TRUTH TELLING BY HEALTHCARE PROVIDERS TO TERMINALLY ILL CANCER PATIENTS AT OCEAN ROAD HOSPITAL IN DAR-ES-SALAAM

Raymond Athanas, BA

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By

Raymond Athanas

A Dissertation Submitted in (Partial) Fulfillment of the Requirements for the Degree of Master Science of (Bioethics) of

Muhimbili University of Health and Allied Sciences
October, 2018

CERTIFICATION

The undersigned certify that they have read and hereby recommends for acceptance by Muhimbili University of Health and Allied Sciences a dissertation entitled **"Truth Telling by Healthcare Providers to Terminally ill Cancer Patients at Ocean Road Hospital in Dar-es-salaam",** in (partial) fulfillment of the requirements for the degree of Master of (Bioethics) of Muhimbili University of Health and Allied Sciences.

_____

Dr. Gasto Frumence (PhD)

(Supervisor)

Date: _____

_____

Renatha S. Joseph, (MD, MMed, MBE)

(Co-Supervisor)

Date: _____

DECLARATION AND COPYRIGHT

I, **Raymond Athanas**, declare that this **dissertation** is my 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

With love of a son, I humbly and sincerely dedicate this dissertation to my beloved late daddy *Marko Athanas Mkhai*, for enduring severe pains and sufferings of throat cancer. His love and desire to the truth telling stirred me to carry this work through, truth telling put him perpetually free.

ABSTRACT

Truth telling by healthcare providers to terminally ill cancer patients is not only an important aspect of patient care but also a medical fundamental right of a patient. Despite available evidence of significance of truth telling, and the recommendation by the General Medical Council as the statutory regulatory for the medical profession in the United Kingdom (UK) since 2009 and currently Tanzania National Healthy Research Forum, recommend that healthcare providers should give patients information they want or need in a way they can understand, its implementation is still low especially in developing countries. In Tanzania, little is known regarding the factors influencing implementation of the ethical standard of truth telling to cancer patients.

This study aimed at examining the factors influencing truth telling by healthcare providers to terminally ill cancer patients at Ocean Road Cancer Institute in Dar-es-Salaam.

The study employed exploratory case study research design using a qualitative approach of data collection to explore factors influencing the implementation of the bioethical standard of truth telling by healthcare providers to terminally ill cancer patients at Ocean Road Cancer Institute (ORCI) in Dar-es-Salaam. Cancer patients at a terminal stage and healthcare providers were purposively selected to participate in this study. Data was collected by using a well-structured set of interview guides to key informants with open ended questions and audio-recorder; they were Tran-scripted and translated. Thematic analytical approach was applied to arrive at categories through the process of coding and forming key themes. Data was collected between; early April up to early May 2018.

Twenty-one (21) study participants were involved; of these 13 were healthcare providers and terminally ill cancer patients were 8. The implementation of ethical principle of truth telling to terminally ill cancer patients by healthcare providers at ORCI was less implemented than what ought to be. This was reported to be influenced by a number of factors; those stemming from healthcare providers include: lack of a comprehensive understanding of Healthcare providers, sympathetic feeling, limited time, doctor-patient's relationship, telling as both good and bad thing, lack of guidelines, lack of adequate facilities, number of patients and multi-disciplinary team. Those factors stemming from

patients include; level of understanding, freedom of choice to information, rights to information, lack of prior information, psychological condition and faith and beliefs. And those factors stemming from socio-cultural include; traditional beliefs and cultural communication style and family collusion.

There is a gap of truth telling to terminally ill cancer patients by healthcare providers at ORCI. Healthcare providers at ORCI should have ongoing trainings so as to be equipped with knowledge and communication skills about truth telling. The ORCI should have well stipulated guidelines on truth telling to terminally ill cancer patients as how, when, to whom and by whom. The guidelines should spell clearly the qualities of a multi-disciplinary team which by all means should include experts' personnel like oncologists, nurses, psychiatrists, medical ethicists, psychologists and spiritual leaders.

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ABBREVIATIONS

GMC	General Medical Council
MNH	Muhimbili National Hospital
MUHAS	Muhimbili University of Health and Allied Sciences
MUSC	Medical University of South Carolina
ORCI	Ocean Road Cancer Institute
USA	United States of America

OPERATIONAL DEFINITION

Key Terms and Concepts

Truth

The term truth is defined as something to be revealed or discovered of what was previously hidden into the open, as something that is generated through various systematic medical discourses(1). It is most often used to mean being in accord with fact or reality. Operationally then, truth is considered as the correspondence of thought to an independent reality about prognosis of a terminally ill patient. Truth telling is a total openness and transparency in revealing medical information by a health provider to a patient or caretaker about the prognosis.

Terminal illness

Terminal illness means an incurable and irreversible disease that has been medically confirmed and willed within reasonable medical judgments can produce death within six months. Therefore, operationally, a terminally ill cancer patient is a person with incurable and irreversible cancer disease that has been medically confirmed and willed within reasonable medical judgments that will face death within a limited time, and currently is on a dying process(2).

Diagnosis and Prognosis

Diagnosis is a process of determining which disease or condition that explains symptoms and signs of a person. The process can be challenging because many signs and symptoms are nonspecific and can be associated with so many disorders. Prognosis has to do with all sorts of forecasting, foreknowing and foreseeing of the possible outcome of a medical situation.

It includes the expected duration, function and description of the course of the disease such as progressive decline, intermittent crisis and unpredictable crisis(3).

Dying and death

It is the process and a point at which human vital physical functions cease. However, it is for the science of medicine to give a clear and precise definition of dying and the moment

of death. Because now days with medical advances in life prolonging treatments and supports, the line between who is alive and who is dead has become unclear. Death is normally preceded by a dying process marked by fear, anxiety, loneliness, and isolation(4).

Benevolent Deception

Benevolent implies being good and caring, while deception implies tricking someone. Benevolent deception therefore is to suppress information about diagnosis and prognosis in hopes of not causing patients emotional harm. It is usually used by healthcare providers to give false hope to a patient who has little chance of recovery from a fatal or terminal illness(5).

CHAPTER ONE

1.0I NTRODUCTION

1.1 Background to the study

Both original and classical versions of the Hippocratic Oath suggest that every healthcare provider should by no means keep patient's information confined from patient. But the modern version tends to be more specific than the original one in terms of a subject concern. While the original one speaks of 'in the life of men', the classical version talks of 'in the lives of my patients'(6). Medical ethical codes however suggest that, patients should not be denied information by healthcare providers pertaining to their own health and life(7–9).

Truth Telling Efficacy

A patient as a moral autonomous agent has a fundamental right to know and to be given information about own illness and treatments(10). Informed consent requires that a patient should receive all reasonable information about the essential nature of the proposed treatment and its benefits; risks, side-effects, consequences, and cost as well as any reasonable and moral legitimate alternative, including no treatment at all(11–13).

Truth Telling Dilemma

The main dilemma encountered by healthcare providers is whether to inform or not, truth and nothing but that truth telling or deceiving for hope? Should they inform patients over criticality of their health and generally in so doing lessening hope or should they deliberately suppressing the information and misleading patients so as to improve chances of survival by instilling hope. The supporters of this side of the dilemma argue that, protecting and fostering hope can be more valuable than truth telling (5).

Old way versa Vis New way of Resolving the Dilemma

There has been an old way of dealing with the medical ethical dilemma of truth telling whereby healthcare providers ought to act on behalf of a patient for the benefits of a patient. This meant that a healthcare provider could as seems medically and morally reasonable for

him to suppress any medical information for the benefits of a patient or just opting to give partial information which is literally true but deceptive. This was more common under the circumstances and conditions whereby the nature of patient's illness has stigmatizing diagnosis or poor prognosis. Although even up to date the method is still in use by some healthcare providers (14).

Withholding the truth by healthcare providers adhering to the old version is a form of medical paternalism. It is merely adopted by healthcare providers mainly with the intention of protecting a patient from physical and or emotional harms(15). The new version of medical ethics of truth telling is definitely committing healthcare providers to respect for autonomy of a patient and rejection of paternalism. Although again depending on circumstances and conditions, there may still be some benefits and advantages in deceiving a patient, since at a grave point cheating a patient can be medicine(15,16).

Truth telling- a Professionals' Dilemma

Truth telling therefore has been a medical common professional dilemma. Some of healthcare providers still incline to paternalism and others adopt new medical ethics of patient centered autonomy. Still there are some of healthcare providers who tend to integrate the two versions(15–17).

Truth Telling Dilemma in Context

A truth telling dilemma in context has been considered in the sense that, the subjects of the study are terminally ill cancer patients, and to tell a terminally ill cancer patient or merely a cancer patient that 'you have cancer', it is already an issue that leads a patient to lose hope. Also, when comes to an African culture particularly to Tanzanian culture, we do not have a sense of individualism rather a communal kind of concern. Therefore, a healthcare provider gets stuck on a crossroad to tell a patient over the diagnosis and prognosis because of African social cultural values which one is inclined to(18–20).Likewise, to make a prognosis is very difficult task of healthcare providers in context, due to insufficient medical tools and other medical logistics as explained into the section of prognosis challenges. There is a need to

bridge the gap by linking and reconciling the dilemma with the two truth telling versions, while taking into account truth telling and deception for hope, benevolent deception and patient centered, medical professionalism and social cultural values(15,21,22)

Benevolent Deception

Ethically speaking, healthcare providers are morally obliged to follow the doctrines of autonomy and beneficence. But some healthcare providers may mistakenly use benevolent deception because of how it honors the principle of beneficence. They do cheat for benefits of a patient especially when find out that telling would cause more harm than benefit(5). Benevolent deception overall should not be utilized in everyday medical practice because it dis-respects autonomy of a patient ((23).

Truth Telling Coverage

Globally, the magnitude of telling and of not telling the truth to terminally ill cancer patients varies from one place to another. In the United States of America (USA) 83% of a sample of 219 healthcare providers reported that they would opt to tell the truth over a medical report to their terminally ill patients(24,25) to their terminally ill patients. In Turkey, a significant proportion of cancer patients (44%) were not told over their diagnosis and prognosis(24). The great majority of healthcare providers (79%) in Kuwait would withhold the truth if the patient's family requested them to do so(26). Moreover, in Saudi Arabia 75% of healthcare providers preferred to discuss information with close relatives rather than patients themselves even when they are mentally competent(4,27)**.** Japanese patients generally are not concerned about their own medical treatment decisions. Their moral consent and autonomy is subjected to that of their family members(28)**.**

Truth Telling in African Countries

Generally, in African countries, caring for the sick is not charity but an ethical obligation. The cultural factor in Africa for respecting autonomy makes it both individual and communal affairs(29).

Truth Telling in Sub-Sahara Countries

Different socio-cultures give different significances to truth telling to the patients in the Sub-Sahara African countries. In Ethiopian culture, a patient's hope relies on a healthcare provider to cure illness and help to manage pain. Honesty and integrity of a healthcare provider is not questioned, whether decides to tell or not (18).In Kenya, the ethical medical tradition did not see the need to affirm the patient's right to know the truth about his or her health. Current studies provide little and limited information about the tendency of healthcare providers telling or not telling the truth to terminally ill cancer patients(20).In Tanzania, the interviews conducted indicate that some healthcare providers believe in telling family members of elderly cancer patients about the prognosis especially if the disease is terminal. It was reported that, in many circumstances some elderly patients when told of their terminal condition, tend to give up hope and die prematurely(19).

Prognosis Challenges

It is known that, information reliability of prognosis has some challenges that include; genetic alterations; which is diverse and represent only small subsets of patients in certain tumor types, which limits testing their clinical impact in biomarker-driven clinical trials. Reliability of clinical trials; the issues regarding clinical interpretation of large genomic data is the other challenge that makes difficult to use in wide clinical, as well as dealing with tumor heterogeneity and acquired resistance. Immune checkpoints inhibitors; there are minority of patients with immune checkpoints inhibitors that can enable a long-term survival benefits, hence subject prognosis into uncertainties. Validated predictive markers; there are no predictive markers robustly validated, that could help healthcare providers recognize these subsets and optimize treatment delivery and selection. Also, there is a challenge of the need of drug combinations that targeting several molecular alterations or cancer hallmarks(30).

Taking into account the prognosis challenges mentioned above among others, truth telling to a patient however is not only about being accuracy. Truth telling is about letting a patient being aware of what is going on pertaining treatments and disease. Truth telling is giving a due right to a patient. Most terminally ill cancer patients are not aware of complexity of their health,

possible risks and upcoming effects(31). Had they told, would have made an informed decision about whether or not to delay or prolonging dying and death(31).

Generally, there are critical cases for terminally ill cancer patients not receiving realistic medical information from healthcare providers relating to their health during treatment(32).Truth telling is a fundamental right of a patient which is incorporated into medical guidelines of healthcare providers and of palliative care(33). Openness, honest and transparency of healthcare providers over truth telling to terminally ill cancer patients has then been both a medical and moral issue(34,35), and this research is intending to find it out.

1.2 Statement of Problem

General Medical Council as the statutory regulatory for the medical profession in the United Kingdom (UK),recommends that healthcare providers should give patients information they want or need in a way they can understand(12,36)Generally, terminally ill cancer patients are hardly and rarely told the truth about their health progress, the rate varies from country to country(37).The consequences for not telling the truth to terminally ill cancer patients bring lack of advance directives, psychological and spiritual preparations as well as family misunderstandings. Also bring to a patient all sorts of anxiety, tensions and despair, such that they die while unprepared and with a guilty conscious of information denial(25).

Worldwide studies show that, many healthcare providers opt to disclose information to family members other than to patients(4,26,31,38). In Sub-Sahara African countries, cultural aspects like communication style, beliefs, values and customs have been reported to hinder the disclosure of information to patients(32,39,40). Interviews conducted in Tanzania indicate that, some healthcare providers believe in telling the truth to family members because in many circumstances some patients when told of their terminal condition, tend to give up hope and die prematurely(19).

Truth telling to cancer patients is much more practiced in developed countries like in USA than in developing countries (29). In African countries, truth telling is at a very low margin. In Tanzania little is known, due to limited evidence available regarding factors influencing healthcare providers' dilemma of telling or not telling the truth to cancer patients. Therefore, this study aimed to reduce such a knowledge gap by exploring information from Ocean Road Cancer Institute in Dar-es-Salaam as a case study.

1.3The Conceptual Framework

TRUTH TELLING IMPLEMENTATION

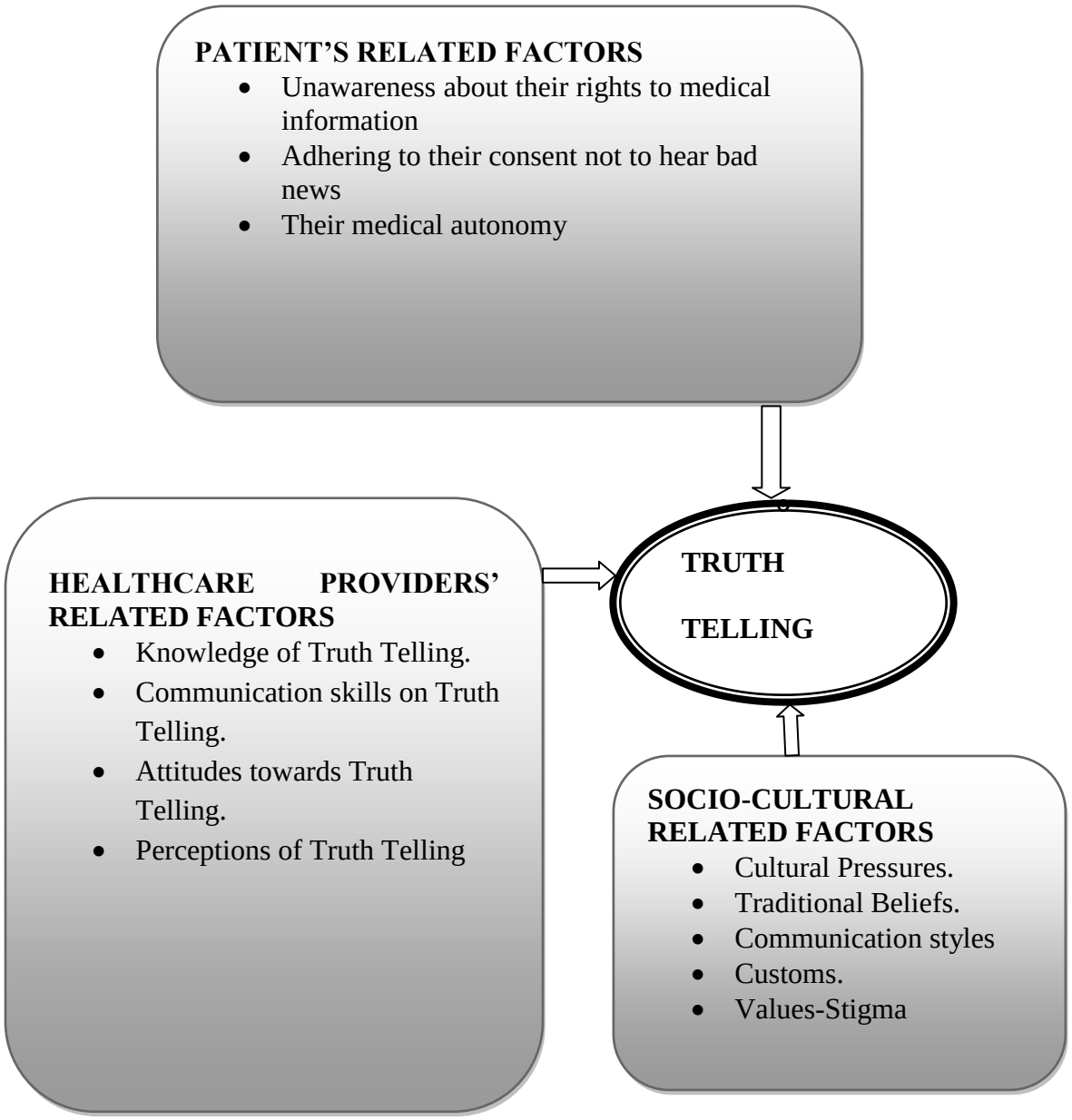


Figure 1: Conceptual Framework about truth telling implementation adapted from(25)(39).

According to the above conceptual framework, truths telling to terminally ill cancer patients can be influenced by a number of related factors include; knowledge level of health providers about truth telling, their perceptions, communication skills as well as attitudes.

Other related factors are of social cultural, which include; cultural pressure, traditional beliefs, values, customs and communication styles(39). However, there are also patient's centered related factors that include; lack of awareness about their rights to medical information, adhering to their consent not to hear bad news and their medical autonomy(41).

1.4 Rationale of the Study

This study aimed to examine truth telling by healthcare providers to terminally ill cancer patients at Ocean Road Hospital in Dar-es-Salaam. The information obtained from this study is expected to provide awareness and alert the healthcare providers about the importance of truth telling, as well as reducing dilemma about telling or not telling the truth. The information is also expected to justify formal training in communication skills and ethics for healthcare providers as well as increased support to cope with difficult task of breaking difficult news to patients. It is expected to stir to both healthcare providers and terminally ill cancer patients to use controlled quality of life considerations with medical inputs, to legitimately determine whether particular life prolonging treatments are optional or obligatory.

It is expected to provide a help on reduction of anxiety, tension and guilt conscious of information denial to cancer patients, hence prepare them psychologically and spiritually to face and accept death.

1.5 Research Questions

There was basically one main research question with other sub research questions that subsist from the main question as here under stipulated.

1.5.1 Main Research Question

What are factors that influence truth telling by healthcare providers to terminally ill cancer patients at Ocean Road Cancer Institute?

1.5.2 Sub-research Questions

1) What are healthcare providers' related factors that influence the implementation of ethical rule of truth telling to cancer patients at ORCI?
2) What are social cultural related factors that hinder the implementation of truth telling by healthcare providers to terminally ill cancer patients at ORCI?
3) What are patient's related factors influencing truth telling by healthcare providers at ORCI?

1.6 Main Objective

To explore factors influencing truth telling by healthcare providers to terminally ill cancer patients at Ocean Road Cancer Institute in Dar-es-Salaam.

1.6.1 Specific Objectives

i. To explore healthcare providers' related factors influencing truth telling to terminally ill cancer patients.
ii. To find out socio-cultural related factors contributing to truth telling to terminally ill cancer patients by healthcare providers.
iii. To find out patient's related factors influencing truth telling by healthcare providers**.**

CHAPTER TWO

2.0 LITERATURE REVIEW

The chapter reviewed the literature from books, journals, codes and guidelines related to the ethical rule of truth telling to cancer patients in the world, and the related factors influencing its implementation by healthcare providers as well as its effects. The review was done based on the specific objectives of this study.

2.1 Related factors influencing truth telling

Global and regional wise studies as per literature review tend to suggest that, the issue of truth telling by healthcare providers to terminally ill cancer patients, is a complicated practice because it is influenced by a number of related factors underpinning from healthcare providers, patients as well as those related to social cultural.

2.1.1 Healthcare providers' factors influencing truth telling

Healthcare provider's factors such as skills, knowledge, perception and attitudes are said to have influence on truth telling to terminally ill cancer patients. Skills of a healthcare provider influence truth telling. It is known that, some healthcare providers are not well trained enough to care for a dying patient and some even refuse to tell truth to patients because they are afraid of how the bad news will be considered(42). It is also known that, healthcare providers are afraid of being asked the inevitable question by a terminal ill cancer patient, 'how long do I have left to live', because it is almost impossible to tell and to predict(43). The most important skill of communication building between healthcare providers and patients is said to be ineffective(42).

Knowledge of a healthcare provider also influences truth telling to terminally ill cancer patients. It is known that a healthcare provider admitted that his medical profession was failing patients by refusing to discuss dying and death, thereby not allowing patients and loved ones to prepare(44).Also it is known that, those healthcare providers who usually decide not to tell the truth to terminally ill cancer patients, do that out of a consequence based understanding.

Since they understand that by withholding the information, they are sparing their patients from negative thoughts and feelings such as anxiety and hopelessness(44,45).

Perception of a healthcare provider can influence truth telling to terminally ill cancer patients. It is known from the research that, few terminally ill cancer patients have ever discussed their critical life situation with a family member or their family healthcare provider(37).It is unknown that, decisions by healthcare providers or family members about dying and death of a terminally ill cancer patient may sometimes not accurately reflect a patient's wishes(31). It is also known that, some healthcare providers perceive that, disclosing medical results and information to terminally ill patients would adversely affect them both psychologically and physiological(46).

Attitude of a healthcare provider also contributes to the implementation of truth telling to cancer patients. There is a reported case that would reflect attitudes of a healthcare provider not telling truth to the patient about her life impossibility, but rather the patient and her family members tried to discover it from severe constant and complexity medical scenarios(47). It is known that, some healthcare providers have attitudes of not telling truth to their terminally ill cancer patients over disease, treatments and life expectant because they are afraid of how the news would be considered, as well as how reliable is the information one is giving to a patient due to prognosis inaccuracy and challenges(44,48,49).

Pertaining to the healthcare providers' related factors, if there is high level of knowledge and skills of healthcare providers it will improve truth telling to terminally ill cancer patients(50). The verse versa would be true when healthcare providers have negative attitudes and perceptions over truth telling to terminally ill cancer patients (51). If healthcare providers have positive attitudes and perceptions towards truth telling to terminally ill cancer patients, then it will result in to a minimization of medical dilemmas and build family mutual understanding. The negative attitudes and perceptions of healthcare providers to truth telling however subject them into a dilemma of telling or not telling and bring about conflict with family members to a patient(25,39).

2.1.1.2 Knowledge gap pertaining to healthcare providers' related factors

In Tanzania, little is known about the healthcare providers' related factors influencing the ethical rule of truth telling to cancer patients because of limited studies that were conducted on the subject matter. It is known that when telling the truth to some elderly patients of their terminal condition, they may give up hope and die prematurely(19).

2.1.2 Socio-cultural factors influencing truth telling

Socio-cultural factors like cultural pressure, traditional beliefs, values, customs and communication styles influencing truth telling by healthcare providers to terminally ill cancer patients(39).It is known that, a cultural competent cancer caring society through her tools like beliefs, values and communication would influence therapeutic outcome and could bring great difference in medical care including truth telling(39,41). It is also known that traditional beliefs, values and customs are understood to have an influence over perceptions and attitudes of both healthcare providers and patients about a particular disease and its treatments(15,41).

It is known that, a culture that emphasizes on a patient centered autonomy is said to have minimal rate of disclosing medical information to other family members, since the issue of truth telling becomes only the affairs between a patient and a healthcare provider(39).However, it is known that a communication style of a culture also may influence a medical relationship between a healthcare provider and a patient, and to a general healthcare system that include truth telling as to whom, when and how to tell(15,52).

In regard to socio-cultural factors that contribute to truth telling to terminally ill cancer patients by healthcare providers, if a particular culture is capable through her beliefs to manipulate communication, perceptions and attitudes of people, it can as well manipulate therapeutic outcomes by providing a framework of reference to interpret the external world and relate to it, this include truth telling over a cancer disease(39,41). If there are positive and objective socio-cultural values, customs and beliefs, it will facilitate and contribute to truth telling to cancer patients by healthcare providers(39,53)

Also, if there are subjective socio-cultural values, customs and beliefs where by a cancer disease is perceived as a myth or something of superstition, it will drug a healthcare provider into a hesitation mode to tell the truth to a terminally ill cancer patient(17,39,50).

2.1.2.1 Knowledge gap pertaining to Socio-cultural related factors

Little is known in Tanzania as to how socio-cultural values, customs and beliefs as well as communication styles may influence truth telling to terminally ill cancer patients by healthcare providers.

2.1.3 Patient's factors influencing truth telling

Patient's factors which include their awareness to medical information's rights, their medical autonomy to treatments and their consent to the breaking of medical good and bad news may influence truth telling by healthcare providers. It is overall known that, 7.8% of the cancer patients were convinced that cancer is incurable and that 59% of them would like to be told the truth over their medical diagnosis and prognosis just at the start of a treatment(39). It is known that, 63% of cancer patients considered fear of truth telling as the most difficult feeling to accommodate, followed by pain (29%), pity (8%), and death (1%)(39). It is also known that, overall 69% of cancer patients would consent to accept their medical cancer prognosis and diagnosis(50). Also, it is known that, culture also influences the interpretation of ethical norms and principles, as well as individual medical autonomy hence contributes to the variability of truth telling attitudes of cancer patients, because imposing the truth to unprepared and unwilling patient is not an act of respect for autonomy(39,48,53,54).

According to patient's factors influencing truth telling, if cancer patients consent to truth telling by healthcare providers, it will influence them to suffer less stigmatization and isolation, as well as enhancing not only their psychological preparations but also spiritual(39).If cancer patients would be aware of their medical rights to information and willing adhere to truth telling by healthcare providers, it will gradually increase their strength to endure all in hope by releasing tensions, anxiety and depression as well as making up of an informed choice(48,50). If patients adhere to their medical autonomy to treatments, it will

make healthcare providers to be reluctant to tell them the truth, because healthcare providers abide to patient's medical autonomy to treatments and information disclosure(13,25).

2.1.3.1 Knowledge gap pertaining to patient's related factors

Little is known in Tanzania concerning patient's factors influencing truth telling by healthcare providers due to limited information. However, anecdotal evidence shows that patients are not aware of their medical rights to information and consent.

2.2 Research gap

Truth telling to cancer patients is much more practiced in Western countries relative to African countries(29). Several studies have been conducted in Western countries on the subject matter and brought forward a vast knowledge concerning various related factors influencing truth telling. According to the knowledge gaps identified by each specific study objective, especially in Tanzania, little is known about the factors influencing truth telling by healthcare providers to terminally ill cancer patients. Therefore, this study aimed to reduce the research gap by exploring information from Ocean Road Cancer Institute in Dar-es-Salaam.

CHAPTER THREE

3.0 METHODOLOGY

The chapter presents the study setting and explains about the research; type, design, area and population, sample size and sampling techniques. It also describes data collection methods; interview guides and instruments, procedures for data collection, data management and analysis plan as well as ethical clearance procedures.

3.1 Study Design

A qualitative case study design was employed in this study in order to allow key informant in-depth interviews about the factors influencing truth telling by healthcare providers to terminally ill cancer patients at Ocean Road Cancer Institute in Dar-es-Salaam. According to Baxter and Jac (2008) case study in qualitative studies provides tools for researchers to study complex phenomena within their contexts. The case study facilitated exploration of a phenomenon within its context using different sources of data collection. Furthermore, Baxter and Jack state that using case study researchers ensure that the issue is not explored through one lens, but rather a variety of lenses which allows for multiple aspects of the phenomenon to be revealed and understood. The ORCI was considered the case for this study. This means the healthcare providers and the cancer patients working and admitted there respectively were included(55).

3.2 Study Area

This study was conducted at the Ocean Road Hospital in Dar-es-Salaam-Tanzania, specifically into Cancer Institute. Researcher purposively selected the area because of its nature and set up that accommodates cancer patients and cancer healthcare providers. The hospital is located at the center of the largest city in Tanzania and so it is the only cancer referral hospital in the country. The ORCI provides cancer care services to all types of cancer to both adult out patients and in patients. According to recent records from the Director of Prevention and Human Resouces at ORCI, the hospital receives an estimated number of 9,000 patients per

year out of which an estimated number of 5,800 patients per year are new cases. Approximately, 257 patients are being treated on daily basis and it has a total number of 19 specialists out of which 11 are females and 8 are males.

3.3 Study Population

The study population was healthcare providers and cancer patients at Ocean Road Cancer Institute in Dar-es-Salaam. Healthcare providers were selected because they are the ones having providence to disclose medical information to the patients. Those healthcare providers who are dealing specifically with terminally ill cancer patients with an advanced life limiting illness in the Institute care settings and who are treated with palliative intent. Thus, key informants to this study were grouped into two categories namely; cancer patients at a terminal stage who can still communicate and healthcare providers (palliative care specialists, oncologists and nurses). The reason for the selection was that, these study participants were knowledgeable, experienced and being directly involved to the study problem.

Selected participants were thought to be capable of giving first hand rich information and insights patterning to the research problem regarding their related factors (healthcare providers and patients) and socio-cultural factors.

3.4 Sample Size

The total number of 21 participants interviewed depended on information saturation, 13 of the participants were healthcare providers and terminally ill cancer patients were 8 purposively selected during the study. It included oncologists, nurses and cancer patients at a terminal stage who can still talk. The patients were deliberately included into this study so as to find out exactly what they need to know about their illness, and at what extent (how much) and when. This study sought information from patients regarding their medical rights and autonomy to information and treatments, as well as regarding to their consent to medical information.

3.5 Purposive Sampling Technique

Purposive sampling technique was used to select study participants. These were palliative care specialists, oncologists and nurses working in Ocean Road Cancer Institute. They were selected because they were knowledgeable, highly experienced in the oncology field with rich first hand information and being directly involved in treating terminally ill cancer patients. Patients selected were those at a real terminal stage admitted at a special room with only palliative intend but who could still communicate.

3.6 Data Collection methods and Instruments

In-depth interview guides were written in English and then translated into Swahili for easy understanding of the key informants where by factual questions about their experiences, views and opinions about the subject under investigation were asked. The questions were asked based on assessing and examining the rule of truth telling by health providers to terminally ill cancer patients during medical treatments. The goal was to arrive at particular solutions to specific objectives. Other interview guides were on specific ethical issues that needed to be seriously assessed regarding to the medical rule of truth telling to terminally ill cancer patients.

The guides also aimed at exploring healthcare providers', patients' and socio-cultural related factors influencing truth telling to terminally ill cancer patients. Interview guides was the main data collection tool which contained specific topics with open ended questions to the key informants. Nonetheless, a note book for writing main themes and key issues was used as well as voice recorder garget for recording information.

3.7 Data Collection Procedures

Data was collected by the principal investigator with a help from two research assistants with advance diplomas on caring for terminally ill cancer patients. Data was collected using a well-structured set of in-depth interview guides which included open ended questions. We introduced ourselves clearly before every key informant, explained to them about the study title, objectives, rationale as well as confidentiality. The in-depth interview guides which

included open ended questions were then asked to each participant exploring factors influencing truth telling to terminally ill cancer patients by healthcare providers. Each interview as for healthcare providers took an average of 30 minutes and for the terminally ill cancer patients took an average of 10 minutes. The principal investigator had to assure the participants on usefulness of this research. Data was collected between, early April 2018 up to early May 2018.

3.8 Pre-testing

A pilot study was conducted on 5 Medical doctors and 5 nurses who provide services to terminally ill patients at Muhimbili National referral hospital and 3 cancer patients. Pre-testing of the interview guide was done at MNH because they also receive cancer patients before they refer them to ORCI. The pilot pretest provided clear indications on the response to the interview guides and average time allocated for interviewing each participant. The results from the pilot pretest showed that data collection instrument had logical flow of questions, completed and suited for exploration of factors influencing truth telling to terminally ill cancer patients by healthcare providers at ORCI.

3.9 Data Management

Data that were generated from the in-depth interviews stored and cared for by the researcher with high level of confidentiality and were only accessed by the two research assistants under the permission from the researcher. Audio recorded information were kept by the researcher in a flash disc and into the researcher’s laptop and after the transcription, the information was deleted by the principal investigator from those storage devices so as to enhance confidentiality. Three quarter of the transcriptions was done by the principal investigator and the remaining part was done by the research assistants. The whole work of translation was entirely done by the principal investigator.

3.10 Data analysis Plan

The data was analyzed using thematic analysis approach which managed to arrive at categories by coding and forming key themes. Audio recorded information was transcribed verbatim by the principal investigator so as to familiarize more with the data and have the general idea. After which, lists of potential and initial codes were created by the principal investigator through data reduction which helped to identify interested data features and made meaningful information. Themes were then sought out from the general lists of the created codes. The focus was on broad patterns in the data, combining coded data with the proposed themes and examined how relationship were formed between codes, themes and different levels of existing themes. After themes identification, the principal investigator read and reviewed the coded data to see if they formed coherent patterns. The existing themes were then defined and refined for presentation in the final analysis that involved report writing in effort to convince the reader on the merits and validity of the analysis. The main themes were elaborated with representative quotations.

The data was analyzed based on three explored key issues namely; healthcare providers', patients' and socio-cultural influencing factors to truth telling to terminally ill cancer patients by healthcare providers from the perspectives of both healthcare providers and patients.

3.11 Ethical Consideration

The principal investigator sought ethical clearance from Muhimbili University of Health and Allied Sciences (MUHAS) Ethical Review Committee so as to obtain permission to conduct the study. The permission to conduct research was also requested from Ocean Road Cancer Institute (ORCI) where study participants work before data collection. The participants were informed about the study objectives and on their rights to withdraw from the study without any penalty, after which each willingly was able to sign the consent form. Although some of patients gave verbal consent form of which their caretakers signed the forms on behalf. Confidentiality and privacy with the participants were maintained throughout and after the

study. However, the participants were free to give out their own opinions, ideas and other contributions which were considered by the principal investigator without reservations.

3.12 Study limitations and mitigation

The study was prone to bias of principal investigator because of his believe and assumptions. To mitigate the principal investigator's bias, triangulation was used which involved the use of data collection method as per the study case, by combining two main methods of data collection: in-depth interviews and documentary review; involving different types of participants ranging from cancer patients and healthcare providers (palliative care specialists, oncologists and nurses).

The results of this study are not generalizable because of the nature of the research that was not meant to generalize findings but intended to get in-depth explorations of the subject matter under investigation. Although the findings can be transferable to other study areas with similar situations, populations and similar subject matter, detailed background data to establish context of study in question should be provided that include the information concerning the number of healthcare providers and cancer patients who took part in this study, criteria of selected participants, the data collection method that was employed, the number and length of the in-depth interview, and the time period over which the data was collected.

Ensuring trustworthiness of the qualitative study was the main question to this study. Guba (1981) suggests different concepts used to ensure trustworthiness in qualitative studies instead of validity and reliability as used in quantitative studies. He suggests a use of *credibility* (in preference to internal validity); *transferability* (in preference to external validity/generalizability); *dependability* (in preference to reliability); and *confirmability* (in preference to objectivity).

Credibility: refers to how congruent the findings of this study will be with reality. In this study in-depth interview was used because it is an appropriate and well recognized research method for collecting depth information from the study participants. Triangulation was done using data collection method as per the study case.

Transferability: is concerned with the extent to which the findings of this study can be applied to other situations. For this study to be transferable detailed background data to establish context of study in question has been done. This include; the information concerning the number of healthcare providers and cancer patients who took part in this study, criteria of selected participants, the data collection method that was employed, the number and length of the in-depth interview, and the time period over which the data was collected.

Dependability: means if this study is to be repeated, in the same context, with the same method and with the same participants, similar results will be obtained. In order for this study to be dependable in-depth methodological description of the study was done enabling a future researcher to repeat the work.

Confirmability: is the degree of neutrality or objectivity in the findings of qualitative studies. It means that the findings obtained from the study are based on participants' responses and not any potential bias or personal motivations of the researcher. In order for this study to be confirmable triangulation was used to reduce effect of investigator bias. Triangulation involved method of data collection, participants and study area. The reasons for favoring one approach over the others were explained and weaknesses in the techniques employed were admitted.

In the course of interviewing terminally ill patients, some interviewee experienced acute pains, which necessitated stopping the interview for a while. In addressing this limitation, the researcher requested for a time out until the patients gained comfortability to continue with the interview. Some of the Healthcare providers refused to participate, cited that they were busy with official's duties elsewhere. To address this limitation, several attempts to make interview appointments with them were done which prolonged data collection period.

CHAPTER FOUR

4.0 RESULTS AND KEY FINDINGS

4.1 Introduction

Data analysis has generated several themes that respond to the original research objectives. Qualitative data was collected with the aim of exploring factors influencing truth telling by healthcare providers to terminally ill cancer patients at Ocean Road Cancer Institute in Dar-es-Salaam, from healthcare providers and patients perspectives. The section presents a demographic characteristics of the interviewed study participants; healthcare providers' factors influencing truth telling to terminally ill cancer patients, patient's factors influencing truth telling by healthcare providers as well as socio-cultural factors contributing to truth telling to terminally ill cancer patients by healthcare providers(56).

4.2 Demographic characteristics of participants

The point of saturation was reached at twenty-one participants (21) interviewed (Table 1), healthcare providers were 13 and terminally ill cancer patients were 8. Ten (10) out of thirteen (13) healthcare providers have more than three (3) years of working experience in clinical oncology (Table 1). Eight (8) out of thirteen (13) healthcare providers hold master degree in clinical oncology (Table 2). Seven (7) out of thirteen (13) healthcare providers were males (Table 1). Ten (10) out of thirteen (13) healthcare providers were oncologists (Table 1). Terminally ill cancer patients had only one variable on sex, where by the ratio was equally selected, four males and four females (4:4)

Table 1: Demographic characteristics of the healthcare providers interviewed at ORCI in Dar-es-Salaam, 2018

Demographic characteristics		Healthcare Provider (N=13)	
		N	%
Sex	Male	7	53.8
	Female	6	46.2
Profession	Nurse	3	23.1
	Oncologist	10	76.9
Education Level	Diploma	2	15.4
	Degree	3	23.1
	Masters	8	61.5
Working Experience (yrs)	≤ 3	3	23.1
	> 3	**10**	**76.9**

4.2.1 Healthcare providers' factors influencing truth telling to terminally ill cancer patients

Healthcare providers were interviewed about factors influencing them to truth telling to terminally ill cancer patients at ORCI in Dar-es-Salaam. The analysis produced the following themes; lack of a comprehensive understanding on concept of truth telling, sympathetic feeling among healthcare providers, limited time to disclose information, doctor-patient's relationship (creating a rapport with patients and honest discussion between doctors and patients), truth telling as both good and bad thing, lack of guidelines on truth telling, lack of adequate facilities (offices/rooms for privacy), number of patients and multi-disciplinary team.

4.2.1.1 Lack of a comprehensive understanding on concept of truth telling

Healthcare providers admitted that, lack of a comprehensive understanding of a general concept of ethical rule on truth telling as it entails in the field of bioethics affect medical information disclosure. Healthcare providers when asked about their knowledge on truth telling said that truth telling is done based on patient's pains managements of which it is more of medical understanding than bioethical.

> *"...because we do not understand that truth telling is a core element in medical care, and we put more emphasis of our service to medical ignoring ethical part of it. We tend to forget social, psychological, bioethical and spiritual part of our patients. And even in our concept of palliative care, bioethical issues are not fully addressed, always what is addressed is a medical palliative issues"* (HCP007-Oncologist)

Another healthcare provider said that:

> *"...other challenges are lack of the knowledge of breaking bad news, of information sharing, as to whom and where to start*" (HCP005-Oncologist)

Another oncologist expressed the concern on the theme by saying that:

> *"I think the major factor towards allows me to break the information is training, it is very crucial. Without having knowledge, without a comprehensively understanding of what bad news means to a cancer patient, is very hard for a healthcare giver to anticipate the reactions, emotions and effects that the information can have"* (HCP010-Oncologist)

4.2.1.2 Sympathetic feeling among healthcare providers

Most of healthcare providers showed their concern on feelings and emotions as they attend patients. They mentioned being overwhelmed by sympathy rather than empathy, and that truth telling is something painful to patients and relatives, sympathy upon presenting a disease itself to a patient. This made one of participant to say that:

> *"Your research I think is going to help us oncologists and doctors on how to talk to our patients, because frankly speaking we are doctors who do not know how to talk to*

> *the patients, may be due to our sympathy or experience I do not know, so this project's results will real help us"* (HCP 007-Oncologist)

The other specialist added that:

> *"Now, how to tell that truth so that a patient can accept is a point of departure from one oncologist or a doctor from another. That is why we will find more patients are lining to a certain oncologist than to the others. What they normally like is how such a doctor is breaking news either sympathetically or empathetically"* (HCP 007-Oncologist)

Participant pinpointed clearly that individual fear of patient's reaction to news affecting their decision to disclose information about the terminal illness as demonstrated in this quote:

> *"individual fears sometime weighed me down to share the information, at first I was fearing when I reflect to myself, sympathy, fear to cope with reactions, some healthcare providers do not know how to cope with reactions, anger, upsets of a patient upon truth telling"* (HCP 010-Oncologist)

Doctors find it difficult to separate themselves from the work, for example having children and attending a child with cancer make the doctor feels the pressure to protect the parent from pain of knowing the child is having terminal illness. The specialist could not hide it all and said that:

> *"I think the empathy that I feel for them and also just putting yourself into their shoes has some influence to the information, and after work you have to try putting that aside and continue with life, so that is a challenge. Separating adults with the children, I treat children, so when they come here with their parents, you cannot separate them from your own children"* (HCP 012-Oncologist)

4.2.1.3 Limited time to disclose information

Most of the interviewed healthcare providers reported that they do not have enough time to digest all of information to their patients. One of them had this to say:

> *"Time also is a challenge; you find yourself with so many patients that need your service and you do not have enough time for each to digest everything, due to this some oncologists do refer patients to palliative care team"* (HCP001-Nurse)

Another oncologist interviewed explained on how time can affect information sharing with patients. Highlighting that, they normally receive patients who are not aware of their medical information because time is normally not their friend.

> *"a doctor may not have an ample time to tell the truth to a patient, you find yourself with so many patients to be attended to in a day such that you give a very minimal minute to each patient of which it is not enough to digest all of the information…time is always not our friend"* (HCP 008-Oncologist)

The other participant acknowledged that time is an attributing factor upon truth telling by saying:

> *"Time is mostly challenge; truth telling does not take much time but there usually no time to do that because there are so many patients to care for. You are in the clinic and usually having ten minutes for a patient, and as a doctor you cannot cut the number of patients per day so as to have ample time for few, as institution it is possible but not as a doctor because you are obliged by the institution to attend as many patients per day as possible"* (HCP 011-Oncologist)

4.2.1.4 Doctor-patient's relationship influence truth telling

Under the theme of doctor and patient relationship, two subthemes emerged as reported to have influence truth telling namely: creating a rapport with patients to facilitate information sharing and honest discussion between doctors and patients.

4.2.1.4.1 Creating a rapport with patients to facilitate information sharing

The participants responded by saying that upon sharing medical information to cancer patients, first and fore most a healthcare provider should create a rapport with patients as this will foster easier way of information sharing. One of the specialists said that:

> *"First when you meet with a patient for the first time you create a rapport, and there are things that both of you will be sharing. So from that you will find out that if you give such kind of information to such a patient can shake or can absorb. You will know this by establishing a good relationship first"* (HCP 008-Oncologist)

When asked another oncologist about the associating factors as would think that influence truth telling to terminally ill cancer patients remarked that:

> *"We should build and establish a rapport, a good relationship with patients, I can call inter personal relationship with them. When you are close to them it gives you a wide chance to deliver information in an open kind of setting. We need also to use a patient centered autonomy in giving out medical information"* (HCP002-Nurse)

4.2.1.4.2 Honest discussion between doctors and patients

One participant responded by giving a theme more weight, added that not merely a good relationship between a doctor and a patient but there should be kind of honest discussion with a patient. This is what he said:

> *"If you create a good relationship with your patients, it will be easier to share information, you will definitely have honest discussion with your patients, it will make you both discuss the treatments options as well, as changing where necessary from curative to palliative care"* (HCP 010-Oncologist)

4.2.1.5 Truth telling as both good and bad thing

Healthcare providers perceive the whole idea of truth telling to terminally ill cancer patients as good thing and as their role. However, there were others who said that truth telling brings burn out to healthcare providers as well as causing loss of hope to a patient and relatives. There is also the sentiment that truth telling to terminal ill cancer patient is not given weight needed. One of them said that:

> *"…many patients usually become depressed and be at a confusion state after receiving such information and even after been given the information usually they do not have an ongoing medical advice, so this in turn contribute to some of patients even to refuse or stop medications and any other follow ups. This issue of truth telling should be given a proper weight and consideration as it is supposed to be"* (HCP 008-Oncologist)

Of the raised issues are the negative aspects of the truth telling to terminally ill cancer patients as pinpointed out in this quote from oncologist:

> *"truth telling to a cancer patient is something that have negative elements in it, so many aspects are needed to consider before, however it is important and should be done sensitively with awareness both to patients and healthcare giver"* (HCP 010-Oncologist)

Truth telling was given a negative perception by another participant as something which bears a negative connotation with it. Here is what was said:

> *"it is a negative thing, I am perceiving it in a negative way, what I can suggest and prefer is counseling a patient and not breaking bad news or truth telling. Because breaking bad news is a bad thing, but counseling is giving hope to a patient and to family members and that is good*" (HCP 013-Oncologist)

4.2.1.6 Lack of guidelines on truth telling

Healthcare providers were probed about the existence of guidelines on truth telling where by oncologists interviewed admitted that there is no guideline so far while some of nurses were on the contrary. Here is the report of one of the oncologists who did not hesitate to say that:

> *"To be frank, we currently do not have any institution guidelines on how to break bad news. And this is a big weakness, as the institution that deals with terminally ill patients who are at the end of life, I think we real need to have guidelines, it is important for sure"* (HCP007-Oncologist)

The other oncologist probed on the same note acknowledged the absence of guidelines on truth telling by saying that:

> *"The institution so far has no guidelines or procedures or protocol on how to break bad news to patients. It all relays on the providence of an oncologist*" (HCP008-Oncologist)

Another participant was able to give more explanation when probed especially on this theme by saying that:

> *"To my knowledge there is no institution guidelines on how to break information to patients, we had some trainings informal ones in which healthcare givers were involved and was done in house, but we do not have come out yet with a structure or protocol for instance as a guideline for truth telling"* (HCP010-Oncologist)

4.2.1.7 Lack of adequate facilities

Some of the participants reported that lack of adequate facilities at the institution like offices and or rooms that ensure privacy influence truth telling to cancer patients. This is because they sometimes feel ethically limited to digest all of the information openly while other patients and people can hear everything. One of the participants expressed that:

> *"…first of all, the issue of breaking bad news is of heartfelt, you need to have a very good conducive environment, where by a patient is comfortable and able to hear and also to cope with the news*" (HCP009-Oncologist)

He added that:

> *"Truth telling is not done here as it ought to be, first of all here we don't have that conducive rooms and facilities where by people should be sitting and doing counseling because counseling is also breaking bad news"* (HCP009-Oncologist)

Another participant when asked about influencing factor to truth telling remarked that:

> *"physical infrastructural support like private office, room and a good place to talk, of which will provide ample time to a patient to digest the news and opportunities to ask questions is important and which is lacking here"* (HCP010-Oncologist)

4.2.1.8 Number of patients influence truth telling

The oncologists interviewed on the influencing factors to truth telling to terminally ill cancer patients acknowledged that an increasing number of patients received at the institute in a day influence truth telling. Healthcare providers are supposed to attend as many patients as possible which limit time as for information sharing. One expressed this by saying that:

> *"…and also patients are so many in the sense that those in charge of giving the information do not have enough time to sit with a patient and share the information wholly*" (HCP009-Oncologist)

Another participant when interviewed said that:

> *"Setting a maximum number of patients to be seen by a doctor per day is the obligation of the institution as for efficiency, because patients are so many here. And other patients do come from very far, travelled all the way, you cannot leave them un attended, and ethically is not even right"* (HCP013-Oncologist)

4.2.1.9 Multi-disciplinary team

All of the healthcare providers interviewed on the influencing factors to truth telling to terminally ill cancer patients acknowledged that it should be properly done by a team of experts. Thus the presence of such a team may improve the efficiency of truth telling and the other way round. This was expressed by the participant who said that:

> *"…also truth telling should not be an issue of one person but should be of multi-disciplinary approach, where we need doctors, psychologists, nurses, bioethicist and spiritual leaders as for efficacy"* (HCP009-Oncologist)

Another oncologist when asked about opinions on how best to improve truth telling to terminally ill cancer patients by healthcare providers, raised the need for team work as explained:

> *"…so what you are asking I think is something that we need to consider. Ideally we ought to have a supportive and a multi-disciplinary team of experts as for breaking the information to patients but due to shortage of personnel that were trained, often the news is given directly to a patient from a healthcare giver*" (HCP010-Oncologist)

Family involvement in care of the patient is important but sometimes can raise concerns for some patients who do not want their information to be shared. One of the oncologists said that:

> *"Sometimes it depends with patients we would refer and involve a palliative care team, but there are patients that can be sent to their family and palliative care team and would take it in a positive manner and others do not. We normally look and find out kind of patients who need to be told the truth from palliative care team"* (HCP012-Oncologist)

4.2.3 Patient's related factors influencing truth telling by healthcare providers.

Healthcare providers and Patients were asked about individual (patients) factors that may influence truth telling by the healthcare providers. The analysis of the findings from the interviewed patients generated six themes namely; patient's level of understanding, patient's freedom of choice to information, rights to information, lack of prior information to patients, psychological condition of the patient and patient's faith and beliefs.

4.2.3.1 Patient's level of understanding

The level of understanding of a patient was reported to have influence on truth telling. The participants said that normally it is difficult to digest all of the information or having an honest and open discussion with a patient who in the first place cannot comprehend some of medical terminologies. This in turn increases a work load to a healthcare provider on breaking the information. One of cancer care specialists said that:

> *"Level of knowledge of a patient influence truth telling, this is because telling about cancer type, the stage and the modality treatments to a patient who is illiterate is very difficult. Making a patient copying and comprehensively understanding the information is very difficult task"* (HCP009-Oncologist)

Patients have different level of understanding and they can feel and see differences in treatments. Hence according to their knowledge level, healthcare provider should disclose the information about the patient's disease and treatments as this healthcare provider expressed:

> *"...presentation of disease itself, its type and stage as well as its modes of treatments and expected effects to a patient who cannot understand is a bit challenging. Although some of patients will know that they are given treatments shorter time compared to others, so from there you must tell the truth as why the variations"* (HCP005-Oncologist)

4.2.3.2 Patient's freedom of choice to information

Freedom of a patient to choose medical information he or she wants was said to have influence on information sharing, there are some patients who would like to be told the truth concerning their diagnosis and prognosis while others would completely resist hearing some of their medical information from healthcare providers. Upon interviewing the participants, one of them said that:

> *"Patients also contribute to truth telling in oncology as from my experience, because some of patients do not want to hear the truth, they do not want to be given certain information especially that which bears a negative element in it like worsening of their health status and or treatments failure. Some prefer to hear information that brings hope and healing"* (HCP011-Oncologist)

However other patient interviewed about the type of information that would want to hear from healthcare providers reported that:

> *"I like a doctor to tell me the truth so as I know, a doctor should not hide the truth from me, I need to be told all so that I know. For instance, when I came here in February, a doctor told me that they have discovered another problem into my kidney and so I should try as much as possible to take a lot of water and fruits. So I was thankful and I need to be told the truth"* (P05-Patient)

The other participant pinpointed clearly the kind of information would like to be given by saying that:

> *"I like to hear and be given information that is good, I need to hear good news, a doctor should tell me that I am doing well, that I am recovering, that I am improving, curing and going home tomorrow. This is the kind of information I would like to hear from doctors. I do not like to hear bad news, news that break my heart, those which makes me be afraid of, put me into fear"* (P06-Patient)

4.2.3.3 Rights to information

Patient's right to medical information was reported to have influence on truth telling by healthcare providers, that a patient is basically and ethically entitled to information concerning diseases, treatments and effects and all other medical information necessary that is unforeseen by a patient. Upon asking one of the participants about patient's influencing factors on truth telling by healthcare providers said that:

> *"Patients usually have rights to know and the concern about what they are suffering from, they use to ask (am I going to be cured?) so if you don't tell the truth to the patients, unfortunately you deny their rights. They will have a lot of hopes and that will disturb a lot of things to them and that is not the role of doctor"* (HCP004-Oncologist)

Another specialist pinpointed the patient's ethical rights to information when said that:

> *"We ought to tell patients, since it is their ethical right to information; they have a right to know. A patient should be aware of what is going on, and should being engaged on decisions making and on goal of care. This is possible only if a patient knows what is going on about himself or herself"* (HCP010-Oncologist)

Another participant said that:

> *"We have a duty to tell our patients that I would call 'the difficulty part of medicines', whether telling their state of diagnosis, or about the outcome of their treatments, may be outcome is not so good, telling the patient about prognosis…so I tell patients because they have rights to know and to decide"* (HCP012-Oncologist)

4.2.3.4 Lack of prior information to patients

The other factor that was reported by healthcare providers as influencing truth telling is lack of prior information to patients. They said that most of patients who come for treatments at ORCI are more or less at terminal stage, they come while the disease is already at a late stage.

They reported that when encounter with such patients for the first time it challenges oncologists to start sharing the information. This is what was said by one of them:

> *"…most of the patients who come here as I said are of palliative care cases and where they came from, could be given different information, so it's difficult for us to start breaking the news. For instance, the patient might be told 'go to cancer hospital and you going to be treated there' but when comes here it's hard for us to tell the patient that the disease is palliative that it cannot be treated at all"* (HCP005-Oncologist)

Truth telling is important for the patient to adhere to the treatment. Patient's stage, type of disease and treatments needed may therefore influence the oncologists. One of the participants reported that:

> *"Talking to a patient who is at late stage takes a lot of time for patient to comprehend and another thing is that our medications that we are giving to cancer patients are very strong in the sense that can shake the body and health of a patient. So if you did not talk to them prior to the medications, some of patients can disappear in the midst of treatments"* (HCP007-Oncologist)

4.2.3.5 Psychological condition of the patient

Truth telling still is said to be influenced by a psychological status and ability of a patient to handle the information. Among the participants interviewed said that patients are never prepared well psychologically to receive medical information. One of the healthcare providers said that:

> *"Truth telling depends on a status of a patient, whether can handle the information or not just by looking at patient's facial expression… at a time a patient cannot handle information comprehensively. In this regards as oncologist, you are obliged to break*

the news slowly part by part while monitoring psychological impression of your patient" (HCP008-Oncologist)

Depression affects many chronically ill patients. In situation where the patient is depressed the doctor will hesitate to tell patient the truth about terminal illness. The oncologist interviewed added that:

"...many patients usually are depressed and be at a confusion state after receiving such information, and even after being given the information usually they do not have an ongoing medical advice. This in turn contributes to some of patients even to refuse or stop medications and any other follow ups" (HCP008-Oncologist)

The other participant acknowledged the influence of psychological state of patients in breaking medical information by saying that:

"Some patients are not psychological stable that is why for example if a patient is not psychologically stable and you tell the news you might end up hurting that patient by causing depression, anxiety, fear and gradual death. Once you tell such a patient will refuse to eat, developing depression, so many things should then need to be weighed out before telling the truth to a patient" (HCP013-Oncologist)

4.2.3.6 Patient's faith and beliefs

Some of the participants pinpointed out that beliefs and faith of a patient influence truth telling. Thus a healthcare provider while disclosing information to a patient should cross check to find out the belief and faith of such a patient. One of them responded that:

"Every human being like hopes, so when you are talking to a patient over bad news, one has to check over a patient's faith whether Muslim or Christian, or walking with patient's culture and tradition while slowly breaking the truth that here in the world we are in fact travelers, and our life is short lived" (HCP007-Oncologist)

Patient's values may influence truth telling as the nurse from this quote said:

"*...faith and beliefs of a patient should be there but I think it should not hinder us from breaking of news, if we opt to take our faith and beliefs all together we will not do a right thing professionally"* (HCP002-Nurse)

Another participant said that:

> *"I believe there are bad news and not want to hear such news that break my heart into pieces, for instance a doctor should not come to me and tell me that these medications will stop healing you in the next few months, so that will be the end of your life. I believe such information is not good, it will break my heart, it is better to give me hope, encourage my faith that the medications will help and God will help as well"* (P02-Patient)

4.2.4 Socio-cultural related factors contributing to truth telling to terminally ill cancer patients by healthcare providers

Healthcare providers and patients were interviewed on socio-cultural factors contributing to truth telling to terminally ill cancer patients by healthcare providers at ORCI. The analysis generated two main themes namely; traditional beliefs and cultural communication style (**cancer is associated with witchcraft)** and family members' influence.

4.2.4.1 Traditional beliefs and cultural communication style

Under the theme of traditional beliefs and cultural communication style subthemes namely; cancer is associated with witchcraft and cultural communication style emerged as reported to have influence on truth telling to terminally ill cancer patients by healthcare providers.

4.2.4.1.1 Cancer is associated with witchcraft

It was reported that some people due to their traditional beliefs tend to associate cancer disease with superstition. With such beliefs it was said that they tend to seek treatments solution from the witch-doctors first before going to hospital. One of the participants expressed that:

> *"Other patients and their relatives associate cancer diseases with witchcraft or a supernatural power and fail to know that cancer is a disease just like other diseases and they come here at a very late stage of palliative and not of curative care because they start first to be cured locally by herbs"* (HCP001-Nurse)

The other participant acknowledged that:

> *"The challenge is on our tradition beliefs because telling a patient that you have a disease that cannot be cured is a bit difficulty. From my personal experience, my grandfather had a lung cancer, he came here at ORCI, when he was told about the news, from that day he refused to eat and he eventual died of hunger- he had negative perception on the disease itself. So our traditions beliefs have no ability to absorb shocks of cancer information"* (HCP008-Oncologist)

4.2.4.1.2 Cultural communication style

The participants expressed how cultural communication style contributes to truth telling by healthcare providers to terminally ill cancer patients. Some said that cultures encourage information confidentiality of a patient that it does not allow information of a patient to be shared or exposed to other people. One of participants elaborated that:

> *"My culture used to protect the patients, so we did discuss the information with family, because if the patient knows will lose hope, get depression, fear, and eventually will die. But now days things have a bit evolved because more are educated and I think the discussion about life limiting illness, death advanced disease become much easier, people are becoming much more coming forth for a truth telling"* (HCP010-Oncologist)

4.2.4.2 Family collusion influence truth telling

It was reported that relatives to cancer patients sometimes in a way contribute to information sharing in both ways telling and or not telling the truth. Upon interviewing the specialist said that:

> *"Family members contribute to not telling the truth, many times I get pressure from family, from patient's relatives who ask healthcare providers not to disclose the information to their patients, okay, so they want to protect"* (HCP013-Oncologist)

In addition, another participant expressed that:

> *"Family members to a patient are the other thing, they can interfere and prevent you from doing the techniques, we need to engage and involve them. Of course we need to respect their cultures since we cannot do it by force. Culturally, the way we are in support with the society, we have to involve family members; we have to respect family members in disclosing the information"* (HCP010-Oncologist)

However, many interviewed patient's participants admitted that they would like their medical information to be shared to the family members. One of them said that:

> *"My relatives also should be informed, they should be told the truth since hiding the truth from them is not a good idea, they are taking care of me, buying medicines and other things for me, so they have a right to know and to be told. How can I hide this cancer disease from my relatives, it is impossible"* (*P*05-Patient)

CHAPTER FIVE

5.0 DISCUSION ON FINDINGS

5.1 Introduction

The chapter discusses key findings obtained as presented in chapter four. The data was collected through in-depth interviews with healthcare providers and patients. The discussion is based on the objectives of this study which aimed at understanding the healthcare providers', patients' and socio-cultural influencing factors to truth telling to terminally ill cancer patients by healthcare providers. The detailed discussion that follows is entirely based on the findings obtained from the 21 participants of this study where by 13 of them were healthcare providers and 8 were terminally ill cancer patients.

5.2Healthcare providers' related factors influencing truth telling to terminally ill cancer patients

The findings revealed that there were a number of factors related to healthcare providers that influence truth telling to terminally ill cancer patients at ORCI. These factors include; lack of a comprehensive understanding on concept of truth telling, sympathetic feeling among healthcare providers, limited time to disclose information, doctor-patient's relationship(creating a rapport and honest discussion), truth telling as good and bad thing, lack of guidelines on truth telling, lack of adequate facilities (offices/rooms for privacy), number of patients and multi-disciplinary team.

5.2.1 Lack of a comprehensive understanding

The key findings of this study revealed that truth telling to terminally ill cancer patients by healthcare providers depends on a comprehensive understanding of the concept itself. Many of participants reported that, if someone does not real know what the concept of truth telling connotes, it will be difficult to such a person implement it. Similar study shows that lack of comprehensive understanding of truth telling by the healthcare providers in medical profession leads to failure in discussing about life limiting information with cancer patients(44).

However, many of the interviewed healthcare providers tried to express how lack of understanding of the concept affects truth telling to the patients. This implies that if a healthcare provider does not understand that truth telling, which is the core element in medical care, definitely will be reluctant to share the information entirely.

5.2.2 Sympathetic feeling among healthcare providers

Sympathetic feeling among healthcare providers was reported to have an influence in truth telling to the patients. The human emotional part of the oncologists sometimes overwhelmed them at the point of failing to execute their professional duties. It was expressed that whenever a healthcare provider come across with a terminally ill cancer patient, it is either saves as a reminder of the late loved ones or just trying to be into the shoes of a patient, thinking as though a patient is your own relative or children. The study findings revealed that putting too much sympathy than empathy will affect truth telling to the patients. It is all because of training in communication and information provision as well as the nature of the disease itself, by telling someone that your cancer is at a late stage one has to think twice since it tends to terrify everyone. This implies that healthcare providers have little that they can tell the truth at this stage. Similar sympathetic feelings of healthcare providers upon sparing their patients from negative thoughts and feelings such as anxiety and hopelessness was among of the factor contributing to truth telling(45). This implies that with sympathetic feelings there will be lack of truth telling unlike with empathetic feelings.

5.2.3 Limited time to disclose information

The findings from this study showed that insufficient time of healthcare providers hinder truth telling to patients. The healthcare providers interviewed reported to have a minimal time available to afford a thoroughly discussion with a patient. Each patient is given a very minimal minute of which is never enough to digest all the information as supposed to. This implies that truth telling to patients needs an ample and enough time of a healthcare provider to discuss and share medical information the way ought to be. Time is always not a doctors' friend as claimed by one of the participant and that is why healthcare providers receive patients who were not told the truth and the assumption is due to time limitation.

5.2.4 Doctor-patient's relationship influence truth telling

The key findings of this study revealed that truth telling is influenced by a doctor-patient's relationship as the main theme whereby subthemes namely; creation of rapport and honest discussion were emerged. The findings reveal that some of healthcare providers do not build a rapport with their patients like a general familiarization that includes; known each other's backgrounds, names, social status and professionals among others, which makes it difficult to disclose medical information. This implies that healthcare providers lack good relationship with their patients, of which it entails that breaking of medical information is lacking or minimal. Furthermore, Good relationship between a patient and a healthcare provider reported by most participants foster the process of breaking the news, where each side can be honest, open and transparent in sharing. An honest discussion is much more possible to people who well known to each other, a doctor will be aware as to whom is sharing the medical information apart from merely to a patient. Likewise, a patient will be honest to information given. The issues of rapport building and honest discussions between a doctor and a patient have been well documented elsewhere as important tools to discover moral arguments for information sharing which can help to solve a moral dilemma of telling or not telling, for benefit or harm of a patient(39,57–60)

5.2.5 Truth telling as both good and bad thing

The manner in which healthcare providers perceive truth telling to their terminally ill cancer patients was reported to have influence. Truth telling to patients was generally perceived by most of participants as a good thing as well as the key role in oncology field. The main issue and concern as for those who perceive it as a fundamental thing in oncology was how to tell, because it was reported that truth telling should never being reduced to merely telling a patient that you have cancer, should go beyond as it connotes. This implies that by the fact that truth telling is perceived as the key role in oncology field, one will try as much as possible to break medical information to patients regardless of how the patient would receive. Although on the contrary where truth telling was negatively perceived as something that can hurts and accelerate sufferings and pains of a patient, one will eventually hesitate to disclose medical information. Other similar studies found that negative perceptions of healthcare providers on

truth telling puts them into a dilemma of telling or not telling as telling would adversely affect patients both psychologically and physiological(25,39,46).

5.2.6 Lack of guidelines on truth telling

Lack of guidelines on truth telling to terminally ill cancer patients by healthcare providers was reported by the participants as one of the contributing factors for failure of healthcare providers to inform patients about their condition. Key findings showed that most of respondents reported lack of institutional and national guidelines on truth telling to patients. Furthermore, healthcare providers reported that lack of guidelines and structure on truth telling into the institution of such a nature that deals with the end of life issues was a big weakness. This implies that truth telling to such patients by healthcare provider only depends on a providence of a healthcare provider. This means that healthcare providers have a wide choice on their ways as an option to tell or not to tell. This also implies that, had the institution has guidelines, procedures or even protocol on how to share medical information to patients by healthcare providers, there would have been an honest implementation of the ethical principle of truth telling. Other studies that were done on truth telling documented a great influence and importance of having well defined bioethical and professional codes into health and medical care that include truth telling(7,8)

5.2.7 Lack of adequate facilities

Findings from this study revealed that lack of adequate facilities like offices or rooms hinder information sharing among healthcare providers and patients. It was reported by healthcare providers that digesting complete information to patients requires a very conducive kind of settings where by each will have a freedom of sharing and listening. Unlike the existing settings of the institution which do not provide a room as for privacy enhancements and fostering of the disclosure of medical information as it ought to be. The participants admitted to be ethically failed by lack of institutional infrastructure like private office, room and a good place as for information sharing. This implies that healthcare providers upon deciding to break medical information in such settings either violate ethical principle of privacy or they do not share medical information honestly to their patients. In a study on Privacy in Practice:

Professional Discourse about Information Control in Healthcare, Anthony and Stablein reported that protection of patient information is part of core professional ethics and it is clearly understood that the protection can only be possible if there are adequate facilities to ensure privacy at the health facilities(61)

5.2.8 Number of patients influence truth telling

Volume of cancer patients was found to have impacts on truth telling at ORCI, as other similar study by Mustafa et al on Factors Related to Truth-Telling Practice of Physicians Treating Patients with Cancer in Turkey, documented that the ever increase of number of new patient's cases per month contributed to the majority of healthcare providers to be reluctant in truth telling due to workload(60).It was reported by most of healthcare providers interviewed that they are obliged to attend on daily basis as many patients as possible because of ever increasing number of patients. Larger number of patients compared to healthcare providers tends to limit adequate disclosure of medical information to patients. The lesser the number of patients to be attended by a healthcare provider suggests the more the time available for information disclosure. Healthcare providers even reported that it would be unethical to spend more time on one patient while there are so many others who travelled all the ways waiting for the service.

This implies that the increase in number of patients on a waiting list forces a minimization of time needed by a healthcare provider to break information wholly, hence medical information is partially shared.

5.2.9 Multi-disciplinary team

The key findings of this study revealed the influence of a multi-disciplinary team approach on disclosing medical information to cancer patients. It was found that truth telling as for efficacy is better and properly done by a team of experts from every field including oncologist, psychologists, psychiatrist, nurses, bioethicist and spiritual leaders. The team of experts can decide on the modality, each or two can decide to have own ample time to talk to a patient to prevent scarring of the patient when the team is large. This would influence the patient's care including truth telling because a human is a totality of aspects and when gets sick, all of

aspects are also affected. Such aspects should as well be addressed by experts so as to facilitate a healing process. This implies that shortage of personnel that were trained to constitute such a multi-disciplinary team of experts brings about inefficacy on truth telling to terminally ill cancer patients at ORCI. Another study documented similar influence of trained multi-disciplinary personnel in breaking bad news as being as important and associated with the self-reported truth-telling practices of healthcare providers(60).

This study has then worth noting to have provided key healthcare providers' influencing factors on truth telling to terminally ill cancer patients as discussed in section 5.1 of chapter five.

5.3 Patient's related factors influencing truth telling

The findings of this study revealed that truth telling by healthcare providers to terminally ill cancer patients was influenced by a number of factors stemming from patients themselves. The main identified influencing factors include; patient's level of understanding, patient's freedom of choice to information, rights to information, lack of prior information to patients, psychological condition of the patient and patient's faith and beliefs.

5.3.1 Patient's level of understanding

Patient's level of understanding was reported to have influenced truth telling as most of healthcare providers interviewed reported to have difficult in disclosing an honest medical information to illiterate patients. This was assumed and taken for granted by healthcare providers that presenting the whole truth about the disease, its type and stage, its modes of treatments and all expected side effects to a mere patient who cannot understand some of complicated medical terminologies and concepts is very difficult. This implies that healthcare providers fail to communicate medical information to their clients simply because their level of understanding is low. Also it implies that healthcare providers lack of communication skills that would adhere and fit to their patients' level of understanding. This is because ethically speaking there should always be away of delivering the information to each patient according to one's capacity to comprehend. A study by Rosario Costas reported that patients'

knowledge may have an influence regarding their ability to participate in the decision-making processes for medical care and treatment choices, which may include seeking truth information about their condition from service providers(62).

5.3.2 Patient's freedom of choice to information

Key findings showed that patient's freedom of choice to information contribute to truth telling. It was said that there are some of patients who would like to be told information while others would prefer not to hear any of their medical information. Still other patients were willing to receive only a certain kind of information over the other. This is because patients have a fundamental ethical medical autonomy to information and healthcare providers have to accept without compromising. It is worth noting that imposing information to unprepared and unwilling patient is not an act of respect for autonomy. Most of participants interviewed however reported that there are patients who are willing to hear information that brings hope and good news. This implies that healthcare providers have a role to educate patients especially those who tend to resist and select only kind of information with effort to break medical information. Other studies documented similar patient's freedom of choice to information as one of the barriers on truth telling in oncology field as it contributes to the variability of attitudes of cancer patients(39,53,54).

5.3.3 Rights to information

Patient's right to medical information was reported to influence truth telling. Most of participants reported that medical information sharing is a basic right of a patient. Furthermore, they said that patients are basically and ethically entitled to truth telling and that healthcare providers are obliged to respect such a right without reservations. This implies that because cancer patients have ethical medical rights to information and healthcare providers should not find an excuse to deny or reduce such a right. Cancer patients ought to be told the truth and being engaged on decisions making. Similar studies have also found that healthcare providers share medical information with their patients because it is their right to information, that patients usually like to be informed of their medical diagnosis and prognosis(14,39).

5.3.4 Lack of prior information to patients

Most of participants reported that lack of prior information to cancer patients makes it even difficult to start breaking medical information pertaining diagnosis and prognosis. This is because once a patient is diagnosed with late cancer stage, it is thought by healthcare providers to be hard to bear the news. Healthcare providers said that it is usually difficult just for a patient to hear it for the first time that the goal of care is a palliative and not curative due to lack of prior information. This implies that cancer patients are better off for truth telling by healthcare providers as earlier as possible during the very first point of medical checkups. Once a cancer patient has prior information, it will never scare such a patient and a healthcare provider even disclosing information at the late stage.

5.3.5 Psychological condition of the patient

Furthermore, findings of this study revealed that psychological condition of a patient contributes to truth telling. Most of healthcare providers interviewed said that truth telling depends on psychological and physical abilities of a cancer patient. They will not dare sharing too much of medical information with their patients when feeling that they would not handle it. Opting to share information with patients who are unstable and disturbed psychologically will lead on losing hope. This implies that healthcare providers sometimes are forced by psychological condition of their patients not to tell the truth but to deceive. It has been documented elsewhere that under grave circumstance healthcare providers may be forced to deceive a patient so as to instill hope and obeys ethical principle of beneficence(63). However, it is also documented in another study that deception generally should not be utilized in everyday medical practice because it dis-respects autonomy of a patient(23).

5.3.6 Patient’s faith and beliefs

In this study healthcare providers reported that patient’s faith and belief shave an influence on truth telling. Some of participants said that before disclosing medical information it is wise to check on faith and belief of your patients. They reported furthermore that upon knowing patient’s faith and belief then one can digest the information slowly part by part in line with the faith of such a patient. It was also said that if faith and belief of patients should be

considered while breaking medical information then it will hinder healthcare providers from doing what is professionally right. This implies that truth telling is partially depending on faith and beliefs of a patient because it was considered by some of healthcare providers as an influencing factor. The study done by Clarissa et all on The Impact of Culture and Religion on Truth Telling at the End of Life showed how faith and belief of patients and families deter them from making decisions about life and death and their reluctance to discuss and accept fatal diagnosis and prognosis from healthcare providers(60).

5.4 Socio-cultural influencing factors to truth telling

This section provides intellectual insight to socio-cultural contributing factors on truth telling to terminally ill cancer patients by healthcare providers as revealed by the participants at ORCI apart from those of patient's and healthcare providers'.

The main provided factors were traditional beliefs (cancer is associated with witchcraft), cultural communication style and family collusion.

5.4.1 Traditional beliefs and cultural communication style

The two subthemes are discussed under this theme.

5.4.1.1 Cancer is associated with witchcraft

The findings of this study revealed that there is misconception among people in the societies that associate cancer diseases with superstition. The results of such misconception is that, cancer patients are never brought to hospital as earlier as possible for checkups and treatments, instead they are first been sent to traditional herbalists. The interviewed healthcare providers reported that even if when such cancer patients once brought to hospital with pre conceived ideas of superstition, it is difficult to start breaking medical cancer information to them.

5.4.1.2 Cultural communication style

Also the findings of this study revealed the influence of cultural communication style to truth telling by healthcare providers to terminally ill cancer patients. As many of African cultures including Tanzanian culture enhance more of a communal kind of concern rather than individualism, in so doing it encourages information confidentiality of a patient. The culture

does not allow much of information to be given directly to their patient aiming at protecting such a patient from losing hope and getting a depression.

The findings entail that some of the traditional beliefs do not have sufficient explanations that can provide a framework of reference to interpret the external world and relate to it. Furthermore, it implies that the society through its tools of traditional beliefs and communication style is capable of influencing therapeutic outcomes and can bring great differences in medical care services including the ability to absorb shocks of cancer information. Similar findings have been well documented in other studies indicating that traditional beliefs and cultural communication style can manipulate the perceptions and attitudes of people on cancer treatments and information sharing including truth telling(15,39,41)

5.4.2 Family collusion influence truth telling

Most of healthcare providers interviewed reported the influence of family collusion on breaking medical information to their cancer patients. The key findings reported further that family members normally request and prevent healthcare providers from sharing information with patients. The findings revealed also that even patients allow such interference and involvements of family members into truth telling and decision making on their behalf. This implies that family members in our societies play a major role in breaking medical information and decisions making. It also entails that family members influence a medical relationship between a healthcare provider and a patient including truth telling. This can be referred to as ‘family medical centered autonomy’. Studies conducted in Northern Ireland by Begley and in Tehran by Zahedi also reported that information sharing in the field of oncology including truth telling is much more influenced by family members. Healthcare providers normally are at dilemma as to whom, when and how to tell(15,52)

CHAPTER SIX

6.0 CONCLUSION AND RECOMMENDATIONS

6.1 Conclusion

The implementation of ethical rule of truth telling to terminally ill cancer patients by healthcare providers at ORCI was less implemented than what ought to be due to the number of factors discussed. Healthcare providers usually are at a dilemma of telling or not telling the truth due to lack of guidelines, trainings on communication skills and information provision. Also truth telling at ORCI is found to be affected by insufficient facilities like offices or rooms, since digesting complete information to patients requires a very conducive kind of settings where by each will have a freedom of sharing and listening as well as privacy assurance. Furthermore, the ever increasing number of cancer patients flocking to seek medical attention at ORCI limit an ample time for a healthcare provider to disclose medical information. However, as its efficacy truth telling is said to be best done by a multi-disciplinary team approach.

6.2 Recommendations

This study revealed that most of the healthcare providers do not tell the truth to terminally ill cancer patients. However, truth telling was reported to be a fundamental key in oncology field by participants, in this regard the following are the recommendations;

i. Healthcare providers at ORCI should have ongoing trainings so as to be equipped in knowledge, communication skills and information provision. This will help them to be more empathetic and objective than be sympathetic and subjective upon telling the truth to their cancer patients.
ii. The management of ORCI should establish more rooms and creating space as for privacy enhancements, freedom of sharing and listening upon disclosing cancer medical information to patients.

iii. The ORCI should have well stipulated guidelines on truth telling to terminally ill cancer patients as how, when, to whom and by whom. The guidelines should spell clearly the qualities of a multi-disciplinary team which by all means should include experts' personnel like oncologists, nurses, psychiatrists, medical ethicists, psychologists and spiritual leaders.

iv. The volume of cancer patients is ever increasing on daily basis at ORCI, thus it is a high time for the management of the Institute to deliberately employ more healthcare providers so as to enhance adequate disclosure of medical information to patients. The lesser the number of patients to be attended by a healthcare provider the more the time available for information disclosure.

6.3 Recommendation for future studies

This study was conducted as the case to ORCI, we therefore recommend that future studies on the subject matter should involve other hospitals and health care institutions which accommodate healthcare providers in general and or cancer patients so as to understand the influencing factors to truth telling national wise.

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APPENDICES

Appendix A: 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 Science in Bioethics (MSc. Bioethics), at Muhimbili University of Health and Allied Sciences (MUHAS). I am doing research on**"** ***Truth Telling by Healthcare Providers to Terminally ill Cancer Patients at Ocean Road Hospital in Dar-es-salaam*****"**.

The aim of the Study

This study aims to explore factors influencing truth telling by healthcare providers to terminally ill cancer patients during medical treatments at Ocean Road Cancer Institute in Dar-es-Salaam.

Procedure

I would like you to participate in this study. You are selected because you are knowledgeable and directly responsible for the subject matter of this 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 safer 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 be used in the written copy of the discussion.

Right to refuse or withdraw

It is your choice to participate in this study. Also you don't have 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 are very important 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 for improving and implementation of truth telling to cancer patients, as well as reducing dilemma about telling or not telling the truth to terminally ill cancer patients among healthcare providers. It will stir to both healthcare providers and terminally ill cancer patients to use controlled quality of life considerations with medical inputs, to legitimately determine whether particular life prolonging treatments are optional or obligatory. Your information will help on reduction of anxiety, tension and guilt conscious of information denial to terminally ill patients, hence prepare them psychologically and spiritually to face and accept death.

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 trigger your emotions, feelings, pains, worries and despair.

Whom to Contact

In case of any inquiry please contact the principal investigator, Mr. ATHANAS, Raymond (MBE) from MUHAS, P. O. BOX 65001, Dar es Salaam, mobile number 0762021208. 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 B: Fomu ya ridhaa kwa mhudumu wa afya/ kwa mgonjwa (kwa Kiswahili)

NAMBA YA FOMU

FOMU YA IDHINI YA KUSHIRIKI KATIKA UTAFITI

Habari, naitwa ……. nikisomea shahada ya uzamili katika fani ya Maadili ya Kimatibabu katika Chuo Kikuu cha Afya na Sayansi Shirikishi Muhimbili (MUHAS).Ninafanya utafiti kuhusu *"Kuambiwa ukweli kwa wagojwa wa kansa na watao huduma katika hospitali ya Ocean Road iliyopo Dar-es-Salaam"*

Lengo la Utafiti

Utafiti huu una lengo la kutafuta mambo yanayochangia wagonjwa wa kansa kuambiwa au kutoambiwa ukweli na watoa huduma wakati wa kupata matibabu, na hasa kwa wale walio mahututi katika hospitali ya Ocean Road iliyopo Dar-es-Salaam.

Utaratibu

Ningependa ushiriki katika utafiti huu. Umechaguliwa kwa sababu unahusika katika kutoa huduma kwa wagonjwa wa kansa na mawazo yako yatasaidia uboreshaji wa huduma hii kwa siku za baadae. Watafiti watapenda kuchukua sauti yako ili kuweza kupata vema mazungumzo yako yote, na watawasiliana nawe ili kupanga muda mwafaka kwako wa 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 itatunzwa sehemu salama hadi hapo nakala ya maandishi itakapotolewa. Mara baada ya kukamilika kwa nakala ya maandishi, sauti

yako iliyotunzwa itafutwa ili kutunza usiri wa utafiti. Hata hivyo, majina yako hayatajumuishwa kwenye nakala ya maandishi.

Haki ya kukataa au kujitoa

Ushiriki katika 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 utasaidia kuwakumbusha watoa huduma kuhusu umuhimu wa kuwaambia ukweli wagonjwa, na hivyo kupunguza utata kwa watoa huduma kuhusu kusema ukweli kwa wagonjwa mahututi wa kansa. Pia itawahamasisha watoa huduma na wagonjwa kutumia njia sahihi na bora za kimatibabu kwa kuzingatia ni aina ipi za huduma ni za lazima au za hiari. Utafiti huu unategemewa kutoa msaada katika kupunguza msongo wa mawazo, wasiwasi na dhamiri ya kuhisi kunyimwa ukweli kwa wagonjwa, na hivi kuwaandaa kisaikolojia na kiroho kukabiliana na kukipokea kifo.

Madhara

Hatutegemei ya kwamba utapata madhara yoyote kwa kushiriki kwako katika utafiti huu ingawa baadhi ya maswali utakayoulizwa ni ya kibinafsina hivyo yataweza kukuletea utofauti wa kihisia, mawazo, wasiwasi, woga na kujisikia uchungu.

Watu wa kuwasiliana nao

Kama una maswali katika utafiti huu unaweza kuwasiliana na mtafiti mkuu, Bw. ATHANAS, Raymond (MBE) kutoka Chuo Kikuu cha Afya na Sayansi shirikishi Muhimbili, S.L.P. 65001, Dar es Salaam. Nambari yake ya simu ni 0762021208. 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 C: 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 influencing truth telling to terminally ill cancer patients at ORCI in Dar-es-Salaam.

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

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

1) Sex
    a) Male
    b) Female
2) Education level_____
3) Did you undergo any training on ethics/medical ethics?
4) Work experience in the Institute (years)……..

Part III: General information:

5) What motivated you to be a healthcare provider especially to cancer patients?
6) What is your experience in taking care of cancer patients?
7) What are your roles at this Institute of Cancer Patients (ORCI)? (**Probe:** length held position, professional background)

Part IV: Criteria of truth telling to terminally ill cancer patients:

8) Based on your roles as you said, kindly tell me what do you understand about the truth telling to terminally ill cancer patients? (**Probe:** Interpret, knowledgably awareness, comprehension)

9) According to your experience on palliative care to cancer patients, tell me on how should a healthcare provider disclose information to terminally ill cancer patients? (**Probe:** Can you tell me more about: The hospital or department guidelines for truth telling, how to tell, to whom and when to tell, any report?)
10) Would you kindly explain about your perceptions of truth telling to terminally ill cancer patients?

Part V: Other associating factors to the truth telling to terminally ill cancer patients:

11) What are the associating factors as you would think that influence truth telling to terminally ill cancer patients? (**Probe:** cultural, beliefs, traditional)

Part VI: Significance of truth telling to the cancer patients:

12) Kindly, explain the importance of truth telling to terminally ill cancer patients by healthcare providers? (**Probe**: benefits to patients, family members, institution/hospital, community)

Part VII: Challenges encounter in truth telling to terminally ill cancer patients

13) What are the challenges encountered over telling the truth to the cancer patients? (**Probe:** family members, guidelines, feedback, inferiority complex, sympathy)

Part VIII: Strategies to improve truth telling to terminally ill cancer patients by healthcare providers.

14) What are your opinions on how best to improve truth telling to terminally ill cancer patients by healthcare providers? (**Probe**: At the Individual level, at the Institutional/hospital level, at the National level)

Part IX: Ending:

15) Do you have any other additional information concerning the study that you find important and would like to share with me pertaining to the whole concept of truth telling to terminally ill cancer patients?
16) (Action to be taken) I should have all the information I need. Would it be alright to contact you in case of any more questions or clarifications?

Thank you very much for your cooperation

Kiambatanisho D: 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 kusababishawatoa huduma kuwaambia ama kutowaambia wagonjwa ukweli katika hospitali ya Ocean Road ya jijini Dar-es-Salaam.

Sehemu I: Utangulizi

Umechaguliwa kama mtu muhimu atakayeweza kujibu maswali yangu, na 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 hivi.

Sehemu II: Taarifa Binafsi

Kama hutajali, uniambie kuhusu

1) Jinsia yako
    a) Mme
    b) Mke
2) Kiwango cha Elimu_____
3) Je umewahi kupata mafunzo yeyote ya kimaadili au maadili ya kimatibabu?
4) Uzoefu wako wa kazi katika Taasisi/ hospitali hii (miaka)……...

Sehemu III: Taarifa za Jumla:

5) Kipi kilichokufanya upende kuwa mtoa huduma wa wagonjwa wa kansa?
6) Je uzoefu wako ni upi katika kuwatunza wagojwa wa kansa?
7) Je unafanya majukumu gani katika taasisi hii ya wagonjwa wa kansa?
   (**Dodoso:** Kwa muda gani, utaalamu wako)

Sehemu IV: Vigezo vya kusema ukweli kwa wagonjwa mahututi wa kansa:

8) Kufuatana na majukumu yako kama ulivyosema, nini unaelewa kuhusu kusema ukweli kwa wagonjwa mahututi wa kansa?
   (**Dodoso:** Tafasiri, utambuzi, mang'amuzi, umuhimu)

9) Kufuatana na uzoefu wako wa kuwatunza wagonjwa mahututi wa kansa,ni kivipi mtoa huduma anamshirikisha mgonjwa mahututi wa kansa taarifa?
(**Dodoso:** Niambie zaidi kuhusu: miongozo ya [hospitali au idara] ya kusema ukweli kwa wagonjwa,namna ya kusema, kwa nani, na lini, taarifa yeyote?)
10) Ni nini mtazamo wako kuhusu kusema ukweli kwa wagonjwa mahututi wa kansa?

Sehemu V: Mambo mengine yanavyochangia kusema au kutokusema ukweli kwa wagojwa mahututi wa kansa:

11) Je unadhani mambo gani yanachangia kusema au kutokusema ukweli kwa wagonjwa mahututi wa kansa? (**Dodoso:** Tamaduni, mila, imani)

Sehemu VI: Umuhimu wa kusema ukweli kwa wagonjwa mahututi wa kansa:

12) Je kuna umuhimu gani kwa watoa huduma kusema ukweli kwa wagonjwa wa kansa walio mahututi? (**Dodoso**: Faida kwa mgonjwa, kwa wanafamilia, kwa taasisi/ hospitali, kwa jamii)

Sehemu VII: Changamoto zitokanazo na kusema ukweli kwa wagonjwa wa kansa walio mahututi:

13) Ni changamoto zipi unazokutana nazo juu ya kusema ukweli kwa wagonjwa mahututi wa kansa? (**Dodoso:** kwa wanafamilia, miongozo, hisia, huruma)

Sehemu VIII: Mbinu kwa watoa huduma zinazoweza kuboresha kusema ukweli kwa wagonjwa mahututi wa kansa.

14) Nini maoni yako kwa watoa huduma ya jinsi ya kuboresha zaidi kusema ukweli kwa wagonjwa mahututi wa kansa? (**Dodoso**: Kwa mtu mmoja mmoja, katika ngazi ya idara/ taasisi /hospitali, Taifa)

Sehemu IX: Hitimisho:

15) Je una maelezo mengine ya nyongeza ambayo ungependa kuniambia kuhusu utafiti huu?
16) Ningependa kupata maelezo yote ninayohitaji katika utafiti huu, je nitaweza kuwasiliana nawe ikiwa nina swali/maswali kwa ajili ya ufafanuzi zaidi?

Aksante sana kwa ushirikiano wako

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

This is a patient's in-depth Interview Guide for finding out patient's related factors influencing truth telling by healthcare providers at ORCI in Dar-es-Salaam. Patients will be asked based on their consent, autonomy and rights to medical information.

Part I: Introduction

You have been selected among others as an important key informant who is able to respond to 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 10-15 minutes' duration.

Part II: Demographic

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

1) Sex
    a) Male
    b) Female
2) How do you get information about your health condition from the healthcare providers?
3) Which specific information would you like to be told?
4) At which extend/how far would you like to be given such specific medical information (if any)?
5) What other people (relatives) would you like to receive information about your health condition? (**Probe;** why?)
6) What type of information that you would not like to be told by the healthcare providers about your health condition? (**Probe;** why?)
7) What is the significant of such specific medical information that you would like to be told?
8) What is your opinion about truth telling to terminally ill cancer patients by healthcare providers?
9) Do you have any other additional information concerning the study that you find important and would like to share with me pertaining to the whole concept of truth telling to terminally ill cancer patients?

Thank you very much for your cooperation

Kiambatanisho F: Mwongozo wa majadiliano na mgonjwa (kwa kiwahili)

Huu ni mwongozo wa majadiliano na mgonjwa unaolenga kuangalia mambo yatokanayo na wagonjwa yanayoweza kusababisha watoa huduma wasiwaambie ukweli kuhusu afya na hali zao katika hospitali ya ORCI iliyopo jijini Dar-es-Salaam. Wagonjwa wataulizwa kulingana na ridhaa, uhuru na haki zao za kupata taarifa za kimatibabu.

Sehemu I: Utangulizi

Umechaguliwa kama mtu muhimu atakayeweza kujibu maswali yangu, na 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 10-15 hivi.

Sehemu II: Taarifa Binafsi

Kama hutajali, uniambie kuhusu

1) Jinsia yako
    a) Mme
    b) Mke
2) Je unapataje taarifa kuhusu hali au afya yako toka kwa watoa huduma?
3) Je ni taarifa zipi hasa ungependa kuambiwa?
4) Je ni kwa kiasi gani ungependa kupewa taarifa hizo?
5) Je ni watu gani wengine ungependa wapewe taarifa kuhusu hali na afya yako? (**Dodoso;** kwa nini?)
6) Je usingependa kuambiwa aina gani za taarifa kuhusu afya na hali yako na watoa huduma? (**Dodoso;**kwa nini?)
7) Je unaweza kuniambia umuhimu wa taarifa ambazo ungependa kuambiwa?
8) Je ni nini maoni yako kuhusu wagojnwa kupewa taarifa kamili za hali zao za afya na watoa huduma?
9) Je una maelezo mengine ya nyongeza ambayo ungependa kuniambia kuhusu kuambiwa ukweli na watoa huduma wa afya?

Aksante sana kwa ushirikiano wako

Appendix G: Approval Ethical Clearance

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

P.O. Box 65001
DAR ES SALAAM
TANZANIA
Web: www.muhas.ac.tz

Tel G/Line: +255-22-2150302/6 Ext. 1015
Direct Line: +255-22-2151378
Telefax: +255-22-2150465
E-mail: dpgs@muhas.ac.tz

Ref. No. DA.287/298/01A/07

23rd February, 2018

Mr. Athanas Raymond
MSc in Bioethics
MUHAS.

RE: APPROVAL OF ETHICAL CLEARANCE FOR A STUDY TITLED: "TRUTH TELLING BY HEALTHCARE PROVIDERS TO TERMINALLY ILL CANCER PATIENTS AT OCEAN ROAD HOSPITAL IN DAR ES SALAAM"

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 23rd February, 2018 to 22nd February, 2019. In case you do not complete data analysis and dissertation report writing by 22nd February, 2019, you will have to apply for renewal of ethical clearance prior to the expiry date.

Prof. P. Muganyizi
ACTING: DIRECTOR OF POSTGRADUATE STUDIES

cc: Director of Research and Publications
cc: Dean, School of Medicine