

**A Qualitative Study on Clinicians' Perspectives on the Mental Health Needs of People with Cancer in Tikur Anbessa Specialized referral Hospital, Oncology Follow-Up Clinic, In Addis Ababa, Ethiopia**

**Research Thesis for the Partial fulfillment of the requirements of the Post Graduate Program in psychiatry**

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## Contents

Acknowledgement .....	3
Abstract .....	4
Acronyms .....	5
Standard definitions .....	<b>Error! Bookmark not defined.</b>
Introduction .....	<b>Error! Bookmark not defined.</b>
Background .....	<b>Error! Bookmark not defined.</b>
Statement of the problem .....	<b>Error! Bookmark not defined.</b>
Significance of the study .....	<b>Error! Bookmark not defined.</b>
Literature Review .....	<b>Error! Bookmark not defined.</b>
Objectives .....	<b>Error! Bookmark not defined.</b>
General objectives .....	<b>Error! Bookmark not defined.</b>
Specific objectives .....	<b>Error! Bookmark not defined.</b>
Methodology .....	13
Study area .....	<b>Error! Bookmark not defined.</b>
Study period .....	<b>Error! Bookmark not defined.</b>
Study design .....	<b>Error! Bookmark not defined.</b>
Source population .....	<b>Error! Bookmark not defined.</b>
Sampling method .....	<b>Error! Bookmark not defined.</b>
Data collection .....	<b>Error! Bookmark not defined.</b>
Data analysis .....	<b>Error! Bookmark not defined.</b>
Data management .....	<b>Error! Bookmark not defined.</b>
Ethical consideration .....	<b>Error! Bookmark not defined.</b>
Results .....	16
Discussion .....	23
Limitation of the study .....	25
Implication of the study .....	25
Recommendation .....	26
Conclusion .....	26
Appendix I: References .....	27
Appendix II: data collection form .....	<b>Error! Bookmark not defined.</b>
Appendix III: Topic guides .....	<b>Error! Bookmark not defined.</b>
IV: participants' information sheet .....	<b>Error! Bookmark not defined.</b>
Appendix V: participant consent form .....	<b>Error! Bookmark not defined.</b>

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## Abstract

**Background:** Significant numbers of people with cancer develop mental health problems at different stages of the disease. Psychological/psychiatric treatment is part of palliative care that is given to people with cancer to make them be able to deal with their problem individually and as a family. The Oncology unit at TASRH is known to be the only cancer referral center in the country. Published data done in Ethiopia were not found on how health care professionals in the oncology units understand, assess or address mental health needs of people with cancer and the obstacles they encounter.

**Objective:** This study aims to explore the clinicians' perspective of mental health needs of people with advanced cancer and the strategies clinicians use to assess and address those needs in TASRH Oncology follow-up clinic.

**Method:** An exploratory qualitative research design was employed and participants were selected purposively based on years of experience. Data was collected, transcribed in Amharic, translated to English and then analyzed through thematic analysis. The study was conducted at TASRH, October 2018.

**Results:** Majority of the participants reported to notice some mental health problems in patients with cancer but have some difficulty to identify symptoms and provide first line treatments. All participants stated that it is advantageous for patients to know about their illness. Participants also suggest the disadvantages patients from knowing about their illness is mainly due to the ways of information delivery. The increased number of patients visiting the clinic on daily basis was a major obstacle.

**Conclusion:** Timely and accurate diagnosis of co morbid mental disorders and addressing psychosocial factors is required to increase quality of life of people with cancer.

## Acronyms

A.A.U. - Addis Ababa University

CIA- Central Intelligence Agency

CMD- Common Mental Disorders

DSM-5- Diagnostic and Statistical Manual of mental health disorders, fifth edition

GAD- Generalized Anxiety Disorder

MDD- Major depressive Disorder

NCD- Non-Communicable Disease

PTSD- Post Traumatic Stress Disorder

PD- Panic Disorder

TASRH- TikurAnbessa Specialized Referral Hospital

USA- United States of America

WHO- World Health Organization

## **Standard definitions (National Cancer Institute dictionary of cancer terms)**

**Advanced cancer**-Cancer that has spread to other places in the body and usually cannot be cured or controlled with treatment.

**Colorectal cancer**- Cancer that develops in the colon (the longest part of the large intestine which includes the ascending colon, cecum, transverse colon, descending colon, sigmoid colon, and rectum) and/or the rectum (the last several inches of the large intestine before the anus).

**Leukemia**- cancer that starts in blood forming tissues like bone marrow and causes large numbers of abnormal blood cells to be produced and enter the bloodstream

**Lymphoma**- cancer that begins in the immune system

**Oncology**-A branch of medicine that specializes in the diagnosis and treatment of cancer. It includes medical oncology (the use of chemotherapy, hormone therapy, and other drugs to treat cancer), radiation oncology (the use of radiation therapy to treat cancer), and surgical oncology (the use of surgery and other procedures to treat cancer).

**Retinoblastoma**- A Cancer that forms in the tissues of the retina (the light-sensitive layers of nerve tissue at the back of the eye).

**Sarcoma**- A cancer that begins in bone, cartilage, fat, muscle, blood vessels or other connective tissues.

**Osteosarcoma**- A cancer of the bone that usually affects the large bones of the arm or leg.

## Introduction

### Background

Ethiopia is a country located In the Horn of Africa occupying 1, 100,000 square kilometers. It is the second most populated country in Africa with over 102 million people. Its capital city is Addis Ababa. Assessing the health profile of Ethiopia, WHO stated that the health status of the country is poor even when compared to other low-income countries including those in sub Saharan African countries. According to data from FMOH of Ethiopia Fact sheet posted in 2015, in 2006, (EFY) there were 156 hospitals, 3335 health centers and 16251 health posts in Ethiopia(33). The data from CIA world fact book which was last updated on January, 2018 states that there are 0.03 physicians(including generalist and specialist medical practitioners) per 1000 population in 2009 in Ethiopia. (3)

Being part of the Addis Ababa University’s School of Medicine, TikurAnbessa Specialized Referral Hospital is the training center for undergraduate and postgraduate medical students, dentists, nurses, pharmacists, laboratory technicians, and others who shoulder the health problems of the community and the country at large.(20)

Table: resources at TikurAnbessa Specialized Referral Hospital (20)

Total beds	600
Beds Devoted to Cancer Care (at the oncology center)	33
Staff physicians	201
Nurses	627
Dedicated Oncology Nurses	26
Pathologists	>10
Hematologists	2
Oncologist	
Clinical oncologists	4
Radiotherapists	4
Pediatric oncologist	1
Specialized surgical oncologists	2
Oncologists in training	
General and specialist surgeons	>30
Equipment	
CT scanners	1
Cobalt radiotherapy Units	2

Linear accelerator units	none
Patients seen in 2010	
Adult cancer patients	>2000
Pediatric cancer patients	>200

Among the many inpatient and follow up clinics in TASRH, the oncology unit is one of them and the hospital is known to be the only cancer referral center in the country (20). Oncology is a branch of medicine that specializes in the diagnosis and treatment of cancer.(17)

According to Harrison’s principle of Internal Medicine, 19<sup>th</sup> edition, Cancer is a general term used to refer to a condition in which the body’s cells begin to grow and reproduce in an uncontrollable way. These cells can then invade and destroy healthy tissue, including organs. Cancer sometimes begins in one part of the body before spreading to other parts. Cancer refers to over 100 different diseases characterized by uncontrolled growth and spread of abnormal cells. Cancer arises from one single cell following abnormal changes in the cell’s genetic material.(7)

Key statistics from WHO, in 2008, showed 7.6 million people died from cancer, which accounts about 13% of deaths worldwide. Among which 70% of the deaths occurred in low and middle income countries.(29).

Data from WHO, cancer country profile in 2014 showed, 14,500 males and 26,200 females died from cancer in Ethiopia. Same data shows breast cancer (24.4%) and cervical cancer (17.5%) were more prevalent in women while leukemia(12.7%) and colorectal cancer (11.2%) were more prevalent in men.(30) The Federal Ministry of Health estimates that there could be more than 150,000 cancer cases in Ethiopia each year, but available data is limited.(20) As the nation’s sole cancer referral center, TikurAnbessa Specialized Referral Hospital is treating only about one percent of these patients.(20)

According to data from the hospital’s oncology unit, more than 500 adult and pediatric cases with hematologic malignancies are seen in the hematology clinics every year.(20) Many patients with cancer are also seen at the surgical, gastrointestinal and gynecology clinics. From which the most common adult cancers seen at the oncology unit are cervical, breast, sarcomas, head and neck, and colorectal cancers, while leukemia, lymphoma, retinoblastoma and osteosarcoma constitute the bulk of pediatric cancers (20).

The poverty and the limited access in health services in sub Saharan African countries led cancer to be detected and diagnosed at an incurable and advanced stage in about 80% of the people.(21) According to the data from TASRH, similar percentage of reported cases of

cancer are diagnosed at advanced stages, when very little can be done to treat the disease. This is largely due to the low awareness of cancer signs and symptoms, inadequate screening and early detection and treatment services, inadequate diagnostic facilities and poorly structured referral system.(26)

Significant numbers of people with cancer develop mental health problems at different stages of the disease. Recent meta-analyses (Ann Oncol. 2010 and Lancet Oncol.2011) showed that approximately one third of people with cancer in acute care hospitals are affected by common mental disorders.(31,32) Of these, depression has been the one most studied.(12) An associations was found between cancer and increased rates of major depression and anxiety disorders (19) In a study done on co morbidity of CMD and cancer in 13 high and low-middle income countries, psychiatric morbidity onset of cancer increases in direct association with the level of disability, advanced illness and pain. The study also suggested timely and accurate diagnosis and appropriate treatment of co morbid mental disorders is required in an effort not only to increase quality of life but also to reduce adverse effects on cancer course, length of hospital stay, treatment adherence and efficacy and possibly prognosis and survival.(19)

A multidisciplinary approach is designed in screening, diagnosing, staging, determining prognosis and treatment for the patient. The primary aims of cancer treatment are to cure the patient, prolongation of life and to improve quality of life(14). A study done in TASRH in 2014 on rehabilitation for cancer patients showed 26% of cancer patients received rehabilitation service at least once. The main rehabilitation services given were nutritional and psychological support, mainly given by oncologists (60.4%), nurses (41.6%) and medical internists (9.9%). Among the patients who received rehabilitation services, 40.6% of them got psychosocial support. Unavailability of supplies lack of professionals and cost of services were among the barriers to receiving rehabilitation services.(26)

Since the treatment plan of the people with cancer is outlined by the health professionals at oncology unit, this study aims to explore the clinicians' perspective of mental health needs of people with advanced cancer and the strategies clinicians use to assess and address those needs.

### **Statement of the problem**

From the review done by American Cancer Society on literatures on psycho-oncology focusing on the epidemiology, assessment, and treatment of psychiatric disorders, emotional distress and mental health problems are very common in people with cancer. About 50% of people with advanced cancer are found to meet criteria for one or more psychiatric disorders. (11)

It is also known that early detection and appropriate treatment of co morbid mental disorders increase quality of life, reduce adverse effects on cancer course, length of hospital stay, treatment adherence and efficacy and possibly prognosis and survival.(19)

The World Health Organization describes palliative care as *"an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual"*(32).

The treatment of cancer has got to extend beyond the physical complaints and should include psychosocial factors that significantly affect the patient's quality of life. Clinician therefore must always care for the person as a whole. Psychological/psychiatric treatment is part of palliative care that is given to people with cancer to make them be able to deal with their problem individually and as a family (14).

On search of the literature, the researcher could not find published data done in Ethiopia on how health care professionals in the oncology units understand, assess or address mental health needs of people with cancer and the obstacles they encounter. understanding the health care providers' perspective on mental health needs of the people with advanced cancer and thus supply better information to fill the gap and improve the quality of service delivered to those in need.

### **Significance of the study**

Ethiopian Federal ministry of Health stated in the National Cancer Control Plan of Ethiopia(2016-2020) that palliative care improves quality of life of patients and families who face life threatening illness by providing psychosocial support from diagnosis to the end of life and bereavement. Building the capacity of health care providers and caregiver on palliative care by providing skill training for the identification, assessment and treatment of distressing symptoms in cancer patients is one of the goals of the cancer control plan. This study will help to have a better understanding on the practice of the health care providers in oncology follow up clinic at TikurAnbessa Specialized Referral hospital regarding the mental health needs of patients with advanced cancer. Thus, it helps to fill the gap and develop the most effective way of building the capacity of the health care providers in assessing and addressing mental health needs of the people with cancer. The study can also serve as a base for further studies on the issue to improve the quality of service in the oncology unit.

### **Literature Review**

About 50% of patients with advanced cancer meet criteria for a psychiatric disorder, the most common being adjustment disorders (11%–35%) and major depression (5%–26%).(11)Also, some patients have pre-existing psychiatric disorders that are exacerbated in the context of advanced disease, whereas others develop new symptoms of anxiety or depression during the course of their illness. (11) Advanced cancer is distressing for both patients and their caregiver(s). In addition to suffering the physical impacts, patients also have to deal with the emotional consequences of their illness and poor prognosis.(11)

In a study done in 2005, by American Cancer Society, Overall, 12% of patients with advanced cancer met criteria for a major psychiatric condition and 28% had accessed a mental

health intervention for a psychiatric illness since the cancer diagnosis. Among those who met criteria for psychiatric condition, 14% of the samples were with minor or major depression, 3.2% had generalized anxiety disorder, 4.8% had panic disorder, 2.4% had posttraumatic stress disorder, and the remaining fulfilled criteria for more than one psychiatric disorder. Mostly depression was found with GAD (17.6%), PTSD (29%) and panic disorder (17%). (18)

In a study done from data derived from world Mental Health survey in 2013, Twelve-month rates of common mental disorders were higher among respondents with active cancer (18.4%).(19)

Anxiety and depression commonly occur in cancer patients who are facing multiple biological and psychosocial stressors. Biologic stressors include the cancer burden, treatment morbidity, neurobiological changes, pain, and physical feelings. Psychosocial stressors include uncertainty, loss of control, changes in life path, and increased dependency, as well as changes in role functioning, appearance, and identity.(10) Anxiety and depression can develop at different points on the treatment continuum from the point of abnormal finding to diagnosis, initiation or completion of treatment, progression of disease, survivorship, and throughout palliative care.(9)

In a study done in Addis Ababa, Ethiopia in 2018 on a descriptive analysis of depression and pain complaints among patients with cancer in a low income country ,the prevalence of major depressive disorder was 16.4%, and sub threshold depression was 17.4%.The odds of having a major depressive symptom were over four times higher among participants who had pain (69.0%). (13)

In 2009 a Study in U.S.A found out that the prevalence rates of psychiatric diagnoses, (MDD, GAD, PD, and PTSD) among cancer patients is 10.8% as cancer got advanced and patients get closer to death. (28)

**Anxiety disorders (GAD, Panic disorder):** According to DSM 5, Anxiety disorders include disorders that share features of excessive fear and anxiety and related behavioral disturbances. (2) Cancer patients experience anxiety and depressive symptoms while undergoing screening test, when the patient is waiting for the results and when receiving diagnosis of cancer results, during treatment or anticipating recurrence or eminent death. (18) In Cancer patients with advanced disease, anxiety is not caused by fear of death but by the issues of uncontrolled pain, isolation, abandonment, and dependency. Their concerns frequently center on loss of control or independence, strained finances, and family dynamics. (6) Cancer related issues such as premature confrontation with mortality, changes in physical appearance, increased dependence on family, disruptions of social life and school/employment because of treatment, and loss of reproductive capacity is distressing are also other causes of anxiety in people with cancer.(22)

In a study done in USA in 2004, survivors of breast cancer expressed similar fears regarding recurrence, death, pain, and suffering (often identified as a larger fear than dying).

They explain, “The anxiety is worse than the pain. Pain, I can deal with it. When you take pain medication, it is relieved. But anxiety, it sticks in your mind”. Concerns about the illness affecting their roles as caregivers and the impact on their families and fears about changes in body image and scarring, were also mentioned. (8)

**Depression:** According to DSM-5, depression is a group of disorders with a common feature of the presence of sad, empty, or irritable mood, accompanied by somatic and cognitive changes that significantly affect the individual's capacity to function. What differ among them are issues of duration, timing, or presumed etiology. (2)

Depression is one of the most common psychiatric conditions following cancer diagnosis and during cancer treatment.(14) In a study done in Addis Ababa, Ethiopia in 2018 The prevalence of major depressive disorder was 16.4%, and sub threshold depression was 17.4%.(13)

**Posttraumatic stress disorder (PTSD):** DSM-5 describes the essential feature of posttraumatic stress disorder (PTSD) as the development of characteristic symptoms following exposure to one or more traumatic events. The traumatic event can be re-experienced in various ways. (2)

In Post-traumatic stress disorder (PTSD), Cancer patients try to avoid thoughts of the illness and studies have reported stress symptoms like avoidant behaviors, intrusive thoughts, and heightened arousal in cancer patients ranges from 3% to 4% in early-stage cancer patients recently diagnosed to 35% in patients evaluated after treatment.(25)

#### **Treatment gap and service utilization**

Although the treatment gap was present in both high income and low-middle-income countries, mental health service utilization was higher in the former than in the latter group.(19) In a study done in 2005 by American Cancer Society, 90% of participants stated that they would seek help if they were aware that they had an “emotional problem.” Of the 86 patients who discussed mental health issues with a health professional after the cancer diagnosis, 54 (62.8%) were offered treatment or given a referral for mental health services; of those 54 individuals, 48 (88.9%) received the treatment offered, antidepressants (22%), psychotherapy (13%), and anxiolytics (8%). (18)In 2013, findings from World Mental Health survey, mental health service utilization of all respondents across participating countries with active cancer, CMDs in the preceding 12 months was assessed, and 59% reported seeking services for mental health problems. Most frequently, they consulted general physicians (37.9%) and/or mental health specialists (29.9%).(19)

From the study done in 2004, most participants were suggesting that they did not receive recommendations from their doctors beyond those related with medical treatment. Several of the patients felt doctors really don't care to listen to what they are worried about, doctors are not sensitive enough to ask or give important information that they have to ask their doctors first in order to get some advice and that they have insufficient time with their doctors.(8)

Data related with the health professionals ways of assessing and addressing mental health needs of people with cancer cannot be found in Ethiopia.

## **Objectives**

### **General objectives**

- To explore clinicians' perspectives on the mental health needs of people with cancer in Tikur Anbessa Specialized Referral Hospital oncology follow-up clinic

### **Specific objectives**

- To explore clinicians' experience of mental health problems in people with cancer and how they may manifest
- To explore the approaches that clinicians use to assess and address the mental health needs of people with cancer
- To identify potential ways to strengthen clinical responses to the mental health needs of people with cancer

## **Methodology**

### **Study area**

The study was conducted in the oncology follow up clinic of TikurAnbessa Specialized Referral Hospital (TASRH) located in Addis Ababa, Ethiopia. TASRH is a teaching center for undergraduate and postgraduate medical students, nurses, pharmacists, laboratory technicians, and other health professionals. The Federal Ministry of Health estimates that there could be more than 150,000 cancer cases in Ethiopia each year, but available data is limited. TASRH is the only cancer referral center in Ethiopia treating only about one percent of these patients.(9) The oncology follow up clinic is one of the many chronic follow up clinics in TASRH working 5days in a week. Mostly patients with advanced cancer are seen in the follow up clinic. The service is rendered by oncologists (n=4), oncology residents (n=24), nurses (n=26), radiotherapy technicians and health professionals who have Master'sDegree in oncology.

### **Study period**

The study was conducted in September- October, 2018G.C.

### **Study design**

An exploratory qualitative research design was employed. This method is appropriate to explore peoples' experiences in-depth and recognize underlying reasons and opinions. It also helps to provide insight in to the problem and may provide a base to develop an idea or hypotheses for further studies. As little is known on this topic in Ethiopia, an exploratory approach is appropriate.

### **Source population**

Nurses who are working at oncology follow up clinic during the time of data collection.

### **Sampling method**

A purposive sampling technique was used to select participants. It is a technique to identify and include participants that are potentially rich with information to meet the purpose of examining the experiences of the health care providers towards the mental health needs of their patients. Participants included are nurses in the oncology follow up clinic who can speak Amharic and are willing to share their experiences.

### **Data collection**

Before beginning data collection, the researcher informed the potential participants about the purpose of the study and explains that they will be approached to invite them to participate but that they are under no obligation to participate. Then the individuals who are willing to participate in the study were encountered individually and the purpose of the study and ethical considerations were discussed with them. They signed a consent form after they agreed to participate and had the interview through audio recording.

Data collection includes information on the profession of the participants and years of experience in the oncology follow up clinic. After this data was obtained, a semi structured face-to-face interview was carried out using a topic guide to help direct the process (see appendix A). In addition, the interviewer also made note of nonverbal communications of participants. Interviews were carried out in Amharic language. The interviews lasted 25 - 45 minutes and was held in private setting (empty ward and OPD after work) in the clinic. Data

collection stopped when it was determined that the study reaches saturation and no new codes are going to be created. Open source software Open Code is used to store and manage the transcripts of the interviews.

Open-ended questions were asked to encourage participants express their own ideas even though they are guided by the interview schedule.

### **Data analysis**

The data collected was analyzed using thematic analysis. The audio recorded data was transcribed in Amharic verbatim by a third party transcriber and then translated to English for analysis. All English translations were compared against the original Amharic transcripts. There were no significant differences between the transcriptions in the overall meaning of the translation. Data collection and analysis took place concurrently in order to modify the topic guides as necessary. Findings were checked back with the original data for discrepancies.

### **Data management**

Anonymity was maintained all the time. Third party transcribed and translated data were deleted after transferred to a personal computer. All the data were kept separately, anonymized and stored in password-protected folder.

### **Ethical consideration**

The study was carried out after ethical approval was obtained from the Department of Psychiatry, College of Health Sciences, A.A.U., research ethical committee and the department of Oncology, A.A.U. The purpose of the study was explained to all potential participants that the findings of the research will only be used for academic purposes. Willing participants gave written informed consent. Cautions were taken to ensure that the study is only to understand their experience and participants should not feel being evaluated or judged. It was explained to the participants to feel free to continue with the interview or that they have the right to reschedule or withdraw from the study. Confidentiality was maintained throughout by avoiding personally identifiable data and proper handling of data as described above in the data management part.

## Results

### Sample

A total of ten participants were interviewed. The characteristic of the participants is presented in Table 2. Among the participants, four were males and six were females. Three participants were interviewed from outpatient clinic and seven participants were from inpatient wards. From the participants eight of them are general nurses while the remaining two are oncology nurses. Only one participant had training in mental health during their BSC Nursing study and Masters in oncology nursing, the remaining 9 participants had mental health training during their BSC Nursing study. Participant's year of experience at oncology clinics ranges from 1 year to 5 year. Participants report to encounter 3-5 patients with advanced cancer in inpatient wards and 8- 10 patients with advanced cancer at the outpatient clinic.

Table 2: characteristic of the participants

Characteristic	Number of participants( total=10)
Sex	
Female	6
Male	4
Level of education	
BSC Nurse	8
Masters in Oncology nurse	2
Place of practice	
Outpatient clinic	3
Inpatient clinic	7
Year of experience at Oncology clinic	
<=1 Year	2
1-2 years	3
2-3 years	3
3-4 years	1
4-5 years	1
Time spent with a single patient	
<= 10 minutes	4
10-20 minutes	3
20-30 minutes	2
30-40 minutes	1
Training in Psychiatry	
During BSC study	9
During BSC and Masters study	1
Other	0

## **Themes identified**

The following were the major themes arising from the thematic analysis.

### **A. Clinical presentations of mental health problems**

#### **1. Emotional symptoms**

Most of the participants responded that they observe patients with cancer showing some emotional symptoms like crying, being upset, irritable and scared. One participant from the outpatient clinic particularly reported that in addition to what has been mentioned, that patients are embarrassed because of their physical condition.

#### **2. Psychiatric problems**

Regarding psychiatric symptoms, most of the participants mentioned that patients are usually restless, and forgetful. They also specify that patients refuse to feed, refuse to take medication, and become difficult to convince them for different investigations.

More than half of the participants noticed patients laughing and talking alone like with someone beside them, where there is no one around them. In addition, patients replying to them in unrelated matter from what they are conversing about all along.

*“.. They laugh alone; talk alone as if someone is beside them talking to them. But no one is really there...” 002 in*

Two participants from the inpatient report that they have witnessed patients blaming their families for the evil act they are doing behind their back. One of the two participants specifies her experience with one patient as follows.

*“.. The patient came in to take chemotherapy, suddenly she started shouting, pushing away her families saying ‘you are going to kill me, you are going to let them kill me, I know your deeds, you are going to attack me..’..”003 in*

Another two participants (one from inpatient and one from outpatient clinic) mentioned that patients sometimes get confused, that they do not really know where they are or who the people around them are, they confuse their family for someone else.

Only one participant specifies that sometimes patients have difficulty maintaining sleep.

### **3. Causes of symptoms**

Most of the participants in the inpatient service suggest that pain is the commonest cause of the behavioral changes witnessed in patients with cancer.

*“.. In most of them it’s their pain; because most of the time they are in pain you can see their unhappiness in their face..”001 in*

More than half of the participants attribute the symptoms for the economic crises the patients has to suffer because of medications, other related costs while staying in Addis Ababa. Only one participant from the inpatient service reports that patients has no financial problems regarding medications as there is a free service for those who cannot afford. The fact that patients has little or no awareness about cancer was also mentioned by most of the participants as it cause patients to think that they are going to die soon from their illness and there is no cure for it.

Some participants also reported that the symptoms could be caused by the side effects of the chemotherapy.

Other causes of symptoms stated by few of the participants is the family issues the patients have. They explained that most patients come from countryside and they have to leave their children, siblings, parents and other close relatives. As there is a long waiting list for investigations, they stay away from their loved ones. Patients missing their families, not being able to work and support their family and feeling that they are a burden for others cause a great deal of stress, which contributes to their symptoms.

*“.. They spent more money for different reasons when they came in for treatment most came from countryside; they left their job, their kids and their family. They sell their cattle, land or other property to get treatment. Some start to beg in the city for their medication. The illness has so much impact on their life...” 007 in*

Only two participants report that the symptoms could be caused by complication of the disease itself when metastasizing to the brain.

### **4. Reaction of patients when told about their illness**

Most of the participants were mentioning that patients mostly are shocked when they were told about their illness for the first time. Other related reactions mentioned by the participant are crying, being upset, being worried and lost hope regarding their health.

When the disease process progress to advanced stage, participants stated that patients become more depressed, hopelessness gets worse, they refuse treatment and insist on visiting a holy water place.

One participant female nurse from the outpatient clinic express how saddened she gets when patients she had seen before gets worse as their illness advances. (She was emotional and tearful when she was describing the following)

*"...as the disease progressed, at the end, they have severe depression, they didn't even care a little for their life... as if their life is not considered as a life anymore,... they are just waiting for death, it's worse than what am telling you right now, I don't even know how to explain that to you..." 002out*

At times patients also become disruptive and physically aggressive towards their family members as reported by some participants.

## **B. Assessment and addressing mental health needs**

### **1. Ways of identifying mental health problems**

All of the participants mentioned that mostly it is through observation of behavioral changes of patients that they learn about their mental health problems.

*"..You notice the behavioral changes they show as days goes by. They are normal when they first came in, it's through time that they develop changes.."004 in*

Most participants mention that they observe behavioral changes like refusing to feed, refusing to take medication, strange behaviors of talking and laughing alone, being agitated and forget full.

*"..They start to act in a different way. For example, they remove their IV line on their own, they refuse to eat, they are upset, they are always angry and they are hopeless.."007 in*

One participant was reporting that patients ask her to leave the room saying she is conspiring with their family to harm them.

Some participants also mentioned that families also complain behavioral change in the patients like being irritable, refusing for investigations and difficulty to get along with them.

All participants report that they do not screen for mental illness by directly asking the patients.

## **2. Measures taken for the mental health needs encountered**

All participants stated that they give advice to both patients and attendants regarding medication side effects and the need to keep having follow up visits as behavioral changes can be caused by chemotherapy side effects. They report to advice families to tolerate patient's change of behavior and to keep an eye on them not to cause any harm on self or others.

Few participants also mention that,they advise patients to be strong in their religious life and to pray, as they are a religious person themselves.

Patients who are difficult to be calmed down with the advices are mostly referred to psychiatry clinic in the hospital compound.

*“.. Those patients who become critical for us by being aggressive, agitated, shouting, disturbing & sometimes trying to pull out their IV lines, they will be difficult to administer chemotherapy so we send them to psychiatry side...”001in*

Only one participant from the outpatient clinic mentioned that she is not aware of the psychiatric clinic in the hospital compound despite working for about 5 years at the oncology clinic.

All participants denied any medication given to patients when they are difficult to manage except for one female participant from the inpatient clinic who stated to remember only one patient who was given diazepam when he was violent.

### **C. Potential ways to strengthen clinical responses**

#### **1. Confidence to identify and provide first line treatment for psychiatric problems**

Participants who have studied their masters on oncology nursing and one nurse with BSC degree reported that although they cannot be certain, they do not have that much trouble in identifying mental health problems. The other participants stated that they have difficulty in identifying such problems.

*“..I am confident; and also I've taken palliative care course in postgraduate level , so based on the signs & the symptoms I know I assess the patients & try to counsel them about their diagnosis & course of treatments and the likes...” 001in*

*“.. I have graduated recently, I had an attachment at Amanuel hospital and I have seen different cases, so although I cannot be fully confident, I think I can easily identify the symptoms when our patients show some...” 003in*

Nevertheless, since there is no adequate training on how to provide first line treatment for such problems, almost all participants reported they are not that confident to proceed. Moreover, all participants suggested that training on psychiatric courses is mandatory in order to improve the service.

*“.. When we have psychiatry course when we study nursing is how to identify symptoms, no one really show us what to do with the symptoms, we are not trained to treat...”002out*

Few of the participants also suggested if they can be provided with guidelines or any related materials by the psychiatric department.

*“I believe if we get more courses, trainings & case based discussions from psychiatry department it would improve our care.. ” 001in*

*“.. It will be better if we are trained or if we are given the copy of psychiatry book or a guideline, so that we can refer to it other than Google, when we have patients with such problem...” 003in*

## **2. Help with mental health problems**

Most participants stated that they did not get any specific help regarding mental health problems from the oncology team, except for one nurse who claims contacting a nurse who studied psychology but not working with the field. Few participants report, it is the doctors (oncologists and residents), whom they communicate first when they encounter patients with psychiatric problems.

Most participants reported that except for referring patients to psychiatry clinic, no one from psychiatry department came and offer help to patients in the oncology clinic.

## **3. Impact of knowing about illness**

All participants mention that the benefit patients get from knowing about their illness weighs more than the disadvantages. Few of the participants also stated that sometimes the families do not want patients to know about their illness, as they would be too stressed and the condition of patients will deteriorate.

Most suggested that knowing helps the patients to understand their illness better and to take care of themselves. Other benefits of knowing reported are to adjust their expectation of their prognosis and plan their life; it protects them from unnecessary cost of money; and to have a say in the decision to make treatment plan together with the treating physician.

Regarding the disadvantage of knowing, most suggested that patients might lose hope, refuse treatment, and make impulse decisions to harm self. According to the participants, the main cause of the disadvantages is inadequate way of informing the patients about their illness. Related to that most of them suggest that breaking the news to patients should be held by a professional, in a private and quiet setting, involving family members and delivering full information piece by piece by taking in to consideration to the background of the individual.

*“..- usually they hear their diagnosis from the doctors but they don't get much counseling when they came to us & I think if we have clinical psychologist with us who would counsel them after they knew about their diagnosis & condition it would be better for the patients...”*  
*001out*

#### **4. Final recommendations**

Most of the participants suggest a collaboration work with psychiatry department is important to improve the quality of care patients with cancer get. Few suggested other than the training for the staffs, group sessions for patients and attendants can be helpful. In addition, they also suggest for one professional from psychiatry department to work at the oncology clinic for individual contact with patients and their families.

## Discussion

In this qualitative study nurses working at the Oncology clinic, TASRH, were given opportunities to describe their experiences and express their opinions regarding mental health needs of patients with cancer and ways to improve them. We believe the findings of this study are essential to create a better insight into the practice at the oncology unit.

Although this study did not explore about the specific psychiatric disorders, most of the clinical presentations reported by our participants can be explained by the disorders what previous studies found out to be common in patients with cancer, major and minor depression, GAD and Panic disorder. (18)

In our study, participants has mentioned, other than the commonest presentations, they have also encountered additional symptoms with patients whose cancer has progressed to advanced stage. The reported additional symptoms are being agitated, forgetful, talking alone as if someone is beside them, laughing alone, being suspicious of their families or the nurses to conspire against them and those who are confused about where they are and who the people around them are. Even though there are no evidences suggestive of these presentations in the studies about the common mental health problems in cancer patients that has been reviewed, the reported symptoms are of a common presentations of a psychiatric disorder which commonly occur in patients who undergo multiple modalities of procedures or treatments. Although delirium is under-recognized in medical settings, according to a journal published in 2017 by cancer network, estimates of delirium range from 43% in general cancer population to 85% in patients with terminal stages of their illness.

We have found that there are different causes mentioned by the participants for the psychiatric problems they have encountered. And these are evidenced by a study as mental health problems (especially anxiety and depression) commonly occur in cancer patients who are facing multiple biological and psychosocial stressors. Biologic stressors include the cancer burden, treatment morbidity, neurobiological changes, pain, and physical feelings. Psychosocial stressors include uncertainty, loss of control, changes in life path, and increased

dependency, as well as changes in role functioning, appearance, and identity.(10) The prevalence of depressive symptoms was higher among patients who had pain. (27) These was also found to be similar in our study as almost all participants stated that pain is the most common causes of the symptoms. Strained finances and disruptions of social life and school/employment because of treatment are other factors that cause distress in patients with cancer (22), which is also similar with our finding.

No published data about health professionals' ways of assessing and addressing mental health needs of people with cancer was found to compare our finding with. However, our participants have mentioned that mostly it is through observation of behavioral changes patients show that they learn about the mental health problems patients have. Some participants also mention families' complaints about the change of behaviors patients show. From this, we can say, some of the mental health needs of patients might be missed by the caregivers or health professionals, which in turn has effect on the mental health care of such patients.

A study done in TASRH in 2014 on rehabilitation for cancer patients showed few of cancer patients received rehabilitation service at least once. The main rehabilitation services given were nutritional and psychological support, mainly given by oncologists, nurses and medical internists(26). Our study has a similar finding as participants reported that they give advice for both patients and caregivers when they encounter psychiatric problems. Participants also mentioned that they refer difficult patients to psychiatry clinic.

Our study found out that although the benefit of knowing one's illness weighs in different aspects more than not knowing, patients might be disadvantaged after they are aware of their illness. This is mainly due to the insufficient way of breaking the news for the patients; this in turn is affected by the busy working hours due to increased number of patients seen at the clinics. This problem has been in a study done in 2004, in which most participants were suggesting that they did not receive recommendations from their doctors beyond those related with medical treatment. Several of the patients felt doctors really don't care to listen to what they are worried about, doctors are not sensitive enough to ask or give important information that they have to ask their doctors first in order to get some advice and that they have insufficient time with their doctors.(8)

### **Limitation of the study**

The significant limitation of the study was we were not able to involve more number of participants working in the oncology clinic due to time constraint and busy schedule of the participants.

Since published data related with health professionals' ways of assessing and addressing mental health needs of people with cancer could not be found, it made it difficult to compare the findings.

Another noted limitation is that the data obtained is much richer than stated on the results. There were important issues that were raised by participants but since a study can only focus on specific questions, it fails to address some important points like how they are breaking bad news.

### **Implication of the study**

One of the outstanding finding of the study was the recognition of psychosocial stressors patients with cancer have in their life because of their illness and the stressors being as one of the main factors in the development of mental health problems. The other finding is the significance of how a bad news should be delivered to a patient can affect the outcome.

The recommendations by the participants are reasonable and can be done with few rearrangements in the current service provision.

## **Recommendation**

Several studies suggest timely and accurate diagnosis and appropriate treatment of co morbid mental disorders is required in an effort not only to increase quality of life but also to reduce adverse effects on cancer course, length of hospital stay, treatment adherence and efficacy and possibly prognosis and survival. Therefore, from our study the following recommendations are made in order to improve the capacity of service provision.

- Training for different levels of health professionals working at Oncology clinic on the different emotions and psychiatric clinical presentations
- Providing skill training on different techniques to identify the different psychiatric problems and actions to be taken
- Training on the difference between giving advice and providing psycho education for those in need of mental health care
- Training on breaking bad news to the patients
- Extending Psychiatric service to the oncology clinic
- Build a collaborative work between psychiatry and oncology departments

## **Conclusion**

Our findings and other evidences have proven that timely and accurate diagnosis of co morbid mental disorders and addressing psychosocial factors is required to increase quality of life of people with cancer (14,19). As the only cancer referral center in country, it is worth considering the above findings and recommendations in order to enhance capacity building and narrow the gap in the mental health care provision.

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## Appendix II: data collection form

### I. Identification

1. Id number/ code
2. Educational status
3. Number of Year of experience at oncology follow up clinic
4. How frequently do you see a patient with advanced cancer?
5. How long do you sit with a patient with advanced cancer during their visit?

### Appendix III: Topic guides

1. What emotional symptoms do you notice in people with advanced cancer?
2. What type of mental health problems do you notice in people with advanced cancer?
  - What types of mental health problems can happen, when a people are told that they have terminal cancer for the first time?
  - What types of mental health problems can happen as the person's condition progresses?
  - What do you think are the main reasons that people get mental health problems?
3. How do you identify mental health problems in advanced cancer patients?
  - Through direct questioning?
  - Through observation of their emotional state?
  - Through observation of physical changes?
  - From verbal complaints of patients?
  - From verbal complaints of family members?
4. What measures do you take when you encounter with people with mental health needs? Why?
  - Probe for referring to religious or spiritual advisors,
  - giving advice to family (what advice?),
  - giving advice to the person (what advice?),
  - referring (what makes them refer? Suicidality?),
  - prescribing (what? How do they decide when to prescribe?)
5. How confident do you feel to identify mental health problems in advanced cancer patients? What would help?

6. How familiar are you with mental health? Any training?
7. How confident do you feel to provide firstline treatment for mental health problems in people with advanced cancer?
  - What would help to make you more confident?
  - Who else in the oncology team might be able to help with mental health care?
  - Who else outside the oncology team might be able to help with mental health care? E.g. spiritual advisors? Social work team?
8. What do you think are the benefits and disadvantages of telling people that they have advanced cancer?
9. What do you think is the best way to tell people that they have advanced cancer?
10. Do you have any other comments about mental health care for people with advanced cancer?

**መረጃ መስጠት በሰበሰብ ቅጽ**

**I. የተሳታፊ መለያ**

1. የመለያ ኮድ-
2. የትምህርት ደረጃ-
3. በካንሰር ህክምና ክፍል የአገልግሎት አመት-
4. በየሰንትራል ክፍሉ የካንሰር ህመም ተጠቃሪ ወያያዣ
5. በህክምና ክትትላቸው ላይ በክፍሉ የካንሰር ህመም ተጠቃሪዎች ጋር ምን ያህል ጊዜ ያሳልፋሉ?

**የርዕስ መግቢያ**

1. በክፍሉ የካንሰር ህመም ተጠቃሪዎች ላይ የሚደረገው ስተዲዎች ለህክምና ስሜት ምን ያህል ይረዳሉ?
2. በክፍሉ የካንሰር ህመም ተጠቃሪዎች ላይ የሚደረገው ስተዲዎች ለህክምና ስሜት ምን ያህል ይረዳሉ?
  - ስተዲዎች ከክፍሉ የካንሰር ህመም ለህክምና ስሜት ምን ያህል ይረዳሉ?
  - የህመምቸው ሁኔታ እና ጤና በህክምና ስሜት ምን ያህል ይረዳሉ?
  - ስተዲዎች ለህክምና ስሜት ምን ያህል ይረዳሉ?
3. በክፍሉ የካንሰር ህመም ተጠቃሪዎች ላይ የሚደረገው ስተዲዎች ለህክምና ስሜት ምን ያህል ይረዳሉ?
  - በቀጥታ ለህክምና ስሜት ምን ያህል ይረዳሉ?

- ያሉበትን የ ስሜት-ሁኔታ ታቦ ማስተዋል?
  - የ ማዕረግ ትንህ ካላዊለ ወጥቦ ማስተዋል?
  - ህመምተኞች በ ቃል ከ ማህ ልፀት?
  - የ ህመምተኛ ወቤተሰቦች በ ቃል ከ ማህ ልፀት?
4. የ አእምሮ ጠፍ እርዳታ የ ማዕረግ ጋብቻ ወሰን ሆኖ ጋጥሞት ምን ዓይነት ትእርምጃዎችን ይወስዳሉ? ለ ምን?
- ወደ ህይወት / እምነት አ ማህ ልፀት ማድረግ?
  - ለ ቤተሰብ ጠቅላይ ማስተዋወቅ? ምን ዓይነት ጥረት?
  - ለ ህመምተኛ ወጥቦ ማስተዋወቅ? ምን ዓይነት ጥረት?
  - የ አእምሮ ህክምና ወደ ማህ ጥበቅ ፍልጠና ማድረግ? ሆስፒታል ወይንም ሌላ ጥረት?
  - ማዕረግ ማህ ልፀት ማድረግ? ምን ዓይነት ጥረት? ማድረግ?
5. በ ከፍተኛ የ ካንሰር ህመም ተጠቅሞት ሆኖ የ አእምሮ ጠፍ ችግሮችን ማህ ልፀት ማድረግ ይቻላል? ምን ስያሜ ስለ ጠላቅ ይቻላል?
6. ስለ አእምሮ ጠፍ ምን ያህል ይታወቃል? ስለ ጠፍ ስወስደ ወይንም ወይንም ይታወቃል?
7. በ አእምሮ ህመም ተጠቅሞት ከፍተኛ ካንሰር ህመምተኞች የ ማዕረግ ያደረጁ እርዳታ ማድረግ ምን ያህል ጠቅላይ ስትይደታሉ?
- በ ራስ ማዕረግ ማድረግ ለ ማዕረግ ማድረግ ማድረግ ይቻላል?
  - በ ካንሰር ህክምና ከ ፍልጠና ጥያቄ አእምሮ ጠፍ እንደ ከፍተኛ ካንሰር ህክምና ለ ማዕረግ ማድረግ ይቻላል?
  - ከ ካንሰር ህክምና ከ ፍልጠና አእምሮ ጠፍ እንደ ከፍተኛ ካንሰር ህክምና ለ ማዕረግ ማድረግ ይቻላል?
8. ለ ህመምተኞች ከፍተኛ ካንሰር ተጠቅሞት ችግር ማድረግ ምን ዓይነት ጥረት ማድረግ ይቻላል?
9. ለ ህመምተኞች ከፍተኛ ካንሰር ተጠቅሞት ችግር ማድረግ ለ ማዕረግ ማድረግ ምን ዓይነት ጥረት ማድረግ ይቻላል?
10. በ ከፍተኛ የ ካንሰር ህመም ተጠቅሞት ሆኖ የ አእምሮ ጠፍ እንደ ከፍተኛ ካንሰር ህክምና ለ ማዕረግ ማድረግ ምን ዓይነት ጥረት ማድረግ ይቻላል?

**IV: participants' information sheet**

I am conducting a research project that focuses on clinicians' perspective on mental health needs of people with advanced cancer.

This form will explain why the study will be conducted, what your role will be the possible benefits of involving in the study and confidentiality of the information you give for the study. There is no expected or perceived harm to you by participating in this study. This will be done by conducting an interview using questions for each participant. The interview will take up to 30-45 minutes but the duration and structure will primarily be determined by your (participant's) responses.

The questions you will be asked are about your perspective on the mental health needs of patients with advanced cancer. With your permission, the interview will be audio-recorded. Your confidentiality will be strictly protected; no names will be recorded during the interviewing process or when stored.

After data is converted into English language, it will be stored in password protected folders. Any personal information that could lead to your identification will never be disclosed in either written or oral form. I will need to hear your true perception and real experiences about the issues and you will not be judged or in any way penalized for what you will say.

You have the right of free choice to participate in the study without any obligation. If there is any question that you don't want to answer you can miss out that question. You can ask further clarifications of questions that are not clear to you. Anytime during the interview, you can ask for a break, to reschedule. You have a full right to withdraw from the study or choose not to participate at any time without consequences. This will have no effect on the carrier. I would also like to inform you that this study is approved by the ethical committees of the Department of Psychiatry, Addis Ababa University and department of Oncology, Addis Ababa University.

The principal investigator is Dr. BethelhemMekasha, Department of Psychiatry, A.A.U.

Email: [bethymek19@gmail.com](mailto:bethymek19@gmail.com)



## Appendix V: participant consent form

My name is \_\_\_\_\_. I have received and understood the information I have been given verbally and in the letter of invitation to take part in the study which composed of an interview to explore my perspective on the mental health needs of people with advanced cancer, in TASRH.

I have understood that participating in the study entirely depends on my decision to participate and that I have all the rights to withhold information, refuse or dropout of the study any time I want to do so without any negative consequences.

Yes

No

I have received adequate information regarding the nature of the study and understood what will be expected from me. I have understood that the confidentiality will be kept for all the information I give during the study.

Yes

No

I agree to the interview being audio-recorded.

Yes

No

I hereby consent to participate in this research study.

Participant's signature:

Date:

Researcher's signature:

Date:

