



**UNIVERSITY of  
RWANDA**

**NEEDS ASSESSMENT OF PATIENTS WITH CANCER ATTENDING OUTPATIENT  
DEPARTMENT AT A SELECTED REFERAL HOSPITAL IN KIGALI**

**MUTEGARABA CHANTAL**

**COLLEGE OF MEDICINE AND HEALTH SCIENCES**

**SCHOOL OF NURSING AND MIDWIFERY**

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DEPARTMENT AT A SELECTED REFERAL HOSPITAL IN KIGALI**

**By**

**MUTEGARABA Chantal**

**218001163**

**A dissertation submitted in partial fulfillment of the requirements for the degree of  
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**In the College of Medicine and Health Sciences**

**Supervisor: Dr.Anita Collins**

**Co-Supervisor: Mrs. UWAYEZU M.Goretti**

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## **DECLARATION**

I do here declare that this research entitled NEEDS ASSESSMENT OF CANCER PATIENTS ATTENDING OUTPATIENT DEPARTMENT AT A SELECTED REFERRAL HOSPITAL IN KIGALI as a part of the requirements in the Degree of Masters in Nursing Sciences at the University of Rwanda, College of Medicine and Health Sciences; it is my original work and has not been submitted before elsewhere. I declare that a complete list of references is provided to indicate all the sources of information.

MUTEGARABA Chantal

## **DEDICATION**

I dedicate this project to Almighty God, my creator, my strong pillar, my source of inspiration, wisdom, knowledge and understanding. He has been the source of my strength throughout this program.

I also dedicate this work to my husband DUKUZE BOYI E. who has encouraged and helped me all the way.

To my children S. Livia, G. Igor who have been affected in every way possible by my studies.

To Dr Andrea Bonachi

To my supervisors

To my brothers and sisters

To my sisters in law

To all my classmates

Thank you.

God bless you

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I recognize all individuals who contributed to the success of this work.

May the almighty God bless you all!

## ABSTRACT

**Background:** Globally cancer diagnosis is a complex problem to the patients and to the health care providers also to the family members of the patients with cancer. Cancer patients have different needs during their disease trajectory. The most needs expressed by cancer patients were fund in providing information about prognosis, medical treatment, information related to their family and psycho social and emotional needs.

**The purpose:** To assess needs of cancer patients attending outpatient department at Rwanda Military Hospital.

**Methods:** In this study, the researcher has used a quantitative approach, descriptive cross section; convenience sampling methods, sample size was 93 adults' cancer patients. Data was gathered and entered into computer, analyzed with SPSS version 21, chi square has been used to assess the association between demographic information with different needs of cancer patients, a logistic regression analysis displaying Odd Ratio and Confidence Interval of 95% has been used. And the results were presented in form of tables.

**Results:** The results shown the high level of needs among patients with cancer in domain of information needs about diagnosis 90.3%, lack of information about different modalities of treatments 71% and need about information on disease prognosis was highly reported to 91.4%. In addition most of participants reported inability to perform their regular job/activities with high proportion of 91.4% but were happy with the support given by the family. The results also showed a strong association between demographic information and needs of cancer patients to be met or unmet.

**Conclusion:** Patients with cancer face many challenges in their disease process; different needs rise as days go on. Unmet needs have been reported in many sensitive domains of needs (information about diagnosis, treatment, and prognosis and psycho social-emotional needs).Health care providers need to be able to assess cancer patients' needs and provide an appropriate care.

## **KEY WORDS**

Need,

Met needs,

Unmet need,

Cancer.

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## **LIST OF SYMBOLS AND ACRONYMS/ABBREVIATIONS**

ACS: American Cancer Society

AIDS: Acquired Immune Deficiency Syndrome

BCCOE: Butaro Cancer Centre Of Excellence

CBHI: Community Based Health Insurance

CHUB: Centre Hospitalier Universitaire de Butare

CHUK: Centre Hospitalier Universitaire de Kigali

CMHS: College Of Medicine and Health Sciences

IRB: Institution Review Board

INT: Institute Nazionale of Timori

KFH: King Faisal Hospital

MMI: Military Medical Insurance

NEQ: Needs Evaluation Questionnaire

NCD: Non-Communicable diseases

SPSS: Statistical Package for the Social Sciences

RMH: Rwanda Military Hospital

RSSB: Rwanda Social Security Board

UK: United Kingdom

US: United States

WHO: World Health Organization

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## **CHAPTER 1. INTRODUCTION**

This chapter one it covers the introduction and background of the study, problem statement, the aim, research objectives, research questions, significance of the study, operational definitions, structure of the study, and conclusion of the chapter.

Globally cancer is the 2<sup>nd</sup> prominent cause of death and was accountable for 8.8 million death cases in 2015, almost 1 in 6 deaths is related to cancer. Identifying and reporting cancer patient's needs are a key for effective disease management. Needs assessment provides a structured opportunity for cancer patients to raise their voice and can be used to normalize and report ongoing challenges following treatment (WHO, 2018).

A need is an inner strength that determines how the patient responds to situations that surround her/him. It is a situation of lack (or surplus) of something and it motivates his/her behavior (Anna and Amelie, 2017). Unmet needs for cancer patients have been described like lack of necessary support to a cancer patient in order to maximize optimal well-being. Patients with cancer reported unmet needs that include problems with physical health and daily living activities, economical, relationship, emotional problems, information transmission and communication needs (Burg et al., 2015).

Diagnosis of cancer, however, not only affects an individual physically but also causes problems in different sides of health. It engenders anxiety and emotional distress related to possible disease progression, potentially shortened lifespan and uncertainty about changes to social role, body image, or treatment option and so forth. After diagnosis, cancer patients often have trouble dealing with and adapting to daily life (Ferrari *et al.*, 2018).

### **1.1. BACKGROUND**

According to World Health Organization, 2012, cancer disease is the most important cause of morbidity and mortality worldwide, nine million people are diagnosed with cancer each year and five million death cases related to cancer are reported each year. In the United States, approximately 1.2 million new cases of cancer are diagnosed each year and 1/15 of all death cases in the U.S are from cancer while the UK counts approximately 273,000 of new cases of cancer diagnosed every year and 160, 000 death cases each year (WHO, 2012).

Cancer is one of the leading causes of death and disease in the U.S. The American Cancer Society (ACS) estimated that roughly 1.7 million new cases of cancer were diagnosed in the

U.S. in 2017 and more than 15 million Americans living today have a cancer history. Not only does cancer take an enormous toll on the health of patients and survivors it also has a tremendous financial impact (J. Singletary, 2017).

However, a study done in Australia, has reported that cancer disease is the foremost cause of death, accounting for nearly one quarter of all deaths (Sanson-fisher et al., 2013). Furthermore, the most commonly explored area of unmet need of cancer patients is within the information need area, the most unmet needs in cancer patients were found to be the provision of information about diagnosis, prognosis, medical treatment, information related to their family and information related on practical and coping issues (Ellegaard et al., 2017)

A study conducted in Denmark has reported that 60% of cancer patients expressed unmet needs in more than one category among numerous categories of needs, and said that once one part of life is affected it affects also other parts of life and this leads to a complex of unmet needs resulting in patient's poor outcome during disease trajectory (Hansen et al., 2013)

In Iran, Tabriz et al., (2017) revealed that the cancer patients had considerable high number of unmet needs in many domains including work and financial, information, access and continuity of care, relationships, and emotional. The elevated incidence of unmet needs among cancer patients has shown the great importance of inserting these needs in daily assessment of all cancer patients (Tabriz *et al.*, 2017b).

Other researchers Fong and Cheah, (2017) in their study, reported that most of cancer patients are dominated by incapability to cope with the situation, emotional variability, matters of body weakness with reduction of physical functioning, a diminished feeling of well-being, inability to maintain social relationships, marital distress, and limited activities of daily living. Unfortunately, the study has shown that many cancer patients are not supported enough to be able to adjust to and manage these challenges (Okediji, Salako and Fatiregun, 2017 p.2)

A study conducted in Iran said that identifying and addressing met and unmet needs of cancer patients they are found to be significant, as many patients come to know their diagnosis more



attention may be given to know their needs, unmet needs were highly reported from 30 to 50% among cancer patients since diagnosis and treatment phase (Tabriz *et al.*, 2017a).

Africa is the continent in which the deaths from cancer occur most frequently, cancer kills more people than malaria, AIDS and tuberculosis combined. Increased rate of cancer disease and mortality as the projection in 2030, that will be newly diagnosed cancer cases of 1.27 million and 0.97 millions of deaths cases, around 85% will be from sub-Saharan Africa and the reasons behind the dramatic situation are population growth and aging in relation to increasing incidence, low socio-economic status and deficient health care infrastructure, resulting in inadequate access to preventive and clinical services also specific exposure patterns (Sylla and Wild, 2012).

African leaders are more interested in cancer prevention, treatments and organizing campaign for people to be aware of cancer disease, however, a little is known regarding cancer patients specific needs in handling patients issues (Søndergaard *et al.*, 2013).

In Nigeria it was found that many cancer patients after cancer confirmation experience a transitory deterioration in their life, however in some cases the diagnosis empowers patients to change viewpoints on their health and life itself (Sylla and Wild, 2012).

Moreover, a study conducted in Ethiopia, showed that information related to cancer disease was vital in patients' needs, the physicians and nurses are the best sources of information and many patients were pleased with the information provided by them (Mekuria *et al.*, 2016). Also it has been pointed out the importance of providing information and education that occupies the chief part in cancer patient's journey. Therefore, the availability of accurate and adequate information does not only lead to good health but also the ability to deal with the disease concerns after its detection (Mekuria *et al.*, 2016).

In Rwanda many people with cancer are diagnosed with advanced stage. This is related to lack of knowledge and special facilities, trained staff to take care and necessary equipment (Thornton J., 2016). As Rwanda becomes increasingly exposed to risk factors for cancer such as tobacco, alcohol use, physical inactivity, sedentarily, factory food and obesity-related illness, infectious diseases; etc., and the burden of cancer is expected to rise. In 2013, the National Institute of Statistics in Rwanda observed that an aging population is expected to increase demand on services for Non-Communicable Diseases in people aged 40 and above.

To take action, the Ministry of Health through Rwanda Biomedical Center developed National Non-Communicable Disease National Strategic Plan (July 2014 - June 2019), which includes cancer-related components and covers prevention of risk factors (including tobacco, harmful use of alcohol, unhealthy diet and physical inactivity). The current cancer patterns in Rwanda indicate that a significant proportion of the future cancer burden may be prevented by planning and implementing prompt preventive actions. The future increases in population and ageing are expected to contribute to further increases in cancer burden unless well planned prevention, early detection and treatment interventions are equitably scaled up across the country.

According to RBC, cancer prevention in Rwanda is based on: controlling unhealthy behaviors like consumption of tobacco and alcohol, control of viral infections like hepatitis B and C which increase the risks of liver cancer, and Human Papilloma Virus causing Cervical Cancer and early detection. Cancer treatment is provided in tertiary level facilities. At present, five hospitals are reported to be delivering cancer care, including CHUK, Rwanda Military Hospital (RMH), KFH(King Faisal Hospital), BCCOE (Butaro Cancer Centre Of Excellence) and Centre Hospitalier Universitaire de Butare (CHUB). The national NCD strategy seeks to allocate resources for all specialties for comprehensive cancer care (including radiation therapy) at 11 provincial referral hospitals and 1 Centre of excellence (reported by RBC, 2016).

In partnership with ministry of education, University of Rwanda has started a postgraduate program for Oncology nursing in order to improve nurses' knowledge and skills for better management of cancer patients in health sectors. But with the effort which is being used still there is a limitation of data about cancer patients met and unmet needs; therefore the present study is of great importance.

## 1.2. PROBLEM STATEMENT

Cancer is the second cause of death in the world. Living with cancer, for many, has become a reality, with all the psychological and physical consequences and needs that this may produce. Living well with cancer and associated treatment is fundamental to a person's well-being and quality of life, and care should wherever possible fit the needs of individual cancer patients and their families. Effective, high-quality cancer care is now viewed as involving more than just the anti-cancer therapy, and increasingly, cancer service providers are required to address patients' care needs (Tabriz *et al.*, 2017a)

The well-being of a cancer patient is determined by how well his or her physical, social, psychological, emotional, and spiritual needs are being met (Ng *et al.*, 2017). It is suggested by Abraham Maslow that the more basic needs in the lower stages must be met before the higher needs can come into focus. However, in the context of cancer therapy, all aspects are assessed and managed concurrently as cancer patients often lose many components of their identity together. Moreover, the distinction between different levels is interlinked and not as disparate as it may seem. For instance, a strong family support may alleviate debilitating physical pain felt by the patients (Ng *et al.*, 2017)

Cancer patients like other patients have different needs during disease process; these needs are categorized in needs related to information, assistance, needs for psychological support, emotional support and physical needs. If patients' needs are not met with the support of knowledgeable health care providers, the patient's health condition will deteriorate (Chiesi *et al.*, 2017).

According to Globocan 2018, in Rwanda number of new cases of cancer, both sex at all ages was 10704 including different types of cancer: cervical(12.2%), breast(10.6%), colorectal(7.8%), stomach(7.5%), liver(6.9%) and others(59%). Among them new cases female were 6184 cases and males were 4520 cases at all ages. The prevalence cases of cancer was 17 997 for 5 years and deaths cases were 7662.

Referred to the data from Statistician at Rwanda Military Hospital, in 2018 the prevalence of cancer cases was 2030 among them new cases were 1155 and old cases were 875.

According to the statistics reported above, the present study is of precious importance as it is intended to reveal much data on needs of cancer patients in Rwanda, precisely at Rwanda Military Hospital.

This is anticipated to help health care providers to be involved in attainment of cancer patient's needs resulting in improvement of quality care provided to them.

### **1.3. THE AIM**

The purpose of the study is to assess needs among cancer patients attending outpatient department at Rwanda Military Hospital.

### **1.4. RESEARCH OBJECTIVES**

To identify needs of patients with cancer attending outpatient department at Rwanda Military Hospital (RMH)

To identify met and unmet needs among cancer patients attending outpatient department at Rwanda Military Hospital (RMH)

To find out an association between met and unmet needs with demographic data among cancer patients at Rwanda Military Hospital (RMH).

### **1.5. RESEARCH QUESTIONS**

What are the needs of patients with cancer attending outpatient department at RMH

What are the met and unmet needs among cancer patients at Rwanda Military Hospital?

What is the relationship between met and unmet needs with demographic data among cancer patients at Rwanda Military Hospital?

### **1.6. SIGNIFICANCE OF THE STUDY**

The study will help in different ways:

**Nursing practice:** Results from this study will inform healthcare policy makers, referral hospitals' administration in particular Rwanda Military Hospital, to recognize needs, met and unmet needs among cancer patients hence providing rationale to develop appropriate multi-disciplinary approaches to meet the cancer patient's needs.

**Nursing education:** The results of this study will provide additional literature as well as contribute to additional knowledge about the met and unmet needs among the cancer patients contributing to nursing education.

**Nursing research:** This study will identify the met and unmet needs among cancer patients at Rwanda Military Hospital therefore the study will provide a basis to further researches.

## **1.7. OPERATIONAL DEFINITION**

**Need:** A need is an inner strength that determines how the patient responds to situations that surround her/him. It is a situation of lack (or surplus) of something and it motivates his/her behavior(Anna and Amelie, 2017)

**Met need:** The need is said to be met once the uncomfortable condition or situation of person is resolved or the person is satisfied with the response from the care/service provider. In the study the met needs mean the satisfied services of cancer patients (David and Hons, 2010).

**Unmet needs:** In this study the unmet needs refers to unsatisfied services provided to cancer patients or those needs which lack the level of service or support an individual perceives is necessary to achieve optimal well-being.(Burg et al., 2015)

**Cancer:** A condition caused by an uncontrolled division of abnormal cells due to unknown cause, this may invade to other body parts. In the present study, cancer patient refers to the patient in whom the cancer disease has been diagnosed (Worldwide International Cancer,2018)

## **1.8. STRUCTURE OF THE STUDY**

This study will be organized in two parts; first part is made of title page then declaration, dedication, abstract, acknowledgement and table of contents, list of tables, list of acronyms and abbreviations. The second part is made of three chapters:

Chapter one that includes the introduction, background and problem statement, aim of the research, objectives of the study, research questions, significance of the study , operational definitions, structure of the study and conclusion to chapter one

Chapter two is the literature review made up of theoretical literature, empirical literature, critical review, research gap identification and conceptual framework.

Chapter three is the methodology that includes study design, research approach, research setting, population, sampling, data collection data analysis methods, ethical considerations, data management, data dissemination, limitations and challenges to study and conclusion to chapter three.

### **CONCLUSION TO CHAPTER ONE**

The chapter one has presented the background, problem statement, purpose of the study, research objectives and questions, operational definitions and significance of the study. The next chapter will present the literature review.

## **CHAPTER 2. LITERATURE REVIEW**

### **2.1. Introduction**

The chapter two presents the existing literature about needs of the cancer patients. It is made of theoretical and empirical literature review. In addition to that, this chapter contains the critical review and research gap identification, theory on adaptation, conceptual framework and conclusion to chapter two.

### **2.2. Theoretical Literature**

#### **2.2.1 Definition**

Cancer is a condition in which human body cells are multiplying uncontrollably and can expand to other organs in the body (metastasis) by circulatory and lymphatic systems.

The cancer cells are different from normal human cells by transformation which is the process by which the normal cell becomes a cancer cell. The cancer cell is autonomous; this process refers to the independence of cancer by which the cancer cell escapes from normal cellular control( Kathryn I. Mc Cance, Sue E. Huether, 2014).

#### **2.2.2. Epidemiology of cancer**

According to WHO (2012), globally, cancer disease is the major cause of morbidity and mortality worldwide, 9 million people newly diagnosed each year and 5million people dying from cancer. Each year approximately 650.000 Africans develop cancer and about 510.000 on the continent die from the disease and the number of new cases is predicted to increase to 1 million annually in 5 years. The cancer mortality rate in Africa is higher than other regions worldwide due to low resources (Dan A. Milner, 2018).

Generally cancer patients have different needs of care delivered to them, since the diagnosis of cancer like other chronic diseases, implies lifestyle changes which most of time requires the health care providers to provide specialized knowledge and take care of them and their needs. When cancer patients 'needs are met, patient health condition improves and when those needs are not satisfied, patients condition worsens.

### 2.2.3. Needs theory

According to Abraham Maslow's theory about needs outlined a hierarchy of needs, with physiological needs at the bottom and self-actualization at the top. Oncological diagnosis affects all aspects of patient's life, including his social environment, and threatens needs fulfillment at every level as many people still perceive cancer diagnosis as a death sentence. Serious illness like cancer raises fear, anxiety and insecurity and presents danger of losing control, of changes in lifestyle and perspectives (Zalenski and Raspa, 2010) .



**Figure 1. Maslow's Hierarchy of Needs** \* Adapted from Abraham Maslow, 1943\*

The cancer patient needs to cope with the fear that accompanies the diagnosis also need to feel that they have control over their life, and they need to cultivate hope, trust and positive outlook on the future. Among the psychological needs, the most important ones included the need to have hope, optimism and strength to fight, followed by the need to have psychological support while waiting for the diagnosis and the need to have an opportunity to discuss one's feelings and fears. However, professionals may support the patient with cancer in his or her own self-actualization process. Thus the experience of having cancer may present an opportunity for personal evolution (Anna and Amelie, 2017)



#### **2.2.4. The needs of cancer patients**

Cancer is a serious, life threatening illness that affects all aspects of a person's life. People living with cancer are faced with many demanding, illness related experiences, including changes to everyday life, effects on quality of life and well-being, uncertainty about treatment options, treatment related toxicity, and concerns about long term outcomes. Uncertainty, hopelessness, dependence, role changes and an ongoing search for meaning throughout the illness since the diagnosis to palliative care are also common experiences among individuals with cancer (Fitch, 2009).

The study has categorized the needs of cancer patients into six groups, including health system and information domain, emotional needs, psychosocial and spiritual, practical and physical. Some research has stated that the most repeated unmet needs are in the psychological domain (Okediji, Salako and Fatiregun, 2017, p.2). Each individual will have a unique cancer journey and healthcare workers play an integral role in the continuum of cancer treatment, service, and care through the disease trajectory. With the increase in the number of cancer, many persons now know cancer as a chronic disease followed by adaptation to a new reality of life.

#### **2.2.5. The psychosocial adaptation theory**

Psychosocial adaptation theory, refers to a "continuous process by which the particular person/patient tries to be able to manage emotional suffering, to solve the exact cancer related difficulties, and gain the ability or gain control of the life events related to this disease condition" (Forjaz, 2005). Adaptation to cancer is a series of constant responses that help the cancer patient to do the different activities related to living with cancer disease, effective coping happen among cancer patients capable of reducing changes due to cancer disease to a minimal emotional stress to live a normal life (Forjaz, 2005)

Folkman and Greer model identified two processes of reactions when a patient is diagnosed with cancer: «appraisal» and «coping».

**In appraisal**, according to Folkman and Greer, the stress process begins when the person realizes that suffering from cancer is likely or cancer is already present. The patient is aware of the cancer process, this becomes a personal challenge (primary appraisal), which is affected by the patient's personal beliefs and values (Forjaz, 2005).

The patient begins an evaluation of possible coping options (secondary appraisal), this is influenced by the degree to which the patient can manage the situation (Forjaz, 2005) .

**Coping** is behavior that a cancer patient applies to adapt to life with cancer; this is influenced by the health care providers, patient's family and community as well as other socio-economic factors that help the cancer patient to attain their needs (Forjaz, 2005).

The success or the met needs are expressed by the excellent quality of life and good prognosis, however the unmet cancer patient needs lead to poor quality of life, deterioration and poor prognosis (Forjaz, 2005).

### **2.3. Empirical Literature**

A recent study demonstrated that patients with cancer who survived less than 1 year had an elevated level of needs comparing to these of more than 1 year and those who will go up to 5 years and above since diagnosis (Velooso et al., 2013).

Some cancer patients needs are described as: physical needs including pain, symptoms, sexual dysfunction, and diet, exercise, and rest; emotional needs as well as panic of cancer re-occurrence, new cancers apparition, even death, hopelessness, nervousness, also negative feelings such as uncertainty toward body, anger, and guilt; psychosocial needs including intimacy, accessibility to support groups, opportunities to use one's own experiences to help others, participation in social activities , and spiritual changes to cancer patients, the effects of such changes may be profound and long-lasting (Burg et al., 2015).

Cancer also brings many changes to family members, so it is important to recognize the needs of cancer patients families because it will help the health care providers to identify the necessary interventions (Burg et al., 2015).

Cancer patients with advanced stage most of the time have acute physical needs, low functional status, and considerable emotional suffering. Healthcare professionals must however take care of cancer patients' holistic needs, as well as the particular religious needs (Pearce et al., 2012).

The recorded data from 2,768 cancer patients showed that 41% needed conversation about spiritual care and that need was unmet in one half of all patients(Pearce et al., 2012).

### **2.3.1. Cancer patient's needs**

The cancer patient's needs are grouped in six types, those are informational needs, related to psychosocial needs, physical needs, emotional, financial needs and spiritual needs (Chiesi *et al.*, 2017) .

### **2.3.2. Informational needs**

Cancer patients' needs information vary over the cancer care process (Halkett *et al.*, 2012). According to Matsuyama *et al.*, 2013 Cancer information needs reduce slightly following treatment. Today, the way patients with cancer consider the information and their involvement in decision making about their management plan affect the fulfillment of this need. Both diagnosis phase and care provision and disease prognosis requires patients to have some information related to their disease (Mekuria, Erku and Belachew , 2016, p.2)

The major aim behind information provision is to make patients ready for their treatment, to heighten adherence to therapy, to increase their strength of living(coping) with the disease, and to ensure recovery (Mekuria, Erku and Belachew , 2016, p.1)

The needs of information of cancer patients differ from one patient to another, studies have shown that demographics (age group, educational status, and sex), the situation during the course of illness and the cancer patient's mindset to cancer disease may influence the need of information relating to cancer disease and cancer related information (Mekuria, Erku and Belachew, 2016).

Cancer patients' specific information includes information on the type of cancer, etiology, physical effects, diagnosis, symptoms and treatments which include drugs side effects, duration if surgery or radiotherapy is needed, as well as its prognosis according to patients' specific cancer (Shea-Budgell *et al.*, 2014)

The information needs are important in all phases of cancer illness, including palliative care, even if the diagnosis phase is the moment at which this group of unmet needs is more expressed. Information represents a crucial aspect of the doctor-patient relationship in oncology and re- quires special attention. Therefore, a specific and appropriate time for doctor-patient dialogue and the information process should be scheduled, even in present times characterized by acceleration of procedures and reduction in costs (Bonacchi *et al.*, 2017).

### **2.3.3. Psychosocial needs**

Some psychosocial disorders such as anger, depression and fear are common in cancer patients. Unmanaged psychosocial problems can affect cancer patients' life and reactions to drugs; also socially can affect the privacy, access to support groups, opportunities to use one's own experiences to help others, and participation in social situations(Akalin and Pinar, 2016)

Cancer patients frequently experience a significant physical and psychological symptom burden with important changes in daily life, which can lead to changes in needs and priorities and the appearance of new needs(Bonacchi et al., 2018).

### **2.3.4 Emotional needs**

Emotional needs are composed of fear of recurrence, new cancers, death; depression, anxiety, and negative feelings such as mistrust toward body, anger, and guilt. Studies on emotional distress in cancer patients report on average a prevalence of depression and anxiety ranging from 8% to 24% (Ferrari et al., 2018).

### **2.3.5. Physical needs**

Physical needs include some symptoms like pain, generalized weakness, nausea, drowsiness, appetite, and shortness of breath. Assistance may also be needed with activities of daily living such as eating, washing, changing position etc. (Cyprus, 2016)

A study done in Italy revealed that some patients believe that suffering (e.g., pain, anxiety, depression, and anger) is inevitable with cancer or that there is no effective treatment to help them face those issues that clinicians do not include in their inquiry and concerns (Bonacchi et al., 2016).

### **2.3.6. Spiritual needs**

Most patients with advanced cancer stage have spiritual needs during the disease process , they hope that religiosity plays a big role in their health and in the recovery period, and wish spiritual care from their healthcare team, religious community, and/or hospital chaplain(Pearce et al., 2012,p.2273).

#### **2.4. Factors predisposing to meet and unmet needs among cancer patients**

Some studies have shown the elevated prevalence of unmet needs among patients with cancer are specifically associated to socio-demographic factors such as age, gender, marital status, income level, occupation, family size, and a number of children ,the type of cancer, stage of the disease (Okediji et al., 2017 p.3).

Akalin and Pinar, (2016) reported that the factors predisposing to met and unmet need are related to age, education, gender, income, geographical location, diagnosis and marital status. Furthermore, according to Abdollahzadeh, et al.(2012), it is reported that the age is the major predictor of unmet care needs as younger patients tend to have more unmet needs than old cancer patients, in addition other socio-demographic factors such as educational attainment, employment status, and income level have also been found to influence unmet needs in cancer patients. Research has suggested that the largest number of unmet needs is in the psychological domain (Okediji, Salako and Fatiregun, 2017, p.2).

#### **2.5. Nursing role in responding to the needs of cancer patients**

Nurses are vital in delivering the best possible health care. Since the diagnosis up to the end of disease trajectory, each patient has specific needs which vary depending on disease stage and there is also recognition of the important role that' nurses have in caring for patients with cancer (Vienna, Austria; Sept.2015)

High rates of unmet needs are related to a low quality of life and a lower satisfaction of patients with their medical care. Moreover, inadequate attention to the needs of cancer patients and their caregivers can lead to an increase in distress and health care costs(Bonacchi et al., 2018).

In addition to this, nurses are required to offer care for the entire course of the patients with cancer, including the process of diagnosis, treatment, recurrence, survival period, palliative care and assistance with a peaceful death. For helping the cancer patients, nurses will have to identify their needs using a holistic assessment and the nursing care will integrate all dimensions of life. The needs of cancer patients generally involve: physical, psychological, social, financial, practical and informational needs (Maria Lavdaniti, July, 2017).

Oncology nurses should teach patients communication skills and provide adequate information with consideration of age to meet unmet needs. Oncology nurses should be aware of the unmet information needs and support patients so that they can communicate with

medical professionals. It is necessary to develop a brief assessment tool to detect the needs of patients with cancer and to encourage oncology nurses to actively assess the information needs of patients. In addition, assisting and educating medical professionals may enhance communication with cancer patients (Miyashita et al., 2015)

## **2.6. Critical Review and research gap identification**

Many studies have been done about cancer and found that the cancer is a foremost cause of morbidity and mortality worldwide and nine millions of people are newly diagnosed of cancer each year and 5 million people dying from cancer each year however there are some limitations of data about the cancer patient's needs attainment (WHO, 2012).

A study done in Australia, Sanson-fisher et al.,(2013) has reported that cancer is the leading cause of death, accounting for approximately one-quarter of all deaths, even though a study done by Chiesi *et al.*,(2017) reported that the cancer patients like other patients have different needs during disease process, once these needs are not met with health care providers, the patient's health condition deteriorate quickly, however there is a scarcity of data about meeting of cancer patient's needs.

Patients with cancer have different needs related in part to illness and in part to the care process. These needs are distributed in main different areas: information and dialogue with physicians, assistance/care, psycho- social support, spiritual issues, and sexual problems. When the needs belonging to these areas are perceived by the patient as not adequately met by the care system, they are considered unmet needs and therefore represent a request, in general, to the health system and, in any clinical setting, to the staff involved in caring (Bonacchi et al., 2017).

In Rwanda many investments have been done to improve quality of care provided to patients including cancer patients, however still there is limited data about cancer patient's needs attainment therefore the present study is of paramount importance and is anticipated to provide a valuable source of data regarding the met and unmet needs of cancer particularly at Rwanda Military Hospital, Rwanda and all over the world in general.

## **2.7. Conceptual framework**

### **2.7.1. Needs theory**

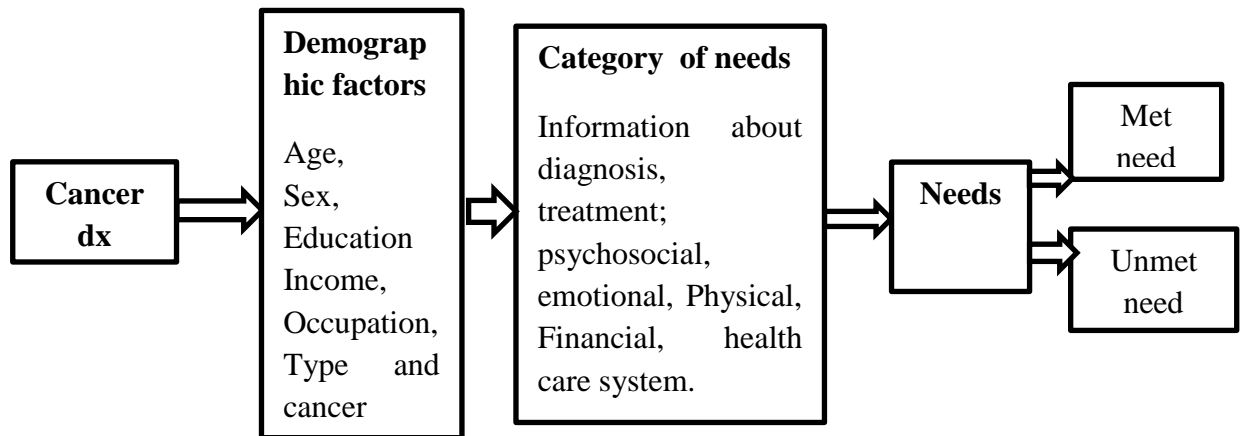
The conceptual framework of the present study is based on the theory of David and Hons framework in 2010 and Maslow need theories. According to David and Hons, met and unmet needs concepts are used, and the cancer patient's needs are met when a cancer patient receives a full adequate quality of health care available and unmet needs in case of inadequate quality of care. Met need and unmet needs are conceptually different and distinct in improving health services delivery and patients' outcomes (David and Hons, 2010).

In addition, Abraham Maslow's needs theory (1943), the human needs are hierarchical. The unfulfilled lower needs dominate patient's thinking, actions, and being until they are satisfied. Once a lower need is fulfilled, a next level of need will be addressed or expressed in everyday life.

Once all of the basic are satisfied, then human beings tend to pursue the higher needs of self-actualization. Indeed, the fulfillment of the basic needs is considered as a requirement to such pursuit.

This conceptual framework describes the possible met and unmet needs and its association with demographic status of cancer patients. Those possible needs of cancer patients are in different category ,information needs about diagnosis, information needs about treatment, information needs about prognosis, physical needs, psycho social and emotional needs, practical needs etc. And the probable associated demographic factors are age, sex, education level, family income, occupation, type of cancer etc.

## Diagrammatic conceptual framework



**Figure 2. Conceptual framework for met and unmet needs** \*Adapted from David and Hons, 2010 and Abraham Maslow\*

## CONCLUSION

In this chapter the literature review, the theoretical review, the empirical review and the conceptual framework guiding have been discussed.



## **CHAPTER 3. METHODOLOGY**

### **3.1. Introduction**

The chapter three is the research methodology; it presents the process and methods that were used in this study. It includes a study design, research approach, research setting, study population, sample size and sampling methods, data collection methods and procedures, data analysis, ethical consideration, data management, data dissemination, problems and limitations of the study and conclusion.

### **3.2. Research design**

The descriptive cross-sectional design with convenient method was used to conduct this research. Descriptive cross sectional study is a research which has a purpose of gaining the true or correct explanation to the features or situations of the people and it is done once in a given period of time with particular population (Polit & Beck 2010).

### **3.3. Research approach**

It is a plan and a procedure that consists of the steps of broad assumptions to detailed method of data collection, analysis and interpretation. It is in this regard this study has used quantitative approach involved statistical measurements in data analysis

### **3.4. Research setting**

This study was conducted at Rwanda Military Hospital (RMH). It is a referral hospital located in Kicukiro District, Nyarugunga Sector, Kanombe cell and Kamashashi village. Regarding the capacity of admission RMH has 310 beds and has different services including specialties. It was built in 1964 at Kanombe as Military Referral Hospital for military personnel and their families. After genocide against Tutsi of 1994, the hospital opened doors for the general population. It has a vision of becoming the best and Quality and tertiary care provider and its mission is to provide quality tertiary healthcare to the general population and military personnel.

Rwanda Military Hospital has a multidisciplinary environment where they offer services for general care and specialized : Accident and emergency, Internal Medicine, Surgical ward (general surgery and orthopedic surgery), Gynecology and obstetrics, Pediatrics and Neonatology, Operating room Service, Outpatient department which has different office for outpatient consultation, Imaging services, Laboratory, Stomatology and Physiotherapy, Ophthalmology and Dermatology, Mental Health services. It also has also: Intensive care unit

(ICU), Neonatal Intensive Care Unit (NICU), Breast Clinic and Oncology Consultation, Oral and dental Surgery, Neurosurgery. It receives all kinds of patients' both civilians and military patients. In addition there is also, Pharmaceutical Services, Pathology Services, Quality Assurance & Risk Management, and Operation Support Services. It was chosen because it is a referral hospital which receives all kind of patients but now is also focusing on cancer treatment by doing daily consultation of cancer patients, and soon will launch officially one of cancer treatment Centre using radiation therapy. A study regarding met and unmet needs of cancer patients has not yet been done in this referral hospital (unpublished data, 2018).

### **3.5. Study Population**

The study population was made of adult patients diagnosed with cancer, receiving their different kind of treatment at RMH. Currently, RMH receives approximately 100 (old and new) cancer patients monthly. And this number was considered as study population.

### **3.6. Sampling**

#### **3.6. 1. Sampling strategy**

The current study used convenience sampling method; convenience sampling method is a non-probability sampling which consists of a group of individuals who have certain criteria, who are available and who accept to participate during the study period.

##### **3. 6.1.1. Inclusion criteria**

This study has included all adult cancer patients, attending outpatient department at RMH during data collection period and accepted to participate in the study.

##### **3. 6.1.2. Exclusion criteria**

The exclusion criteria were: cancer patients who are less than 18 years old, old cases and non-confirmed case for cancer diagnosis, hospitalized cancer patients and cancer patients who do not want to participate.

#### **3.6.2. Sample size**

Data collection period was for 1 month starting from 15<sup>th</sup>/April/2019 to 22<sup>nd</sup> /may/ 2019 and oncology consultation are done from Monday to Wednesday, the researcher has considered all cancer patients who attended oncology clinic at RMH in one month as the sample size of the current study. During data collection period, 100 cancer patients (sample size) consulted oncology clinic of RMH. 93 patients accepted to participate in the study while 7 patients consulted the outpatients department (OPD) for more than one time.

### **3.7. Data Collection**

#### **3.7.1. Data Collection Tool**

The present study used a questionnaire named “needs evaluation questionnaire” that was made by two sections, section one: socio-demographic data. Section two: items related to cancer patients need. The Needs Evaluation Questionnaire which the researcher adapted and used in data collection was developed by Tamburini and colleagues in 2000 has been used both in research principally in order to identify areas for improving cancer care in clinical settings as an intervention tool to reduce the unmet needs of cancer patients. Firstly was developed to be used in hospitalized cancer patients but as the researcher has adapted to outpatient department, the tool has given the similar results as reported by A. Bonacchi in his study about needs of cancer in outpatients (Bonacchi et al., 2016)

After getting permission from Dr. Andrea Bonacchi coworker of Prof. Chiesi, the questionnaire was adapted to the current study and translated into Kinyarwanda, it has been reviewed by an Oncology nurse and an expert in language has reviewed Kinyarwanda version. In addition, the questions were adapted to fit the context of the current study. Some questions were not asked as were not relevant to this study and other questions were added to allow the participant the chance to explain their situation.

#### **3.7.2. Validity of the needs evaluation questionnaire**

The NEQ is a standardized questionnaire, consisting of 23 items, developed and validated at the Psychology Unit of INT (Istituto Nazionale Timori) of Milan-Italy (Chiesi *et al.*, 2017). The items 1 up to 9 are related to demographic factors (age, gender, marital status, education level, occupation, residency area, religion, person living with, type of health insurance which include CBHI-community based health insurance, MMI-Military medical insurance, RSSB-Rwanda social security board and private insurance), 10 is related to types of cancer and 11 is stating the period of disease since diagnosis, items 12 consists of 2 items, is concerned with information related to diagnosis, 13 information about treatment, 14 information about prognosis, 15 is concerned with psychosocial and emotional needs, 16 is related to physical needs, 17 related to practical needs.

The content validity of the original questionnaire was reported by (Chiesi *et al.*, 2017) and this instrument was used in many studies.

**Table 1. Content Validity**

| <b>N.</b> | <b>Research objectives</b>  | <b>Conceptual framework</b>   | <b>Questionnaire items</b>   |
|-----------|---|---|--|
| 1.        | Identify needs of patients with cancer attending OPD department at RMH.   | Cancer diagnosis<br><br>Different categories of needs   | Section A:10 and 11<br><br>Section B: 12,13,14,15,16,17  |
| 2.        | Identify met and unmet needs of patients with cancer attending OPD department at RMH.   | Demographic factors<br><br>Different categories of needs  | Section A: 1,2,3,4,5,6,7,8,9<br><br>Section B:12(2),13(3),14(2),15(1,2,3,4,5,6,7) 16(2,4),17(3)                        |
| 3.        | Find out the association between met and unmet needs with demographic factors among patients with cancer attending OPD department at RMH. | Needs of patients of patients with cancer<br><br>Different categories of needs<br><br>Demographic factors | Section A:1,2,3,4,5,6,7,8,9,10,11<br><br>Section B:12(1,2),13(1,2,3),14(1,2),15(1,2,3,4,5,6,7,8),16(1,2,3,4),17(1,2,3) |

### **3.7.3. Reliability of the needs evaluation questionnaire**

The reliability of the needs evaluation questionnaire used in the current study was reported by Chiesi *et al.*, (2017). The scales of NEQ were highly informative for a wide range of cancer patient needs, this is evidence of the usage of the NEQ in identifying the needs among cancer patients (Chiesi *et al.*, 2017). As the questionnaire was adapted the pilot study was done for verifying its reliability and validity, the pilot study was conducted on 9 cancer patients and was understandable as the results reported cronbach alpha of 0.7.

### **3.8. Data Collection Procedure**

After getting certificate from NIH(National Institute for Health), the researcher applied for the approval from College of Medicine and Health Sciences (CMHS), then the permission to contact the study in RMH was requested. The researcher met the Unit Manager of outpatient department where data were collected and explained the aim, objectives of the study. All participants were explained about the study, its purpose and interest to them. These who were convinced with the purpose of the study were given a consent form to sign for participating in the study. The participants who accepted to sign consent, the questionnaire were filled direct by researcher.

### **3.9. Data Analysis**

Data were captured and analyzed using SPSS 21, the descriptively (frequency, percentages, mean and standard deviation) and inferential statistics (chi-square) was used. Data were entered in SPSS 21 and output was imported into Microsoft Excel, and the results were presented in tables and graphs. The statistician has helped the researcher in analysis of data.

### **3.10. Ethical Considerations**

The researcher has applied for ethical clearance from IRB/CMHS and permission to conduct research from RMH ethical committees. To ensure confidentiality to participants, the codes were used on questionnaires; the softcopies were kept in computer locked by a password which is known by the researcher only. The researcher approached and informed the participants about research purpose and objectives, procedures involved, their rights regarding study participation or withdrawal .The participants were guaranteed the right to refuse the participation and to withdraw from the study at any stage without any negative consequences, therefore participation was totally voluntary and no other reward was provided for participation.

### **3.11. Data Management**

The soft copies are stored on external disk, kept confidential and were used for the purpose of research. The hard copies are kept in a locked cupboard. The data will be kept for 5 years.

### **3.12. Data Dissemination**

The results of this study will be submitted and presented in CMHS, will also be presented in conference and published in reliable journal in order to be accessible to the user in need and the researcher will provide feedback to the study setting in order to improve the quality of care provided to cancer patients and help them to meet their needs.

### **3. 13. Problems and Limitations of the study**

In this study some problems might be encountered for instance delay to get permission to collect data from study setting, financial problems. Also there was a limited space as it was not easy to find a favorable space for the researcher to talk with the participants. The participants might not be willing to participate in this research as the study is time consuming, so the data collection was made very specific and simplified to minimize the time for questionnaire completion to about fifteen minutes.

### **3.14. Conclusion of Chapter Three**

The chapter three has described the procedure and instruments that have been applied by researcher to answer the research questions.

## **CHAPTER 4. RESULTS**

### **4. 1.Introduction**

This chapter presents the results. It includes data obtained from adults' patients with cancer attended outpatient department at RMH; the researcher has interviewed the patients and completed the questionnaire herself. A total number of participants responded to the questionnaire were 93, the majority of the respondents were females which were 50.5% and 63.4% of participants were married. The age of majority of participants was 60 and above. They mainly live in eastern province; the education level for participants was primary at the rate of 41.9% of all participants. The main occupation was cultivators with 38.7%. Majority 86% of participants use community health insurance and dominant cancers were breast cancer 12.9%, prostate cancer 12.9% and leukemia 12.9% all accounts for 38.7% and cervical cancer accounted for 11.8%.

### **4.2. Socio demographic characteristics of the participants**

For this study the total number of the participants were 93, with a response rate of 100%. The majority of the participants were above 60 years old with 45.2%, and female were predominant with 50.5%. Among 63.4% of the participants were married and 41.9% did primary school on level of education while and 38.7% were farmers as their main occupation. 29% of the participants were living in eastern province, 48.4% were catholic as their religion, and regarding to the person they live with 58.1% were living with their partners. On health insurance 86% were using CBHI, and on the type of cancer they suffer from 12.9% were suffering equally prostatic and breast cancer for male and women respectively. 38.9% were diagnosed cancer in the period between 0 and 12 months (Table 2).

**Table 2. Socio demographic characteristics of the participants**

| <b>Variables</b>       | <b>Frequency(n)</b> | <b>(%)</b> |
|------------------------|---------------------|------------|
| <b>Age</b>             |                     |            |
| 18-30                  | 6                   | 6.5        |
| 31-44                  | 15                  | 16.1       |
| 45-59                  | 30                  | 32.3       |
| 60 above               | 42                  | 45.2       |
| <b>Gender</b>          |                     |            |
| Male                   | 46                  | 49.5       |
| Female                 | 47                  | 50.5       |
| <b>Marital status</b>  |                     |            |
| Single                 | 11                  | 11.8       |
| Married                | 59                  | 63.4       |
| Divorced               | 1                   | 1.1        |
| Widow                  | 15                  | 16.1       |
| Separated              | 7                   | 7.5        |
| <b>Education level</b> |                     |            |
| None                   | 27                  | 29         |
| Primary                | 39                  | 41.9       |
| Secondary              | 22                  | 23.7       |
| University             | 5                   | 5.4        |
| <b>Occupation</b>      |                     |            |
| None                   | 15                  | 16.1       |
| Cultivator             | 36                  | 38.7       |
| Farmer                 | 11                  | 11.8       |
| Employed               | 6                   | 6.5        |



|               |    |      |
|---------------|----|------|
| Self employed | 19 | 20.4 |
| Retirement    | 6  | 6.5  |

### **Residence**

|             |    |      |
|-------------|----|------|
| Eastern     | 27 | 29   |
| Western     | 12 | 12.9 |
| Southern    | 23 | 24.7 |
| Northern    | 8  | 8.6  |
| Kigali city | 23 | 24.7 |

### **Religion**

|             |    |      |
|-------------|----|------|
| Catholic    | 45 | 48.4 |
| Adventist   | 7  | 7.5  |
| Protestants | 37 | 39.8 |
| Islam       | 4  | 4.3  |

### **Person living with**

|           |    |      |
|-----------|----|------|
| Alone     | 4  | 4.3  |
| Children  | 23 | 24.7 |
| Parents   | 7  | 7.5  |
| Partner   | 54 | 58.1 |
| Housework | 5  | 5.4  |

### **Health insurance type**

|      |    |      |
|------|----|------|
| CBHI | 80 | 86   |
| MMI  | 1  | 1.1  |
| RSSB | 10 | 10.8 |

|         |   |     |
|---------|---|-----|
| Private | 2 | 2.2 |
|---------|---|-----|

### **Type of cancer**

|                   |    |      |
|-------------------|----|------|
| Breast cancer     | 12 | 12.9 |
| Cervical cancer   | 11 | 11.8 |
| Prostate Cancer   | 12 | 12.9 |
| Gastric cancer    | 13 | 14   |
| Leukemia          | 12 | 12.9 |
| Hep.C. carcinoma  | 11 | 11.8 |
| Osteosarcoma      | 6  | 6.5  |
| Esophageal cancer | 1  | 1.1  |
| Skin cancer       | 3  | 3.2  |
| penile cancer     | 1  | 1.1  |
| Others            | 11 | 11.8 |

### **Period diagnosed cancer**

|            |    |      |
|------------|----|------|
| 0-12months | 36 | 38.7 |
| 1-2years   | 40 | 43   |
| 3-6 years  | 17 | 18.3 |

### **4.3. Different category of needs for patients with cancer**

According to the first objective of the study which is to identify needs of cancer patients including met and unmet needs, the following table of results is going to describe it

Regarding the information needs about diagnosis, 90.3 % of the participants have needed to be more informed, and among them only 49.5% were satisfied about the information given and 50.5% their need were met.

In provision of informational about treatments, 71% of the participants needed to receive information about different modalities of treatments but 93.5% of the participants received explanation on current treatment while only 44.4% of the participants were satisfied about the

information provided, means that the remaining 55.9% were not satisfied by the information given.

Ninety one point four of the participants needed to be informed on their disease prognosis while 35.5% of the participants were not satisfied by the information given and 64.5% of participants reported to be unmet.

In category of psycho social and emotional needs many patients reported not be informed about psycho social services as it was not an easy situation for them to be informed they have cancer. A total of 65.6% reported that no need of psychologist but with explanation was because of lack of information. 74.2% have said that the psychologist review could be a helpful session after or before disclosure of cancer diagnosis.

Approximately 61.3% of the participants needed help from someone else in daily living activities, and 71% of the participants were satisfied by the support given and among them 82.8% of the participants had symptoms like pain, nausea and vomiting when waiting physician for consultation and only 45.2% were satisfied by the support given in the management of the above symptoms and 54.8% reported to be not satisfied by the way they were cared.

Regarding met and unmet needs on the practical part, only 8.6% of the participants were agreed to perform their usual work after diagnosis and 91.4% reported the inability to perform their usual work, and 52.7% of the participants reported to have sometimes tiredness while working, and 77.4% of the participants were satisfied by the support given by their family members or workmates.

**Table 3. Different category of cancer patients needs**

| <b>Needs category</b>             |  |      | <b>N(%)</b> |
|-----------------------------------|--|------|-------------|
| Information need on diagnosis     | Need more info about diagnosis           | Non  | 9(9.7%)     |
|                                   |  | Yes  | 84(90.3%)   |
|                                   | Met information need                     | Non  | 47(50.5%)   |
|                                   |  | Yes  | 46(49.5%)   |
| Information need about treatment  | Info about modalities of treatment       | Non  | 66(71%)     |
|                                   |  | Yes  | 27(29%)     |
|                                   | Need Info on current treatment           | Non  | 6(6.5%)     |
|                                   |  | Yes  | 87(93.5%)   |
|                                   | Met need on current treatment info given | Non  | 52(55.9%)   |
|                                   |  | Yes  | 41(44.1%)   |
| Information about prognosis       | Need info on prognosis                   | Non  | 8(8.6%)     |
|                                   |  | Yes  | 85(91.4%)   |
|                                   | Met need of info given on prognosis      | Non  | 60(64.5%)   |
|                                   |  | Yes  | 33(35.5%)   |
| Psycho social and emotional needs | Reaction after disclosure of diagnosis   | Bad  | 16(17.2%)   |
|                                   |  | Good | 77(82.8%)   |
|                                   | Needs to talk to psychologist            | Non  | 61(65.6%)   |
|                                   |  | Yes  | 32(34.4%)   |

|  |                      |     |           |
|--|----------------------|-----|-----------|
|  |                      |     | %)        |
| Psychologist review is helpful             | Non                  | 24  | (25.8%)   |
|  | Yes                  | 69  | (74.2%)   |
| Need family involvement                    | Non                  | 8   | (8.6%)    |
|  | Yes                  | 85  | (91.4%)   |
| Family reaction                            | Bad                  | 60  | (64.5%)   |
|  | Good                 | 33  | (35.5%)   |
| Family support                             | Non                  | 13  | (14%)     |
|  | Yes                  | 80  | (86%)     |
| Feel hopeless                              | Non                  | 24  | (25.8%)   |
|  | Yes                  | 80  | (86%)     |
| Where/who to be with in hopeless condition | Fam. member          | 33  | (35.5%)   |
|  | Physician            | 22  | (23.7%)   |
|  | Someone with Cancer  | 6   | (6.5%)    |
|  | Pastor/priest        | 1   | (1.1%)    |
|  | Alone                | 13  | (14%)     |
|  | Church               | 12  | (12.9%)   |
|  |                      |     |           |
|  |                      |     |           |
| Physical needs                             | Needs someone's help | Non | 36(38.7%) |
|  |                      | Yes | 57(61.3%) |

|                                 |                                    |           |           |
|---------------------------------|------------------------------------|-----------|-----------|
|                                 |                                    |           | %)        |
|                                 | Satisfied by support               | Non       | 27(29%)   |
|                                 |                                    | Yes       | 66(71%)   |
|                                 | Symptoms: pain, N/V                | Non       | 16(17.2%) |
|                                 |                                    | Yes       | 77(82.8%) |
|                                 | Satisfied by help given            | Non       | 51(54.8%) |
|                                 |                                    | Yes       | 42(51.2%) |
| Practical needs                 | Ability to do regular job          | Non       | 85(91.4%) |
|                                 |                                    | Yes       | 8(8.6%)   |
|                                 | Tired easily while working         | None      | 4(4.3%)   |
|                                 |                                    | Sometimes | 49(41.9%) |
|                                 |                                    | Often     | 39(41.9%) |
|                                 |                                    | Always    | 1(1.1%)   |
|                                 | Satisfied by support of colleagues | Non       | 21(22.6%) |
|                                 |                                    | Yes       | 72(77.4%) |
| Total of participants =93(100%) |                                    |           |           |

#### 4.4. Association between met and unmet needs with demographic factors among cancer patients RMH.

According to the study objectives of the current study, second objective of the study is to find out the association between met and unmet with demographic factors. The significant association will be reported into the table and variables without significance association will be ignored in some tables.

##### 4.4.1. Association between information needs about diagnosis and demographic factors

To assess the association between information needs about diagnosis and demographic information bivariate and multivariate logistic regression have been performed and information need on diagnosis was significantly associated with education level with COR=1.789 and P value 0.041.while on the level of satisfaction marital status was significantly associated with satisfaction with COR=2.469 and P value 0.035,and satisfied about information was also significantly associated with type of cancer with COR=0.746 and P value 0.005.

**Table 4. Association between information needs about diagnosis and demographic information**

| Determinant     | Information need on diagnosis |       |                |       | Satisfied about information |       |                |       |
|-----------------|-------------------------------|-------|----------------|-------|-----------------------------|-------|----------------|-------|
|                 | P Value                       | OR    | 95% C.I.for OR |       | P value                     | OR    | 95% C.I.for OR |       |
|                 |                               |       | Lower          | Upper |                             |       | Lower          | Upper |
| Marital status  | .813                          | .692  | .033           | 14.66 | .035                        | 2.469 | 1.068          | 5.711 |
| Education level | .041                          | 1.789 | .394           | 8.129 | .843                        | 1.086 | .482           | 2.444 |
| Type of cancer  | .346                          | .864  | .638           | 1.170 | .005                        | .746  | .609           | .914  |

#### 4.4.2. Association between Information needs about treatment and demographic factors

To assess the relationship between the information needs about treatments and demographic factors, education level was significantly associated with demographic data with COR=2.704 and P value 0.024, while residence was also significantly associated with demographic factors with COR=1.493 and P value 0.032. other variables were not statistically significant with information needs about treatment.

**Table 5. Association between Information needs about treatment and demographic factors**

| Determinants              | Satisfied about information given on Treatment |       |                 |       |
|---------------------------|--|-------|-----------------|-------|
|                           | P value  | OR    | 95% C.I. for OR |       |
|                           |  |       | Lower           | Upper |
| Education level           | .024   | 2.704 | 1.137           | 6.432 |
| Residence of participants | .032   | 1.493 | 1.036           | 2.150 |

#### 4.4.3. Association between the information about prognosis and demographic factors

To assess the relationship between the information need about prognosis and demographic factors bivariate and multivariate analysis was performed and only occupation was significantly associated with information about prognosis with COR=0.308 and P value 0.035, other social demographic information was not statistically associated with information on prognosis.

**Table 6. Association between the information about prognosis and demographic factors**

| Determinants | P value | COR (95% CI)       |
|--------------|---------|--------------------|
| Occupation   | .035    | 0.308(0.103-0.920) |



#### 4.4.4. Association between Psycho-social and emotional needs and demographic factors of the participants

The association between the psycho social, emotional needs and demographic data of the participants bivariate and multivariate logistic regression was performed and was significantly associated with diagnosis disclosure and unusual hopeless with COR=21.3 and 79.6 with P value 0.36 and 0.004 respectively. Residence was significantly associated with helpful psychological review with COR=0.676 and P value 0.041, Education level was significantly associated with family support with COR=3.47 and P value 0.039. Types of cancer was significantly associated with family involvement with COR=0.623 and P value 0.027, for other variables were not significantly associated with demographic factors.

**Table 7. Association between Psycho-social and emotional needs and demographic factors of the participants**

| Determinants      | Disclos.di<br>agnosi |      | Psycholo<br>gy<br>review<br>helpful |       | Family<br>involvem |       | Famil<br>y sup |           | unusual<br>hopeless |      |
|-------------------|----------------------|------|-------------------------------------|-------|--------------------|-------|----------------|-----------|---------------------|------|
|                   | P Value              | OR   | P value                             | OR    | P value            | OR    | P<br>value     | OR        | P<br>valu           | OR   |
| Age               | .026                 | .102 | .232                                | 1.56  | .839               | 1.16  | .999           | 1.00      | .021                | .205 |
| Sex               | .036                 | 21.3 | .140                                | 2.98  | .059               | .040  | .753           | .729      | .004                | 79.6 |
| Marital<br>status | .822                 | .855 | .480                                | .755  | .924               | 1.06  | .410           | .661      | .739                | 1.24 |
| Education le      | .316                 | .540 | .442                                | .730  | .510               | 1.68  | .039           | 3.47      | .857                | .902 |
| Occupation        | .052                 | .572 | .322                                | .810  | .730               | .879  | .155           | .652      | .181                | .668 |
| Residence         | .893                 | .960 | .041                                | .676  | .459               | .765  | .289           | .765      | .596                | 1.16 |
| Religion          | .466                 | .774 | .415                                | .813  | .319               | 1.723 | .413           | .745      | .622                | 1.17 |
| Person<br>Living  | .320                 | 1.94 | .857                                | .936  | .211               | 1.854 | .830           | 1.12      | .341                | 1.64 |
| Insurance         | .194                 | 2.4  | .075                                | 2.277 | .073               | .262  | .508           | .664      | .362                | 1.94 |
| Type of<br>cancer | .355                 | 1.1  | .559                                | 1.056 | .027               | .623  | .477           | 1.10<br>4 | .296                | 1.14 |

#### 4.4.5. Association between Physical needs and demographic factors

For the assessment of the relationship between physical needs and demographic factors ,bivariate and multivariate logistic regression analysis has been performed and age ,sex and occupation were significantly associated with physical needs with COR=2.122,0.149 and 1.641 with P values 0.045,0.015 and 0.043 respectively. Other demographic variables were not significantly associated with physical needs.

**Table 8. Association between Physical needs and demographic factors**

| Determinants | P value | COR (95%CI)        |
|--------------|---------|--------------------|
| Age          | .045    | 2.122(1.018-4.429) |
| Sex          | .015    | 0.149(0.032-0.690) |
| Occupation   | .043    | 1.641(1.015-2.654) |

#### 4.4.6. Association between Practical needs and demographic factors

For the assessment of the relationship between practical needs and demographic data age, education level and residence of the participants were significantly associated with practical needs with COR=3.075, 3.467 and 0.534 and P value 0.027, 0.024 and 0.011 respectively.

**Table 9. Association between Practical needs and demographic factors**

| Determinants              | P value | COR (95%)           |
|---------------------------|---------|---------------------|
| Age                       | .027    | 3.075(1.140-8.296)  |
| Education level           | .024    | 3.467(1.176-10.229) |
| Residence of participants | .011    | 0.5343(0.329-0.868) |

## **CHAPTER 5: DISCUSSION**

This chapter discusses the main findings of the study. It focuses on the study objectives which are to identify needs of cancer patients and to find out an association between those needs with demographic information.

### **5.1. Socio demographic characteristics of the participants**

The majority of the participants (45.2%) were above 60 years old and it is similar to the study conducted in D.B. Tejani Cancer Institute to assess socio demographic profile of cancer patients, where advanced age were predominant compared to other age groups( Patel et al,2018, P.155). The results of current study also showed that female were predominant 50.5% the same results was found in a study conducted in Italy about use of the Needs Evaluation Questionnaire among cancer patients in outpatient department (A.Bonachi et al.2016).

In this study 63.4% of the participants were married ,and 41.9% attended primary school level, while majority ( 38.7%) of the participants do farming on a small scale. Similarly to the study findings by(Andrade et al., 2013; Patel et al., 2018) revealed that the majority of respondents were female. However the study by( Patel et al,2018, P.155) pointed out that majority of participants were illiterate.

The study pointed out that majority 48.4% of the participants were living in the eastern province and most of them were Catholics. In this study majority of respondents were using CBHI as their health insurance. According to findings from this study, it revealed that male had prostatic cancer 12.9%, while female participants were diagnosed to have breast cancer on the same percentage with the male participants and the diagnosis was revealed to participants within a period of 1- 12 months. In a similar study by (Park and Hwang, 2012) also revealed that both male and female had the same types of cancer.

### **5.2. Different categories of met and unmet needs among patient with cancer**

In this study the researcher will discuss on the different categories of met and unmet needs among patient with cancer and the way these needs are addressed. Regarding the information needs on diagnosis 90.3% of the participants needed to know more about their diagnosis, similar study was conducted where the high proportion of participants needed to know about the diagnosis and the findings (A.Bonachi et al,2017).

This study revealed that 50.5% of respondents reported having a need on information about diagnosis as it was not met according to the findings, and 71% of the study participants have reported the lack of information about different modalities of cancer treatment, and 93.5% were informed about current treatments and their side effects but only 44.1% were satisfied and the majority 55.9% of study participants reported to be unsatisfied by the information given about their current treatment and its side effects, the study done in Australia, revealed similar results (White et al., 2011).

The study findings revealed that 91.4% needed to be informed about the prognosis of the disease and only 35.5% were satisfied about the information on the prognosis of their disease but 64.5% reported to be unsatisfied by the information given. The majority of the study participants 82.8% reported to have bad reaction after disclosure of their diagnosis, among them 74.6% found psychologist review helpful session and 91.4% of the study participants needed family involvement in the treatments process while 64.5% of the family member had bad reaction after disclosure of diagnosis. In addition 86% of the participants have reported to be happy by the support from their family.

The results of current study ,showed that (74.2% )of the participants reported to feel sometimes hopeless and in activities of daily living the majority of study participants (61.3%) reported a need of someone's help and this is similar to the study done in Italy ( Stephania De Miceli et al,2017).

The majority of the study participants (82.8%) reported to have symptoms like pain, nausea and vomiting while waiting the physician for consultation and 54.8% of them were not satisfied with the management to the above symptoms. Regarding practical needs( 91.4%) have reported not to be able to perform their regular job and activities of daily living as they used to do and 52.7% of the participants often feel tired easily while working and 77.4% were satisfied by the support given by their colleagues, the similar results were reported by ( Friðriksdóttir,2010; Patel et al., 2018).

### **5.3. Association between met and unmet needs with demographic factors among cancer patients at RMH.**

#### **5.3.1. Association between information needs about diagnosis and demographic factors**

To find out the association between informational needs on diagnosis and demographic factors bivariate and multivariate logistic regression have been performed. The information need on diagnosis was significantly associated with education level contrary to the study conducted in Korea where there was no association between two variables (Park and Hwang, 2012).

On the level of satisfaction marital status was significantly associated with satisfaction about information was also significantly associated with type of cancer and similar result was found in the study conducted in Turkish (Ogce, Ozkan and Baltalarli, 2007).

#### **5.3.2. Association between information needs about treatment and demographic factors**

To assess the association between the information needs about treatments modalities and demographic factors education level was significantly associated with demographic data with COR=2.704 and P value 0.024. Other variables were not statistically significant with information needs about treatment and demographic information.

#### **5.3.3. Association between the information about prognosis and demographic factors**

To assess the association between the informational need about prognosis and demographic factors bivariate and multivariate analysis was performed only occupation was significantly associated with information about prognosis with COR=0.308 and P value 0.035 similar results was found in a study conducted in Iran (Abdollahzadeh et al., 2014). Other social demographic information was not statistically associated with information on prognosis.

#### **5.3.4. Association between psycho-social and emotional needs and demographic factors of the participants**

In analysis of this association between the psycho social ,emotional needs and demographic data of the participants, gender was significantly associated with bad reaction after disclosure of diagnosis and unusual hopeless respectively the same results was found in Arabic countries (Abdollahzadeh et al., 2014). Residence area was significantly associated with helpful psychological review with COR=0.676 and P value 0.041, Education level was significantly associated with family support with COR=3.47 and P value 0.039 similar result was found in Australia(Harman, Francis and Thomas, 2001). Types of cancer was

significantly associated with family involvement with COR=0.623 and P value 0.027 similar results to the study was reported(Okediji, Salako and Fatiregun, 2017), other variables were not significantly associated with demographic data.

### **5.3.5. Association between Physical needs and demographic factors**

For the assessment of the association between physical needs and demographic data , age ,sex and occupation were significantly associated with physical needs with COR=2.122,0.149 and 1.641 with P values 0.045,0.015 and 0.043 respectively the above association was found in a study conducted in western countries(Harman, Francis and Thomas, 2001; Ogce, Ozkan and Baltalarli, 2007).Other demographic variables were not significantly associated with physical needs.

### **5.3.6. . Association between Practical needs and demographic factors**

The association between practical needs and demographic factors which are age, education level and residence of the participants were reported in the present study significantly with practical needs with COR=3.075(age), 3.467 (residence) and 0.534(education level) and P value 0.027, 0.011and 0.027 and the same results were revealed in the study conducted in western Australia(White et al., 2011).

## **CHAPTER 6. CONCLUSION AND RECOMMENDATIONS**

### **6.1. Conclusion**

The results of the present study provide important information about met and unmet needs of cancer patients in Rwanda Military Hospital. In summary the results on the information needs about the diagnosis, treatment and prognosis the participants reported that were not met, the psycho social needs, the study results showed high level of met needs. For physical needs, the majority of respondents did not appreciate the support given by the health care providers regarding their health condition when they present pain, nausea and vomiting. And on practical needs most of them reported inability to perform their usual work after being diagnosed with cancer.

Regarding the association between demographic factors and other variables; education level, marital status, residence were associated with information needs about diagnosis and the satisfaction of information needs on diagnosis and treatment were significant while age, gender, residence and education level were significantly associated with psychosocial and emotional needs. Physical needs with age, sex and occupation had the association and finally age, education level, residence was associated with practical needs of cancer patients. An appropriate assessment of cancer patients' needs must be applied by healthcare providers to ensure that cancer patients are well equipped to meet their needs during disease trajectory.

### **6.2. Recommendations**

#### **6.2.1. Nursing administration**

According to the study findings the patients with cancer need an advocacy, because they have different needs in their disease trajectory, the most reported needs are in information category about diagnosis, treatment, prognosis in the management of some symptoms when waiting the physician before consultation. The researcher encourages the advocate to Oncologist doctors to have time for their patients and provide needed information and nurses to assess needs of patients with cancer and provide necessary support on time.

#### **6.2.2. Nursing research**

More studies are needed in this area to understand the problems that met by cancer patients in their daily living, here are some suggested studies to be conducted:

To encourage other researchers to conduct other studies related to needs of hospitalized cancer patients to assess met and unmet needs of patients with cancer.

### **6.2.3. Nursing practice**

Assessment of needs of patients with cancer is back bone of caring the patients. The researcher recommends healthcare providers to be more knowledgeable about needs of patients with cancer by doing holistic assessment in order to be able to meet needs addressed by cancer patients.



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## **APPENDICES**

## **ANNEXE 1. QUESTIONNAIRES**

### **I.1.Original questionnaire**

#### **Needs Evaluation Questionnaire**

- 1) I need more information about my diagnosis
- 2) I need more information about my future condition
- 3) I need more information about the exams I am undergoing
- 4) I need more information about the treatments
- 5) I need to be more involved in the therapeutic choices
- 6) I need clinicians and nurses to give me information which is easier to understand
- 7) I need clinicians to be more honest with me
- 8) I need to be able to talk more with the doctors
- 9) I need some of my symptoms (pain, nausea, insomnia, etc.) to be better controlled
- 10) I need more help with eating, dressing, and going to the bathroom
- 11) I need more respect of my privacy
- 12) I need to be treated with more respect by the nursing staff
- 13) I need to be reassured more by the doctors
- 14) I need the hospital to provide better services  
(i.e. bathrooms, food service, cleanliness)
- 15) I need more financial/insurance information regarding my illness
- 16) I need economic help
- 17) I need to speak with a psychologist
- 18) I need to speak with a spiritual guide
- 19) I need to speak with people who have had my same experiences
- 20) I need more reassurance from my relatives
- 21) I need to feel more useful in my family
- 22) I need to feel less left on my own
- 23) I need to feel less pitied by other people

## I.2.Tool used in data collection

### QUESTIONNAIRE

This questionnaire will take 15 minutes to complete it. The information that you provide will remain strictly confidential.

#### Section A: Demographic data

##### 1. Age:

|       |       |       |              |
|-------|-------|-------|--------------|
| 18-30 | 31-44 | 45-59 | 60 and above |
|       |       |       |              |

2. Sex: Male:            Female:

##### 3. Marital status:

|        |         |          |       |           |
|--------|---------|----------|-------|-----------|
| Single | Married | Divorced | widow | Separated |
|        |         |          |       |           |

##### 4. Educational level:

|      |         |           |            |
|------|---------|-----------|------------|
| None | Primary | Secondary | University |
|      |         |           |            |

##### 5. Occupation:

|      |            |        |          |                  |                    |
|------|------------|--------|----------|------------------|--------------------|
| None | Cultivator | Farmer | Employed | Self<br>employed | Retirement/Pension |
|      |            |        |          |                  |                    |

##### 6. Residency area (province):

|         |         |          |          |             |
|---------|---------|----------|----------|-------------|
| Eastern | Western | Southern | Northern | Kigali City |
|         |         |          |          |             |

##### 7. Religion:

|          |           |            |       |             |
|----------|-----------|------------|-------|-------------|
| Catholic | Adventist | protestant | Islam | Traditional |
|          |           |            |       |             |

**8. Person living with:**

|             |          |         |         |                   |
|-------------|----------|---------|---------|-------------------|
| Him/herself | Children | Parents | partner | If other, specify |
|             |          |         |         |                   |

**9. Type of Health insurance:**

|                                  |     |      |         |
|----------------------------------|-----|------|---------|
| Community based health insurance | MMI | RSSB | Private |
|                                  |     |      |         |

**10. Type of cancer**

|               |                 |                 |                |          |                       |       |
|---------------|-----------------|-----------------|----------------|----------|-----------------------|-------|
| Breast cancer | Cervical cancer | Prostate cancer | Gastric cancer | Leukemia | Hepato cell.carcinoma | Other |
|               |                 |                 |                |          |                       |       |

**11. When did you know that you have a cancer?**

|           |           |          |                   |
|-----------|-----------|----------|-------------------|
| 0-12month | 1-3 years | 3-6years | 6 years and above |
|           |           |          |                   |

**Section B. Questions related to different category of patients with cancer needs**

**12. Information needs about my diagnosis**

1. Did you need to have more information about your diagnosis?

|     |  |
|-----|--|
| yes |  |
| no  |  |

2. Were you satisfied by the information given to you?

|     |  |
|-----|--|
| Yes |  |
| No  |  |

### 13. Informational needs about treatment

1. Were the different modalities of treatment (ex: chemotherapy, radiotherapy ,surgery, palliative care, etc ) for treating your disease explained to you?

|     |  |
|-----|--|
| Yes |  |
| No  |  |

2. Were you explained about your current treatment and its side effects?

|     |  |
|-----|--|
| Yes |  |
| No  |  |

3. Were you satisfied by the explanation given to you?

|     |  |
|-----|--|
| Yes |  |
| No  |  |

### 14. Information about prognosis

1. Did/do you need to know about your disease prognosis?

|     |  |
|-----|--|
| Yes |  |
| No  |  |

2. Were you satisfied by the information given to you?

|     |  |
|-----|--|
| Yes |  |
| No  |  |

### 15. Psycho-social and emotional needs

1. After disclosure of your diagnosis, how did you react?

|      |  |
|------|--|
| Good |  |
| Bad  |  |

2. Did you need to talk to the psychologist?

|     |  |
|-----|--|
| Yes |  |
| No  |  |



3. Is the psychologist review a helpful session?

|     |  |
|-----|--|
| Yes |  |
| No  |  |

4. Did you need your family to be involved in your treatment?

|     |  |
|-----|--|
| Yes |  |
| No  |  |

5. How did your family react to your condition?

|      |  |
|------|--|
| Good |  |
| Bad  |  |

6. Do you feel supported by your family since your disease diagnosis?

|     |  |
|-----|--|
| Yes |  |
| No  |  |

7. Do you sometimes feel unusual hopeless?

|            |  |
|------------|--|
| <b>Yes</b> |  |
| <b>No</b>  |  |

8. While you are in that condition, who do you need to talk to or what you need to do?

| Family member | Your Physician | Counselor | Pastor/priest | Someone with the same condition | To be alone |
|---------------|----------------|-----------|---------------|---------------------------------|-------------|
|               |                |           |               |                                 |             |

### 16. Physical needs

1. Do you need someone to help you in your daily activities (ex: bathing, eating, walking/moving etc.)

|     |  |
|-----|--|
| Yes |  |
| No  |  |

2. Are you satisfied by the support given to you?

|     |  |
|-----|--|
| Yes |  |
| No  |  |

3. Do you sometimes have symptoms like pain, nausea and vomiting while waiting for the physician?

|     |  |
|-----|--|
| Yes |  |
| No  |  |

4. Do you feel satisfied by the way your condition is being managed?

|     |  |
|-----|--|
| Yes |  |
| No  |  |

### **17. Practical needs**

1. Since your disease diagnosis, do you manage to do your regular job?

|     |  |
|-----|--|
| Yes |  |
| No  |  |

2. Do you feel tired while doing your job?

| Never | Sometimes | Often | Always |
|-------|-----------|-------|--------|
|       |           |       |        |

3. Are you satisfied by the way you re supported by your colleagues?

|     |  |
|-----|--|
| Yes |  |
| No  |  |

**Thank you very much.**

## IBIBAZO

Igika cya 1: Umwirondoro:

1. Imyaka:

|       |       |       |             |
|-------|-------|-------|-------------|
| 18-30 | 31-44 | 45-59 | 60 kuzamura |
|       |       |       |             |

2. Igitsina: Gabo  Gor

3. Irangamimerere :

|          |          |                               |            |                             |
|----------|----------|-------------------------------|------------|-----------------------------|
| ingaragu | urubatse | Mwaratandukanye<br>mumategeko | Umupfakazi | Mwaratandukanye<br>bisanzwe |
|          |          |                               |            |                             |

4. Amashuli:

|       |        |            |          |
|-------|--------|------------|----------|
| Ntayo | Abanza | ayisumbuye | Kaminuza |
|       |        |            |          |

5. icyo ukora:

|        |          |          |                    |           |                         |
|--------|----------|----------|--------------------|-----------|-------------------------|
| Ntacyo | ubuhinzi | ubworozi | Umukozi<br>wa leta | Uwikorera | Ikiruhuko<br>kizabukuru |
|        |          |          |                    |           |                         |

6. Aho utuye (Intara):

|               |                |           |              |                  |
|---------------|----------------|-----------|--------------|------------------|
| Uburasirazuba | uburengerazuba | Amajyepfo | Amajyaruguru | Umujyi wa Kigali |
|               |                |           |              |                  |

7. Idini:

|          |                |                |         |         |
|----------|----------------|----------------|---------|---------|
| Gatolika | Abadiventisiti | abaprotestanti | Isilamu | Gakondo |
|          |                |                |         |         |

8. Umuntu mubana murugo:

|         |              |          |                    |                      |
|---------|--------------|----------|--------------------|----------------------|
| Uribana | Umwana/Abana | Ababyeyi | Uwo<br>mwashakanye | Umukozi wo<br>murugo |
|         |              |          |                    |                      |

9. Ubwishingizi mukwivuzza:

|          |     |      |               |
|----------|-----|------|---------------|
| Mituweli | MMI | RSSB | Uwiyishyurira |
|          |     |      |               |

10. Nubuhe bwoko bwa Kanseri bakubwiyeko ufite:

|                |                  |                       |                |                  |                    |                          |
|----------------|------------------|-----------------------|----------------|------------------|--------------------|--------------------------|
| Kanseri yibere | Kanseri yubugabo | Kanseri ya nyababyeyi | Kanseri yigifu | Kanseri yamaraso | Kanseri y'umwijima | Ubundi bwoko bwa kanseri |
|                |                  |                       |                |                  |                    |                          |

11. Ni ryari wamenyeye uburwayi bwawe

|             |            |            |                   |
|-------------|------------|------------|-------------------|
| Ukwezi 0-12 | Umwaka 1-2 | Imyaka 3-6 | Imyaka 6 kuzamura |
|             |            |            |                   |

**Igika cya 2: Ibibazo bijyanye nibyifuzo bitandukanye byabarwayi bafite kanseri**

**12. Amakuru kuburwayi bwawe**

1. Ese washatse kumenya birushijeho kubijyanye nindwara yawe? **yego:** **Oya:**
2. Ese amakuru wahawe yarakunyuze? **Yego** **Oya**

**13. Amakuru kubijyanye nimiti**

1. Ese wasobanuriwe uburyo butandukanye bwakoreshwa mukukuvyura (imirasire, kubagwa, guterwa imiti, nibindi)? **Yego:** **Oya:**
2. wasobanuriwe ubuvuzi uhabwa nibijyanye ningaruka zayo? **Yego:** **oya:**
3. Ese ibisobanuro wahawe byarakunyuze? **Yego** **oya**

**14. Amakuru ajyanye naho uburwayi bwerekeza**

1. Ese ushaka wigeze ushaka kumenya aho uburwayi bwawe bwerekeza? **Yego:** **oya:**
2. Ese ibisobanuro wahawe byarakunyuze? **yego** **oya**

**15. Ibibazo nozamubano ,nuburyo bwimitekerere ndetse namarangamutima**

- 1.Ese nyuma yo kubwirwa uburwayi bwawe wabyakiriye ute? **Nabi: Neza:**
- 2.Ese wakeneye kuvugana nushinzwe mu ifasha myumvire ndetse nubujyanama? **Yego: Oya:**
- 3.Uburyo mwaganiriyemo bwarakunyuze? **Yego oya**
- 4.Ese umaze kubwirwa uburwayi bwawe wifujeko abumuryango wawe bagira uruhare muburwayi bwawe? **Yego: Oya:**
5. Ese abo mumuryango wawe bakiriye gute uburwayi bwawe?**Neza: Nabi:**
- 6.Ese ubona abo mumuryango wawe bakwitaho?**Yego oya**
7. Hari gihe ujya wumva wihebye cyg ukumva ufite umubabaro udasanzwe?**Yego: Oya:**
- 8.Mubihe nkibyo niki cyg ninde mwaganira ukumva uruhutse?

| Abo mumuryango | Umuganga wawe | umukansel a | Pasieri/Padiri | Uwo muhuje ikibazo | Kujya gusenga cyg kuririmba? | Kuba wenyine |
|----------------|---------------|-------------|----------------|--------------------|------------------------------|--------------|
|                |               |             |                |                    |                              |              |

**16. Uburyo uburwayi bwawe bwitabwaho**

1. Ese ukenera umuntu wo kugufasha mubikorwa byawe bya buri muni(urugero: gukaraba,kurya,kugenda cyg no kwambara)? **Yego: Oya:**
- 2.Ese wumva unyuzwe nuburyo bagufashamo? **yego Oya**
3. Ese harubwo ujya ugira ububabare,iseseme cyg kuruka mugihe utegereje Kubonana na muganga? **Yego: oya:**
4. Ese mugihe bimeze bityo uburyo bakwitaho burakunyuze?**Yego oya**

**17.Ibibazo bijyanye nimirimo muri rusange**

1.Kuva watangira kurwara ubasha gukora akazi kawe nkibisanzwe? **Yego: Oya:**

2.Ese ujya wumva umunaniro udasanzwe mugihe urimo gukora akazi kawe cg imirimo isanzwe?

|            |          |           |          |
|------------|----------|-----------|----------|
| Ntanarimwe | Rimwe na | Kenshi na | Burigihe |
|            | rimwe    | kenshi    |          |

3. Ese wumva unyuzwe nuburyo bagenzi bawe cg abo mubana bakuba hafi mugihe ugize intege nke kandi utarangije inshingano zawe? **Yego Oya**

**Murakoze cyaneee!!!!!!!!!!!!!!!!!!!!**

## **ANNEXE 2. CONSENT FORM IN ENGLISH**

**Title of the study” Needs of cancer attending outpatient department at RMH**

Principal investigator :**MUTEGARABA Chantal**

**CONTACT: 0788224336**

You have been requested to be a part of research study. It very important to understand the concepts which apply to all participants of this study.

- i. Participation is voluntarily
- ii. The study is intended to contribute to explore needs of cancer attending outpatient department at RMH
- iii. There are no penalty for refusing to participate
- iv. You are free to ask questions after being explanation so that you can appreciate the nature of the study.
- v. You have the right to withdraw in the study if you are not comfortable.

### **Assurance of confidentiality of volunteers’ identity**

All information including records of your participation as research subject shall remain **confidential**, your names will not be used in any report resulting from this study .You shall be supplied by a copy of this consent form. For information or answers to question concerning your rights as a research subject you may contact. The chairman of College of Medicine and Health Sciences Institution Review Board, ask through this phone number **0788 490 522 and Deputy Chairperson (0783 340 040)**. If there is any portion of this consent sheet that you do not understand , ask the investigator before signing . I acknowledge receipt of this agreement, to include: the consent explanation and the informed consent agreement

Principal investigator : **MUTEGARABACHantal**

**signature** -----

### **ANNEXE 3. PATIENT'S CONSENT FORM**

After being received an explanation about the purpose of this study, my contribution and being reassured that my rights shall be protected, I hereby accepting to sign on this sheet and I agree to participate in this study by answering to questions asked

I have well read and understand this document and accept to make signature freely without any oppression from whomever.

Date:

Signature



## **Kinyarwanda version**

### **INYANDIKOMVUGO YO KWEMERA KUGIRA URUHARE MU BUSHAKASHATSI**

Kugira ngo nsoze amasomo y'icyiciro cya gatatu cya kaminuza mu buvuzi bwo kwita kubarwayi ba kanseri mu buforomo, MUTEGARABA Chantal ndashaka gukora ubushakashatsi ku **“Kubyifuzo byabarwayi bafite uburwayi bwa kanseri bivuzwa bataha mubitaro bya Gisikare byu Rwanda”**

Ubwo bushakashatsi bukazakorera ku barwayi bakuze basuzumwe indwara ya kanseri. Ku barwayi bazaba bivuzwa mubitaro bya Gisirikare byu Rwanda I kanombe .Ni muri urwo rwego mbasaba Kugira uruhare muri ubu bushakashatsi mudufasha gusubiza ibibazo byanditse.

#### **Uburenganzira bwanyu:**

Mufite uburenganzira bwo kwemera cyangwa kwanga kugira uruhare muri ubu bushakashatsi no kubwivana mo igihe icyo ari cyo cyose bibaye ngombwa mutabajijwe ibisobanuro. Ibisubizo byanyu bizagirirwa ibanga kuko mudasabwa kwandika amazina yanyu ku mpapuro zasubirijwe ho ndetse n'ubafasha kuzuza urupapuro rw'ibibazo ntagomba kumenya amazina yanyu.

Muzamenyeshwa kandi ibyavuye muri ubu bushakashatsi binyujijwe ku bigo nderabuzima.

Mbaye mbashimiye ubufatanye bwanyu muri ubu bushakashatsi

Umukono n'Amazina y'Umushakashatsi: MUTEGARABA Chantal

Telephone 0788224336

#### **Icyemezo kigaragaza umugore wemeye gufasha mu bushakashatsi**

Maze gusobanurirwa intego y'ubu bushakashatsi, uruhare rwange ndetse nkanabwirwa uburyo uburenganzira bwange buzubahirizwa, nemeye gushyira umukono kuri iyi nyandiko kubushake, nk'icyemezo nemeye gusubiza ibibazo bibazwa muri ubu bushakashatsi. Nasobanuriwe neza iyi nyandiko kandi nayisobanukiwe neza niyo mpamvu nshyizeho umukono nta gahato.

Itariki & Umukono

#### **ANNEXE 4. STUDY BUDGET**

The budget is an estimation of revenue and expenses over a specified future period of time; my budget will estimate the expenses during my research.

| <b>No.</b> | <b>DESCRIPTION</b>               | <b>AMOUNT</b> |
|------------|----------------------------------|---------------|
| 1          | Preparation for the study        | 100.000frs    |
| 2          | Study survey                     | 250.000frs    |
| 3          | Study suppliers                  | 150.000frs    |
| 4          | Production of the report         | 300.000frs    |
| 5          | Workshop for research production | 100.000frs    |
|            | Total budget                     | 900.000frs    |

## ANNEXE 5. REQUEST OF A TOOL

MUTEGARABA Chantal

Tel:+250788224336

Email: [mutegachantal1@gmail.com](mailto:mutegachantal1@gmail.com)

Country:RWANDA

City:Kigali City

On 24th/April/2018

Object:Request of a tool

Dear Sir/Madam,

I do here apply this letter for requesting you to help me to access to your tool (Needs Evaluation Questionnaire) which you used during your research article which was entitled:Assessing unmet needs in patients with cancer: An investigation of differential itemfunctioning of the Needs Evaluation Questionnaire across gender, age and phase of the disease.

In fact,I am rwandan,a professional nurse. I am doing my masters program in Nursing Sciences, Oncology track in University of Rwanda.My research topic is:Assessment Of Unmet Needs of Hospitalised Cancer Patients and I need your tool to be used as in data collection.

Once my request will be considered,I will acknowledge you in my work.

Yours faithfully,



Chantal MUTEGARABA

## ANNEXE 6. ACCEPTANCE TO USE THE TOOL

**Andrea Bonacchi** <andreabonacchi2016@gmail.com> Wed, 2 May 2018, 16:14

to me, Francesca

Dear Chantal Mutegaraba,

I am Dr. Andrea Bonacchi MD, PhD, coworker of Prof. Chiesi.

In attachment we send you the NEQ questionnaire in English, in the inpatient version.

Do you need to develop a version in your own language before the use? In that case we can support you suggesting a appropriate procedure.

Moreover we are very interested in your research topic and - if you want- we could establish a collaboration in which we can support you with methodological suggestions, statistical analysis of dataset and writing of the paper.

best wishes,  
Andrea

## ANNEXE 7. ACCEPTANCE TO CONDUCT



March 29, 2019

Ref.: RMH/IRB/007/2019

### REVIEW APPROVAL NOTICE

Dear MUTEGARABA Chantal  
School of Nursing and Midwifery, CMHS  
University of Rwanda

Your Research Project: "Met and Unmet Needs of Cancer Patients Attending Outpatients Department at Rwanda Military Hospital".

With respect to your application for ethical approval to conduct the above stated study at Rwanda Military Hospital, I am pleased to confirm that the RMH/Institutional Review Board (IRB) has approved your study. This approval lasts for a period of **12 months** from the date of this notice, and after which, you will be required to seek another approval if the study is not yet completed.

You are welcome to seek other support or report any other study related matter to the Research office at Rwanda Military Hospital during the period of approval.

You will be required to **submit the progress report** and any major changes made in the proposal during the implementation stage. In addition, you are required to **present the results** of your study to the RMH/IRB before publication.

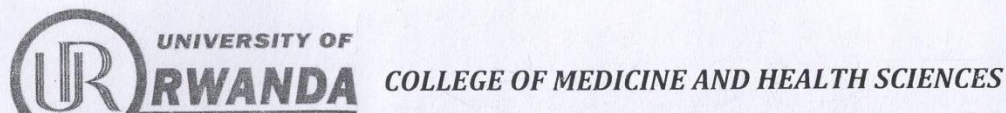
Sincerely,

Prof. Alex M. Buteera  
Colonel

Chairperson Institutional Review Board, RMH



## ANNEXE 8. ETHICAL CLEARANCE



CMHS INSTITUTIONAL REVIEW BOARD (IRB)

Kigali, 14/01/2019  
Ref: CMHS/IRB/040/2019

**MUTEGARABA Chantal**  
School of Nursing and Midwifery, CMHS, UR


Dear **MUTEGARABA Chantal**

**RE: ETHICAL CLEARANCE**

Reference is made to your application for ethical clearance for the study entitled "*Met and Unmet Needs of Cancer Patients Attending Outpatients Department at Rwanda Military Hospital*"

Having reviewed your protocol and found it satisfying the ethical requirements, your study is hereby granted ethical clearance. The ethical clearance is valid for one year starting from the date it is issued and shall be renewed on request. You will be required to submit the progress report and any major changes made in the proposal during the implementation stage. In addition, at the end, the IRB shall need to be given the final report of your study.

We wish you success in this important study.

  
Professor Jean Bosco GAHUTU  
Chairperson Institutional Review Board,  
College of Medicine and Health Sciences, UR


Cc:

- Principal College of Medicine and Health Sciences, UR
- University Director of Research and Postgraduate studies, UR


ANNEXE 9. NIH CERTIFICATE



**Certificate of Completion**



The National Institutes of Health (NIH) Office of Extramural Research certifies that **Chantal MUTEGARABA** successfully completed the NIH Web-based training course "Protecting Human Research Participants."



**Date of Completion:** 01/16/2018

**Certification Number:** 1825722

