctor is accurate or not |
| 8.1 | F | Do you wish to get more information about available medicines? |
| | 19 | I rely on myself if I need new information I LOOK FOR IT FROM PEOPLE OR SOCIAL MEDIA |
| 8.2 | F | Do you wish to discuss options with your doctor before making decisions? |
| | 19 | yES, IF THE DOCTOR IS PREPARED TO DISCUSS WITH ME before making decision |
| 8.3 | F | Do you want to take responsibility for the treatment options chosen? |
| | 19 | Yes, if all the potentials are clear before me and the doctor explained them to me and there is no risk |
| 8.4 | F | Is there anyone you feel can participate in determining the treatment options? |
| | 19 | No, no one. I like to make decisions relating to my health by myself after consulting the doctor |
| 8.5 | F | Do you have any information to add? |
| | 19 | I hope electronic channels can be activated to help in determining appointment, diagnosis such as explaining symptoms which makes it easy to communicate with doctors, dispense of medications and when coming to the appointment the picture would be clear to the doctor and the doctor usually |

| | | |
|--|----|--|
| | | suggests medications and if there is a new medication I always search by myself |
| | F | Before ending the interview there are three questions for you to answer |
| | 19 | Ok |
| | F | Thanks once again for participating in this study and here is a copy of the study summary you can keep with you. |

Name of Researcher: F

Patient's Code: 20

| Question# | | |
|-----------|----|---|
| | | I introduce myself as the researcher Fatima. First, thank you for agreeing to participate in this study. I will give a brief explanation about the study. This study is concerning views on how to participate in medical decision-making, its importance for patients as well as your opinion on the same. Your answers to the questions in this study will remain unknown to anyone else and do not affect your medical treatment in any case. Also, I would like your permission to record the interview in order to save the information only and will not reach anyone else other than the researcher. Before starting the interview, here is an approval form. Please go through it and, if acceptable, sign at the bottom of the page |
| | 20 | I do not mind. |
| | F | Are you ready to start the interview? First there are general questions to answer. |
| | 20 | Ok |
| 1 | F | Date of Birth? |
| | 20 | 13/5/1398 |
| 2 | F | Sex |
| | 20 | Female |
| 3 | F | Place & date of residence? |
| | 20 | Riyadh, since I was born |
| 4 | F | When was Diabetes type1diagnosed? |
| | 20 | 4 years, but the doctor didn't tell me which type |
| 5 | F | Have you seen more than one doctor during this year? Did you get more information from some of the doctors than from others and what information did you get? Was there anything different between the doctors? |
| | 20 | Yes, I visited two doctors and there was a big difference between them |
| | F | Did you get more information from some of the doctors than from others and what information did you get? |

| | | |
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| | 20 | THE FIRST female DOCTOR WAS VERY GOOD AND EXPLAINS TO ME AND SIMPLIFY THE INFORMATION and helps me more than the first male doctor who only wrote the medication and does not discuss information. For example he asked me what I want and I said the same medication and he just wrote it down to me and did not ask me later if it was suitable or not or if there are any side effects nor did he demanded any tests to check the medication is suitable |
| 6.1 | F | How did you speak with your doctor? |
| | 20 | I don't remember he explained anything to me. He said I should follow with them regularly on medication and diet, I don't know anything about diabetes except its name |
| 6.2 | F | Did the doctor explain to you the nature of diabetes? |
| | 20 | Yes, he explained it is hereditary for usbut did not explain its symptoms or its nature, which I already know from my diabetic mother |
| 7.1 | F | What was the medication suggested by the doctor for you? |
| | 20 | He gave me regulator pills and insulin injections |
| 7.2 | F | Did your doctor give you treatment options? |
| | 20 | No, he just said the available cure is insulin and regulators and I can see it is the same medication used by mother for 15 years |
| 7.3 | F | Did your doctor explain the advantages and disadvantages of the medication? |
| | 20 | No, he didn't give me. He just prescribed the medication. He doesn't even talk about complications and my daughter reads them out from the medicine instructions insert. Sometimes I take the medication without knowing the advantages and disadvantages |
| 7.4 | F | Did the doctor give you specific information about how to manage your illness? |
| | 20 | Yes, he suggested to me food program to follow and to exercise and referred me to health education for food programs and general instructions about diet and change of food program |
| 7.5 | F | Do you trust that your doctor offers you the best advice on treatment? |
| | 20 | Surely the doctor looks for his patient's interest and offers the best he has |
| 8.1 | F | Do you wish to get more information about available medicines? |
| | 20 | Yes, certainly I wish to get more information because the doctor doesn't explain treatment steps or talk with me about new medications |
| 8.2 | F | Do you wish to discuss options with your doctor before making decisions? |
| | 20 | No I don't wish to discuss options I prefer leave it to the doctor as he is well informed on diseases and the medications |
| | F | |

| | | |
|-----|----|--|
| | 20 | Once again we asked the same question in another way: In case the doctor provides all information relating to choices, do you wish to discuss or leave it to the doctor? The doctor alone |
| 8.3 | F | Do you want to take responsibility for the treatment options chosen? |
| | 20 | No, I don't want to bear responsibility for any decision relating to my health. I like to leave it to the doctor who is supposed to bear responsibility |
| 8.4 | F | Is there anyone you feel can participate in determining the treatment options? |
| | 20 | I always leave this to the doctor who knows more than me |
| 8.5 | F | Do you have any information to add? |
| | 20 | No thanks |
| | F | Before ending the interview there are three questions for you to answer |
| | 20 | Ok |
| | F | Thanks once again for participating in this study and here is a copy of the study summary you can keep with you. |

Name of Researcher: F

Patient's Code: 21

| Question# | | |
|-----------|----|---|
| | | I introduce myself as the researcher Fatima. First, thank you for agreeing to participate in this study. I will give a brief explanation about the study. This study is concerning views on how to participate in medical decision-making, its importance for patients as well as your opinion on the same. Your answers to the questions in this study will remain unknown to anyone else and do not affect your medical treatment in any case. Also, I would like your permission to record the interview in order to save the information only and will not reach anyone else other than the researcher. Before starting the interview, here is an approval form. Please go through it and, if acceptable, sign at the bottom of the page |
| | 21 | I do not mind. |
| | F | Are you ready to start the interview? First there are general questions to answer. |
| | 21 | Ok |
| 1 | F | Date of Birth? |

| | | |
|-----|----|---|
| | 21 | 32 |
| 2 | F | Sex |
| | 21 | Female |
| 3 | F | Place & date of residence? |
| | 21 | Riyadh, since I was born |
| 4 | F | When was Diabetes type1diagnosed? |
| | 21 | I don't know the meaning of type but I know it means increase of blood sugar |
| 5 | F | Have you seen more than one doctor during this year? Did you get more information from some of the doctors than from others and what information did you get? Was there anything different between the doctors? |
| | 21 | No, I never visited more than one doctor, Sometimes the hospital of the diabetes center organize explanatory lectures about diabetics and these lectures provide usefull knowledge and information about food program |
| | F | Who organize these lectures? |
| | 21 | The Health Education in the Medical Center |
| | F | Did you get more information from some of the doctors than from others and what information did you get? Was there anything different between the doctors? |
| | 21 | Yes, the information from the lectures was vey useful |
| 6.1 | F | Did the doctor explain the nature of disease? |
| | 21 | I remember my first appointment when I found out I had diabetes the doctor explained to me everything associated with diabetes and how I deal with the disease and its nature and referred me to the health education . The health education organizes lectures about diabetes which were very useful to me as I got a lot of information and the services by the center in terms of information about the disease and what to do if sugar rises, also diet and food program. The doctor was concerned about my health and if he notice any increase of sugar he gets angry with me and treated me as one of his daughters, I'm happy and satisfied with the doctor |
| 7.1 | F | What was the medication suggested by the doctor for you? |
| | 21 | In the first appointment the doctor suggested I should follow a diet with regulator pills and after two month she gave me insulin injections because sugar was very high |
| 7.2 | F | Did your doctor give you treatment options? |
| | 21 | yes, she did |
| | F | How? |
| | 21 | SHE EXPLAINED TO ME HOW TO TAKE INJECTIONS AND THERE WERE two kinds of pills and she told me which type was more suitable for me |
| | F | What did she tell you about pills? Did she explain advantages and disadvantages? |

| | | |
|-----|----|---|
| | 21 | Yes, she said the regulator might cause fatiguebin stomach but I would say the second is more suitable for you. He told me to try it for a month and if not good he can change it |
| 7.3 | F | Did your doctor explain the advantages and disadvantages of the medication? for example insulin and pump? |
| | 21 | No, she never explained this |
| 7.4 | F | Did the doctor give you specific information about how to manage your illness? |
| | 21 | Yes, she explained the diet and food program, sports and health education, and in the lectures organized periodically by the center they present examples of some cases and how to deal with and the symptoms |
| 7.5 | F | Do you trust that your doctor offers you the best advice on treatment? |
| | 21 | Yes, because the doctor does the best he can to satisfy his patients |
| 8.1 | F | Do you wish to get more information about available medicines? |
| | 21 | Yes I do if there is something new |
| | F | Do you expect o get such information from the doctor? |
| | 21 | yES, THE DOCTOR ALWAYS PROVIDES INFORMATIONAND I DON'T NEED TO GET INFORMATION FROM OTHER SOURCES and I'm satisfied by the level of information provided to me by the doctor |
| 8.2 | F | Do you wish to discuss options with your doctor before making decisions? |
| | 21 | Yes, I do have a strong desire to discuss options if there be better options and if the doctor provides all information I like to decide the choice suitable to me |
| 8.3 | F | Do you want to take responsibility for the treatment options chosen? |
| | 21 | No, I don't want to bear responsibility the doctor who is supposed to bear responsibility since he knows better and more experienced |
| 8.4 | F | Is there anyone you feel can participate in determining the treatment options? |
| | 21 | No, the doctor only |
| 8.5 | F | Do you have any information to add? |
| | 21 | No thanks |
| | F | Before ending the interview there are three questions for you to answer |
| | 21 | Ok |

| | | |
|--|---|--|
| | F | Thanks once again for participating in this study and here is a copy of the study summary you can keep with you. |
| | | |

Name of Researcher: F

Patient's Code: 22

| Question# | | |
|-----------|----|---|
| | | I introduce myself as the researcher Fatima. First, thank you for agreeing to participate in this study. I will give a brief explanation about the study. This study is concerning views on how to participate in medical decision-making, its importance for patients as well as your opinion on the same. Your answers to the questions in this study will remain unknown to anyone else and do not affect your medical treatment in any case. Also, I would like your permission to record the interview in order to save the information only and will not reach anyone else other than the researcher. Before starting the interview, here is an approval form. Please go through it and, if acceptable, sign at the bottom of the page |
| | 22 | I do not mind. |
| | F | Are you ready to start the interview? First there are general questions to answer. |
| | 22 | Ok |
| 1 | F | Date of Birth? |
| | 22 | 30/1/1997 |
| 2 | F | Sex |
| | 22 | Female |
| 3 | F | Place & date of residence? |
| | 22 | Riyadh, since I was born |
| 4 | F | When was Diabetes type1diagnosed? |
| | 22 | This year - type one |
| | F | What type of medication are you taking |
| | 22 | Insulin injections |
| 5 | F | Have you seen more than one doctor during this year? Did you get more information from some of the doctors than from others and what information did you get? Was there anything different between the doctors? |
| | 22 | Yes, two doctors |
| | F | Did you get more information from some of the doctors than from others and what information did you get? Was there anything different between the doctors? |
| | 22 | |

| | | |
|-----|---------|--|
| | F 22 | <p>The first doctor checks and follows with me and the second doctor is nutritional specialist but all the information was the same I didn't notice any difference. The nutritional specialist guides were to determine the type of food suitable to diabetics and the diet. The first doctor gave me general information about diabetes and following treatment</p> <p>Was there anything different between the doctors?</p> <p>No absolutely,</p> |
| 6.1 | F 22 | <p>Do you remember the first appointment with the doctor?</p> <p>I was in Intensive Care Unit as I had diabetes coma and after that I was transferred to the private doctor after I was discharged from the ICU.</p> <p>The doctor informed me it was the first type and it is necessary I take insulin and follow a diet and food program and he explained to me the causes of the high sugar and gave me all sufficient information about sugar and its nature and how to adapt with it. The doctor consulted with me in every step during diagnosis, e.g. he told me why he did the tests and so on</p> |
| 7.1 | F 22 | <p>What was the medication suggested by the doctor for you?</p> <p>Insulin and regulator</p> |
| 7.2 | F 22 | <p>Did your doctor give you treatment options?</p> <p>Yes, the doctor gave me two choices; the pump and insulin but I refused the pump and he left the decision to me.</p> <p>I like the doctor to involve me in decision</p> |
| 7.3 | F 22 | <p>Did your doctor explain the advantages and disadvantages of the medication? for example insulin and pump?</p> <p>Yes he gave me all information about the pump and insulin injections. I prefer insulin injections as I feel it is easier for me. He strongly recommended the pump but I refused.</p> <p>Advantages and disadvantages of insulin or pump?</p> <p>Yes, he explained in detail</p> |
| 7.4 | F 22 | <p>Did the doctor give you specific information about how to manage your illness?</p> <p>Yes, he explained in detail such as diet, sports and referred me to a health education specialist to help me more in finding alternatives</p> |
| 7.5 | F 22 | <p>Do you trust that your doctor offers you the best advice on treatment?</p> <p>Yes of course, he always gives me the best choices and guides and leaves decision to me</p> |
| 8.1 | F | <p>Do you wish to get more information about available medicines?</p> |

| | | |
|-----|----|---|
| | 22 | I sometimes look for any information I search online, or social media or sometimes I ask the doctor during appointments |
| 8.2 | F | Do you wish to discuss options with your doctor before making decisions? |
| | 22 | I sometimes give choices to the doctor and discuss with him and guides me if the choices are useful to my health, and if he gives me two alternatives I choose the one suitable to me |
| 8.3 | F | Do you want to take responsibility for the treatment options chosen? |
| | 22 | Yes, since I have chosen it provided I have all information that help me to choose the best solutions |
| 8.4 | F | Is there anyone you feel can participate in determining the treatment options? |
| | 22 | I like to hear opinions from those around me but eventually it is my decision, even with the doctor I listen to his opinion but I make the decision |
| 8.5 | F | Do you have any information to add? |
| | 22 | No thanks |
| | F | Before ending the interview there are three questions for you to answer |
| | 22 | Ok |
| | F | Thanks once again for participating in this study and here is a copy of the study summary you can keep with you. |
| | | |

Name of Researcher: F

Patient's Code: 23

| | | |
|-----------|----|--|
| Question# | | |
| | | I introduce myself as the researcher Fatima. First, thank you for agreeing to participate in this study. I will give a brief explanation about the study. This study is concerning views on how to participate in medical decision-making, its importance for patients as well as your opinion on the same. Your answers to the questions in this study will remain unknown to anyone else and do not affect your medical treatment in any case. Also, I would like your permission to record the interview in order to save the information only and will not reach anyone else other than the researcher. Before starting the interview, here is an approval form. Please go through it and, if acceptable, sign at the bottom of the page |
| | 23 | I do not mind. |
| | F | Are you ready to start the interview? First there are general questions to answer. |

| | | |
|-----|------|---|
| | 23 | Ok |
| 1 | F | Date of Birth? |
| | 23 | 1/7/1394 |
| 2 | F | Sex |
| | 23 | Female |
| 3 | F | Place & date of residence? |
| | 23 | Riyadh, since I was born |
| 4 | F | When was Diabetes type1 diagnosed? |
| | 23 | Five years ago |
| | F | What type of medication are you taking? |
| | 23 | Injections |
| 5 | F | Have you seen more than one doctor during this year? Did you get more information from some of the doctors than from others and what information did you get? Was there anything different between the doctors? |
| | 23 | No, only one doctor who follows my case |
| 6.1 | F | What was the diagnosis of your case? |
| | 23 | Diabetes type one |
| 6.2 | F | Did the doctor explain the nature of the disease? |
| | 23 | No, he didn't explain. I read about it in newspapers, the internet and TV programs. I don't remember the doctor explained anything. She talked about complications and diet. |
| | F | Do you remember your first appointment with the doctor? |
| | 23 | Yes, I just remember this information I told you but didn't explain disease nature in detail until she prescribed the medication and it was supposed she shouldn't have prescribed it because I was |
| 7.1 | F | What was the medication suggested by the doctor for you? |
| | 23 | No, she gave me insulin injections at the beginning gave me a regulator and diet but I didn't follow carefully and then she gave me insulin injections |
| 7.2 | F | Did your doctor give you treatment options? |
| | 23sn | No, she didn't give choice, She prescribed the medication as available in the pharmacy and well-known to all diabetics |
| 7.3 | F | Did your doctor explain the advantages and disadvantages of the medication? for example insulin and pump? |
| | 23 | She didn't explain anything. She wrote the prescription and we take from the pharmacy. She didn't even talk about insulin complications. I read about it online. I remember once I refused to take the medication she wrote to me in a prescription and I didn't know when I came to the pharmacy because I wasn't accustomed to it and when I returned to the doctor she said it was the available medication. She didn't even tell me that she changed medication. Sometimes I search for information and |
| | F | |
| | 23 | |

| | | |
|-----|----|--|
| | F | <p>then ask her about it. My husband is a pharmacist and helps me in choosing the best medication if prescribed by the doctor.</p> <p>Even if I had new symptoms and told her she wouldn't change the quantity of medication. They are not cooperative and no relationship between the doctor and his patients . the diabetic should be knowledgeable and aware of everything because it may result in his death but the doctors do not offer us proper attention i feel the patient needs more information on medication and thier complications. the doctor didn't even explain to me that she changed medication i was surprised in the pharmacy when i found quantity of medication changed without being informed on the reason and when there is new medication in the pharmacy she didn't tell me or when there are choices in medication she also didn't tell me</p> |
| | 23 | <p>Advantages and disadvantages of insulin or pump?</p> <p>no, i never heard of the pump</p> |
| 7.4 | F | Did the doctor give you specific information about how to manage your illness? |
| | 23 | When I first had diabetes he transferred me to health education and I got sufficient information on food, diet and sports |
| 7.5 | F | Do you trust that your doctor offers you the best advice on treatment? |
| | 23 | No, there is no trust, Now one is scared when you take any medication you don't know why it was prescribed and you cannot discuss with the doctor on medications. All the information provided by doctors is already well known to every one and there is nothing new |
| 8.1 | F | Do you wish to get more information about available medicines? |
| | 23 | of course every one wishes to learn about new things relating to the disease what is useful and what is harmful and the choices i think if i don't follow with the doctor it will be better because there is nothing new |
| 8.2 | F | Do you wish to discuss options with your doctor before making decisions? |
| | 23 | yes it is better that the patient discuss the options that helps him on medication |
| 8.3 | F | Do you want to take responsibility for the treatment options chosen? |
| | 23 | it depends on the treating doctor if i see him trust worthy then i bear responsibility for choice of suggested medication . it is better for the patient to make his own desicion |
| 8.4 | F | Is there anyone you feel can participate in determining the treatment options? |
| | 23 | if i feel hesitant i like to consult my husband or the doctor to help me in the desicion but it is my own desicion |
| 8.5 | F | Do you have any information to add? |

| | | |
|--|----|--|
| | 23 | yes i hope to get everything and information that help diabetics to choose suitable medications because sometimes we try home remedies |
| | F | Before ending the interview there are three questions for you to answer |
| | 23 | Ok |
| | F | Thanks once again for participating in this study and here is a copy of the study summary you can keep with you. |
| | | |

Name of Researcher: F

Patient's Code: 24

| Question# | | |
|-----------|----|---|
| | | I introduce myself as the researcher Fatima. First, thank you for agreeing to participate in this study. I will give a brief explanation about the study. This study is concerning views on how to participate in medical decision-making, its importance for patients as well as your opinion on the same. Your answers to the questions in this study will remain unknown to anyone else and do not affect your medical treatment in any case. Also, I would like your permission to record the interview in order to save the information only and will not reach anyone else other than the researcher. Before starting the interview, here is an approval form. Please go through it and, if acceptable, sign at the bottom of the page |
| | 24 | I do not mind. |
| | F | Are you ready to start the interview? First there are general questions to answer. |
| | 24 | Ok |
| 1 | F | Date of Birth? |
| | 24 | 1/7/1397 |
| 2 | F | Sex |
| | 24 | Male |
| 3 | F | Place & date of residence? |
| | 24 | Riyadh, since I was born |
| 4 | F | When was Diabetes type1 diagnosed? |
| | 24 | Five years ago |
| | F | What type of medication are you taking? |
| | 24 | Injections |

| | | |
|-----|----|--|
| | | |
| 5 | F | Have you seen more than one doctor during this year? Did you get more information from some of the doctors than from others and what information did you get? Was there anything different between the doctors? |
| | 24 | no |
| 6.1 | F | did the doctor explain the disease nature ? |
| | 24 | that means what is the disease nature |
| 6.2 | F | Did the doctor explain for example the complications and ways of protection?? |
| | 24 | yes he explained but i don't remember. i remember he said that diet and sport are necessary |
| | F | Do you remember when the first diagnosis was done? |
| | 24 | 5 years agoand i remember he transferred me to health education for diet and food program |
| 7.1 | F | What was the medication suggested by the doctor for you? |
| | 24 | he gave me just insulin |
| 7.2 | F | Did your doctor give you treatment options? |
| | 24 | no, he prescribed without asking me because i expect it was the available |
| 7.3 | F | Did your doctor explain the advantages and disadvantages of the medication? |
| | 24 | What does advantage mean? |
| | F | For example did he tell you about insulin penefit?are there alternatives or did he explain insulin complications ? |
| | 24 | yes, he usually explains such things when he prescribes insulin if not taken there will be complications but he doesn't explain in details |
| | F | what do you mean by details? |
| | 24 | it means he didn't say anything about sugar regulator that it does so and so, he just told me to be carefull and take care and not forget injections because it might cause coma |
| | F | Advantages and disadvantages of insulin or pump? |
| | 24 | no, it is the first time i hear about pump |
| 7.4 | F | Did the doctor give you specific information about how to manage your illness? |
| | 24 | he transferred me to health education specialist who gave me a paper and food programs to follow and i need to know all information because it is relating to my life and the doctor usually never gives you information i know the high risk of the disease it is just i didn't take all information from the doctor. sometimes i |

| | | |
|-----|----|---|
| | | hear from programs or other patients who had complications but the doctor rarely takes in anything related to diabetics. |
| 7.5 | F | Do you trust that your doctor offers you the best advice on treatment? |
| | 24 | i don't have any choice better than the doctor i have to trust him otherwise i will not accept medication |
| 8.1 | F | Do you wish to get more information about available medicines? |
| | 24 | yes i have a wish to know new medications that can help diabetics |
| 8.2 | F | Do you wish to discuss options with your doctor before making decisions? |
| | 24 | yes it is better he give me choices and explains which is better if the doctor gave you advantages and disadvantages of medication and leave desicion to you what would you decide? |
| | f | its better he give me one choice only. it is his duty to provide me information and finds out the best for me. |
| | 24 | |
| 8.3 | F | Do you want to take responsibility for the treatment options chosen? |
| | 24 | yes but the doctor should share it with me and i decide |
| 8.4 | F | Is there anyone you feel can participate in determining the treatment options? |
| | 24 | i like that i decide and the doctor provide consultation |
| 8.5 | F | Do you have any information to add? |
| | 24 | i prefer the doctor involves me because doctors write down prescription without consulting in new things |
| | F | Before ending the interview there are three questions for you to answer |
| | 24 | Ok |
| | F | Thanks once again for participating in this study and here is a copy of the study summary you can keep with you. |
| | | |

Name of Researcher: F

Patient's Code: 25

| Question# | | |
|-----------|--|---|
| | | I introduce myself as the researcher Fatima. First, thank you for agreeing to participate in this study. I will give a brief explanation about the study. This study is concerning views on how to participate in medical decision-making, its importance for patients as well as your opinion on the same. |

| | | |
|-----|----|--|
| | | Your answers to the questions in this study will remain unknown to anyone else and do not affect your medical treatment in any case. Also, I would like your permission to record the interview in order to save the information only and will not reach anyone else other than the researcher. Before starting the interview, here is an approval form. Please go through it and, if acceptable, sign at the bottom of the page |
| | 25 | I do not mind. |
| | F | Are you ready to start the interview? First there are general questions to answer. |
| | 25 | Ok |
| 1 | F | Date of Birth? |
| | 25 | 1/7/1382 |
| 2 | F | Sex |
| | 25 | Female |
| 3 | F | Place & date of residence? |
| | 25 | Riyadh, since I was born |
| 4 | F | When was Diabetes type1diagnosed? |
| | 25 | Three years ago |
| | F | What type of medication are you taking? |
| | 25 | Injections |
| 5 | F | Have you seen more than one doctor during this year? Did you get more information from some of the doctors than from others and what information id you get? Was there anything different between the doctors? |
| | 25 | no |
| 6.1 | F | do you remember the first appointment with the doctor ? |
| 6.2 | 25 | i had a general check up and i discovered a high blood sugar and i was shocked that i had diabetes and i was admitted to hospital |
| | F | Did the doctor explain the nature of the illness? |
| | 25 | yes she explained and said it is risky and has complications and you need to take care of diabetes. i was afraid of the disease but after seeing the doctor she reassured that all is fine.at the begining i refused to take injections and she explained to me and demonstrated to my by showing me an orange and inserted the needle in it and said it is so easy don't be scared. she didn't explain anything to me but my daughter explained to me because she knows everything and read about it . the doctor asked me generally she was aware that i have experience she told me to pay attention to its complications |
| | F | where did you get this information? |
| | 25 | from tv,my daughters and my sisters |

| | | |
|-----|----|---|
| 7.1 | F | What was the medication suggested by the doctor for you? |
| | 25 | just insulin and regulator |
| 7.2 | F | Did your doctor give you treatment options? |
| | 25 | no, she didn't ,the doctor told me to try and if it don't suit me she will change it for example she prescribed the regulator and it did not suit me and caused diarrhoea and in the following appointment she changed it |
| 7.3 | F | Did your doctor explain the advantages and disadvantages of the medication? |
| | 25 | she always choose the best to me based on her opinion because i don't know tybes of medication |
| | F | |
| | 25 | Advantages and disadvantages of insulin or pump? |
| | F | no, she doesn't explain if i told her it doesn't suit me she changes it |
| | 25 | |
| | F | |
| | 25 | |
| 7.4 | F | Did the doctor give you specific information about how to manage your illness? |
| | 25 | yes explained about diet and sport and transferred me to health education |
| 7.5 | F | Do you trust that your doctor offers you the best advice on treatment? |
| | 25 | yes of course because she has experience and always looks for better choices to her patients. i can discuss with her if i have experience in medication tybesbut if i am ignorant about medication no.it is she who decides and certainly she choses the best |
| | f | does she inform you about desicions? |
| | 25 | no she never informs she choses because she look at test |
| 8.1 | F | Do you wish to get more information about available medicines? |
| | 25 | yes certainly i search for medication sometimes i like to know and look by myself and if there is new medication or suitable to me . the patient said {it is supposed as patient i should search and ask} |
| 8.2 | F | Do you wish to discuss options with your doctor before making decisions? |
| | 25 | yes but if for example i heard on a tv program a doctor saying sometimes i can't give you this medicine because it does not suit you . as a patient if i heard information and asked my doctor and |

| | | |
|-----|---------|--|
| | f 25 | he sayed he didn't hear about it and who told you that i wouldn't know who i should believe the doctor on tv or the doctor i follow with . for this reason i leave choice for the doctor. the doctor according to the patient worth is the one who knows what suits his patients and look for the best to them but doctors generally don't give choices. it is they who decide and we are accustomed to thier manner and thier tretment is traditional.the patient said {i heard there is insulin pump in kuwait and heard about it in program also and when i asked the doctor she said it isn't available so i don't know if it suits my situation or not} |
| 8.3 | F | Do you want to take responsibility for the treatment options chosen? |
| | 25 | i wouldn't take risk and bear responsibilty i will choose if the doctor says take it i measure the rate of risk and if it high i wouldn't take it i will leave it for the doctor it is she who decides if advantages are high and disadvantages lower i would take it but if the opposite i will leave it to the doctor whether bills,injections or pump and surely the doctor takes the best choices to me |
| 8.4 | F | Is there anyone you feel can participate in determining the treatment options? |
| | 25 | i expect the doctor to be always sincere in his work and has experience better than me sometimes i see my sister being treted in another hospital and for the same disease and i ask her if she is following the same steps and medication and she tells me and advices me |
| 8.5 | F | Do you have any information to add? |
| | 25 | yes, i hope the doctor would simplify information to patient and should not be contradictory to tv programs so that we make sure of every new information about diabetes |
| | F | Before ending the interview there are three questions for you to answer |
| | 25 | Ok |
| | F | Thanks once again for participating in this study and here is a copy of the study summary you can keep with you. |
| | | |
| | | |

Name of Researcher: F

Patient's Code: 26

| | | |
|-----------|--|--|
| Question# | | |
| | | I introduce myself as the researcher Fatima. First, thank you for agreeing to participate in this study. I will give a brief explanation |

| | | |
|-----|----|---|
| | | <p>about the study. This study is concerning views on how to participate in medical decision-making, its importance for patients as well as your opinion on the same.</p> <p>Your answers to the questions in this study will remain unknown to anyone else and do not affect your medical treatment in any case. Also, I would like your permission to record the interview in order to save the information only and will not reach anyone else other than the researcher. Before starting the interview, here is an approval form. Please go through it and, if acceptable, sign at the bottom of the page</p> |
| | 26 | I do not mind. |
| | F | Are you ready to start the interview? First there are general questions to answer. |
| | 26 | Ok |
| 1 | F | Date of Birth? |
| | 26 | 1/7/1391 |
| 2 | F | Sex |
| | 26 | Female |
| 3 | F | Place & date of residence? |
| | 26 | Riyadh, since I was born |
| 4 | F | When was Diabetes type1 diagnosed? |
| | 26 | 2 years approximately |
| | F | What type of medication are you taking? |
| | 26 | Injections |
| 5 | F | Have you seen more than one doctor during this year? Did you get more information from some of the doctors than from others and what information id you get? Was there anything different between the doctors? |
| | 26 | no |
| 6.1 | F | do you remember the first appointment with the doctor ? |
| | 26 | no , i don't remember i forgot |
| 6.2 | F | Did the doctor explain the nature of the illness? |
| | 26 | yes in the first appointment after the test she said your sugar is high and insulin is necessary he told me about its complications and that its hereditary and she referred me to health education to show me how to take injections and gave me papers about diet and food program to be followed and i have to excercise. i visited health education only once |
| 7.1 | F | What was the medication suggested by the doctor for you? |
| | 26 | insulin only and i asked the doctor to give me bills better and she told me only the injections are suitable |
| 7.2 | F | Did your doctor give you treatment options? |
| | 26 | no, she didn't |
| | f | didn't she give you choice such as insulin or pump? |

| | | |
|-----|----|--|
| | 26 | no, i swear i don't know anything about insulin pump they just gave me injections such as insulin pen she gave choice between insulin syringe or insulin pen to take twice a day |
| 7.3 | F | Did your doctor explain the advantages and disadvantages of the medication? |
| | 26 | no i swear i sometimes decide medication dose and she never explains to me and prescribes the regulator which i don't know its complications and tired me until the following appointment and i tell her and sometimes i ask the pharmacist who says it is better to ask your doctor to determine to you |
| | f | Advantages and disadvantages of insulin or pump? |
| | 26 | no, we have never discussed on this |

| | | |
|-----|----|--|
| 7.4 | F | Did the doctor give you specific information about how to manage your illness? |
| | 26 | yes by means of health education such as diet or sport |
| 7.5 | F | Do you trust that your doctor offers you the best advice on treatment? |
| | 26 | no i trust doctors or cooperative some of them never speak much to patient just prescribe medication and keep silent |
| | f | |
| | 25 | |
| 8.1 | F | Do you wish to get more information about available medicines? |
| | 26 | yes i wish she provides me with more information because reading a book or booklet is not the same as discussing with the doctor and there should be medication choices in a better way so that the patient can choose |
| 8.2 | F | Do you wish to discuss options with your doctor before making decisions? |
| | 26 | yes i hope so |
| | f | like what? |
| | 26 | such as the pump i heard about it from people and i asked the doctor and she said it doesn't suit me |
| | | . |
| 8.3 | F | Do you want to take responsibility for the treatment options chosen? |

| | | |
|-----|----|---|
| | 26 | yes conditional that the doctor gives sufficient information so that one will not harm himself by choosing something and later on doesn't suit him and the doctor bears part of responsibility because he provides available choices to patient |
| 8.4 | F | Is there anyone you feel can participate in determining the treatment options? |
| | 26 | yes my husband i always involve him because he is also diabetic |
| 8.5 | F | Do you have any information to add? |
| | 26 | no thanks |
| | F | Before ending the interview there are three questions for you to answer |
| | 26 | Ok |
| | F | Thanks once again for participating in this study and here is a copy of the study summary you can keep with you. |

Name of Researcher: F

Patient's Code: 27

| Question# | | |
|-----------|----|---|
| | | I introduce myself as the researcher Fatima. First, thank you for agreeing to participate in this study. I will give a brief explanation about the study. This study is concerning views on how to participate in medical decision-making, its importance for patients as well as your opinion on the same. Your answers to the questions in this study will remain unknown to anyone else and do not affect your medical treatment in any case. Also, I would like your permission to record the interview in order to save the information only and will not reach anyone else other than the researcher. Before starting the interview, here is an approval form. Please go through it and, if acceptable, sign at the bottom of the page |
| | 27 | I do not mind. |
| | F | Are you ready to start the interview? First there are general questions to answer. |
| | 27 | Ok |
| 1 | F | Date of Birth? |
| | 27 | 1/7/1387 |
| 2 | F | Sex |
| | 27 | Female |
| 3 | F | Place & date of residence? |
| | 27 | Riyadh, since I was born |
| 4 | F | When was Diabetes type1diagnosed? |
| | 27 | 25 years approximately |

| | | |
|-----|-------------------|--|
| | F 27 | What type of medication are you taking? Insulin |
| 5 | F | Have you seen more than one doctor during this year? Did you get more information from some of the doctors than from others and what information did you get? Was there anything different between the doctors? |
| | 27 | no |
| 6.1 | F | Did the doctor explain to you the nature of disease? |
| 6.2 | 27 F 27 | I explained to the doctor the symptoms of disease and she asked for for tests and found out I had diabetes. The doctor scared me at the beginning and said I want to tell you something you should accept . I was scared and expected it was cancer and she said it infects every one and then she said I had diabetes and explained it was hereditary and explained its complications and then she showed me around to health education and asked me to start a diet Do you remember how the doctor explain the nature of the disease? yes she explained in details about its complications and asked me to start a diet. |
| 7.1 | F | What was the medication suggested by the doctor for you? |
| | 27 | She gave me diet and regulator at the beginning for a period of one year and then she prescribed insulin |
| 7.2 | F | Did your doctor give you treatment options? |
| | 27 F 27 | Yes, she suggested to me How did she suggest to you and what were the available choices? She prescribed injections and I didn't agree to take them because I'm scared of syringes and she said the insulin pen is much lighter than injections you don't experience any pain |
| 7.3 | F | Did your doctor explain the advantages and disadvantages of the medication? |
| | 27 F 27 | Yes, she explained to me the insulin benefits that it decreases sugar and the regulator and told me to continu on it and take injections on time and she gave me some advice such as dose complications if is higher or if forgotten. Advantages and disadvantages of insulin or pump? No, she didn't tell me about this |
| 7.4 | F | Did the doctor give you specific information about how to manage your illness? |

| | | |
|-----|----|---|
| | 27 | Yes, she gave me diet and food program and advised me to exercise and referred me to health education to get further information. |
| 7.5 | F | Do you trust that your doctor offers you the best advice on treatment? |
| | 27 | Sure |
| | F | How? |
| | 27 | Yes, I expect they give more details and for my own interest I have to trust them and they have experience and I tell them any problem they advise and guide me |
| 8.1 | F | Do you wish to get more information about available medicines? |
| | 27 | Yes, I do and I hope to hear the information from my doctor since I trust him |
| 8.2 | F | Do you wish to discuss options with your doctor before making decisions? |
| | 27 | I always ask the doctor why he gives me this and so on and I like to discuss with the doctor and it is necessary he she explains to me |
| 8.3 | F | Do you want to take responsibility for the treatment options chosen? |
| | 27 | No, it is the doctor who should bear responsibility because he is well informed of the information he can provide to me and I trust him |
| 8.4 | F | Is there anyone you feel can participate in determining the treatment options? |
| | 27 | I may consult one from the family who had diabetes. Sometimes I ask my daughters to share some responsibility and help me in collecting information about diabetes and give me advice |
| 8.5 | F | Do you have any information to add? |
| | 27 | Doctors should inform patients in case of any new information or medications easier to use |
| | F | Before ending the interview there are three questions for you to answer |
| | 27 | Ok |
| | F | Thanks once again for participating in this study and here is a copy of the study summary you can keep with you. |

Name of Researcher: F

Patient's Code: 28

| | |
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| Question# | |
|-----------|--|

| | | |
|-----|----|--|
| | | <p>I introduce myself as the researcher Fatima. First, thank you for agreeing to participate in this study. I will give a brief explanation about the study. This study is concerning views on how to participate in medical decision-making, its importance for patients as well as your opinion on the same.</p> <p>Your answers to the questions in this study will remain unknown to anyone else and do not affect your medical treatment in any case. Also, I would like your permission to record the interview in order to save the information only and will not reach anyone else other than the researcher. Before starting the interview, here is an approval form. Please go through it and, if acceptable, sign at the bottom of the page</p> |
| | 28 | I do not mind. |
| | F | Are you ready to start the interview? First there are general questions to answer. |
| | 28 | Ok |
| 1 | F | Date of Birth? |
| | 28 | i am 44 years old |
| 2 | F | Sex |
| | 28 | Female |
| 3 | F | Place & date of residence? |
| | 28 | Riyadh, since I was born |
| 4 | F | When was Diabetes type1 diagnosed? |
| | 28 | 6 years |
| | F | What type of medication are you taking? |
| | 28 | Insulin injections |
| 5 | F | Have you seen more than one doctor during this year? Did you get more information from some of the doctors than from others and what information id you get? Was there anything different between the doctors? |
| | 28 | yes i visited more than one doctor |
| | F | Did you get more information from some of the doctors than from others and what information id you get? |
| | 28 | yes i did and there are big differences between doctors. in medical centers they aren't qualified and don't have experience and the doctors in salman center provided me with all the information that i need even the emergency are always available it depends on your comfortability with the doctor . some of them like to speak and explain and simplify information and some of them don't reply to your questions . even in medication there is difference |
| 6.1 | F | Do you remember the first appointment with the doctor? |
| | 28 | he told me blood sugar is high and the accumulative is high |
| 6.2 | | did the doctor explained the disease nature? |

| | | |
|-----|----|---|
| | | yes of course he explained everything and disease complications ,diet and sport and transferred me to health education and gave me booklets to read and i feel the information i got was sufficient. |
| 7.1 | F | What was the medication suggested by the doctor for you? |
| | 28 | he told me that diabetes cure is insulin and how to use it and prescribed a regulator with it |
| 7.2 | F | Did your doctor give you treatment options? |
| | 28 | no he didn't give me options because diabetes is treated only by insulin and regulator. i expect if there was a better option the doctor would have told me |
| 7.3 | F | Did your doctor explain the advantages and disadvantages of the medication? |
| | 28 | yes for example he prescribed sugar regulator and said it may cause acidity in stomach and if it does not suit you come back to us to give you an alternative and i expect all doctors should explain |
| | F | advantages and disadvantages of insulin or pump? |
| | 28 | no, it is the first time i've ever heard of the pump as the doctor has never discussed it with me. |

| | | |
|-----|----|---|
| 7.4 | F | Did the doctor give you specific information about how to manage your illness? |
| | 28 | yes he transferred me to health education and gave me information about diet,food program , sport and walking and recommended to me many things |
| 7.5 | F | Do you trust that your doctor offers you the best advice on treatment? |
| | 28 | yes , i have to trust him i don't have other option and information to decide by myself {then why the doctor studied medicine since i wouldn't trust him should i go to alternative medicine} |
| | F | |
| 8.1 | F | Do you wish to get more information about available medicines? |
| | 28 | yes i wish to know more and the doctor always tells me if i need anything. and if there is anything new my husband works for Health Ministry and he tells me |
| 8.2 | F | Do you wish to discuss options with your doctor before making decisions? |
| | 28 | no, I prefer to leave decision to the doctor he knows more about my health and if the medication suits me I don't change it |

| | | |
|-----|----|---|
| | F | If the doctor informs you the advantages and disadvantages of medication and leaves decision to you, what would you decide/ |
| | 28 | The doctor alone |
| 8.3 | F | Do you want to take responsibility for the treatment options chosen? |
| | 28 | nO, IT IS THE DOCTOR WHO SHOULD BEAR RESPONSIBILITY since I have no experience and I don't know what is good for me or well suits me |
| 8.4 | F | Is there anyone you feel can participate in determining the treatment options? |
| | 28 | Yes, my husband. I always ask him and sometimes he attends the appointment with me and discusses on my behalf because he has knowledge and experience |
| 8.5 | F | Do you have any information to add? |
| | 28 | No, thanks |
| | F | Before ending the interview there are three questions for you to answer |
| | 28 | Ok |
| | F | Thanks once again for participating in this study and here is a copy of the study summary you can keep with you. |

Name of Researcher: F

Patient's Code: 29

| Question# | | |
|-----------|----|---|
| | | I introduce myself as the researcher Fatima. First, thank you for agreeing to participate in this study. I will give a brief explanation about the study. This study is concerning views on how to participate in medical decision-making, its importance for patients as well as your opinion on the same. Your answers to the questions in this study will remain unknown to anyone else and do not affect your medical treatment in any case. Also, I would like your permission to record the interview in order to save the information only and will not reach anyone else other than the researcher. Before starting the interview, here is an approval form. Please go through it and, if acceptable, sign at the bottom of the page |
| | 29 | I do not mind. |
| | F | Are you ready to start the interview? First there are general questions to answer. |
| | 29 | Ok |
| 1 | F | Date of Birth? |

| | | |
|-----|----|---|
| | 29 | 1/6/1960 |
| 2 | F | Sex |
| | 9 | Male |
| 3 | F | Place & date of residence? |
| | 29 | Riyadh, since I was born |
| 4 | F | When was Diabetes type1 diagnosed? |
| | 29 | 7 years |
| | F | What type of medication are you taking? |
| | 29 | Insulin injections and regulator |
| 5 | F | Have you seen more than one doctor during this year? Did you get more information from some of the doctors than from others and what information id you get? Was there anything different between the doctors? |
| | 29 | No |
| 6.1 | F | What was the diagnosis of your case? |
| | 29 | he told me I had diabetes |
| 6.2 | F | did the doctor explained the disease nature? |
| | 29 | He told me to refrain from seet food only and told me about diet and sports. |
| | F | What information do you have about diabetes? |
| | 29 | I don't know anything. |
| | F | Don't know how to deal with diabetes? |
| | 29 | Through experience I adapted to it and I didn't ask the doctor and he said nothing |
| | F | Did he referred you to health education? |
| | 29 | No. I just heard from other diabetics who suffer from complications, but the doctor asked me if I knew anything about diabetes and I said yes, and that was all. Then he prescribed the medication even he asked for lab tests but didn't say why this was required |
| 7.1 | F | What was the medication suggested by the doctor for you? |
| | 29 | Insulin injections and regulator |
| 7.2 | F | Did your doctor give you treatment options? |
| | 29 | No, he didn't give me any options. He prescribes as the available in the pharmacy |
| 7.3 | F | Did your doctor explain the advantages and disadvantages of the medication? |
| | 29 | No, he never explains but he says in case of any complication we change the medication. |
| | F | Advantages and disadvantages of insulin or pump? |

| | | |
|--|----|--|
| | 29 | No, I swear, this is the first time I've heard of the pump. It has been seven years on insulin injections and regulator only. He never suggested to me any medication options, In every appointment the doctor writes prescription and look at the tests and never discusses and the pharmacists sometimes gave me an alternative for sugar regulator in case it was not available in the pharmacy |
| | | |

| | | |
|-----|----|---|
| 7.4 | F | Did the doctor give you specific information about how to manage your illness? |
| | 29 | Yes, he informed me in the first appointment about diet and to keep away from sweet food and carbohydrates, and talked about sports but didn't refer me to health education for more information |
| 7.5 | F | Do you trust that your doctor offers you the best advice on treatment? |
| | 29 | Yes, I trust but I want them to explain and give patients from their time and communicate with them in a better way |
| 8.1 | F | Do you wish to get more information about available medicines? |
| | 29 | Every one wishes to get more information. I have been on the same medication for seven years but nothing changed, the same routine. Getting information could help in facilitating the patient's situation |
| 8.2 | F | Do you wish to discuss options with your doctor before making decisions? |
| | 29 | Yes, I have a wish to be involved in decisions provided I have already sufficient information so as to participate with the doctor |
| 8.3 | F | Do you want to take responsibility for the treatment options chosen? |
| | 29 | Yes, if I choose convincingly and the choice benefits be more than its risks and involves no harm to me and if there is any harm the doctor should bear responsibility |
| 8.4 | F | Is there anyone you feel can participate in determining the treatment options? |
| | 29 | The doctor alone |
| 8.5 | F | Do you have any information to add? |
| | 29 | Yes, I hope the doctor like you said, would be interested to discuss options, as well as the tests and listen to my opinion. Maybe because the doctor is busy he wouldn't discuss with every patient. Just prescribes medication. |
| | F | Before ending the interview there are three questions for you to answer |
| | 29 | Ok |

| | | |
|--|---|--|
| | F | Thanks once again for participating in this study and here is a copy of the study summary you can keep with you. |
|--|---|--|

Name of Researcher: F

Patient's Code: 30

| Question# | | |
|-----------|----|---|
| | | I introduce myself as the researcher Fatima. First, thank you for agreeing to participate in this study. I will give a brief explanation about the study. This study is concerning views on how to participate in medical decision-making, its importance for patients as well as your opinion on the same. Your answers to the questions in this study will remain unknown to anyone else and do not affect your medical treatment in any case. Also, I would like your permission to record the interview in order to save the information only and will not reach anyone else other than the researcher. Before starting the interview, here is an approval form. Please go through it and, if acceptable, sign at the bottom of the page |
| | 30 | I do not mind. |
| | F | Are you ready to start the interview? First there are general questions to answer. |
| | 30 | Ok |
| 1 | F | Date of Birth? |
| | 30 | 20/1/1983 |
| 2 | F | Sex |
| | 30 | Male |
| 3 | F | Place & date of residence? |
| | 30 | Riyadh, since I was born |
| 4 | F | When was Diabetes type1 diagnosed? |
| | 30 | 6 moths |
| | F | What type of medication are you taking? |
| | 30 | Insulin pump |
| 5 | F | Have you seen more than one doctor during this year? Did you get more information from some of the doctors than from others and what information id you get? Was there anything different between the doctors? |
| | 30 | No |
| 6.1 | F | How do you speak with your doctor about medications? |
| | 30 | Yes, he explained to me about the pump and insulin injections and discussed with me on the dose |
| 6.2 | F | Did the doctor explained the disease nature? |

| | | |
|-----|----|---|
| | 30 | Of course at the beginning diabetes was a shock to me and I was scared of its complications. He explained to me the disease complications and how to deal with it. But he doesn't talk much . I asked him because it was the first appointment I read about the disease complications on the internet and when I went to the doctor I had a lot of questions and he referred me to health education to obtain more information. |
| 7.1 | F | What was the medication suggested by the doctor for you? |
| | 30 | Insulin injections and pump |
| 7.2 | F | Did your doctor give you treatment options? |
| | 30 | Yes, of course, he should me options and I have the right to choose because when I went to the doctor in the first appointment I told him I want choices and I do not prefer one option only. |
| | F | Who did you feel satisfied by? |
| | 30 | |
| 7.3 | F | Did your doctor explain the advantages and disadvantages of the medication? |
| | 30 | Yes, frankly he explained both and gave me the advantages and I chose the pump as I felt it is suitable to me, even for the regulator he gave me several choices. |
| | | |

| | | |
|-----|----|--|
| 7.4 | F | Did the doctor give you specific information about how to manage your illness? |
| | 30 | Yes, he referred me to a health education specialist |
| 7.5 | F | Do you trust that your doctor offers you the best advice on treatment? |
| | 30 | Yes of course, but it depends on the information he provides to me and the available choices |
| 8.1 | F | Do you wish to get more information about available medicines? |
| | 30 | Surely, I want to obtain a lot of information and I search the internet and newspapers, programs, and the doctor usually doesn't provide the patient with more options. For example, in the appointment I put forward all the choices to the doctor and discuss them with him, and choose the one suitable to me provided it doesn't involve any harms, but the doctor usually doesn't provide a lot of information. |
| 8.2 | F | Do you wish to discuss options with your doctor before making decisions? |
| | 30 | Yes, I wish to discuss choices and that is my right and the doctor's duty is to provide choices to me |
| | F | If the doctor informs you advantages and disadvantages of medication and leaves decision to you, what would you decide? |

| | | |
|-----|----|---|
| | 30 | Me alone |
| 8.3 | F | Do you want to take responsibility for the treatment options chosen? |
| | 30 | Yes, I bear responsibility for my choice provided the doctor explains to me all available potentials and I decide eventually. |
| 8.4 | F | Is there anyone you feel can participate in determining the treatment options? |
| | 30 | No, just the private doctor |
| 8.5 | F | Do you have any information to add? |
| | 30 | No |
| | F | Before ending the interview there are three questions for you to answer |
| | F | Thanks once again for participating in this study and here is a copy of the study summary you can keep with you. |