FACTORS INFLUENCING DIABETIC PATIENTS' PARTICIPATION IN SHARED DECISION MAKING AT MUHIMBILI NATIONAL HOSPITAL

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FACTORS INFLUENCING DIABETIC PATIENTS' PARTICIPATION IN SHARED DECISION MAKING AT MUHIMBILI NATIONAL HOSPITAL

By

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A Dissertation Submitted in (Partial) Fulfillment of the Requirements for the Degree of Master of Bioethics of the Muhimbili University of Health and Allied Sciences

October, 2019

CERTIFICATION

The undersigned certify that they have read and hereby recommend for acceptance by Muhimbili University of Health and Allied Sciences a dissertation entitled "***Factors Influencing Diabetic Patients Participation' in Shared Decision Making at Muhimbili National Hospital***" in (Partial) fulfillment of the requirements for the degree of Master of Bioethics of Muhimbili University of Health and Allied Sciences.

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(Co-Supervisor)

Date: _____

DECLARATION AND COPYRIGHT

I, **Osward Vedasto,** declare that this **dissertation** is my own original work and that it has not been presented and will not be presented to any other university for a similar or any other degree award.

Signature_____ Date_____

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DEDICATION

This study is dedicated to my lovely parents, my lovely brothers and sisters and all those who seek for wisdom.

ABSTRACT

BACKGROUND

Patients' participation in shared decision making (SDM) regarding their treatment is defined in ethical, legal and human rights standards in the provision of care that concerns health providers and the entire community. SDM is accepted worldwide as it involves patients' rights to informed consent for medical intervention so as to avoid medical paternalism.

AIM: To explore the factors that influence diabetic patients' participation in shared decision making at Muhimbili National Hospital (MNH) in Dar es Salaam.

MATERIALS AND METHODS: This study employed a phenomenological study design using in-depth interview (IDI) data collection technique. Data collection was done between April and May of 2019 whereby 4 IDIs and 7 IDIs were conducted to healthcare providers and patients respectively. Study participants were patients with diabetes visiting and receiving care at the clinic and healthcare providers working at Muhimbili national hospital. Content analysis method was used during analysis whereby categories were reached through the process of coding with assistance by Nvivo 12 software.

RESULTS: The study found that healthcare providers (HCPs) related factors including preference, institution support, time and HCP-patient relationship influence shared decision making (SDM). Patients' related factors including patients' preference for SDM, patients' literacy and HCP-patient relationship influence SDM. Beliefs and values are socio-cultural factors found to influence SDM. Also, the study found that decision aids are need for SDM execution.

Conclusion:

The study revealed that shared decision making (SDM) is a desirable model. Decision aids are important for execution of SDM. Further search is needed to assess how the involvement of relatives in SDM does not interfere with patients' autonomy.

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LIST OF ABBREVIATIONS

HCP	Health Care Provider
MNH	Muhimbili National Hospital
MUHAS	Muhimbili University of Health and Allied Sciences
SDM	Shared Decision Making
TDA	Tanzania Diabetes Association
UK	United Kingdom
USA	United States of America

OPERATIONAL DEFINITION OF KEY TERMS AND CONCEPTS

Autonomy

Autonomy refers to individual self-governance, determination of freedom of choices in decision making(1).

Beneficence

This is the action done for the benefit of others or action done to prevent or remove harm from others or improve the welfare of others(2).

Paternalism

This means that healthcare providers as professionals are knowledgeable of everything that patients need. It implies that the physician has knowledge to act and make decisions for the best interest of the patients even for those who could make the decisions for themselves(3).

Chronic Disease

This refers to the disease that persists for a long time(4).

Shared decision making

This is a collaborative communication process in which health decisions are made jointly by healthcare providers and patients. It is an approach to care that seeks to fully inform patients about the risks and benefits of available treatments and engage them as participants in decisions about the treatments(5,6).

Decisions aids

Decision aids are the structured tools that make decisions explicit, provide information on options, benefits and harms and help patients clarify their values associated with outcomes of options(7,8).

CHAPTER ONE

1.0 INTRODUCTION

1.1 Background to the Study

Patients' participation in shared decision making (SDM) regarding their treatment is defined in ethical, legal and human rights standards in the provision of care that concerns health providers and the entire community(9). The origin of SDM is traced back in the ancient Europe, ancient Egypt, china and India civilizations(10). It is well integrated into healthcare provision in developed countries like USA, UK and other western countries (11).

SDM is an approach to care that involves collaborative partnership between patients and providers who are both considered experts and are expected to participate in deliberation about treatment decisions(12,13). SDM involves patients' right to informed consent for medical intervention to avoid medical paternalism(14). In medical practice SDM includes the principle of autonomy which underlies the patient's right to self-determination(15). SDM is slight different from patient centered care which recognizes patients' values and preferences to be central in the delivery of care(16,17). Another difference is that the patient should be the judge of patient centered care(18,19).

Shared decision making (SDM) needs three essential elements to occur. First, the healthcare provider (HCP) and the patient must recognize and acknowledge that a decision is truly needed. Second, both of them must know and understand the best available evidences concerning the risks and benefits of each option. Lastly, decisions must consider the HCP's guidance and the patient's values and preferences(11). Moreover, SDM involves the use of patient decision aids. These are structured tools such as leaflets, booklets, posters, and interactive online applications that provide a summary of the available evidences relevant to a given decision that ideally help the patient to clarify his or her relevant values and preferences(11,20).

Shared decision making (SDM) is concerned with a principle of autonomy which is rooted in the liberal moral and political traditions of enlightenment in Western Europe (21). This principle advocates that an action can be ethically justified when done without any coercive influence and entered by free and informed agreement.(2). Autonomy in western developed

countries is different from Asian and African communities. Whereas western developed countries do less consultation and tend to inform others of their decision, Asian and African communities tend to make consultations and seek for advice(22,23).

Given its supreme importance in clinical ethics, SDM is endorsed and implemented in the USA and other European countries as it helps patients with decision-making ability to voice their medical treatment preferences. Also, patient's participation in decision-making regarding his or her treatment is important in patient's compliance with secondary preventive actions, satisfaction and recovery. Moreover, patient's engagement in decision making results to adherence to treatment plans, confidence in self-management, increases patient's motivation and hence improve treatment outcome(24).

1.1.1 Shared Decision Making Dilemma

The ethical dilemma that is encountered by the healthcare providers (HCPs) is whether or not to engage patients into decision-making regarding their treatment. Proponents of SDM argue that there is an ethical imperative to involve patients properly into decisions regarding their health care services because there is increasing evidence that this approach is beneficial(25). However, those who oppose SDM argue that the sick constitute a group with less autonomy than when they were healthy; therefore they require some elements of paternalistic treatment. For them, paternalism is a response to incapacity, not a negation of rights(26).

Shared Decision making as a Professional's Dilemma

Shared decision making (SDM) is not routinely used in clinical practice(27), and those who are not in favor of it argue that paternalism is a response to incapacity in the sense that a sick person has less autonomy. Moreover, following the Hippocratic Oath and the principles of non-maleficence and beneficence, not engaging the patient into medical treatment is for the best interest and wellbeing of the patient. Since healthcare professionals are better informed and have a higher status in the society, embracing SDM is like diminishing their profession and their status(10,13,28,29).

The Context of Shared Decision Making Dilemma

The investigator thinks that shared decision making in the Tanzanian context like in other African cultures, is challenging. The healthcare providers encounter a cross road of whether to engage patients into decision making or not. Diabetes is a chronic and lifelong condition that cannot be cured but the effects can be treated to minimize its effects and prevent potentially devastating complications, this can cause patients to start losing hope(30). In the African culture, when it comes to decision making, family's autonomy is higher than the individual's autonomy. Family units want to play a pivotal role in decision making when risks of treatment involving their family member are explained. Since in our context there is still veneration for the opinions of elders, the educated and the physicians, such esteem is carried into healthcare provider's rooms and offices by patients. In this context, the patient expects the healthcare provider, particularly the doctor, to tell him what is wrong with him despite his capacity to make decisions(31). Therefore, there is a need to bridge the gap of the western way of making decisions whereby an individual has full autonomy and the African approach whereby family's autonomy supersedes patient autonomy and collective autonomy is appreciated(25,31).

1.1.2 The Implementation of Shared Decision Making

The magnitude of shared decision making (SDM) to diabetic patients worldwide varies from one place to another. Within western tradition, decisions concerning patients treatments fall within the SDM model and is highly practiced(10,21). Evidence has suggested that paternalism still dominates in India and China civilizations where doctors have a high status in society. Therefore, in China and India SDM is still in a low margin(10). In Malaysia, SDM is practiced in a low margin as family opinions supersedes persons decisions(31). In the Netherlands, young people, highly educated people and women prefer being involved in decisions regarding their healthcare and SDM is to a great extent implemented(32).

Similar to western industrialized countries, caring for the sick in Africa is a moral obligation and a legal requirement. However, contrary to the western traditions, Africa has generally a different approach in dealing with medical decision making. In Africa, family members, elders

and educated people play a pivotal role in decisions making regarding the treatment of the patient. This is due to the reason that African culture is collective and hierarchical(31).

There is a shared reality in the Sub-Saharan Africa in medical decision making despite the variation of cultures. In Sub-Sahara Africa, there is no narrative on breach of medical ethics by healthcare providers but paternalism is prevalent as studies show that patients expect doctors to tell them what is wrong with them despite their capacity to make decisions(31). A study done in Democratic Republic of Congo indicates that patients are not involved in medical decisions and hence calls for improvement(33). A recent study in Malawi indicates the absence of truth telling, poor relationship between health care providers and patients, and patients reported the experience of neglect, verbal and physical abuse from nursing staff(34). In Tanzania, a recent study indicates that patients were satisfied with health care services received at Muhimbili National Hospital(35).

1.2 Problem Statement

Most of the world wide studies advocate for a shift from paternalistic model to a shared decision making (SDM) model(10,37,38). Studies indicate that in developed countries, patients' participation into SDM has contributed to patient's adherence to recommended therapy, satisfaction and positive view of health status (33). However, studies show that SDM is not routinely used in clinical practice for diabetic patients with a variation from one country or region to another(27,39). The failure to involve diabetic patients into SDM results into lack of trust, non-adherence to treatment requirements, poor relationship between HCPs and patients, disrespect and hence poor quality of the health services(40).

Despite the fact that in various clinical settings patients prefer to be involved in decision making, yet studies show that most patients in Sub-Sahara Africa including Tanzania are not involved into medical decision-making (12). One recent study indicates that the extent of not involving patients into SDM in sub-Sahara Africa is bigger but the problem is that little attention has been paid about conducting studies concerning SDM(36). It has been found that in Sub-Sahara Africa, paternalism of the HCPs in hospital and clinical work is common even though this phenomenon is often not talked about openly(31). A recent study conducted in

Tanzania indicates that women, poor individuals, members of minority ethnic groups and less educated are discriminated against by decision making bodies(41).

Participation to SDM by diabetic patients is highly encouraged and more practiced in industrialized developed countries like USA and UK than in developing countries(11,36). In Africa particularly the region of Sub-Sahara, patients participation to SDM is at a lower margin and it is not highly studied(34,36,41). To reduce such a gap, this study aimed at exploring the factors that influence diabetic patient's participation in SDM at Muhimbili National Hospital in Dar es Salaam.

1.3 A Conceptual Framework for Execution of Shared Decision Making

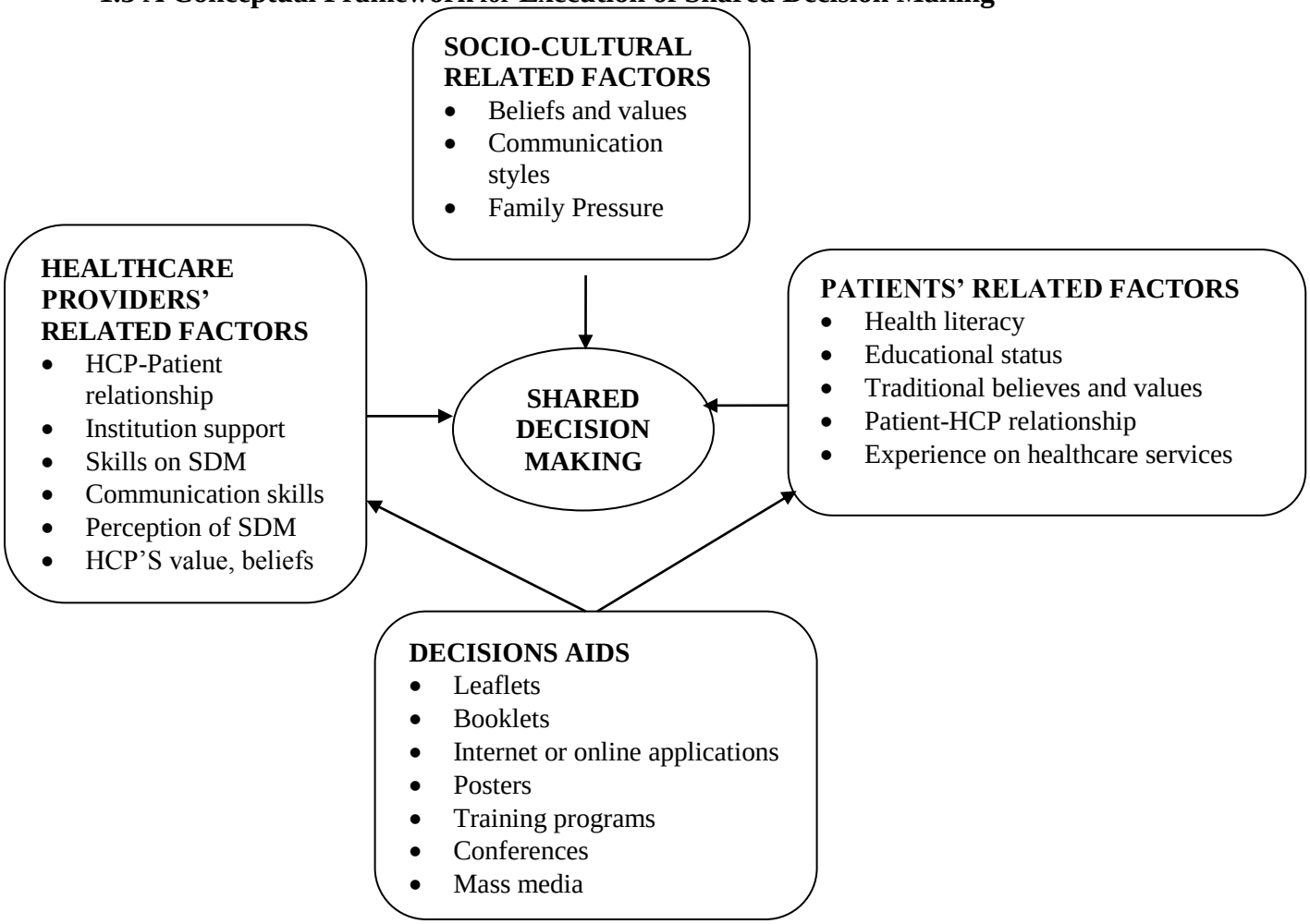


Figure 1: Conceptual framework, Source: a Researcher's own design.

According to the given conceptual framework, diabetic patients' participation to SDM making is influenced by different related -factors including HCPs' related factors like HCPs-patient relationship, skills on SDM, institution, communication skills, perception of SDM as well as HCPs, values and beliefs(37,42). The other are patient's related factors which are health literacy, education status, traditional believes and values, patient-HCPs' relationship as well as experience on health services(43). Moreover, socio-cultural related factors including traditional beliefs, communication styles and customs and values influence diabetic patients to participate in SDM(31,44). The HCPs' related factors and the patients' related factors are enhanced by the decisions aids like training programs, leaflets, posters, booklets, internet and online applications as well as mass media and conference in order to execute SDM properly(11,40).

1.4 Rationale of the Study

The study aimed at exploring factors that influence diabetic patients' participation in shared decision making (SDM) at Muhimbili national hospital (MNH) Dar es Salaam. However, in Tanzania there is limited information concerning diabetic patients' participation to SDM. In this sense the study findings will help in:

1. Giving an alert to the healthcare providers (HCPs) and all health stakeholders of the importance of SDM, its ethical dilemmas as well as its challenges.
2. Showing the factors influencing patients with diabetes to participate or not participate in SDM.
3. Showing the importance of the use of decisions aids in order to enhance SDM easily and to strengthen relationship between patients and HCPs.
4. Giving a way of a shift to a new approach that is globally encouraged as a way of increasing quality of health care, quality of life and compliance of treatment by diabetic patients as well as other critical and chronic illnesses patients.

1.5 Main research question

What are the factors that influence diabetic patients' participation in shared decision making at Muhimbili National Hospital?

1.5.1 Specific research questions

1. What are the healthcare providers' related factors that influence diabetic patients' participation to SDM at MNH?
2. What are patients' related factors that influence diabetic patients' participation to SDM at MNH?
3. What are the socio-cultural related factors that influence diabetic patients' participation to SDM at MNH?
4. What are the decisions aids used to implement SDM at MNH?

1.6 Main objective

To explore factors that influence diabetic patients' participation in shared decision making at Muhimbili National Hospital.

1.6.1 Specific Objectives

1. To explore the healthcare providers' related factors that influence participation in SDM for diabetic patients at MNH
2. To find out patients' related factors that influence participation in SDM at MNH
3. To assess the socio-cultural factors that influence participation in SDM for diabetic patients at MNH
4. To assess the decisions aids used to implement SDM at MNH

CHAPTER TWO

2.0 LITERATURE REVIEW

2.1 Healthcare Providers' Related Factors that Influence participation to Shared Decision Making

Healthcare provider's (HCP) factors such as HCP-patient relationship, skills of SDM, communication skills, perception, values and beliefs as well as institutional support are believed to influence diabetic patients to participate into SDM(10,37). An HCP-patient relationship influences participation to SDM. Enhancing patient-provider communication has been shown to result in greater patient satisfaction, adherence to treatment plans, patient's self-management, and improved health outcomes like emotional health, symptom relief and physiological measures of disease control in western developed countries and the USA(24). Hence when the provider does not develop a good communication with the patient it may results in dissatisfaction, termination of treatment even unhealthy emotions(43,45).

Skills of shared decision making (SDM) are said to be very important for the implementation of SDM. HCPs need these skills as ensuring that a patient has appropriate information regarding the diagnosis and treatment is essential for providing safe and quality services(46). In one study clinicians acknowledged that their performance falls short of ideals because of inadequate skills and they indicated the need of training, decisions aids and information system in order to implement SDM properly(13).

A communication skill is another factor that influences participation to SDM. It is said that a HCP has to be conversant in communication skills as SDM is collaborative communication process in which health decisions are made jointly by the HCPs and patients(47). Efforts to improve communication skills among the HCPs is very important in order to simplify the implementation of SDM(20). It has been found that most complaints about doctors are related to issues of communication and not clinical competence. In this sense, patients want HCPs who can skillfully diagnose and treat their illnesses as well as communicate with them effectively(37,48).

HCPs' perception is another influence of SDM. Normally the execution of SDM depends on the particular HCP's perception of shared decisions. For instance, a provider might not have positive perception on SDM and hence he will rely on the belief of beneficence and the Hippocratic Oath that commits the practitioner to using his special knowledge and skills to benefit the patient(29).

As a HCP is born in the society, it is undeniable that he must have values and beliefs that he takes for granted in his career which in one way or another influences the participation in SDM(49). It has been found that in Africa, a health practitioner may not implement SDM to diabetic patients because his beliefs and values on decision making are rooted in a culture that does not believe individual decisions but collective or societal decisions(36).

It is suggested that institution aspects of the healthcare system have some influences on the desire for involvement in decisions. When HCPs get a support from institution like the decisions aids tools for SDM that are appropriate to a particular cultural setting, they become motivated to involve patients in the SDM approach(12,46). Decisions aids like; leaflets, self-management programs, phones computers, make decisions explicit, provide information on options, benefits and harms and help patients clarify their values associated with outcomes of options(11).

2.1.1 Knowledge Gap Pertaining Healthcare Providers

In western developed countries and the USA the issues of healthcare provider (HCP)-patient relationship is highly observed(13,50). HCPs are introduced to skills for communication and hence they are conversant with skills for shared decision making (SDM), therefore they have a positive perception in communication skills(5). As SDM in Africa is novel and regarding African environment, little is known concerning the influence of HCPs to SDM(36,41). Therefore this study aims find out the HCPs' related factors influencing participation in SDM

2.2 Patients' Related Factors that Influence Participation to Shared Decision Making

Patients' related factors including health literacy, educational level, traditional believes and values, experience and HCP-Patient relation are said to influence the implementation of SDM. Starting with health literacy, this has been said to play a greater role in patients' involvement in medical decision making. Health literacy encompasses personal characteristics and social

resources needed for people to access, understand, and use information to make decision about their health (51). In the context of diabetes, which is a complex chronic illness, continuous medical care that has multifactorial risk reduction strategies beyond glycemic control is needed. In developed countries health literacy is implemented with the use of decision aids (36).

Patients' education is a necessary part of care, not only for technical but also for ethical reasons(2). One study based in west Africa has found that low education levels are barriers to a good shared decision making (SDM) process in African countries(36). It has been found that the lack of basic education has debilitating effects on autonomy. Being less educated, patients feel less autonomous to participate into SDM feeling that they do not know(31). One study done in Africa indicates that less educated individuals, women, poor people and members of minority ethnic groups are discriminated against in decision making bodies if compared to the educated individuals(41).

Patients' values and beliefs play a greater role in the process of SDM. Patients from collective societies are not ready to engage in treatment decisions unless at least one of his/her relative like father, mother or other sibling is involved. This is the case in Africa where an individual's decision on treatment matters must involve members of the family or community. This is a belief and anyone who violates it, is thought as immoral(32,36). On the other hand, patients from individualistic societies do value and believe in the individual autonomy. This makes them to engage in SDM as they feel liberal and autonomous free from the controlling influences. Patients' values and preferences in developed or countries are important aspects of decision making in clinical practice(2,47).

Patient-HCPs relationship is another aspect that influences participation to SDM. A mutual communication between patient and HCPs is a necessary factor as it gives a patient a sense of control and responsibility(46). Normally, a patient is ready to share his or her illness problems with a healthcare provider whom he or she trusts. This trust is rooted in the good relationship they have developed(12). It is demonstrated that much patient dissatisfaction and complaints are due to breakdown in the patient-HCP relationship(37).

Patients' experience is another factor influencing participation to SDM. Patients experience with healthcare settings matters in the course of participation to treatment decisions. Being familiar with the healthcare setting and the HCPs, diabetic patients are able to identify the behaviors of their care givers. Experience shows that patients will never care how much does the HCP knows until they know how much he or she cares(37). Given that diabetes is a chronic disease whose care takes place in the daily basis, the actual experience with the therapy may influence patient to participate into SDM or not depending on the efficacy of the therapy or the approach of the care giver(52,53).

2.2.1 Knowledge Gap Pertaining to Patients' Related Factors

In the USA and western developed countries patients' health literacy, educational level, perception, patient's believes and values as well patient-healthcare provider relationship has greatly influenced participation to shared decision making (SDM)(5,8,54). In Africa particularly the sub-Sahara Africa including Tanzania little is well known on how these factors influence diabetic patients to participate in SDM. Therefore study responds to this objective.

2.3 Socio-Cultural Related Factors

Patients' participation to SDM is also influenced by socio-cultural factors. Beliefs and values affect the HCP-patient relationship and interaction. It is indicated that even if patients and HCPs come from the same social and cultural background, they view ill health in different ways. While HCPs use the biomedical model to understand illness, patient's beliefs are influenced by social and behavioral factors(37). This brings a dilemma to the HCPs whether to engage patients into SDM or not. This is due to the reason that a patient wants to be treated according to what his or her beliefs and values while the HCP sees that those beliefs and values are incompatible to the biomedical model(53).

Communication style is another socio-cultural related factor influencing SDM among the patients. In western developed societies where individual autonomy is highly considered, patients are more likely to participate into SDM than into societies perpetuating collectivism or communalism. In sub-Sahara Africa, the medical treatment decisions must be communicated to the family members. In this context, the family needs to be involved in any stage of treatment decisions as they are the ones who know their patients better than the HCP.

This means that a patient is ready to participate to SDM so long as one of his or her relative will be communicated to and involved(31).

Family pressure in collective societies influences the patient to participate into SDM or not. This is due to the reason that most of the time; the family plays a greater role in taking care of the patient. In the issue of decision making, normally the family members have to know what the decisions are reached. This is because they want to know whether they can afford treatment costs and other requirements needed. This makes the patients to participate into SDM so long as the family members are involved(31,36). This is quite different with developed countries where individual autonomy is much more exercised and the patient is free from the influence of the family(11).

2.3.1 Knowledge Gap Pertaining to Socio-Cultural Factors

In the western developed countries where the socio-cultural setup embraces individual autonomy in making decision, shared decision making process is greatly encouraged(44,55,56). However this is not the case of Africa where people value collective decision making in health related matters(21,57). Therefore this study aims to understand how social factors like beliefs and values and family pressure influence diabetic patients to participate in shared decision making.

2.4 Decision Aids Used to Implement Shared Decision Making

Shared decision making (SDM) involves the use of patient decision aids such as leaflets, booklets, posters and interactive online applications. Decision aids provide information about the decision, available treatment options, benefits and risks of each option and ways to clarify values(58). SDM is relevant when there is a close trade-off between the harms and the benefits of a screening or treatment decision that could be altered by individual patient values and preferences(59). Also, decision aids are preferred as they are knowledge tools that facilitate SDM in such a way that they help individuals to arrive at a decision about screening and treatment(54).

A person’s health literacy status is an important potential consideration in decision aids development and SDM. This is due to the fact that health status affects individual’s ability to utilize health information and services as well as their health outcomes(60). Therefore,

designers of decision aids are required to ensure that their tools can be accessed and understood by all individuals including those with lower health literacy(60). In 2005, the International Patient Decision Aids Standard Collaboration indicated that a person's ability to effectively use a decision aid will be determined by both their health literacy skills and the quality and suitability of the decision aids(61).

In developed countries patient decision aids have been proven to be effective in involving patients in shared decision making (SDM) and improving their decision quality. For instance, in 2011 80% internet users in the USA searched for health information(61). A recent study done in Malaysia indicates that it is crucial to consider the healthcare culture and system particularly in developing countries where concepts of SDM and patient decision aids are still novel(58). A study done in West Africa suggests that there is a need to develop more decision aids that focus on decision making with patients(36).

2.4.1 Knowledge Gap Pertaining to Decision Aids

In western developed countries, the use of decision aids like leaflets, brochures, posters and online interactive applications have influenced patients with diabetes to participate into shared decision making (SDM)(8,62). In Africa, including Tanzania little is known about the use of decisions aids to facilitate the implementation of SDM(31,36). To reduce this knowledge gap, this study aimed to assess the application of decision aids at Muhimbili National hospital.

CHAPTER THREE

3.0 Methodology

3.1 Study Design

A phenomenological study design was employed to understand the experience of both healthcare providers and patients with diabetes regarding the exercise of shared decision making at Muhimbili national hospital.

3.2 Study Area

The study was conducted at the MNH Diabetic Clinic which is under the department of Internal medicine. During the conduct of this study the clinic had about 4 physicians and 3 nurses. There are three days for patients with diabetes to visit the clinic. The clinic receives 40 to 60 clients per clinic day. The clinic does not offer free of charge service except for few patients who are exempted the consultation fee by the government. This clinic was purposively selected as it offers specialized services for patients with diabetes mellitus and its complications.

3.3 Study Population

The study population included diabetic patients aged 18 years and above attending the clinic and the healthcare providers working in the clinic. The study participants were purposively selected to meet objectives of the study. Patients were recruited during their clinic visits. Physicians and nurses providing care to patients in the clinic were also recruited because they are key in clinical decision making for care of patients as well as providing health education on diabetic care including diets.

3.4 Sample Size

A total of 11 informants were interviewed including 2 physicians, 2 enrolled nurses and 7 diabetic patients as a sample size. This sample size was reached after reaching saturation point on the 11^{th} interview by identifying recurring information after each interview. The point of saturation is reached when no new information or knowledge is generated to the themes or when there is a repetition of themes (63).

3.4.1 Inclusion Criteria

- Diabetic patients who were attending clinic care and treatment at MNH for at least six months.
- Healthcare providers who were working directly at the Diabetes clinic for at least 1 year
- Participants aged 18 years and above

3.4.2 Exclusion Criteria

- Diabetic patients who were not able to communicate, including those with stroke and other conditions that would make it difficult to interview were excluded.
- Healthcare providers who were working at the clinic for less than 1 year.

3.5 Sampling Procedure

Purposive sampling was used in this study. Knowledgeable participants with rich information concerning the study were purposively selected. Purposive sampling was used because of its feasibility in terms of time and money as all participants were recruited at the clinic.

3.6 Data Collection Methods

In-depth interview method was used to collect data. The interview guides written in English and translated in Kiswahili which is the common language of Tanzania were employed under this method to answer the study objectives. With the permission of the informant or participant the interviews were audio recorded and some notes were taken to enhance analysis and discussion of the findings. Appointments with the participants were made initially before beginning the interview so as to avoid interference with the informant's time table.

3.7 Data Collection

The collection of data took place at the Diabetes Clinic in Muhimbili national hospital (MNH) between April and May 2019. Data collection involved the principle investigator and one research assistant. The role of principal investigator was to coordinate the research and interviewing while the role of research assistant was to take note. Length for interview was between 30-45 minutes. A research assistant was recruited three days before starting the work of collecting data. Such a research assistant had experience of research work in communities.

The research assistant was trained on how to collect data via the in-depth interviews and its tools. Moreover, the research assistant was trained on how to obtain consent and to respect the participants, to observe privacy and confidentiality as well as all ethical issues.

3.8 Data Analysis

Content analysis method was used. After the end of each interview the principal investigator and research assistant discussed the recurring emerging issues so as to determine saturation point. Saturation point was reached on the 11^{th} interview and this marked the end of data collection. After data collection audio-recorded voices were transcribed verbatim and translated to English then checked for errors. Through the use of content analysis method categories were reached through the process of coding being assisted by NVivo 12 Software.

3.9 Ethical Issues

Ethical clearance to carry out this research was obtained from Muhimbili University of Health and Allied Sciences Institutional Review Board (MUHAS IRB). Permission to conduct a research was granted by MNH administration. All study participants were consented and signed the consent forms prior the conduct of interviews. Special permission to audio record interviews was requested and given by participants. Participants were informed that participation is voluntary, and can withdraw from the study at any time. To ensure privacy and confidentiality interviews were carried out in rooms at the clinic by applying low voice so as not to be heard in nearby rooms. Moreover, participants' information in the notebook or recorded audio was labeled numbers instead of their names.

3.10 Trustworthiness

Trustworthiness was ensured in this study. All study informants were consented to conduct interview. This enhanced the interview as they were able to respond freely without any fear and thus it helped to avoid and reduce biased responses. Moreover, to avoid distortion of data I, as the principal investigator participated fully to collect data via in-depth interview guide through digital voice recorder whereby the research assistant was taking note so as to get rich information from informants. A very brief feedback in relation to collected data was provided to informants after each interview so as to test and verify the accuracy of the given

information. Also, the brief feedback in relation to collected information was provided to informants to ensure and maintain transparency or clarity.

In addition, patients with diabetes and healthcare providers who met inclusion criteria were recruited in the study. Triangulation of study participants was enhanced aiming at getting rich information whereby in-depth interviews were done with nurses and physicians. During data analysis content analysis method was employed by creating categories through coding process via NVivo software.

Lastly, quotations from study informants were included in the results section to ensure that description of the results conforms to what informants responded. All descriptions of the results section are accompanied by the quotations from informants to bring clarity and precision.

CHAPTER FOUR

4.0 Findings

Description of Participants

Demographic characteristics of healthcare providers

Four healthcare providers (HCPs) were interviewed; among them 2 were female nurses and 2 male physicians. The age of HCPs ranged from 30 years to 40 years. All nurses were registered with a diploma of nursing, while all physicians had the postgraduate (Mmed) level of education**.**

Demographic characteristics of patients

7 patients with diabetes were interviewed, among them 3 females and 4 males. The age of patients ranged from 46 years to 76 years. All patients were married. Education level for patients ranged from standard seven to advanced diploma level. 2 females were home mothers, one female was an entrepreneur, 2 males were retired civil servants, one male was a driver and mechanic and one male was a businessman and entrepreneur**.**

Themes Obtained in the Study

Four themes were obtained in relation to the factors that influence diabetic patients' participation in shared decision making at Muhimbili national hospital (MNH). These themes are the influence of healthcare providers' related factors to participation in shared decision making (SDM), the influence patients' related factors to participation in SDM, the influence of socio-cultural related factors to participation in SDM and the assessment of decision aids.

The Influence of Healthcare Providers' Related Factors to Shared Decision Making

Healthcare providers (HCPs) preferred patients to be engaged in shared decision making (SDM). HCPs argued that the participation of patients helps them to determine the patients' understanding of a disease, to understand their chief complains, to adhere to HCPs' instructions, to do self-management at home and it enhances a good relationship between HCPs and patients. For example a doctor responded,

> "*When a patient participates helps me to know his chief complain and so that I can decide the appropriate course of action to take. You know diabetic patients are under self-management therefore for them it is very important.*" (# 02D)

It was revealed that Muhimbili national hospital (MNH) has not supported the availability of appropriate standard guideline of treatment and decision aids that are very important for diabetic patients to participate in SDM. It was also revealed that the available standard guideline of treatment is not known to all physicians and nurses. Some HCPs complained that the available standard guideline of treatment does not satisfy the demand of a tertiary hospital. They said;

> "*Our Muhimbili standard guideline of treatment has to be improved again because there are many new included drugs.*" (# 02D)

It was acknowledged that time for engaging patients in shared decision making (SDM) is required. However, it was noted that there is not enough to engage patients in SDM). Healthcare providers (HCPs) held that time to actively involve patients in SDM is not enough due to a big number of patients as well as other HCPs' responsibilities. They said that;

> "*You find a patient who I need to stay with at least for 15 minutes but time is very little and patients are many.*" (# 03D)

Healthcare providers acknowledged that Good (HCP)-patient relationship matters for the patients' participation in shared decision making (SDM). For good HCP-patient relationship to exist, HCPs need to have good communication skills. This helps to do away with paternalism as HCPs give their patients a chance and autonomy for deliberation about screening and treatment options provided that they are well informed. They said that;

> "*You know communication skills develop a good relationship, and this question needs good relationship that's why in companies there are offices for public relations therefore good relations are developed by good language.*" (# 04N)

The Influence of Patients' Related factors to Participation in Shared Decision Making

Patients acknowledged that when they are engaged in decision making it will be easy for healthcare providers (HCPs) to know a kind of treatment a patient prefers and what he does not prefer. Also it helps HCPs to know a kind of drugs that works well to a particular patient. Patients said that;

> "*It is important as the doctor will know which medication or drug works for me and that which doesn't. Also it will help him to know drugs that a patient prefers and those he or she doesn't prefer and why*." (# 07P)

Literate status for health related matters and patient's rights influences patients participation in shared decision making (SDM). Some patients revealed to be health illiterate and knew little about SDM. Patients said that;

> *"I about patients' participation in making decision……unh I know nothing maybe if you can enlighten me"* (# 7P)

Illiteracy challenges shared decision making as healthcare providers (HCPs) revealed that they engage a patient who is somehow knowledgeable. HCPs said that;

> "*……But you have sometimes to look on the education level of your patients.*" (# 02D)

Patients revealed of the existence of good healthcare provider (HCP)-patient relationship. Yet, some patients revealed that to some extent paternalism exists as decision is done by physicians hence patients comply on what physicians recommend them to do. Patients said that;

> *"……for decisions no, but on my date to come like today the doctor is the one to decide which drugs are suitable for me. Is that not a decision?*" (# 06P)

The Influence Socio-cultural Related Factors to Participation in Shared Decision Making

It was portrayed that beliefs and values of patients influence the execution of shared decision making (SDM). Both patients and healthcare providers demonstrated that SDM is a challenge as some patients embrace cultural beliefs and values that do not make them to know or question providers on their rights or their health services. A patient said that;

> "*According to our traditional values you can't question a witchdoctor, but you have only to comply on what he directs like bringing him a cock or whatever. This applies to our professional doctors.*" (# 08P)

Both patients and healthcare providers (HCPs) preferred their relatives to be involved in shared decision making (SDM). This is because both patients and HCPs are in a society whose communication style on medical treatment decisions needs family members to be involved. They rendered that if a patient cannot comprehend easily what a healthcare provider discusses

with him or her, relative will be able to understand. Also, relatives have to be engaged because they live with patients. They said;

> "*Yes, it is okay if a relative is engaged because when you find that I can't easily understand my relatives can help me to remember the description I have been given.*" (# 05P)

Healthcare providers said that;

> *"…….when we provide education on diet or medicine we prefer relatives to participate because when a patient gets sick at home the only person to help him or her is the close relative whom they live together.*" (# 04N)

Assessment of Decision Aids

Healthcare providers acknowledged that they use different decision aids as a tool for making sure a diabetic patient is able to know and understand appropriate diet, complications of diabetes as well as diabetes treatment. Decision aids used are face to face conversations, pictures, charts, leaflets and other domestic utensils like plates. They sometimes tell patients to search for diabetes information on websites. They said that decision aids are as helpful as among them. Patients proposed decision aids that they think are easier for them to access and understand so that they can participate fully in decision making. They said that;

> "*All of them are good but for example on TV not all of us have televisions. Leaflets are suitable for those who can read or who went to school. However radio and TV are good because they use Kiswahili and Not English also those who can't read and write can understand them respectively*." (# 08P)

However, both physicians and nurses complained that though decision aids are very helpful, they are encountered by the challenge of inadequate decision aids particularly leaflets and brochures. They depend on aids from the Tanzania Diabetes Association (TDA) and stakeholders like pharmaceutical companies. This is very challenging as they insisted that;

> "*Leaflets are available but they are scarce. They are sometimes available and the other times we at Muhimbili cannot produce them therefore we have to request them from the office of TDA (Tanzania Diabetes Association) or from the pharmaceutical companies.*" (# 02D)

CHAPTER FIVE

5.0 DISCUSSION

In general the study revealed that both healthcare providers (HCPs) and patients preferred patients to be engaged in shared decision making (SDM). Different factors were found to influence the implementation of SDM in the diabetic clinic at Muhimbili national hospital (MNH)

Different healthcare providers' (HCP) related factors have been identified to influence the execution of shared decision making (SDM) differently. HCPs prefer engaging patients as it encourages HCP-patient relationship, helps patient self-management, adherence to treatment plans and it helps HCPs to understand their patients and decide for a required treatment. This has been indicated in other studies(19,24,64). However, HCPs' preference for engaging patients in SDM is challenged by the lack of enough support from the institution. For example the outdated standard guideline of treatment is a challenge for SDM. This challenge is perhaps facing most of African hospitals because some studies have indicated the same(36,57,65).

Healthcare providers demonstrated that they need enough time to implement shared decision making (SDM). This is due to the reason that SDM needs a discussion and agreement between a patient and a HCP(37,46). However, at Muhimbili national hospital diabetic clinic SDM is constrained by a lack of enough time. This is due a big number of patients if compared to a number of HCPs and a tight timetable for other responsibilities of HCPs. This coheres to a recent study done in Rwanda whereby time insufficiency was indicated to constrain execution of SDM(19).

Healthcare providers (HCPs) declared that it is easy to engage patients in shared decision making (SDM) if there is a good relation. This demonstration has been indicated by various studies that HCP-patient relationship is enhanced by good communication skills of HCPs that make patients to feel autonomous to participate in SDM(19,37,66). However, the contention of the HCPs may imply that some HCPs are not skilled in communication skills and this probably impedes SDM as it was the case in one study done Malawi which indicates the same situation(34). Therefore, good HCP-patient relation is a prerequisite for SDM.

Different patients' related factors influence patients with diabetes to participate or being engaged by healthcare providers (HCPs) in shared decision making (SDM). Patients contented that they prefer to be involved in SDM as they get opportunity to opt for the treatment or drugs they desire and can afford. This coheres to most studies which indicate that when patients' values and preferences are considered they will participate in SDM(12,46,67).

Patients indicated that literacy influences their participation in shared decision making (SDM). Literate patients like to be involved if compared the illiterate patients. Moreover HCPs are likely to engage a literate patient because in most cases literate patients have some awareness concerning their rights and responsibilities of HCPs. This has been the case in many developing countries(36,41,58). However, patients' illiteracy has influenced them not to participate because of fear and unawareness of what to talk before HCPs. This has been the case even in western African region(36).

Patients with diabetes indicated that healthcare provider (HCP)-patient relationship is another factor that influences shared decision making (SDM). They denoted that patients prefer doctors who are friendly to them. However they noted that some HCPs do not engage them in decision. This implies that either HCPs are paternalistic or patients do not like to be engaged because of fear or illiteracy of health related matters. This concurs with literatures that have indicated that poor HCP-patient communication influences patients not to engage in SDM(12,31,46).

Socio-cultural related factors were indicated by both patients and healthcare providers (HCPs) to influence shared decision making (SDM). As patients live in a collective culture which embraces collective decision and hierarchy, this has affected most of patients with diabetes as they prefer their relatives to be engaged in SDM. This is not contrary to most African regions where collective culture demands family members to be involved in all decision making processes(36,58). However, preference for engaging patients in SDM contradicts the principle of autonomy. To ensure privacy and confidentiality, the principle demands patients capable for self-determination should decide without being intervened by a third party like

relatives(22,31,68–70). Therefore the preference of relatives to be involved in SDM brings an ethical dilemma particularly to the HCPs. Not involving relatives is seen by both patients and their relatives as unfair to their values while involving relatives is a violation of the principle of autonomy.

Both healthcare providers (HCPs) and patients with diabetes acknowledged that decision aids influence patients to participate in shared decision making (SDM). Patients know screening and treatment options and thus adhere to treatment plans through the applications of decision aids. This coheres to studies which have portrayed that decision aids are preferred as they are knowledge tools that facilitate SDM(58,59).

However healthcare providers (HCP) portrayed that there is a scarcity of decision aids like leaflets, brochures and others. The only available decision aids are offered by Tanzania Diabetes Association (TDA) and pharmaceutical companies. This challenge of scarcity of decision aids faces most sub-Saharan Africa countries(36). Therefore, this challenge calls for collective initiatives from the hospital administration and government to make decision aids that suit Tanzanian setting are available and accessible.

5.1 Study Limitation and Mitigation

This study might have a risk of bias due to the employed study design, data collection method and sampling procedure. However, the risk of bias has been minimized by appealing to triangulation of study participants, transparency of collected data to informants and clear description of results. Moreover, the findings of this study reflect only the diabetes clinic of the Muhimbili national hospital setting and should not be generalized to the other hospitals of Tanzania.

CHAPTER SIX

6.0 CONCLUSION AND RECOMMENDATION

6.1 Conclusion

Generally the results of this study titled "*Factors Influencing Diabetic Patients Participation in Shared Decision Making at Muhimbili National Hospital*" revealed that both healthcare providers (HCPs) and patients preferred patients to be involved in shared decision making (SDM). Both patients and HCPs acknowledged the usefulness of decision aids in decision making.

Healthcare providers (HCPs) related factors that influence patients with diabetes to participate in shared decision making are HCPs' preference, institutional support, time or insufficient time to engage patients in decision making and HCP-patient relationship.

The identified patient related factors that influence patients with diabetes to participate in shared decision making include preference for patients to be engaged, patients' literacy and literacy on health related matters, as well as healthcare provider-patient relationship.

Socio-cultural related factors that were indicated to influence shared decision making are beliefs and values that embrace collective decision. Due to collective culture both patients preferred patients' relatives to be engaged in decision making.

On the assessment of decision aids, both healthcare providers and patients acknowledged that decision aids are helpful. However, scarcity of decision was reported. Therefore the scarcity of decision aids calls for initiatives from stakeholders to design and make decision aids available.

6.2 Recommendation

Healthcare providers should involve all self-determined diabetic patients in shared decision making to avoid paternalism as the results indicated some patients are not involved.

Healthcare provider-patient relationship should be maintained by facilitating training to healthcare providers on communication skills.

Patients with diabetes should be continually enlightened about their rights and the importance

of shared decision making regardless of their values that discourage individual autonomy.

To do away with the time limit, a number of healthcare providers should be increased to accommodate the number of attending patients. Also the time to begin the clinic should be adjusted.

Muhimbili national hospital administration in cooperation with other stakeholders should look for the possibility to support the availability and accessibility of decision aids to patients with diabetes.

Moreover, I recommend that a further search be carried out to assess the impact of relatives of patients' participation in decision making without affecting the principle of autonomy.

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APPENDICES

Appendix 1: Informed Consent Form for a Health Care Provider/ a Patient (English Version)

ID. NO ☐

CONSENT FORM FOR PARTICIPATING IN A RESEARCH STUDY

Hello greetings! My name is …… I am studying Master of Bioethics (MBE), at Muhimbili University of Health and Allied Sciences (MUHAS). I am doing a Study on "*Diabetic Patients' Participation to Shared Decision Making and the Decisions Aids Used at Muhimbili National Hospital*"

The aim of the Study

The study aims to explore factors that influence the diabetic patients to participate to shared decision making and the decisions aids used to facilitate its implementation at Muhimbili National Hospital.

Procedure

I would like you to participate in this study. You are selected to participate because you have rich information concerning my study. Interview guides will be given to you and privacy will be maintained as much as possible. The researcher would like to audio record the interview as part of the study. An interviewer will contact you to make some sort of an arrangement for a convenient time and day of your choice for the interview. We hope that you will be willing to share your information with the research team. If you have questions about this research, including questions about how to schedule for the interview or about your participation, please you do not hesitate to ask or contact the research team at any time.

Confidentiality

All information and issues relating to your participation in the study will be treated confidential, no any unauthorized person who will have access to your information. The audio

recorded will be placed into a safe place and storage until a written copy of the discussion has been created. As soon as this process is complete, the audios will be deleted so as to enhance research confidentiality. Furthermore, to protect confidentiality, your names will not appear in the written copy of the discussion.

Right to Refuse or Withdraw

Your participation in this study is voluntary. It is not a must to talk about anything you don't want to and you may end the interview at any time. However, I encourage you to participate because your views have great importance in this study.

Benefits

There are no direct benefits to you from being in the study, however, your participation in this study will provide useful information necessary for the improvement and implementation of participation to shared decision making. Also it will provide the awareness to both health care providers and their clients of the importance of the use of decision aids. Moreover, it will help healthcare providers to do away with the ethical dilemma of not engaging diabetic patients in decision making regarding their treatment.

Risks

There will be no any harm to you as a result of participation in this study although some questions will be personal which might arouse your feelings, worries and despair.

Whom to Contact

In case of any inquiry please contact the principal investigator, VEDASTO, Osward (MBE) from MUHAS, P. O. BOX 65001, Dar es Salaam, mobile number 0768065178. If you ever have questions about this study you may call, the Chairperson of the (Research and Publications Committee, MUHAS. P.O. Box 65001, Dar es Salaam-Tanzania, Tel +2552150302-6)

I ……... have read the contents of this form and understand. My questions have been answered. I agree to participate in this study.

Signature of participant…… Date…….

Signature of researcher/research assistant …….

Kiambatanisho cha 2: Fomu ya Ridhaa kwa Mhudumu wa Afya/ kwa Mgonjwa (Swahili version)

NAMBA YA FOMU ☐

FOMU YA IDHINI YA KUSHIRIKI KATIKA UTAFITI

Habari, naitwa ……. nasoma shahada ya uzamili katika fani ya Maadili ya Kimatibabu katika Chuo Kikuu cha Afya na Sayansi Shirikishi Muhimbili. Ninafanya utafiti kuhusu *"Ushiriki wa Wagonjwa wa Kisukari katika Kufanya Maamuzi ya Pamoja na Nyenzo za Maamuzi zinazotumika katika Hospitali ya Taifa ya Muhimbili"*

Lengo la Utafiti

Utafiti huu unalenga kutafuta mambo yanayochangia wagonjwa wakisukari kushirikishwa au kutoshirikishwa katika kufanya maamuzi ya pamoja na nyenzo za maamuzi zinazotumika kuwezesha utekelezaji wake katika hospitali ya taifa ya Muhimbili.

Utaratibu

Ningependa ushiriki katika utafiti huu. Umechaguliwa kwa sababu naamini una taarifa za kutosha kuhusiana na utafiti wangu. Utapewa mwongozo wa mahojiano na faragha itaimarishwa kadri inavyowezekana. Watafiti watapenda kuchukua sauti yako ili kuweza kupata vema mazungumzo yako yote, na watawasiliana nawe ili kupanga muda mwafaka wa kufanya mahojiano. Tunatumaini utakuwa tayari kushirikiana na watafiti. Endapo utakuwa na maswali kuhusu utafiti huu pamoja na maswali ya namna ya kupanga ushiriki wako, tafadhali usisite kutuuliza ama kuwasiliana na watafiti muda wowote.

Usiri

Taarifa zote za ushiriki wako ni siri na wala hakuna mtu yeyote asiyehusika atakayeruhusiwa kuziona wala kuzifuatilia. Sauti yako itakayochukuliwa itahifadhiwa sehemu salama hadi hapo nakala ya maandishi itakapotolewa. Mara baada ya kukamilika kwa nakala ya maandishi, sauti

yako iliyohifadhiwa itafutwa ili kutunza usiri wa utafiti. vilevile, majina yako hayataonekana kwenye nakala ya maandishi ili kuimarisha usiri.

Haki ya Kukataa au Kujitoa

Ushiriki wako kwenye utafiti huu ni wa hiari. Pia hulazimishwi kuongea jambo lolote ambalo usingependa kuliongea. Unaweza kusitisha mahojiano wakati wowote endapo utaona ni vyema kufanya hivyo. Licha ya hayo tungependa ushiriki wako katika utafiti huu kwani maoni yako yana umuhimu mkubwa.

Faida

Hakuna faida za moja kwa moja kwako kutokana na utafiti huu, hata hivyo ushiriki wako katika utafiti huu utawezesha kupatikana kwa mawazo muhimu ya yatakayosaidia uboreshaji na utekelezaji wa ushiriki katika kufanya maamuzi ya pamoja. Utafiti utaongeza uelewa kwa wahudumu wa afya na wateja wao juu ya umuhimu wa matumizi ya nyenzo zinazosaidia kufanyika kwa maamuzi. Lakini pia, utafiti huu utasaidia wahudumu wa afya kuondokana na mtanziko wa kimaadili katika kushirikisha wagonjwa wa kisukari kwenye maamuzi ya pamoja yanayohusiana na matibabu yao.

Madhara

Hakuna madhara yatakayopatikana kutokana na ushiriki wako kwenye utafiti huu ingawa baadhi ya maswali utakayoulizwa ni ya kibinafsi na hivyo yataweza kukuletea utofauti wa kihisia, wasiwasi, woga na mawazo.

Watu wa kuwasiliana nao

Kama una maswali katika utafiti huu unaweza kuwasiliana na mtafiti mkuu, ndugu VEDASTO, Osward (MBE) kutoka Chuo Kikuu cha Afya na Sayansi Shirikishi Muhimbili, S.L.P. 65001, Dar es Salaam. Nambari yake ya simu ni 0768065178. Kama utakua na swali lolote kuhusiana na utafiti huu, unaweza kuwasiliana na Mwenyekiti wa kamati ya chuo ya utafiti na machapisho, MUHAS. S.L.P 65001, Dar es Salaam-Tanzania, Tel +2552150302-6.

Mimi…….....……nimesoma fomu hii ya idhini na nimeielewa. Maswali yangu yamejibiwa. Nakubali kushiriki katika utafiti huu.

Saini ya mshiriki…… Tarehe……

Saini ya mtafiti/ mtafiti msaidizi ……..

Appendix 3: In-Depth Interview Guide for Health Care Provider (English Version)

This is an in-depth Interview Guide for exploring healthcare providers' and socio-cultural related factors that influence diabetic patients' participation to shared decision making and the decisions aids used.

Part I: Introduction

Your responses are and will be accepted without reservations, so kindly feel free. I would like to remind you that, this interview will be recorded as for easy remembering of what you shared, and it will take about 30-45 minutes' duration.

Part II: Demographic Information

If you don't mind, kindly tell me about your

1) Age
2) Sex
    a) Male
    b) Female
3) Education level_____
4) Have you undergone any training on ethics/medical ethics?

Part III: General Information:

5) What influenced you to be a healthcare provider in particular to diabetic patients?
6) What is your experience in taking care of diabetic patients?
7) What are your roles in this department?
   (**Probe:** length held position, professional background)

Part IV: General questions

8) Based on your roles and experience, kindly tell me what do you understand about diabetic participation to shared decision making**? (**Probe: perception, skills and understanding)
9) What do you understand about decisions aids? (Probe: skills, training, experience)

10) Can you tell me more about the hospital or department guidelines for ensuring shared decision making and the use of decision aids?

Part V: Other related Factors That Influence Diabetic Patients' Participation to Shared Decision Making:

11) What are the related factors as you think that influence diabetic patients to participate into shared decision making?(**Probe:** skills, values and beliefs, healthcare-patient relationship, communication skills, institution support)

Part VI: Significance of Shared Decision Making and the Use of Decisions Aids

12) Kindly, explain the importance of engaging diabetic patients to shared decision making? (**Probe**: benefits to patients, family members, healthcare providers, department/hospital)

13) Kindly explain the importance of using decision aids in executing shared decision making? (**probe**: benefits to patients, healthcare provider, family member, institution)

Part VII: Challenges Encountered in Shared Decision Making with Diabetic Patients

14) What are the challenges encountered in the exercise of shared decision making with diabetic patients? (**Probe:** family pressure, guidelines, language, inferiority complex, time, professionalism experience, decisions aids)

Part VIII: Strategies to Improve the Execution of Shared Decision Making

15) According to the challenges against shared decision making what are your opinions on how best to implement shared decision making? (**Probe**: At the Individual level, at the Department/hospital level, at the National level)

16) What do you think are the viable decisions aids in our setting? (**Probe**: leaflets, booklets, internet or online application, posters, training programs, mass media)

Part IX: Ending:

I really appreciate the time you took for this interview. Do you have any other additional information that you find important and would like to share with me pertaining to the study?

I beg your cooperation once again when I will need more clarification about our interview.

Thank you very much for your cooperation

Kiambatanisho cha 4: Mwongozo wa Majadiliano na Mhudumu wa Afya (Kwa kiswahili)

Huu ni mwongozo wa majadiliano na mhudumu wa afya unaolenga kuangalia mambo ya kitamaduni na kijamii na yale ya mtoa huduma mwenyewe yanayokwamisha ama kusababisha wagonjwa wa kisukari kushiriki kwenye maamuzi ya pamoja nakujua nyenzo za maamuzi zinazotumika kwenye hospitali ya taifa Muhimbili.

Sehemu 1: Utangulizi

Umechaguliwa kama mtu muhimu atakayeweza kujibu maswali yangu, na majibu yako yatapokelewa pasipo shaka yoyote, hivyo jisikie huru. Ningependa pia kukukumbusha kuwa, majadiliano haya yatachukuliwa sauti ili kurahisisha kumbukumbu ya yale utakayonishirikisha na yatadumu kwa muda wa kati ya dakika 30-45.

Sehemu II: Taarifa Binafsi

Kama hutajali, naomba uniambie kuhusu

1) Umri wako
2) Jinsia yako
    a) Mme
    b) Mke
3) Kiwango cha Elimu_____
4) Umewahi kupata mafunzo yeyote ya kimaadili au maadili ya kimatibabu?

Sehemu III: Taarifa za Jumla:

5) Kipi kilichokufanya upende kuwa mtoa huduma kwa wagonjwa wa kisukari?
6) Una uzoefu gani katika kuhudumia wagonjwa wa kisukari?
7) Majukumu yako ni yapi katika idara hii ya wagonjwa wa kisukari? (**Dodoso**: Kwa muda gani, utaalamu wako)

<u>Sehemu IV</u>: Maswali ya Jumla:

8) Kulingana na majukumu na uzoefu wako wa kazi, unaelewa nini kuhusu kufanyika kwa maamuzi ya pamoja? (Dodoso: Tafsiri, uelewa, mtazamo, ujuzi)
9) Unaelewa nini kuhusu nyenzo za maamuzi? (dodoso: ujuzi, mafunzo, uzoefu)
10) Unaweza kunipa maelezo zaidi kuhusu miongozo inayotumiwa na idara au hosopitali kuhakikisha utekelezaji wa kufanyika maamuzi ya pamoja na matumizi ya nyenzo za maamuzi?

<u>Sehemu V:</u> Mambo Mengine Yanayochangia Wagonjwa wa Kisukari Kushiriki au Kutoshiriki Katika Kufanya Maamuzi ya Pamoja

11) Unafikiri ni mambo gani mengine yanachangia wagonjwa wa kisukari kushiriki au kutoshiriki katika kufanya maamuzi ya pamoja? (**Dodoso**: ujuzi, imani na maadili, ujuzi wa mawasiliano, uhusiano wa mhudumu wa afya na mgonjwa, msaada wa taasisi)

<u>Sehemu VI:</u> Umuhimu wa Kufanya Maamuzi ya Pamoja na Utumiaji wa Nyenzo za Maamuzi

12) Naomba unieleze umuhimu wa kushirikisha wagonjwa katika kufanya maamuzi ya pamoja. (**Dodoso**: kwa wagonjwa, ndugu wa mgonjwa, wahudumu wa afya, idara/hospitali)
13) Naomba unieleze umuhimu wa kutumia nyenzo za maamuzi katika utekelezaji wa kufanyika kwa maamuzi ya pamoja. (**Dodoso**: kwa wagonjwa, wahudumu wa afya, ndugu wa mgonjwa, idara/hospitali)

<u>Sehemu VII</u>: Changamoto Zitokanazo na Ushiriki wa Wagonjwa wa Kisukari Katika Kufanya Maamuzi ya Pamoja

14) Ni changamoto gani unazokutana nazo katika kushirikisha wagonjwa wa kisukari kwenye maamuzi ya pamoja? (**Dodoso**: shinikizo la familia, miongozo, lugha, kutojiamini, muda, uzoefu wa kitaalamu, nyenzo za maamuzi)

<u>Sehemu VIII</u>: Mikakati ya Kuboresha Utekelezaji wa Kufanya Maamuzi ya Pamoja

15) Kulingana na changamoto zinazojitokeza dhidi ya ushirikishaji wa wagonjwa wa kisukari kwenye maamuzi ya pamoja maoni yako ni yapi ili kuboresha utekelezaji wake? (**Dodoso:** kwa wahudumu wa afya, wagonjwa, idara/hospitali, ngaziya taifa)

16) Unafikiri ni nyenzo gani sahihi za maamuzi zinazofaa kutumiwa kwenye mazingira yetu? (Dodoso: vipeperushi, vijitabu vidogo vya taarifa, intaneti, mambango, vyombo vya habari)

<u>Sehemu IX</u>: Hitimisho:

Nakushukuru sana kwa kujitolea muda wako kwaajili ya kushiriki mahojiano haya. Unachochote muhimu cha kuongeza ambacho ungependa kunishirikisha kinachohusiana na utafiti huu?

Naomba ushirikiano wako tena pale nitakapohitaji ufafanuzi zaidi kuhusu mahojiano yetu.

Ahsante sana kwa ushirikiano ulionipa.

Appendix 5: In-depth Interview Guide for Patients (English Version)

This is a patient's in-depth Interview Guide for finding out patient's related factors that influence diabetic participation to shared decision making and the decisions aids used at Muhimbili National Hospital.

Part I: Introduction

I have selected you among others hoping that you have rich information and you are capable of responding my questions. Your responses are and will be accepted without reservations, so kindly feel free. I would like also to remind you that, this interview will be recorded as for easy remembering of what you shared, and it will take about 30-45 minutes' duration.

Part II: Demographic Information

May you kindly tell me about your

1) Age:
2) Sex:
    a) Male
    b) Female
3) Marital status
    a) Single
    b) Married
4) Occupation_____
5) Education level_____

PART III: General Question

6) What do you understand about patients' participation to shared decision making and the use of decisions aids?

PART IV: Specific Questions

7) What are the decisions aids used by healthcare providers to provide medical information? (Probes: leaflets, posters, face to face interview, mass media, internet) what decisions aids you like?
8) What do you think are the importance of engaging a diabetic patient to shared decision making? (Probes: for a patient, healthcare provider, family relative)
9) Do you think a patient's relative has to be involved in decision making regarding his or her relative treatments? Why?
10) How far do you know about patients' rights? (Probes: treatment guideline, informed consent form, where to claim your rights)
11) In your experience in health services what do you think are the challenges that hinder patients' participation to SDM? (Probes: beliefs and values, inferiority complex, patient-healthcare relationship, family pressure, health literacy, time)
12) What are your suggestions on the diabetic patient to participate in decision making regarding his or her treatment?

PART V: ENDING

Do you have any other additional information concerning the study that you find important and would like to share with me pertaining to patients' participation to shared decision making and the use of decision aids?

I beg your cooperation once again when I will need more clarification about our interview.

Thank you very much for your cooperation

Kiambatanisho cha 6: Mwongozo wa Majadiliano na Mgonjwa (Kwa Kiswahili)

Huu ni mwongozo wa majadiliano na mgonjwa unaolenga kuangalia mambo yatokanayo na wagonjwa yanayoweza kukwamisha ama kusababisha wagonjwa wa kisukari kushiriki kwenye maamuzi ya pamoja nakujua nyenzo za maamuzi zinazotumika kwenye hospitali ya taifa Muhimbili.

SEHEMU I: Utangulizi

Nimekuchagua wewe kati ya wengine nikitumai kwamba una taarifa za kutosha na unaweza kujibu maswali yangu. Majibu yako yatapokelewa pasipo shaka lolote, hivyo jisikie huru. Ningependa pia kukukumbusha kuwa, majadiliano haya yatachukuliwa sauti ili kurahisisha kumbukumbu ya yale utakayonishirikisha na yatadumu kwa muda wa kati ya dakika 30-45.

<u>Sehemu II:</u> Taarifa Binafsi

Kama hutajali, uniambie kuhusu

1) Umri wako
2) Jinsia yako
    a) Mme
    b) Mke
3) Hali ya Ndoa_____
4) Kazi unayofanya_____
5) Kiwango cha elimu_____

SEHEMU III: Swali la Jumla

6) Unaelewaje kuhusu ushiriki wa wagonjwa katika kufanya maamuzi ya pamoja na matumizi ya nyenzo za maamuzi?

SEHEMU IV: Maswali Mahsusi

7) Ni nyenzo zipi za maamuzi zinazotumiwa na wahudumu wa afya kutoa taarifa za matibabu? (Dodoso: vipeperushi, mabango, mahojiano ya ana kwa ana, intaneti au mtandao, vyombo vya habari). Ni nyezo zipi unazipenda?
8) Unadhani ndugu wa mgonjwa anapaswa kushirikishwa katika kufanya maamuzi ya matibabu ya ndugu yake? Kwanini?
9) Unafahamu haki za wagonjwa? (Dodoso: muongozo wa matibabu, fomu ya ridhaa, sehemu ya kupeleka malalamiko)
10) Kulingana na uzoefu wako katika kupokea huduma za afya, unafikiri ni changamoto zipi zinazokwamisha wagonjwa kushiriki kufanya maamuzi ya pamoja? (Dodoso: imani na maadili, kutokujiamini uhusiano wa mgonjwa na mhudumu wa afya, ufahamu wa maswala ya afya, muda)
11) Una maoni gani kuhusu wagonjwa wa kisukari kushiriki katika kufanya maamuzi yanayohusu matibabu yao?

SEHEMU V: Hitimisho

Una nyongeza yoyote kuhusiana na utafiti unayoona ni muhimu na ungenpenda kunishirikisha ambayo inahusu ushiriki wa wagonjwa wa kisukari kwenye maamuzi ya pamoja na utumiaji wa nyenzo za maamuzi?

Naomba ushirikiano wako tena pale nitakapohitaji ufafanuzi zaidi kuhusu mahojiano yetu.

Ahsante sana kwa ushirikiano ulionipa

Appendix 7: Ethical Clearance

MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES
OFFICE OF THE DIRECTOR OF POSTGRADUATE STUDIES

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Ref. No. DA.287/298/01A/ 14th February, 2019

Vedasto, Osward,
Master of Science in Bioethics,
MUHAS.

RE: APPROVAL OF ETHICAL CLEARANCE FOR A STUDY TITLED: "FACTORS INFLUENCING DIABETIC PATIENTS PARTICIPATION IN SHARED DECISION MAKING AT MUHIMBILI NATIONAL HOSPITAL"

Reference is made to the above heading.

I am pleased to inform you that, the Chairman has, on behalf of the Senate, approved ethical clearance for the above-mentioned study. Hence you may proceed with the planned study.

The ethical clearance is valid for one year only, from **22nd January, 2019 to 21st January, 2020.** In case you do not complete data analysis and dissertation report writing by **1st January, 2020,** you will have to apply for renewal of ethical clearance prior to the expiry date.

Dr. Emmanuel Balandya
ACTING: DIRECTOR OF POSTGRADUATE STUDIES

cc: Director of Research and Publications
cc: Dean, School of Public Health and Social Sciences, MUHAS