

**ADDIS ABABA UNIVERSITY
COLLEGE OF HEALTH SCIENCES
SCHOOL OF NURSING AND MIDWIFERY**

**Prevalence of Depression and Associated Factors among
Primary Caregivers of Adult Cancer Patients Attending
Hawassa University Specialized Hospital Oncology Unit South
Ethiopia, 2019: Mixed Study Design**

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Acronyms/ Abbreviations

| | |
|-------|---|
| AAU | Addis Ababa University |
| ECOG | Eastern Cooperative Oncology Group |
| EB | Ethiopian Birr |
| HUSH | Hawassa University Specialized Hospital |
| OPD | Out Patient Department |
| PHQ-9 | Patient Health Questionnaire 9 items |
| QOL | Quality of Life |
| ZBI | Zarit Burden interview |

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Summary

Introduction. Cancer is a primary and devastating health problem. Because of large population growth and increased life expectancy, prevalence of cancer is rising. The impact of cancer trajectory is beyond cancer patients as it affects the social environment of the patients. The effect of cancer on the psychological well-being of the caregivers of cancer patients could result a raised risk of psychiatric morbidity as relater to stressful life events. However, the caregivers have been ignored or overlooked team. Early identification and treatment of depression, can improve their physical and mental health, their quality of life, limit suffering, and can improve their service/care giving role to patients with cancer.

Objective. To determine prevalence of depression and associated factors among caregivers of cancer patients attending Hawassa university specialized hospital oncology unit, South Ethiopia, 2019.

Methodology. Institution based mixed study design will be conducted among family caregivers of adult cancer patients attending Hawassa University Specialized Hospital oncology unit. For quantitative method, convenient sampling technique considered to be used and sample size determined by calculating using single population proportion and became 422 sample size. But the service takers are not more than 300 per month; because of this census technique will be considered. For qualitative method, purposive sampling technique will be used and sample size will be determined based on the saturation of the information. The data will be collected using structured and semi-structured questionnaires. The data will be analyzed using SPSS version 24 and MAXQDA version 18.1 and the results will be triangulated and displayed by tables, figures and texts.

Expected outcome: High rate of depression, burden and disrupted quality of life and different significantly associated factors will be expected from this study. And the study will benefit the cancer patients, caregivers, and nurses at large.

Budget: To conduct this project for about 40,419.30EB is needed.

CHAPTER ONE: INTRODUCTION

1.1. Background

Cancer is a primary and devastating health problem(1). According Global Burden of Disease for 2018 there were 18.1 million and 9.6 million new cancer cases and death worldwide respectively(2). Because of large population growth and increased life expectancy, prevalence of cancer is rising. The probability of developing lifetime invasive cancer is estimated about 42% and 38% for men and women respectively. Nowadays, because of increased early detection, advanced treatment and improved health behaviors of the population increased cancer survivors. Cancer survivors might experience recurrence or develop secondary cancer in the future, and/or might live with fearing future diagnosis of the disease(3).

Based on population based Cancer registry data the incidence of cancer in Ethiopia was estimated that there were 64,285 new cases (4) and more than 44,000 mortality annually and total national mortality accounts for about 5.8%. The risk of diagnosed with cancer and dying from the disease is 11.3% and 9.4% respectively(5).

The impact of cancer trajectory is beyond cancer patients as it affects the social environment of the patients. The effect of cancer on the psychological well-being of the caregivers of cancer patients could result a raised risk of psychiatric morbidity as relater to stressful life events [2].

The diagnosis and treatment of cancer is a traumatic event that has a significant burden upon caregivers and can cause emotional responses of shock, uncertainty, anxiety and depression(6). Caregiver is an important member of oncology team but many times the caregiver has been ignored or overlooked team. The impacts of care start from diagnosis through treatment and, goes in more than half of a million cases per year, to death. These impacts of care giving largely remain unknown in developing countries. Most often the family member of the patient are spouse, son, daughter, friend or other close relatives

become the caregiver and the caregiver play an important role in the care and recovery of the patient(7, 8).

Cancer disrupts the quality of caregivers in many ways; but greatest burden related to their psychological well-being. When the responsibilities placed on caregivers higher than their capacities, caregivers feel exhausted and report high stress. The stress has a negative effect on the caregiver's psychological wellbeing, and if it is unresolved, can negatively affect their physical well-being as well. The effects on the psychological domain of quality of life appear as increased emotional distress/depression; feelings of helplessness and loss of control; and difficulty in coping with care giving roles(9). Family caregivers are the long-term care providers of cancer patients, however, they receive little preparation, information, or support to perform their vital role (10).

Studies show that depression in general population of Africa is lower than other continents. However, there is a limitation of studies on caregivers of cancer patients. The same is true in Ethiopian context; as far as strongly searched, there is no study found on depression among caregivers of cancer patients (11-14).

1.2. Statement of the Problem

Depression is a serious condition of health problem that affects patients with cancer and their caregivers. It is one of the most prevalent and treatable mental health and regularly seen by the wide spectrum of health care providers(15, 16). Caregivers of patients with cancer experiences distress as a result of care giving role, and have been shown to continue over time and may also be aggravated by the patients' disease progression(8).

Most cancer patients' caregivers developed high level of emotional distress or psychiatric morbidity (mild to major depression illness). Caregivers of patients with advanced cancer or patients receiving palliative care developed about 30-50% psychiatric morbidity and also depression contributes for early death of the caregivers of cancer patients(17).

Although some studies suggest that caregivers experience approximately equal symptoms of psychological distress, such as depressed or anxious mood when compared with patients, others report that caregivers have higher levels of depression even does not remit over time than do the cancer patients that they care for. A review found that prevalence rates for caregiver depression ranged from 20 to 73% and those higher levels of depression in caregivers are often associated with higher sleep disturbance, fatigue, anger, guilt, and irritability, as well as with lower quality of life and satisfaction with life (18-20).

As investigations indicate, depression is significantly associated with burden of caregivers. The transition of a cancer patient from curative to palliative stage is one of the more difficult and challenging phases of cancer care, both to the physician and to family caregiver. Caregivers of cancer patients stay for longer hours/days and not only support but also perform complex medical or nursing tasks. As a result they face higher burden situation which is higher than that of non-cancer patients' caregivers' burden(20).

Despite some controversies, there are studies supporting those socio-demographic characteristics of caregiver and patient as factors of developing caregiver depression. Additionally literatures mentioned that clinical characteristics of the patient also affect the psychological well-being of the caregivers (21-24).

Caregivers are often without desired training and preparation to give care. On the other way, caregivers with limited resources (financial problem), lack of support, disrupted social functioning and impact on schedules of caregivers and also self-esteem and health condition of caregivers are the main cause of caregivers' burden which finally result depression (25).

Caregivers have psychological needs that everyone should consider to address so they can maintain their own health and provide the best care possible to the patient. Referral of caregivers to their primary care providers for depression screening may result in early identification and treatment of depression, which can improve their physical and mental health, improve their quality of life, limit suffering, and can improve their service/care giving role to patients with cancer. The caregivers can be supported by delivering psych-education, skills training and therapeutic counseling (19, 26-28).

CHAPTER TWO: LITERATURE REVIEW

2.1. Introduction

The aim of this literature review is to summarize what has already been existing knowledge base about caregivers of cancer patients and associated factors, to discuss the impact of the research findings to clinical practice, and to identify gaps in caregivers of cancer patients in Ethiopia. As a baseline, literatures have been reviewed and collected on prevalence of depression, demographic characteristics of the cancer patients and caregivers and clinical characteristics of patients and caregivers' burden, which have an impact on depression and quality of life among caregivers of adult cancer patients.

2.2. Prevalence of Depression

It is very challenging to study depression as the occurrence of symptoms span on a spectrum that ranges from sadness to major depression. The overall prevalence rate of depression in caregivers of cancer patients remains vague and wide variation of prevalence rates reported in previous studies done. This variation can be by the difference in conceptualization of depression, differences in methodological approaches used to diagnose depression and different population groups studied with respect to different attributing factors.

Recent studies have found that 32%–50% of caregivers had depressive symptoms at a level suggesting moderate to high clinical depression(19). One study conducted on caregivers of end stage of cancer patients indicate about 30% of caregivers develops depression symptoms. On the other hand study done on caregivers of colorectal cancer patients in Miami shows the development of depression symptom is about 6%(8, 29, 30).

Studies conducted in different countries represented that the prevalence of depression was 82.2% in Korean(21) and 26% in Uganda(22). Depression of caregivers of cancer patients investigated in Putra, Malaysia was 29.4% (31)and Adana, Turkey 24.7%, 20.7% and 12.7% were mild, moderate and severe depression respectively(32).

One study conducted in Freiburg, Germany among caregivers of cancer patients (spouse) was 26%(10) and another study from United Kingdom show the prevalence of depression among caregivers of long-term survivors of cancer patient was about 3% (33).

2.3. Associated Factors of Depression and Quality of Life

The prevalence of depression in caregivers of cancer patients is unlikely to be explained mere by the psychological impact of cancer diagnosis alone. Different demographic characteristics, length of hours stay caring the cancer patient, clinical variables of the patient and caregiver experience or burden have been considered to play a role in the development of depression and poor quality of life in caregivers of cancer patients(19, 34).

2.3.1. Socio-demographic Characteristics of Patients and Caregivers

Study conducted in Turkey show higher prevalence of caregivers' depression with varying for women 10-25% and for men 5-12% which indicates depression in women is higher than men in this study are(32). However, the study in Nigeria indicate the male caregivers were more likely experience high level of depression(35).

Recent study in India showing gender variable scores are statistically significant that females suffer more developing depression. The study groups explain that the reason may be due to the dual role of maintaining the home and caring of the patient [29]. A prospective study in Morocco show that depression was more common in female relatives and, may be because of women are more vulnerable and close to the relatives of Moroccan population(36). One study show that univariate analysis indicate there was significant correlation between male cancer patient and caregivers' depression(37).

A study conducted in Athens Greece show that the age of caregiver not related to depression of the caregiver.(17) Similar study in Japan indicates similar result(37). However, other study indicated that younger caregivers develop more depression.(35)

Study in Turkey found that educational level, occupational status and income inversely correlated with depression among caregivers.(30) Another study found that those caregivers with less than a high school education were more depressed than with higher level of education.(37)

Cancer is a family's illness because a diagnosis of cancer deeply affects the relationship and roles among family members. Partners in comparison to other informal caregivers, are more likely to experience burden and become ill themselves and experience higher rates of psychiatric symptoms.(38)

Caregivers who were unmarried suffer from increased psychological distress, as they perceive loss of social support. Spouses experience more emotional distress than other kinship. Spouses in particular become restricted in their activities and socially isolated in their care-giving task. Problems of communication, sexual difficulties, neglect of their children and significant others and absenteeism in their professional work are leading to emotional stress. [29]

2.3.2. Caregivers' Burden

The potential demands and subsequent burden on caregivers are significant. About 61% of 750 caregivers reported that care giving was the center of their activities and 58% of this sample, indicated that to provide care, and required to give up many other activities(39). Another study shows most of the caregivers depressed by their care giving activities. This is because of the caregivers having not had professional training and preparation for caring(8).

Study conducted in Melbourne, Australia on family caregivers of palliative care show that low level of optimism, greater impact on schedule and loss/decline of social function and lack of social support significantly related to the development of depression symptoms(20). Another study identified caring for patients with advanced stage of cancer are more likely than individuals in the general population to develop depression(40).

Study conducted in Taiwan on family caregivers of terminally ill cancer patients the indicates prolonged psychological distress and burden/physical demands significantly disrupts the QOL of family caregivers (41).

2.3.3. Clinical Characteristics of the Patient

Study have shown the caregivers depression increases as the patients' functional status declines and as the patients' disease progress or as the disease become advanced(42).

Care giving for older cancer patients (>70years old) leading to increased caregivers' burden which finally leads to depression. This is may be because of as become older the morbidity or co-morbidity increases which rises the demand of caring(37).

There are statistically significant changes of emotional distress in caregivers' caring for patients with variable cancer type. Patient's type, schedule, and side effect of treatment, anxiety regarding the intervention procedures, cost of treatment and outcome of the treatment all leads to distress in caregivers, as they are the ones who would actively be there with the patient through all this process and a part of decision making in choosing the treatment option for the patient. This study shows that the treatment category has statistically significant results as associative factors of caregivers' depression [29].

Studies have shown that caregivers of patients with advanced disease and receiving palliative care, reported 30-50% of depression. A patient in the later stages of illness is likely to need more physical care and provoke more concerns for the caregiver because, as the illness progressed, caregivers experienced more depression, a greater adverse impact on their own health and daily lives and spent more time helping patients cope with daily living activities. As the patients experience more physical symptoms like pain and deteriorate functional status, caregivers' distress increases (17, 43, 44).

2.3.4. Length of Stay Caring the Patient

As the caregivers spent more hours per day caring the cancer patients, quality of life and mental health the caregivers became worsen(34).

2.4. Conceptual Framework of the Study

The conceptual framework showed below developed after reviewing different literature from several countries (8, 9, 17, 20, 29, 30, 32, 34-38, 40, 43, 44). It shows the effect of independent variables on dependent variable (Depression).

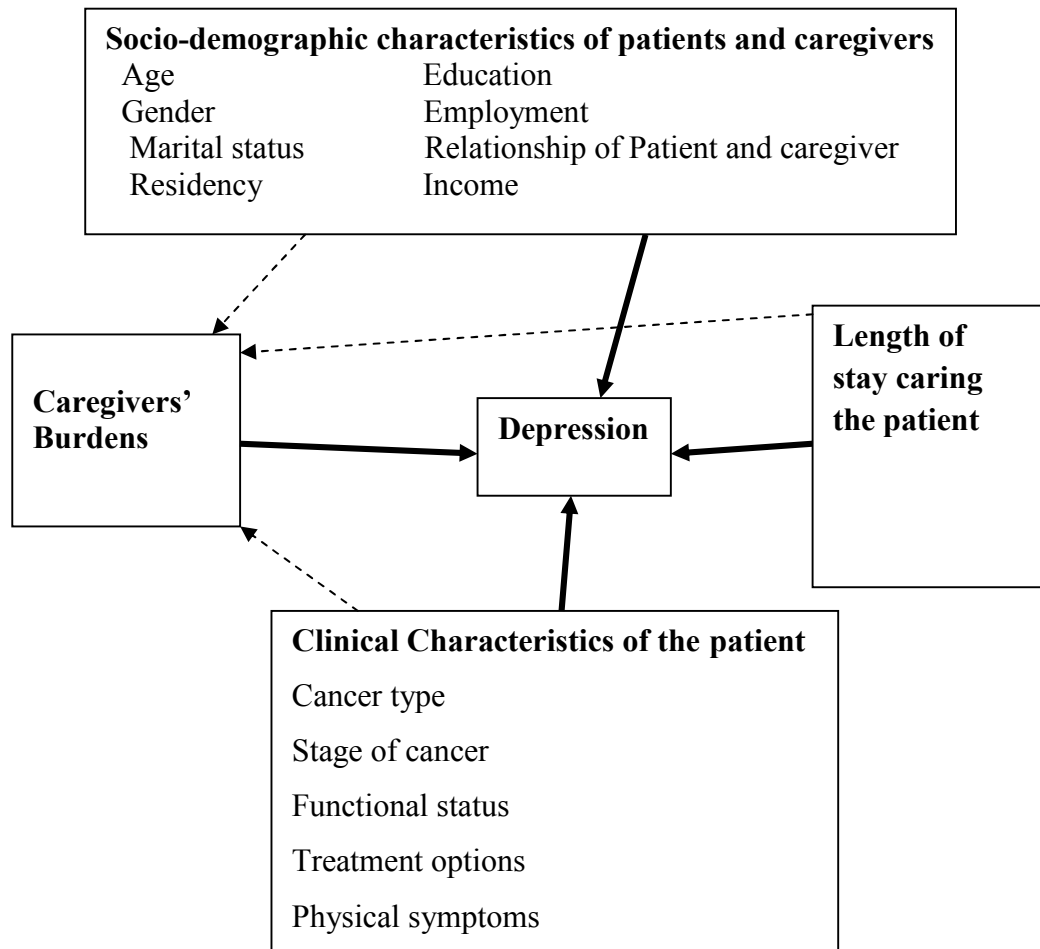


Figure 1: Conceptual framework of depression and associated factors among caregivers of cancer patients(6).

2.6. Justification of the Study

The main aim of this study is to assess the prevalence of depression and associated factors among caregivers of cancer patients attending HUSH oncology unit. The cancer disease pattern is increasing leading to dependency and the high burden of the caregivers increased across the world.

Despite, the government has a program on the issues of non-communicable diseases with special emphasis on cancer to reduce the incidence and mortality of cancer patients, the caregivers are overlooked(5). Although the presence of studies on prevalence and associated factors among caregivers, none of them concern about caregivers of cancer patients. However, scholars mentioned psychological threats of caregivers of cancer patient more than other caregivers did(20).The need to measure prevalence of depression and associated factors among caregivers of cancer patients is important in Ethiopia.

2.7. Significance of the Study

It will be baseline data and information about psychological well-being of the caregivers of cancer patients and it will indicate the prevalence of depression and associated factors among caregivers of cancer patients. Therefore, it will have an implication to caregivers in addition to treating the cancer patients' symptoms, the caregivers' specific symptom to reduce their psychological problems.

This study will have valuable implication for oncology nurses by increasing the awareness/knowledge of the caregivers' psychological burden, as with their routine discussions of the physical, psychological, and social impact of cancer and treatment with patients; would have similar discussions with caregivers to identify those exhibiting symptoms of depression.

It also contributes for the policy makers of government and Non-Governmental Organizations who are interested in health care improvement, to promote programs on the health care of caregivers of cancer patients and for other health care communities to give attention for them.

CHAPTER THREE: OBJECTIVES

3.1. General Objective

1. To determine prevalence of depression and associated factors among primary caregivers of adult cancer patients attending Hawassa university specialized hospital oncology unit, South Ethiopia, 2019.

3.2. Specific Objectives

1. To identify prevalence of depression among primary caregivers of adult cancer patients attending Hawassa university specialized hospital oncology unit, South Ethiopia, 2019.
2. To determine associated factors of depression among primary caregivers of adult cancer patients attending Hawassa university specialized hospital oncology unit, South Ethiopia, 2019.
3. To describe the experiences of primary caregivers of adult cancer patients attending Hawassa university specialized hospital oncology unit, South Ethiopia, 2019.
4. To identify coping styles of primary caregivers of adult cancer patients attending Hawassa university specialized hospital oncology unit, South Ethiopia, 2019.

CHAPTER FOUR: METHODOLOGY

4.1. Study Area and Study Period

This study will be conducted in Hawassa city University Hospital, which is about 300km far away from the capital city of Ethiopia Addis Ababa to the south. The Hospital is the biggest Hospital in the Southern Nation, Nationalities and People of Ethiopian region. It has different specialty departments including oncology unit. The hospital started to serve breast cancer chemotherapy by 2012 and nowadays it is serving adult cancer treatment for solid tumors including lymphomas and gynecologic cancers. Though the center does not have radiotherapy, it has inpatients and OPD services. The study period will be from January to June, 2019.

4.2. Study Design

Institution based mixed study will be conducted among caregivers of cancer patients receiving services at the outpatient and inpatient of the oncology unit in HUSH.

4.3. Source Population

The source population will be all cancer patients' caregivers who attend HUSH oncology unit.

4.4. Study Population

The study population will be informal/family caregivers of the cancer patients and one caregiver for the corresponding patient will be included in the study.

4.5. Inclusion and Exclusion Criteria

4.5.1. Inclusive Criteria

The caregivers who fulfill the following criteria will be included in the study.

Caregivers age >18 years

Caregivers who can understand Amharic

Caregivers with sufficient general conditions to interview

4.5.2. Exclusive Criteria

Professional caregivers or paid caregivers

Caregivers stayed with caring the patient less than two weeks

Caregivers with previous history of depression

4.6. Sampling Procedure & Sample Size

For quantitative method, convenient sampling technique will be used and sample size is determined by calculating using single population proportion.

Sample size calculation formula $n=(z_{\alpha/2})^2pq/d^2$.

Using a confidence level of 95% ($\alpha=0.05$; $z_{\alpha/2}= 1.96$ and a maximum permissible error of 5% and since there is no similar study found in Ethiopia $p= 50\%$ is used. The result of the calculation is $n=384$ caregivers and considering 10% for missing data and for non-response rate then $n=422$. But the center gives service for about 300 patients per month. Finally, census sampling technique will be considered.

In addition, for qualitative method, purposive sampling method will be used. The sample size will be determined based on the saturation of the information.

4.7. Study Variables

4.7.1. Dependent

- ❖ Depression

4.7.2. Independent

- Socio-Demographic Characteristics of Patient and Caregivers

Age

Gender

Marital status

Income

Educational level

Residency

Employment

- Clinical Characteristics of the patients
 - Cancer type
 - Physical functional status
 - Stage of cancer
 - Treatment
 - Physical functional status
- Caregivers Burden
- Length of stay with caring the patient

4.8. Data Collection Procedures and Quality Assurance

The data collection process planned to include three data collectors and one supervisor who will be trained for 1 day. The data collectors will be BSc nurses who are working in the hospital including oncology unit and will be selected purposively to get the nurse with good data collection and communication skills. The supervisor will be nurse MSc holder. The data collection will be from February to March, 2019.

- A. For the quantitative method,** the caregivers will be identified by asking the patient who is your caregiver and stay with longer caring and then if the caregiver fulfils the inclusion criteria, interview will be started with structured questionnaires. To assess the depression level of caregivers, patient health questionnaire-9(PHQ-9) model will be used. This is validated for screening and diagnosis of depression of patients(45), caregivers(14) and population level(46); it is also validated in Ethiopia (47). To assess caregivers' burden, Zarit burden interview (ZBI) will be used(48, 49). Zarit burden interview questionnaire will be translated to Amharic language and Ethiopian context and back to English for checking its consistency. The clinical variables of patients will be collected from patients' health care profile by preparing local format based the clinical variables needs to be collected.
- B. For qualitative method,** data will be collected using semi-structured questionnaire in-depth interview with audio recording and note taking. The participants included in this interview will be from the same participants of the quantitative interviewee, but the interviewer will take consideration that the one that can tale him/her more.

- C. Pretest-** will be done 1 week before data collection on the same study population and study subjects interviewed for pretest will be excluded from the study. In addition, the ZBI will be tested for its consistent on few study subjects for the study area.
- D. Data quality Assurance-**The quality of data will be assured by proper designing and pre-testing of the checklists in 5% of caregivers and by giving training for the data collectors and supervisors before the actual data collection. Appropriate modifications will be made after viewing the pre-test result and overall supervision will be made by the principal investigator. Every day after data collection, checklists will be reviewed and checked for completeness, accuracy and clarity by the supervisors and principal investigator and the necessary feedback will be offered to data collectors in the next morning. The possibility of repetition of interview will be avoided by using patient's hospital number and asking both the patient and caregiver there were asked or not.

4.9. Data Synthesis and Statistical Analysis

All filled checklists/questionnaires will be checked for completeness and consistencies, cleaned manually and will entered into statistical package for social science (SPSS) windows version 24 and an in-depth audio recorded interview will be changed to text and checked for consistency and grouped into themes then entered to MAXQDA version 18.1 software for analysis and final it will be triangulated.

Descriptive statistics will be computed for the socio-demographic, caregivers' related burden and clinical variables of the patient and depression. Pearson correlation will be used to identify the correlation of variable. T-test will be used to examine the strength of associations of caregivers' burden, and socio-demographics of caregivers and patients and clinical characteristics of the patient with depression of caregivers. The variable with a p-value less than 0.05 will be declared to be associated with dependent variable (depression). Multivariate logistic regression will be conducted to examine whether and which of the socio-demographic, clinical characteristics and caregivers' characteristics predict caregivers' depression.

4.10. Ethical Consideration

Ethical approval for this study will be obtained from college of health science school of nursing and midwifery.

The study will be conducted with individual informed consent after taking permission from HUSH.

4.11. Dissemination of the Result

Finally, the result of this study will be presented for different seminars and workshops and submitted for the academic school of Nursing and Midwifery of Addis Ababa University, HUSH, for Ministry of Health of Ethiopia and reputable journals.

3.12. Operational Definitions

Caregiver – In this study, is an individual nominated by the patient, and who providing consistent help/ care. The study caregiver of this research can be close friends or family members who will not paid for caring the patient and should be the one who stay with patient caring for more than two weeks.

Caregiver burden-The caregiver burden measured using short form Zarit Burden Interview (ZBI-12) and who score greater than or equal to 10 will be taken as burdened caregiver.

Depression in caregiver- depression in caregiver will be measured by using PHQ-9 depression assessment tool. And caregivers who score 10-27 will be taken as depressed.

Physical functional status-is the general well-being and how the patient performs his/her activities of daily life. This is measured based on the following ECOG performance status grade.

| Grade | ECOG performance status scale |
|-------|---|
| 0 | Fully active, able to carry on all pre-disease performance without restriction |
| 1 | Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work |
| 2 | Ambulatory and capable of all self-care but unable to carry out any work activities. Up and about more than 50% of waking hours |
| 3 | Capable of only limited self-care, confined to bed or chair more than 50% of waking hours |
| 4 | Completely disabled. Cannot carry on any self-care. Totally confined to bed or chair |

Informal caregivers – An informal caregiver is an individual who has no special training of caring for cancer patient and provides unpaid assistance and cancer-related care.

Primary caregiver- are family members and/or close friends who care the patient. Family members can be father, mother, sister, brother, daughter, son, uncle, ant, grandfather or mother, partner, son and/or daughter in law and other blood relatives.

CHAPTER FIVE: PLANNING AND MONITORING OF ACTIVITIES

5.1. Work Plan

Table 1: Tentative action plan of the thesis project

| Activities | Months | | | | | | Responsibility |
|--|---------|----------|-------|-------|-----|------|--|
| | January | February | March | April | May | June | |
| Writing research Proposal | | | | | | | Principal investigator |
| Training for data collectors and supervisor | | | | | | | Principal investigator |
| Data collection | | | | | | | Data collectors |
| Data tabulation and feeding to SPSS and MAXQDA | | | | | | | Data collectors, supervisor and Principal investigator |
| Research analysis | | | | | | | PI Principal investigator |
| Summit the research thesis for comment to advisers | | | | | | | Principal investigator |
| Final summation of the research thesis | | | | | | | Principal investigator |

5.2. Budget Plan

Table 2: Tentative table of budget showing list of items and total cost of the study needed.

| Budget Category | | No | Qualification | Each Cost | No of days | Total Cost (Birr) |
|------------------|-----------------------------------|-----------------|---|---------------------------|--------------|-------------------|
| 1. | Personnel | | | | | |
| 1.1 | Training | | | | | |
| | Data collectors | 3 | BSC nurses | 300 | 1 | 900.00 |
| | Supervisors | 1 | MSc Nurses | 300 | 1 | 300.00 |
| 1.2 | Data collection | | | | | |
| | Principal investigator | 1 | MSc oncology nursing student | ----- | ----- | ----- |
| | Data collectors | 2 | BSC nurses | 200.00 | 30 | 12000.00 |
| | Supervisors | 1 | MSc Nurses | 300 | 30 | 9000.00 |
| 2 | Translators | 2 | Fluent speakers of both Amharic and English language for questionnaire and audio interpretation | 5000 | | 10,000.00 |
| Sub total | | | | | | 32,200.00 |
| 3 | Supplies & equipment's | Quantity | Unit price | Multiplying factor | Total | |
| | Checklist/questionnaires | 1688 | 0.90 | 1688 | 1519 .00 | |
| | Print for proposal and thesis | 6 copies | 50 | 6 | 300.00 | |
| | Pen | 4 | 7.00 | 4 | 28.00 | |
| | Paper | 4reams | 135.00 | 4 | 540 .00 | |
| | Pencil | 4 | 4.00 | 4 | 16.00 | |
| | Eraser | 4 | 5.00 | 4 | 20.00 | |
| | CD (read only) | 15 | 10.00 | 150 | 150.00 | |

| | | | | | |
|--|------------------------|---|-------|---|--------------------------------|
| | Binding | 4 | 50.00 | 4 | 200.00 |
| | Audio recorder | 1 | 5000 | 1 | 5000 |
| | Sub total | | | | 7,773.00 |
| | Total | | | | 39973.00 |
| | Contingency 10% | | | | 3,997.30 |
| | Grand Total | | | | 43,529.30 ETB |

CHAPTER SIX: REFERENCE

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CHAPTER SEVEN: ANNEX

Annex A. Information Sheet

Title of the Research proposal: Prevalence of Depression and Associated Factors among Primary Caregivers of Adult Cancer Patients Attending Hawassa University Specialized Hospital Oncology Unit South Ethiopia, 2019.

Name of Investigator: Gulema Demissie (BSC)

Name of the Organization: Addis Ababa University, College of Health science, school of Nursing and midwifery, Oncology track.

Name of the Sponsor: Addis Ababa University

Introduction: This information sheet is prepared for Hawassa University Specialized Hospital Hawassa, Ethiopia. The aim of the form is to make the above concerned office clear about the purpose of research, data collection procedures and get permission to conduct the research.

Purpose of the Research project: To determine the prevalence of depression and associated factors among caregivers of cancer patients attending Hawassa University specialized hospital oncology unit, South Ethiopia, 2019.

Procedure: In order to achieve the above objective, information, which is necessary for the study will be taken from caregivers of cancer patients by structured questionnaire face-to-face interview and semi-structured questionnaire in-depth interview with audio recording and note taking. Clinical variables will be collected from patient's health profile

Risk and /or Discomfort: Since the study will be conducted by taking appropriate information interviewing the caregivers of cancer patients, and as it takes some of their time they may feel discomfort; but the study will only start after informed consent and they put their signature. Otherwise it will not inflict any harm both to the patient and caregiver. The name or any other identifying information will not be recorded on the questionnaire and all information taken from the chart will be kept strictly confidential and in a safe place. The information extracted will be kept secured by locked in to locker by key. After

the data collected, it will be entered in to the computer by password. The information retrieved will only be used for the study purpose.

Benefits: The research has no direct benefit for those who will be interviewed in this research. However, the indirect benefit of the research for the participant and other clients in the program is clear. This is because if program planners are preparing predicted plan there is a benefit for clients in the program of getting appropriate care and treatment services for the caregivers of cancer patients. Of all, the research work has a paramount direct benefit for health care professional, planners and managers.

Confidentiality: To ensure confidentiality the information will be collected without the name of the clients. The information collected from this research project will be kept confidential and will be stored in a file. In addition, it will not be revealed to anyone except the investigator and it will be kept in key and locked system with computer password.

Person to contact: This research project will be reviewed and approved by the institutional review board of college of health sciences, school of nursing and midwifery, Addis Ababa University. If in case you want to know more information about the research and its undertakings, you can contact my advisors through the address below.

1. Niguse Tadele: niguse99@gmail.com
2. Sezer Kisa: sezkis@oslomet.no
3. Tadesse Bedada: tadesse.bedada@gmail.com

Permission: Lastly but not least, you are kindly requested to permit and forward your permission to concerned body in your organization so that the researchers can get cooperation from the data clerks and other responsible bodies in place.

ANNEX B: Amharic version of informed consent sheet

የአማርኛ መረጃ መስብሰቢያ መሳሪያ

በሀዋሳ ዩኒቨርሲቲ specialized ሆስፒታል ካንሰር ህክምና ክፍል በተመላላሽና ተኝተው የሚታከሙ የካንሰር ህመማን ተንከባካቢዎችን ድብርትና ተያያዥ ጉዳዮችን ለማጥናት የተዘጋጀ መጠይቅ።

ሀ. የተሳታፊዎች የጥናቱ መረጃ መግለጫ

ሰላምታ፡ እንደምን ዋልሽ/ክ ወይም እንደምን አደርሽ/ክ

ስሜይባላል። በአዲስ አበባ በህክምናና ጤና ሳይንስ ኮሌጅ የ2ኛ ድግሪ ተመራቂ ተማሪ የሆነው ጉልማ ደምቤ በሚያካሂደው ጥናት ላይ የመረጃ ሰብሳቢ ነኝ። የካንሰር ህመማን ተንከባካቢዎችን ችግር አስመልክቶ ከ10-15 ደቂቃ ሊዎስድ የሚችል ጥያቄዎችን ልጠይቀዎት እወዳለሁ። የእርሰዎ ምላሽ የካንሰር ህመማን ተንከባካቢዎችን የስነልቦና ችግርና ተያያዥ ጉዳዮችን ለመለየት እና የመፍትሄ አቅጣጫዎችን ለማስቀመጥ እንደሚያግዝ አምናለሁ። መጠይቁ ፍቃደኛ የሆኑትን የካንሰር ህመማን ተንከባካቢዎችን ሁሉንም ያካትታል።

ጥናቱን አስመልክቶ አንዳንድ ነገር ግልፅ ለማድረግ ያህል፡-

የጥናቱ ርዕስ፡- በሀዋሳ ዩኒቨርሲቲ specialized ሆስፒታል ካንሰር ህክምና ክፍል የካንሰር ህመማን ተንከባካቢዎች ድብርትና ተያያዥ ጉዳዮች የሚል ነው።

የጥናቱ አላማ፡- በሀዋሳ ዩኒቨርሲቲ specialized ሆስፒታል ካንሰር ህክምና ክፍል በተመላላሽነትና ተኝቶ ህክምና ተገልጋዮች የካንሰር ህመማን ተንከባካቢዎችን ድብርትና ተያያዥ ጉዳዮችን መመርምር ነው።

የጥናቱ ጥቅም፡- ምንም እንኳን በጥናቱ ላይ የሚሳተፉ ሰዎች በቀጥታ የሚያገኙት ጥቅም ባይኖርም ከጥናቱ የሚገኘው መረጃ በሀዋሳ ዩኒቨርሲቲ specialized ሆስፒታል ካንሰር ህክምና ክፍል በተመላላሽነትና ተኝቶ ህክምና ተገልጋዮች የካንሰር ህመማን ተንከባካቢዎችን ድብርትና ተያያዥ የሚመጡ ችግሮችን ለመቅረፍ ከማስቻል በላይ በሀገር ደረጃ የራሱ አስተዋጽኦ እንደሚኖረው ይታመናል።

የጥናቱ ስጋት፡- በጥናቱ ላይ መሳተፍ ለተሳታፊዎች ምንም የሚያመጣው ችግር የሌለ እና የሚሰጡት መረጃ ሚስጥራዊነቱ የተጠበቀ ነው።

የተሳታፊዎች መብት፡- በጥናቱ ላይ መሳተፍም አለመሳተፍም ሙሉ መብት ያላቸው ሲሆን ተሳታፊዎችም በማንኛውም ጊዜ አራሳቸውን ከጥናቱ ማግለል ይችላሉ፤ ከዚህም በተጨማሪ በጥናቱ ላይ ምንም አይነት ጥያቄዎች ካሏቸው የበለጠ እንዲብራራላቸው መጠየቅ ይችላሉ።

የጥናቱ ሚስጥራዊነት፡- ማንኛውም መረጃ ሚስጥራዊነቱ የተጠበቀ ሲሆን በመጠይቁ ላይ የተሳታፊዎችን ስም አይግለጽም። ከማንነትም ጋር በቀጥታ ተያያዥነት ያላቸው መረጃዎች በሙሉ በዋና ተመራማሪው ሚስጥራዊ በሆነ የመረጃ ጥንቅር ዘዴ ከተቀየሩ በኋላ ብቻ ለምርምር ሂደቱ የሚውል ይሆናል።

ለ. የስምምነት ቅጽ

ከላይ ያነበብኩልዎትን መረጃ በሚገባ ከተረዱት በጥናቱ ላይ ለመሳተፍ ፈቃደኛ ነዎት ?

- 1) አይደለሁም (አመሰግናለሁ) 2) አዎ (ቃለ መጠይቁ ይቀጥላል)

የተጠያቂው ፊርማ ቀን.....

ቃለ መጠይቁ የተካሄደበት ቀን.....

የመረጃ ሰንሰብሰቢው ስም-----

ጥናቱን የሚያካሄደው ተማሪ :- ጉልማ ደምሴ

የቃለ መጠይቁ ዉጤት

1) መልስ ሰጭው ፍቃደኛ ያልሆነበት

2) በክፊል የተሞላ

3) የተፈጸመ(ሙሉ-ሰሙሉ የተሞላ)

ያረጋገጠው ተቆጣጣሪ ስም.....ፊርማ.....ቀን.....

ሐ. ለድምጽ ቅጂ

በዚሁ ቀጥልን አንዳንድ ማብራሪያ የሚፈልጉ ጥያቄዎችን ምናልባትም ተጨማሪ 20-30 ደቂቃ ሊፈጅ የሚችል ብጠይቅህ ፍቃደኛ ነህ?

- 1. አዎ
- 2. አይደለሁም

የመጠይቁ ዉጤት

- 1. ሙሉ-ሰሙሉ ተቀድቱዋል-ድምጽ
- 2. በክፊል ተቀድቱዋል-ድምጽ
- 3. ተሳታፊው አልተሰማም

Annex C. Data Collection Tools

Table 3: Checklist format for Socio-demographic characteristics of both cancer patients and their caregivers and clinical variables of the patients attending HUSH oncology unit, South Ethiopia, 2019.

| S.No | Patient's Socio-demographic status | Caregiver's socio-demographic status |
|------|------------------------------------|---|
| 1. | MRN | Age |
| 2. | Age | |
| 3. | Gender | Male Female |
| 4. | Residency | Urban Rural |
| 5. | Relationship | 1. wife/husband 2. Daughter 3. Son 4. Sister 5. Brother 6. Father 7. Mother 9. Others ----- |
| 6. | Marital status | 1. Single 2. Married 3. Divorced 4. Other----- 4. Other----- |
| 7. | Occupation | 1. unemployed 2. employed |
| 8. | Education | 1. Illiterate 2. Primary(1-8) 3. Secondary (1-12) 4. Higher level 1. Illiterate 2. Primary (1-8) 3. Secondary (1-12) 4. Higher level education |
| 9 | Number of family | |
| 10 | Religion | |
| 11 | Ethnicity | |
| 112 | Monthly Income | |

1. Are you living with your relative? 1. Yes 2. No
2. Do you know the diagnosed disease of the patient?
1. Yes 2. No
3. How many hours do you stay caring your relative per day?
Mention-----

Table 4: በHUSH ካንሰር ህክምና ክፍል ከሚመጡ የካንሰር ህመማን ተንከባካቢዎችን እና የህመማንን ስነ-ማህበራዊ ሁኔታ ቸክሊስት ፎርም, 2019.(Amharic version)

| ተራ ቁ. | የታማሚው ስነ-ማህበራዊ ሁኔታ | | የተንከባካቢው ስነ-ማህበራዊ ሁኔታ |
|-------|--------------------|---|---|
| 1. | ካርድ ቁ. | | ኮድ----- |
| 2. | እድሜ | | |
| 3. | ጾታ | ወንድ ሴት | ወንድ ሴት |
| 4. | የመኖሪያ አካባቢ | ክልል----- ከተማ ገጠር | ክልል----- ከተማ ገጠር |
| 5. | ግንኙነት | | 1. ሚስት 2. ባል ሴት ልጅ 3. ወንድ ልጅ 4. እህት 5. ወንድም 6. አባት 7. እናት 9. ሌላ ----- |
| 6. | የትዳር ሁኔታ | 1. ያላገባ/ች 2. ባለትዳር 3. የትፋታ/ች 4.ሌላ----- | 1. ያላገባ/ች 2. ባለትዳር 3. የትፋታ/ች 4.ሌላ----- |
| 7. | የስራ ሁኔታ | 1. ስራ የለለው 2. ስራተኛ ዘርዘር----- | 1. ስራ የለለው 2. ስራተኛ ዘርዘር----- |
| 8. | የትምህርት ደረጃ | 1. ምንም ያልተማረ/ች 2. አንደኛ ደረጃ(1-8) 3. ሁለተኛ ደረጃ (1-12) 4. ከፍተኛ | 1. ምንም ያልተማረ/ች 2. አንደኛ ደረጃ(1-8) 3. ሁለተኛ ደረጃ (1-12) 4. ከፍተኛ |
| 9. | የባለቤቱ ብዛት | | |
| 10. | ሀይማኖት | | |
| 11. | ብሀር | | |
| 12. | ወርሀዊ ገቢ | | |

1. ከታማሚዎች ጋር ነው የሚኖሩት?
 1. አዎ 2. አይደለም
2. ታማሚህ/ሽ ምን አይነት በሽታ እዳለበት ታውቃለህ/ሽ?
 1. አዎ 2. አላውቅም
3. በቀን ምን ያክል ሰዓት በመንከባከብ ታሳልፋለህ/ሽ?
ግለጽ-----

Table 5: Short Form Zarit Burden Interview (ZBI-12) for the assessment of burden among caregivers of cancer patients attending HUSH oncology unit, 2019.

| Do you feel? | | Never (0) | Rarely (1) | Sometimes (2) | Quite frequently (3) | Nearly always (4) |
|--------------|--|--------------|---------------|------------------|-------------------------|----------------------|
| 1 | That because of the time you spend with your relatives that don't have enough time for yourself? | | | | | |
| 2 | Stress between caring for your relative and trying to meet other responsibilities (work/family)? | | | | | |
| 3 | Angry when you are around your relative? | | | | | |
| 4 | That your relative currently affects your relationship with family members or friends in a negative way? | | | | | |
| 5 | Strained when you around your relative? | | | | | |
| 6 | That your health has suffered because of your involvement with your relative? | | | | | |
| 7 | That you do not have as much privacy as you would like because of your relative? | | | | | |
| 8 | That your social life has suffered because you are caring for your relative? | | | | | |
| 9 | That you have lost control of your life since your relative's illness? | | | | | |
| 10 | Uncertain about what to do about your relative? | | | | | |
| 11 | You should be doing for your relative? | | | | | |
| 12 | You could do better job in caring for your relative? | | | | | |

Table 6: በHUSH ካንሰር ህክምና ክፍል ከሚምጠ የካንሰር ህመምን ተንከባካቢዎችን ጫና መመርመሪያ አጭር Zarit Burden Interview (ZBI-12) ፎርም, 2019.(Amharic version)

| | በፍጹም (0) | አልፎአልፎ (1) | በተደጋጋሚ (2) | ብዙ ጊዜ (3) | ሁለ ማለት ይቻላል (4) |
|----|-------------|---------------|---------------|--------------|-----------------------|
| 1 | | | | | |
| 2 | | | | | |
| 3 | | | | | |
| 4 | | | | | |
| 5 | | | | | |
| 6 | | | | | |
| 7 | | | | | |
| 8 | | | | | |
| 9 | | | | | |
| 10 | | | | | |
| 11 | | | | | |
| 12 | | | | | |

Table 7. Patient Health Questionnaire-9 format for the assessment of depression among caregivers of cancer patients in Hawassa University Specialized Hospital oncology unit Hawassa, 2019.

| S. No | Over the past two weeks, how often have you been bothered by any of the following problems? | Not at all(0) | Several days (1) | More than one-half the days(2) | Nearly every day (3) |
|--------------|--|---------------|------------------|--------------------------------|----------------------|
| 1 | Little interest or pleasure in doing things | | | | |
| 2 | Feeling down, depressed, or hopeless | | | | |
| 3 | Trouble falling or staying asleep, or sleeping too much | | | | |
| 4 | Feeling tired or having little energy | | | | |
| 5 | Poor appetite or overeating | | | | |
| 6 | Feeling bad about yourself—or that you are a failure or have let yourself or your family down | | | | |
| 7 | Trouble concentrating on things, such as reading the newspaper or watching television | | | | |
| 8 | Moving or speaking so slowly that other people could have noticed. Or the opposite—being so fidgety or restless that you have been moving around a lot more than usual | | | | |
| 9 | Thoughts that you would be better off dead, or of hurting yourself in some way | | | | |
| Total | | | | | |

Table 8. የታካሚ ጤና መጠይቅ(ፒ.አቸ.ኪው-9) በHUSH ካንሰር ህክምና ክፍል ከሚምጠ የካንሰር ህመምን ተንከባካቢዎችን ድብርት መመርመሪያ 2019.(Amharic version)

ባለፉት ሁለት ሳምንታት ከታች በተዘረዘሩት ገጠመኞች ምን ያህል ተቸግረው (ታውከው) ነበር መመሪያ ለመረጃ ሰብሳቢ፣ ምላሾቹን ደግመው ያንብቡላቸው

| ተራ ቁ. | | በፍጹም 0 | ከሰባት ቀናት ያነሰ 1 | ከሰባት ቀናት በላይ 2 | ከሞላ ጎደል በየቀኑ (3) |
|--------------|--|-----------|----------------------|-------------------------|------------------------|
| 1 | ነገሮችን ሲሰሩ ፍላጎትዎ ወይም የሚያግኙት ደስታ በጣም ትንሽ(እምብዛም) ነብር? | | | | |
| 2 | የትካዜ የበታችነት፣ የጭንቀት፣ የመደበር ወይም ተስፋ የመቁረጥ ስሜት ነበረዎት? | | | | |
| 3 | እንቅልፍ የመተኛት፣ ተኝቶ የመቆየት ችግር ወይም ከመጠን በላይ የመተኛት ችግር ነበረዎት? | | | | |
| 4 | ድካም የመሰማት ወይም አቅም የማነስ ሁኔታ ነበረዎት? | | | | |
| 5 | የምግብ ፍላጎት አለመኖር ወይም በ ጣም ብዙ የመብላት ችግር ነበረብዎት? | | | | |
| 6 | ለራስዎ መጥፎ ስሜት ተሰምቶት ወይም አልትሳካልኝም ብለው አስበው፣ ወይም ቤተሰቤን አሳፈርኩ ብለው አስበው ነበር? | | | | |
| 7 | ነገሮች ላይ ሀሳቦዎችን መሰብሰብ ወይም ልብ የማለት ችግር ነበረብዎት? ለምሳሌ ጋዜጣ ሲያነቡ ወይም ቴሌቪዥን ሲመለከቱ? | | | | |
| 8 | ከተለመደው ውጪ አረፍት የማጣት ወዲና ወዲህ የማለት ወይም በተቃራኒው ሌሎች ሰዎች ሊገነዘቡት በሚችሉት ሁኔታ ቀስ ብሎ የመናገር ወይም የመንቀሳቀስ ችግር ነበረብዎት? | | | | |
| 9 | ብሞት ይሻላል ወይም እራሴን በሆነ መንግድ ብሳጥ ትሻላል ብለው ያሰቡበት ጊዜ ናበር? | | | | |
| Total | | | | | |
| 10 | ከነዚህ ከላይ የጠሰናቸው ችግሮች አጋጥሞዎት ከነበሩ ችግሮቹ ስራዎችን እንዳይሰሩ የቤስን ሃላፊነትዎን እንዳይወጡ እራስዎን ለመጠበቅ ወይምከሌሎች ሰዎች ጋር ባልዎት ግንኙነት ለእስከ ምን ያህል አስቸጋሪሬዳጋች) ነበሩ? | | | | |

A. Semi-structured Questionnaire for qualitative data collection

1. ዘመድህን በመንከባከብ ምን አይነት ስሜት ይሰማሃል?

እስቲ አብራራልኝ

2. እክብካብ በሚሰበጥት ወቅት ምን ምን አይነት ሁኔታዎች አጋመዎት ነበር?

መጎትጎቻ

ሀ. ከገንዘብ ጋር በተያያዘ

ለ. ከድጋፍ ጋር

ሐ. ከጤናዎ ጋር

መ. ከስራ ፕሮግራምዎ ጋር

ሰ. በራስ የመተማመንዎት ላይ

ረ. በማህበራዊ ህይወትዎ ላይ

3. በእክብካብ ወቅት የነበሩትን ችግሮች እንዴት ነበር ሲወጡት የነበረው/ለመወት የሞከሩት?

መጎትጎቻ

ሀ. በመጸለይ

ለ. ድጋፍ በመየቅ

ሐ. -----

4. በእክብካብ ወቅት የነበረህ ስጋትና የምትበቀው ነገር ምንድነው?

መጎትጎቻ

ሀ. የተሻለ ውት ለ. ተስፋ መቁረ ሐ. ችግሩ የመባባስ

B. Clinical variables of the adult cancer patients attending HUSH oncology unit, South Ethiopia, 2019.

1. ECOG-----

2. Cancer type-----

3. Stage-----

4. Treatment

1. Chemotherapy 2. Radiotherapy 3. Surgery 4. Hormonal 5.

Others specify -----

5. Physical symptoms

1. Pain, 2. Vomiting 3. Loss of appetite 4. Other mention-----

6. Is there co-morbidity? 1. Yes 2. No

If yes, how many? -----, What types? -----

Annex D. Training Manual Guide for Data Collectors and Supervisors

Topic: Prevalence of Depression and Associated Factors among Primary Caregivers of Adult Cancer Patients Attending Hawassa University Specialized Hospital Oncology Unit South Ethiopia, 2019.

Introductions: this training manual helps the research team to be familiar with words and sentences used in the checklist, in adopting with data collection techniques and help to get experience for correctly recording of the data of study subjects. It also helps on how to perform supervision and how to control data quality.

Objectives of the research; To determine prevalence of depression and associated factors among caregivers of cancer patients attending Hawassa university specialized hospital oncology unit, South Ethiopia, 2019.

Purpose of the training:

- To familiarize the data collectors & supervisors with unfamiliar words and sentences used in the checklist.
- To adopt data collectors & supervisors with techniques to be followed in data collection and supervision procedures
- To enable data collectors& supervisors in resolving problems in case of inconveniences

Methods of training: Discussion of data collection tool, Filed practice/pre-testing

Responsibility of research team members:

Principal investigators – control the overall activities of the study

Supervisors - monitor for the correctness of data collections at the spot in the filed

- Monitor for constancy and completeness of data at the spot of data collection
- Monitor for availability of necessary supplies for the Data collection
- Ensure data quality at the spot of data collection

Data collectors

- handle necessary supplies to perform the study
- perform the Data collection and enumerate correctly

- handle and manage any inconveniences properly
- communicate with supervisors and principal investigator for solving problems which are beyond their capacity, and for information which needs more clarifications
- check for completeness of checklists at the site

How to fill the checklists: each data collector should be checked whether he/she has pencils and checklist to be filled before starting.

Table 9: Training schedule for data collectors and supervisors.

| DAY1 | ACTIVITIES |
|------------------------------------|--|
| Time breakdown (all in local time) | |
| 2:30–4:00 AM | <ul style="list-style-type: none"> • Welcome, survey objectives and training overview |
| 4:00-4:15 AM | TEA BREAK |
| 4:15-6:00AM | Overview of survey methodology <ul style="list-style-type: none"> • Key aspects of survey design • Roles and responsibilities of personnel |
| 6:00–7:30 PM | LUNCH |
| 7:30–9:00 PM | Data collection procedures <ul style="list-style-type: none"> • Preparation for data collection • Procedures before, during and after observing data extraction forms of cc at oncology department • What to do at the end of data collection |
| 8:30-8:45 PM | TEA BREAK |
| 8:45-11:00 PM | Logistics for data collection Instructions for completing the form, Key rules to remember Final comments, evaluation of workshop and Closing of the workshop |

Annex E. Approval Sheet

**Addis Ababa University
College of Health Sciences
School of Nursing and Midwifery**

I, the undersigned MSc student, declare that I have submitted my original proposal work on a title “**Prevalence of Depression and Associated Factors among Primary Caregivers of Adult Cancer Patients Attending Hawassa University Specialized Hospital Oncology Unit South Ethiopia, 2019**” for the examination.

Submitted by:

| Name of student | Signature | Date |
|------------------------|-----------|-------------------|
| Gulema Demissie | | 05/02/2019 |

This thesis work has been submitted for examination with my approval as an advisor.

Approved by:

| | | |
|-----------------------|-----------|-------|
| 1. Niguse Tadele | _____ | _____ |
| Name of Major Advisor | Signature | Date |

| | | |
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| 2. Tadesse Bedada | _____ | _____ |
| Name of Co-Advisor | Signature | Date |