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The role of communication in cancer consultations;

An exploratory study of doctor-patient-family caregiver communication in Uganda and Ethiopia.

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ABSTRACT

Doctor-patient communication is essential for quality of health care. Little has been done about doctor-patient communication in Africa in general, and in Uganda and Ethiopia in particular. In this study, we focus on two issues. First, we describe and analyze how doctors, cancer patients and family caregivers experience their communication concerning a) general experiences and satisfaction; b) breaking bad news to cancer patients and their family caregivers and the ways patients and family caregivers receive bad news, c) language usage during consultation meetings, and d) the cultural issues that influence patients' health seeking behaviors in Uganda and Ethiopia. Second, we analyze public awareness about cancer diseases in both countries.

Methods: both qualitative and quantitative methods were used. In both countries, 27 doctors, 86 patients, 43 family caregivers were interviewed and 46 doctor-patient-family caregiver interaction video recordings were made. We transcribed all the video recordings and part of the interviews. In addition, 284 questionnaires were analyzed. We used simple descriptive statistics.

Results: a). Doctors experience challenges associated with influx of patients, language barriers, illiteracy levels, lack of cancer awareness, inabilities/unwillingness of patients and family caregivers to ask questions. Patients and family caregivers are not satisfied with the information about cancer and the manner in which doctors give them information, complain about nurses' attitudes and physical environment. There is great need of information about cancer disease. b). Public perception about cancer diseases is low in all age groups, female respondents hear more about the disease but male respondents have more knowledge about the scourge, and more need for information about cancer.

Conclusion: Many patients and family caregivers need more information about cancer yet their doctors underestimated their need. Problems associated with doctor-patient and doctor-family caregivers' communication are so frequent and negatively influence patients' emotional and psychological wellbeing. Some of the most common problems include patients' inability to ask questions, lack of communication skills by doctors, influx of patients and language barriers. Some of these problems can be eliminated if doctors get communication skills training. Communication as a course has to be emphasized in the medical school curriculums in order to equip physicians with the skills needed to succeed when communicating with patients and their family caregivers. More so, the masses should be sensitized about cancer disease since now it kills more people than HIV, Malaria and Tuberculosis combined.

Key Words; communication, health, cancer, doctor-patient communication, doctor-family caregiver communication, culture

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1. INTRODUCTION

1.1 BACKGROUND

In every aspect of life, communication is very vital in reaching a mutual understanding and to ease our day-to-day lives. Just like a car without an engine, so is a profession without communication. For any profession to succeed, there must be good communication between the representatives of these professions, as well as between the professionals and laymen. Not only in professions but also in families, communication plays a big role in shaping our attitudes and emotions among other things.

Communication is important in establishing a therapeutic doctor-patient relationship; if successful, it can aid the delivery of high-quality health care, Ha & Longnecker [16]. A lot of patient dissatisfaction and complaints may arise due to a breakdown in the doctor-patient relationship. Studies have proved that good communication has tangible benefits such as doctor communication skills and patients′ satisfaction, Simpson. M. et al [22]. Several studies and reviews clearly indicate a correlation between effective communication and improved health outcomes, Ha & Longnecker [16]. However, many physicians tend to underestimate the power of good communication with their patients. More so, doctor-family caregiver communication plays an important role in the patient wellbeing both physically and emotionally, and to some extent can determine the health outcomes of the patient. "Over the past two decades, psycho-oncological studies have reported that poor physician communication could lead to uncertainty and denial, anxiety and depression, non-compliance, and problematic psychological adjustments to cancer" Ong L. M et al [17].

The World Health Organization fact sheet [42] indicate that cancers are among the leading cause of morbidity and mortality worldwide, with approximately 14 million new cases and accounting for 8.2 million deaths in 2012. The number of new cases is expected to rise by about 70% over the next two decades [42] According to Fred Hutchinson Cancer Research Center [27], cancer kills more people in Sub-Saharan Africa than HIV, Tuberculosis and Malaria combined. This paper presents an exploratory study of the role of communication in cancer consultation meetings in Uganda and Ethiopia. Focus lies on doctor-patient and doctor-family caregiver communication as the latter is common. Communication experiences of doctors, cancer patients and their family caregivers, the influence of culture on the health-seeking behaviors of cancer patients and the level of public awareness of cancer disease in both countries is analyzed. The study was conducted at Uganda Cancer Institute, Mulago Hospital (Kampala-Uganda) and Black Lion (TIKUR ANBESSA) Hospital (Addis Ababa- Ethiopia) respectively. The respective hospitals stand to be the only referral cancer centers in both countries.

According to Uganda Cancer Institute [39], Mulago National Referral Hospital, the number of cancer cases reported shot from 1899 patients in 2013 to 2265 patients in 2014. Over 60 percent of the patients present advanced cases of the disease. The Institute is the only cancer referral center in Uganda but also serves patients from Djibouti, Eritrea, Somalia, Western Kenya, Rwanda, Burundi, South Sudan and the Eastern Democratic Republic of Congo. Research by Fred Hutchinson Cancer Research Center [27] shows that infectious diseases cause six out of ten of common cancers in Uganda, and nearly one-third of patients diagnosed with cancer, are infected with HIV. The most common registered cancers are Kaposi's sarcoma, cervical, breast, prostate, head and neck, sarcoma and leukemia/lymphoma. Others include colorectal cancer, skin cancer, esophageal cancers, bladder, liver, kidney, non-Hodgkin lymphomas, Burkitt's lymphoma.

According to the International Network for Cancer Treatment and Research (INCTR) [38], the current information available about cancer in Ethiopia indicates that there are more than 60,000 cases of cancer reported each year, but available data is limited. In 2010, the hospital registered more than 2000 adults and 200 children with cancer. The most common types of cancer in Ethiopia are cancers of the breast, cervical, head and neck, esophageal, and sarcoma. Others include, colorectal cancer, liver cancer, non-Hodgkin lymphoma and skin cancers for adults and in children leukemia, lymphoma, retinoblastoma, Wilms tumor, bone and soft tissue sarcomas.

1.2 OBJECTIVE OF THE STUDY

The objective of the research was to address the general communication experiences between doctors and patients, and doctors and family caregivers with the focus on breaking bad news and language usage. We also wanted to address the doctors, patients and family caregivers' opinions about the role of communication in cancer consultations and the cultural issues related to health seeking behaviors. We also investigated the level of public knowledge and awareness of cancer disease in both countries respectively.

1.3 RESEARCH QUESTIONS

In order to carry out our exploratory study of the role of communication, we chose to focus on the following questions;
Research question 1. How do doctors, cancer patients, and family caregivers experience their communication during consultations? Focus lies on;

a). Communication experiences amongst doctors, patients and family caregivers, b). The way doctors break bad news to cancer patients and their family caregivers, c). The way patients and family caregivers receive bad news d). Language used by doctors, cancer patients, and family caregivers in consultations, e). Doctors', patients' and family caregivers' opinions about the role of communication in cancer consultation meetings, and f). Cultural issues that influence patients and family caregivers' health seeking behaviors.

Research question 2. What is the level of public awareness of cancer disease in Uganda and Ethiopia?

This paper consists of six chapters. The first chapter called introduction comprises of background, objective of the study and research questions. The second chapter gives an overview of concepts of previous studies about doctor, patient and family caregiver communication in relation to our study. Chapter three describes methodological background with details of data collection, ethical consideration, eligibility, recruitments and consents. The fourth chapter presents the research findings for both qualitative and quantitative methods and the fifth chapter gives a detailed discussion of the results. The last chapter comprises of conclusion, future research suggestions and the acknowledgement.

2. THEORETICAL FRAMEWORK

2.1 COMMUNICATION

As people come together for a common goal or to accomplish a certain task, they interact with one another in order to exchange or share ideas, reach a mutual understanding and express their satisfaction or dissatisfaction among others. During the process of interaction, verbal and nonverbal communication occurs. Nonverbal communication is exhibited through facial expressions, head nods, hand movements, vocal sounds etc, whereas verbal communication is exhibited through words (spoken or written). Allwood [1] defines communication as,″ the transmission of content X from a sender Y to a recipient Z using an expression W and a medium Q in an environment E with a purpose/function F,″

Relating this definition to our study, 'Context X' involves shared information, shared intentionality, and shared meaning in cancer consultations. 'Sender Y to a Recipient Z' involves co-communicators or interlocutors, in this case, the doctors and cancer patients or patient's caregiver. 'Expression W' represents a communicative act, a sign or a signal, in this case, the act of diagnosing or counseling and treating. 'Medium Q' involves face to face communication between doctors and cancer patients or their caretakers. 'Environment E' represents the physical environment, in this case, can be the doctor's office in the hospital or the cancer patients' wards. The social environment, in this case, can be the doctors, cancer patients and their caregivers, and other staff members. The cultural environment, in this case, can be the medical personnel and the artifacts such as medical facilities. The Purpose/ Function F represents the Why, Intention, Social bonding, Keep the conversation going and avoiding system breakdown. In this case, the doctor and/or the medical personnel communicates with patients or their caretakers because he/she wants to examine their health conditions and give them treatment. The patients in return, want to get treatment and counseling from the doctors to get well. Giffin & Patton [6] define communication as a process involving the sending and receiving of messages.

Poor communication, particularly with cancer patients, has been shown to be associated with worse clinical and psychosocial outcomes, including worse pain control, worse adherence to treatment, and confusion over prognosis and dissatisfaction at not being involved in decision making, Payne Jacqueline [34]. For the clinician, communication difficulties lead to worse job satisfaction and higher stress levels, as well as being behind a high proportion of errors and complaints, Payne Jacqueline [34]. According to Allwood [1], a communicative act "is successful if it is perceived, understood, and evaluated by the listener and it is maximally successful for the speaker if all its evocative intentions meet with success, i.e. in the case of a statement, that the interlocutor not only perceives, understands and evaluates but also is able and willing to believe the claim made." Research by Schyve [20], indicate that effective communication does not occur if there is no or less degree of understanding and "when effective communication is absent, the provision of health care ends or proceeds only with errors, poor quality, and risks to patient safety."

A good doctor-patient and doctor-family caregiver relationship develops confidence in patients and their caregivers which helps them to feel free discussing their conditions, feelings, concerns and can easily consent to treatment procedures. Healthcare communication "is seen to have relevance for virtually every aspect of health and well-being, including disease prevention, health promotion and quality of life," Rimal Rajiv & Lapinski Maria [36]. Research by Lindström Nataliya [9] shows that "asking questions is the most common way to elicit information from the interlocutor and statements are used to provide information. Using feedback is a way to indicate information acknowledgment and verify the information provided.” (p.15). Research by Lindström Nataliya [9] shows further that the role of the physician in a medical consultation, is to assist the patient to solve health problems and the patient's role, is to provide relevant and adequate information to the physician. Verbal and non-verbal communication skills play an important part in improving doctor-patient relationship since it can lead to better caring for patients and helps them to comply with their illness and to accept treatment, Arbabi M. et al [12]. “Physicians' failure in communication skills leads to patients’ resentment and also inspires the feeling of incompetency in physicians to control the patients' pain and symptoms” Arbabi M. et al [12].

2.2 DOCTOR-PATIENT COMMUNICATION

According to Schyve [20], effective communication between doctors and patients is a necessity in health care. This kind of communication includes active listening by both parties, the language used during the interaction and environmental factors among other things. ″Patients anxiety and dissatisfaction is related to uncertainty and lack of information, explanation, and feedback from the doctor. Yet doctors often misperceive the amount and type of information patients want. Simpson. M. et al [22] state that the language doctors use is often unclear, both as regards the use of jargons and in relation to a lack of expected shared meanings of relatively common terms,″ (p.1385). Doctors attending to patients need to encourage them to discuss their main concerns without interruptions or premature closer to enhance the satisfaction and efficacy of the consultation, Simpson. M. et al [22, p.1386]. For that reason, Simpson et al [22] mentions that, this calls for the doctor's efforts to elicit patients' perceptions of the illness and associated feelings and expectations (p.1386). More importantly, most of the crucial diagnostic information arises from the interview and the personal physician skills also determine the patient's satisfaction and compliance and positively influence the patient's health outcomes.

The kind of communication that takes place between a doctor and a patient determines the relationship and level of trust that patients gain from the doctor. The more effective the communication, the better results in terms of trust and the doctor-patient relationship. For that matter, Braithwaite & Schrodt [4] state that interpersonal communication is more than information transmission between two people but the way humans create and negotiate meaning, identity, and relationships through social interaction. Interpersonal communication refers more specifically to communication that occurs between people and creates a personal bond between them, Baxter & Braithwaite [2]. The most important purpose of any doctor-patient communication is to improve the patient's health and medical care. According to Selman L. [21], lack of information coupled with unanswered important questions relating to living with a progressive incurable disease is cited among the major issues for both patients and care givers. More so, patients and caregivers need more information in the key areas of the causes and progression of the disease, its symptoms and treatment. Research by Selman L. et al [21] shows that patients and caregivers state that, “poor provision of information has a detrimental effect on patients’ and caregivers’ ability to cope.”

2.3 DOCTOR-FAMILY CAREGIVER

As much as doctor-patient communication is important to improve the patient's health outcomes, so is doctor-family caregiver communication because with it comes less stress and illness for the caregiver, more efficient use of doctors' time, reduced costs for the health care system, and more satisfaction for all people concerned, Cherlin Emily et al [14]. Doctor-family caregiver communication in cancer patients mostly focuses on the state of the patient's illness, different medical alternatives and expected side effects, communication of the patient's life expectancy and the possibility of using hospice. Right from the time a patient is diagnosed with cancer, a family caregiver is expected to learn new illness, get involved in the new treatment setting with the patient and engage actively in decision making. All these responsibilities entrusted on family caregivers can cause strong emotions equivalent or exceeding those experienced by the patient during diagnosis and treatment, National Cancer Institute USA [31]. Family caregivers normally step in as a patient's backer and main decision maker at the request of the patient and how well the caregiver perform that responsibility may depend on his/her prior relationship with the patient and the level of agreement between them, National Cancer Institute USA [31].

Research done by Kiguli Sarah et al [19] indicate that caregivers want doctors to build relationship with them by demonstrating verbal and non-verbal communication skills such as, maintaining eye contact, using appropriate gestures and voice during communication, and not being judgmental. More so, caregivers want doctors to consider their beliefs, concerns and expectations about their patients' illnesses, and effects on their lives, Kiguli Sarah et al [19]. For that matter, Selman L. et al [21] state that, "specific needs for information vary between individual people, who may rely on healthcare professionals for information on a range of topics depending on their changing needs and preferences" and "communication should therefore be individually tailored according to needs, preferences, and abilities, assessed repeatedly at key points in the disease trajectory. According to Selman L. et al [21], physicians should give information in lay terms.

2.4 LANGUAGE

For any communication to take place, there must be a form of language to be used. Allwood [1] defines language as "an instrument for communication which systematically interrelates thought, behavior, artifacts and aspects of the natural environment." or "an instrument for communication which systematically interrelates physical, biological and psychological properties with social properties." Language and communication consider the use of words, grammatical constructions and texts, and their influence on people's ideas, social relations, actions and exchanges of information. Schyve [20] states that "the language differences themselves are a barrier to effective communication."

Language services, in hospitals, are mostly given by self-declared bilingual health workers and other impromptu interpreters such as family members or friends who have never been trained for medical interpreting, Regenstein [35]. Research done by Regenstein [35], indicates that using unqualified individuals lead to increased medical errors, less effective patient-clinical provider communication and poorer follow-ups and adherence to clinical instructions, as well as possible conflicts with patient privacy rights. According to Allwood [1], language is related to social activities since it is probably the most important instrument of inter-individual coordination, most social activities rely extensively on linguistic communication for their accomplishment. It is through language that doctors communicate important messages such as diagnosis, available treatment and procedures, side effects, and prognosis for patients and their family caregivers for them to make proper decisions. So language is always at the center of any communication.

2.5 BREAKING BAD NEWS

Being able to break bad news is an important skill for all doctors because it often has to be done throughout their career. There are some specific skills needed to successfully fulfill this uneasy task. Fallowfield and Jenkins [15] defines bad news as "any information that produces a negative alteration to a person's expectations about their present and future.". Barclay S. Joshua et. al [13], further defines the term bad news as, "news that results in a cognitive, behavioral, or emotional deficit in the person receiving the news that persists for some time after the news is received" (p. 960). The two definitions indicate that bad news is individually determined and can be understood in many ways, depending on one's personal experience. The inability by oncologists to successfully break bad news to patients and their family caregivers is due to lack of communication skills. Barclay S. Joshua et al [13]'s research reports that communicating bad news creates an everlasting repercussion on the patients' and family caregivers' reminiscences of a medical encounter (p. 960). Bad news situations in cancer patients include (but not limited to), disease recurrence, metastasizing of the disease, failure of treatment to affect disease progression, the presence of irreversible side effects, results of genetic tests and talking about palliative care. Arbabi M. et al [12] research mentions that, “The way of presenting bad news affects the patients’ understanding of the disease, their psychological adjustment to the disease, satisfaction of medical care and level of hope,”

Research done by the National Council for Hospice and Specialist Palliative Care Services [32] reveal that breaking bad news often becomes stressful for doctors and evidence indicates that most times, doctors experience strong emotions such as anxiety, a burden of responsibility for the news and fear of a negative response which can result in a reluctance to deliver bad news (p. 3). "When staff are uncomfortable breaking bad news they can avoid discussing distressing information, such as poor prognosis or convey unwarranted optimism to the patient that may predispose to depression," National Council for Hospice and Specialist Palliative Care Services [32, p. 5]. Effective communication, especially in breaking the bad news results into better outcomes, significant satisfaction, improved understanding, increased adherence to treatment and decreased litigation whereas the reverse can be devastating for patients and families, affecting their psychological adaptation to illness, Barclay S. Joshua et al [13, p. 959]. Not only doctors but also nurses play an important role in breaking bad news, because most of the time they answer questions concerning prognosis and treatment, act as interpreters, arrange meetings and they liaise patients and family caregivers to the doctors. For that matter, patients and family caregivers describe them as a primary source of information and emotional support.

2.6 HEALTH, DISEASE, ILLNESS, SICKNESS

The World Health Organization [42] defines health as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity (p. 100). Health is the condition of being sound in body, mind, or spirit. In cases of people who suffer from chronic diseases such as cancer and, there seems few or no chances of getting whole, the public determines their health basing on the physical conditions. In most cases, doctor-patient communication plays a very important role to improve the health conditions of patient's outcomes. This is because, the patient can freely express his/her mind and feelings to the doctor that in return helps the doctor to give a proper diagnosis and treatment. "The level of psychological distress in patients with a serious illness is less when they perceive themselves to have received adequate information," Simpson. M. et al [22, p. 1385].

To measure ill health conditions, we have used three concepts namely illness, disease and sickness. Their trilogy seems related in a complex way thus the concept of health has been defined and understood in many different ways. Wikman et al [23] defines illness as, “the ill health the person identifies themselves with, often based on self-reported mental or physical symptoms." The illness is described by only minor or temporary problems, however, in some cases self-reported illnesses may include severe health problems or acute suffering that may involve health conditions that limit the person's ability to lead a normal life. On the other hand, a disease is defined as "a condition that is diagnosed by a physician or other medical expert"

Wikman et al [23]. Never the less, many medical diagnoses are based on subjective information from patients concerning pains and feelings, and others based on syndromes and complex interrelations between different organ systems. Sickness is the social role a person with illness or sickness takes or is given in society, in different spheres of life, Wikman et al [23]. In summary, a disease refers to the medical establishment's perspective, a sickness refers to society's perspective and illness is the way the patient perceives their condition.

2.7 CANCER

The World Health Organization [42] defines cancer as a generic term for a large group of diseases that can affect any part of the body. In other words, cancer is a disease of the gene and a gene is a small part of DNA (the master molecule of the cell) which make proteins that are the ultimate workhorses of the cells, Medical dictionary [30]. The mutation (alteration) to the DNA molecule can disrupt the genes and produce faulty proteins. This causes the cell to become abnormal and lose its restraints on growth. The abnormal cell begins to divide uncontrollably and eventually forms a new growth known as a malignant tumor or neoplasm, Medical dictionary [30]. So, the main feature that describes cancer is the sudden creation of abnormal cells that grow beyond their usual boundaries, and then invade adjoining parts of the body and then spread to other organs. This leads to the latter process of cancer which is known as metastasizing. Metastases are the major cause of death in cancer patients, WHO fact sheet [42].

WHO [44] reports indicate that among men, the 5 most common sites of cancer diagnosed in 2012 were lung, prostate, colorectum, stomach, and liver cancer whereas among women the 5 most common sites diagnosed were breast, colorectum, lung, cervix, and stomach cancer. About a third of cancer deaths are due to five leading behavioral and dietary risks namely; high body mass index, low fruit and vegetable intake, lack of physical activity, tobacco use and alcohol use. In the mentioned behaviors, tobacco use is the most important risk factor for cancer causing around 20% of global cancer deaths and 70% of global lung cancer deaths. Cancer causing viral infections such as Hepatitis B Virus (HBV), Hepatitis C Virus (HCV) and Human Papilloma Virus (HPV) are responsible for up to 20% of cancer deaths in low- and middle-income countries. WHO [44] research indicates that, "More than 60% of world's total new annual cases occur in Africa, Asia and Central and South America. These regions account for 70% of the world's cancer deaths." According to WHO [44], annual cancer cases are expected to rise from 14 million from 2012 to 22 within the next two decades.

2.8 CULTURE

Donal Carbaugh (as cited by Enrigue Ruiz, 2009) [11], defines culture as "a system of expressive practices fraught with feelings, a system of symbols, premises, rules, forms, and the domains and dimensions of mutual meanings associated with these." Lustig & Koester [10], define culture as “a learned set of shared interpretations about beliefs, values, and norms, which affect the behaviors of a relatively large group of people (P.30). Culture involves sharing interpretations of beliefs, values, norms and social practices, however, these shared interpretations affect the behaviors of people giving them guidelines on what is important, and what should or not should be done, and thus establishing predictability in human interactions. To relate this to our study, the way patients and family caregivers interact with the doctors is partly influenced by their cultural background. More so, culture plays a big role to influence patients’ health seeking behaviors. Davis [5] defines culture as, “The pattern of shared beliefs and values that give members of an institution meaning, and provide them with the rules for behavior in their organization.”

Hofstede [8] claims that “Culture is the collective programming of the mind which distinguishes the members of one human group from another” (p.24). According to Schyve [20], cultural differences are usually associated with language differences that hinder effective communication He argues that it is not obvious that a person who is born in the same society and speaks the same language shares all the features of a common culture. “Therefore, there is a risk of either underestimating the effect of cultural differences or of stereotyping individuals by their culture” Schyve [20].

2.9 COUNTRIES OVERVIEW: UGANDA AND ETHIOPIA

2.9.1 Uganda

Uganda, officially known as the Republic of Uganda is a landlocked country in East Africa. The country is bordering east by Kenya, north by South Sudan, west by the Democratic Republic of Congo, southwest by Rwanda and north by Tanzania. Uganda is the world’s second populated landlocked country after Ethiopia and takes its name from the Buganda kingdom, which encompasses a large portion of the south of the country including the capital Kampala. The southern part of the country has a substantial portion of Lake Victoria, shared with Kenya and Tanzania, situating the country in the African Great Lakes region, Wikipedia [45]. The country lies within the Nile basin and has a varied but equatorial climate. Uganda ranks among the poorest countries in the world, with 37.7% of the population living on less than $1.25 per day. Poverty remains deep-rooted in the country's rural areas, which are home to more than 85 percent of Ugandans.

The country has diverse cultures with around 40 languages, but the official language is English and Swahili though Luganda, a central language is spoken widely across the country. Uganda has many kingdoms like Buganda, Busoga, Bunyoro, and Toro. Ugandans are distinctively friendly, and religion plays an important part of their daily life. The 1991 -2002 population census indicate that Catholics were the largest religious denomination with 42% of the population, followed by the Anglicans with 36%, Moslems with 12% and the Pentecostals with 4.6%, Uganda Population and Housing Census, Main Report [40, p.11]. Ugandans are strong in their faith but find it not offensive to hold to some traditional beliefs in that in times of trouble, people may also consult a local oracle or healer in addition to praying to God. There are many active shrines where people go to consult the spirits. Life expectancy at birth is estimated to be 54.46 according to Central Intelligence Agency (CIA) World Factbook published in 2014 [25].

It is in Uganda where the first combination chemotherapy to treat cancer occurred, and the Epstein-Barr virus was first discovered from a tumor sample removed from a child with lymphoma in Uganda in 1958. This was the first human cancer found to be caused by an infectious disease. Uganda has a distinctive set of conditions in which to investigate infection-related cancers [39]. With a population of 37 million, it has one of the highest rates of cancer in the world. According to Fred Hutchinson Cancer Research Center, the two hardest cancer hit groups are children under the age of 12 and middle-aged adults. The center indicates that one-third of patients diagnosed with cancers is infected with HIV and that six out of ten of common cancers in Uganda are caused by infectious diseases. This makes the country an ideal environment for learning about the etiology, biology, treatment and prevention of infection-associated cancers that can lead to saving thousands of lives.

Report from Kampala Cancer Registry report [29], shows that in males, Kaposi sarcoma was the most commonly diagnosed malignancy with (606 cases) between 2007 and 2009, followed by prostate cancer (236 cases), followed by non-Hodgkin lymphoma (181 cases), esophagus

(118 cases) and liver cancer (107 cases). Cancer of the cervix uteri is the most commonly diagnosed malignancy in women, with 492 cases in three years followed by Kaposi sarcoma (429 cases), breast (317 cases), non-Hodgkin lymphoma (117 cases) and liver cancer (93 cases), The cancer registry statistics cover only the area of Kyadondo County, which comprises Kampala district and part of Wakiso district. Apart from Kampala registry report statistics, the total number of registered cancer cases country wide is not available. Uganda Cancer Institute registered 1899 patients in 2013 and 2265 patients in 2014. The institute registers between 8 to 17 new cases every week from Monday to Friday and on average, 50 new cases are registered every week and 200 new cases every month.

Uganda Cancer Institute [39] is composed of five sections namely; the out-patient department (OPD), the lymphoma treatment center (LTC), the solid tumor center (STC), the private wing and the children's ward. The lymphoma treatment center was established following a corporation of Makerere University Medical School, Ministry of Health (MOH) and the National Cancer Institute (NCI) in the USA. The genesis of the idea began in 1965 in Kampala the capital city of Uganda, during a meeting regarding the treatment of Burkitt's lymphoma. The lymphoma treatment center (LTC) was dedicated to Denis Burkitt, the first surgeon who described the unusual children tumor that targets the jaw and the abdomen in the 1950s. Burkitt described that this particular cancer could be cured with chemotherapy other than surgery. The lymphoma treatment center was opened in August 1967 with 18-bed ward in the old Mulago hospital. Its success led to the establishment of a sister unit called the Solid Tumor Center (STC) in 1969 to enable additional investigations in adult cancers especially hepatocellular carcinoma, Kaposi's sarcoma, and malignant melanoma to be carried out. The two units along with the associated laboratories form the Uganda Cancer Institute (UCI).

2.9.2 Ethiopia

Ethiopia is officially known as the Federal Democratic Republic of Ethiopia, and it's situated in the Horn of Africa with estimated 90 million inhabitants. The country is bordered by Eritrea to the North, and northeast Djibouti and Somalia, to the East Sudan and South Sudan to the West and Kenya to the South. Ethiopia is the most populated landlocked country in the world and ranks as the second most populated nation in the continent of Africa. It is a multilingual nation with about 80 ethnic groups and 90 individual languages, Wikipedia [46].

Ethiopia is the only country in Africa that has never been colonized by Europeans. The country is the first independent African member of the 20th century League of Nations and United Nations, and it is the birthplace of coffee bean. Ethiopia has different natural features like fertile land in the west, forests, various rivers, the largest cave in Africa and the world's hottest place called Dallol that is located in the north. According to UNESCO, Ethiopia has the highest number of heritage sites in Africa. The country has a unique calendar that is seven years and around three months behind the Gregorian calendar, and time is also counted differently in Ethiopia compared to other countries. Unlike other countries considering the day to begin at 6 AM, Ethiopia's day begins at 12 AM with the sunshine throughout the year. To convert Ethiopian clock to Western clocks, one needs to add or deduct 6 hours to the Western time. (Wikipedia). In 1980's, Ethiopia suffered from severe famine and the situation worsened by civil wars, however, the country has now recovered and has become one of the fastest growing economies in East and Central Africa, Wikipedia [46]

The 2007 Ethiopian population and housing census shows that 43.5% of the population are Orthodox Christians, 18,6% are Protestants, 0.7% Catholics, and 33.9% Muslims. Traditional believers account for only 2.6%, and other religious groups take 0.6%, Federal Democratic Republic of Ethiopia Population Census Commission report [26]. According to the Central

Intelligence Agency (CIA) World Factbook published in 2014 [25], the life expectancy at birth in Ethiopia is 60.75. The World Health Statistics (2014) indicate that three physicians are expected to attend to 10,000 patients. Non-communicable diseases including cancer have just gained government attention as a public health issue in the recent past years but before the country's health care resources were released to treat and prevent diseases such as malaria and diarrhea. It is recent that the government has realized the growing burden of cancer in the country. According to the International Network for Cancer Treatment and Research (INCTR) [38], the current information available about cancer in Ethiopia indicates that there are more than 60,000 cases of cancer reported each year, but available data is limited. Many cancer patients in Ethiopia do not seek medical treatment and the few who do, may not be referred to the sole cancer referral center. This center known as the Black Lion Hospital and located in Addis Ababa is treating only one percent of these patients, Wikipedia [46].

Black Lion Hospital in association with Addis Ababa University's School of Medicine, is a teaching center for undergraduate and postgraduate medical students, dentists, nurses, pharmacists, laboratory technicians, and others who take care of the country's health problems, The International Network for Cancer Treatment and Research [38]. Addis Ababa Population Based Cancer Registry (AAPBCR) [24] is the first population based cancer registry in the country and was founded in September 2011 at Radiotherapy Center at Black Lion Referral Hospital. It registers patients who reside in Addis Ababa city only. From September 2011 to August 2014, a total of 5701 cancer cases were registered. Among the registered, 3820 (67%) were females and 1881 (33%) males, Addis Ababa Population Based Cancer Registry [24].

According to Black Lion Hospital Cancer Institute, the most common adult cancers are: cervical cancer, breast cancer, sarcoma, head and neck cancer, oesophageal cancer, colorectal cancers, liver cancer, non-Hodgkin lymphoma and skin cancer. Common children's cancers are leukemia, lymphoma, Retinoblastoma, Wilms tumor (nephroblastoma) and osteosarcoma, Black Lion Hospital Cancer Institute [3]

3. RESEARCH METHODOLOGY

We used a combination of qualitative and quantitative methods to collect data. Partially, different procedures were used depending on the requirements of the research and ethics committees of Uganda and Ethiopia. We used interviews, video recordings of medical consultations and questionnaires to collect data for our thesis. Below we present qualitative and quantitative ethical considerations and approvals, participants′ eligibility and selection, recruitments and consents, and data collection methods.

3.1 QUALITATIVE RESEARCH METHODS

With qualitative data, we extracted meanings, describe and understand experiences, ideas, beliefs and values. "Qualitative research is an approach that allows you to examine people's experiences in detail, by using a specific set of research methods such as in-depth interviews, focus group discussion, observations, content analysis, visual methods and life histories or biographies." Hennink et al [7, p. 9]. To get a deeper understanding of the role of communication in cancer consultation meetings, our qualitative research methodology included in-depth interviews and video recordings with a focus on doctor-patient communication and doctor-family caregiver communication. In-depth interviews enable us to understand participants' experiences with the nature of communication.

3.1.1 ETHICAL CONSIDERATIONS AND APPROVAL

Uganda

This study was approved by the Department of Applied IT at Chalmers University of Technology / University of Gothenburg and Mulago Hospital Research and Ethics Committee (REC). It was subjected to the regulations governing research in Uganda as set by the country's National Council of Science and Technology. The committee stamped all interview questions and consents papers as its research policy demands and it is only the stamped documents that were allowed to be used during the study. After REC approval, another permission was obtained from Uganda Cancer Institute (UCI) to collect the necessary data. UCI viewed the study as sensitive since it involved video recordings stating that it can cause legal implications to the institute and so requested for a photocopy of all signed consents for each of the participants enrolled in the study and submit these copies to the research office in a file which would later be transferred to UCI regulatory office. UCI also requested for a certificate from National Institutes of Health (NIH) Office of Extramural Research about "Protecting Human Participants", which was submitted after completing an online course about Protecting Human Participants. An agreement to abide by UCI conditions was signed before permission was granted to enroll participants.

Ethiopia

The study proposal was reviewed and approved by the Department of Applied IT at Chalmers University of Technology / University of Gothenburg to conduct the study in Ethiopia. In order to obtain the approval from Black Lion (Tikur Anbessa) Referral Hospital, cancer institute Addis Ababa- Ethiopia, the author had personal meetings and discussions with the Dean of Addis Ababa University Black Lion Hospital. After few days' meetings and discussions, the study proposal was approved by the dean and the approval was transferred to Medical director who stamped and signed it before the commencement of data collection.

3.1.2 ELIGIBILITY IN SELECTION OF PARTICIPANTS

Uganda

The eligibility was based on participants' ability to communicate in English or Luganda and aged 18 years and above. All patients who had been diagnosed with cancer and were undergoing part of their initial treatment at Uganda Cancer Institute (UCI), Mulago Referral Hospital were viewed as eligible for the study. All family caregivers to cancer patients and all doctors working with cancer patients both oncologists and other specialized doctors were eligible for the study. Potential candidates were identified from the outpatient department, solid tumor ward, lymphatic treatment center, private wing and children′s ward. From the children′s ward, only family caregivers were eligible for the study because only participants from 18 years and above were viewed as potential for the study. The author sought approval from the attending physician before potential candidates were asked to participate in the study.

Ethiopia

All patients who had been diagnosed with cancer from 18 years and above and undergoing part of their initial treatment at Black Lion (Tikur Anbessa) Referral Hospital, cancer institute were eligible for the study. These patients had to communicate in either English or Amharic (Ethiopian official language). The author identified potential candidates from the outpatient department (OPD), oncology ward, and day-care. Senior oncologist and resident oncologist at Black Lion (Tikur Anbessa) Referral Hospital, cancer institute and family caregivers above 18 and who follow their patient to the doctor.

3.1.3 RECRUITMENT AND CONSENTS, PARTICIPANTS SELECTED FOR THE STUDY

Uganda

After being introduced to the participants by UCI study coordinator, the research was described briefly to participants in order to obtain their oral consent after which a detailed description of the study was discussed to those participants who agreed to participate. After a disclosure of the purpose of the study and a description of each of its components, the process of recruiting participants began. Participants were recruited from outpatient department (OPD), lymphatic treatment center (LTC), solid tumor ward (STC), private wing and children ward.

Table 1; Study population at Uganda Cancer Institute.

Participants	Study population	ID code	ID color	Gender	Those participated	Did not participate
Doctors	12 doctors	Dr. 001 -	Green ID stickers	11 males 1 female	10 males 1 female	1 male 0 female
Patients	40 patients	Pt. 001 -	Blue ID stickers	11 males 18 females	11 males 21 females	7 males 1 female
Family caregivers	25 caregivers	FCG. 001 -	Purple ID stickers	10 males 15 females	7 males 14 females	3 males 1 female
Doctor-Patient-Family caregiver	22 video interactions	Dr.&Pt. 001 -	Maroon Id stickers	14 males 10 females	14 males 10 females	0 female 0 female

The different categories of participants were given identity numbers that were made in different colors according to each category to simplify handling of data. The doctor participants were identified with green identity stickers with numbers written on from 001 to 012. The patient participants were given blue identity stickers with numbers from 001 to 040. The family caregivers were identified by purple identity stickers with numbers from 001 to 025 and the video participants were identified by maroon identity stickers with numbers ranging from 001 to 024. All these identity stickers were attached on the respective consent forms. In total, the author conducted 67 informant interviews.

Before obtaining consent from the participant, the author explained in details the purposes of the data collection activities and how data will be used, the importance of the participant's participation, the right to withdraw at any time of the study, the confidentiality of the data and that all participants remain anonymous in this research. All this information was communicated effectively to the participants in English and Luganda for those who don't speak English, and all technical terms were translated to best of the participant's understanding. All the participants signed a written consent prior to the interview. The interviews were conducted within a period of 5 weeks (every day- five days a week) at Uganda Cancer Institute, Mulago Referral Hospital.

Ethiopia

The head of oncologist department introduced the author to other oncologists first: they in turn introduced the author to eligible patients and family caregivers. The author described and discussed the purpose of the study in details to the participants. After elucidated the study purpose and each of its components, the author obtained written consent from patients to videotape their consultations and oral consents to interview the doctors, patients and family caregivers.

Table 2; Study population at Black Lion cancer institute

Participants	Study population	ID Code	Gender	Those participated	Did not participate

Doctors	16 doctors	Dr.m1/Dr.f1	11 males 5 females	11 males 5 females	0
Patients	54 patients	Pt.m1/Pt.f1	20 males 34 females	20 males 34 females	0
Family caregivers	22 family caregivers	Fcm1/Fcf1	11 males 11 females	11 males 11 females	0
Doctor-patient-family caregiver	22 video interactions	-	11 males 11 females	11 males 11 females	0

Participants were informed about the purpose of the study before giving their consent to participate. They were informed of their right to withdraw from the study at any time during the interview and videotaping. The anonymity of participants has been respected and were also guaranteed that the data obtained from them would only be used by doctors and researchers, only for the purpose of research and teaching, assessing or learning about consultation techniques which will be for the long term benefit of patient care.

3.1.4 VIDEO RECORDINGS FOR MEDICAL CONSULTATIONS

Uganda

Prior to recording, doctor participants were contacted by telephone and face to face inviting them to participate in the study. Upon agreement, their patients and their family caregivers were informed verbally about the study and were requested to participate. Patients who accepted to participate signed the consent form for video recording before the consultation was recorded. The consultation was recorded only if the doctor and patient and family caregiver if present at the consultation accepted to participate. Participants first gave a verbal consent, followed by a written consent that was signed before and after the recording. The consent forms were written in English and verbally translated in Luganda for patients who do not speak English. After obtaining consent from both parties, the camera was set in the doctor's room and was remote controlled. In total, the author recorded 24 videos and the recordings were conducted within a period of 5 weeks at Uganda Cancer Institute, Mulago Referral Hospital. Total recording time of all the videos is 5:16:08.

Ethiopia

Participants for the video recording were doctors, patients and family caregivers who were all informed about the study and were requested to participate. Doctor participants, who were willing to participate in the study gave their verbal consents. Patient participants who were willing to participate in the study signed the consent form for video recording before and after the consultation was recorded, and family caregivers gave verbal consent to participate. The consent forms where written in English and translated in Amarinja for patients and their family caregivers. The consultation was recorded after obtaining consent from both parties and it took place in outpatient department and inpatient ward. The author was present only to put on and switch off the camera in the consultations. The author recorded 22 videos in total and the total recording time of the video is 2:21:17. The recordings were conducted at Black Lion cancer institute in a period of 5 weeks.

Table 3; Video recordings for doctor, patient and family caregiver consultation meetings

	Study population	Gender	Participants engaged	Time
Uganda	24 video recordings	14 males & 10 females	24 video interactions	5:16:08
Ethiopia	22 video recordings	11 males &11 females	22 video interactions	2:21:17

3.1.5 OVERVIEW OF DATA COLLECTION FROM UGANDA AND ETHIOPIA

Table 4; Ethical approvals in each country

Uganda	Ethiopia
1. Approved by Mulago Research and Ethics committee (MREC)	1. Approved by the department of Applied IT at Chalmers University of Technology / University of Gothenburg.
2. Permission granted by Uganda Cancer Institute (UCI)	2. Permission granted by Black Lion Referral Hospital, cancer institute Addis Ababa Ethiopia.
3. Obtained certificate for Protecting Human Participants from NIC	3. Data collected from Black Lion referral hospital, cancer institute
4. Data collected from Uganda Cancer Institute (UCI)	4. Obtained written and oral consents from participants.
5. Obtained written consents from participants	5. Participants were identified with numbers.
6. Participants were identified with numbers written on ID stickers	6. Data collected within a period of six weeks
7. Data collected within a period of five weeks	

Table 5; Study population.

Uganda	Ethiopia
12 Doctors recruited; 11 doctors participated (10 males, 1 female), 1 withdrew	16 Doctors recruited; (11 males and 5 females)
25 Family caregivers recruited: 22 participated (7 males, 15 women)	22 Family caregiver recruited; (11 males and 11 females)
40 Patients recruited; 32 participated (11 males, 21 females).	54 Patients recruited; (20 males and 34 females)
Participants were recruited from; Outpatient department (OPD), Lymphatic Treatment Center (LTC), Solid Tumor Center (STC) & Private wing and children's ward at Uganda Cancer Institute	Participants were recruited from; Out patients Departments (OPD), Day Care and Oncology ward at Black Lion (Tikur Anbessa) cancer institute
24 videos recorded; 20 transcribed	22 video were recorded and transcribed 22 videos.
Patients had the following kinds of cancers; Kaposi's sarcoma, cervical, breast, prostate, leukemia, adenocarcinomas, esophagus cancer, Hodgkin lymphoma, choriocarcinoma, lung, tongue, stomach and kidney cancers	Patients had the following kinds of cancers; breast, cervical, intestine, rectal, oral cavity, esophageal, lacrimal gland, nasopharyngeal and Hodgkin lymphoma

3.1.6 INTERVIEWS

Interview questions

The content of the selected questions in the interviews were prudently matched to the research questions in order to elicit the necessary data.

The questions focused on the following issues:

Experience of communication

Concerning the general experience of communication, the doctor was asked a). Do you meet cancer patients? b) If yes, what kind of cancer do they have? c) How do you experience your communication with cancer patients? d) What do you think works fine and what is more difficult?

The same questions were asked to the patients and family caregivers with a slight change on question ′a′ and ′b′. The questions above are related to research question (1) subsection (a)

Breaking bad news

The issue of breaking bad news, the doctor was asked a) Do you happen to break bad news? b) If yes, how do you usually break bad news to cancer patients? c) What problems are related to this? d) What happens after you deliver bad news to patients? e) How do you manage their reactions? f) What information do you consider appropriate to give to patients?

The patients were asked: a) How did you know about your diagnosis? b) How did you experience the way this information was delivered to you? c) Where you together with anyone? d) What was problematic? e) How did you manage your reactions? f) Were you satisfied with the way the doctor communicated to you about your condition? g) What information do you consider appropriate to receive from the doctor?

The family caregivers were asked: a) How did you know about your patient′s diagnosis? b) How did you experience how this information was delivered to you? c) Where you together with your patient? d) What was problematic? e) What happened after the doctor delivered the bad news? f) How did you manage your and your patient′s reactions? g) How much time did the doctor spend on it? h) What information do you consider appropriate to give to a patient and to you?

The above questions are related to research question (1) subsection (b)

Language usage

About language usage, the doctors were asked a) while talking to patients and family caregivers, do you consider what language you use? b) Do you use technical language or a layman language? c) Do you experience any lack of understanding due to language barrier? d) If yes, how do you handle it?

The patients were asked the same questions except ′a′ While doctors talking to you, do they use technical language or layman language? The same questions apply to the family caregivers. The above questions are related to research question (1) subsection (c)

The opinions about the role of communication

Doctors, patients and family caregivers were asked, a) what do you think is the role of communication in cancer consultations? b) Have you ever encountered poor communication with any cancer patients or the family caregivers? c) If yes, what impact did it cause? d) What do you think hinders effective communication between doctors and patients and family caregivers and how do you overcome these problems?

The above questions are related to research question (1) subsection (d)

The cultural issues involved

The doctors were asked; a) Do you put into consideration the cultural issues related to cancer while talking to patients and their family caregivers? The same question was paraphrased and asked to patients and family caregivers
The above questions are related to research question (1) subsection (e)

3.2 QUANTITATIVE RESEARCH METHOD

With a quantitative data collection method, we measure variables and verifying existing theories. We focus on data to generate new hypothesis based on the results of data collected about different variables. With quantitative research, we are able to measure, count, quantify a problem and answer questions such as how much? How often? What proportion? and relationships in data. "Quantitative research, quantifies a research problem to measure and count issues and then to generalize these findings to a broader population" (Hennink et al, 2011:16). With quantitative research methods, we used questionnaires in order to collect the statistics and variables for our research.

3.2.1 ELIGIBILITY UGANDA AND ETHIOPIA

In both Uganda and Ethiopia, all members of the general public both male and female aged 14 years and above who were able to read and understand English language, were eligible to participate in the study.

3.2.2 RECRUITMENT

In Uganda, the respondents were picked at random from public places such as markets, schools, government organizations and friends within Kampala city. Out of the 150 questionnaires expected to be served to respondents, 134 were completely filled, two were half way filled and 14 were not returned by respondents. The questionnaires were served within a period of eight weeks within Kampala city and its suburbs. The aim and purpose of the study were explained to all participants prior to the consent. A verbal consent was obtained from all respondents and were also informed of their right to withdraw from the study anytime.

In Ethiopia, the respondents were picked randomly from places such as cafeteria, restaurants, high schools, universities, family and friends in Addis Ababa. 150 questionnaires were given to the respondents during different time within a period of eight weeks. Most of the questions in the questionnaires were answered. Respondents were elucidated about the purpose of the study before giving their consent to participate. They were informed of their right to withdraw from the study at any time and verbal informed consent was sought from all the respondents before they started filling the questionnaire.

3.2.3 QUESTIONNAIRES

Public knowledge and awareness was elicited in a questionnaire, which contained questions about cancer, with a focus on question 1, 2, 3, 8,10, 11,16 and 17 (See appendix 27, 28, 29 &31).

3.3 RELIABILITY AND VALIDITY

The examination of trustworthiness plays an important role to verify reliability in qualitative research. Seale 1999 cited in Golafshani [28], indicate that the "trustworthiness of a research report lies at the heart of issues conventionally discussed as validity and reliability" (p.601) To disclose the consistency of reliability and validity in qualitative research, Golafshani [28, p.601-602] assert that, "Since there can be no validity without reliability, a demonstration of the former [validity] is sufficient to establish the latter [reliability]."

Since reliability in research data refers to the degree to which an assessment consistently measures whatever it is measuring, we have been consistent in handling our data in that we used specific questions that were answered by participants. The interviews were open-ended and participants were free to discuss the questions and to express their opinions in an uninhibited manner while being led to remain focused to the topic of interest. Digital audio recordings were done for all interviews and the interviews were done until data saturation was reached. In total, we conducted 156 key informant audio interviews and 45 video recordings. All participants were picked at random and there was proper care and persistence in the allocation of controls.

The selected cancer institutes are the sole cancer referral centers in both countries, treating cancer patients and having doctor-patient and doctor-family caregiver communication. This makes the research valid and reliable because it is possible for other researchers to perform exactly the same experiment, under the same conditions and generate the same results.

In quantitative research Joppe 2000 as cited in Golafshani [28] defines reliability as: The extent to which results are consistent over time and an accurate representation of the total population under study is referred to as reliability and if the results of a study can be reproduced under a similar methodology, then the research instrument is considered to be reliable (p. 1) Validity regulates if the research candidly measures that which it was intended to measure or how truthful the research results are. Joppe 2000 as cited in Golafshani [28] mention that a high degree of stability indicates a high degree of reliability, which means the results are repeatable. In our quantitative research, we randomly picked 280 respondents from Kampala- Uganda and Addis Ababa- Ethiopia and served them with the same questionnaires. Basing on that, the results of the research could be generalized.

According to Joppe 2000 as cited in Golafshani [28], we regard this research as reliable and valid because the method used for the empirical and theoretical study certifies reliability and the study measures the research results.

3.4 RELEVANCE

The research unveils the role of communication in doctor-patient and doctor-family caregiver interaction in cancer consultation meetings and the level of public awareness of cancer disease in Uganda and Ethiopia. With this research, doctors are able to grasp the kind of information appropriate to give to patients and their family caregivers, the best way to deliver it and the impact good communication causes on patients and their family caregivers. This will help physicians in Uganda and Ethiopia to adopt effective communication skills when interacting with patients and their family caregivers. In both countries, the study gives a hint of public perception of cancer and this will enable the respective governments to sensitize their people about cancer disease.

3.5 LIMITATION

Since the research is about a sensitive topic touching personal health issues, patients, and family caregiver participants were to a small degree hesitant to express themselves freely fearing to lose their relationship with the doctors or interfere with their treatment plan in case the information leaks. So, we believe, some of these participants just kept on being positive in order to maintain the relationship they have with doctors. Doctor participants were not comfortable of discussing their interpersonal communication skills and had very limited time due to high work demand. In our video recording, we believe that some doctors didn’t portray 100% of their communication behaviors because they knew, they would be evaluated by the researchers. There was limited space to conduct interviews as most of the rooms were occupied by doctors, patients and family caregivers. During video recordings, we experienced a lot of interruptions from attending nurses, other patients and family caregivers and in some cases noise from outside would override recorded video sound.

4. RESULTS

This chapter unveils our research findings as obtained from the participants′ interviews, video recordings and questionnaires. The data has been summarized in different themes so as to justify the research and report the case findings. The findings are based on the participants′ experiences. The country results are presented in two separate sections.

4.1 Uganda

4.1.1 RQ1 (a) Communication Experiences

Doctor-patient and doctor-family caregiver communication is important in the medical industry; it cannot be substituted but rather done by the physicians themselves. This is because most of the important diagnostic information emerges during the interaction between the doctor and the patient and family caregivers respectively.

Doctors' experiences: - Influx of patients limits time for interaction

Doctor participants at Uganda Cancer Institute (UCI) describe their communication experiences as fair though they meet some challenges. They attributed the challenging part to the overwhelming influx of patients which limits the time they can spend with each patient:

"I would say overall fair, probably the challenge we have here is that there are so many patients so we are not able to exhaustively communicate and tell them all about their disease and answer their questions… but we try to give them the basic facts about the disease, the stage, the treatment plan, the expected side effects of the treatment basically that." (Dr. 004)

Patients and family caregivers do not ask questions

Another challenge is the inability of patients and caregivers to ask questions. Doctors allege that patients do not ask questions even when they are expected to do it:

"Communication with cancer patients has two main components, there is when you give them information and there is when they ask for the information. So when they come in, we talk to them and then you expect them to ask questions. The challenge I get is, patients do not ask as many questions as possible, they are timid, they don't want to know, they avoid asking questions that maybe be related to prognosis," (Dr. 007).

Lack of understanding

Patients and family caregivers' inabilities to take in the given information is still a stumbling block in cancer consultation meetings:

"Before I communicate with any patient, I first initiate a relationship with him/her and during the process I gauge their level of education and understanding. This helps a lot to know the best way I communicate with the patient so that we understand each other. My biggest aim of communicating to my patients is to understand each other. However, in some patients, it is very hard to make them understand however much you break the language to suit their level of understanding, they don't understand. It's the biggest challenge we have," (Dr. 011).

Another doctor claims that it is not clear if the patients understand but just do not always follow what the doctor asks them to do;

"There are some patients you explain to them, they seem to have understood, but they go and do the contrary, maybe they don't come exactly the day you told them to come... You communicate to them well, but sometimes they don't follow exactly what you say," (Dr.009).

Language barriers

Doctor participants cited language hurdles as another challenge faced during consultation meetings:

"There is always a big challenge in communication, you know here we have so many ethnic groups with various languages and this is the only referral center for cancer care so we always see people from all over the country and even beyond. We definitely have challenges in communicating to them and their caretakers… I think the key challenges there is that, we are not multi-linguistic. You can be able to know five or six languages but this is a country of like 52 different tribes so really cutting across all that is a very big challenge, so we don't actually comprehend some of their languages and we have to use a third party to interpret…" (Dr. 001).

Patients and family caregivers' experiences

Doctors communicate well

The majority of cancer patients and family caregivers at Uganda Cancer Institute describe doctors' communication as good basing on the positive attitudes demonstrated both verbally and nonverbally during the consultation meetings. They claim that positive attitudes by doctors help them to feel free with the doctors which in return enables them to understand all the given information and also be able to ask questions concerning their lives. They narrate their experiences below:

"Communication is so good because, doctors are always concerned about my health and they give me time to express myself. They ask me how I feel, … so I feel ok with them. They are friendly. I have not seen any rudeness in doctors since I started treatment. The doctors I have met here are always calm," (Pt. 006).

"Communication has been fair. Doctors are so concerned about patients' well-being. They are approachable. You can ask the doctor about your condition and then he explains well to you. I feel free from anxiety and I understand the information given to me well," (Pt. 009).

The above interview extracts exemplify doctor's attitudes towards patients or their family caregivers, establish a doctor-patient or a doctor-family caregiver relationship. It helps the patient and the family caregiver to be free from anxiety which affects their understanding and their ability to ask questions when communicating to the doctors.

In the excerpt from a video-recording presented below, the doctor successfully explains the treatment procedure to the patient and her family caregiver and they seem to understand each other.

Excerpt (1U)

1. Doctor: Now, madam
2. Patient: Mmm
3. Doctor: The reason we asked you to do a CT scan
4. Patient: Yes, doctor
5. Doctor: Is to locate the disease and how far it has spread. We use CT scan because it is more clear and reliable than other tests we can possibly do. According to the test results, you have a small tumor in the bladder.
6. Family caregiver: Yes doctor
7. Doctor: The tumor is still in one place and has not spread further. It is a bit large, approximately two centimeters long so we can do the surgery and remove it. Have you understood?
8. Patient: Mmm
9. Doctor: So you are going for surgery, have you understood?
10. Patient: Yes, I have understood
11. Doctor: During the surgery, we use a surgical instrument called cystoscope. Have you ever heard of it?

12. Patient: I have never heard of it, doctor.
13. Doctor: That instrument ….
14. Family caregiver: Cysto…
15. Doctor: Cystoscope
16. Family caregiver: Cystoscope
17. Doctor: Eee, a cystoscope is a surgical instrument that is inserted through the urethra into the bladder. You know the urine path; it is where this cystoscope will be inserted into the bladder. The cystoscope has a light on top which helps to give light inside the bladder and it also has scalpels (surgery knives), that operates and at the same time radiates. The process is similar to that of a biopsy but this time they are going to remove the tumor. After the tumor is removed, we radiate the place where the tumor has been so that it doesn't reappear. Still, that is not enough since cancer has a tendency of re-appearing so you will be coming back here every after three months and we do the scan, just to be sure the tumor is not back. Many patients don't come back after the surgery is done because they feel much better, by the time they think to come back when cancer has spread to much. Cancer is not reliable, it reappears, they can operate and you feel ok and you think it has vanished but in most cases it reappears... Have your thyroid glands ever been examined?
18. Patient: No
19. Doctor: Eee, when you swallowed I saw as if there is a tumor but when I touch there, I don't feel it. Ok, do you have any questions?
20. Family caregiver: No
21. Doctor: Have you understood all that we have talked about?
22. Family Caregiver: Yes, we have understood
23. Doctor: So now we are going to refer you to a radiologist to do the operation. Are you ready?
24. Family caregiver: Yes, doctor
25. Doctor: Ok. Did the nurse take your blood pressure?
26. Family Caregiver: Yes, doctor
(Dr. & Pt. 001)

It can be seen in the interaction that the patient, family caregiver, and the physician give feedback to each other and control the level of understanding (7, 8, 9, 10). The doctor tries to explain the technical terms in order to suit the patient's and her family caregiver's understanding (11, 12, 13, 14, 15, 16, 17). He asks many times the patient and her family caregiver if they have understood (7,9, 21) and he gives them a chance to ask questions (19). In the excerpt, the family caregiver seems to dominate the patient in the interaction and she is answering most of the questions directed to the patient. Since the family caregiver spends more time with the patient than the doctor, it is appropriate for her to be very attentive so that she understands all the information.

Work overload as a reason for communication problems

Similar to the doctors, the patients mention that work overload for doctors negatively influences communication. Some patients and family caregivers state that the doctors' communication would have been better but the influx of patients exhaust doctors which negatively affect their communication skills, as one patient and family caregiver explains below in an interview extract:

"Some are rude, but others are good. I think they over work because the number of patients is high and sometimes handling patients' files is not easy for them. Sometimes files get lost and tracing them is problematic," (Pt. 004).

"Doctors really try to communicate well with patients and their family caregivers but sometimes they are overwhelmed by the massive number of patients. I think they get so tired that is why sometimes they fail to communicate well, but overall I can say, they communicate well," (FCG 010).

Since Uganda Cancer Institute still uses paper filing system, patients' files usually get lost or misplaced which delay patients' consultations with the doctors and treatment. Sometimes, patients are forced to pause their treatment and restart after sometime which disrupt their treatment outcome.

Communication skills should be improved
The minority of patients and family caregivers view doctors' communication as lacking, basing their judgment on the kind of information doctors give to them, the manner in which this information is given to them and the doctors' inability to answer their questions. They describe nurses as rude and unfriendly.

" Some doctors are good, but others are so rude. When you ask them a question, they don't listen nor respond. They don't give you enough time even when you need help from them," (FCG 001).

"They used to communicate so well, but nowadays, they are so rude. They used to give us counseling, and explain in details what we are supposed to do but now, it's different," (FCG 016).

It appears that the patients and family caregivers judge doctors' communication competencies basing on their attitudes towards them and they seem not satisfied with the information they give to them.

4.1.2 RQ1 (b) Doctors -breaking bad news

Doctors:- Break the bad news in steps
Some doctor participants at Uganda Cancer Institute report breaking bad news in steps and prepare their patients for every step of the bad news. Breaking bad news is one of the most difficult tasks for doctors because the medical education system gives them little formal preparation for this heavy task. Breaking bad news comes even harder when it comes to serious diseases such as cancer especially when it has reached it advanced stage. It is coupled with emotions and it can have a profound effect on the patient′s psychological well-being. Sometimes if not handled well, the patient can die because of shock, the doctors say:

"Well, we break bad news in steps, right from the time somebody comes in here, we try to prepare somebody's mind about the eventualities that may occur specially to do with cancers that have difficult treatment outcomes, especially with the cancers that are advanced at the beginning where you know that the treatment intend may not actually be cure. So you tend to introduce the idea that this cancer has reached far or this cancer is a difficult one to treat, as we are going through the treatment we expect some challenges, we expect some resistant to whatever interventions we are going to put. That gives us the way that every time we meet with them, we reaffirm that we may anticipate challenges in future so when that time comes when you are there to tell them that, 'we have reached the end of the road, we can't proceed any more', they already have a degree of preparedness because over time you have been hinting to them that I'm not guaranteeing win here," (Dr. 001).

It appears that the doctors are careful when breaking bad news and they are aware of the eventualities in case they break the bad news to the patient at once. This shows how they care about patients' feelings and well-being even though they can't change the fact that some cancers are not curable.

Some doctors break bad news in a progressive manner and others do it at once if the patient asks and desires to have the information:

I do it in a progressive manner. I don't do it at one session. I start, introducing it at the first session, the first visit we talk about the disease and the extent. We don't talk about the outcomes at that point. And then during the second visit, the patient is coming back with the reports, after the investigations have been done and at that point we talk about the extent of the disease and its implications and we hint on the outcomes and its treatment and subsequently, on the third or fourth visit, at that time we probably start to talk about the *prognosis and the intent. By the end of the treatment, the patient should really know their prognosis and the outcomes but that changes if the patient is asking questions. If the patient wants to know, and we usually encourage them to ask, if they are asking, we usually give them the information right away. If they are not asking, we try to probe them to ask and if we see that they are not ready, we don't give the information at that point. We do it gradually. (Dr. 007)*

In the above two interview extracts, the doctors seem to communicate bad news bit by bit in order to prepare their patients and family caregivers for the worst. They prepare a patient's mind to expect challenges during the course of treatment so that once any challenge comes, it is easier for them to communicate it to the patient.

Depends on a situation

In some cases, by the time patients reach Uganda Cancer Institute, they already know or have been prompted by someone about their prognosis and in this case, doctors find it easier to break the bad news. As much as many do it in stages, the situation changes if a patient is inquisitive to know. In such a situation, the doctors give all the necessary information to the patient or the family caregiver at once. In other case, there is no routine to breaking bad news and it varies patient to patient depending on how much information the patient or the family caregiver has:

"Is there a routine? No, there isn't. First of all, it comes with a situation. There are patients who really have at least an idea or who have already been prompted before you meet them and they seem to know what is happening and then, there are those who really did not expect anything completely. So, according to those two situations, I handle them differently," (Dr.008).

A video interaction below illustrates how the doctors break bad news to the patients and the family caregivers:

Excerpt 2U
1. Doctor: (…) Did you do the operation?
2. Patient: No
3. Doctor: Eee, really? you refused? You are not operated? To remove the disease
4. Family caregiver: No, we didn't do the operation
5. Doctor: Then we are wasting our time. We are wasting time. Where is the X-ray? Is it among these?
6. Family caregiver: Yes
7. Doctor: The disease is there.
8. Family caregiver: Is it here or there? (pointing at the X-rays)
9. Doctor: Do you see the difference? Show me the difference in these two Xray
10. Family caregiver: The illness is here (pointing at one of the X-ray)
11. Doctor: You see the difference? Don't you see the difference? Look at this bone the way it is, and the other one, you see the difference?
12. Family caregiver: Mmm
13. Doctor: Where is the difference?
14. Family caregiver: I see the difference on the left bone
15. Doctor; Aaa haa, the illness is settled there, waiting. Now we have wasted time. If it was me who met you first, I was not going to give you any medication today. The foot has to be cut off, if you want or not. That is the truth.
16. Family caregiver: Is it the foot or the leg?
17. Doctor: The leg ( ) It has to be cut off that is if you want to live. I won't lie to you, this kind of disease is serious and whoever refuses to cut off the leg, loses the life at the end. No jokes here and I don't want to say what you want to hear, but I want to tell you the whole truth. With this kind of illness, we only do the operation when it was still in it's early stage, ... but in your case, we cannot rescue the leg.
18. Family caregiver: Mmm
19. Doctor: All I believe, you were told to do the operation, and you just refused. You were referred here from Kiwoko…

20. Family caregiver: Doctor… referred us here
21. Doctor: He said, he was going to perform surgery in November and you didn't turn up. Now, it would be easier for you if you go back to doctor… to do the operation.
22. Family caregiver: Hmm
23. Doctor: Is the patient your daughter?
24. Family caregiver: Yes, she is my daughter.
25. Doctor: If you don't do the operation, you will lose your daughter. If we do the operation, we may save her life.
26. Family caregiver: Doctor … had told us that the patient can begin with the medication
27. Doctor. No, you finished all the medication, six injections which is not right. She would have received two injections prior to the operation.
28. Family Caregiver: Doctor … had suggested for a bone radiation
29. Doctor: We don't have such services in Uganda, it's abroad. We can't afford such services here.
…
30. Doctor. Is the joint movement ok?
31. Patient: Head shake (no)
32. Doctor: Can you move the joint normally or you limp?
33. Family caregiver: She limps a bit
34. Doctor: They will cut off your leg and give you an artificial leg so that you live, ok? Have you heard?
35. Patient: Yes, doctor.
36. Doctor: You have lumps?
37. Patient: I don't think so
38. Doctor: (Examines patient) I don't feel lumps. Take this note to doctor…, after the operation, come back here, have you understood?
39. Family caregiver: Yes, doctor
40. Doctor: Young girl (referring to the patient), have you understood? They will make for you an artificial leg after the operation. Have you understood young girl (referring to the patient)?
41. Patient: No response
42. Doctor: Young girl, have you understand why we should cut off the leg?
43. Patient: No response
44. Doctor: The illness is attached to it so much, if not removed, it will cost your life. We are now done unless you have any question! After the operation, come back here. Do you have any question?
45. Patient & Family caregiver: No response.
46. Doctor: Losing one leg doesn't mean that you can't do what other people can do. You will still manage to do all things as other people. Have you understood?
47. Patient: No response
48. Doctor: And don't make a mistake, don't make a mistake, don't make a mistake of not coming back. The scan shows, small tumors in the stomach, it may be an illness, have you understood? You come back and we give you medication.
49. Family caregiver: No response
50. Doctor: I'm not so sure, but the scan shows it. This means that the patient may require other two injections
51. Family caregiver: Is it not possible for the patient to be operated from here?
52. Doctor: Go to that hospital I have recommended, there is an influx of patients here, I think you have witnessed that. It may take you three months yet doctor…can do the operation this week. You don't want to go back to Kiwoko hospital?
53. Family caregiver: No response.
(Dr. & Pt. 002)

In the interaction above, the doctor directly tells the patient and her family caregiver that the disease is serious. He is seen being assertive in order to emphasize the seriousness of the disease (17, 19, 25). However, the patient and the family caregiver seem not buy the idea that the doctor is giving to them as portrayed in the instances when the doctor asks them questions and they both keep quiet (41, 43, 45, 47, 49, 53) and the family caregiver tries to provide alternatives to the treatment procedures (26, 28).

Problems associated with breaking bad news and the impact caused;
Psychological breakdown
The problems related to breaking bad news and their impact as described by doctors include psychological breakdown by patients after receiving the bad news, lack of time for counseling the patients and their family caregivers, many patients get shocked and break down which affects their cooperating mechanisms to treatment options and the challenge of interpreting cancer terminologies into the local language.

"*I still remember instances whereby you tell the patient that this is this and this is what we able to do, some of them may not take long and then they pass on. It may not be exactly that they were too sick, but the sickness is now because of the news they have got and then they get sick in mind and the body can't work and they die. I think we have seen quite a number of many. there others who accept it and say well you have done what you have to do, and so on…" (Dr. 009).*

Managing reactions

Doctors manage patients′ reactions by giving them counseling and allowing them to break down which they believe help patients to cope up with the situation and make right treatment decisions:

"A good number of patients get shocked, a fair number kind of expect it so we normally give a cooling of time to allow the patient digest and we give them time to let us know what they are thinking," (Dr. 004).

Doctors claim to give patients and their family caregivers some time to regain their senses after the shock of the bad news and it is upon the patients to inform their doctors when they are ready for the treatment procedures.

Appropriate information to give;
The kind of cancer, treatment and side effects
All doctors agree to it that patients and their caregivers should be given all information about the disease, treatment plan and the expected side effects and the stage of the disease. If the disease is in its advanced stage, the information is given in an indirect manner.

"First of all the condition they have, what options of treatment they have and which ones are available at our institution. It is also important to tell them how much they will benefit from the treatment which you are going to offer to them. You can give them a prognosis of the condition they really have and also I find it important if they have a caregiver and if it is ok for them for the caregiver to be around in a discussion because the caregivers tend to understand more the concept than the patients and in case of any questions they usually speak to their caregivers …" (Dr. 008).

Doctors recognize the importance of family caregivers in the cancer consultation meetings because they handle the patients' care, treatment and its side effects, and hospital appointments. So they need to have all the necessary information at fingertips. More so, during consultation meetings, family caregivers tend to perceive more the information than the patients.

4.1.3 RQ1 (c) Experiences of cancer patients and family caregivers receiving bad news

Unprepared and inadequate information
Patients and family caregivers report experiencing getting bad news in different ways. Some claim to have not received counseling or adequate information concerning their disease from doctors. The manner in which the information is delivered to them is viewed as inappropriate:

"I was in Kiboga and went to one doctor who took my biopsy and told me that I should call him for results after two weeks. When I called him, he asked me to go meet him. When I met him, he told me that your results are not good but am going to refer you to Mulago hospital. I asked him, 'what is it doctor?' and he replied that you have cervical cancer. He then asked me, 'what are you going to do? And I responded, I'm going to die.' I got so scared and begun to sweat ... He spoke in a reluctant manner, just as most educated people do

... and he spent very little time with me. Apart from giving me the results, he didn't explain anything to me," (Pt.013).

The family caregiver also comments:

"When he saw the image, he was like uhm, this is really bad!! I had a feeling that maybe my patient had cancer so I was not surprised, but I was terrified... when I confirmed it, my heart wanted to jump out. He told me that you have to be strong and follow the doctor's treatment plan so it was nothing like comforting. Actually, we didn't get any information, they told us it was cancer and they asked us about the causes whether smoking or drinking alcohol. I was like no, he doesn't smoke, but he has been drinking for some time. So that was the only information we got that it was caused by drinking and that's all we know," (FCG. 022).

The above interview extracts from the patient and the family caregiver indicate that they were not prepared before receiving the news and nothing was done to calm their reactions. They contradict with the doctors' claims that they prepare patients and family caregivers before breaking the bad news.

Lack of information

However, there are some patients and family caregivers who were prepared in a form of counseling before they received the bad news but still, they were not given enough information.

"The doctors told me that I had cancer. They prepared me before giving me the results… They didn't tell me the stage at which the disease is. Doctors in Mulago told me that the first doctor messed up with my life that cancer wouldn't have spread ..." (Pt. 020.)

"When I came with the results, the doctor told me, 'you have cancer', …They didn't give me the details of my condition," (Pt. 004).

The above interview extracts show that even though patients and family caregivers were informed of the kind of cancer they have, they still needed more information about the disease and their condition which were not given to them.

Appropriate information to get - patients and caregivers perspective

All information about the disease

To patients and family caregivers, all the information concerning the patient's disease, treatment, and care is appropriate to be given both to them:

"The midwife told my patient that things are not good .... The information was not perfect, because we need to know a lot like how cancer affects people, the signs and symptoms, how can we prevent it but I think there was no time to tell us all that information. What the doctor told us was only the treatment and other tests to carry out. Personally, I feel people have a right to know what is happening because many are ignorant and they are lacking information. ... doctors are so brief yet in such situations, patients need deep explanation concerning the disease and the treatment," (FCG 005).

Patients and family caregivers think that all the information about cancer, its treatment, side effects and patient's care should be given to them. Because they have little or no knowledge about cancer, it is important for them to know the expectations, the dos, and don'ts.

4.1.4 RQ1 (d) Language

Since we all use language to communicate or verbalize ourselves and put our ideas across in order to connect with people to whom we are speaking to, language is the basis of every culture because it enables us to create the meaning of human experience, thought, feeling, appearance, and behavior. It is through language that we are able to create reality itself by replacing words for the direct experience.

Doctors' experiences: - Interpreting medical terms is a challenge

Doctors have their professional language coupled with medical jargons which are mostly understood by medical personnel, so communicating with patients and their family caregivers requires these medical terms to be interpreted in a layman's language in order to be understood. Interpreting some medical jargons to local language especially in a country like Uganda that has over 40 languages, still remains a challenge as some doctors mention below:

"*We use layman language and we try to convert whatever medical term it is into layman's language because most patients don't understand even when you tell them that you are going for an ultrasound, instead you tell them, they're going to use some machine and place it on your abdomen and see what is inside." (Dr.* 003)

However, sometimes it is complicated to convert the term cancer and its associated terminologies:

"Well, we try to avoid technical terms but there are some which you can't avoid for example when you are talking about cancer you must call it cancer, you just try to describe it... I have learnt over time that the more you stay with these patients the more they begin understanding some of the technical things for example even here you can see a four-year-old patient who can ask me, 'Is my hemoglobin good?' That is after some time they already know the key routine things we do during their treatment plan." (Dr. 001)

Existence of many local languages

The existence of many languages in the country coupled with additional local languages of patients from neighboring countries, also contributes to language barriers:

"I try to speak in the language that is best understood by the patient and the caregivers but on few occasions, it is very hard especially with people who come from outside this country, or people who come from very small ethnic groups, where getting a person within who can translate in the language they understand is very hard." (Dr. 010)

Problems finding interpreters are mentioned:

"I have had language misunderstanding quite often, people coming here and speak a language that I don't understand and they don't understand what I say, we have patients who come from neighboring countries, they speak their local languages at home and they have no one to interpret, I have had it like three times, sometimes you try to find someone to help you get the basic information." (Dr. 005)

Use of interpreters

The dominant languages used at Uganda Cancer Institute are English and Luganda. Besides these two languages, the help of an interpreter is always sought. All doctors admitted using interpreters in case a patient or family caregiver doesn't understand the language they speak however they cited a problem that sometimes the interpreters misinterpret and deliver a wrong or different message:

"*The problem still comes because the other person may not be able to put some things well or interpret things the way you want or mean. In such cases, we are left with no choice but to leave it the way it is." (Dr. 003)*

Patients and family caregivers' language experiences

Language is understandable

The majority of patients and family caregivers claim to understand the kind of language doctors use and have never experienced any lack of understanding due to medical terms used by doctors. They admit seeking help from other medical staff, in case they face any lack of understanding once in a while. However, the minority of the patients and family caregivers expressed lack of understanding when communicating to doctors due to some medical terms used and English language:

"*They speak in either English or Luganda and I understand both languages but one day my mother came to me saying that the doctor communicated to her in English that she didn't understand anything.*" *(Pt.031)*

Education level is a contributing factor

To some patients and family caregivers, doctors communicate to them basing on their level of education. To the highly educated, doctors use both technical and layman's language. These participants assert that, even if they are educated, they don't understand the medical language since it is not their area of expertise:

"*To me, I just assume, they assume you are a learned person and you know what you are asking so they use technical language which is medical language of which we are not conversant with and others use layman's language to communicate. So I think it depends on the way they take you*" *(FCG 022)*

Since some medical terms have no local names or the names are unknown by doctors, they communicate these terms to patients and their family caregivers in the technical language regardless of their level of education and understanding. This is demonstrated in the following video excerpt:

Excerpt 3U

1. Doctor: Are you still on medication
2. Patient: No
3. Doctor: Here it says, you stopped in 2014 and this is 2015. Do you get any injections?
4. Patient: No
5. Doctor: So, you still take Pamidronate?
6. Patient: Who is that?
7. Doctor: The one they inject in the hand?
8. Patient: Nothing at all
9. Doctor: Where did you receive Carbimazole from?
10.Patient: Which one is that?
11. Doctor: The one you take for thyroids?
12. Patient: Down there (pointing finger)
13. Doctor: You mean outpatient medical?
14. Patient: Hmm
15. Doctor: Do you take it well?
16. Patient: Yes, when they give it to me, I take it well
....
17. Doctor: Have you ever tested for diabetes? (used a local name for diabetes which is similar to sugar)
18. Patient: No, I don't drink sugar
19. Doctor: I don't mean sugar we drink but for the body
20. Patient: No I have never
21. Doctor: Try to test it
(Dr. & Pt. 017)

In the excerpt above, the patient seems to have a hard time understanding what the doctor is saying due to the medical terms involved (5, 9. 17). The doctor seems not to know the medications names in the local language or he just ignores the fact that the patient does not understand what he is saying.

4.1.5 RQ1 (e) Opinions about the role of communication

Doctors' opinions: - It helps to achieve proper diagnosis

All doctor participants believe that communication plays a key role in cancer consultations and without it, it's impossible to treat patients. In their opinion, communication, if done effectively, helps to achieve proper diagnosis since patients feel free to express their concerns to doctors:

"*Communication is paramount because if you are a pure communicant then you probably going to come out with proper diagnosis.*" *(Dr. 002)*

Channel of information giving

It is through communication that patients get information concerning their disease, the available treatments, and associated side effects, and the impetus to come back for follow-ups, and treatment.

"*Communication is very necessary because, through it, you educate patients about their disease, that it is going to be on for a long time… So if a person understands you well, they will always come back for their follow-up and in case of treatment, there will be compliance...communicating very well also shows a sense of understanding towards patients." (Dr. 003)*

Creates a relationship

Communication determines the doctor-patient relationship. This means that a good communication produces a good relationship between doctor and the patient which boosts patient confidence.

"*I think, good communication is key to good cancer outcomes and even to allay anxiety among patients when they need to know, you need to communicate. They need to feel you the doctor communicating. It helps to build confidence in the patient." (Dr. 007)*

Means of education

Through communication, patients and their family caregivers learn the dos and don'ts associated with cancer care, treatment, and its side effects.

"*Communication is very important more than giving chemotherapy because if someone doesn't understand, will not do the right thing and you get wrong results so communication is very key in cancer treatment." (Dr. 009)*

Causes of poor communication

Doctor perspective: - Misinterpretation of messages

All participant doctors admit having experienced poor communication in their carrier stating that patients and family caregivers misinterpreted the messages which resulted in missing appointments for follow-ups and treatment. Others don't understand the message at all in that when they get the first treatment, or when they experience side effects during treatment, they don't come back for more treatment:

"*Communication gaps make patients not come back for follow-ups or continue with their treatment." (Dr.002)*

"Defaulting is very high, people forget the days they are supposed to come back for treatment and actually that can affect the outcome of their treatment. It is the leading cause of defaulting and the leading cause of poor outcomes," (Dr. 011)

Shortage of time

The influx of patients, vis a vis few doctors limits the time doctors spend with each patient. In a less busy day, one doctor sees between twenty to thirty-five patients and on a busy day, he/she sees over fifty patients. The number of patients is overwhelming yet there are very few doctors. This limits the time a doctor can spend with every patient because he/she wants to meet every patient in the queue.

"*Patient numbers visa vie the number of doctors, is so disproportionate, you can't spend as much time as you would wish with patients because of the numbers. It's exhausting." (Dr.010)*

Communication skills lacking

Some doctors lack communication skills because they didn't attend communication courses. Some doctors have the communication skills, but the working environment doesn't give them a chance to communicate effectively:

"The first thing is with the doctors. Some of us may not have the good communication skills because we have not gone back for those refresher course for communication skills, but they are very important. We have many patients being attended to by few care providers. Sometimes you are taken by the need to see all the patients that you have on the queue and that still leaves a big gap. Some of us the doctors, our communication skills need to be sharpened whereas others have the skills but they cannot provide the services to the patients because of the number of patients they need to see." (Dr. 008)

Workload

Excessive workload was also cited among the hindrances of effective communication at the Institute in that doctors get so tired since they work long hours and see many patients:

"*Our clinics are very big, if we are going to stick to standard norms of communication then, there will be an issue of fatigue and burnout on the side of the physician which can affect the quality of service. Either way, communication empowers patients to seek health and get close follow-up but again the capacity we have in our setting doesn't favor us." (Dr. 001)*

Patients and family caregivers' opinions about the role of communication

Vital to decision-making and influences health seeking behaviors

Patient and family caregiver participants describe communication as a necessity in cancer consultations because it plays a big role in the decisions they take concerning treatment and it greatly influences their health seeking behaviors.

"*Cancer is a serious disease, so painful. So, if doctors talk to cancer patients in a good way, we understand the information, gain trust in doctors and have a hope of getting better. Good communication helps patients to make decisions like accepting treatment and coming back for follow-ups."* (*Pt. 004)*

"It helps us to accept the available treatment and associated procedures and even understanding all the information given to us. So communication gives us the courage to come back in the hospital because through it, we get all the vital information which eases the decisions we take concerning treatment." (FCG 016)

Reduces stress and creates hope

Patients and family caregiver testify that if they have good communication with their doctors, it reduces their stress, increases their understanding of the given information, and gives patients hope of recovery:

"Communication can help you to have the hope of recovering quickly and when they explain about the drug they are going to give you, you really feel helped and gain hope of recovering quickly. I feel happier when doctors talk well with me." (Pt. 006)

"Once you communicate effectively, the one you are giving information understands you and may follow-up what you have communicated but if there is bad communication, I may not take what you are saying serious..." (FCG 005)

Causes of poor communication

Patient and family caregiver perspective: - Anxiety, discontentment, and stress

The majority of patients and family caregivers have ever encountered poor communication it caused anxiety and discontentment, negatively affected their health seeking behaviors, produced stress which affects their understanding and made them lose hope of getting well:

"When you are in pain and somebody harasses you, you get annoyed and don't come back. Poor communication brings misunderstanding. When am in pain and you don't talk well with me I just decide to go home and don't come back." (Pt. 014)

Few doctors compared to patients

Patients and family caregivers share the same opinion with doctors concerning the few number of doctors compared to patients which they think make doctors tired and work for long hours;

"Communication would have been better but now in Uganda, we are lacking doctors. Had there been enough, it would have been better. For example, yesterday I left at six in the evening because there was one doctor who runs the X-rays and he is a human being, he gets tired but if they were many, they would be serving us well." (Pt. 012)

"The ratio of doctor to patient is big. Like in government hospitals, one doctor sees 40 patients, and to complete those patients within a limited time, is too much. So the doctors just be brief and even miss out some important stuff." (FCG 005)

Low Salaries

Low salaries versus workload were cited among the hindrances of effective communication as it contributes to poor reception.

"I think these doctors are paid very low salaries and they work a lot. They are stressed in one way or the other because they work long hours yet they earn so little." (FCG 018)

Patients come when stressed

Some patients and family caregivers come to the hospital when they are confused and stressed due to domestic affairs and this affects their understanding when given information. Sometimes they misperceive ways in which doctors communicate to them:

"*Patients have their burdens like home problems, no food at home, maybe abandoned by the husband in addition to the pain. Patients have their own issues of which hinder them from understanding what doctors tell them no matter how much the doctors try. This prompts the doctors to raise the voice at patients just to awaken them up. I don't think they intend to be rude." (Pt. 007)*

Despite doctors' communication weaknesses, patients and family caregivers have their issues that stress them and suppress their level of understanding. This affects their understanding no matter how good the doctors can communicate. Stress also influences the way patients and family caregivers perceive doctors' communication abilities.

4.1.6 RQ1 (f) Cultural issues involved

Doctors' experiences: - Use of traditional herbs

All doctor participants admitted taking into consideration cultural issues related to cancer during consultation meetings and during treatment. They cited several cultural issues that they have experienced which hinder patients' health seeking behaviors and affect treatment outcomes. Most patients present advanced cases of the disease because they first use traditional herbs and after realizing negative response, they come to the cancer institute as the last choice. To some patients even after reporting to the cancer institute, they still use local herbs along with cancer medicine which deteriorates their health condition:

"*Most of them say, 'we don't go to the western medicine', and they resort to traditional herbs where the disease grows to advanced stages. Some, their family members carry them away from the hospital and take them to traditional healers and bring them back when the disease has worsened or others pass on from there.*
...Some people come when they are on herbs and these herbs have an effect on cancer. You may not know and you may be treating, giving your chemotherapy and then you see the patient having severe neutropenia..." (Dr. 009)

According to the above extract, most patients and family caregivers seem to have trust in traditional herbs in that even when they begin cancer treatment medicine, they continue with the herbs alongside it.

Religious aspects

In some cases, patients refuse blood transfusions alleging that their religion forbids it. Others, after knowing their prognosis, they say their pastors will pray for them and faith will heal them. So, they stop coming to the hospital for a long period and return later when they are severely sick:

"Jehovah witnesses, don't accept blood transfusions and you have to respect their opinion and belief. Some patients say pastors will pray for me and get healed. In such instances, you can do nothing much to help." (Dr. 002)

In other instances, some women don't accept intimate examination by male doctors in the absence of their husbands alleging that it is against their religion for example Islam. They also keep a distance from male doctors and limit the time they interact with them:

"If a patient is, for example, a Muslim woman, they are difficult, you can't touch them, you can't communicate much, the husband has to be available, and sometimes they can't accept treatment until the husband has been consulted... You can't treat them, whatever you do, they have to first go ask their husband and come back to the clinic." (Dr. 007)

Social perception of women

Traditionally, women are trained to accede to their husbands and other men, and to demonstrate their subordination to men in public. So, women have less powers when it comes to decision making even when the issue concerns their lives. They always seek permission from their husbands which delays their treatment as one doctor narrates:

"Recently, we have experienced some cases where someone has to go back and first consult maybe with their spouse about the form of treatment we are going to give them. We consider it still as cultural because they put their husbands before them...they express their fears and problems they are going to get with their spouse, not putting their lives first but their spouse so they have to go back and seek for their permission." (Dr. 008)

Patients and family caregivers' cultural issues: - Lack of cancer awareness

Because of lack of awareness of cancer disease in Uganda, most patients and family caregivers admit having sought help from traditional healers thinking that they were bewitched. They also used traditional herbs before coming to the cancer institute.

Stigma

Since many people perceive cancer as a death sentence, patients are stigmatized once the society identifies them as cancer victims. Some are directly stigmatized whereas others are indirectly stigmatized. The most stigmatized cancer patients are those with visible cancers and those with cancers that cause them to have an odor. People don't feel comfortable to associate with them even though cancer is not contagious;

"*Back home, I am stigmatized by the members of the public. They always don't want to associate with me, saying, 'that one is on medication, something like that." (Pt. 032)*

"My husband abandoned me when my breasts were cut off. Some patients fear treatment procedures and side effects, so they don't come to the hospital. They fear to be segregated by family members and the community in case they lose some body parts as a treatment procedure..." (Pt. 026)

4.2 ETHIOPIA

4.2.1 RQ1 (a) Communication Experiences

All 16 recruited doctors and 54 patients participated in the study. Out of 22 recruited family caregivers, 21 participated in the study and one withdrew in the middle of the interview due to unknown reason. All participants who were recruited for the video recordings participated in the study. Of the 24 video recordings 21 were transcribed and used in the study but three videos couldn't be used because one video was in oromiffa language and the other two had poor quality sound. All the doctors' interviews were transcribed and used in the study and some selected patients and family caregivers' interview were also transcribed and used in the study. The author conducted 91 interviews and 24 video recordings in total.

Doctors' communication experiences: **- Illiteracy levels and lack of awareness**

The majority of doctors in Ethiopia, Black Lion Cancer Institute describe their communication as very challenging attributing it to the high levels of illiteracy and lack of awareness about the disease;

"The major gap between physicians and our patients is literacy level. Most of the patients are illiterate… the other thing is cancer has become more prominent disease entity in the recent years. So most of patients are not aware of it even if they literate." (Dr.f1)

Language barriers

Ethiopia is known as a country of diversity with different cultures, ethnic and linguistic groups. There are more than 80 languages spoken in the country and each ethnic group practice their own language. Amharic is the country's official language and also the working language at Black Lion's Hospital. Physicians at Black Lion hospital face language problems in communication with patients and family caregivers. If patients only speak other language than Amharic it is hard for the physicians who don't speak the same language as patients do. Usually the physicians seek help from family caregivers or other people around when they realize misunderstanding between them and the patients.

"One of the challenge we have in our communication is language especially most of the patients come from Oromiya region and most of us cannot communicate with Oromiffa (language spoken by Oromo people). That is our difficulty. We try to use the nurses, attendants or other patients to provide basic information." (Dr. f5)

Due to the vast number of languages that is spoken in the country, the hospital does not provide interpreters. Thus, doctors and patients have to find themselves someone who can interpret. It can be family caregivers or other patients and nurses.

High numbers of patients

Black Lion cancer institute is the solely institute in the country. Patients come from different parts of Ethiopia to get treatment there. Doctors do not get sufficient time to convey adequate information to the patients due to the limited number of physicians and the influx of patients:

"The number of patients that a single physician encounter per day is more than expected, so that you may have no time to deliver all the information to the patients as you want. Sometimes you will take one minute or two, it is so exhausting because of the workload." (Dr.m11)

The physical environment

All doctor participants share the same experience concerning the lack of privacy examining room. The patients at outpatient department (OPD) are examined in a small - office type room with one stretcher in the room and there is no privacy. Patients have to undress in the view of the doctor, the nurse and also whoever else may be around at the time. Most of the time the patients and their family caregivers have difficulties to discuss their problems in this small room with no privacy and it takes a while to open up:

"The only problem that I am facing is to do the right communication with the patients, …because there is no special private room for patients, there is no adequate time for all patients that you can give and there is no regular opportunity to see you all patients whenever they face any problem about their disease, their investigation, the treatment and its outcome." (Dr. m5)

Communication experiences of patients and family caregivers

Most of the patients and family caregivers at Black Lion Cancer Institute, view doctors' communication as satisfying basing on the fact that they are friendly and kind;

"Communication we have with doctors is very good, they show sympathy to my patient and most of the time they give us hope." (Fc.f 1)

Positive feedback and support are appreciated

Patients appreciated positive feedbacks and support that they obtained from doctors. They claim that doctor's positive approach can gives them hope and courage to move on with their life as a cancer patient:

"I experience good communication with doctors; they approach me kindly, they give me hopes, telling that I will be fine and the cancer I have is curable and so on. As a cancer patient, I really need to hear positive feedbacks every day, and that give me hopes and courage." (Pt .m20)

In general, a positive experience and good outcome

"Doctors are very nice with me, when I first came here I was in a serious condition, thanks to them I'm now much better and they are very helpful. My communication experience with doctors is very good." (Pt.m16)

The above extract illustrates how some patients perceive doctors' positive feedbacks as a form of psychological treatment.

However, they complain about their communication with doctors in terms of obtaining insufficient information and ignored when they ask questions.

*"Most of the doctors are very nice and humble when they speak to you. But when you ask them information about the diseases, they don't usually give you adequate information. I know nothing about cancer before, and this is a right place to get information, but they don't give you. I don't know, maybe they don't have enough time or they don't have sufficient knowledge about cancer. I can understand that they have a lot to do, but at least there must be someone who can give you and your patient basic and important information." (*Pt.f 31)

Limited time and load of work

According to some patients, doctors spend very few minutes with them and due to load of work which make them stressed and not able to satisfy each and every patient. Since the institute is the only cancer institute in the country, the oncology doctors are few in numbers and they treat dozens of cancer patients every day:

"A lot of patients come from different places to this hospital to get treatment and I think we are a burden to physicians which make them stressed and that is why we get limited time with them" (Pt. f8)

Misunderstanding due to insufficient information

Both patients and family caregivers think that obtaining inadequate information increases misunderstanding among doctors, patients and family caregivers. Patients want to understand their prognosis, purpose of care and treatment outcomes:

"They don't have any communication at all with me. They communicate with my patient and I hear everything from her yet, I am here with her all the time. Whenever I ask a question they either give a short answer or ignored it." (Fc.f 3)

Lack of privacy

Patients do not have a private room where they can speak with their doctors without being interrupted. It is rather difficult for patients and family caregivers to disclose their concerns when other people are around. The other discomforting part is interacting with different doctors and each doctor gives you different information, which is hard to recall both for patients and family caregivers:

"Doctors are nice, they speak politely, and they are willing to help most of the time. The problem I have is we meet different doctors every time and we get different information from different doctors. The other thing I experienced is either nurse or other patients always interrupt them while they are talking to you." (Fcm.10)

The excerpt below taken from doctor, patient and family caregiver interaction in consultation meeting illustrates language issues and lack of privacy:

Excerpt 1E
1. Doctor: When did the disease begin?
2. Family caregiver: hum… she
3. Doctor: No, ask the patient.
4. Family caregiver: interprets
5. Patient: Five months.
6. Doctor: Five months, what are the problem, vaginal bleeding, and fluid from the uterus?
7. Patient: There are a few discharges, but I had treatment, for the appointment prolonged I told them to write me drug prescription and upon receiving it there is some improvement.
8. Doctor: Is there bleeding and discharge now?
...
9. Recording interrupted (…)
Recording continues
10. Doctor: Where are you from? How many children do you have?
11. Family caregiver: six
12. Doctor: What was said there in gynecology department about the uterus?
13. Family caregiver: She gave a sample from the uterus and we are on the appointment to know the result
14. Doctor: Um, not informed of something like to go to radiotherapy department for treatment?
15. Patient: No information in this regard.
16. Doctor: Was the patient informed that the carcinoma is of cervical?
17. Family caregiver: They have informed only me.
18. Doctor: What about the patient?
19. Family caregiver: No, she doesn't know.
20. Doctor: Did they directly send you to the radiotherapy department?
21. Patient: Yeah we directly came here.
22. Doctor: You will be treated with chemotherapy for four months, but there might be so many patients waiting for it.
23. Family caregiver: we have a result of the black lion hospital.
24. Doctor: Let me see, do you have ultrasound result?
...
25. Doctor: So, you said the patient has distress, she wants to go urinate now and then. Ok, I will prescribe an anti-pain now ( ) the main treatment is a radiotherapy treatment and also chemotherapy and that will be done upon waiting the queue.
26. Family caregiver: How much time would it take?
27. Doctor: Just a few ( ) another nurse came over and the video interrupted again……….
Recording continues …
28. Doctor: Tell her to go to examining bed I want to examine her.

The excerpt above shows that the patient was not informed of her disease but the family caregiver received the information concerning the patient (16, 17, 18 19). The patient could not interact with the doctor because they both speak different languages (3, 4, 5), but the family caregiver helped them by interpreting and it is easier to inform the family caregiver all the information since the patient could not speak the same language as the doctor (4). The interaction was interrupted several times by nurses and other patients that indicate patients and family caregivers lack privacy to open up and discuss with the doctor as they want (between 9, 10 and 27).

4.2.2 RQ1 (b) Doctors- breaking bad news

One of the most difficult duties that doctors in oncology must do as part of their job is delivering bad news, which includes cancer diagnosis, failure of therapy and death are among other issues. The study result shows how oncology doctors in Black Lion Hospital deliver the bad news and how cancer patients and family caregiver ascertain the cancer diagnosis and receive the bad news.

It's challenging

All of the oncology doctors at Black Lion Hospital agree that breaking bad news is one of the most significant yet most challenging tasks to do. However, they think that conveying the bad news to patients and family caregivers differs from physician to physician.

Doctors involve other professionals and caregivers

A few number of doctor participants break the bad news to patients involving other professionals and they ask patients if they are willing to include their family caregivers during the interaction, asking also the family caregivers if they are willing to participate in the interaction. The doctors break the bad news depending on the patient's knowledge about the disease and the desire they have to know more or less about it:

"I will arrange nurses and other professionals if possible and I will ask the patients also do you prefer your families about this information, if he says yes what type of family, I will ask also the family members if they are ready or not, then I will ask the patient how much does he know about his disease he will tell me I do not know or I know this much () then I will ask him how much does he want to know about his disease if he say all, I will give him all, if he says stop beyond this I do not want to know give to my relatives or to my father and so forth, then I will give them all the information and I will ask them or summarized what I have said if they really do understand or if there is something missed very important to add on it." (Dr.m5)

Prefer family caregivers

Some doctor participants prefer breaking the bad news directly to family caregivers:

"I break bad news to the family caregivers, first I ask the relationships they have, if it is a mother, a father, sister, spouse etc. I am sorry I don't have real good news this is a difficult disease all treatment modalities that we are going to give is only to palliate the symptom not to cure, and I don't want to completely blacken them out I would say this is all from me but what is from God is still with God. Obviously it is good to tell the families they have to be prepared to be ready and give the best palliative care, and show love and care. And the spirituality is all in all communicated with them and that where we stop." (*Dr.m10)*

"You should tell the family caregivers about the diagnosis, the prognosis and about the treatment options because, these are the people that would care for these patients while he/she is incapacitated ( ) while he/she cannot support himself/herself and they should know what they are dealing with." (Drm4)

Appropriate to give facts to patients about their disease

To other doctors it is essential to disclose facts about diagnosis directly to patients and similarly to their family caregivers:

"I don't have any specific technical training on this aspect (breaking bad news) but as far as my understanding and conviction is concerned telling the truth for a patient is something that should be done; we should not hide anything from a patient we should not deceive a patient and we should always be trustworthy for the patient so, as far as the disease is in advanced stage, the prognosis is poor, the patient may die in the next few months and so on, all these things must be told and I don't think these all things are dangerous, sensitive or inappropriate." (Dr. m7)

Inappropriate to break bad news to patients

On contrary, some doctors do not break bad news stating that it is a negative and painful experience for patients who do not have cancer awareness and it affect their psychological wellbeing which sometimes results into early deaths:

"Why do I do that? I do not break bad news to patients, you know in Ethiopia there is lack of awareness about cancer disease it doesn't matter whether the patient is educated or not. Telling patients, they have cancer will only hasten their death so I prefer not to break bad news." (Dr. m11)

Family involvement

In Ethiopian society the family dominates over individuals and patients usually come with family members. Therefore, any information regarding the patient can be delivered to the family members. Families have tendencies to protect their patients from knowing their disease in order to maintain hope and show endless support. Most of the time doctors collaborate with the family members by not breaking bad news to patients:

"Breaking bad news is actually the most difficult issue. But initially I inform the attendant or close relatives of the patient, through that I approach the patient. Otherwise conveying bad news directly to the patient is so difficult." (Dr. m2)

Discussing openly terminal illnesses

Discussing openly about patient's' terminal illnesses evokes strong emotional reactions in patients and their families in Ethiopia. Some doctors avoid an open discussion with patients:

"Most of the patients don't have cancer awareness and when you explain about the diagnoses they don't understand you, but the minute you begin to talk about death, like you have 6 months to live or less than, they get frustrated and even want to beat you or verbally abuse you and I remember one instance after I delivered the bad news the patient got so mad and he tried to beat me then I had to call security so, it is so difficult to deal with breaking bad news here." (Dr. f3)

Managing patients' reactions

Managing patient's reaction after delivering bad news is a difficult thing for physicians to handle. A small percentage of doctors try to offer support to the patient basing on the religious faith.

"I do it smoothly and in a sort of understandable way and I also try to incorporate it with a religious aspect. If they are Muslims I speak their language if they are Christians and if they are whatever they are I just try to tell them that, in humanly possible way we have helped the patient and other than this, it's a job of a creator so we just have to accept what's going to happen next, and somehow this is how they accept it." (Dr.f1)

4.2.3 RQ1 (c) Experiences of cancer patients and family caregivers receiving bad news

Receive the bad news

The majority of patients and family caregivers were overwhelmed by the bad news they received from the oncology physicians, however they were satisfied with the psychological support they obtained from the physicians:

"I was accompanied with my husband when the doctor broke the bad news. The doctor gave me enough time and consoled me as much as he could but I was overwhelmed by the news" (Pt.f27)

"First time, the doctor broke the bad news to my patient, in the second result he told us the family caregivers. The doctor gave us enough time after his working hours and comforted my patient." (fc.f4)

Most of the patients and family caregiver participants describe the way they obtained bad news from oncology doctors as heart breaking:

"The first doctor we met told me that my daughter has tumor and I don't have to worry about it and she will get help at Black Lion Hospital and referred her here. But when we came at Black Lion Hospital, the doctor

told me that your daughter has cancer and it is expensive to get treatment and I don't think you can afford it. I told him that, even if I can't afford it I can at least beg, and he said if you can, go and buy the medicine so she can begin the treatment." (Fc.f 6)

In the transcription above, the doctor under estimated what the family caregiver can afford basing his judgment on the physical appearance however, the family caregiver proved him wrong when she managed to buy the medicine.

"After I did breast operation in my region, the cancer spread and they referred me to Black Lion Hospital to obtain medication. I am poor, I could not afford to buy any medicine and it took five months to obtain the first chemotherapy treatment so; the bad news was not having cancer but knowing that you cannot afford to buy the medicine." (Pt. f29)

Economical issues play a role in communication, patients with low economic status cannot afford medicine since it is expensive to take cancer treatments, so during the interaction, the patient focuses more on where to get the money than the information which the doctor give him/her.

All information is appropriate

Information about the disease, the stage at which it is and the available treatment options is considered appropriate information to obtain from the doctor as some patients and family caregivers state:

"As far as I understand it is appropriate to give patients and their family caregivers the information which is important to them like knowing the type of disease and stages, the therapy side effects etc." (Pt.m13)

Insufficient information

Most of the patients and family caregivers complained about insufficient information given about the disease and they also state that there was a lack of consoling and it is inappropriate to discourage both patients and family caregivers and additionally telling the patients directly about their diagnosis:

"The doctor told me that you know your patient has reached the fourth stage, she was supposed to take chemotherapy three weeks after the operation. First I didn't know anything about the cancer stages, second nobody has informed my patient or me about the chemotherapy after the operation. All the information we obtained was to wait six months in the queue. After the bad news I felt terrible, couldn't control myself, all the emotions came at once and didn't get any help from the doctor that was so devastating. "(Fc.f3)

"It is inappropriate to tell patient that he/she has cancer instead of telling to their family caregivers." (Pt.f33)

Managing reactions

Most of the patient get comfort from family members who provide them with support right from the start to the end. Family caregivers control their emotions in the presence of their patients and they are very careful not hurt their patients' feelings. However, some patients manage their reactions without any consolation from anybody while others manage with the help of faith in God.

"I cried a lot, the doctor and my husband console me eventually I managed my reaction. " *(Pt.f27)*
"After the doctor delivered the bad news I was shocked but did not cry I gave everything to Allah." (Pt.f49)

"After the diagnosis my patient consoled herself. She managed her reactions smoothly without any one from the family involved

4.2.4 RQ1 (d) Language

Language is the most important aspect in clinical practice and it aids doctors and patients to share information about diagnosis and treatment plans however it is essential that both parties speak the language they understand. Ethiopia is a multi-diversity country with a variety of cultures and languages. Amharic is the official language in Ethiopia and it is a working language in Black Lion Hospital. Since Black Lion Hospital, is the only cancer referral center, they receive patients of different languages from different parts of the country.

Language barrier

Most of doctor participants consider language barrier as an obvious challenge during interaction with patients and their family caregivers, not only speaking different languages but also translating medical terms to Amharic and another language:

"There is actually a problem to interpret medical words to Amharic or to other languages, so we often face such kinds of problems. But as much as possible, I always try to use the language they know especially Amharic and Tigrinya that is what I know. Patients who are literates understand better than those who are illiterates. For illiterate patients, it is difficult to tell them what cancer is in the beginning, leaving alone the types of cancer they have, they do not know what cancer is." (Drm 9)

Adopt to layman's language

All participating doctors try to use layman language and avoid using technical language as much as possible in order to evade misunderstandings and ambiguity however, patient's educational background matters whether the doctors can use medical jargons or not. Some participant doctors stated:

"As much as possible I try to avoid technical terminologies because the patients cannot comprehend them. But if the patient has some degree of knowledge and education, and if he/she is versed with some medical understanding we may also use some technical language." (Dr.m7)
"It depends on the patient's education background. If the patient is illiterate or less educated, I use the language that he/she can understand. If the patient is well educated and if he/she can easily understand, then, I use medical terms as well." (Dr.m1)

Finding right terms is hard

Speaking similar language can ease doctors, patients and family caregivers' interaction however, choosing the right words that can be understood by each patient or caregiver, is challenging.

"I try all means to be understood by my patients and their family caregivers, and I make sure that the patients understand everything that I say before they leave. Samba Nekersa (tuberculosis) is known throughout the country, and cancer is called nekersa in Amharic, so when you tell them you have cancer (nekersa) the patients and the family caregivers might relate it with tuberculosis (samba nekersa) and they might think the disease is contagious. It is vital choosing right words and terms that the patients can understand." (Dr.m5)

Language is understandable

Most of patient participants and family caregivers never experienced language barrier in communication with doctors. They also think that the majority of doctors do not use medical terms during interaction:
"I speak Amharic language, and all doctors here speak Amharic so language has never been an issue." (Pt.f2)

Doctors use layman language when they communicate with my family caregiver and me. I never experience any misunderstanding or difficulty so far. (Pt.f33)

"They use a layman language and I never had any problem concerning language and so is my patient." (fc. f10)

No interpreters

However very few patients and family caregiver participants experienced language barriers because doctors do not speak their language and they could not find interpreters:

"One of the problem I have here is language, I do not speak Amharic, I speak oromiffa. Most of the doctors speak Amharic, so I have to always come with my family caregiver who can speak Amharic. There were instances where my family caregiver was not around and I had to deal with the doctor alone that was too difficult, I must say. Even if your family caregiver or others around you can help you by interpreting yet, there is always kind of misunderstanding and also it is so difficult to express your feelings when your family member is the one who is interpreting." (Pt.f6)

"If you do not understand Amharic, they will tell you to find someone who can understand your language and can interpret in to Amharic." (Fcm 5)

As the extract mentioned above, lack of interpreters is one of the issue that affects doctors, patients, and family caregivers' communication. Due to the vast number of language that is spoken in the country, the hospital does not provide profession interpreters to patients and their caregivers, they have to find someone who can interpret in case the language issue arise.

Technical language

Few patient and family caregiver participants claim that doctors use technical language during interaction and they experienced misunderstanding:

"They use medical terms when they speak with me, I can understand few medical terms and I ask if I do not understand, but there are a lot of patients who are not educated, for them it must be difficult. I think doctors should consider what language they use when they speak with patient in order to avoid misunderstanding."(Pt,m16)

"My patient does not understand what the doctors talk about during round, they do not explain to her what they have been talking or discussing about. Most often she experiences misunderstanding. "(fcf3)

An excerpt illustrating some of the language issues faced at Black Lion Hospital.

Excerpt 3E

1. Doctor. Do you have cough?
2. Patient. No response due to language barrier; (she turned to her family caregivers and asked in Oromiffa)
3. Family caregiver. Interprets
4. Doctor. Only one person is enough. (As two family caregivers respond to him at the same time) Doctor: Does she have cramp in her stomach?
5. Family caregiver. Interprets
6. Patient. No.
7. Doctor: what is your weight now?
8. Family caregiver. Interprets
9. Patient. First 46 kg and now decreased to 42 kg.
10. Doctor. Last time you were 44 kg.
11. Family caregiver. Last time she was 46 and now 42
12. Doctor. Now you are 44
13. Patient. No.
14. Doctor. Ok, come and measure your weight
15. Patient. Okay.

The doctor could not speak Oromiffa and the patient does not understand Amharic, during the interaction there were family caregivers who have tried to help interpreting (1,2,3,4,5). The family caregivers tried to solve the discussion.

4.2.5 RQ1 (e) Opinions about the role of communication

The study exhibited that all the participant doctors, patients and family caregivers consider communication as a vital instrument that can play significant role in doctor, patient and family caregivers' interaction.

Doctors

Communicating a treatment plan

In order to manage treatment plans patients and family caregivers need to understand well all the information that are given by their doctors, and doctors must be sure that the information they delivered to the patients and their family caregivers has been well understood.

"Good communication is very important because it will have an influence on patients' compliances with the medications, so if you don't treat these patients and their families as you should they usually ran away from follow up they might make their kids quit from the treatment. So good communication is crucial in communicating treatment plans." (Dr.f4)

"You just give to patient a prescription to buy the medicine, the patients sometimes get bored because you do not expect the patient to take medicine for three months without explaining the benefit of the medication so good communication with patient is important." (Dr.m3)

Trust

Communication plays an important role in building trust between doctors and patients or doctors and family caregivers. Doctor participants claim that with good communication, patients and their family caregivers gain trust in doctors hence opening up to them.

"When the patient and his/her family caregiver trust the physician, he/she can freely and openly discuss their disease and physician can get the possibility to understand the patient's feelings and expectations associated with cancer. It enhances the physician's morale." (Dr.f3)

Managing conflicts

Through communication conflict can be resolved and managed. Most of the doctors experienced conflicts in one way or the other when they interact with patients and their family members due to misunderstanding. Usually conflicts occur when there are misunderstandings and misinterpretations:

"Mostly when you tell a cancer patient that his/her disease cannot be treated or cured they usually get angry and depressed they even create conflict with you and others around them. I try to treat the patient emotionally; sometimes I think emotions works fine than medication so communication has a big role in conflict managing. (Dr.m11)

Causes of poor communication

Misunderstanding

Misunderstanding is a common problem in communication with patients and family caregivers as doctor participants illustrate in the study. Very often misunderstandings occur when doctors explain about the diagnosis, prognosis, treatment plans and decision-making to patients and family caregivers:

"It is a longstanding habit of not talking about the problem openly and more freely so patients and family caregivers might not understand or misinterpret the information they obtain that usually leads to misunderstanding" (Dr.m4)

"There is misunderstanding between doctors and patients, we clerk the patient, we give the medication, and we do not take the time to explain and we do not consider the emotional states of the patient." (Dr.m3)

Lack of communications skills

The majority participant doctors admit lacking communication skills yet it is important in creating and maintaining doctor, patient and family caregiver's information flow.

"Communication skill is very important but we have no experienced and highly trained health personnel on communication, even the government has not given special attention for this type of discipline, they just train the generation and let them work with different attitude with the patients that is one of the communication barrier we have here. Communication skill should be given to all health personnel equivalent to other disciplines." (Dr.m5)

"There is poor communication in our setup, it is a new subspecialty oncology unit and I think most of us do not communicate well with our patients. There is no training on how to communicate with patients, we do it from what we are seeing from our seniors and there is a communication gap." (Dr.f3)

Shortage of physicians

There are very few oncology doctors in Black Lion Referral Hospital and the number of patients are increasing every time. Physicians do not get enough time to spend with their patients and family caregivers, as they should and this hinders good communication:

"Physicians do not have time to tell everything like the side effects, this thing is not commonly applied in Ethiopia. But practically it should happen." (Dr.m9)

Socioeconomic status

Patients with low socioeconomic status often lack the financial support and it is difficult to communicate treatment plans with them since they focus on their financial status and pay less attention to the given information. This creates poor communication:

"The majority of the patients come from rural areas and they have low socioeconomic status they cannot afford to buy a simple painkiller, usually it is so hard to communicate treatment plans when you know the patients cannot afford it." (Dr.m10)

Opinions of the role of Communication

Patients and family caregivers perspective: - Patient's satisfaction

Most of patients and family caregivers believe that communication if done effectively gives satisfaction and improves patient's psychological well-being:

"Good communication with doctors reduces my anxiety and stress, I get somehow psychologically well because other people do not understand your situation as doctors do, so communication is essential." (Pt.m16)

"Communication plays a big role in doctor patients and family caregivers' interaction, when there is good communication there will not be any misunderstanding and you follow doctors' advice and it eases what you can do and cannot do to your patient that gives you satisfaction." (Fc.f9)

Feelings and expectations

Through communication, patients express their feelings and expectations to the doctors and this helps to elicit information that can be used in patients' diagnosis.

"Through communication doctors can understand how I feel and what I expect from the treatments." (Pt.m13)

Causes of poor communication

Lack of information

Most of patient and family caregiver participants do not obtain information from the doctors. Lack of information causes poor communication:

"During interaction doctors usually prefer reading my personal file than asking me how I feel and what information I need from them. Sometimes, some doctors direct you to the nurse to get information, and that makes me sad and lose the interest to interact. "(Pt.m12)

Influx of patients

According to patient and family caregiver participants, doctors meet a lot of patients per day and that contributes to poor communication. They complain about the long time they spend in a queue waiting to meet the doctors, which they said makes them so tired and affects their understanding hence resulting into poor communication:

"You have to come early in the morning around 4:00 am for the queue and by the time you meet doctors you are so tired, angry and anxious and of course sick. It is sometimes hard to understand and to take in all the information given." (Pt.f10)

"We live 500 km outside Addis Ababa, after the journey you have to wait for the queue and you do not know how long you are going to wait. The guards usually do not let you in or out as you want and that makes us the family caregivers suffer due to this we get angry and stressed. Stress and anger are what we experience most of the time which I think can affect our interaction" (fc.m10)

4.2.6 RQ1 (f) Cultural issues involved

Doctors

Traditional healers

Some patients from rural areas seek health care from traditional healers before they visit medical doctors. Traditional healers mostly implement herbs and spiritual healing to treat diseases. By the time the patients come for treatment to the hospital the cancer has spread too far, so the doctors only provide them palliative care.

“Most of the patients come from rural areas and they first try traditional medicine and if that does not work then they come to hospital, by the time they come the cancer is already spread” (Dr.m1)

Stigma

Most of doctor participants state that, stigma prevents patients from seeking treatment. They fear to be isolated from their families and the society. Due to cancer disease and its treatment side effects, some patients lose hair and weight, and most people mix cancer with HIV thinking that cancer is a communicable disease. So, they do not want to communicate with cancer patients:

“When patients request a sick leave, they usually tell us not to mention the diagnosis because if their colleagues find out about their disease, they might exclude them or treat them differently. Patients with breast cancer have very much limited sick leave annually but patients with HIV/Aids have no limited sick leave.” (Dr.m8)

On contrary, a few number of doctor participants state that cancer patients are not stigmatized as compared to some other patients with communicable diseases such as tuberculosis and Aids:

"I think there is no stigma related to cancer disease, cancer patients are not stigmatized as HIV patients." (Dr.m2)

Taboo

In most parts of Ethiopia, sex is something that people do not discuss about in public or private. They do not talk about their marital sexual life and sexual preferences with their partners. The majority of female patients with breast and cervical cancer have problems to open up and discuss about their disease:

"In some cultures it is difficult to ask the sexual behavior of the patient. It is like taboo to ask patient if he/she has multiple sexual partners. But in other cultures people do not mind, they can tell you frankly so cultures matter in communication." (Dr.f1)

"I know that there are some cultural issues particularly patients with cervical cancer. Some patients, when they do have fistula and can't control their urine, you know the smell of urine speaks louder than words, so they feel so ashamed and do not want to be examined. I communicate to the patient in the presence of the family caregivers because the caregivers should understand why the smell is coming so they might not outcast the patient and they can talk about it." (Dr.m10)

Religious aspects

Many Ethiopian Orthodox Christians represent the largest religious group and they believe in the power of holy water. According to doctor participants, patients who are orthodox Christians usually take holy water when they get sick and after the diagnosis.

"Orthodox Christian patients, often take holy water and the problem is they cannot combine the medicine and the holy water together so they discontinue medical treatment and take only the holy water. If the holy water does not help them, they return to the hospital and usually they come when the cancer has spread." (Dr.m3)

Masculine society

Most often, male family caregivers are the one who make decisions and discuss the patient's issues especially when it comes to children as patients:

"Usually, male family members are the ones who make decisions for the patients, especially if the patient is a child it's often the father who makes the ultimate decision" (Dr.f2)

Other doctor participants do not consider cultural issues in doctor, patient and family caregiver's communication:

"I think patients do not think about cultural issues all they think is to be cured, so culture does not play much role in communication." (Dr.f3)

Patients' say about cultural issues in communication:

Most patients and family caregivers do not mind about the cultural issues related to health seeking behaviors but one patient witnessed others who use traditional herbs:

"I have never tried any tradition medicine but I have seen some patients here, who has taken traditional medicine and got worsen and the doctors could not help them much, it is painful to watch." (Pt. f3)

Brief summary of findings for both Uganda and Ethiopia for RQ1

All participants from Uganda and Ethiopia state that communication plays a big role in doctor-patient-family caregiver communication. They assert that if done effectively, it brings about positive emotional and psychological results for all parties involved. They believe that bad communication leads to negative repercussions. In both countries, there are many similar problems that hinder effective communication both on the side of doctors, and patients and family caregivers. For instance, the influx of patients' vis-á-vis doctors, language barriers and lack of information among others. The slight differences emerge from Institutes' settings in both countries. While doctors at Uganda Cancer Institute don't find it offensive to break bad news to the patients, some doctors in Ethiopia, Black Lion Cancer Institute think it is inappropriate for them to break bad news directly to patients, rather to break it to the family caregivers. In both countries, patients and family caregivers desire to have more information about cancer disease yet doctors think, they give them enough information.

4.3 RQ2 Public awareness of cancer disease in Uganda and Ethiopia

In total 300 questionnaires were randomly distributed to respondents, 150 in Uganda and 150 in Ethiopia. 134 questionnaires in Uganda were fully completed but 26 questionnaires were not returned by the respondents. All the questionnaires distributed in Ethiopia were completed. In total, 284 respondents successfully completed the questionnaires in both countries within a period of six weeks. In Uganda, the respondents were selected from Kampala city and some parts of Wakiso district whereas in Ethiopia, respondents were selected from Addis Ababa city. The intention of these questionnaires was to gauge public awareness and knowledge about cancer disease in both countries respectively. In Uganda, male respondents accounted for 47.76% [64 in number] and female respondents 52.23% [70 in number] and in Ethiopian male respondents constituted for 66% [99 in number] and female respondents were 34% [51 in number].

4.3.1 RQ2 (a) Age and Gender

Respondents' age ranged from 18 years to 53+ in both countries. In Uganda, respondents aged 18-22 in both male and female dominated in the study. Male respondents accounted for 45.31% and female 58.57%. The least respondents in male were aged between 43-52 years accounting for 1.56% whereas in women, it was 53+ years constituted 1.43%. (See Appendix 32)

In Ethiopia, respondents aged 23-27 years in both male and female dominated in the study. Male respondents were comprised of 38.38% and female 35.29%. The least respondents for male were between 38-42 years with 1.01% while female between 48-52 accounted for 1.96%. Table 11, presents a general overview of the respondents' age group and gender. (See Appendix 34)

4.3.2 RQ2 (b) Education Level

In Uganda, the dominant group of respondents were secondary school unfinished, constituting 39.06% in males and 44.29% in females. They were followed by college and university respondents who accounted for 39.06% in males and 40% in females. No respondent falls into home education and didn't attend school category. (See Appendix 32)

In Ethiopia, respondents in the college/university category, dominated the study with 78.79% in males and 74.51% in females. They were followed by secondary school unfinished with 12.12% in males and 11.76% in females. There was no male respondent in home education category. (See Appendix 34)

4.3.3 RQ2 (c) The respondents' frequency of hearing about cancer

In both countries, respondents revealed how often they hear about cancer. In Uganda, all respondents had ever heard of cancer disease. On a daily basis, female respondents took a lead with 30% and on a weekly basis, male respondents dominated with 39.06%. The least category of respondents who heard about cancer once in a year constituted 6.25% in males and 4.29% in females. In general, female respondents hear about cancer more often than males. (See Appendix 32)

In Ethiopia, some of the participants had never heard of cancer disease. This group constitutes 1.01% males and 5.88% females. Female respondents who hear about cancer once in a year, dominated in the study with 31.37% and they also dominated in a daily basis category. The overall results show that women hear about cancer more often than men. (See Appendix 34)

4.3.4 RQ2 (d) How much the respondents think they know about these types of cancers

The respondents revealed how much they think they know about the types of cancers mentioned. In Uganda, 17% of female respondents knew nothing about cervical cancer and 34.29% knew little about it. 15.63% of male participants knew nothing about cancer whereas 31.25% of them knew little about it. The results show that female respondents knew very much about cervical cancer than their male counterparts. (See Appendix 32) In Ethiopia, both male and female respondents who know 'nothing' about cervical cancer took a lead in this study category, males accounting for 43.43% and females 41.18% respectively. Only 8.08% of male respondents know very much about cervical cancer and women constituted 9.80% in this category. (See Appendix 34)

Results from Uganda indicate that female respondents know 'very much' about breast cancer, accounting for 28.57% while their male counterparts showed high numbers in having 'little' knowledge about the disease with 29.69%. Results show that very few males [9.38%] and females [0.57] respondents know 'nothing' about breast cancer disease. On contrary, the general results from Ethiopia indicate that men are more knowledgeable about breast cancer than women. The constitute 22.22% in the 'very much' category while the females account for 19.61%. Those who no 'nothing' about breast cancer comprise of 7.07% males and 11.76% females. (See Appendix 32&34)

Concerning lung cancer, male respondents from Uganda indicate a high percentage [23.44%] in having 'enough' knowledge about lung cancer whereas female respondents show high percentages [22.86%] in having 'little' knowledge about this type of cancer. Both respondents indicate that there is still a high percentage of people who know 'nothing' about lung cancer with 18.75% in males and 25.71% in females. (See Appendix 32) In Ethiopia, male respondents indicate having 'very much' knowledge about lung cancer with 14.14% whereas their female counterparts think they have 'enough' knowledge about this type of cancer with 25.49%. Both males and females show a high number of respondents who know 'nothing' about lung cancer i.e. 20.20% in males and 23.53% in females. (See Appendix 34)

Brain cancer knowledge is quite low in Uganda. Results for both respondents show high percentages of the public having 'nothing', 'little' and 'very little' knowledge about this type of cancer. (See Appendix 32&33) The case slightly changes with Ethiopia in that they are aware of brain cancer than Ugandans. Results indicate that male respondents are more knowledgeable about brain cancer than female respondents. (See Appendix 34&35)

Though Kaposi sarcoma is the leading type of cancer to affect people in Uganda, the public has no knowledge about it. The results from the study indicate that 76.56% of male respondents and 98.57 % of their female counterparts know ‘nothing’ about this type of cancer. Male respondents take a lead in having some knowledge about Kaposi sarcoma than female respondents. (See Appendix 33) In Ethiopia, Kaposi sarcoma is among the ten common cancers in the country. Not different from Uganda, Ethiopian’s knowledge about this cancer is so limited. 62.63% of male respondents and 80.39% of female respondents know ‘Nothing’ about Kaposi sarcoma. Still men take a lead in having some knowledge about this type of cancer than women. (See Appendix 35)

Apart from the mentioned types of cancers above only two respondents in Uganda mentioned three other types of cancers called skin, prostate and Esophageal cancer. (See Appendix 33) In Ethiopia, respondents mentioned nine other types of cancers called pancreatic renal, skin, rhabdomyo sarcoma, melanoma, Ewing sarcoma, blood cancer, lever, nasopharyngeal and carcinoma. (See Appendix 35)

4.3.5 RQ2 (d[i]) Public Perception about cancer disease in Uganda

In Uganda, 50% of male respondents and 43% of females answered ‘Yes’ to a statement that ‘Cancer happens when abnormal cells of body grow without control. However, 11% of males and 4% of female respondents answered ‘No’. 39% of male respondents and 53% of females answered ‘I don’t know’. 28% of male respondents and 21% of females answered ‘Yes’ to a statement that ‘Cancer is cause by virus’. In the same statement 52% of male respondents and 30% of females answered ‘No’. The ‘I don’t know’ answers accounted for 20% in male respondents and 49% in females. No male respondents answered ‘Yes’ to a statement that ‘Cancer is caused by a curse’ but 1% of female respondents did. The majority of both respondents answered ‘No’ to the statement accounting for 78% males and 80% females respectively. 22% of male and 19% of female respondents answered ‘I don’t know’.

More so, only 1.5% of male and 1% of female respondents answered ‘Yes’ to a statement that ‘Witchcraft can cause cancer (evil eye)’. Most of the respondents answered ‘No’ to this statement with 97% of male and 76% of female respondents respectively. More so, 1.5% of male and 23% of female respondents answered ‘I don’t know’. Respondents’ reaction to ‘Fate/destiny causes cancer’ was ‘Yes’ by 5% of male respondents and 8% of females. The majority of respondents answered ‘No’ with 67% of males and 66% of female respondents respectively. The ‘I don’t know’ answers, constituted for 28% of male and 26% of female respondents.

About ‘HIV can cause cancer’, the majority of respondents answered ‘No’ (63% of males and 43% of females) respectively. The percentage of respondents who answered ‘Yes’, accounted for 28% of male respondents and 31% of female respondents. The ‘I don’t know’ answers constituted 9% in males and 26% of females. A big percentage of male respondents answered ‘Yes’ with 58% on a statement that ‘Old people usually get cancer’, while their female counterparts had 31%. In the ‘No’ section male respondents have 31% and 43% of female respondents. In the ‘I don’t know’ section, male respondents accounted for 11% while female 26%.

25% of male and 24% of female respondents answered ‘Yes’ to a statement that ‘Cause of cancer is unknown’ while a 62.5% of males and 56% of females answered ‘No’. The ‘I don’t know’ category, constituted of 12.5% of male and 20% of female respondents. The majority of both respondents answered ‘Yes’ (84% of male and 86% of female) on the statement that ‘anybody can get cancer’ while 16% males and 7% answered ‘No’. Only 7% of female respondents answered ‘I don’t know’ and no male respondents marked in this column. To a statement that ‘Cancer is not a life threatening disease’, the majority of respondents answered ‘No’ with 70% of males and 76% of females. Only 22% of males and 14% of female respondents answered ‘Yes’ to the statement. The ‘I don’t know’ category was comprised of 8% of males and 10% of female respondents.

Furthermore, respondents’ reaction about ‘There are no specific symptoms and early detection of cancer is difficult’ was comprised of 42% of male respondents and 34% of female respondents saying ‘Yes’. A same percentage (53%) appeared for both males and females who answered ‘No’, and 5% males and 13% females saying ‘I don’t know’. About ‘Cancer is an infectious disease’, the majority of respondents answered ‘No’ (64% of males and 57% of females). 30% of males and 26% of female respondents answered ‘Yes’ whereas 6% of males and 17% of female respondents answered with ‘I don’t know’.

The majority of respondents agree to the statement that ‘Smoking can cause cancer’ and they constitute 89% of male respondents and 91% of females. 8% of male respondents answered ‘No’ and 0% for female respondents. 3% of male respondents and 9% of females answered ‘I don’t know’. Further still, most male and female respondent answered ‘Yes’ to the statement that ‘Alcohol addiction can cause cancer’. They constitute 64% of males and 73% of female respondents. 22% of males and 13% of female respondents answered ‘No’ to this statement and 14% for both males and females answered ‘I don’t know’.

The majority of respondents concur with the statement that ‘Much sun exposure or ultra violet rays can cause cancer’, accounting for 64% of males and 57% of female respondent whereas 17% of males and 19% of females answered ‘No’. 19% of males and 24% of female respondents in this category answered ‘I don’t know’. 63% of male respondents and 61% of females answered ‘Yes’ to the statement, ‘A balanced diet reduces the possibility of getting cancer’ while 20% and 23% respectively answered ‘No’. 17% of male and 16% of female respondents answered ‘I don’t know’ in this statement.

High percentages also appear in the ‘Yes’ column of ‘Regular health checkup detects cancer early’ (94% of male and 90% of female respondent). A small percentage comprised of 5% of males and 4% of females don’t agree with the statement, whereas 1% of males and 6% of female respondents answered ‘I don’t know’. More high percentages in ‘Yes’ column appear in a statement that ‘Self breast examination is the best way to detect cancer’ with 63% of male respondents and 64.4% of females. 20% of males and 21.4% of females answered ‘No’ to this statement while 17% of males and 14.2% of females marked ‘I don’t know’ column.

The ‘Yes’ column in the ‘Regular exercise reduces the chances of getting cancer’ still dominated with 50% of male respondents and 41% of females whereas 31% of male respondents and 30% of females, marked ‘No’. 19% of male respondents and 29% of females responded with ‘I don’t know’. ‘Uncontrolled sexual behavior can cause cancer’. On this statement, 42% of male respondents and 51.43% of females answered ‘Yes’, 36% of males and 27.14% of female respondents marked ‘No’ and the ‘I don’t know’ category was comprised of 22% of males and 21.43% of female respondents.

28% of male respondents and 43% of females believe that ‘If you are a religious person (you have faith), faith can cure you’. On the other hand, 61% of males and 44% of female respondents don’t believe it whereas the ‘I don’t know’ category constitutes of 11% of males and 13% of females. A big percentage of male respondents (91%) and (86%) of females disagree with the statement that ‘Sacrifice things to gods can cure cancer’. Only 1% of males and 3% of female respondents answered ‘Yes’ and 8% of male respondents and 11% females answered ‘I don’t know’.

‘Medicine men can help with herbs to cure cancer’. In this statement, 27% of males and 23% of female respondents answered ‘Yes’ while the ‘No’ answers have 56% for both male and female respondents. The ‘I don’t know’ category was comprised of 17% males and 21% females respectively. 69% of male respondents and 40% of females answered ‘Yes’ to a statement that the ‘Hospital is the last place you turn to after you get cancer’. 25% of males and 57% of female respondents answered ‘No’ and only 6% of males and 3% of females answered ‘I don’t know’. (See Appendix 33)

4.3.6 RQ2 (d [ii]) Public Perception about cancer disease in Ethiopia

In Ethiopia, 70% of male and 61% of female respondents answered ‘Yes’ to a statement that ‘Cancer happens when abnormal cells of body grow without control. However, 9% of male respondents and 0% of female respondents answered ‘No’. 21% of male respondents and 39% of female respondent answered ‘I don’t know’. 33.33% of male respondents and 22% of female respondents answered ‘Yes’ to a statement that ‘Cancer is cause by virus’. In the same statement 45.45% of male respondents and 43% of female respondents answered ‘No’. The ‘I don’t know’ answers accounted for 21.21% in male respondents and 35% in female respondents.

8% male respondents and 12% females answered ‘Yes’ to a statement that ‘Cancer is caused by a curse’. The majority of both respondents answered ‘No’ to the statement accounting for 66% males and 51% females respectively. 26% of male and 37% of female respondents answered ‘I don’t know’. More so, only 4% of male and 6% of female respondents answered ‘Yes’ to a statement that ‘Witchcraft can cause cancer (evil eye)’. The majority of the respondents answered ‘No’ to this statement with 79% of male and 69% of female respondents respectively. More so, 17% of male and 25% of female respondents answered ‘I don’t know’. Respondents’ reaction to ‘Fate/destiny causes cancer’ was ‘Yes’ by 13.13% of male and 14% of female respondents. The majority of respondents answered ‘No’ with 62.62% of males and 57% of female respondents respectively. The ‘I don’t know’ answers, constituted for 24.24% of male and 29% of female respondents.

The percentage of respondents who answered ‘Yes’, to a statement that ‘HIV can cause cancer’ are 35.35% of male respondents and 31.37% of female respondents. The ‘No’ respondents are 49.49% of males and 41.17% of females and the ‘I don’t know’ answers constituted 15.15% in males and 27.45% of females. A big percentage of male respondents answered ‘Yes’ with 52% on a statement that ‘Old people usually get cancer’, while their female counterparts had 39%. In the ‘No’ section male respondents have 30% and 39% of female respondents. In the ‘I don’t know’ section, male respondents accounted for 18% while female 22%.

46% of male and 51% of female respondents answered ‘Yes’ to a statement that, “Cause of cancer is unknown’ while 36% of males and 25% of females answered ‘No’. The ‘I don’t know’ category, constituted of 18% of male and 24% of female respondents. The majority of both respondents answered ‘Yes’ (77% of male and 71% of female) on the statement that ‘Anybody can get cancer’ while 17% males and 21% answered ‘No’. Only 6% of male respondents and 8% of their female counterparts answered ‘I don’t know’.

To a statement that ‘Cancer is not a life threatening disease’, the majority of respondents answered ‘No’ with 75% of males and 55% of females. Only 16% of males and 27% of female respondents answered ‘Yes’ to the statement. The ‘I don’t know’ category was comprised of

9% of males and 18% of female respondents. Furthermore, respondents' reaction about 'There are no specific symptoms and early detection of cancer is difficult' was comprised of 42.42% of male respondents and 49% of female respondents saying 'Yes'. 41.41% males and 33% female respondents answered 'No', and 16% males and 18% females saying 'I don't know'. About 'Cancer is an infectious disease', most of respondents answered 'No' (58% of males and 47.05% of females). 25% of males and 25.49% of female respondents answered 'Yes' whereas 17% of males and 27.45% of female respondents answered with 'I don't know'.

The majority of respondents agree to the statement that 'Smoking can cause cancer' and they constitute 85% of male respondents and 82% of females. 8% of male respondents answered 'No' and 8% for female respondents. 7% of male respondents and 10% of females answered 'I don't know'. Further still, most male and female respondent answered 'Yes' to the statement that 'Alcohol addiction can cause cancer'. They constitute 80% of males and 72% of female respondents. 8% of males and 4% of female respondents answered 'No' to this statement while 12% males and 24% of females answered 'I don't know'. The majority of respondents concur with the statement that 'Much sun exposure or ultra violet rays can cause cancer', accounting for 79% of males and 74% of female respondent whereas 9% of males and 2% of females answered 'No'. 12% of males and 24% of female respondents in this category answered 'I don't know'.

75% of male respondents and 61% of females answered 'Yes' to the statement, 'A balanced diet reduces the possibility of getting cancer' while 7% and 8% respectively answered 'No'. 18% of male and 31% of female respondents answered 'I don't know' in this statement. High percentages also appear in the 'Yes' column of 'Regular health checkup detects cancer early' (93% of male and 82% of female respondent). A small percentage comprised of 2% of males and 4% of females don't agree with the statement, whereas 5% of males and 14% of female respondents answered 'I don't know'.

More high percentages in 'Yes' column appear in a statement that 'Self breast examination is the best way to detect cancer' with 78% of male respondents and 76% of females. 15% of males and 6% of females answered 'No' to this statement while 7% of males and 18% of females marked 'I don't know' column. The 'Yes' column in the 'Regular exercise reduces the chances of getting cancer' still dominated with 80% of male respondents and 59% of females whereas 6% of male respondents and 6% of females, marked 'No'. 14% of male respondents and 35% of females responded with 'I don't know'. 'Uncontrolled sexual behavior can cause cancer'. On this statement, 56% of male respondents and 43% of females answered 'Yes', 27% of males and 16% of female respondents marked 'No' and the 'I don't know' category was comprised of 17% of males and 41% of female respondents.

62% of male respondents and 65% of females believe that 'If you are a religious person (you have faith), faith can cure you'. On the other hand, 27% of males and 21% of female respondents don't believe it whereas the 'I don't know' category constitutes of 11% of males and 14% of females. 57% of male respondents and 35.29 of females disagree with the statement that 'Sacrifice things to gods can cure cancer'. 21% of males and 37.25% of female respondents answered 'Yes' and 22% of male respondents and 27.45% females answered 'I don't know'.

'Medicine men can help with herbs to cure cancer'. In this statement, 29.29% of males and 33.33% of female respondents answered 'Yes' while the 'No' answers have 43.43% for male and 27.45% female respondents. The 'I don't know' category was comprised of 27.27% males and 39.21% females respectively. 44.44% of male respondents and 33% of females answered

‘Yes’ to a statement that the ‘Hospital is the last place you turn to after you get cancer’. 42.42% of males and 53% of female respondents answered ‘No’ and only 13.12% of males and 14% of females answered ‘I don’t know’. (See Appendix 35)

4.3.7 RQ2 (e) Respondents’ need for more information about cancer.

In both countries, respondents expressed need for more information about cancer disease indicating that most of the people especially in the rural areas are not aware of cancer. In Uganda, 95.31% of male respondents and 94.29 females need more information about cancer. Only 4.67% of male and 1.43% of female respondents don’t need the information. 4.29 of female respondents don’t know if they need more information about cancer and there is 0% of male respondents in this category. (See Appendix 33) In Ethiopia, 92.93% of male respondents and 100% of females need more information about cancer disease. Only 6.06% of male respondents do not need the information and 1.01% don’t know if they need the information. (See Appendix 35)

4.3.8 RQ2 (e) Respondents’ opinion about public awareness of cancer disease.

The respondents’ opinion about public awareness of cancer disease was measured and the findings indicate that in Uganda 48.44% of male respondents and 58.57% of females think that the public is aware of cancer disease. 45.31% of male respondents and 27.14 of their female counterparts think that the public is not aware of cancer disease whereas 6.25% males and 14.29% females do not know. (See Appendix 33) In Ethiopia, 21.21% of male and 27.45% of female respondents think that the public is aware of cancer disease whereas 71.27% males and 70.59% of female respondents think otherwise. Only 7.07% of male respondents and 1.96 of females do not know. (See Appendix 35)

5. DISCUSSION

In this study, doctor-patient and doctor-family caregiver’s communication experiences, breaking bad news, language, cultural issues, and the role of communication in cancer consultation meetings of the two study hospitals were addressed. Secondly, public awareness about cancer disease in Uganda and Ethiopia, was also investigated.

5.1 Discussion RQ1 - Uganda

5.1.1 RQ1(a) Communication experiences

At the Uganda Cancer Institute, the influx of patients that limits the time doctors spend with patients, language hurdles, the inabilities of patients and family caregivers to ask questions and lack of understanding are perceived challenges that doctors experience during cancer consultation meetings. Our findings about lack of understanding yield positive relation to Schyve [20] research that “in the absence of comprehension, effective communication does not occur.” In our findings, most patients don’t want to ask questions that lead to their prognosis. Similarly, Barclay et. al [13] mentioned that “One of the areas that patients are least likely to ask about is prognosis.” Language problems coupled with high number of patients and limited time, make it almost impossible for the doctors to practice effective communication. Our investigations connect with Payne Jacqueline [34] that “For the clinician, communication difficulties lead to worse job satisfaction.” As a point to note, even though doctors, patients and family care givers live in the same country, they speak different languages which contribute to language obstacles during cancer consultation meetings.

Patients and family caregivers at Uganda Cancer Institute share the same challenge about the influx of patients which they say not only limit the time doctors spend with them but also exhaust doctors hence affecting their communication skills. Though the majority of patients and family caregivers seem satisfied with the doctors' communication, the minority expressed dissatisfaction with the manner in which doctors give them information. They were also critical of the doctors' inability to answer their questions and the rudeness of nurses. Our findings yield positive relation with Selman L. et al [21], "lack of information coupled with unanswered important questions relating to living with a progressive incurable disease is cited among the major issues for both patients and care givers in Uganda" Patients and family caregivers claim that when doctors express positive attitudes towards them, they feel free to express their concerns to the doctors, understand the given information and also be able to ask questions concerning their lives. Research for example Arbabi M. et al [12] indicates that, "verbal and nonverbal communication skills play an important part in improving doctor-patient relationship." Also Simpson. M. et al [22] mentioned that "the level of psychological distress in patients with a serious illness is less when they perceive themselves to have received adequate information." (p. 1385)

5.1.2 RQ1 (b) The way doctors break bad news

In this study, doctors at Uganda Cancer Institute break bad news mostly in stages and in a progressive manner so as to prepare patients and family caregivers for every step of the bad news. Doctors tend to be careful when breaking bad news and they are aware of the eventualities in case they break the bad news to the patient at once. This connects with Barclay et al [13] research that "With good communication, patients report better outcomes, greater satisfaction, improved understanding, enhanced adherence to treatment and decreased litigation." Our investigations indicate that breaking bad news has no static formula and it varies patient to patient and depending on the situation. In the same manner, Barclay et al [13] mentioned that, "patients often vary in their desire for prognostic disclosure over the course of illness," and Selman L. et al [21] added that, "communication should therefore be individually tailored according to needs, preferences, and abilities, assessed repeatedly at key points in the disease trajectory". This connects with our findings that sometimes breaking bad news vary from patient to patient, depending on the situation and the kind of information they wish to know.

Our investigations indicate that the problems related to breaking bad news include shock and psychological breakdown by patients after receiving the bad news which affects their cooperating mechanisms to treatment options, lack of time to counsel patients and their family caregivers, and challenges to interpret cancer terminologies into the local languages. These results relate to Arbabi M. et al [12] that "The way of presenting bad news affects the patients' understanding of the disease, their psychological adjustment to the disease, satisfaction of medical care and level of hope." Doctors manage patients' reactions by giving them counseling and allowing them to break down which they believe help patients to cope up with the situation and make right treatment decisions.

Doctors agree that patients and their caregivers should be given all information about the disease, treatment plan and the expected side effects and the stage of the disease. If the disease is in its advanced stage, they give the information in an indirect manner. Doctors recognize the importance of family caregivers in the cancer consultation meetings because they handle the patients' care, treatment and its side effects, and hospital appointments. So they think family caregivers should have all the necessary information at fingertips. Our findings indicate that during consultation meetings, family caregivers perceive the information more than the patient.

5.1.3 RQ1 (c) The way patients and family caregivers receive bad news

Our findings indicate that the majority of patients and family caregivers were not prepared for the bad news and did not get adequate information about their disease. Even though some were prepared, they did not get any information concerning their condition. Patients and family caregivers describe the manner in which the information was delivered to them as inappropriate. As much as the patients and their family caregivers were informed of the kind of cancer they have, they still needed more information about the disease and their condition which was not given to them. This relates to Simpson. M. et al [22], report that, "doctors often misperceive the amount and type of information patients want." (p.1385) Patients and family caregiver wish to have all the information about their prognosis but they want this information to be presented to them in a positive manner. They contradict with the doctors' claims that they prepare patients and family caregivers before breaking the bad news. However, they share the same view with doctors about the appropriate information to get from doctors like all the information about cancer, its treatment, side effects and patient's care.

5.1.4 RQ1 (d) Language usage

Just like Simpson M. et al [22] state that "the language doctors use is often unclear, both as regards the use of jargons and in relation to a lack of expected shared meanings of relatively common terms," (p. 1385), the data we obtained indicate that doctors face a big challenge to interpret medical jargons to local languages. Additionally, the existence of many languages in the country coupled with additional local languages of patients from neighboring countries and lack of interpreters are perceived obstacles of language usage at Uganda Cancer Institute. This is similar to Schyve [20] statement that "the language differences themselves are a barrier to effective communication. Lack of interpreters also relate to Regenstein [35] research data that "language services are frequently provided by self-declared bilingual clinical providers and ad hoc interpreters, such as family members, friends or staff who have not been trained and assessed in medical interpreting." More so, our findings indicate that the use of unqualified interpreters who sometimes misinterpret and deliver a wrong or different message was cited among language barriers. This finding still connects to what Regenstein [35] that "using unqualified individuals lead to increased medical errors, less effective patient-clinical provider communication and poorer follow-ups and adherence to clinical instructions."

5.1.5 RQ1 (e) The role of communication in cancer consultations

Our findings indicate that doctor participants at Uganda Cancer Institute believe that communication plays a big role in achieving a proper diagnosis, it's a channel of information giving and a means of education. To patients and family caregivers, communication plays a vital role in decision making, influences their health seeking behaviors, and reduces stress and creates hope if done effectively. In support to what Schyve [20] called "triple treat", our participants identified the causes of poor communication as misinterpretation of messages, shortage of time, lack of communication skills, workload and a disproportionate number of doctors to patients. Other causes are low salaries for physicians, stress, anxiety and discontentment were perceived critical causes of poor communication.

5.1.6 RQ1 (f) Cultural issues involved

The critical cultural barriers to health seeking behaviors at Uganda Cancer Institute include the use of traditional herbs, social perception of women and lack of cancer awareness. Others are stigma and religious aspects such as unacceptance to blood transfusion, believing in prayers to cure cancer and women's refusal of male intimate examination. Somehow, this relates to Kiguli Sarah et. al [19] that caregivers want doctors to consider their beliefs, concerns and expectations.

5.2 Discussion RQ1 Ethiopia

5.2.1 RQ1(a) Communication experiences

Our study results from Black Lion Cancer Institute exhibit the significance of communication among doctors, patients and family caregivers during cancer consultation meetings. As Rimal et al [36], stated that healthcare communication considered as pertinent for practically every future of health and wellbeing, which include disease prevention, health promotion and quality of life.

All participants in the study agreed that communication plays a vital role however; they experience their communication differently. Doctor participants experience their communication as challenging basing on Patient's literacy level, lack of awareness about cancer, language barriers, the influx of patients and the physical environment. Lack of physical environment hampers patients from expressing themselves freely since other people come and interrupt the interaction between doctor and patient. Patient's literacy level is also another factor that hinders doctor's communication with patients and their family caregivers and also lack of awareness about the disease is another issue. The influx of patients and physicians number are not proportional and that contribute to load of work for physicians. The mentioned challenges lead to misunderstanding and that hinder effective communication. When misunderstanding occurs in communication it creates, stress, dissatisfaction, anxiety and it can also put patient's safety at risk. Schyve [20] indicates that "when effective communication is absent, the provision of health care ends or proceeds only with errors, poor quality, and risks to patient safety."

Patients and family caregivers describe their communication with doctors satisfying only basing on the fact that they are friendly and kind. They also appreciated positive feedbacks from physicians which can give them hope and courage to fight the disease. Simpson et al, [22], mentioned that, "Doctors attending to patients need to encourage them to discuss their main concern without interruptions or premature closure to enhance the satisfaction and efficacy of the consultation." (P.1386) However, they complain about obtaining inadequate information and feel disregarded when they ask questions. Due to doctor's load of work patients get limited time and they receive insufficient information that can lead to misunderstanding. Patient participants and family caregivers claim that some doctors lack knowledge of how to deliver information and disregard patients' and family caregivers' questions, which often cause anxiety, dissatisfaction and discourage patients. Simpson. M. et al [22, 1385], states that "Patients anxiety and dissatisfaction is related to uncertainty and lack of information, explanation, and feedback from the doctor." Lindström [9] also mentions that "the physicians' responsibility in a medical consultation is to help patients to solve their health problems and patients' part in the consultation is to deliver pertinent and sufficient information to physicians.

5.2.2 RQ1 (b) The way doctors break bad news

Our study indicates that all the doctor participants agree that breaking a bad news is vital yet challenging. Even if they all contemplate that conveying the bad news is significant, but the way they deliver it differ from one another. Some doctors prefer involving other professionals, family caregivers and others prefer only patients. Physicians have different ways to deliver the bad news, for instance the doctors who only involve family caregivers believe that it is in appropriate telling facts for the patients about their disease as it can worsen their health outcome. Other doctors contemplate that it is appropriate to deliver the bad news to patients, patients have to know the fact about their disease, like the type of the disease, the stage and the treatments options etc. Additionally, doctor participants deliver the bad news depending on the patient's educational backgrounds. Arbabi M. et al [12] points out that the physician's "way of conveying bad news influence patient's understanding of the disease, their psychological adjustment to the disease and also affect satisfaction of medical care and their level of hope."

5.2.3 RQ1 (c) The way patients and family caregivers receive bad news

Some patients and family caregivers recall their experience after receiving bad news as heartbreaking basing on the ways doctors delivered it. Barclay S. Joshua et al [13, p.959], state that "Communicating bad news creates an everlasting repercussion on the patients' and family caregivers' reminiscences of a medical encounter. Our study shows that most of patient and family caregiver participants consider all information as appropriate, and they want to obtain all information that concerns their health. They contradict with the doctors' claims that delivering facts about the disease and it stages can worsen patient's health outcome.

5.2.4 RQ1 (d) Language usage

Our findings illustrate that language barrier, adapt to layman's language and finding the right terms are some factors that affect effective communication. Most of the doctor participants consider language barrier as an obvious challenge during interaction with patients and their family caregivers. The difficulty is not only patients speak different language but also to be able translate medical terms to Amharic and other languages. This relate to Simpson. M. et al [22, 1385] research that "doctors often use language which is unclear as regard of jargons and in relation to a lack of expected shared meanings of relatively common terms."

Black Lion Cancer Institute does not provide interpreters and whenever the doctors meet patients who do not speak Amharic they have to find someone to interpret who could be a nurse or other patients or family caregivers. This negatively effects both physicians and patients as it can be difficult for doctors to diagnosis patients if they do not get right information from the patients. On the other hand, patients find it hard to get someone who can interpret for them. Also patients might not express sensitive issues for family caregivers if family caregiver is the only alternative they have to interpret. Schyve 2007 state that [20], "the language differences themselves are a barrier to effective communication." Most of the patients and their family caregivers never experienced language barrier in communication with doctors, and they also describe that the majority doctors do not use medical terms during interaction. However, few patients and family caregiver participants experienced language barriers because doctors do not speak their language and it is hard for them to get interpreters. Patients and family caregivers often told to find someone who speaks their language and can help them to interpret. Regenstein [35] indicates that using unqualified individuals lead to increased medical errors, less effective patient-clinical provider communication and poorer follow-ups and adherence to clinical instructions, as well as possible conflicts with patient privacy rights.

5.2.5 RQ1 (e) The role of communication in cancer consultations

Our study shows that all doctor, patients and family caregiver participants regard communication as a vital instrument that can play a significant role in doctor, patient and family caregivers' interaction. With good communication, doctor participants claim that patients and family caregivers gain trust in doctors hence opening up to them. Through communication conflict can be resolved and managed. Doctors experienced conflicts in one way or the other when they interact with patients and their family caregivers due to misunderstanding. Usually conflicts occur when there are misunderstandings and misinterpretations.

In order to manage treatment plan patients and family caregivers need to understand well all the information that is given by their doctors. And also doctors must be sure that the information they delivered to the patients and family caregivers have well understood. Barclay S. et al [13] state that "With good communication, patients report better outcomes, greater satisfaction, improved understanding, enhanced adherence to treatment and decreased litigation." (p. 95). Our investigations indicate that doctors, patients and family caregivers believe that effective communication gives satisfaction and improves patient's psychological well-being. Meaning that good communication reduces their anxiety and stress. According to Simpson. M. et al [22], "The level of psychological distress in patients with a serious illness is less when they perceive themselves to have received adequate information." Patients also state that with good communication they can express feelings and expectations to physicians that help to elicit information that can be used in patients' diagnosis. According to some patient participants it is vital for health communication that doctors have communication skill for better out comes. As Arbabi M. et al [12] assert that, "Physicians' failure in communication skills leads to patients' resentment and also inspires the feeling of incompetency in physicians to control the patients' pain and symptoms."

5.2.6 RQ1 (f) Cultural issues involves

Our results show that only a few number of doctors put into consideration cultural issues related to cancer during consultations. They identified several cultural issues that hinder patients' health seeking behaviors such as, traditional healers, stigma, taboo, religious aspects and masculine society. They state that, most of the patients who come from rural areas seek traditional healers first before coming to the hospital. Most Orthodox Christians go to holy water to get healed yet this interrupts their medical treatment. Most of them come back to the hospital in critical conditions after realizing that the holy water didn't work. In some cultures, men are socially dominant since they have the ultimate power to make decisions for patients. And in some cases they do not allow their wife to be examined without the man's presence. Some doctor participants state that cancer patients are not stigmatized as compared to some other patients with communicable diseases such as tuberculosis and Aids. They think that culture doesn't hinder patient's health seeking behaviors and affect treatment outcomes. As Schyve [20] mentions, "there is a risk of either underestimating the effect of cultural differences or of stereotyping individuals by their culture. Both will interfere with the effectiveness of communication."

5.3 Discussion RQ2 Uganda & Ethiopia

5.3.1 RQ2 (a) Age, gender and education level

The dominant age group in our study from Uganda is 18-22 years whereas in Ethiopia, it is 23-27 years. The least age group of respondents ranges from age 43 -52 years and in Ethiopia 38-42 years. The majority of respondents' education background in Uganda is secondary school unfinished and college/university level. In Ethiopia, college/university dominated.

5.3.2 RQ2 (b) Respondents' frequency of hearing about cancer

In Uganda, all respondents have ever heard of cancer and female respondents hear more about cancer on a daily basis than males however male respondent hear about cancer more on a weekly basis than females. In Ethiopia, there is a slight difference between male and female respondents who hear about cancer on a daily and weekly basis. However, there is a small percentage of male and female respondents who have never heard of cancer disease in the study.

5.3.3 RQ2 (c) How much the respondents think they know about these types of cancers

About cervical cancer knowledge, the results from Uganda indicate that male and female respondents compete but the majority of the respondents have little knowledge about the disease. Comparing to Uganda, Ethiopian respondents have little knowledge about cervical cancer. In this country, the majority of respondents know nothing about the disease. Concerning breast cancer knowledge, results from Uganda show that female respondents know very much than their male counterparts. However, the case changes with Ethiopia in which men are more knowledgeable about the disease than their female counterparts. Results from Uganda indicate that male respondents dominate in having enough knowledge about lung cancer than females while high numbers of less knowledge and no knowledge appear in the female respondents. In Ethiopia, male respondents know very much about lung cancer and the females tend to have enough knowledge about the disease. The percentage of those who know nothing about lung cancer still remains high in both. In Uganda, most male and female respondents are not informed of brain cancer but female respondents are more uninformed than their male counterparts. In Ethiopia, however, both respondents are more knowledgeable about brain cancer than their counterparts from Uganda. Despite Kaposi sarcoma being common in both countries, the majority of respondents know nothing about it. Out of 134 respondents from Uganda, only two respondents mentioned other types of cancers while in Ethiopia, out of 150 respondents, 17 respondents mentioned other types of cancers.

5.3.4 RQ2 (d) Public perception about cancer in Uganda and Ethiopia

Respondents' reactions about the cause of cancer, detection and beliefs reveal that female respondents are more uncertain in their responses than males in both countries. The 'I don't know' column of female respondents has high percentages almost in all statements than males yet they claim to hear more often about cancer disease than males. This brings to one's attention to investigate the content of the information female respondents receive which they cannot apply in their responses to the questionnaire. A significant number of both respondents from both countries are aware that cancer happens when abnormal cells of the body grow without control, smoking can cause cancer, alcohol addiction can cause cancer, anybody can get cancer, much sun exposure can cause cancer, a balanced diet reduces cancer, regular health check-up detects cancer early, self-breast examination is the best way to detect cancer and regular exercise reduces the chances of getting cancer. More so, a big percentage of respondents do not believe that cancer is caused by a curse, witchcraft can cause cancer, fate/destiny can cause cancer, sacrifice things to gods can cure cancer and medicine men can help with herbs to cure cancer. Unlike Ugandan respondents, the Ethiopian's respondents believe that if one has faith, he/she can be cured of the infirmity. There are contrasting responses to 'hospital is the last place you turn to after you get cancer.' In Uganda, the majority of male respondents think the hospital is the last place you turn to after you get cancer while the majority of female respondents think otherwise. Similar responses appear in Ethiopia for both respondents.

5.3.5 RQ2 (e) Respondents' need for more information about cancer

In both countries, results indicate that need for more information about cancer is high and the respondents think the public is not aware of the disease.

6. CONCLUSION

The data we have collected proves that problems associated with doctor-patient and doctor-family caregivers are frequent and negatively influence patients' emotional and psychological wellbeing. Problems like language barriers, lack of communication skills, patients' inabilities to ask questions among others can be eliminated by the doctors if they get communication skill training. On the other hand, the government plays an important role to provide an environment that is conducive for the doctors to exercise their communication skills. Otherwise even if the doctors have the skills when the environment doesn't permit them, poor communication will still remain a problem. Communication as a course has to be emphasized in the medical school curriculums in order to equip physicians with the skills needed to succeed when communicating with patients and their family caregivers. More so, the masses should be sensitized about cancer disease since now it kills more people than HIV, Malaria and Tuberculosis combined.

6.1 Implications for future research

This study can be a starting point for the future researches in the field of health and communication. More investigation should be applied countrywide about doctor-patient and doctor- caregiver communication in general hospitals. More still, countrywide investigation about public awareness of cancer disease should be carried out. Future investigations should focus on 1). How do environmental factors affect doctor-patient and doctor-caregiver's communication? 2). Does poor communication have a long term physical effect on patients' health outcomes? 3). Is it possible to implement effective communication when the number of doctors is disproportionate to the number of patients?

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