

**PATIENTS PARTICIPATION IN THEIR MEDICAL CARE AND
DECISION MAKING AT OCEAN ROAD CANCER INSTITUTE**

Sikudhani A. Luambo

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Muhimbili University of Health and Allied Sciences
Department of Bioethics and Health Professionalism



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By

Sikudhani A. Luambo

**A Dissertation Submitted in (partial) Fulfillment of the Requirements for the Degree
of Master of (Bioethics) of**

**Muhimbili University of Health and Allied Sciences
October, 2017**

CERTIFICATION

The undersigned certify that he has read and hereby recommend for acceptance by Muhimbili University of Health and Allied Sciences a dissertation entitled: *“Patients Participation in their Medical Care and Decision Making at Ocean Road Cancer Institute”* in (partial) fulfillment of the requirements for the degree of Master of Bioethics of Muhimbili University of Health and Allied Sciences.

Prof. Twalib Ngoma

(Supervisor)

Date

DECLARATION AND COPYRIGHT

I, **Sikudhani A. Luambo**, 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.

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DEDICATION

This study is dedicated to my lovely family, especially my lovely daughter “Mozzah” and all those around me in the difficulty I have been through.

ABSTRACT

Background

Participation of patients in decision making is an ethical, legal and regulatory procedure, in medical care. Informed decision is accepted. In this process patients need to be informed about risks, benefits, and alternatives of the treatment intervention.

Objectives

The objective of the study was to explore the involvement of patients in their medical care and decision-making at Ocean Road Cancer Institute.

Methodology

The study used qualitative research method, where in-depth interview was employed. The study informants were cancer patients and doctors from Ocean Road Cancer Institute. The interviews were captured using a tape recorder. The recorded discussions were transcribed, and analyzed using thematic content analysis with the help of NVivo software.

Findings

The study found most patients indicated preference to be involved in their medical care and decision making. Face to face method was mostly employed. The provided information was inadequate. There was poor awareness about patient's involvement. Little application of informed consent during involvement, and patients need not wanted to make decision.

Conclusion

Due to participant's explanations about patient's participation in their medical and decision making, the study finding revealed that patients were not well involved as required by ethical principles, and also as it is directed by World Health Organization. This is due to the used decision method during provision of information, and other challenges relating to the involvement process. Among other, the involvement process, could be facilitated by management of Ocean Road Cancer Institute as well the entire Ministry of Health to take initiatives on making sure patients and all citizens are aware on their medical rights.

LIST OF ABBREVIATIONS

CIOMS	International Organizations for Medical Sciences
DMRET	Dartmouth MUHAS Research Ethics Training Project
EBM	Evidence-based medicine
HCP	Health Care Providers
IPDAS	International Patient Decision Aids Standards
IRB	Institutional Review Board
MCDM	Medical Care and Decision Making
MUHAS	Muhimbili University of Health and Allied Sciences
ORCI	Ocean Road Cancer Institute
PHC	Primary health care
PI	Principle investigator
QDA	Qualitative data analysis
SDM	Shared / Participatory decision-making
WHO	World Health Organization

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DEFINITION OF TERMS

Informed decision making, refers to the act of the patients who have the capacity to make decisions about their care and permitted to do so voluntarily when having all relevant information regarding their condition and alternative treatments, including possible benefits, risks, costs, other consequences, and significant uncertainties around any of the information(1)

Informed consent; refer to the process of communication between a patient and physician that results in the patient's authorization or agreement to undergo a specific medical intervention (2).

Paternalism refers to a type of medical decision making in which health care professionals exercise unilateral authority over patients (medical dictionary).

Shared decision making refers to the process when clinicians and patients make decisions together using the best available evidence (3).

Participation refers to as the collective involvement of local people in assessing and prioritizing their needs and organizing strategies to meet those needs (4).

Patient participation refers to the involvement of the patient in decision making or expressing opinion about different treatment methods which includes sharing of information, feelings, and signs and accepting health team instruction (5).

NOTE:

The terms “patient participation” and “patient involvement” are used interchangeably in this study.

Stakeholders in health care refer to managers, care providers, patients, and the leaders and members of communities (6).

Decision Aids/Methods defined as clinical tools (handouts, audios, audio visual) that translate medical evidence into patient-friendly terms, and guide patients and families through shared decision method (SDM) process by making the decision explicit, providing information about the options, associated risks, and benefits, and clarifying patient and family values and preferences (7).

CHAPTER ONE

1.0 INTRODUCTION

1.1 Background Information

Participation of patients in decision making after having informed is an ethical, legal and regulatory procedure in medical care (8). The process is required by ethical principles which emphasize on individual self-determination (9). It is also directed by the World Health Organization (WHO)(10,11). It is common and applied in different countries. It is practiced in the Middle East, Europe, and North and South America. In countries like the United Kingdom and United States, their government officially endorsed its application(3).

Patient involvement process is determined by three essential elements. First element is recognition and acknowledgment of a decision by both doctors and the patient. Second both must have knowledge and should understand the existing evidence. Last element, decision making should be under provider's guidance and patient's value preferences (12). Patients who lack capacity in preference making, HCP should take into account (13).

Patients participation involves the use of patient decision aids/methods (12). There are more than 500 decisional aids used. These are used by different organization and academic institution over the world, aiming on simplifying understanding. Approximately, around 1999 there were about 15 decisional aids. Decision aids now are available even through internets. However, their quality varies hence debate rises. The International Patient Decision Aids Standards (IPDAS) was established to overcome the raised problems (14).

Involvement needs patient to make decision. Among the principles in the Primary health care (PHC), is to engage stakeholders in decision making process. This was described in the Alma-Ata Declaration (6). In the United States the participatory decision making is well promoted. The reason behind is to improve population health and individual patient, also to control care cost (12). Decision making should be made voluntarily (15–17). This is very crucial in attaining quality service and it leads to valuable outcomes (5).

During 20th century and before paternalistic model in clinical set up was highly applied (6). Around 1970s the necessity of providing medical information to patients was recognised which was associated by the introduction of the use of informed consent

(18,19). Patients' involvement needs doctors to know the understanding of their patients when providing information. Also they needed to satisfy themselves about the reality of the information provided (9). Assessment of understanding to patients will be difficult, if the patient is not informed. This also will hold back the establishment of informed preferences (9). Information provided should include alternative treatments, possible benefits, risks, costs and important doubts(15–17).

On involving patients, individual self-determination should be considered in decision making. Doctors should support the patients. Though sometimes giving the patient chance to decide seems to be like abandoning, in reality it does not abandon the patient(9).

Seeking patient consent is another important part in involvement. In case of serious condition like the late cancer stage, family members consent on behalf of their patients(15). Patient usually consent after been provided information. This is applied by some developed countries like in the United State, Netherlands, and Canada(20). In developing countries, consenting is mostly affected by culture, especially when comes to the point of individual autonomy(8).

Legally accepted informed consent in medical care involves a list of well-explained risks. Patient should be committed to the procedures and sign a form (if present) (21). They are encouraged to asks questions, state doubts, and express their preferences (22), though the expression of preferences is not compulsory. This is determined by the awareness of the patient. Consent usually occurs before the procedure(21). Written consent is highly advised for patients during their treatment process such as surgery, radiotherapy, chemotherapy, and genetic testing, (for cancer patients), and other forms of treatment(6).

Decentralization of health planning authorities to regional and district levels in Tanzania began in 1970s. This was noted as an example of democratization of the decision-making process at lower levels (4). Decentralization policy as well as the health sector reform, gives consideration on community participation in medical care decision making. The aims of the policy were to ensure active participation of the community in knowing their health problems (23,24).

Patient involvement process is associated with different challenges. The challenges may influence patients, HCP, or institution. Among the challenges includes lack of knowledge for HCP, this may result in under-standard care (7,25). Others includes the youth attitudes that based on the necessity and usefulness of a decision aids, dilemma of the right clinical situation be involved (e.g. new diagnoses, chronic illnesses, complex decisions or urgent decisions) and also decrease efficiency and workflow of decision aids (7).

1.2 Problem Statement

A study done by Shayo and others on 2012 at Mbarali district in Tanzania, indicated that, to some extent there is involvement of patients in their MCDM(6). Moreover some Tanzanian HIV and AIDS guidelines and studies signify the involvement of HIV and AIDS patients in their medical care interventions(26–28). However little is known about the involvement of cancer patients' in their MCDM in Tanzania.

Based on these, this study was initiated to assess the involvement of cancer patients in their MCDM mainly on the decision methods for provision of information used, and challenges influencing the involvement process. The disease was selected as it is a chronic disease and its treatment needs a multidisciplinary approach. Moreover cancer patients need to be involved in their MCDM so as to find out how to cope with the disease and possible known risks of their treatments.

1.3 Rationale of the study

- i. Knowledge from the study findings will raise awareness of health care providers on involving patients in their medical care and decision making.
- ii. Based on challenges and suggestions towards patients' involvement, the study findings will help to inform health care providers on the adherence of basic practice of involving patients in their medical care and decision making.

1.4 Research questions

- i. What are the decision methods used by doctors when involving patient in their medical care and decision making?
- ii. What are the challenges encountered when involving patients in their medical care and decision making?

1.5 Research objectives

1.5.1 Broad objective

To explore patients participation in their medical care and decision making at Ocean Road Cancer Institute.

1.5.2 Specific Objectives

- i. To assess the decision methods used by doctors during provision of information when involving patient in their medical care and decision making from both doctors and patients at ORCI.
- ii. To asses challenges encountered on involving patient in their medical care and decision making from both doctors and patients.

1.6 Conceptual framework

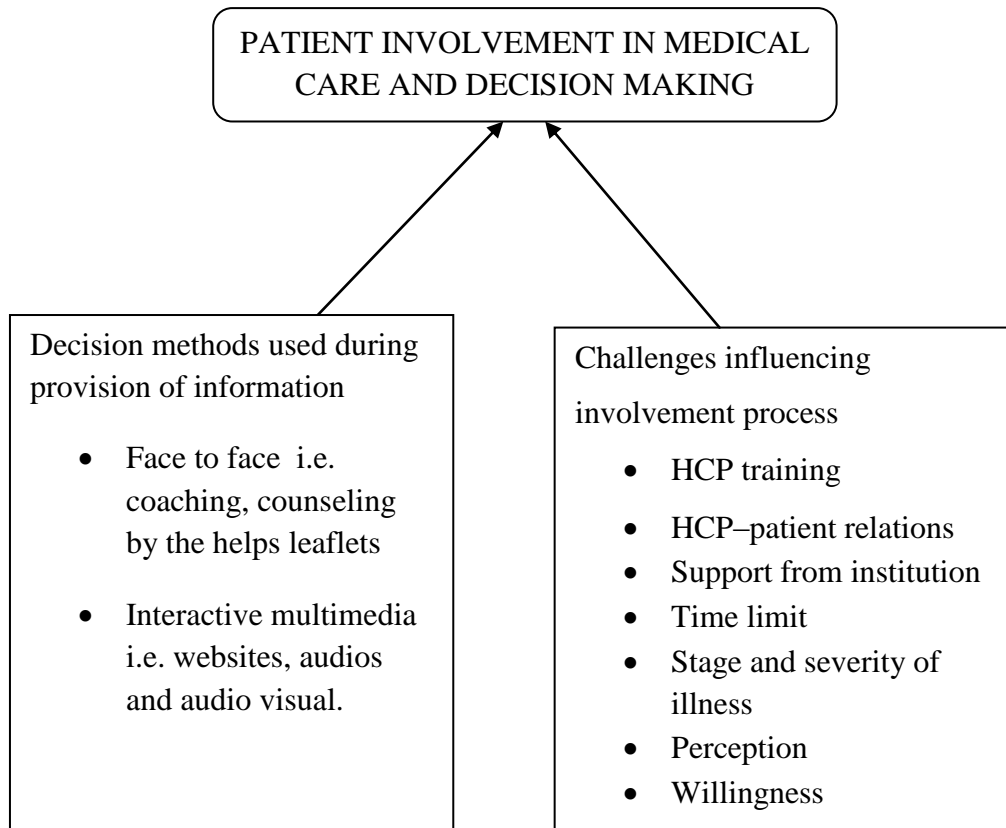


Figure 1;

Patient involvement in medical care as dependent variable can be influenced by decision methods used during provision of information and challenges facing the involvement process. (Own source)

CHAPTER TWO

2.0 LITERATURE REVIEW

Cancer patients like all other patients have the opportunity to participate in medical care and decision-making when introduced in any treatment options (16). In some places around the world, patients are well involved in their medical care and decision making (MCDM). In England and Canada, it was revealed that most people likes to be involved in their MCDM (1,29).

2.1 Participation and decision making

In Tanzania participation in medical care and decision making is mostly considered as it was present in the World Health Organization (WHO) constitution and confirmed in the Alma-Ata Declaration (30). It is described in the Decentralization policy and the health sector reform (23,24,31). Participation is valuable due to the fact that it include personal experiences and understanding of non-medical issues. In turn participation contributes to asking unpredictable questions to health care providers (HCP). The central government in Tanzania continues to authorize the responsibilities towards lower level. Through this, the planning and health service delivery extend closer to the society, at the same time citizen are encouraged to participate in the process (30). Few studies conducted in Tanzania demonstrate the necessity of patients' involvement in their MCDM.

The study done by Kamuzora et al in 2013 at Mbarali district show that, in developing countries the participation is characterized by weak democratic institutions and low public awareness. Moreover the study concluded that, there is a need for effective mobilization of both communities and health systems (30).

Another study done by Mubyazi G.M. at Muheza and Lushoto Tanga Tanzania, declared that people's participation depend mainly on the political and economic system of a place in which it takes place. Participation needs adequately information. There is no sense when participation is without information. Information should be ongoing process and not otherwise. It should also be a means and not an end in itself. Participation process should go together with professional training (4).

Another study done in USA, founded that together with current research, there should be important things to adhere during patients and health care providers interaction. The study revealed that communication with patients should include relevant health information.

Screening and treatment should address patient and family attitudes, values, beliefs, and descriptive social norms. The study recommends further studies to identify the need of health information to simplify decision making (32).

2.2 Decision methods used when providing information during involvement

Participation of patients in their MCDM is well facilitated by the use of decision methods. In Canada it was revealed that, the demand for people to participate in their MCDM was high once patients had proper and adequate information and skills (29). Uses of decision methods fulfil the demand hence make patients be able to make decision.

In Washington DC, patients demonstrated that, communication skill between patients and their HCP bring about adequate information (33). On the other hand the adequate information and good communication during patients' involvement depends on each other. These can be attained by the use and help of good decision methods.

Use of good decision methods on cancer screening, minimizes rate of decision conflict, as it add to adequate information on risks, potential benefits, and scientific doubts (33). This lift up the patient manages the required decision about the intervention. In Australia, patients undergoes cancer screening, were able to make decision once they understand the benefit and risks of their interventions. Their understanding and confidences was a product of the use of decision methods (34).

Good decision methods ease the process of providing information to patients. This in turn will make the decision attained to be meaningful. Doctors are encouraged to use good decision methods which deliver information in a way it will be easy to comprehend (15). In Europe it was revealed that use of decision methods by HCP produces good results in involving patients, and for patients in decision making (14,35).

The decision methods used are differing. They range from face to face to interactive multimedia. Face to face methods includes coaching or counseling by the helps leaflets e.t.c. whereas interactive multimedia involves the use of websites, audios and audio visual. It was revealed that in Canada public websites was less effective than the specially designed Internet decision methods (19).

It was revealed in African countries, including sub-Saharan countries like Tanzania that information is among the barrier for cancer preventing and control (36). As provision of information is facilitated by the use of decision methods, there is a need for skilled HCP.

Due to poverty, most of African countries fail to manage. Tanzanian (Tanganyika) code of ethics and the medical association in Tanzania authenticate that, HCP have to provide adequate information to patients, so as to make them manage to decide about their intervention (37,38). This can be well implemented by the use of decision methods.

Generally decision aids help to make options explicit, provide information about harms and benefits, and clarify patient values, this also was revealed in USA (9,39). The aids are used by patients to prepare themselves for talking with doctors before intervention or sometimes doctors provide decision aids during intervention (39). Generally in USA decision aids increase patients knowledge, make things realistic, and decrease decisional quarrel (9,40). In addition, in Canada decision methods has trimendose effect towards decision making (34).

Use of decision aids is vital in cancer treatment e.g. cancer of head and neck (laryngeal cancer). In USA the use of decision aids helps to manage and assure patients understanding(41). The success for implementing decision aids in clinical practice needs skilled doctors. Also needs conducive environment structures, this was revealed in Canada (19).

According to the reviews, it was seen that most studies for assessing decision methods was conducted in developed countries. Little is known in developing countries like Tanzania. Therefore, this study was aimed to understand methods used by doctors when involving patient in their MCDM.

2.3 Challenges encountered during patient involvement

Involving cancer patients in medical care decision-making is an issue. Some obstacles were observed in some cancer studies conducted. It was already known that, in oncology the involvement is below the standard. In Canada, a total of 1057 patients made about 3552 medical decision. Among the decision made, informed decision was only 9%. Mostly doctors have no propensity of inquiring patient's choices. Recently study proves that only half a time, doctors used to asks for patients preferences (29). Though there is no study found to make this valid, but most of African countries suffer from same challenge. In Tanzania as an example, we suffer from having the shortage HCP (36), probably the presented one have no time ask for patients choice.

Cancer patients also experience the challenge of decisional conflict towards making preferences. In Canada, most of breast cancer women with early stage have doubt to choose their treatment. The women failed to decide as whether to undertake mastectomy or lumpectomy with radiation therapy. Some with advanced cancer fail to decide whether to have their end-life care at home or in a health care institution. Few lung cancer patients were sure to select chemotherapy (19). This also faces African countries. Usually most patients are unaware about screening and treatments of cancer. The study done in Kenya by Maranga I.O et al in 2013 revealed that some patients had heard of a cervical screening. Some had ever had a cervical smear; among them some did not wanted to receive their results (42). Health illiteracy and poor understanding contribute to unawareness. This also faces most of Tanzanian patients as it is among the sub-Saharan countries (36).

In Tanzania, it was revealed that most patients are not ready to cooperate with their doctors. Reason for the behavior is mainly cultural difference. Doctors had responsibility of making decision on behalf of the patient. Things like wealth, education level as well as gender influence the involvement and decision making. Basing in this, men, rich people and even leaders have high chances to explore their preferences, and make their decisions. Others like women, and low income people does not have the chance (6).

Decision methods for the provision of information, and other patient personal problems hinder patients' involvement. This was revealed in different countries including Tanzania. Personal problems includes; diseases emotions, financial problems, complexity of treatment options, health literacy, and lack of experience with medical care system (12,29,41). Another challenge revealed in Tanzanian context is the bias. This is related to perceptions of women, the less educated and poor individuals as all having less knowledgeable, and lower thinking capacity. As a result these hinder the implementation of democratic and justice theory (6). It was revealed that, shortage of time in US, (12) logistics, and lack of training in Canada, contributes to difficulties in involvement (29) same as in Tanzania, though there is not yet been researched.

Another challenge is about implementation. There is documentation about patient decision making, without explanation of how to achieve (9).

In Africa, specifically the sub-Saharan Africa, persist same and other challenges. The main challenge that hinders involvement is infrastructure. There is the shortage of radiotherapy machine. Patients use most of their time waiting for radiotherapy (36). Their

minds are just thinking on obtaining the treatment without thinking on risks and ways of minimizing the risks associated with the treatment. As there are many patients in need of the service, HCP use most of their time in arranging patients on obtaining treatment without using the time to inform the patients on risk, benefit and other important things.

Again, mostly these challenges are revealed from developed countries. Though they are general challenges encountered in patients' involvement processes. This study was designed to assess challenges encountered on involving cancer patient in their MCDM, specifically in Tanzania as a developing country.

CHAPTER THREE

3.0 METHODOLOGY

3.1 Study design

Qualitative study was designed to assess lived experience described by participants. The designed tool of data collection was formulated basing on the study objectives. In depth interview was used to answer the reseach questions so as to have rich information(43).

3.2 Study duration

The study took place for three months i.e. June, July and August 2017.

3.3 Study area

The study was conducted at ORCI. The Institution is at Dar es Salaam region, along with the Indian Ocean about 200 meters from the beach. It is the oldest health institutions in Tanzania founded by the German colonial government in 1895 (44). The institution was purposefully selected due to its specialization in cancer treatment in Tanzania.

3.4 Study population

The targeted populations were cancer patients undergoing medical treatment and HCP at ORCI. Patients were enrolled as they were receiving care, i.e. already consulted physician. Some were outpatients others were inpatients. The HCP were enrolled based on their qualifications and obligation to adhere accurately to rules and principles of medical care during the treatment process.

3.5 Inclusion criteria

Patients with 18 years and above, who were diagnosed with any type cancer, undergoing treatment, as well as HCP at ORCI.

3.6 Exclusion criteria

Mentally or severely sick patients were not recruited as study informants. Also internship HCP was not recruited.

3.7 Sampling procedure

Purposive sampling method was used. Patients as study informants were obtained based on their information recorded in the files. After obtaining permission from ORCI management, the PI went to the reception office, meet with the in charge. After expression, the in charge sent her to the departmental nurses. Nurses sort the convenient patients' sample. A respective nurse also gives some information about convenient doctors. The PI used to contact the doctor based on nurse's information and negotiate about the interview. This was a way used to obtain participants within the limited time.

3.8 Data collection procedure

During data collection in-depth interview was used. Consent was requested from individual participant before interview. During the interview the Swahili prepared tools was used. Guide modification was done after the first few interviews. The aim was to incorporate the missing themes which were beneficial for the study. Voice recorder and a phone were used for recording. Field notes were taken, and then verbatim expressions were expanded soon after interviews.

3.9 Data analysis

Thematic method for data analysis was used. Before analyzing data, the interviews were transcribed. The transcripts then were read and re-read to familiarize with the emerging themes and concepts. Pre-determined code and the one obtained during the study was assorted and used to code with the obtained study information. Interview information was categorized into number of themes. Organization of data was done with the help of NVivo software program.

3.10 Ethical consideration

The study was conducted after obtaining ethical clearance from Research and Publication Committee of Muhimbili University of Health and Allied Sciences. Permission to conduct the study was given by ORCI administration. Written informed consent was given to patients, followed by oral explanations about the study. Participants consent was asked after they understand the aim, benefits and even risks of the study. Participants also were asked to be recorded during interview process. All patients were agreed, except one doctor, therefore note book was used. Though there was no one withdrawn, voluntariness and rights to withdrawal was highly considered. Most of interviews were carried out in private rooms. About first three interviews were carried out in the hall were patients used to have their chemotherapy. The PI tried her level best to maintain confidentiality as it was written in the informed consent form. On maintaining confidentiality, the PI use low voice, moreover the participants real names had not been used, interview numbers were used instead. Data reporting was done without the identification of participants names.

CHAPTER FOUR

4.0 FINDINGS

This chapter presents findings from involvement of patients in their medical care and decision making study. The study involves eleven patients and five HCP at ORCI Dar es salaam-Tanzania. From the information gathered, seven categories emerged.

4.1 Demographic

Sixteen people were included in the interview; among them 11 were patients and 5 doctors. Some patients had primary education, others secondary and college level education. Only one patient possessed a bachelor degree. Doctors also had different education level; there were general and specialist doctors. The participants were between 22 and 58 years of age.

Table 1: Demographic Information of patients and HCP

Groups	Patients	HCP
Gender		
Male	5	3
Female	6	2
Age group		
21-31	1	1
32-42	3	4
43-53	5	0
54-64	2	0
Education level		
Primary	4	0
Secondary	4	0
College	2	0
Graduate	1	2
Postgraduate	0	3
Marital status		
Single	2	3
Married	6	2
Widow	3	0
Divorced	0	0
TOTAL	11	05

4.2 Decision methods used by HCP when providing information to patients

Face to face method of delivering information to patients was mostly preferred by HCP. Most patients replied that, usually HCP used to talk with them verbally. In some departments like radiotherapy, patients were given information about the intervention, but the modality of imparting information was face to face. The interviewed patients responded that;

“Face to face, he/she speaks you respond to such a question if asked, and you ask a question, he/she respond, you keep the same style” (IDI # 7)

Also doctor said;

“When I attended the patient usually we sit together, only two of us, so I will give you knowledge, I ask if you have a question, so it’s a verbal conversation, if there will be necessity of drawing, I will draw. If you do not understand completely, now I will ask you to go on video or to counselor, but mostly it is verbal, and the first is verbal” (ID#4)

Mostly patients said they were not given anything to facilitate their understanding. In rare cases, the HCP use leaflets. This was usually done during the morning. When patients came, they were asked to read the information in the handout. The aim was to understand some of the risks associated with their treatments, a patient said;

“The way they used to make us understand, is by the use of leaflets. We were given leaflets, when we come on the morning. We were told to read for our benefit, we will contact with same symptom. They told us in case of any question you have, you can ask or sought any doctor and described, he will explain, or even a nurse who passed, you try to tell them, they will explain” (IDI #11).

Also doctors said that:

“On explaining certain cancer, its symptoms, there are leaflets given to patients, so they were given, and they read. This helps to open mind, and get understanding” (IDI # 12)

During seminars the HCP preferred to use videos. In other situation they use counseling, as the doctor said:

“First we have palliative canceling unit to those patients who are in the final stages of the disease, and also in the morning, they used to have patients seminars” (IDI # 13).

Another doctors said;

“When patients arrive in the morning, while they are waiting to see a doctor or while they are waiting for a cure in the waiting area, there is a HCP who talk to them about treatments and challenges, and how to get treatment and everything. There’s also the video in which the patient is looked at, and show how we offers treatment“ (IDI # 8).

4.3 Inadequate information provided to patients during intervention

Doctors experienced difficulties on providing detailed information to patients who they think have poor understanding. They said with the exception of insurance patients, most of local patients have low education level; hence their understanding is very poor. Among the doctor said;

“Mostly we encounter patients who have low education level, they are standard seven, secondary, especially on public institution, so even in talking / conversation, we could share, they would ask questions, but education still be as a bridge” (IDI # 4).

Most patients and doctors said among the things that lead to inadequate information is time. Time is not conducive. Doctors are required to encounter many patients. They consume a lot of time, therefore they failed to provide adequate information, they said;

“Sometimes we have many patients, the doctor may find no enough time to describe, you find the patient you described afterwards got out and another patient comes in, need also description” (IDI # 8)

Some doctors have doubts on telling patients the truth when the disease is in the late stage. They have a hard situation when they know the possibility of recovery is negligible, they said;

“Sometime a patient who is coming at the late stage, telling him that you will never be cured or that your recovery is tough, you know it is a challenge” (IDI # 12).

Patients said they never heard anything about their condition and intervention from their HCP. They had no information on how to live after completion of their treatments. The information they had, was conveyed by their fellow patients. They also said some HCP used to provide information under certain condition. Sometime they need to know patients marital status, a patient said;

“For example, there is one doctor asked me, if I have a husband, I said I have no husband we were divorced, the doctor replied, if you had a husband I would tell you some of the things” (IDI # 9).

Nearly all patients agreed on having chance to question. Among those who agreed, some fail to use the chances effectively, some tried. Among them said;

“I asked one, because one week and a half before my therapy, I suffered from malaria, I finished taking a malaria medicine dose(mseto), I asked; If I finished taking in the dose within one week, then I started taking “chemotherapy” does not be bad” (IDI # 1).

Some patients observed, in adequate information is contributed to their tendency of not asking questions. They used to ask and share information among them. Some of the patients did not like to share information among them. The information shared mostly is not correct, among them said;

“Like what I told you before, that there is a tendency of taking too much information to someone who is not a professional, now, after been taken information from the person who is not a specialist is that, when you go to a doctor, already you have your information about everything which is going on, so even in the opportunity of asking, you failed, because already you have your own outside words” (IDI # 7).

HCP also experiences the behavior. Moreover they said information shared misleads patients. Among the doctor said;

“ For the few who are aware they asked, but majority of the patients I see, are afraid to ask , they are more comfortable talking to their fellow patients” (IDI # 8).

4.4 Awareness about patients’ involvement in their MDCM

On assessing about patients involvement in their MDCM, different views were explored. Doctors tried to respond to the question by explaining the way they involve their patients in their intervention. Others tried to describe the way they understand. Among the doctors said;

“I know when the patient arrives to a doctor, I should read responses, and give the available medical treatment options, while the patient will be described the effects and benefits of each option and availability” (IDI # 4).

Another doctor said;

“To my little knowledge is that, it means that, first a patient must understand his disease, at what stage is it, what is the curable possibility, after that, we also must share about treatment, how will it be, the purpose of the treatment, if there is side effects in the treatment and the like” (IDI # 8).

Some patients also agreed that they were involved in their intervention. They appreciated the services they had. Among the patients who agreed to be involved, when they asked to described the way they had been involved they said;

“I am satisfied because up to this moment, nurses take us, they call us, they direct us to show where we should stay, they tell us what’s follows next, I think involvement is well, in such a way that you cannot be fail to know where you will go to get treatment” (IDI # 5).

Another patient said;

“For sure, often they involve me, that you have reached this stage and so on, because myself when I met with them I usually enquiry them” (IDI # 13).

4.5 Patients’ decision making during patients’ involvement

HCP said they provide chances to patients to make decision during involvement. But most patients were not ready to make decision, and they had no confidence. They do not like to decide at all. This was also confirmed by one of the patients who said;

“I think a doctor tells you to do something after seeing how your problems rise” (IDI # 11).

Another patient said;

“After knowing my distress, themselves planned the therapy, I cannot choose, I cannot know” (IDI # 14).

Some other patients said, they were ready for decision making, and they need the opportunity. They complain that HCP did not give them the opportunity. Usually HCP make decision without considering patients’ needs. Patients eager to have a chance, they said;

“I longed for it, if I would be given alternative, I would choose the best, but you are told this is the best, now if it is the best, I could not tell them give me another which is not the best” (IDI # 9).

4.6 Application of Informed consent during patient involvement

Informed consent was applied in some departments i.e. radiotherapy and in surgery. In other department mostly the application is none, once occurred, it is verbally. Basing on their working situation, some doctors said they have no time for consenting. Others said that there is no need on the use of consent. Other doctors said there is no even a specific form for consenting. Among them said;

“Requesting informed consent is not necessary, often consent applies to the surgical treatment, for normal treatment usually it is orally, the patient is told his medical problems as well as required treatment, there is no such format all” (IDI # 12).

Some doctors go beyond and see the necessity of applying written informed consent in all departments. Now day’s life is changing. Patients may accuse the doctor as result of having no written informed consent. Among them said;

“for my thought preparation is needed, I think we need to obtain the patient consent, because apart from providing them with treatment, there are many side effects as well, a patient might complain later, I was not informed about this and this and this, therefore it can bring legal problems later” (IDI # 8).

4.7 Needs and suggestions on improving participation and decision making

Patients had their preferred method. They said they prefer more counseling. Counseling raises their comfort and reduces their sorrow. Other patient who had been already be treated in other places, explained the way counseling remove fear, and made them feel happy. The patient said;

“In where I was, there was counselors, after diagnosed me with cancer, they counseled me, they said, you have the disease, we will give you medicines one two three, but they told me something which helped me at the time, that the healing of your body is not up to us, is up to you. To make medicine work, you should be stress free; medication does not need stress, to receive medication for fun” (IDI # 15).

The patient continues that:

“Cancelling was Indeed very helpful to me, when I use the drugs at first, it was very easy, first I removed fear, I was thinking as if I am not suffering, I used to plan my life as normal, I became so happy”(IDI # 15).

Patients were also interested with doctor’s affection. They need friendship relation with their doctors. Among them said;

“It is only about doctors to change attitudes, doctors should be in friendship with patients, although mostly are friends, it’s still not enough, that participation has not been in a good level, now we should talk, as you came here, we sit, we spoke, you be my friend, at the end of the day, I will be open, I will be all open, so it becomes a very good way” (IDI # 6)

Doctor had consideration on active patient involvement. They advise to increase number of attendant, others advised about mass education to patient so as to be aware with their medical rights, a doctor said;

“May be by telling patients their rights, from there, make them knew their rights and duties” (IDI # 4)

There is a doctor who also insisted about the existence of counseling people. Counselors’ role will be providing information to patients. Another doctor shows the importance of patients coming with their relatives. The relative will be on behalf of their relatives for everything. This will also give hope to the patient. Doctors will impart severely patient relative’s knowledge, accurate and adequate information, as well as treatment procedures, he said;

“Relatives also should be included, i.e. if the patient comes to the hospital, he/she should come with a close relative, who can be with him/her, at least understand his/her trouble” (IDI # 12).

HCP also insisted on the taking initiatives which will make the patients know their rights, as far as they (doctors) know. Among the doctors said;

“Mostly patients we see, have low education, they are standard seven, or secondary, especially in the public institution. In such a situation, even in talking / conversation, where we could share, they would ask me questions, knowledge will remain as a building part. Maybe by telling their rights since there, where they will know their rights and responsibility. I know the patient rights, but probably, they do not know” (IDI # 4)

CHAPTER FIVE

5.0 DISCUSSION, LIMITATION AND MITIGATION

5.1 Discussion

Most of participant's age range between 32 years to 64 years. For patients this indicated that they were matured enough and ready for making decision about their treatments. HCP were younger in age as compared to most of the patients. Based on this, doctors manage to involve their patients as they are in the generation of patient centred.

Most patients have low education level i.e. primary to secondary. This impair with their understanding and hence compromises with the involvement and decision making process. In some cases, patients' marital status was used as criterion for provision of information. This is wrong way of involving patients. Patients have the right to be involved in their treatments, irrespective of any factor. The author explores information from both patients and HCP so as to balance the reality.

Involving patients in their MCDM needs the HCP to have skills of applying decision methods effectively. They should have skills to communicate the information to patients so as to make them understand. Though most of doctors are younger, by means that they are equipped with skills and knowledge of applying different decision methods, when providing information, (learned from colleges) the study revealed that, they fail to integrate the decision methods. They mostly apply face to face method i.e. make more use of verbal conversation. There was no much use of hand-outs, audios and videos. Possible explanation for this is there is poor utilization of decision methods. Elwyn et al, insist that decision methods can act as a catalyst when involving patients (9). Therefore; it is encouraged to integrate decisional method when involving patients in their MCDM (9, 38).

Among the basic bioethics principles insisted on doing good and avoiding harm to patients.

This is for all countries around the world including Africa. Based on the non-maleficence principle, the Tanzania Code of Ethics directs the HCP to struggle so as to have adequate standard equipment and necessary supplies for practice (44). Therefore our HCP at ORCI were required to demonstrate use of decision methods effectively. Another possible explanation for limited application of decision method is poor budget.

Good utilization of decision methods, enhance adequate information. On its second principle which is about rights of the patient's rights to information, the Tanzanian Guiding Principle of Medical Ethics and Human Rights insisted on provision of adequate information to patients (44). This study revealed that there was inadequate information provided during normal intervention. Most participants agreed they were given information. The study revealed the information given, was mainly about risks of radiotherapy and chemotherapy. There is the lack of information on the benefit of intervention, and the alternative intervention.

The study revealed inadequate information was influenced by different sub factors. These include; Stage and severity of illness, patients poor understanding, and limited time. Other sub factors includes patients tendency of not asking, instead shares information among them, in which they miss concept. Last sub factor as it is revealed in this study is the tendency of informing patients basing on certain criteria. This creates bias. All patients should be treated equally irrespective of their marital status as this study found.

The finding of inadequate information in this study did not march with Tanzanian Code of Ethics and the Guiding Principle of Medical Ethics and Human Rights. Both of the two above insist on the provision of adequate information so as to enable patients to make their decision (37,38).

In USA, it was revealed involvement needs adequate information (14). Also it was revealed in Washington that, adequate information minimizes decision conflicts (32). In Africa also put emphasis on patient involvement. In this study it was seen that, patients they did not understand the concept of involvement, therefore their involvement is questionable. This is signified by patient's failure to describe their involvement. The finding seems not to match with guiding principle of medical ethics and human rights on its eleventh principle. The principle put emphasis on involving the community in their MCDM (37). The only possible explanation for this is lack of patient's awareness about involvement.

Patients' involvement includes decision making. The study revealed that; some cancer patients are not ready to make their own decision, instead leave doctors to decide on their behalf. Though in African context there are no enough studies about patients decision

making, they still obliged to practice as it is required by ethical principles and recommended by the WHO (9–11).

Seeking patient consent is important when involving a patient. Consent should be applied even in case of serious condition like the late cancer stage. In such a condition family members should be involved on behalf of their beloved patients (14). Any type of consent can be applied, but the written consent is highly advised to be used (6). This study revealed that there is neither application of oral nor written consent in chemotherapy and screening departments at ORCI. Little application of it was observed in surgery and radiotherapy departments as patients responded.

Application of informed consent is well recommended by different African articles. The South African General Ethical Guidelines for the Health Care Professions and the Ghana Health Service Patient Charter insist on the application of informed consent in each medical intervention (45,46). Current study is not consistent with Tanzanian Code of Ethics and the Guiding Principle of Medical Ethics and Human Rights. Both of the two above insist on the provision of adequate information so as to enable patients to make their decision (37,38).

There are several possible explanations for this. That; use of informed consent is irrelevant has no beneficial implication, or the management did not like the use of it, or HCP did not like the use of informed consent, or HCP are so busy hence they have no time for consenting.

Compassion was among the advices for combating challenges. HCP were advised to show compassion to their patients. This is very important, as it was revealed by other studies (9). Compassion to patients will create trust among them; hence the patient would eliminate fear and would be able to speak openly. This advice further supports the previous study done by Shuman et al (2017). Regarding its treatment, doctor-patient interaction is very important for attaining the patient informed decision. This also will enhance patient centred and assuring patient autonomy (40).

Another advice revealed by the study is about increasing the number of counsellors. This will ensure the provision of information to patients. Counsellors will enhance awareness and made patients have detail information. Counsellors also will help reduce the work load.

5.2 Study limitation and mitigation

Major study limitation was on data collection. The study needed to balance the information from both participants i.e. patients as well as HCP. Unfortunately it was difficult to interview specialists as it was planned by the PI. This was because they were so busy. The PI tried to make appointment with some of HCP, yet it was failed. By considering point of saturation, the interviews was conducted to some experienced general doctors and some specialist doctors.

Another limitation was about confidentiality. Most outpatients have no time for interview, thought they were ready to be interviewed. They need to be interviewed while they were taking chemotherapy.

CHAPTER SIX

6.0 CONCLUSION AND RECOMMENDATIONS

6.1 Conclusion

During the exploration about patients' participation in their MCDM, the used decision method for provision of information was realized as well as challenges that influence the involvement process. In general findings in this study revealed that patients were not well involved in their medical care and decision making as required by ethical principles, and also as it is directed by WHO. It was realized that, there were the use of one decision method during provision of information. This led the challenge of inadequate information, which in turn hinders the involvements process. In other hand, inadequate information is contributed by other sub factors like, stage and severity of illness, patient's poor understanding, and limited time. Also patient's tendency of not asking and the tendency of providing information based on certain criteria. The latter creates bias.

Other influencing challenges include the awareness about patients' involvement in their MCDM, patients' being not ready to make decision, and little application of informed consent.

To some extent the encountered challenges that bring difficulties on involving patients, looks similar to that of developed countries. The differences are in terms of ways of tackling challenges. In most of developing countries there are no intentions and strategies of alleviating the challenges.

Among the suggestions for achieving the involvement of patients in our context is to increase number of attendants, especially counselors. They will provide information to patients, instead of the job to be done by doctors.

There is a need for further research on alleviating challenges, so as to achieve the satisfied patient participation in medical care and decision making.

There is a need for more research to assess ways of eliminating the influenced challenges so as to ensure patients are well involved in their MCDM.

6.2 Recommendations

In medical care interventions, the HCP should provide individual patients with relevant and adequate information. The information provided should be free, irrespective of any condition.

HCP should apply different methods when informing their patients. They should integrate the used methods from face to face to multimedia.

Consenting is among the factors that ensure legal and ethical patient rights. During their daily treatment interventions, HCP should make use of written informed consent in all departments rather for specific department.

The ORCI management as well as Ministry of Health should make sure informed consent is fully applied so as to meet the legal and ethical patient's rights.

Management of ORCI as well the entire Ministry of Health should take initiatives to make sure patients and all citizens are aware on their medical rights. This will raise patient's awareness and confidence on questioning and making decision, and also will facilitate the involvement process,

REFERENCES

1. Veroff D, Marr A, Wennberg DE. Enhanced support for shared decision making reduced costs of care for patients with preference-sensitive conditions. *Health Aff.* 2013;32(2):285–93.
2. Schenker Y, Fernandez A, Sudore R, Schillinger D. Interventions to Improve Patient Comprehension in Informed Consent for Medical and Surgical Procedures: A Systematic Review. *Med Decis Mak.* 2011;31(1):151–173.
3. Ng C-J, Lee P-Y, Lee Y-K, Chew B-H, Engkasan JP, Irmi Z-I, et al. An overview of patient involvement in healthcare decision-making: a situational analysis of the Malaysian context. *BMC Health Serv Res.* 2013;13(1):408.
4. Kamuzora P, Maluka S, Ndawi B, Byskov J, Kamuzora P, Maluka S, et al. Promoting community participation in priority setting in district health systems: experiences from Mbarali district, Tanzania. *J Public Health (Bangkok).* 2013;9716(October 2017):12.
5. Vahdat S, Hamzehgardeshi L, Hessam S, Hamzehgardeshi Z. Patient involvement in health care decision making: a review. *Iran Red Crescent Med J.* 2014;16(1):e12454.
6. Shayo EH, Norheim OF, Mboera LEG, Byskov J, Maluka S, Kamuzora P, et al. 28. Challenges to fair decision-making processes in the context of health care services: a qualitative assessment from Tanzania. *Int J Equity Health.* 2012;11(1):30.
7. Boland L, Mcisaac DI, Lawson ML. Barriers to and facilitators of implementing shared decision making and decision support in a paediatric hospital: A descriptive study. *Paediatr Child Heal.* 2016;21(X):1–5.
8. Grady C. Enduring and Emerging Challenges of Informed Consent. *N Engl J Med.* 2015;372(9):855–62.
9. Elwyn G, Frosch D, Thomson R, Joseph-Williams N, Lloyd A, Kinnersley P, et al. Shared decision making: A model for clinical practice. *J Gen Intern Med.* 2012;27(10):1361–7.

10. Coulter A, Parsons S, Askham J. Where are the patients in decision-making about their own care? *Heal Syst Heal Wealth*. 2008;1–26.
11. World Health Organization. Exploring patient participation in reducing health-care-related safety risks. WHO: Geneva. 2013. 190 p.
12. France L, Witteman HO. Shared decision making: Examining key elements and barriers to adoption into routine clinical practice. *Health Aff*. 2013;32(2):276–84.
13. Consent to Medical Treatment in South Africa. 2011. p. 44.
14. Elwyn G, Connor AO, Stacey D, Volk R, Edwards A, Coulter A, et al. Developing a quality criteria framework for patient decision aids: online international Delphi consensus process. *BMJ*. 2006;10(August):1–6.
15. Brach C. Even in an emergency, doctors must make informed consent an informed choice. *Health Aff*. 2016;35(4):739–43.
16. Fowler FJ, Gallagher PM, Bynum JPW, Barry MJ, Lucas FL, Skinner JS. Decision-making process reported by medicare patients who had coronary artery stenting or surgery for prostate cancer. *J Gen Intern Med*. 2012;27(8):911–6.
17. Shuman a. G, Larkin K, Thomas D, Palmer FL, Shah JP, Patel S, et al. Patient Priorities in Decision Making for Laryngeal Cancer Treatment. *Otolaryngol Head Neck Surg*. 2014;151(1 Suppl):P176–P176.
18. Medical W, Lisbon A, General WM a, Bali A, Session C. World medical association declaration of lisbon on the rights of the patient. 2005;(October):2–4.
19. Stacey D, Samant R, Bennett C. Decision Making in Oncology: A Review of Patient Decision Aids to Support Patient Participation. *CA A Cancer J Clin*. 2008;58(5):293–304.
20. Krumholz, H. Spatz, E. Moulton B. The New Era of Informed Consent Getting to a Reasonable-Patient Standard Through Shared Decision Making. *Jama*. 2017;315(19):2063–4.

21. S. Yael and M. Alan. Informed Consent Clinical Care. 2011;305(11):1130–1.
22. Informed Consent in Anticipate and Communicate: Ethical Management of Incidental and Secondary Findings in the Clinical ., In 2016. p. 1–23.
23. The United Republic Of Tanzania, Tanzania National eHealth Strategy June , 2013 – July , 2018. 2013.
24. The United Republic of Tanzania, Ministry of Health; National Health Policy. 2003-2008. 2008.
25. Brom L, Hopmans W, Pasma HRW, Timmermans DR, Widdershoven GA, Onwuteaka-Philipsen BD. Congruence between patients' preferred and perceived participation in medical decision-making: a review of the literature. BMC Med Inform Decis Mak. BMC Medical Informatics and Decision Making; 2014;14(1):25.
26. Njau B, Ostermann J, Brown D, Mühlbacher A, Reddy E, Thielman N. HIV testing preferences in Tanzania: a qualitative exploration of the importance of confidentiality , accessibility , and quality of service. BMC Public Health. 2014;14(838):1–9.
27. Nationa AIDS Control Programme (NACP). National Guidelines For the Management of HIV AND AIDS. 3rd editio. Dar es salaam; 2009.
28. Government of Tanzania. Adherence Counselling for HIV Care and Treatment. Dar es salaam, Tanzania: Ministry of Health and Social Welfare, National AIDS Control Programme (NACP); 2013.
29. Légaré F, Stacey D, Brière N, Desroches S, Dumont S, Fraser K, et al. A conceptual framework for interprofessional shared decision making in home care: protocol for a feasibility study. BMC Health Serv Res. BioMed Central Ltd; 2011;11(23):1–7.
30. Mubyazi GM, Mushi A, Kamugisha M, Massaga J, Mdira KY, Segeja M, et al. Community views on health sector reform and their participation in health priority setting: case of Lushoto and Muheza districts , Tanzania. 2017;29(2):147–56.

31. Boex J, Fuller L, Malik A. Decentralized Local Health Services in Tanzania. *Urban Inst.* 2015;(April).
32. Thompson VLS. Making decisions in a complex information environment : evidential preference and information we trust. *BMC.* 2013;13(Suppl 3):7.
33. Kerns JW, Krist AH, Woolf SH, Flores SK, Johnson RE. Patient perceptions of how physicians communicate during prostate cancer screening discussions: A comparison of residents and faculty. *Fam Med.* 2008;40(3):181–7.
34. Stacey D, Cl B, Mj B, Nf C, Kb E, Lyddiatt A, et al. Decision aids for people facing health treatment or screening decisions (Review). *Cochrane Collab.* 2012;(10):1–36.
35. Salkeld G, Cunich M, Dowie J, Howard K, Patel MI, Mann G, et al. The Role of Personalised Choice in Decision Support: A Randomized Controlled Trial of an Online Decision Aid for Prostate Cancer Screening. *PLoS One.* 2016;10(1371):1–17.
36. Morhason-Bello IO, Odedina F, Rebbeck TR, Harford J, Dangou JM, Denny L, et al. Challenges and opportunities in cancer control in Africa: A perspective from the African Organisation for Research and Training in Cancer. *Lancet Oncol [Internet]. Elsevier Ltd;* 2013;14(4):10.
37. Medical Association in Tanzania, *Guiding Principles on Medical Ethics and Human Rights in Tanzania.* 1995. p. 27.
38. Medical Council of Tanganyika *Code of Ethics and Professional Conduct For Medical and Dental Practitioners In Tanzania,* 2005. p. 22.
39. Elwyn G, O'Connor AM, Bennett C, Newcombe RG, Politi M, Durand MA, et al. Assessing the quality of decision support technologies using the International Patient Decision Aid Standards instrument (IPDASi). *PLoS One.* 2009;4(3):1–9.
40. Hamori CJ, Kaplan RM. Internet Patient Decision Support. *Arch Intern Med.* 2008;168(4):363–9.
41. Shuman AG, Larkin K, Thomas D, Palmer FL, Fins JJ, Baxi SS, et al. Patient Reflections on Decision Making for Laryngeal Cancer Treatment. *Am Acad Otolaryngol.* 2017;152(2):299–304.

42. Maranga IO, Hampson L, Oliver AW, Gamal A, Gichangi P, Opiyo A, et al. Analysis of Factors Contributing to the Low Survival of Cervical Cancer Patients Undergoing Radiotherapy in Kenya. *PROS ONE*. 2013;8(10):9.
43. Creswell J. *Research Design Qualitative, Quantitative, and Mixed Method Approaches*. 4th ed. United States of America: Sage Publications, Inc.; 2014. 342 p.
44. ORCI. *Facts About Ocean Road Cancer Institute*. Tanzania; 2014. p. 10.
45. Oti AA, Owusu-dapaah E, Adomako-kwaakye C, Sabbah DK, Obiri-yeboah S, Amuasi A, et al. Informed Consent under the Ghana Health Service Patients Charter: Practice and Awareness. 2016. p. 63–7.
46. *Guideline: Informed Consent*. 2012. p. 1–6.

APPENDICES

Appendix I: Interview guide questions for patients in English

Site.....
 Interview No
 Moderator.....
 Assistant moderator.....
 Date.....
 Start.....
 End.....

INTRODUCTION

As I have said earlier, my name is Sikudhani A. Luambo, a second-year student from Muhimbili University undertaking masters' degree in Bioethics. I am here to conduct an interview with you, for my study titled PATIENTS PARTICIPATION IN THEIR MEDICAL CARE AND DECISION MAKING. I chose you, because you have rich information for my study, which later will help us to have better environment for patients to participate in their medical care decision making, therefore I expect to hear more from you. Feel free and be open to talking whatever you want within our topic, as I have said you have a chance of abandon some question(s) that you think is not valid to you, though myself I beg you to participate fully in answering all of my questions. We already talked about the purpose, benefit, and risks for you to participate in the study and that, our interview will cover about 30 to 45 minutes, as far as you volunteer to participate in the study, let we start our interview by signing the consent form, followed by a simple background of the study.

BACKGROUND

Patient participation refers to the involvement of the patient in decision making or expressing an opinion about different treatment methods which includes sharing of information, feelings, and signs and accepting health team instruction(5).

Informed decision making, refers to the act of the patients who have the capacity to make decisions about their care and permitted to do so voluntarily when having all relevant

information regarding their condition and alternative treatments, including possible benefits, risks, costs, other consequences, and significant uncertainties around any of the information(1)

Participation of patients in decision making after being informed is an ethical, legal and regulatory procedure which is accepted to be applied worldwide.

(Transition: Let me have your personal information)

1.0 DEMOGRAPHIC INFORMATION

- 1.1 Gender.....
- 1.2 Age.....
- 1.3 Education.....
- 1.4 Marital status.....
- 1.5 Currently, what do you do.....

I will try my level best to make sure the gathered information will be of secret, and will only be used by the researcher. As it is difficult to capture all of the information in a notebook, I beg your permission to record our interview.

(Transition to the next form of question)

2.0 GENERAL QUESTION

- 2.1 What do you understand about patient participation in medical care decision making?

(Transition to the next form of questions)

3.0 STUDY QUESTIONS

- 3.1 What were the methods did the doctors used to provide medical information?

Probes:

- Did they talk with you face to face to convey medical information?
- Did you understand the provided information?
- Did you have a chance to ask questions?
- What information did you remember the doctor provide to you and how did he/she provide?

3.2 What are the challenges on involving patients to participate in their medical care decision making?

Probes:

- How did you see, is the doctors time allow involving you in making decision?
- How far are you willing and ready to make your own decision about your treatment? Is it easy?
- How does the environment situation allow physicians to involve patients to participate in making their decision?
- What do you say about accessing your treatment information while you are still undergoing treatment?

3.3 What is your suggestion(s) on the patient to participate in their medical decision making?

(Closing the Interview)

- I appreciate the time you took for this interview. Is there anything else concerning our discussion that would be helpful and can successfully be used for the betterment of involving patients in their medical care decision making?
- Would it be alright to call you other time if I have any more questions?

THANKS

Appendix 2: Interview guide questions for doctors in English

Site.....
 Interview No
 Moderator.....
 Assistant moderator.....
 Date.....
 Start.....
 End.....

INTRODUCTION

As I have said earlier, my name is Sikudhani A. Luambo, a second-year student from Muhimbili University undertaking masters' degree in Bioethics. I am here to conduct an interview with you, for my study titled PATIENTS PARTICIPATION IN THEIR MEDICAL CARE AND DECISION MAKING. I chose you, because you have rich information for my study, which later will help us to have better environment for patients to participate in their medical care decision making, therefore I expect to hear more from you. Feel free and be open to talking whatever you want within our topic, as I have said you have a chance of not answering the question(s) that you think is not valid to you, though myself I beg you to answer all of my questions. We already talked about the purpose, benefit, and risks of the study, our interview will cover about 30 to 45 minutes, as far as you volunteer to participate in the study, let we start our interview by signing the consent form, followed by simple background of the study.

BACKGROUND

Patient participation refers to the involvement of the patient in decision making or expressing an opinion about different treatment methods which includes sharing of information, feelings, and signs and accepting health team instruction(5).

Informed decision making, refers to the act of the patients who have the capacity to make decisions about their care and permitted to do so voluntarily when having all relevant information regarding their condition and alternative treatments, including possible benefits, risks, costs, other consequences, and significant uncertainties around any of the information(1).

Participation of patients in decision making after being informed is an ethical, legal and regulatory procedure which is accepted to be applied worldwide.

(Transition: Let me have your personal information)

1.0 DEMOGRAPHIC INFORMATION

- 1.1 Gender
- 1.2 Age
- 1.3 Education.....
- 1.4 Marital status.....
- 1.5 Education level.....

I will try my level best to make sure the gathered information will be of secret, and will only be used by the researcher. As it is difficult to capture all of the information in a notebook, I beg your permission to record our interview.

(Transition to the next form of question)

2.0 GENERAL QUESTION

- 2.1 What do you know about patient participation in medical care decision making?

(Transition to the next form of questions)

3.0 STUDY QUESTIONS

- 3.1 What are the methods do you use to provide medical information?

Probes:

- Do you use to talk with your patient's face to face to convey medical information?
- How do you know if your patients understand the information?
- Mostly what are their position in making decision after being informed and understand? (accepting/refusing)

- 3.2 What are the challenges for involving patients to participate in their medical care decision making?

Probes:

- How do you see about time, is it conducive to involve the patient in making decision?

- How about your patients, do they willing and be ready to participate in making decision?
- What do you say about environment situation, is it friendly for you to involve patients in making decision?

3.3 What are your suggestions about patient participation in their medical decision making?

(Closing the Interview)

- I appreciate the time you took for this interview. Is there anything else concerning our discussion that would be helpful and can successfully be used for the betterment of involving patients in their medical care decision making?
- I will contact for more information in need.

THANKS.

Appendix 3: Informed consent form in English

Introduction

Hello, my name is SIKUDHANI A. LUAMBO, a second-year student from MUHIMBILI UNIVERSITY. For the time being, I would like to inform you about the study titled PATIENTS PARTICIPATION IN THEIR MEDICAL CARE AND DECISION MAKING. After understanding information about the study, kindly I request your consent orally, so as to participate in the study. Herewith is my research assistant.

Purpose of the study

The study will be conducted to explore information about the participation of patients in their medical care and informed decision making. I would like to explore information so as to understand your opinion, knowledge, and experience about the issue. Some patients and health care providers will be interviewed and observed their conversation.

Study procedures

I welcome you to participate in the study, so as to get your views on the issue. Once you will volunteer to participate, I will ask you question about the study interest, you will answer as per your degree of understanding. After consenting, observation and interview will be done within the premises but at the place where you will be comfortable to answer questions. A total of 25 participants will be enrolled in where 15 will be health care providers and 10 patients. Duration for an interview will be about 30 to 35 minutes. The research assistant will be used to collect data. There is no direct benefit for participating in the study, instead, your beautiful opinion generated from your knowledge and experience will help to mold the accepted model of care, which is the patient-centered care. The study will start by observing and then followed by an interview. Notebooks and recorder will be used to enhance the process.

Confidentiality

The explored information will be kept confidential, you are information will be accessed only by research members of this study. There will be no name mentioned so as to link with your information, no implication to your current and future status to social services including health services. Your name will not be mentioned in any paper or report about this study.

Participation

Participants are free to participate in the study. They have the right to refuse or withdraw from the study by any reason of their interest. As it is a volunteer participation, you may decide not answer any of the questions if you will be not interested. Even after consent, you may decide to withdraw from participating. Your decisions to participate or not will not in any way interfere with your right to receive any available medical care.

Ethical clearance

To conduct the study, ethical clearance was obtained from MUHAS research committee and the approval was asked from ORCI management.

Contact

In the case of any inconveniences, which need more clarification, misunderstanding or quarrel, about the study, you may contact the following; principle investigator mobile number 0716 260 097 or e-mail address siku.luambo@gmail.com. Questions about your rights you may contact Dr. Joyce Masalu, mobile number +255 22 2152489 – MUHAS.

Any question so far?

YES (answer all)

NO (jump to another)

Are you willing to participate?

YES (continue)

NO (abandon)

Declaration

Myself I understand the study purpose as it seeks to explore information about the participation of patients in their medical care and informed decision making. I got a chance for questioning and appreciate the way principle investigator (PI) responds. Willingly, I volunteer to participate in the study and free to drop out once I wanted.

Signature of the respondent.....Date.....

Signature of the interviewer.....Date.....

THANKS FOR PARTICIPATING

Kiambatanisho cha 4: Muongozo wa maswali kwa wagonjwa kwa kiswahili

Sehemu ya mahojiano.....	
Namba ya anaehojiwa.....	
Anaehoji.....	
Msaidizi.....	
Tarehe.....	
Muda wa kuanza	
Muda wa kumaliza.....	

UTANGULIZI

Kama nilivojambulisha kabla, naitwa SIKUDHANI A. LUAMBO ni mwanafunzi wa mwaka wa pili kutoka chuo kikuu MUHIMBILI nikisomea shahada ya udhamili inayohusu maadili katika afya (Bioethics). Dhumuni la kuwepo hapa ni kufanya mahojiano na wewe kuhusu uafiti wangu wenye kichwa cha habari KUSHIRIKISHWA WAGONJWA KUFANYA MAAMUZI YANAYOHUSU TIBA ZAO. Nimekuchagua wewe sababu, nimeona ni muhimu katika kukamilisha utafiti huu, kwani una taarifa muhimu ambazo zitasaidia kuboresha ushirikishwaji wa wagonjwa katika kufanya maamuzi yanayohusu tiba zao, nategemea mengi toka kwako. Jisikie huru na kuwa wazi kuongea vyote kuhusu mada yetu hii, kama nilivosema una nafasi ya kutojibu swali usilolipenda, japokua nilipenda unijibu yote. Wakati naomba ridhaa tulishaongea yote muhimu kama vile dhumuni la utafiti, faida na hasara ya kushiriki. Pia nilisema mahojiano yetu yatumia kati ya dakika 30 na 45. Kwa kua uliridhia kushiriki, naomba tuanze mahojiano yetu kwa kusaini fomu ya ridhaa, na kuangalia kwa ufupi taarifa tangulizi ya utafiti wetu.

TAARIFA TANGULIZI

Ushirikishwaji inamaana ni hali ya kuwajumuisha wagonjwa katika kufanya maamuzi au kutoa maoni kuhusu njia tofauti za tiba zao, ambapo inajumuisha kubadilishana mawazo, kutoa hisia na pia kukubaliana na maelekezo ya wataalamu wa afya/waganga.

Kufanya maamuzi yanayohusu tiba (informed decision-making) ni hali ya mgonwa mwenye uwezo/ufahamu mzuri, kuruhusiwa na kwa hiari yake kuamua, baada ya kua na taarifa muhimu kuhusu hali yake na pia kuambiwa mbadala wa tiba hiyo. Taarifa hizo zinajumuisha faida, hasara, gharama na mengineyo.

Ushirikiswaji wa wagonjwa katika kufanya maamuzi yanayohusu tiba zao ni jambo linalokubalika kimaadili na kisheria duniani kote.

(Kuhama: sasa naomba unipatie taarifa zako binafsi)

1.0 TAARIFA BINAFSI

- 1.1 Jinsia
- 1.2 Umri
- 1.3 Kiwango cha elimu
- 1.4 Hali ya ndoa
- 1.5 Unafanya kazi gani.....

Kama nilivosema awali kuwa taarifa zitakazochukuliwa nitajitahidi kuzihifadhi kwa usiri, na zitatumwa na mtafiti tu, na kwa kua siwezi kunakili mahojiano yetu yote, naomba uniruhusu niweke mahojiano haya katika kumbukumbu, ili baadae niweze kuyafanyia kazi.

(Kuhama na kwenda aina nyingine ya swali)

2.0 SWALI LA UJUMLA

- 2.1 Unaeleweje kuhusu mgonjwa kushiriki katika kufanya maamuzi ya tiba yake?

(Kuhama na kwenda aina nyingine ya maswali)

3.0 MASWALI YA KIUTAFITI

- 3.1 Njia zipi mganga alitumia kukufikishia taarifa za kimatibabu?

Muendelezo:

- Alikupatia taarifa hizo mkiwa pamoja?
- Ulifahamu taarifa za kimatibu ulizopewa?
- Ulipata nafasi ya kuuliza maswali?
- Ni taarifa zipi unakumbuka mganga alikupatia, na alikupatiaje?

- 3.2 Nini changamoto za kumshirikisha mgonjwa katika kufanya maamuzi yanayohusu matibabu yake?

Muendelezo:

- Unaonaje, kwamba muda aliokuanao mganga unatosha kukufanya ushiriki katika kufanya maamuzi ya matibabu yako?

- Ni kwa kiasi gani unautayari na nia ya kushiriki kufanya maamuzi hayo? Unaonaje, ni rahisi kushiriki?
- Mazingira na nyenzo, vinamruhusu mganga kumshirikisha mgonjwa katika kufanya maamuzi?

3.3 Nini maoni yako kuhusu wagonjwa kushirikishwa katika kufanya maamuzi yanayohusu matibabu yao?

KUFUNGA MAHOJIANO

- Nashukuru kwa kutumia muda wako kwa kufanya mahojiano, una lolote la zaidi kuhusu mahojiano haya ambalo unahisi ni muhimu katika kuboresha ushirikishwaji wa mgonjwa katika maamuzi yanayohusu afya yake?
- Naomba ushirikiano wako kama huu nitakapo kuhitaji tena teerifa kuhusu mahojiano haya.

ASANTE

Kiambatanisho cha 5: Muongozo wa maswali kwa waganga kwa kiswahili

Sehemu ya mahojiano.....
 Namba ya anaehojiwa.....
 Anaehoji.....
 Msaidizi.....
 Tarehe.....
 Muda wa kuanza
 Muda wa kumaliza.....

UTANGULIZI

Kama nilivojitambulisha kabla, naitwa SIKUDHANI A. LUAMBO ni mwanafunzi wa mwaka wa pili chuo kikuu MUHIMBILI nikisomea shahada ya udhamili inayohusu maadili katika afya (Bioethics). (Nilieongozana nae ni msaidizi wangu anaitwa.....)
 Dhumuni la kuwepo hapa ni kufanya mahojiano na wewe kuhusu utafiti wangu wenye kichwa cha habari. KUSHIRIKISHWA WAGONJWA KUFANYA MAAMUZI YANAYOHUSU TIBA ZAO Nimekuchagua wewe sababu, nimeona ni muhimu katika kukamilisha utafiti huu, kwani una taarifa muhimu ambazo zitasaidia kuboresha ushirikishwaji wa wagonjwa katika kufanya maamuzi yanayohusu tiba zao, nategemea mengi toka kwako. Jisikie huru na kuwa wazi kuongea vyote kuhusu mada yetu hii, kama nilivosema una nafasi ya kutojibu swali usilolipenda, japokua nilipenda unijibu yote. Wakati naomba ridhaa tulishaongea yote muhimu kama vile dhumuni la utafiti, faida na hasara ya kushiriki. Pia nilisema mahojiano yetu yatatumia kati ya dakika 30 na 45. Kwa kua uliridhia kushiriki, naomba tuanze mahojiano yetu kwa kusaini fomu ya ridhaa, na kuangalia kwa ufupi taarifa tangulizi ya utafiti wetu.

TAARIFA TANGULIZI

Ushirikishwaji inamaana ni hali ya kuwajumuisha wagonjwa katika kufanya maamuzi au kutoa maoni kuhusu njia tofauti za tiba zao, ambapo inajumuisha kubadilishana mawazo, kutoa hisia na pia kukubaliana na maelekezo ya wataalamu wa afya/waganga.

Kufanya maamuzi yanayohusu tiba (informed decision-making) ni hali ya mgonwa mwenye uwezo/ufahamu mzuri, kuruhusiwa na kwa hiari yake kuamua, baada ya kua na

taarifa muhimu kuhusu hali yake na pia kuambiwa mbadala wa tiba hiyo. Taarifa hizo zinajumuisha faida, hasara, gharama na mengineyo.

Ushirikiswaji wa wagonjwa katika kufanya maamuzi yanayohusu tiba zao ni jambo linalokubalika kimaadili na kisheria duniani kote

(Kuhama: sasa naomba unipatie taarifa zako binafsi)

1.0 TAARIFA BINAFSI

- 1.1 Jinsia
- 1.2 Umri
- 1.3 Kiwango cha elimu
- 1.4 Hali ya ndoa
- 1.5 Idadi ya miaka kazini.....

Kama nilivosema awali kuwa taarifa zitakazochukuliwa nitajitahidi kuzihifadhi kwa usiri, na zitatumiwa na mtafiti tu, na kwa kua siwezi kunakili mahojiano yetu yote, naomba uniruhusu niweke mahojiano haya katika kumbukumbu, ili baadae niweze kuyafanyia kazi.

(Kuhama na kwenda aina nyingine ya swali)

2.0 SWALI LA UJUMLA

- 2.1** Ulikua unaelewaje kuusu mgonjwa kushiriki katika kufanya maamuzi ya tiba yake?

(Kuhama na kwenda aina nyingine ya maswali)

3.0 MASWALI YA KITAFITI

- 3.1** Ni njia zipi unazitumia kufikisha taarifa za kimatibabu kwa wagonjwa wako?

Muendelezo:

- Unaonana nao moja kwa moja?
- Unafahamu vipi kama wagonjwa wameelewa taarifa?
- Baada ya kuwafikishia taarifa wengi wao wanakuwa upande upi? (kukubali, kukataa)

3.2 Nini changamoto ukimshirikisha mgonjwa katika kufanya maamuzi yanayohusu matibabu yake?

Muendelezo:

- Unaonaje kuhusu muda, unatosha na kumshirikisha mgonjwa?
- Kimtazamo wagonjwa wanautayari wa nia ya kushiriki maamuzi?
- Unaongeleaje kuhusu mazingira; yanaruhusu kuwashirikisha wagonjwa?

3.3 Nini maoni yako kuhusu wagonjwa kushirikishwa katika kufanya maamuzi yanayohusu matibabu yao?

KUFUNGA MAHOJIANO

- Nashukuru kwa kutumia muda wako kwa kufanya mahojiano, una lolote la zaidi kuhusu mahojiano haya ambalo unahisi ni muhimu katika kuboresha ushirikishwaji wa mgonjwa katika maamuzi yanayohusu afya yake?
- Naomba ushirikiano wako kama huu nitakapo kuhitaji tena kwa taarifa kuhusu mahojiano haya.

ASANTE

Kiambatanisho cha 6: Fomu ya ridhaa: kwa Kiswahili

Utangulizi

Habari, jina langu SIKUDHANI A. LUAMBO ni mwanafunzi wa mwaka wa pili kutoka chuo kikuu MUHIMBILI. Kwa muda huu ningependa kuwafahamisha kuusu utafiti wenye kichwa cha habari KUWASHIRIKISHA WAGONJWA KWENYE KUFANYA MAAMUZI YA MATIBABU YAO. Baada ya kufaham maelezo nitakayoyotoa, naomba ridhaa yenu ili mshiriki katika utafiti huu. Nilieongozana nae ni mtafiti msaidizi.

Dhumuni la utafiti

Utafiti unaofanyika unahusu ushilikishwaji wa wagonjwa kwenye maswala ya matibabu yao na kufanya maamuzi yao. Nitazungumza na wewe nakupata taarifa zitakazonifanya nielewe maoni na mawazo yako pia na maamuzi yako katika hili. Baadhi ya wagonjwa na waganga watahojiwa nakuangaliwa wanavohojiana.

Taratibu za utafiti

Nawakaribilisha kushiriki, utakapojitolea kushiriki nitakuuliza maswali yenye manufaa na utafiti na utanijibu kulingana na uelewa wako. Mahojiano yatafanyika ndani ya eneo hili, lakini uko huru kuchagua na kukaa sehem ambayo utakua huru. Jumla ya washiriki watakua 25, ambapo 15 niwaganga na 10 ni wagonjwa. Takriban dakika 30 hadi 35 zitatumika. Mtafiti msaidizi atasaidia zoezi la kukusanya taarifa. Hakuna faida ya moja kwa moja katika utafiti huu, badala yake maoni yenu yatakayotokana na ufaham na uzoefu wenu, yatasaidia kufikia malengo yakutekeleza mfumo wa “patient –centered care” not books na vinasasauti vitatumika kukusanya taarifa.

Usiri

Taarifa zitakazochukuliwa zitahifadhiwa nakutumiwa na mtafiti wa utafiti huu. Hakutakua na majina yatakayooanishwa na taarifa yoyote na hakutakua na athari zozote sasa na baadae za kijamii ikiwa ni pamoja na kiafya. Jina lako halitatajwa kwenye ripoti ya utafiti huu.

Ushiriki

Mshiriki yupo huru kushiriki utafiti. Kwasababu zao, wanahaki ya kukataa au kujiondoa kwenye utafiti. Kama ilivo ni hiari, unaweza amua kutojibu swali lolote utakaloona kama hukuridhishwa nalo. Hata baada yakuridhia, unaweza kujitoakushiriki. Uamuzi wako wa kushiriki au kutoshiriki hauingiliani na haki yako ya kupata huduma za afya na matibabu.

Kibali cha utafiti

Kibali cha ruhusa ya kufanya utafiti huu imetoka kamati ya maadili ya utafiti ya chuo kikuu cha Muhimbili, na kukubaliwa na uongozi wa taasisi ya ORCI.

Mawasiliano

Kama kutahijika maelezo zaidi kuusu utafiti, malalamiko au kutoeleweka, wasiliana na mtafiti kupitia simu ya mkononi namba 0716 260 097 au barua pepe siku.luambo@gmail.com. Maswali yanayohusu haki, wasiliana na Dkt. Joyce Masalu, mobile number +255 22 2152489 – MUHAS.

Kuna swali lolote?

NDIO (jibu yote)

HAPANA (nenda swali lingine)

Unakubali kushiriki?

NDIO (endelea)

HAPANA (muache)

Azimio

Nimeelewa dhumuni la utafiti ni kuangalia ushilikishwaji wa wagonjwa kwenye maswala ya matibabu yao na kufanya maamuzi yao. Nimeuliza maswali pale ambapo nilikua sijaelewa na nimeridhika na majibu yake. Bila kulazimishwa na kwa hiari yangu nimekubali kushiriki na pindi nitakapoamua kujitoa, nina haki ya kufanya hivyo.

Sahihi ya Mshiriki.....Tarehe.....

Sahihi ya Mtafiti.....Tarehe.....

ASANTE KWA KUSHIRIKI