



**ADDIS ABABA UNIVERSITY**

**COLLEGE OF HEALTH SCIENCES**

**SCHOOL OF PUBLIC HEALTH**

**Compassionate care among oncology patients at Tikur Anbessa  
Specialized Hospital: tool validation and measurement of practice in  
Addis Ababa, Ethiopia**

By

Merkeb Zeray

**A Thesis Submitted to the School of Public Health, Addis Ababa University  
in Partial Fulfillment of the Requirements for the Degree of Masters of  
Public health (MPH), in health service management**

November, 2018

Addis Ababa, Ethiopia

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## **Abbreviations and Acronyms**

AVE	Average Variance Extracted
CRC	Caring Respectful and Compassionate
CFA	Confirmatory Factor Analysis
CFI	Comparative Fit Index
CR	Construct Reliability
EFA	Exploratory Factor Analysis
FMOH	Federal Ministry of Health
Df	Degree of freedom
HCS	Pre-qualifying healthcare students
HSTP	Health Sector Transformation Plan
IFI	Incremental Fit Index
KMO	Kaiser-Meyer-Olkin
NCD	Non-Communicable Disease
RMSEA	Root Mean Square Error Approximation
SRMR	Standardized Root Mean Residual
PAF	Principal Axis Factoring
TASH	Tikur Anbessa Specialized Hospital
TLI	Tucker-Lewis Index
UK	United Kingdom
USA	United State of America

## **Abstract**

**Background:** Compassionate care is a hallmark of quality health care in any health system. However, this issue only has got attention very recently in the Ethiopian context. In addition, there is no locally applicable measurement tool to assess the compassionate care practice in the Ethiopian context.

**Objectives:** The objective of this study was to assess the validity of the Schwartz Center Compassionate Care Scale and to measure compassionate care practice among oncology patients at Tikur Anbessa Specialized Hospital.

**Methods:** An institutional based cross-sectional study supplemented by qualitative approach was conducted from March- May 2018. A total of 423 oncology patients were selected using a systematic random sampling technique. Descriptive statistics were used to summarize socio-demographic and clinical characteristic of the study participants. Construct validity and reliability analyses were conducted to determine the psychometric property of the tool and then compassionate care practice was measured. The analysis was done by statistical package for social science version 23.0, Amos version 23 and Open code version 4.02.

**Results:** Two hundred seventy five (66.4%) of the participants were females. The mean age of the participants was 47 and breast cancer was the leading cause of facility visit 122 (29.5%). The Schwartz Center Compassionate Care Scale is a two factor structure with a good model fit and has high scale reliability of 0.88 and 0.83, 0.84 subscale reliability respectively. The overall compassionate care practice was found to be 45.7% and high patients' flow, bed shortage and being treated by different physicians were among the factors that identified to be a barrier for compassionate care practicing.

**Conclusion and recommendations:** The Schwartz Center Compassionate Care Scale can be applied to measure compassionate care practice in the Ethiopian context and the practice is found to be low. Actions should be taken to improve the compassionate care practice.

## **1. Introduction**

### **1.1. Background**

Compassion is having deep emotional sensitivity to human suffering which requires personal understanding of the suffering of others and caring for them in the way that brings comfort to the sufferer (1). Compassion is all about recognizing, understanding and resonating emotionally with another's concerns, distress, pain or suffering coupled with acknowledgement, motivation and relational action to ameliorate them(2).

Compassion in health care is cognitive, affective, and behavioral process consisting of the following five elements: "recognizing suffering; understanding the universality of suffering in human experience; feeling moved by the person suffering and emotionally connecting with their distress; tolerating uncomfortable feelings aroused (e.g., fear, distress) so that we remain open to and accepting of the person suffering; and acting or being motivated to act to alleviate suffering"(3).

Compassionate care is witnessed when the health professional recognize and validate the concerns of the patients and their families (i.e. pain, distress, or suffering) and take action to address those concerns(4).

Recently, the Ethiopian Federal Ministry of Health (FMOH) in the Health Sector Transformation Plan (HSTP) started to give emphasis to organize the health system in a way which can provide respectful and compassionate care (CRC), which is one of the transformation agenda, to the maternal and child health services in particular and to the whole system in general (5).

Compassionate care is more appreciated among chronic disease patients and oncology patients are among the common customers of health facilities who visited hospitals frequently for various treatment options based on the progress of their disease.

## **1.2. Statement of the problem**

Without compassion, the care provided by health care providers is impersonal and mechanistic no matter how much they are technically competent. This will lead failure to address the unique aspects of a particular patient's needs and circumstances(6).The absence of compassionate care is also resulted in dissatisfaction of both patients and health professionals. Also, healthcare systems that gain reputations for their inhumane care become incompetent and lose their revenue (7).

Globally, numerous patients experience de-humanizing and impersonal treatment. This crisis in the health system becomes destructive not only for patients but also for their families, health professionals and the health system itself (8). The current depersonalization and dehumanization of healthcare often leave patients feeling like 'the kidney in Room 5,' or 'the liver in Room 10', rather than persons, unique individuals with a unique story of illness (7).

Now a day, since health care providers begin to measure the profession by how much it pay, the number of role model professionals is decreasing. The absence of compassionate care in the health system can be witnessed by different activities. For example, senior physicians cancel their outpatient clinics without informing their patients, elective surgeries get cancelled, admitted patients are by default getting the care they need from their relatives since nurses for various reasons have limited their role to providing injections and securing IV lines, poor counseling during dispensing of drugs and poor quality assurance process and laboratory tests can explain lack of compassion(9).A review study by the Health Professionals Ethics Federal Committee of Ethiopia showed that among the 60 complains within three years; 23% of the medical malpractices complain were results from health professionals' negligence. The review has also showed that this has resulted in death and disability of the patients (10).

Oncology patients; who have limited access and non-affordable treatment option; make this group of patients vulnerable and fragile. In Ethiopia, like most of the 3<sup>rd</sup> world countries, oncology treatment is lagging behind, to have comprehensive treatment option (Surgery, Medical or Radiotherapy) based on the biology of cancer. The need of giving compassionate care for this group of a patient is mandatory (11).

Since the perception of experience of a compassionate care by patients at different health institutions varies from country to country due to a culture and religion difference, health professionals' competency level and the enabling environment; the direct utilization of tools developed in the western setting might not be able to assess what we intended to grasp for without conducting a validation study in our context. Measuring compassionate care with a tool that has gone through the validation path and with a robust analysis findings which supports that the tool can be applied for the intended purpose then this will helps us to undertake the necessary steps to enhance and improve the compassionate care delivery and to improve patients centered care (12).

Lack of study in Ethiopia on a tool that has a validation evidence of to be able to measure compassionate care and the status of practice among oncology patients warranty this study.

So this study was undergone to look for validation analysis finding which favor the applicability of the compassionate measuring tool and to measure the practice of compassionate care among oncology patients at Tikur Anbessa Specialized Hospital (TASH), Addis Ababa, Ethiopia.

### **1.3 Significance of the study**

The results of this study were linked to practical recommendations for improving the skills of healthcare providers to deliver care with compassion to their clients particularly oncology patients aimed at improving quality patient care. This study will provide information for policy makers including top managers of the FMOH, TASH and other interested stakeholders on how to develop and improve strategies to improve the compassionate care practice of healthcare professions. The findings of this study will be more useful for the chief executive managers of hospitals by acting the compassionate care as one objective measurements of competency of their healthcare professionals. Scientifically this study will provide contextualized compassionate care practice measuring tool. In addition the findings of the study will be used as baseline data for future studies in the area of compassionate health care.

## **2. Literature review**

### **2.1. Importance of compassionate care**

Studies have been conducted to get insight in to patients and health care providers 'reflections on the importance of compassionate care practicing. For instance a study done in USA 85% of patients and 76% physicians said that compassionate care is "very important" in order to have a successful medical treatment (1). Another study done in Canada patients described that the care that they received have been with compassion and such care was highly important to their condition (13).

### **2.2. The role of compassionate care**

Compassionate and compassionate related care has been resulted in alleviating pain, prompting fast recovery from acute illness, assisting in the management of chronic illness, relieving anxiety, better resource management and reducing costs (14-17). Compassionate care has also physiological benefits such as altering heart rhythm and brain function (18).

Health care providers' effort to understand and relieve patients suffering has been resulted in improved patient's condition. For instance; health care provider's empathy has been result in diabetic and cholesterol control(19). An effective communication that has been conducted between the health care provider and patients has builds trust and resulted a reduction in the number of malpractice claims (20).A similarly robust body of evidence links effective communication with patient adherence to treatment recommendations and patient satisfaction with communication at hospital discharge has been associated with significantly lower readmission rates(21).

### **2.3. Compassionate care measurement tools**

Measuring compassionate care is difficult and there is a need for psychometrically validated instruments. Compassionate care measurement tools that have been developed in Western settings may not be applicable in other country settings without modification

because of many factors, including socio-cultural difference. Compassionate care measurement tools help us to assess health care provider's demonstration of compassionate care practice. Identification of compassionate care practice level can help in showing the level of the problem for decision makers and in identifying areas for improvement and evidencing whether a change or intervention is needed.

There are many tools used to measure compassionate care practice of health care providers from patient's perspective. These include the Schwartz Center Compassionate Care Scale (SCCCS) used to measure patient perceptions of care provided by attending physician (4), the compassionate care assessment tool (CCAT) used to evaluate compassionate nursing care in acute hospital environments (12), patient compassion model (PCM) (22) and five-factor structure of compassion (23). None of the above compassionate care measuring tools has been assessed examined for their validity, or adopted and used to measure compassionate care in the Ethiopian context. Among the above listed compassionate care measurement tool this study will focus on SCCC, since it is comparatively has been assessed its reliability and validation in the western setting.

### **2.3.1 The Schwartz Center Compassionate Care Scale (SCCCS)**

The SCCC tool is considered as a reliable and valid measure of patients' perceptions of compassionate healthcare of physicians and healthcare team's. There isn't an evidence which showed that the SCCC translations in to other languages than English.

The instrument was used to measure patients' perceptions of compassionate healthcare of physicians and healthcare team's during a recent hospitalization. Patients complete the items of the tool using a ten-point scale from 1 (not at all successful) to 10 (very successful). The items were initially developed by a committee consisting of patients, family members of patients, and individuals working in healthcare policy and advocacy, and were fine-tuned in five focus groups with patients, physicians, and nurses (3, 4). The generated items; which

were initially 16 items were assessed for validity and reliability in USA among 800 recently hospitalized patients and 510 physicians through national phone interview. The psychometric property analysis result showed that the SCCCS is uni-dimensional compassionate care measuring tool with 12 items(4). The SCCCS tool was applied in the Ireland setting and the reliability and validity analysis result was consistent with the USA's findings (24).

### **2.3.2 Utilization of the Schwartz Center Compassionate Care Scale**

The SCCCS has been used in various settings for different purposes. To mention some; the tool was used to assess compassionate care practice in USA(1), to assess the predictors of compassionate care in USA (25),to compare with other tools in Canada(26) and UK (3) and to examine the reliability and validity of the tool in a study conducted in Ireland (24). In two countries in USA and Ireland, the validity and reliability of the tool was examined and the results showed that the tool is potentially useful in different settings for measuring compassionate care practice (4, 24).

### **2.4 Compassionate care practice**

As a health care provider; practicing compassionately has to begin with understanding of what it meant and believing that little actions have a big impact on patient's perception. A study done in England among health professionals and pre-qualifying healthcare students and another study which was also conducted in England among dementia patients care givers supports the idea that practicing compassionately is creating an emotional bond and paying attention to the small actions that could help patients to feel cared for such as 'Holding the lady's hand and just talking, just being there' (27, 28).

As a healthcare professional being compassionate; have to be a core value of practice but this doesn't mean that such care is solely has to be provided by healthcare providers only. Patients could also get compassionate care from their close family members, and friends. A study done in United Kingdom (UK) among people who suffer from serious weight difficulties

showed that majority of the study participants get compassion from their close family members in the form of encouragement and praising of achievements when participants lost weight (29).

Concerned government body; such as ministry of health should formulate policy that puts ground strategies which facilitates the implementation of compassionate care and then it will be possible to assess compassionate care from different perspectives. For example; a study done in USA showed that; 53 percent of patients and 58 percent of physicians said that the health care system generally provides compassionate care, and the practice of compassionate care is only 54 percent from patients perspective and 78 percent from physicians perspective (1). Another study conducted in Tigray region of Ethiopia, has showed that 55% of the study participants has good experience of caring, respectful and compassionate during their stay in the health facilities(30).

Qualitative studies have been also conducted to assess the experience of compassionate care by the care recipients. A study done in Australia among people who had recent experience of acute health care on the compassionate care provision of nurses have shown that compassionate care was about more than just about feeling cared for; it was the catalyst for patient empowerment and participation in the care. For example among the study participant the one who was a cancer patient has described a nurse's demonstration of compassionate care as "there must have been something that she (nurse) could see." The nurse leant forward and whispered in my ear, 'It's going to be OK, and you can do this.'"But not all nurses provided compassionate care(31). The uncompassionate care practice experience was also explained in the Macmillan cancer support patient's and staffs stories report in which one of the patients stated the compassionate care practice of nurses as "I felt all the nurses weren't particularly kind to me. When I came up from surgery, and I'd had one of my lymph nodes

removed from under my arm, so my right arm was quite limited, they made me wriggle across from the theatre bed on to my own bed. They didn't help me.” (32).

Studies have been also conducted to assess the elements of compassionate care from patient's and health care provider's perspectives mostly through qualitative approach. A qualitative study done in Netherlands among chronic patients and nurses concluded that attention, listening, confronting, involvement, helping attitude, presence and understanding as elements of compassionate care(33). Another study conducted in Kentucky, in USA; which has studied the description of compassionate care among burn survivors has shown respect the person, communication, and, provision of competent care were primary themes of compassionate care which are in other words elements of compassionate care (34). A qualitative study among advanced cancer patients in Calgary, in Canada revealed that compassionate care elements are virtues, relational space, virtuous response, seeking to understand, relational communication and attentive needs (35).

In general, compassionate care is a necessity for providing a quality patient centered care. Studies have shown that compassionate care plays a major role in pain and various diseases management, to better resource management and to reducing health care cost. Despite of such a promising benefit of compassionate care the health care system with its human power and budgets is missing such care delivery to the patients who came to use health care services. And this is putting us to lose trust from our consumers and negative consequences such as anxiety, depression to the patients.

Compassionate care measuring tools aren't being utilized across different setting. This might be due to that the area has received recent attention.

Almost most of the study that have been conducted to assess compassionate care had employed a qualitatively approach; this could be due the nature of compassionate care; which

is more of linked to emotions but quantitative studies have been also conducted and provided evidences which made policy makers to give a due emphasis to compassionate health care. Studies that have been conducted to assess the compassionate care generally implied that the compassionate care practice of health workforce isn't in a satisfactory level.

### **3. Objective of the study**

#### **3.1. General objective**

The general objective of this study was to assess the validity of the Schwartz Center Compassionate Care Scale and to measure the practice of compassionate care using the validated tool among oncology patients at Tikur Anbessa Specialized Hospital, Addis Ababa, Ethiopia 2017/2018.

#### **3.2. Specific objectives**

- ❖ To assess the validity of the Schwartz Center Compassionate Care Scale of compassionate care for application within the Ethiopian setting among oncology patients at TASH
- ❖ To measure compassionate care practice using the validated tool and the same study participants that are used to validated the tool

## **4. Methodology**

### **4.1. Study setting and period**

This study was conducted at the adult clinical oncology unit of TASH. TASH was established in 1972. In 1998, the TASH, the largest referral hospital in the country, was transferred to Addis Ababa University by the Federal Ministry of Health, and it has since become a University teaching hospital. TASH has several departments such as internal medicine, surgery, gynecology and obstetrics, pediatrics, radiotherapy, clinical oncology, pediatric oncology, hematology, nuclear medicine, psychiatry, laboratory, orthopedics, and pharmacy(36).

The adult clinical oncology unit of TASH is a sole cancer referral center in Ethiopia and gives chemotherapy, radiotherapy and palliative care for oncology patients. The clinical oncology unit has 19 beds and monthly on average 728 patients' visit the outpatient section of the adult clinical oncology unit on follow up base and the inpatient part of the adult clinical oncology unit admits around 164 patients monthly. This study was conducted at the inpatient and outpatient follow up section of the adult clinical oncology unit. A pilot study was conducted at the satellite oncology center found near 5<sup>th</sup> Police Station. The satellite oncology center has 12 beds and provides an inpatient and outpatient services.

This study was conducted in Tikur Anbessa Specialized Hospital from March to May, 2018.

### **4.2 Study design**

In this study institutional based cross sectional study design was applied. In addition qualitative study approach was used to substantiate the quantitative measurement of compassionate care practice.

### **4.3 Source population and study population**

The source population was all adult oncology patients who came to the inpatient and follow up adult clinical oncology unit of TASH. The study population constitutes all adult oncology

patients whether admitted in the inpatient unit and who were on follow up at the adult oncology unit of TASH from March-May 2018.

#### 4.3.1 Inclusion criteria's

- Age 18 years and above
- A patient with any type of oncology
- No demonstrable signs of confusion
- Able to provide written informed consent
- Patients who came for 2<sup>nd</sup> follow up
- Hospitalized (at least 2 days)
- Patients who can speak Amharic

#### 4.3.2 Exclusion criteria

For ethical reason, patients who are not told that they have cancer had been excluded from this study. In order to exclude those patients, first we asked the duty nurse if there had been patients who aren't informed about their diagnosis. Then, we asked their families to make sure that the patients were aware of their diagnosis.

#### 4.4 Sample size determination

A single population proportion formula was used to estimate the sample size. The required sample size was determined using EPI info ver.7.2.1.0 stat calc.

<p><b>1<sup>st</sup> specific objective-</b>To assess the validity of the Schwartz Center Compassionate Care Scale of compassionate care for application within the Ethiopian setting among oncology patients at TASH</p>	<p>p- value of 50% ( there is no previous similar study done on compassionate care tool validation in Ethiopia), <math>Z_{\alpha/2}=1.96</math>, d= 5% and 10% non-response rate <b>n= 423</b></p>
<p><b>2<sup>nd</sup> specific objective-</b> To measure compassionate care practice using the validated tool</p>	<p>P- value of 55%( a study done in Tigray), <math>Z_{\alpha/2}=1.96</math>, d= 5% and 10% non-response rate <b>n= 418</b></p>

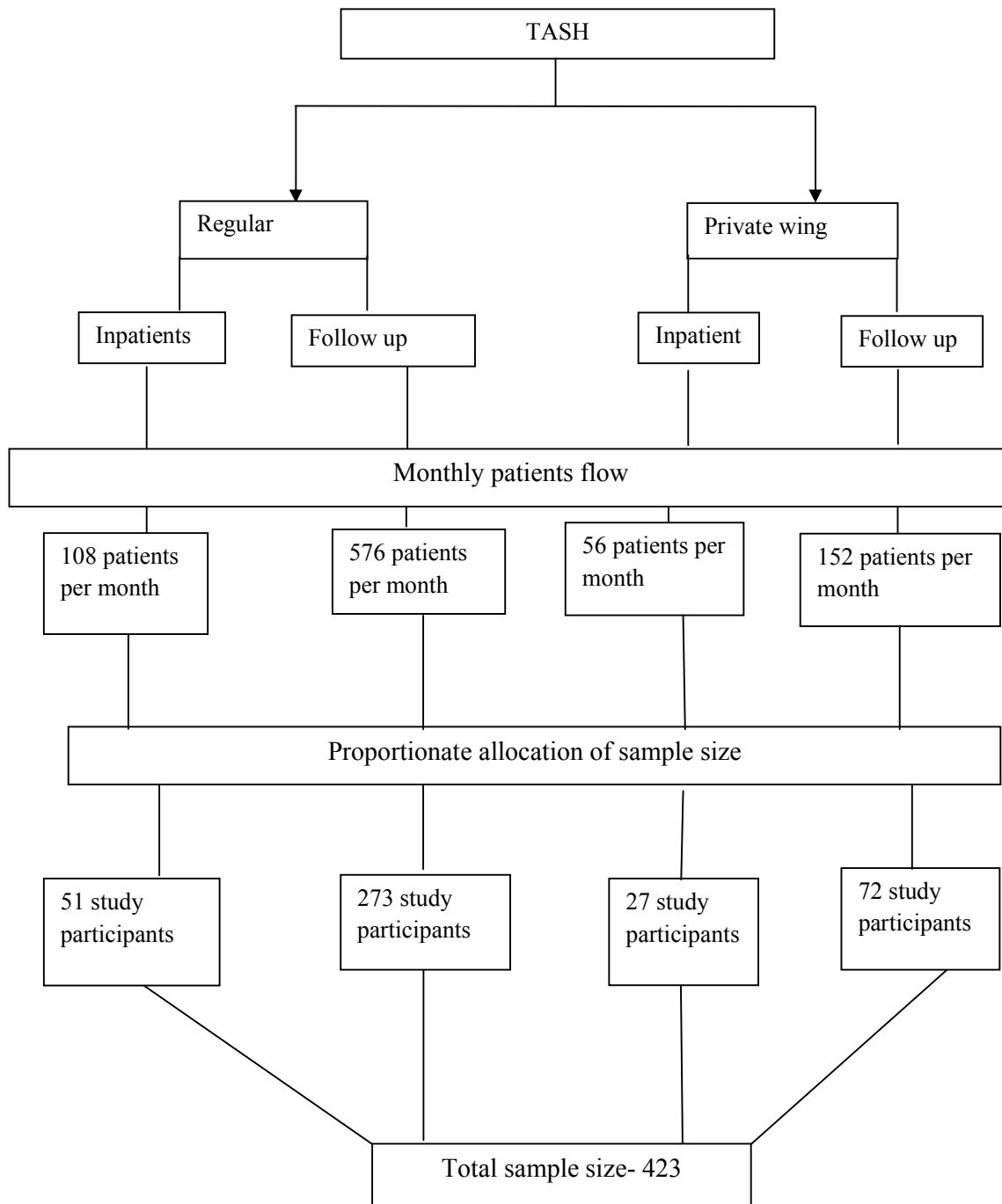
Since the first objective revealed the highest sample size this study was conducted among **423** oncology patients.

For the qualitative approach the plan was to interview 10 oncology patients but in-depth interviewing was stopped after information saturation point was reached.

#### **4.5 Sampling procedure**

Study participants were selected using systematic random sampling technique. Initially the oncology patients were stratified into regular and private wing patients and then this two categories were further stratified into inpatient and follow up regular patients similarly inpatient and follow up private wing patients. The total sample size was proportionately allocated in to each strata based on the monthly patient flow data that has been obtained from the head of nurse of adult clinical oncology. According to the proportional allocation result; of the total study participants 324 were regular patients and 99 were private wing patients. Of the 324 regular, 51 were inpatients and 273 were on follow up and of the 99 private wing, 27 were inpatients and 72 follow up (**figure1**).

For the qualitative approach, study participants were selected using purposive sampling technique.



**Figure 1** Schematic presentation of sampling procedure for compassionate care practice, TASH, Addis Ababa, Ethiopia 2018

#### **4.6 Variables**

Sex, age, region, residence, ethnicity, religion, marital status, educational status, diagnosis, hospitalization days, frequency of hospitalization, frequency of follow up, previous hospitalization, the 12 items of compassionate care practice and level of compassionate care practice.

#### **4.7 Operational definition**

**Compassionate care practice:** to say that health care provider has demonstrated compassionate care study participants has to rate 9 or 10 to the elements of compassionate care (4). Since the validation analysis have shown that the SCCCS has 10 items with a two factor structure the minimum cut point to say that compassionate care is demonstrated by the health care provider is 90 point.

#### **4.8 Data collection tool and procedure**

##### **4.8.1 Data collection instrument**

**The Schwartz Center Compassionate Care Scale (SCCCS):** The SCCCS was developed for measuring compassionate care practice among hospitalized patients and physicians in USA(4). The instrument is composed of 12 items that must be answered by the participant checking on one of the 10 possible answers, on a ten-point scale, ranging from 1 (not at all successful) to 10 (very successful). The initial statement is based on the question “How successfully did your doctor (or other healthcare provider).The SCCCS contains 12 questions on a scale of 1 to 10; where 1 is not at all successful and 10 is very successful. These 12 items are, express sensitivity, caring and compassion for your situation, strive to understand your emotional needs, consider the effect of your illness on you, your family, and the people most important to you, listen attentively to you, convey information to you in a way that was understandable, gain your trust, always involve you in decisions about your treatment, comfortably discuss sensitive, emotional or psychological issues, treat you as a person not

just a disease, show respect for you, your family and those important to you, communicate test results in a timely and sensitive manner and spend enough time with you.

**Socio-demographic questionnaire:** socio-demographic questions were included to assess study participants' characteristics using the following variables: sex, age, region, residence, ethnicity, religion, marital status, educational status, diagnosis, hospitalization days, frequency of hospitalization, frequency of follow up and previous hospitalization those who were on follow up.

The tool was translated into Amharic by two persons who are fluent both in Amharic and English and was checked by a third person to validate the two person's translation. After we made sure that the translators produce the exact Amharic version of the questionnaire the tool was translated back to English by two another person's; who were blinded for the original English version of the SCCCS.

### **Qualitative study**

A study guide was developed by the principal investigator to conduct the in-depth interview.

#### **4.8.2 Training of data collectors and supervisor**

Two BSc nurse were recruited for data collection purpose and one public health officer professional was recruited to supervise the data collection. The training of the data collectors mainly focused on the process of obtaining informed written consent, the eligibility criteria, the interpretation of the variables in the data collection tool and the steps of the data collection process. On the other hand training of the supervisor focused on how to check the collected data. It took half day to train the tool for the data collectors and the supervisor.

After this, there were two days of practical sessions to familiarize the data collectors and the supervisor with the data collection tool. Those sessions were used to identify the gaps of the data collectors and the supervisor and provide feedback accordingly.

### **4.8.3 Data collection procedure**

Written ethical approval was obtained from school of public health, Addis Ababa University (AAU). Then formal letters were submitted to the satellite cancer center and adult clinical oncology unit of TASH in order to get permission to carry out the study.

Pre-test was conducted by using structured Amharic version of SCCCS among 42 oncology patients. In the pre-test; study participants were asked about the meaning of each item, if the questions were easily understandable, if they had a difficulty on understanding the questions and anything they thought that has to be added. The timing was also assessed. The instrument was found to be easily conceivable, simple, clear, and appropriate for the assessment of compassionate care among this group. The time taken to complete the questionnaire ranges from a minimum of ten minute to the maximum of 20 minutes. And then we proceed to the main study data collection among the inpatients and those who were on follow up oncology patients at TASH.

During the data collection the supervisor were responsible for making sure that oncology patients who were admitted in the ward and on follow up were assessed based on the eligibility criteria of the study. The supervisor was also responsible for making sure that the needed information was gathered and handled appropriately. In addition to the supervisor, the investigator of the study also monitored the progress of the data collection process twice a week. During this supervision, the investigator ensured that the data collectors were collecting as per the need of the study, the collected data were checked and corrections were made whenever needed, and the required support was provided.

For the qualitative part, Key informants were selected based on the assumption that they were more knowledgeable about the topic of interest and can speak about compassionate care. The principal investigator carried out the in-depth interview with the assistance of a note taker.

The interview process continued until the saturation point is reached and eventually that point reached after 12 patients were interviewed. The interview was tape recorded, translated and transcribed in the same day of the interview.

#### **4.9 Data quality control**

Data quality was maintained in three phases. During the tool development, data collection and data management and analysis phase. A pilot study was done on 42 of the study population to ensure the agreement of the questionnaire with the need of the study. Error found during the process of the pilot study was corrected and modified. Data collectors were trained for three days before the process of data collection. Supervision and checking was conducted to ensure completeness and consistency of the collected data. All collected data was examined for completeness and consistency in data management, storage, and analysis.

#### **4.10 Ethical considerations**

The data collection process was initiated after Scientific and Ethical approval was obtained from the research ethics committee of School of Public Health, AAU. Following the endorsement by the research ethics committee, TASH adult clinical oncology department was informed about the study through a support letter from School of Public Health, AAU and then reviewed by the adult clinical oncology department ethical committee and was approved. The eligible study participants were included in the study only after they gave written informed consent and were not forced to participate. Confidentiality of information and privacy of participants' interview was respected; the study participant was told that information that he/she provided was only for the purpose of this study. The information regarding the study participants was kept confidential by using specific identification code for each of them.

#### **4.11 Data management, analysis procedures and presentation**

At the end of the data collection, the completeness and consistency of the questionnaires were checked visually and the variables were recorded. After this the data were entered into Epi data version 4.2.0.0 software to minimize errors during entry and exported to SPSS version 23.0 for cleaning, editing and analysis. Descriptive statistics was used to describe the baseline characteristics of the study participants. Mean and standard deviation (SD) were used for the description of continuous data while frequencies and percentages were used for to describe categorical data. The qualitative data was first transcribed and then the data was entered to Open Code version 4.02.

The two techniques (exploratory factor analysis and confirmatory factor analysis) of factor analysis were employed to determine the number and nature of latent variables or factors. A number of steps have been undertaken to conduct the two techniques of factor analysis.

Firstly, suitability of the data for factor analysis was checked by running the Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy, Bartlett's test of sphericity and determinant of R matrix. The Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy; shows us whether or not the variables are able to be grouped into a smaller set of underlying factors. The value of KMO should be 0.5 and above to be considered as suitable for factor analysis. The other thing that we have checked is the Bartlett's test of sphericity which tests the hypothesis that the correlation matrix is an identity matrix; there is no relationship among the item. The Bartlett's Test of Sphericity should be significant ( $p < 0.05$ ) for factor analysis to be suitable. In order to avoid for extreme multicollinearity and singularity; which shows perfect correlation, determinant of R matrix; in which its value should be  $> 0.00001$  have been also assessed.

Secondly, we have undergone the factor extraction analysis using the principal axis factoring (PAF) way of factor extraction. The eigenvalue, scree test and cumulative percentage of

variance were used as criteria's to determine the number of common factors to be retained. Factors with eigenvalues of greater than 1.0 were kept and the rest were discarded. Together with the PAF a varimax rotation method was selected in order to have a more interpretable and simplified solution. Items were removed from the EFA if they are double loaded (i.e., 0.40 or above on more than one factor), unique and do not load into any factor (37, 38).

The appropriateness of the factor structure of the SCCCS identified in the EFA model was assessed by conducting confirmatory factor analyses using Amos for structural equation modeling. The confirmatory factor analysis was computed using the Maximum Likelihood estimator after we made sure that responses were approximately normally distributed. Several fit indices were used to assess how well the proposed model fits the sample data. Firstly, the Chi<sup>2</sup> statistic was used as a measure of fit between the sample covariance and fitted covariance matrices. In addition to the Chi<sup>2</sup> statistic other fit indices were used to evaluate including the Comparative Fit Index (CFI) and the Tucker Lewis Index (TLI). The model with values >0.95 for the CFI and TLI indicate a reasonable fit. The Root Mean Square Error of the Approximation (RMSEA) and Standardized Root Mean Residual (SRMR) were the other fit index which takes into account to assess the model fitness. RMSEA and SRMR values <0.05 indicate a good model fit (39, 40).

Construct validity of the SCCCS was assessed by convergent validity (factor loadings, average variance extracted and reliability), and discriminant validity. High factor loadings indicate convergence and statistically significant. Average variance extracted (AVE) is calculated as the mean variance for the items loading on a construct and is summary of indicator of convergence. If AVE is greater than 0.5 then we can say that it is adequate convergence. Construct reliability should be > 0.7 to warrant good reliability. The construct validity of the tool was assessed by using the following indicators. These are estimated

loadings of 0.5 or higher, AVE of 0.5 or higher to support convergent validity, AVE estimates for two factors should exceed the square of the correlation between two factors to provide evidence of discriminant validity, and, construct reliability should be 0.7 or higher to suggest convergence and internal consistency.

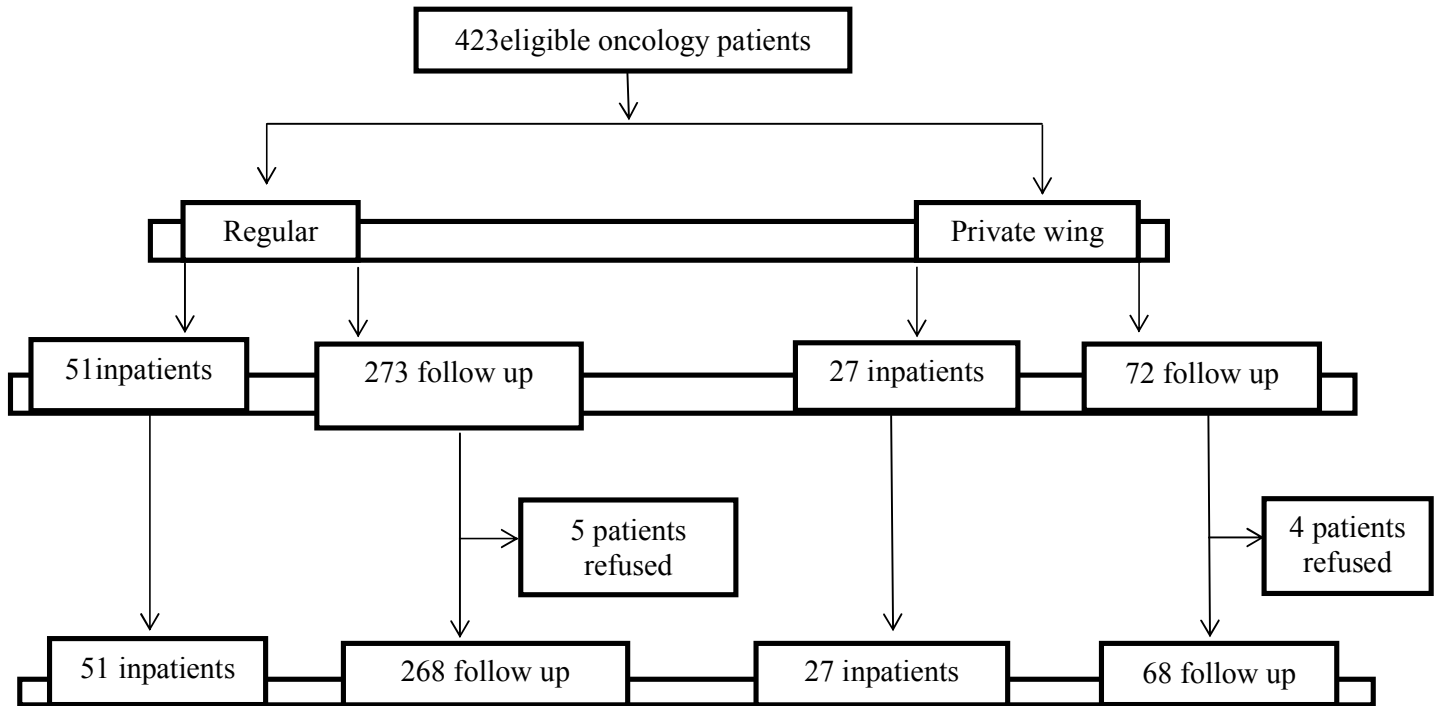
Using the validated tool compassionate care practice of the health care providers was measured using the operational definition of demonstrated compassionate care. The minimum rating to say there was compassionate care is 9. Study participants who rated 9 and 10 was summed up and we create a new variable with two options. The first options has a score 90 and above and the other scoring 89 and below. The sum of scores which has 90 and above was considered as the demonstration of compassionate care. The finding of the qualitative study was interpreted with incorporating with the quantitative compassionate care practice finding.

#### **4.12 Dissemination of result**

The result of this study will be presented to the University of Addis Ababa, school of public health as partial fulfillment of the degree of Master of public health. It will be submitted to TASH adult clinical oncology unit and ministry of health and other concerned bodies. It will also be presented at seminars, national and international conferences as acceptable. An attempt will be made to peer review journals for publication.

## 5 Result

In this study, a total of 414 oncology patients from the clinical oncology unit of Tikur Anbessa Hospital (TASH) were participated (**figure 2**). The response rate of the study was 97.9%.



**Figure 2: Flow chart of the final study units of oncology patients in clinical oncology unit of Tikur Anbessa Specialized Hospital, Addis Ababa, Ethiopia, 2018**

## 5.2 Socio-demographic description

Among the oncology patients participated in the study, 275 (66.4%) of them were females.

The mean age of the study participants was 47 years, SD=±13.05, range= 18 to 75. Majority of the study participants were from Addis Ababa 154(37.2%) and above 85% lives in the different towns of Ethiopia. About 173(41.8%) of the participants were Amhara and 306 (73.9%) were orthodox religion followers. Around 288 (69.6%) of the study participants were married and but only 125(30.2%) were educated up to secondary (**table 1**).

**Table 1 Socio-demographic characteristics of oncology patients at TASH, Addis Ababa, Ethiopia, 2018 (n=414)**

Socio-demographic variables	Frequency (%)	Socio-demographic variables	Frequency (%)
<b>Sex</b>		Tigray	17 (4.1)
Male	139 (33.6)	Welayta	8 (1.9)
Female	275 (66.4)	Other	22 (5.3)
<b>Mean age ±SD</b>	47±13.05	<b>Religion</b>	
<b>Place /region</b>		Orthodox	306 (73.9)
Tigray	7 (1.7)	Muslim	66 (15.9)
Afar	3 (0.7)	Protestant	37 (8.9)
Amhara	72 (17.4)	Catholic	3 (0.7)
Oromia	124 (30.0)	Other	2 (0.5)
Somali	1 (0.2)	<b>Marital status</b>	
Benshangul Gumuz	4 (1.0)	Single	62 (15.0)
SNNP <sup>1</sup>	41 (9.9)	Married	288 (69.6)
Harari	6 (1.4)	Divorced	15 (3.6)
Addis Ababa	154 (37.2)	Separated	9 (2.2)
Dire Dawa	2 (0.5)	Widowed	40 (9.7)
<b>Residence</b>		<b>Educational status</b>	
Urban	354 (85.5)	Can't read and write	83 (20)
Rural	60 (14.5)	Can read and write	21 (5.1)
<b>Ethnic group</b>		Primary	78 (18.8)
Afar	1 (0.2)	Secondary	125 (30.2)
Amhara	173 (41.8)	College and above	107 (25.8)
Guragie	32 (7.7)		
Hadiya	1 (0.2)		
Oromo	141 (34.1)		
Sidama	3 (0.7)		
Sltie	16 (3.9)		

<sup>1</sup> SNNP= South Nations and Nationality People

### **5.3 Clinical conditions of patients**

Breast cancer was found to be the leading cause of facility visit 122(29.5%) followed by cervical cancer 83(20%). Of the admitted patients 79(19%); majority of them 74 (95%) stayed in the ward for three days and 60 (77%) where previously hospitalized for about 1-6 times. Among the patient who were on follow up 336 (81.2%), most of them 191 (57%) visited the hospital on a follow up base 1-10times and 23(58%) has been previously hospitalized for three days in the inpatients ward (**table 2**).

**Table 2: Clinical conditions of oncology patients at TASH, Addis Ababa, Ethiopia, 2018**

(n=414)

<b>Clinical condition</b>	<b>Frequency (%)</b>	<b>Clinical Condition</b>	<b>Frequency (%)</b>
<b>Disease category</b>		<b>Follow up</b>	
Breast ca	122 (29.5)	Regular	268 (79.8)
CUP1	2 (0.5)	Private wing	68 (20.2)
Cervical ca	83 (20)	<b>Hospitalization (inpatient)</b>	
Ano-rectal ca	43 (10.4)	3rd day	74 (94.8)
Esophageal ca	8 (1.9)	5th day	4 (5.1)
Gastric ca	8 (1.9)	<b>Frequency of hospitalization</b>	
Kaposi's sarcoma	1 (0.2)	1-6 times	60 (76.9)
Liver ca (HCC)2	7 (1.7)	7-9 times	9 (11.5)
Lung ca	6 (1.4)	10-12 times	6 (7.7)
NPC3	8 (1.9)	>12times	3 (3.8)
NHL4	6 (1.4)	<b>Frequency of hospital visit</b>	
Ovarian ca	5 (1.2)	1-10th visit	191 (56.8)
Prostatic ca	6 (1.4)	11-20th visit	100 (29.8)
Renal cell ca	2 (0.5)	21-30th visit	25 (7.4)
Sarcoma	10 (2.4)	31-40th visit	14 (4.2)
Testicular ca	8 (1.9)	41-62th visit	6 (1.8)
Thyroid ca	26 (6.3)	<b>Hospitalized (follow up)</b>	
Uterine Fibroma	3 (0.7)	Yes	40 (11.9)
Vulvar ca	1 (0.2)	No	296 (88.1)
Other Neoplasms	59 (14.3)	<b>Hospitalization day (follow up)</b>	
<b>Contacting patient</b>		A day	5 (12.5)
At inpatient ward	78 (18.8)	2 days	4 (10)
At follow up clinic	336 (81.2)	3 days	23 (57.5)
<b>Inpatient</b>		4 days	2 (5)
Regular	51 (65.4)	5 days	6 (15)
Private wing	27 (34.6)		

<sup>1</sup> CUP= Cancer of Unknown Primary Origin

<sup>2</sup> HCC= Hepatocellular Cancer

<sup>3</sup> NPC= Naso- Pharyngeal Cancer

<sup>4</sup> NHL= Non-Hodgkin's Lymphoma

## **5.4 Validity and reliability analysis result**

The psychometric properties of the SCCCS were assessed by conducting exploratory factor analysis and confirmatory factor analysis. Using the finding of the psychometrics analysis the construct and discriminant validity of the SCCCS was examined. The result of each component is displayed in the preceding sub-sections.

### **5.4.1 Exploratory factor analysis**

The exploratory factor analysis was done by principal axis factoring with varimax rotation. Data suitability for factor analysis was checked by referring to the KMO measure of adequate sampling, Bartlett's test of sphericity and determinant of R matrix. For this study's sample, the KMO measure of adequate sampling was 0.906. This result indicates that the data represented a homogeneous collection of variables that were suitable for factor analysis. Meanwhile, Bartlett's test of sphericity was also significant for the sample [ $\chi^2 = 2499.825$ ,  $df=66$ ,  $p < .000$ ], which indicates that the set of correlations in the correlation matrix were significantly different from zero and thus suitable for factor analysis. The determinant of R matrix was 0.002. Of the 12 items, Table 3 (1<sup>st</sup> part) shows that 10 items had high loading regarding their intended factors, while two items (i.e., item 6 and item 10) have double loaded and the items were dropped. Furthermore, the analysis was conducted for the remaining 10 items.

The KMO measure of adequate sampling, Bartlett's test of sphericity and determinant of R matrix was done for a second time to assess suitability of the data for factor analysis on the remaining 10 items. The KMO measure of adequate sampling was determined to be 0.879. Bartlett's test of sphericity was significant for the sample [ $\chi^2 = 1940.835$   $df=45$ ,  $p < .000$ ], which indicates that the set of correlations in the correlation matrix were significantly different from zero and thus it is suitable for factor analysis and the determinant of R matrix value was 0.009. The result yielded a two-factor structure, with factor loadings of items that

settled at each subscale of the SCCCS with two factors varied between 0.41 and 0.85. Factor 1 explained 26.441% of the total variance (eigenvalue= 5.996); factor 2 (explained 51.900% (eigenvalue= 1.087) (**Appendix II**).

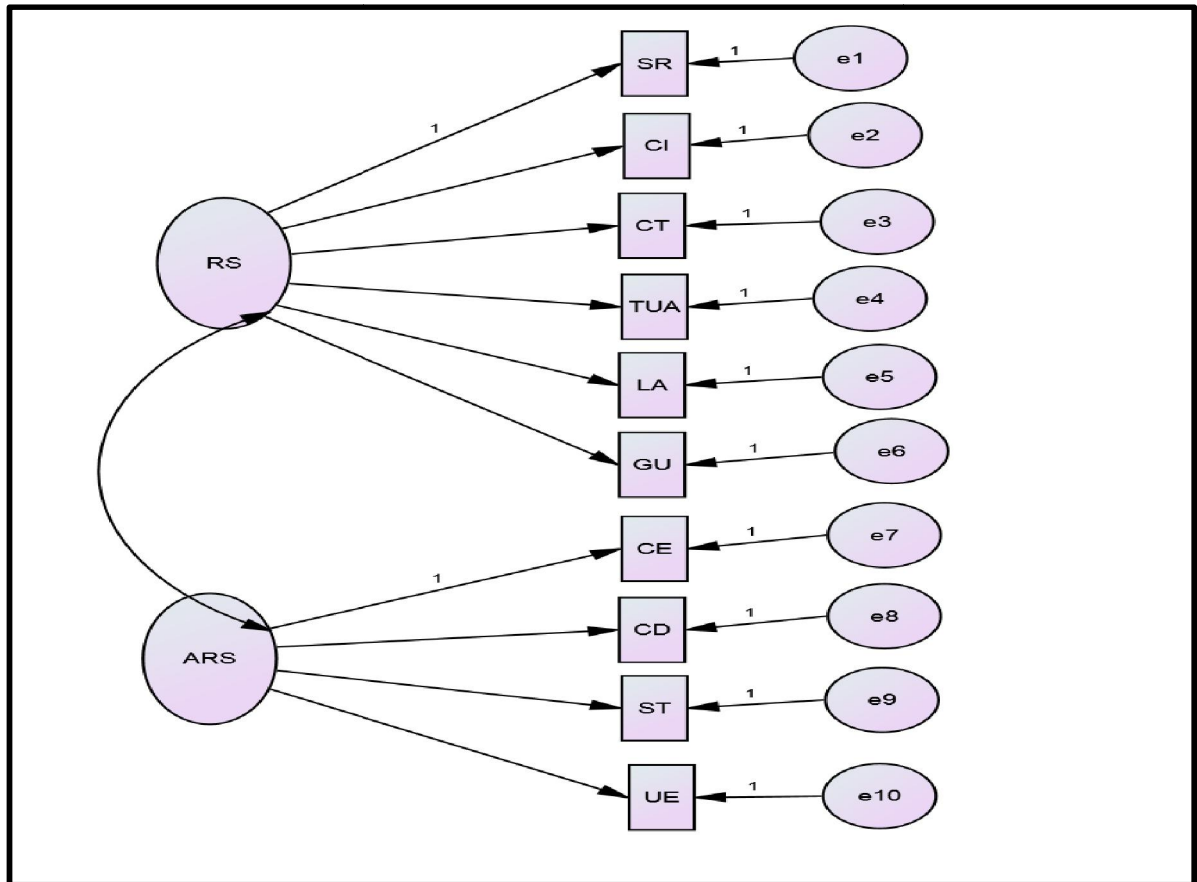
**Table 3: Factor loadings for exploratory factor analysis with varimax rotation of the SCCCS**

The 12 items of Schwartz center compassionate care scale	First		Second	
	Component		Component	
	First factor	Second factor	First factor	Second factor
Show respect for you, your family, and those important to you;	0.651		0.666	
Convey information to you in a way that is understandable	0.625		0.614	
Communicate test results in a timely and sensitive manner	0.456		0.440	
Treat you as a person, not just a disease	0.820		0.851	
Listen to you attentively	0.671		0.649	
<b>Always involve you in decisions about your treatment</b>	<b>0.489</b>	<b>0.405</b>		
Gain your trust	0.439		0.417	
Consider the effect of your illness on you, your family, and the people most important to you		0.605		0.463
Comfortably discuss sensitive, emotional, or psychological issues		0.729		0.733
<b>Express sensitivity, caring, and compassion for your situation</b>	<b>0.459</b>	<b>0.592</b>		
Spend enough time with you		0.574		0.586
Strive to understand your emotional needs		0.838		0.793

#### 5.4.2 Confirmatory factor analysis

The appropriateness of a two factor structure model representing the SCCCS was assessed by analysis of momentum structure (Amos). The ten measures (subscales of compassionate care practice measure) were: show respect (SR), convey information (CI), communicate test results (CT), treat you as a person (TUA), listen to you attentively (LA), gain your trust (GU), consider the effect of your illness (CE), comfortable discuss (CD), spend enough time with you (ST), and understand your emotional need (UE). The two factor model is posited whereby the observed measures of show respect, convey information, communicate test results, treat you as a person, listen to you attentively, gain your trust conjectured to load on a latent dimension of recognizing suffering (RS), and the observed measures of consider the effect of your illness, comfortably discuss, spend enough time with you, and understand your

emotional need are predicted to load onto a distinct latent factor of acting to relieve suffering (figure 3).



**Figure 3:** Path diagram and input data for two-factor CFA model of recognizing suffering and acting to relieve suffering. SR=show respect, CI=convey information, CT= communicate test results, TUA= treat you as a person, listen to you attentively (LA), GU=gain your trust, CE=consider the effect of your illness, CD=comfortable discuss, ST=spend enough time with you, and UD=understand your emotional need. All indicators measured on scales ranging from 1 to 10 (a score of 9 or 10 implies the exercise of compassionate care by the health care providers).

The measurement model presented in Figure 3 contains 21 freely estimated parameters: 8 factor loadings (SR and CE serve as marker indicators and thus their factor loadings will be fixed), 10 error variances, 2 factor variances, and 1 factor covariance. The model is over identified with  $34df(55-21)$ .

Since the skewness, kurtosis and outliers result showed normality of the data (**appendix II**) the CFA analysis was conducted using maximum likelihood estimation. Overall goodness-of-fit indices suggested that the two-factor structure model does fit these data poorly:  $X^2(34) = 194.65, p = 0.00$ , SRMR = 0.059, RMSEA = 0.107 (90% CI = 0.093 – 0.122), CFI = 0.917, TLI = 0.889. Modification indices were used to identify misfit of the two factor model of compassionate care and using the modification indices results, a constrained observed measure was freed until a fitted model is displayed and finally the two- model was fitted well with these data:  $X^2(24) = 30.258, p = 0.176$ , SRMR = 0.0218, RMSEA = 0.025 (90% CI = 0.000 – 0.050), CFI = 0.997, TLI = 0.994 (**figure 4**). Standardized residuals were also used to assess the fitness of the model and the value ranges from 0.000-1.184. This showed the absence of localized areas of ill fit in the solution (**appendix II**). No relationships among the indicators are substantially under or overestimated by the model's parameter estimates. Under this fitted model, correlations between latent factors were 0.72 ('recognizing suffering' with 'acting to relieve suffering'). The standardized factor loadings ranges from 0.451-.841 (**table 4**).

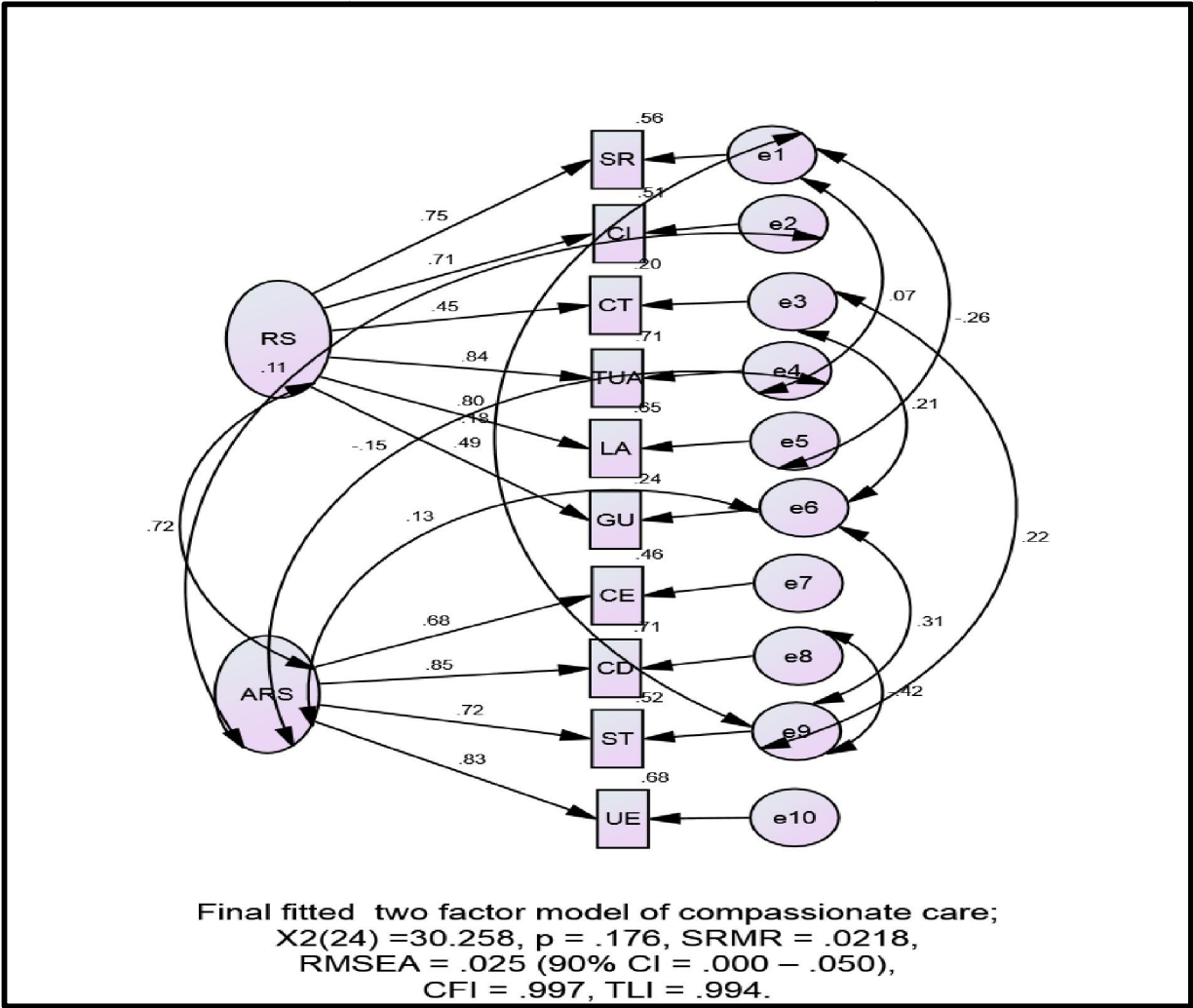


Figure 4: A fitted final two factor model of compassionate care

**Table 4:** Standardized regression weights:

<b>The two constructs of SCCCS with the corresponding items</b>	<b>Estimate</b>
SR <---RS	0.749
CI <---RS	0.711
CT<---RS	0.451
TUA<---RS	0.841
LA<---RS	0.804
GU<---RS	0.487
CE<---ARS	0.676
CD<---ARS	0.845
ST<---ARS	0.724
UE<---ARS	0.827

### **Reliability**

**internal consistency reliability:** We calculated internal reliability estimates for the total scale and the two subscales. The results confirmed that the SCCCS has a high internal reliability. We determined that the internal consistency coefficient of the total scale to be 0.88. The subscales for recognizing suffering and acting to relieve suffering of the SCCCS have high internal consistency (0.83 and 0.84 respectively).

### **5.4.3 Examining model validity**

The factor loadings except for items communicate test results timely (0.45) and gain your trust (0.49) from the recognizing suffering factor; which has a factor loading value below 0.5 the factor loading value for the rest of the items it is good. The value of Average variance extracted (AVE) is 0.52 and the construct reliability is 0.88 which is acceptable. Based on the above results it was found to be possible to conclude the acceptability of that the SCCCS tool convergent validity. This was with the exception of the low factor loading of the two items communicate test results timely (0.45) and gain your trust (0.49). As it is indicated in the Amos graphics result on figure four, the two constructs of SCCCS tool are unique. Differ from each other, and there is no cross-loading. Therefore its discriminant validated. Since the convergent and discriminant validity are within acceptable range then we can conclude that

the construct validity of the SCCCS is valid and the tool can be applied to assess compassionate care with in the Ethiopian setting.

### **5.5 Compassionate care practice of health care providers**

The overall compassionate care practice of health care provider at the oncology unit of TASH was found to be 45.7%. The qualitative finding showed that, except one of the patients interviewed, all of them were described the compassionate care practice of health care providers as “Good”.

A 34 years old cervical cancer patient stated it as:

*“Here in TASH there is no compassion, they see us not as human. When you are suffering they don’t understand, they just say go out They don’t like to listen to us. It is so hard. I came here because I don’t have any other option.”*

This low status of compassionate care practice can be due to factors outside of health care provider’s capacity. This is figured out by the qualitative study which showed high patient flow, shortage of beds and being treated by different physician barriers for practicing compassionately.

A 50 years old male thyroid cancer patient said:

*“High patient flow with the disease resulted for the absence of comprehensive treatment and diagnostics services, such as investigations like CT-scan in other hospital”*

A 34 years old female colonic cancer patient said:

*“Here all health care professional are good. However, the facility has shortage of beds that affects many patients, through the result of frequent visit to the facility to get bed, and also the absence of care services with free of charge”*

A 60 years old female breast cancer patient said:

*“You know when I came for appointment the doctor who have examined and gave me medication previously, could change on the next visit and he/she would ask me from the scratch and turned my document”*

A 26 years old male maxillary cancer patient said:

*“Owww I’m getting tired of being asked about my problem since it beginning and explaining it for each new physician. Would it be better if we are being followed by the first physician who diagnosed and started us the treatment?”*

A 33 years old male colonic cancer patient said:

*“I’m very happy by everything that they did but it would even be better than this if we are followed and treated by the same doctor who contacted us from the very beginning.”*

### **5.5.1 Compassionate care each item demonstration**

Of the compassionate care elements treat you as a person, not just a disease have got the highest percent next is listen attentively to you.

**Table 5 : Oncology Patients rating for items of compassionated care as it is demonstrated by health care providers at TASH, Addis Ababa, Ethiopia, 2018**

S.N	Element of compassionate care	Patients rating of the items 9/10
		Frequency (%)
1	Show respect for you, your family, and those important to you	294 (71)
2	Convey information to you in a way that is understandable	254 (61.3)
3	Communicate test results in a timely and sensitive manner	237 (57.2)
4	Treat you as a person, not just a disease	310 (74.9)
5	Listen attentively to you	303 (73.2 )
6	Gains your trust	281(68)
7	Consider the effect of your illness on you, your family, and the people most important to you	230 (55.6)
8	Comfortably discuss sensitive, emotional, or psychological issues	240 (58)
9	Spend enough time with you	225 (54.3)
10	Strive to understand your emotional needs	246 (59.4)

A qualitative study participants also stated that, a compassionate care have to consist various elements such as; providing medication (such as radiotherapy, pain relief), respect, helping and reassuring.

A 50 years old male thyroid cancer patient said:

*“They treat me, are helpful, serve me with the maximum potential they have, take carrying of me, warm greeting, and call my name and inviting to explain my condition.”*

A 26 years old female cervical cancer patient stated as:

*“Provide medication properly for instance radiotherapy.”*

A 57 years old male bone cancer patient said:

*“They ask me about my condition, provide me medication, respects, talks and advise to me, I hope that they will provide me accruable medication so that I will get better soon and start my normal activity.”*

A 35 years old female colonic cancer patient said:

*“They are ready to help me, gives me pain relief, they are very welcoming, they reassure me and they do not disrespect and mistreat me.”*

A 34 years old female colonic cancer patient said:

*“They explain to me about the disease, reassure me when I’m worried and in tension, advise me that I should eat properly, listen to me attentively, and provide me my test result timely.”*

### **5.5.2 Socio-demographics characteristics by demonstration of compassionate care practice**

Thirty three percent of female patient participants have experienced compassionate care.

Those with less than and greater than of the mean age (47.46) had similar level of compassionate care practice experience from health care providers (21.3% versus 24.4%).

Similarly, those who came from Oromia and Addis Ababa had similar level of experience of compassionate care practice from health care provider, 15.2%, 16.2%, respectively (**table 6**).

**Table 6: Socio-demographics characteristics by demonstration of compassionate care practice at TASH, Addis Ababa, Ethiopia, 2018**

Variable	Status of compassionate care	
	Demonstrated	Not demonstration
	Frequency (%)	Frequency (%)
<b>Sex</b>		
Male	53 (12.8)	86 (20.8)
Female	136 (32.9)	139 (33.6)
<b>Age</b>		
Below mean(<47.46)	88 (21.3)	118 (28.5)
Above mean(>47.46)	101 (24.4)	107 (25.8)
<b>Place /region</b>		
Tigray	2 (0.5)	5 (1.2)
Afar	1 (0.2)	2 (0.5)
Amhara	34 (8.2)	38 (9.2)
Oromia	63 (15.2)	61 (14.7)
Somali	0 (0)	1(0.2)
Benshangul Gumuz	2 (0.5)	2 (0.5)
SNNP <sup>1</sup>	18 (4.3)	23 (5.6)
Harari	2 (0.5)	4 (1)
Addis Ababa	67 (16.2)	87 (21)
Dire Dawa	0 (0)	2 (0.5)
<b>Residence</b>		
Urban	156 (37.7)	198 (47.8)
Rural	33 (8)	27 (6.5)
<b>Ethnic group</b>		
Afar	0 (0)	1 (0.2)
Amhara	81 (19.6)	92 (22.2)
Guragie	11 (2.7)	21 (5.2)
Hadiya	1 (0.2)	0 (0)
Oromo	66 (15.9)	75 (18.1)
Sidama	2 (0.5)	1 (0.2)
Sltie	8 (1.9)	9 (2.2)
Tigray	2 (0.5)	6 (1.4)
Welayta	6 (1.4)	10 (2.4)
Other	12 (2.9)	10 (2.4)

<sup>1</sup> SNNP= Southern Nations and Nationality

On the other hand, 31.9% among those who were married have experienced compassionate care. Study participants who can't read and write have experienced compassionate care than those who can read and write, with 10.1%, 1.7%, respectively, But those in primary level, secondary level, and college, and above (10.1%,13%, &10.6%) respectively, had similar level of experience of compassionate care from health care providers (table 7).

**Table 7: Socio-demographics characteristics by demonstration of compassionate care practice at TASH, Addis Ababa, Ethiopia, 2018**

Variable	Status of compassionate care	
	Demonstrated	Not demonstrated
	Frequency (%)	Frequency (%)
<b>Religion</b>		
Orthodox	142 (34.3)	164 (39.6)
Muslim	30 (7.2)	36 (8.7)
Protestant	14 (3.4)	23 (5.6)
Catholic	2 (0.5)	1 (0.2)
Other	1 (0.2)	1 (0.2)
<b>Marital status</b>		
Single	28 (6.8)	34 (8.2)
Married	132 (31.9)	156 (37.7)
Divorced	5 (1.2)	10 (2.4)
Separated	3 (0.7)	6 (1.4)
Widowed	21 (5.1)	19 (4.6)
<b>Educational status</b>		
Can't read and write	42 (10.1)	41 (9.9)
Can read and write	7 (1.7)	14 (3.4)
Primary	42 (10.1)	36 (8.7)
Secondary	54(13)	71 (17.1)
College and above	44 (10.6)	63 (15.2)

### **5.5.3 Clinical condition of study participants characteristics by demonstration of compassionate care practice**

Status of compassionate care practice is higher among breast cancer patients followed by other neoplasm patients 5.8%. The level of experienced and non-experienced compassionate care among breast cancer is the same (14.7%) (table 8).

**Table 8: Clinical condition characteristics by demonstration of compassionate care practice at TASH, Addis Ababa, Ethiopia, 2018**

Variables	Status of compassionate practice	
	Demonstrated Frequency (%)	Not demonstrated Frequency (%)
<b>Disease category</b>		
Breast ca	61 (14.7)	61 (14.7)
CUP <sup>1</sup>	0 (0)	2 (0.5)
Cervical ca	42 (10)	41(9.9)
Anorectalca	21 (5.1)	22 (5.3)
Esophageal ca	2 (0.5)	6 (1.4)
Gastric ca	6 (1.4)	2 (0.5)
Kaposi's sarcoma	0 (0)	1(0.2)
Liver ca (HCC) <sup>2</sup>	1 (0.2)	6 (1.4)
Lung ca	0 (0)	5 (1.2)
NPC <sup>3</sup>	3 (0.7)	3 (0.7)
NHL <sup>4</sup>	3 (0.7)	2 (0.5)
Ovarian ca	3 (0.7)	2 (0.5)
Prostatic ca	4 (1)	2 (0.5)
Renal cell ca	0 (0)	2 (0.5)
Sarcoma	6 (1.4)	4 (1)
Testicular ca	2 (0.5)	6 (1.4)
Thyroid ca	9 (2.2)	17 (4.1)
Uterine Fibroma	2 (0.5)	1 (0.2)
Vulvar ca	0 (0)	1 (0.2)
Other Neoplasms	24 (5.8)	36 (8.7)
<b>Contacting patient</b>		
At inpatient ward	35 (7.7)	47 (11.4)
At follow up clinic	157 (37.9)	178 (43)
<b>Inpatient</b>		
Regular	24 (30.4)	28 (35.4)
Private wing	8 (10.1)	19 (24.1)
<b>Follow up</b>		
Regular	130 (38.8)	137 (40.9)
Private wing	27 (8.1)	41 (12.2)

<sup>1</sup> CUP= Cancer of unknown primary origin

<sup>2</sup> HCC= Hepatocellular carcinoma

<sup>3</sup> NPC=Nasopharyngeal carcinoma

<sup>4</sup> NHL= Non-Hodgkin's Lymphoma

The experience of compassionate care was similar among those who were admitted and on follow up on regular bases (30.4 & versus 38.8%); similarly, the level of compassionate care practice demonstrated is similar among those who were admitted and follow up on private wing (10.1% versus 8.1%) (table 9).

**Table 9: Clinical condition characteristics by demonstration of compassionate care practice at TASH, Addis Ababa, Ethiopia 2018**

Variables	Status of compassionate practice	
	Demonstrated Frequency (%)	Not demonstrated Frequency (%)
<b>Hospitalization days (inpatients)</b>		
3 <sup>rd</sup> day	31 (39.2)	44 (55.7)
5 <sup>th</sup> day	1 (1.3)	3 (3.8)
<b>Previous hospitalization history (inpatients)</b>		
1-6 times	22 (27.8)	39 (49.4)
7-9 times	6 (7.6)	3 (3.8)
10-12 times	3 (3.8)	3 (3.8)
>12times	1 (1.3)	2 (2.5)
<b>Total visit numbers</b>		
1-10 <sup>th</sup> visit	95 (28.4)	95 (28.4)
11-20 <sup>th</sup> visit	46 (13.7)	54 (16.1)
21-30 <sup>th</sup> visit	9 (2.7)	16 (4.8)
31-40 <sup>th</sup> visit	5 (1.5)	9 (2.7)
41-62 <sup>th</sup> visit	2 (0.6)	4 (1.4)
<b>Have you ever been hospitalized at Tikur Anbessa Specialized Hospital for this case?</b>		
Yes	18 (4.3)	22 (5.3)
No	171 (41.3)	203 (49)
<b>How many days were you hospitalized during your last admission?</b>		
A day	2 (26)	3 (7.5)
2 days	1 (2.5)	3 (7.5)
3 days	11 (27.5)	12 (30)
4 days	2 (26)	0 (0)
5 days	2 (26)	4 (10)

## **6 Discussion**

An institutional based cross-sectional study substantiated by a qualitative approach was conducted in Tikur Anbessa Specialized Hospital at the adult clinical oncology unit among oncology patients to validate one of the compassionate care measurement tool in the Ethiopian setting; The Schwartz Center Compassionate Care Scale and to measure the compassionate care practice using the validated SCCCS.

The results of the validity analyses provided psychometric support that the SCCCS could be used in local context with two dimensions and 10 items to better measure compassionate care practice among oncology patients at TASH. The results also showed that the scale has high internal consistency. The convergent validity analysis results of the SCCCS revealed except for the two items which have low factor loading (communicate test results timely (0.45) and gain your trust (0.49)), the average variance extracted and construct reliability results were indicators of convergent validity. The discriminant validity result was also supportive for construct validity. The exploratory factor analysis findings suggest that the SCCCS is two-factor structure and in the confirmatory factor analysis; upon examining the path diagram and output file according to maximum likelihood, the fit indexes indicated that the SCCCS is a two factor scale of compassionate care measurement tool. In conclusion, the results from this validity analysis suggest that the SCCCS is a reliable and valid scale to use in research related to compassionate care measurement among oncology patients in the Ethiopian setting.

Both the exploratory factor analysis and confirmatory factor analysis finding of the current study is contradicted with the finding of a study done in USA, which showed that the SCCCS is a uni-dimensional factor structure compassionate care measuring tool (4). The possible reason for the observed difference could be due to the analysis procedure followed; in the USA study in which firstly the 16 items were split into two item sets and administered to 800 recently hospitalized patients and 510 physicians; half were asked to answer item set one and

half item set two. The authors conducted EFA and CFA for each set of items separately and concluded that items within each set were uni-dimensional. However, they did not conduct analyses on all of the items, making it impossible to determine whether the scale as a whole is uni-dimensional, or whether the measure consisted of two separate scales or subscales.

Another validity and reliability study on the SCCCS was done in Ireland and the result showed that the SCCCS is a uni-dimensional with 12 items compassionate care practice measurement tool (24), which is still against the current study finding. The reason for this disparity could be due to technical difference in the study participant selection, data collection and analysis path followed in studies conducted in USA and Ireland. The other possible reason could be that socio-cultural difference.

The overall compassionate care practice was found to be 45.7% and the qualitative result showed that high patient flow, bed shortage and being treated by different physicians were among the barriers. Treat you as a person, not just a disease (74%) and listen attentively to you (73%) were elements of compassionate care with highest rating.

The status of compassionate care practice at TASH, 45.7% is lower than a study done in USA with a result of 53%(1). This difference could be due to the lower attention given for patient centered care. This low result of the present study, is supported by reasons; lack of role models in many health facilities, measuring the worth of a profession by how much it pays, admitted patients are by default getting the care they need from relatives, than nurses, for various reasons; which were a finding from a review of malpractice claims (10), that initiated the Ethiopian ministry of health to give much emphasis to compassionate care and made CRC as one of the transformation agenda (41).

Current study finding is even lower than a study conducted in Tigray region to assess the status of CRC which revealed a 55%(30). This difference could be due to the difference in sample size and data collection instrument used to collect the study.

A study conducted in Canada to examine patient centered care (PCC) provision showed that patient-centered care has been implemented to moderate extent (42), still current study findings is lower.

Generally the status of compassionate care practice at TASH was the lowest than similar studies done previously in different settings, but this does mean than previous studies done at different place on assessing compassionate care practice is much better than the current finding. The reason for being the lowest in this study could be due to the use of different assessment tool, on targeted study participant, assessed health care providers. The other possible reason which can explain current study finding is that the area of compassion has gotten attention recently in our country and healthcare professions give much emphasis to the scientific aspect of medical services provision like to disease diagnosis, ordering lab investigation and prescribing medication.

Oncology patients who visited the TASH are mainly getting the pharmacological treatments to relief their suffering and health care professionals are not integrating compassion as a core value of practice. This might be due to that the health care professionals are under strain from compassion fatigue and burnout. If compassionate care is to be delivered as for ensuring quality care, it could be a good opportunity to have frequent trainings for the health care providers. The more the health care provider practiced compassion the lesser the patients will be dissatisfied and annoyed. This will help to relieve the pain resulted from the disease and improve treatment adherence. However, to practice compassion, enabling conditions (such as team work, compassionate approach between health care providers towards each other), enabling environment and formed policies implementation should be underlined.

The Ethiopian health system has been started to implement CRC agenda, however, there are no organization costumed compassionate practicing principles which guides health care providers to practice compassion. Though CRC training manual was developed and available,

trainings are not provided for majority of the health care providers. Since CRC is a recent issue in Ethiopia, it was not included in the existing curriculums that are used to train health sciences students. This resulted in the graduation of health care providers without being taught about compassion, the role it could play in alleviating and relieving patients' conditions and the self-benefit that could be gained by being compassionate. These could result in having only technically competent health care providers and compromised quality of health care. These facts indicate that we are away back from what we have planned to achieve in regard to CRC.

## **7 Strengths and limitations of the study**

### **7.1 Strength of the study**

- This study used a mixed method, both qualitative and quantitative to assess the compassionate care practice.

### **7.2 Limitations of the study**

- The construct validity of the SCCCS would have been comprehensive and strong if test retest reliability and interpretability of the tool was assessed.
- Since it is new era of research in our country it was difficult to get literature for comparison

## **8 Conclusion and recommendations**

### **8.1 Conclusion**

In this study, we found that the Schwartz Center Compassionate Care Scale has high internal consistency and acceptable construct validity value among the oncology patients. Further we found that the compassionate care practice among oncology patients to be 45.7% with high patient flow, bed shortage, and being treated by different physicians as barriers to compassionate care practicing. Further researches should be done to determine the replication of the SCCCS validity and reliability among different disease type patients and with mix type of health facilities. By considering the validity, practice measurement and qualitative results, it is reasonable to conclude that the Schwartz Center Compassionate Care Scale can be applied in measuring compassionate care practice in the Ethiopian setting and the practice is low.

### **8.2 Recommendations**

#### **8.2.1 Recommendations for health care providers**

- Health care providers should take in to account compassionate care during contacting oncology patients.
- Health care providers should develop the skills of compassionate care as such of the scientific knowledge of medicine.
- Health care providers should make compassionate care as necessary as wearing the gowns and caring stethoscopes.

#### **8.2.2 Recommendations for policy makers**

- Continuous training should be given for health care providers to ensure the sustainability of compassionate care practicing.
- Efforts need to be made in order for health facilities to have better working environments for compassionate care practicing.

### **8.2.3 Recommendations for Tikur Anbessa Specialized Hospital**

- Skills needed for compassionate practicing have to be delivered on any occasions that health care provides spent all together.
- The hospital should take compassionate care delivering as one of performance measurement indicator.
- For those who are newly employed staffs compassionate care training should be given during induction training.
- Compassionate care role models should be identified and appraised accordingly and they should share their experience to others.

### **8.2.4 Recommendations for researchers**

- Studies should be conducted to assess compassionate care by combing with a tool that assesses respectful and caring practice so that will have CRC assessing instrument.
- Future researches should identify factors that could affect compassionate care provision among oncology patients.
- In future, the effect of compassionate care on oncology patients' health outcome should be assessed.

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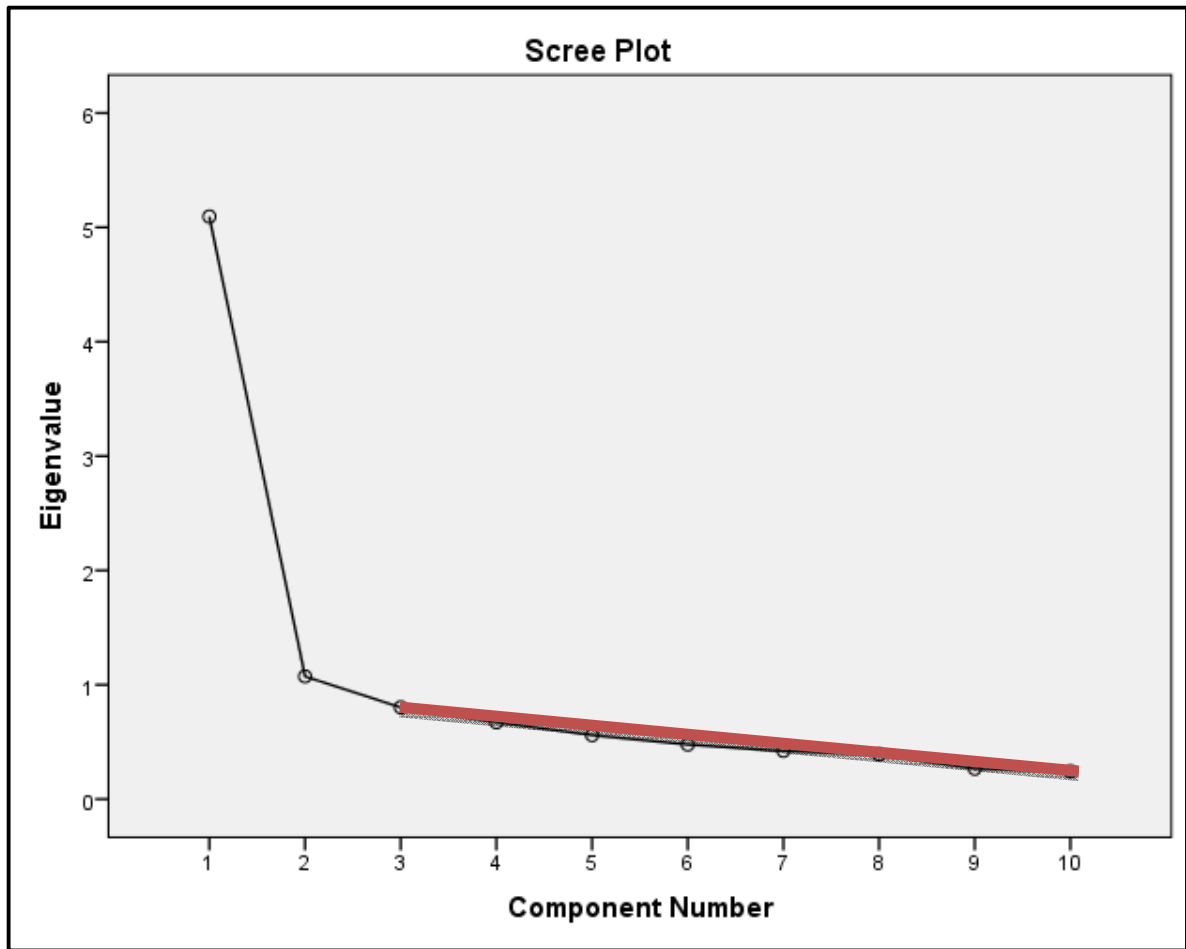
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**Annex**

**Annex I: Model Fit Summary**



### Assessment of normality

Variable	min	max	skew	c.r.	kurtosis	c.r.
Understand your emotional needs	1.0	10.0	-1.56	-12.95	1.63	6.77
Spend enough time you	1.0	10.0	-1.28	-10.64	.89	3.70
Comfortably discuss issues	1.0	10.0	-1.60	-13.30	1.82	7.57
Consider effect of illness	1.0	10.0	-1.43	-11.86	1.15	4.76
Gain your trust	1.0	10.0	-1.74	-14.43	2.85	11.83
Listen attentively	1.0	10.0	-2.25	-18.68	5.60	23.26
Treat you as a person	1.0	10.0	-2.41	-20.05	7.17	29.79
Communicate test results	1.0	10.0	-1.38	-11.49	1.40	5.80
Convey information	1.0	10.0	-1.71	-14.16	2.89	12.01
Show respect	1.0	10.0	-1.90	-15.80	3.78	15.69
Multivariate					158.67	104.20

### Standardized Residual Covariance (Group number 1 - Default model)

	GU	UE	ST	CD	CE	LA	TUA	CT	CI	SR
GU	.061									
UE	-.500	-.003								
ST	.097	.057	.052							
CD	-.109	-.028	-.077	-.003						
CE	1.050	-.077	-.398	.457	-.002					
LA	.006	.357	.263	-.030	-.065	.000				
TUA	-.105	-.323	.631	-.471	.488	.024	.002			
CT	.047	.163	.386	-.742	.608	-.640	-.274	.079		
CI	.185	-.110	.814	-.622	.443	-.014	.195	1.022	.000	
SR	.708	-.341	.568	-.312	-.134	-.030	-.092	1.184	-.464	-.098

Model	NPAR	CMIN	DF	P	CMIN/DF
Default model	31	30.258	24	.176	1.261
Saturated model	55	.000	0		
Independence model	10	1960.616	45	.000	43.569

Model	RMR	GFI	AGFI	PGFI
Default model	.102	.986	.968	.430
Saturated model	.000	1.000		
Independence model	1.942	.349	.204	.285

Model	NFI	RFI	IFI	TLI	CFI
	Delta1	rho1	Delta2	rho2	
Default model	.985	.971	.997	.994	.997
Saturated model	1.000		1.000		1.000
Independence model	.000	.000	.000	.000	.000

<b>Model</b>	<b>PRATIO</b>	<b>PNFI</b>	<b>PCFI</b>
<b>Default model</b>	.533	.525	.532
<b>Saturated model</b>	.000	.000	.000
<b>Independence model</b>	1.000	.000	.000

<b>Model</b>	<b>NCP</b>	<b>LO 90</b>	<b>HI 90</b>
<b>Default model</b>	6.258	.000	24.499
<b>Saturated model</b>	.000	.000	.000
<b>Independence model</b>	1915.616	1774.421	2064.168

<b>Model</b>	<b>FMIN</b>	<b>F0</b>	<b>LO 90</b>	<b>HI 90</b>
<b>Default model</b>	.073	.015	.000	.059
<b>Saturated model</b>	.000	.000	.000	.000
<b>Independence model</b>	4.747	4.638	4.296	4.998

<b>Model</b>	<b>RMSEA</b>	<b>LO 90</b>	<b>HI 90</b>	<b>PCLOSE</b>
<b>Default model</b>	.025	.000	.050	.952
<b>Independence model</b>	.321	.309	.333	.000

<b>Model</b>	<b>AIC</b>	<b>BCC</b>	<b>BIC</b>	<b>CAIC</b>
<b>Default model</b>	92.258	93.955	217.060	248.060
<b>Saturated model</b>	110.000	113.010	331.423	386.423
<b>Independence model</b>	1980.616	1981.163	2020.874	2030.874

**Annex II: Characteristics of In-depth interview respondents**  
**Socio-demographics and clinical condition characteristics of qualitative study at TASH,**  
**Addis Ababa, Ethiopia, 2018**

<b>Respondents</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>	<b>10</b>	<b>11</b>	<b>12</b>
<b>Age</b>	50	60	43	26	21	34	57	60	26	33	35	34
<b>Sex</b>	Male	Female	Female	Female	Male	Female	Male	Female	Male	Male	Female	Female
<b>Region</b>	Amhara	Oromo	Oromo	Amhara	Oromo	Oromo	SNNP	Oromo	A.A	Amhara	Oromo	A.A
<b>Residence</b>	Town	Town	Town	Town	Town	Town	Town	Town	Town	Town	Town	Town
<b>Religion</b>	Orthodox	Orthodox	Orthodox	Orthodox	Orthodox	Orthodox	Orthodox	Orthodox	Orthodox	Orthodox	Orthodox	Protestant
<b>Marital status</b>	Married	Married	Married	Married	Singles	Married	Married	Widowed	Singles	Married	Married	Married
<b>Educational status</b>	More than secondary	Elementary	More than secondary	No education	More than secondary	Elementary	No education	No education	More than secondary	More than secondary	Elementary	More than secondary
<b>Diagnoses</b>	Thyroid ca	Lung ca	Anal ca	Cervical ca	CUP	Cervical ca	Bone ca	Breast ca	Maxillary ca	Colonic ca	Colonic ca	Colonic ca
<b>Inpatient</b>			✓				✓		✓	✓	✓	✓
<b>Private wing</b>	✓	✓				✓						✓
<b>Regular Hospitalization days</b>			✓ 3 <sup>rd</sup> day		✓		✓ 3 <sup>rd</sup> day	✓	✓ 3 <sup>rd</sup> day	✓ 3 <sup>rd</sup> day	✓ 3 <sup>rd</sup> day	3 <sup>rd</sup> day
<b>Previous admission</b>			10times				First time		12times	7times	5times	14times
<b>Follow up</b>	✓	✓		✓		✓		✓				
<b>Number of visit</b>	15times	30times		10times	3times	5times		20times				
<b>Previous admission</b>	No	3 days		No	No	4 days		No				

### **Annex III: English version questionnaire**

#### **Study information sheet and informed consent form**

##### **A. Study information sheet**

Good day: My name is ..... I am here on behalf of Merkeb Zeray, a student of Addis Ababa University School of public health. She is conducting a research on "assessment of compassionate care practice among oncology patients at Tikur Anbessa Hospital". She received permission from Addis Ababa university school of public health and clinical oncology unit of Tikur Anbessa Hospital to conduct this study.

You are selected by systematic random sampling method to participate in this study because you are currently attending inpatient care/ follow-up. Your participation is purely based on your willingness. You have the right to choose not to take part in this study. If you choose to take part, you have the right to stop at any time. If you are willing to participate or refuse or decide to withdraw later, you will not be subjected to any ill-treatment.

If you agree to participate in the study, you will be asked to answer some questions about yourself, compassionate care practice of health care provider.

The study will help you to receive a compassionate care which in turn improves the quality of care you will receive. It can also provide baseline data for policymakers and other researchers for further improvements of compassionate care. Your responses will be kept confidential and names will not be written in the questionnaire and only codes will be used and this data will not be used for any purposes other than this study. Participating in this study will not have any kind of risks and you may not directly benefit or get payment from participating in this study. Completing this questionnaire can take about 10 to 20 minutes of your time and we greatly appreciate your cooperation. If you have any question which is not clear for you, you welcome to ask at any time.

If you need any further information or explanation regarding to this study, you can contact the principal investigator. Here are her contact details;

Address: Cell phone +251967036236

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

Do I have your permission to continue?

Yes

No

If yes, thank him/her and proceed to the informed consent and to the questionnaire

If no, thank him/her and go to the next participant

### **B. Written Consent Form**

I have understood this form and clearly understood its purpose, what is expected from me and

I am willing to voluntarily participate in this study.

Informed consent Certified by:

Respondent's signature \_\_\_\_\_ Date \_\_\_\_\_

Data collector: Name \_\_\_\_\_ Signature \_\_\_\_\_

Date of interview(Ethiopian calendar) \_\_\_/\_\_\_/\_\_\_\_\_

Time started \_\_\_\_\_

Time completed \_\_\_\_\_

Result of interview:

1. Completed.....
2. Refused .....
3. Respondent not available.....
4. Partially completed ...

Checked by supervisor; Name ..... Signature..... Date .....

**Part I: characteristics of patient respondents**

**Instruction: for each of the following questions please circle the alternative that fit for respondent's response.**

Code	Question	Answer category	Skip
101	Sex	1. Male      2. Female	
102	What is your age in completed years?	_____	
103	The place(region) he/she comes from	1. Tigray 2. Afar 3. Amhara 4. Oromo 5. Somali 6. Benshangul Gumuz 7. Southern nations and nationality people 8. Gambella 9. Harari 10. Addis Ababa 11. Dire Dawa	
104	Residence	1. Urban 2. Rural	
105	Ethnicity	_____	
106	What is your religion?	1. Orthodox 2. Muslim 3. Protestant 4. Catholic 5. Other specify _____	
107	What is your current marital status?	1. Single 2. Married 3. Divorced 4. Separated 5. Widowed	
108	What is your educational level?	1. Cannot read and write 2. Can read and write 3. Grade 1-6 4. Grade 7-12 5. Diploma and above	

**Part II: patient's medical history**

**Instruction: this part of questionnaire deals with study participants information about their illness, hospitalization and frequency of visit. please ask the study participants the provided questions and with great attention to the skip pattern.**

Code	Question	Answer category	Skip
201	Where does the patient found	1. At inpatient oncology ward 2. At oncology OPD	If the study participant is an outpatient then skip to Q205
202	Full name of the diagnosis		To be filled from patient card
203	Number of hospitalization days(inpatients)	_____	
204	How many times have you hospitalized including your current admission since you started the treatment?	_____	Go to Q301
205	How many visits have you made including your today visit since you started the treatment?	_____ _____	Skip to Q301 for inpatient study participant.
206	Have you ever been hospitalized at Tikur Anbessa Hospital for this case?	1. Yes      2.No	If no skip to Q301
207	How many days were you hospitalized during your last admission?	_____	

**Part III: assessment of compassionate care practice of providers from patient aspect**

**Instructions: for the following questions please mark on 1 when the patient says the doctor (or other healthcare provider) not at all successful, mark on 10 when the patient says the doctor (or other healthcare provider is very successful and for neutral mark on 2,3,4,5,6,7,8 and 9.**

Code	Elements of compassionate care	1	2	3	4	5	6	7	8	9	10	Skip
<p>“Now, I would like to turn to an approach to treating patients known as compassionate health care that focuses on improving the relationships between doctors, nurses and other professional caregivers and patients and their families. Its particular focus is to improve the communication and emotional support that patients receive from their doctors, nurses and other professional caregivers. On a scale of 1 to 10, where 1 is not at all successful and 10 is very successful, how successfully did your doctor (or other healthcare provider):</p>												
301	Show respect for you, your family, and those important to you											
302	Convey information to you in a way that is understandable											
303	Communicate test results in a timely and sensitive manner											
304	Treat you as a person, not just a disease											
305	Listen attentively to you											
306	Always involve you in decisions about your treatment											
307	Gain your trust											
308	Consider the effect of your illness on you, your family, and the people most important to you											
309	Comfortably discuss sensitive, emotional, or psychological issues											
310	Express sensitivity, caring, and compassion for your situation											
311	Spend enough time with you											
312	Strive to understand your emotional needs											

**Thank You!**

## **Key informant in-depth interview guide**

### **Greeting!**

Hello Dear participant! With the aim of assessing compassionate care practice, having an in-depth interview with you has become an important idea. I hope that the interview I would be having with you is very much helpful to improve problems related with the practice of compassionate care. In doing this interview, I will raise questions about Have you ever experienced compassion? Can you explain to me your previous experience of compassion? Entering to interview, I would like to appreciate you for your voluntary participation in this interview/discussion.

### **Discussion points to the patients**

1. In your opinion, what does compassion mean for you?
2. Have you ever experienced compassion care?
3. In your opinion, how do you explain the compassionate care practice of health care providers here in the clinical oncology unit?

Finally, I would like to express my heartfelt thanks for your voluntary participation in this in-depth interview. You have contributed your best!

**Thank you!**

**Annex V: Amharic Version of Questionnaire**

**አዲስ አበባ ዩኒቨርሲቲ**

**ጤና ሳይንስ ኮሌጅ**

**የማህበረ-ሰብ ጤና ትምህርት ቤት**

ሀ. የስምምነት ቅፅ

እንደምን አደረግኩ/ዋለችሁ፣ስሜ \_\_\_\_\_ ይባላል። እዚህ የመጣሁት በአዲስ አበባ ዩኒቨርሲቲ ጤና ሳይንስ ኮሌጅ

የማህበረ-ሰብ ጤና ትምህርት ቤት ተማሪ የሆኑት መርከብ ዘርአይ በጥቁር አንበሳ ሆስፒታል በክትትል እና ተኝተው በመታከም ላይ ያሉ ካንሰር ህመምተኞች ርህራሄ ያማከለ የጤና ባለሙያዎች ህክምና አሰጣጥ ዙርያ ለሚያደርጉት ጥናት መረጃ ለመስብሰብ ነው።

ይህንን ጥናት እንዲያካሂዱም ከአዲስ አበባ ዩኒቨርሲቲ ጤና ሳይንስ ኮሌጅ የማህበረ-ሰብ ጤና ትምህርት ቤት እና ጥቁር አንበሳ ሆስፒታል ካንሰር ህክምና ክፍል ፍቃድ አግኝተዋል። በዚህ ጥናት እንድትሳተፉ የተመረጣችሁ በአጋጣሚና በፈላጊነት ነው።.

በዚህ ጥናት የመሳተፍና ያለመሳተፍ እንዲሁም ለመመለስ የማትፈልጉት ጥያቄዎች ካሉ ያለመመለስና በማንኛውም ጊዜ በጥናቱ ላይ ላለመሳተፍ መወሰን ይችላሉ። ይሁን እንጂ ለእነዚህ ጥያቄዎች የሚሰጡት ታማኝ መልሶች በጥቁር አንበሳ ሆስፒታል በክትትል እና ተኝተው በመታከም ላይ ያሉ ካንሰር ህመምተኞች ርህራሄን ያማከለ የጤና ባለሙያዎች ህክምና አሰጣጥ ዙርያ ምን እንደሚመስል ለማወቅ ይረዱናል። የሚሰጡን መረጃ ሚስጥራዊነቱ የተጠበቀ እና ለጥናታዊ ተግባር ብቻ የሚወልድ እና ለማንም የማይገለጽ ይሆናል። ተሳታፊዎችን ለመለየት ልዩ የመለያ ቁጥር ስለምንጠቀም ስሞትን መንገር አስፈላጊ አይደለም። በዚህ ጥናት መሳተፋችሁ ርህራሄን ያማከለ የጤና ባለሙያዎች ህክምና አሰጣጥ እንቅስቃሴ ላይ ከፍተኛ አስተዋፅኦ አለው። በዚህ ጥናት ላይ በመሳተፍዎ ምንም አይነት ጥቅምም ሆነ ክፍያ አይኖርም። ነገር ግን በእያንዳንዱ ጥያቄ ላይ የእርስዎ ታማኝነት እና ትክክለኛ መልስ የጥናቱን አላማ ከግብ ለማድረስ ከፍተኛ ሚና ይኖረዋል።. ለዚህ መጠይቅ ከ10 እስከ 20 ደቂቃዎች ወስዳችሁ በመመለሳቸው ለትብብራችሁ በጣም እናመሰግናለን። ከጥያቄዎቹ ወስጥ ግልፅ ያለሆነ ካለ በማንኛውም ሰዓት መጠየቅ ትችላላችሁ።

ለበለጠ መረጃ ወይም ማብራሪያ ከፈለጉ የዚህ ጥናት ባለቤት በሚከተለው አድራሻ ማግኘት ይችላሉ።

ስም: መርከብ ዘርአይ

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ለመቀጠል ፈቃደኛ ነዎት?

አዎ  አይደለሁም

አዎ ካሉ በማመስገን መቀጠል

ካልተስማሙ በማመስገን ወደ ሌላ ተሳተፊ ይቀጥሉ

2: የስምምነት መግለጫ ቅፅ

ከላይ የተጠቀሰው መግለጫ ስለተረዳሁ ለመስተፍ ፈቃደኛ ነኝ

ያረጋገጠው፡፡

የተሳታፊ ፊርማ \_\_\_\_\_ ቀን \_\_\_\_\_

የመረጃ ሰብሳቢ ስም \_\_\_\_\_ ፊርማ \_\_\_\_\_

የቃለ-መጠይቁ መረጃ ቁጥር \_\_\_\_\_

የጀመረበት ሰዓት \_\_\_\_\_ ያለቀበት ሰዓት \_\_\_\_\_

አዲስ አበባ ዩኒቨርሲቲ

ጤና ሳይንስ ኮሌጅ

የማህበረ-ሰብ ጤና ትምህርት ቤት

የሆስፒታሉ ስም \_\_\_\_\_

ክፍል 1: ማህበራዊ እና የሰነ- ህዝብ መረጃ

መመሪያ: እባክዎን ቀጥሎ የቀረቡትን ጥያቄዎች ና የተሰጡትን አማራጮች ድምፅዎን ከፍ አድርገው በማንበብ

የተሳታፊዎቹን ትክክለኛ ምላሽ ያክብቡት።

ተ.ቁ.	ጥያቄ	የመልሶችምድብ	ይለፉት
101	ፆታ	1. ወንድ 2. ሴት	
102	ዕድሜዎት ስንት ነው (በሙሉ-ዓመት)?	_____	
103	የመጡበት ክልል	1. ትግራይ 2. እፋር 3. አማራ 4. አሮሞ 5. ሶማሊ 6. ቤንሻንጉል ጉሙዝ 7. ደቡብ 8. ጋምቤላ 9. ሀረር 10. አዲስ አበባ 11. ድሬዳዋ	
104	መኖርያዎ	1. ከተማ 2. ገጠር	
105	ብሄር		
106	ሃይማኖትዎ ምንድን ነው?	1. አርቶዶክስ 2. እስልምና 3. ፕሮቴስታንት 4. ካቶሊክ 5. ሌላካለ(ይገለጽ) _____	
107	የጋብቻ ሁኔታ?	1. ያላገባች 2. ያገባች 3. የተፋታች 4. ተለያይታ የምትኖር 5. የትዳር አጋር የሞተባች	
108	የትምህርት ደረጃዎን ይግለፁ?	1. ማንበብ እና መፃፍ አልተችልም 2. ማንበብ እና መፃፍ እችላለሁ 3. ከ 1-6 ያጠናቀቀ/ች 4. ከ 7-12 ያጠናቀቀ/ች 5. ዲፕሎማ እና ከዛ በላይ	

**ክፍል2: የታኪሚዎቹ የህክምና ሁኔታ**

**መመሪያ: በዚህ ክፍል የቀረቡት ጥያቄዎች የዚህ ጥናት ተሳታፊ ህመማን ስለህመማቸው፣ ሆስፒታል ስለመግባታቸው፣**

**እና ስለተደጋጋሚ የሆስፒታል ጉብኝታቸው ዝርዝር መረጃ በመስጠት ላይ ያተኩራል። ይህንን ጥያቄ ይዘለሉት**

**በሚለው ላይ ትልቅ ትኩረት በማድረግ አባክዎ የዚህን ጥናት ተሳታፊዎች ቀጥሎ የቀረቡትን ጥያቄዎች ይጠይቋቸው።**

ተ.ቁ.	ጥያቄ	የመልሶችምድብ	ይለፉት
201	ታኪሚዎች የተገኘበት ቦታ	1. ተኝቶታኪሚ 2. ተመላላሽ	መልሱ 2 ከሆነ ወደ ጥያቄ ቁጥር 206 ያምሩ።
202	የታኪሚው ህመም ሙሉ መጠርያ		እባክዎን ከካርድ ይመለከቱ።
203	የታኪሚው የህክምና ዙር		እባክዎን ከካርድ ይመለከቱ።
204	ለምን ያህል ጊዜ ሆስፒታል ጉብኝት ታክመዋል? (በቀናት ይገለጹ)	_____	
205	አሁን ሆስፒታል ጉብኝት ህክምና የጀመሩበትን ጨምሮ ከዚህ በፊት ለምን ያህል ጊዜ ሆስፒታል ጉብኝት ታክመዋል?	_____	
206	ህክምና ከጀመሩበት ጊዜ ጀምሮ ( የዛሬውን ጨምሮ) ለምን ያህል ጊዜ ተመላልሰው ታክመዋል?	_____	አልጋ የያዘ ታኪሚ ከሆነ ወደ ጥያቄ ቁጥር 301 ያምሩ።
207	ከዚህ በፊት በጥቁር አንበሳ ሆስፒታል ጉብኝት ታክመው ያውቃሉ?	1. አዎ አውቃለሁ 2. አላውቅም	መልሱ “አላውቅም” ከሆነ ወደ ጥያቄ ቁጥር 301 ያምሩ።
208	ከዚህ በፊት ለመጨረሻ ሆስፒታል በገቡበት ጊዜ ለምን ያህል ቀናት በሆስፒታል ቆዩ?	_____	

**ክፍል ሶስት፡ ርሀራሄ ተኮር የህክምና አገልግሎት ሰጪዎችን አስመልክቶ የታካሚዎች ግምገማ**

**መመሪያ፡ ቀጥሎ ለቀረቡት ጥያቄዎች አስቀድሞ የቀረቡትን ዝርዝር መግለጫዎች ለተሳታፊዎች ካነበቡላቸው በሀዋላ**

**ዶክተሩ ወይም ሌላ የጤና ተንከባካቢ ውያደረጉትን ርሀራሄ ተኮር ህክምና ከአንድ ጀምሮ እስከ አስር ማርክ በመስጠት**

**ይግለፁ።**

	የርሀራሄ እንክብካቤ የሚያካትቱ ነገሮች	የምላሽ ደረጃ										ይታለፍ	
		1	2	3	4	5	6	7	8	9	10		
	ቀጥሎ በዶክተሮች፣ ነርሶችና የጤና ተንከባካቢ ባለሙያዎች በህመማችን እና በቤተሰቦቻቸው መሃከል ሊኖር የሚገባውን ግንኙነት ለማሻሻል ስለሚደረገው የርሀራሄ ተኮር ህክምና አቀራረብ እወስድዎታለሁ። ዋና አላማው ህመማችን (ታካሚዎች) ከዶክተሮች፣ ነርሶችና ከጤና ተንከባካቢ ባለሙያዎች ሊያገኙት የሚገባውን ርሀራሄ እንዲሁም መግባባት ለማሻሻል የታለመ ነው።												
	የሚያከምዎ/ የምታከምዎ ዶክተር ለእርስዎ ያላቸው ርሀራሄ እና እንክብካቤ እጅግ አስደሳች ከሆነ አስር ማርክ ይሰጣሉ። ርሀራሄው ና እንክብካቤው ዝቅ ያለ ከሆነ እንደ ደረጃው ከአስር ዝቅ ያለ ማርክ ይሰጣሉ። እንደ ማርክ ሰጡ ማለት ርሀራሄ እና እንክብካቤ ሙሉ በሙሉ የጎደላቸው ናቸው ማለትም ነው።												
301	ዶክተሩ፣ ነርሷ፣ የጤና ባለሙያው ለእርስዎም፣ ለቤተሰቦችዎም፣ ለቅርብ አጋሮችዎም አክብሮት ይሰጣል /ትሰጣለች።												
302	እርስዎ በደምብ ሊረዱት በሚችሉት መልኩ ሁኔታዎችን በማብራራት ይገልፃልዎታል/ ትገልፃልዎታለች።												
303	የምርመራ ውጤትዎን በተገቢው ሰአት ና ፍጥነት ይሰጥዎታል/ ትሰጥዎታለች።												
304	ሃኪምዎ የሚመለከትዎት በሽተኛ አድርጎ ሳይሆን አክብሮት ሊሰጥዎት እንደሚገባ ሰው ነው።												
305	እርስዎ የሚናገሩትን በአግባቡ ያዳምጣል/ ታዳምጣለች።												
306	ሃኪምዎ የህክምና ውሳኔ የሚሰጠው/ የምትሰጥዎት እርስዎን ካማከረ/ ካማከረች በሀዋላነው።												
307	በሃኪምዎ ላይ ሙሉ በሙሉ እምነት አለዎት።												
308	ሃኪምዎ ህመምዎ በራስዎ ላይ፣ በቤተሰቦችዎና አጋሮችዎ ላይ ጫና እንደሚፈጥር በደምብ ይረዳል።												
309	ሃኪምዎ ስጋትዎን፣ የውስጣዊ ስሜቶችዎን ና የሚያስጨንቅዎትን ነገሮች ሁሉ በነፃነት እንዲያካፍሉት ያደርጋል።												
310	ሃኪሙ/ ሃኪሟ እርስዎ ላሉበት ሁኔታ ተገቢ ትኩረት፣እንክብካቤ ና ርሀራሄ ይሰጣሉ።												
311	ሀኪሙ/ ሃኪሟ ከእርስዎ ጋር በቂ ጊዜ ያሳልፋሉ።												
312	ሃኪሙ/ ሃኪሟ ውስጣዊ ስሜትዎን ለመረዳት ይጥራሉ።												

**በክፍል ስትራቴጂያዊ የሆኑ ቃለ መጠይቅ መሪ ጥያቄዎች**

ይህ መረጃ መሰብሰብያ ክፍል የካንሰር ህመምተኞች ስለርህራሄ ተኮር እንክብካቤ ያላቸውን የግንዛቤ ደረጃ ለማወቅ የተዘጋጀ ነው።

ተራ ቁጥር	ጥያቄዎች	ማረጋገጫ
1.	በእርስዎ አተረጓጎም “ርህራሄ” ማለት ምን ማለት ነው?	
2.	ርህራሄ ተደርጎልዎት ያውቃል?	
3.	ከዚህ በፊት ስለተደረገልዎት ርህራሄ ሊያብራሩልኝ ይችላሉ?	

**Assurance by principal investigator and approval by primary advisor**

**Assurance by principal investigator**

The undersigned agrees to accept responsibility for the scientific ethical and technical conduct of the research project and for provision of required progress reports as per terms and conditions of the Research Publications Office in effect at the time of grant is forwarded as the result of this application.

**Name of the student:** Merkeb Zeray

Date:Signature: \_\_\_\_\_

**Approval by primary advisor**

**Name of primary advisor:** Mr. Alemayehu DessalegnHailu

Date:Signature: \_\_\_\_\_