

ADDIS ABABA UNIVERSITY
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GRADUATE STUDY PROGRAM

ASSESSMENT OF ADULT CANCER PATIENTS' OPINION TOWARDS CANCER
CHEMOTHERAPY RELATED INFORMATION NEEDS IN TIKUR ANBESSA
SPECIALIZED REFERRAL HOSPITAL, ADDIS ABABA, ETHIOPIA.

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This thesis by _____ is accepted in its present form by The Board of Examiners as satisfying thesis requirement for the Degree of Masters of Science in Adult Health Nursing.

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List of Abbreviations /Acronyms/

AA	Addis Ababa
AAU	Addis Ababa University
BSc.N	Bachelor of Science in Nursing
df	degree of freedom
Dx	Diagnosis
DRC	Departmental Review Committee
MA	Master of Art
MOH	Ministry of Health
MSc.N	Master of Science in Nursing
OPD	Out Patient Department
QOL	Quality of Life
RM	Registered Midwifery
RN	Registered Nurse
SPSS	Statistical Package for Social Science
TASRH	Tikur Anbessa Specialized Referral Hospital
WHO	World Health Organization
X ²	Chi-Square

ABSTRACT

Background: Many people have some type of altered cell growth such as moles and skin tag. Most of altered cell growth are harmless (benign) and do not require intervention. Malignant cell growth or cancer, however, is serious and, without intervention, leads to death. Even though, providing care to clients and families experiencing cancer is complex and challenging, giving patients with adequate information, advice and support around treatment is an important component of care in which nurses play an important role. Patients desire different types and amounts of information depending on their type of cancer, the extent of disease progression, and their unique personal life circumstances.

Method: Institution based cross-sectional qualitative and quantitative descriptive study designs were employed on 395 patients in Tikur Anbessa Specialized Referral Hospital from February 2011 to March 2011 with convenience sampling technique to explore cancer patients' opinion towards cancer chemotherapy related information needs. Data was collected by face-to-face and through an in-depth interviews using structured and semi structured questionnaires. Cleaned and coded data were entered to epi-info software and then exported into a Statistical Package for Social Science Version 16 software for analysis purpose. Calculations of proportions were recorded on frequency tables and cross tabulation were done for selected variables. Also Pearson's chi square test was calculated in order to show association between selected variables. Qualitative data obtained through an in-depth interview was transcribed by arranging the record according to forwarded questions and analyzed manually by identifying common themes.

Result: In this study, 395 study participants were involved; 385 for quantitative and 10 for qualitative. Out of which 290 (73.42%) were females and 107(27.08%) were males. As a qualitative result the majority of the participants had negative opinions towards cancer

chemotherapy related information and quantitatively 144 (37.4%) study participants had neutral opinions and 135 (35.1%) had negative opinions. Whereas, Only 106 (27.5%) of them had reported positive opinions towards cancer chemotherapy related information. Majority of the participants were believed that “unless age difference should be considered health education should not be successful. Participants were also got insufficient information while they had favorable attitude towards cancer chemotherapy related detailed information in the form of booklets. Patients’ economic status and their specific diagnosis were found to have statistically significant association with their level of opinion at p-value of .014 and .000 respectively.

Conclusion and Recommendation: The study showed that majority of the study participants got less information related to cancer chemotherapy. To this reason, most of them did not know what chemotherapy they have taken or currently taking. Regarding to this, nurses should get communication training and trainings which helps them to show empathetic behavior to patients.

Key words: Cancer patients, Opinion, Chemotherapy, Information needs.

CHAPTER I

INTRODUCTION

1.1 Background

Many people have some type of altered cell growth such as moles and skin tag. Most of altered cell growth are harmless (benign) and do not require intervention. Malignant cell growth or cancer, however, is serious and, without intervention, leads to death. Some types of cancer can be prevented; others have better cure rates if diagnosed early. Most people fear cancer and consider a cancer diagnosis to involve suffering and death. In affluent countries however, more than 50% of people diagnosed with cancer are cured, and thousands of others live 5 years or longer after the diagnosis [1].

Even though, providing care to clients and families experiencing cancer is complex and challenging, giving patients with adequate information, advice and support around treatment is an important component of care in which nurses play an important role [2, 3].

Information can enable cancer patients to adapt to their disease and to cope with their potentially traumatic treatment. Their anxiety and anguish can be abated when nursing and medical staff provide them with information about their condition and proposed treatment [4].

The information needs of cancer patients vary considerably across individuals. Patients desire different types and amounts of information depending on their type of cancer, the extent of disease progression, and their unique personal life circumstances [5, 6].

Recall of information from a medical consultation is important for patients' health and well-being, as it has been associated with decision making, good adherence to recommended treatment and patient satisfaction [7, 8, 17]. However, patients forget much of the information provided [5]. So far, very few studies focused on the specific information needs of cancer

patients surrounding their chemotherapy treatment. Given the growing incidence of cancer, insight in these needs is crucial.

1.2 Statements of the Problem

There is no clear evidence to suggest that the need for detailed information is especially elevated among cancer patients and their families. However, the general pattern that emerges from the literature is that large numbers of patients with cancer often report poor understanding and recall of what health professionals told them and in addition, often expresses dissatisfaction with the quantity and quality of information they receive about aspects of their disease and treatment [9-11]. Cancer can evoke immediate, adverse and life-changing reactions. The diagnosis combined with treatment protocols and repeated hospital admissions, can rapidly diminish an individual's sense of mastery, and induce feelings of powerlessness and helplessness. These disruptive cognitions pose limitations for the self-efficacy of an individual. Self-efficacy is the belief an individual possesses in their ability to control events that are affecting their welfare [12]. Doctors often communicate poorly with patients who have cancer; so that diagnosis is unnecessarily traumatic and patients do not receive the help they need to understand treatment options [13]. It has been suggested that regardless of rationality, education or sophistication, the attitudes or beliefs that lead to fear of cancer exist to some extent in everyone. This attitude may create a barrier to communication between patients and health care professionals and may influence decision making about referral to specialist services and the selection of appropriate treatments [14-15].

Poorly informed patients are less likely to comply with treatment and adhere to medical advice, or participate in the medical decision-making process. They are also more likely to experience a high

degree of uncertainty and anxiety, or seek scientifically unacceptable therapies, for example, from alternative healers [16-20].

Over the years, various methods for providing information to cancer patients have been developed, including the use of written material, audiotapes, videotapes, telephone help lines, multimedia resources and the internet. Recent reviews of controlled clinical trials of information-giving approaches have demonstrated that, these methods are valued by patients and are effective in enhancing understanding, knowledge and recall, and promoting satisfaction with communication. With regard to anxiety and depression-emotional distress outcomes in general- the evidence is equivocal, because a number of studies have shown positive effects, whereas others have shown no benefit. Much less is known about the impact of information-giving approaches on quality of life (QoL) or functional ability. To date, the evidence from the few controlled clinical trials that have been conducted is inconclusive, hence this issue merits further exploration [17, 21-26].

The provision of verbal information to patients supplemented with written material in the form of booklets, handouts, general cancer literature and specifically designed information packages, has long been the mainstay of information-giving approaches. Research has shown that the majority of patients receiving written information express favorable attitudes towards it. Written material is a relatively simple and cost-effective method to implement. The content can cover all important points, and it is also available to patients and significant others for future reference. A large part of this material has been devoted to preparing patients for cancer treatment, and booklets have been used extensively. Most commonly, such booklets contain a combination of sensory, procedural and practical information, and are given as an adjunct to information presented orally [17, 27-31].

It has been shown that in order to be effective, preparatory information should be responsive to patients' needs, be clear and easy to comprehend and be distributed before cancer treatment commences [18, 30, 31]. However, most of our knowledge and practice in this area is not well developed. Even though the cause of the problem is not clearly stated whether it is from professionals or patients' side, its effect remains one of the most determinants of patients' health outcome. While this problem is critical to be researched, no attempt is undertaken to solve it. Hence, the purpose of the study is to explore and adapt some important points from cancer patients' opinion towards cancer chemotherapy related information needs.

1.3 Significance of the Study

The benefits of good patient education for cancer patients may include greater satisfaction with treatment choices, improved ability to cope during the diagnosis, treatment, and post-treatment phases, and reductions in anxiety and mood disturbances [2, 3]. Thus, this study will try to complement a considerable part to the delivery of holistic health care by investigating a new strategy on how to enhance older cancer patients' information recall capacity, which in turn enriches knowledge to the field of study. It also contributes more for practitioners to modify health education sessions appropriate to their clients in terms of age. In addition to these, the study will put some baseline information for those interested to investigate more on related issues. On the other hand, the findings of the study may influence planners and policy makers to give great attention for delivery of comprehensive health care to chronic illnesses in general and cancer in particular.

1.4 Conceptual Framework

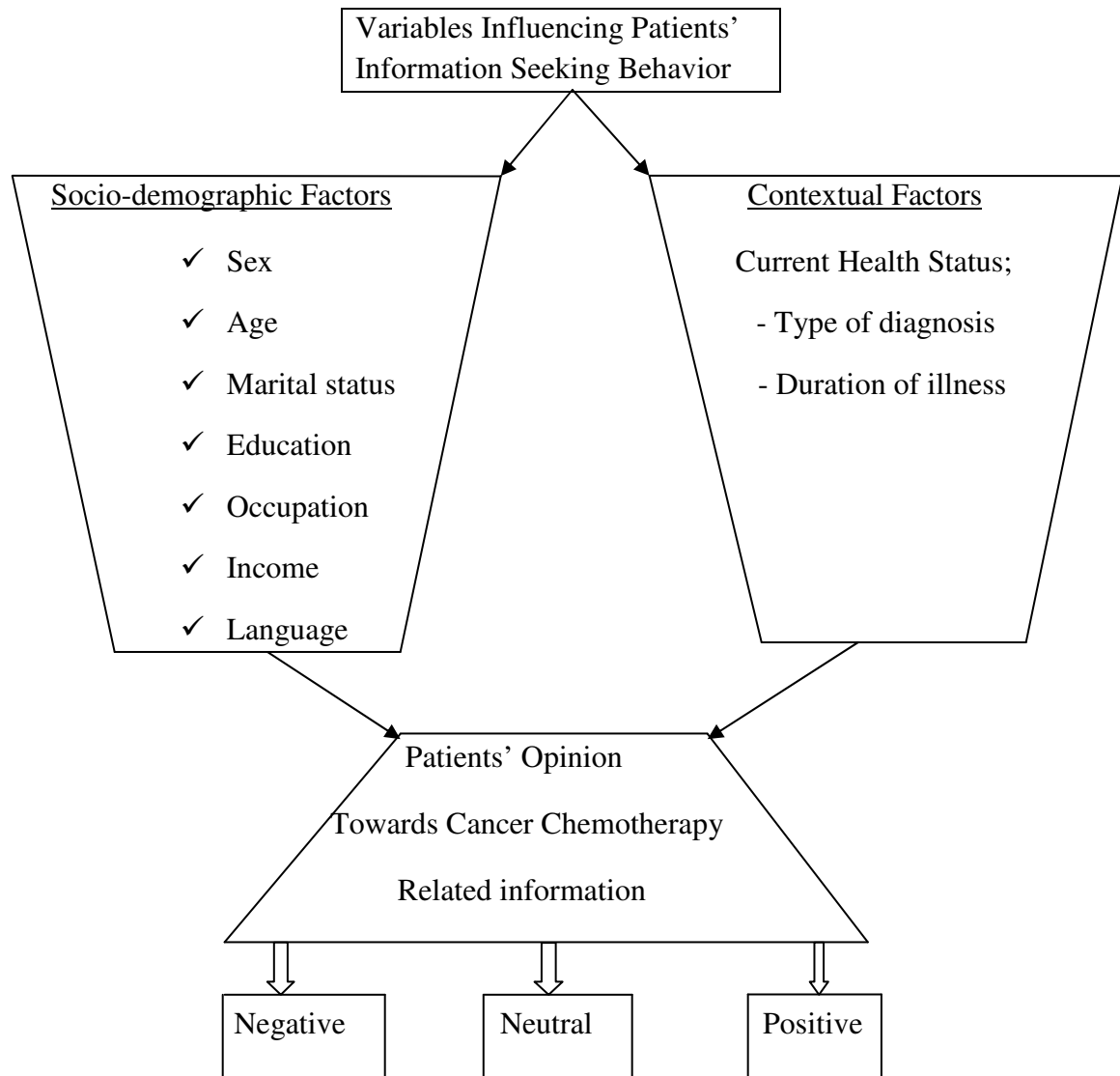


Figure 1:- Self-developed conceptual framework showing relationship of dependent and independent variables.

As shown from the above figure, different factors may influence cancer patients' information seeking behavior. To these regard patients' demographical, social, and economical factors in one hand and other contextual factors, patients' current health status, like type of diagnosis and duration of illness to the other hand, directly or indirectly affects their level of opinion towards cancer chemotherapy related information needs to be negative, neutral and positive.

CHAPTER II

LITERATURE REVIEW

2.1 General Trends of Cancer

Worldwide prevalence of cancer is approximately 6.1%. From this, the highest prevalence occurs in North America with 1.5% of the population affected and diagnosed in the previous 5 years. This corresponds to over 3.2 million individuals. Western Europe, and Australia and New Zealand show very similar percentages with 1.2% and 1.1% of the population affected (about 3.9 and 0.2 million cases respectively). Japan and Eastern Europe form the next batch with 1.0% and 0.7%, followed by Latin America and the Caribbean (overall prevalence of 0.4%), and all remaining regions are around 0.2%. Cancer prevalence in developed countries is very similar in men and women, 1.1% of the sex-specific population, while in developing countries the prevalence is some 25% greater in women than men, reflecting a preponderance of cancer sites with poor survival such as liver, esophagus and stomach in males [32].

Overall, there were 10.9 million new cases, 6.7 million deaths, and 24.6 million persons alive with cancer (within 5 years of diagnosis). The most commonly diagnosed cancers are lung (1.35 million), breast (1.15 million), and colorectal (1 million); the most common causes of cancer death are lung cancer (1.18 million deaths), stomach cancer (700,000 deaths), and liver cancer (598,000 deaths). In terms of prevalence, breast (17.9%), colorectal (11.5%), and prostate (9.6%) cancers are the most common. The ratio between prevalence and incidence is an indicator of prognosis; thus, breast cancer is the most prevalent cancer in the world, despite there being fewer new cases than for lung cancer, for which the outlook is considerably poorer [33].

For the world as a whole, the sex ratio for cancer deaths is 1:3 (M: F), greater than the sex ratio of incidence (1:15) because, overall, the cancers with high fatality (lung, stomach, liver,

esophagus) are more common among men than women. For men, the incidence of cancer is highest in North America 18.2%, a consequence of the high contemporary rates of prostate cancer. The risk of dying from cancer, in contrast, is highest in Eastern Europe, with a cumulative risk of dying from cancer 10.4%. As in males, the region with the highest incidence of cancer in women is North America with cumulative incidence, 16.7% while mortality is highest in East Africa with cumulative Mortality, 8.2% followed by Northern Europe, North America, Southern Africa, and Western Europe. In men, cumulative mortality is just 18% higher in developed than developing countries, while in women, cumulative mortality in developing countries is actually higher than in the developed world. There are several reasons for this. As described below, the majority of cancers in developed countries are those associated with affluence—the so-called Western lifestyle—such as cancers of the colon and rectum, breast, and prostate, with a rather good prognosis. In developing countries, cancers of the liver, stomach, and esophagus are relatively more common; these all have a poor prognosis [33].

2.2 Information Needs of Cancer Patients

Numerous studies have been evaluated cancer patients' information needs and suggested that the vast majority of cancer patients want as much information as possible whether it is good or bad [34, 35]. However, a recent systematic literature review revealed that hardly any studies investigated the specific needs of older cancer patients surrounding treatment [36]. The authors therefore included studies in the review in which some of the patients were older (i.e. 65 years or older) and the presence or absence of age differences were reported. They identified 17 studies that met their inclusion criteria, the results of which suggest that the majority of older cancer patients want to receive relevant information about their treatment. Yet, the results also indicate that although older patients prefer to receive information about the most important aspects of the

disease and treatment, they are relatively less interested in extensive and detailed information [36].

Two randomized controlled trial studies have been conducted in southern and eastern European countries, one in Spain and the other in Italy and they both produced positive results. In Spanish, hospitalized breast cancer patients were given information booklets on surgical procedures 2–3 days before surgery and an additional booklet specific to adjuvant chemotherapy 1 month after surgery. Experimental group patients reported better adjustment in their working, domestic and sexual lives as time progressed compared with women who did not receive written information. The study from Italy assessed the impact of oral, written and video information about chemotherapy on cancer patients who were about to start treatment. At follow-up, before the following cycle of chemotherapy, the results demonstrated that significantly more patients in the oral, written and video information group felt their QoL had improved as compared with those in the less intensive information groups. In addition, patients were positively disposed toward the provision of booklets and videotapes and reported high levels of utilization [36].

A recent observational study showed that Greek cancer patients reported a high need for factual information and expressed a strong preference for chemotherapy-related written material relevant to their condition and management [14].

The current single-center randomized trial study done in London about Communicating with Patients; Improving Communication, Satisfaction and Compliance corroborate previous evidences that the provision of well-structured and adequate written information about cancer treatment is greatly appreciated by patients and exerts beneficial effects on a number of outcomes. Patients provided with the information booklet reported significantly higher rates of satisfaction with the information and overall with medical care than those allocated to the control

group, felt significantly more and better informed, and perceived the information received as being clearer and detailed. In contrast, the intervention produced no significant benefits in terms of anxiety, depression or quality of life. The booklet was read by almost all patients and to a great extent by significant others. The vast majority of patients were highly satisfied overall with the booklet, reported that they would recommend it to other patients, and considered it as being useful in general and helpful in refreshing their memories of chemotherapy-related information [16].

In Greece and other Mediterranean countries, the attitude of withholding detailed information from the patient is still dominant, although in recent years there has been a tendency towards increased openness, following the trends set in Anglo-Saxon and northern European societies [36- 38]. The fear of causing damage to the patient has been the main argument in favor of withholding information [38]. Contrary to this opinion, our study, together with the two earlier studies from Italy and Spain [39, 40], indicates no harmful effects of providing information to the patient. However, considering the diverse communication preferences among cultures, comparable studies in other non-Anglo-Saxon countries are needed to clarify further which findings are of universal significance [38, 41].

A qualitative research conducted in Netherlands reveals that the provision solely of information without elements of counseling or psychotherapy may not have been sufficiently powerful to improve psychological well-being. Both cognition and affect are known to be important in medical communications [42].

A study conducted in University of Amsterdam, Amsterdam, Netherlands revealed that older patients may experience fewer cancer-related losses than younger patients due to the age-associated reduction in the time left to live. For example, older patients may feel less disturbed in

their future plans than younger patients do. Furthermore, for older patients, their illness may have less impact on their appreciation of life than for younger patients. Besides, older patients seem to need less support in coping with the disease and treatment than younger patients do. Therefore, younger people may need more information from the health care professional in order to cope with their disease and treatment; in contrast, older patients may be overwhelmed by the information. As this study showed, information should be offered in a structured manner in which the most important, personally relevant information should be summarized and repeated. Furthermore, information should be offered step-by-step, to enable patients to let the information sink in, to consider the personal relevance and make him- or herself familiar with it. Another key factor that affects comprehension of the information is the language level used to convey the message. Nurses should avoid using technical and jargon words. Also in this study, patients him/herself brought a relative to the consultation, because patients and relatives both will remember different aspects of the information. For instance, let's state one study participant's quote from University of Amsterdam study findings. "I thought it was pleasant that I brought my children with me. In this way they knew what was going on". Moreover, showing empathy and support to the patient is an important aspect of patient education to which the patients (and relatives) feel understood and creates a trustful environment, both during and after the consultation, which is a prerequisite for reflection on the information provided and the decision to undergo treatment. As of reports of this study, information about patients' disease and treatment, like diagnosis, prognosis, side effects of the treatment, complications, and practical information were patients' preference [43].

Strengthening the affective component of the intervention should have positive effects on mood, particularly for patients who are found on screening to experience severe levels of emotional

distress. In fact, a recent meta-analysis of controlled clinical trials suggested that psychosocial interventions, including psycho-education, should be planned for at least 12 weeks if reliable benefits to quality of life are to emerge.

Thus, the effectiveness of multi-component and more intensive, yet non-obstructive programs to the practice of oncology clinics needs to be addressed further [44].

CHAPTER III

OBJECTIVES

3.1 General Objective

To explore adult cancer patients' opinion towards cancer chemotherapy related information needs in TASRH, Addis Ababa.

3.2 Specific Objectives

- To determine association of adult cancer patients' socio-demographic variables with their opinion levels.
- To identify adult cancer patients' opinion towards various aspects of information needs about cancer chemotherapy treatment.
- To assess adult cancer patients' opinion towards different information giving approaches for younger and older patients during nursing consultations preceding cancer chemotherapy treatment.
- To determine adult cancer patients' opinion towards detailed information needs related to their chemotherapy and disease condition.

CHAPTER IV

METHODS AND MATERIALS

4.1 Study Area

The study was conducted in AA, the capital city of Ethiopia; Tikur Anbessa Specialized Referral Hospital (TASRH). AA is one of the densely populated cities with 3,627,934 as of 2007 and an estimated area of 530.14 Square Kilometer [45]. TASRH is the only governmental Hospital providing oncology treatment in the country and also provides multidimensional aspect of care to the clients. Roughly 20,000 cancer patients have got health care services from this Hospital and from that majority of them were received primarily and adjuvant chemotherapy. The setting for TASRH oncology unit is outfitted with one radiotherapy unit and eighteen beds ready to serve all patients throughout the country. Even though there are few private Hospitals like Ethio-Vision and St.Gebreal which provides oncology treatment, large segment of the population attending TASRH, due to low medical costs and that was a reason this governmental Hospital was selected.

4.2 Study Period

The study was conducted from February 2011 to March 2011.

4.3 Study Design

Institution based cross-sectional qualitative and quantitative descriptive study designs were employed to this research.

4.4 Source Population

All adult cancer patients who attended TASRH for cancer chemotherapy treatment were source populations.

4.5 Sample Population

All adult cancer patients who took cancer chemotherapy treatment in TASRH during the study period were the sample populations.

4.6 Eligibility Criteria

4.6.1 Inclusion Criteria

All volunteer adult cancer patients who received cancer chemotherapy treatment in TASRH oncology department during the study period were included to the study.

4.6.2 Exclusive Criteria

All adult cancer patients who were not on cancer chemotherapy treatment, bedridden and critically ill patients were excluded from the study as it was not believed to get appropriate response to the questions.

4.7 Sample Size Determination

A. Qualitative: Purposely selected 10 participants were involved.

B. Quantitative: Sample size for quantitative method was calculated by using single-population proportion formula.

$$\begin{aligned}n_o &= \frac{z_{1-\alpha/2}^2 p (1-p)}{d^2} \\ &= \frac{(1.96)^2 \times 0.5(1-0.5)}{0.05^2} \\ &= 385\end{aligned}$$

$$\begin{aligned}\text{Where: } p &= 50\%, \\ Z &= 95\% \text{ CI} \\ d &= 5\% \text{ (margin of error),} \\ n_o &= \text{Initial sample size}\end{aligned}$$

4.8 Sampling Technique

The sampling technique used in this study was convenience sampling. For qualitative method, study participants were selected purposely from the sample population. Number of study units involved in an in-depth interview was determined by the evidence of redundancy of responses.

4.9 Data Collection

4.9.1 Methods

Data for qualitative method was collected by using an in-depth interview guided by semi structured questions or checklists. On the other hand, all study participants were interviewed by data collectors from the prepared structured questionnaires to collect quantitative information.

4.9.2 Data Collectors

Data was collected by four trained diploma nurses and one supervisor with the same qualification.

4.9.3 Instruments

A structured and semi structured questionnaires were designed based on study objectives, and review of literatures, which contain five parts; Part I: Questions related to socio-demographic information (9 questions), Part II: Questions related to study participants' current health status and treatment taken (4 questions), Part III: Questions related to study participants' opinion towards cancer chemotherapy related information needs (8 questions), Part IV: Questions related to study participants' opinion towards ways of information delivering approaches (4 questions), Part V: Questions related to study participants' opinion towards detailed information needs (5 questions); from part I to part V a total of 30 questions which all were used for quantitative method and the last part, Part VI: An in-depth Interview questions or checklists; a total of 5

questions which have been used together with socio-demographic questions as a vital tool to collect qualitative data.

The questionnaire was initially prepared in English language and then translated into Amharic by an expert to make it easily understood by most of study subjects.

Most of the questions were self developed, while some was adopted from previous studies. Questions adopted from other studies were slightly modified to Ethiopian context in order to fit with the purpose of the current study.

For qualitative aspect of the study, semi structured questions were prepared to guide an in-depth interview.

4.9.4 Pre-test

10 days before actual data collection period, clarity and completeness of the questionnaire was checked by principal investigator on 19 similar study populations in St. Gebreal General Private Hospital. The focus was to screen out potential confusions and to make early modification. The pre-test had also planned to estimate the duration of actual data collection period.

4.9.5 Validity and Reliability of Instrument

Questionnaires were examined by senior experts to the area of study for content validity. Moreover, self-prepared questions were compared with WHO standard questionnaires.

4.10 Study Variables

4.10.1 Independent Variables

- Socio-demographic variables (sex, age, marital status, religion, education, occupation, income ethnic group, language)
- Current health status (type of diagnosis and duration of illness)

4.10.2 Dependant Variables

- Adult cancer patients' opinion towards their chemotherapy related information.

4.11 Operational Definition

Adjuvant therapy: Chemotherapy used along with surgery or radiation. **Adult cancer patients:** Patients who are above 18 years and diagnosed as having a malignant cell growth. **Cancer chemotherapy:** A treatment of cancer with anticancer drugs. **Information needs:** The recognition that once knowledge of anticancer drug is inadequate to satisfy a goal that he/she has. **Older adults:** Patients whose age is above 65 years. **Opinion:** A personal belief or judgment towards chemotherapy related information needs that are not founded on proof or certainty. It is a conceptual definition. However, in this research it can be measured as **positive**, **neutral** and **negative** opinion levels when the participants able to answer 68-85, 60-67 and ≤ 59 scores from opinion questions which have a total of 85 scores respectively. **Younger adults:** patients whose age is between 18 years to 64 years.

4.12 Data Quality Control

Before data collection, discussion was made on the questionnaire and interview techniques among data collectors in order to have common understanding of the research objectives. Pre-test was done on 5 % of similar populations in St. Gebreal General Private Hospital 10 weeks prior to actual data collection period. Potential problems were identified and discussed and amendments were made before the actual work. All data collectors and supervisor have had half day training on the methods and procedures of data collection. During data collection time continuous supervision and cross checking were carried out by supervisor and principal investigator for making sure of completeness and consistency of each questionnaire.

4.12 Data Processing and Analysis

The collected data was cleaned, coded, and entered to epi-info software and then exported in to SPSS V 16.0 for analysis purpose. Calculations of proportions were recorded on frequency tables and cross tabulation was done for selected variables. Also Pearson's chi square test was calculated in order to show association between selected variables and different tables, charts and narrations were used to present the result.

Data from an in-depth interview was transcribed by arranging the record according to forwarded questions and finally, after common themes were identified and annual analysis were made.

4.13 Ethical Considerations

Initially the proposal was ethically cleared from the department ethical review committee (DRC). Prior to data collection period, permission letter was taken from department of Nursing and Midwifery to TASRH medical director office. Permission letter were received from the Hospital director and study participants were informed about the objective of the study during data collection and asked to cooperate for an interview through oral consent. The participants of this study were also insured for preservation of confidentiality and anonymity. Moreover, they have been given opportunity to consent or decline to take part in the study.

4.14 Dissemination of the Result

The result of the study has been presented to AAU College of Health Science Department of Nursing and Midwifery. It can also be disseminated by local journals such as Ethiopian Nurses Association journal or kept in Centralized School of Nursing library for reference. Moreover, attempts will be taken to have opportunity for publication to different national and international journals. Different governmental and other relevant supporter organizations working on cancer can have the access to get the results for their health care activities.

CHAPTER V

RESULTS

The total numbers of study participants enrolled for this study were 395 which made the response rate 100%.

Part I: Quantitative Results

5.1 Socio-demographic Characteristics

From the total number of study participants involved for quantitative method of the study regarding to sex; 282 (73.3%) were females and the rest 103 (26.7%) were males. About age distribution; 162 (42.1%) were between 30 and 44, 156 (40.5%) between were 45 and 64, 35 (9.1%) were less than 24, 32 (8.3%) were above 65 years. Related to marital status; 237 (61.6%) were married, 73 (19%) were single and the rest were divorced and widowed. As of religion; 64.4% (248) were Orthodox Christian followers, 83 (21.6%) were Muslims and 51 (13.2%) were protestant followers. Regarding educational level majority of them 101 (26.2%) were only 8th grade complete, 91 (23.6%) were illiterate and 82 (21.3%) were above 12th grade. About occupational status; 135 (35.1%) were house wives followed by 77 (20%) farmers and 69 (17.9%), 55 (14.3%) and 49 (12.7%) government employee, private, employee and merchant (business) respectively. Related to economic status; half of the participants 195 (50.6%) have earned less than 420 birr per month. Whereas, 107 (27.8%) have earned 420-1000 birr/month and only 23 (6%) have earned higher monthly income; above1000 Ethiopian birr. regarding to ethnicity; half of the study participants 195 (50.6%) were belonging to Amhara ethnic group followed by Oromo 107 (27.8%). Regarding to language of study participants; Amharic, Oromifa and Guraghegna leads by 212 (55.1%), 98 (25.5%), 30 (7.8%) respectively as shown bellow by table 1.

Table 1:- Distribution of frequencies and percentages of adult cancer patients by socio-demographic data in TASRH, AA, 2011.

Socio-demographic data		Frequencies	Percentage
Sex	Male	103	26.7
	Female	282	73.3
	Total	385	100
Age	Below 30	35	9.1
	30 – 44	162	42.1
	45 – 64	156	40.5
	Above 65	32	8.3
	Total	385	100
Marital status	Single	73	19.0
	Married	237	61.6
	Widowed	36	9.4
	Divorced	39	10.1
	Total	385	100
Religion	Orthodox	248	64.4
	Muslim	83	21.6
	Protestant	51	13.2
	Others	3	.8
	Sub-total	385	100
Education	Illiterate	91	23.6
	1 – 8	101	26.1
	9 – 10	49	12.7
	11 -12	38	9.9
	Above 12	82	21.3
	Others*	24	6.2
Total	385	100	
Occupation	Government employee	69	17.9
	Private employee	65	14.3
	Business	49	12.7
	Farmer	77	20.0
	Others	135	35.1
	Total	385	100
Income	< 420	195	50.6
	420-1000	8	20.8
	>1000	110	28.6
	Total	385	100
Ethnicity	Amhara	195	50.6
	Oromo	107	27.8
	Tigre	23	6.0
	Somale	8	2.1
	Afar	2	.5
	Others	50	13.0
Total	385	100	
Language	Amharic	212	55.1
	Tigre	22	5.7
	Oromifa	98	25.5
	Somaligna	7	1.8
	Guraghegna	30	7.8
	Others	16	4.2
	Total	385	100

*Those study participants who can read and write without accessing formal education.

5.2 Association of some Independent Variables with the Dependent Variable.

A. Socio-demographic Variables

The socio-demographic characteristic that has shown statistically significant association to participants, opinion level towards chemotherapy related information needs was income with a p-value of .014. However, statistically significant associations were not found between study participants' opinion level and the rest of socio-demographic variables.

Table 2:- Association of study participants socio-demographic characteristics to their opinion level in TASRH, AA, 2011.

Socio-demographic data	Opinion Level			total [n (%)]	X ²	df	p-value
	[n (%)]						
	Negative	Neutral	Positive				
Income							
<420	70	69	56	195			
420-1000	17	41	22	80	12.523	4	.014 → S*
>1000	48	34	28	110			

❖ X² (4) =12.523, P<0.05=> S* = Significance

❖ Study participants' monthly income has direct or indirect association with their opinion level.

B. Type of Diagnosis and Duration of Illness

Unlike adult cancer patients' duration of illness, their specific diagnosis has been found to have statistically significant association to their opinion towards chemotherapy related information needs with a p-value of .000.

Table 3:- Association of study participants' diagnosis and duration of illness to their opinion level in TASRH, AA 2011.

Socio-demographic data	Opinion Level			total [n (%)]	X ²	df	p-value
	[n (%)]						
	Negative	Neutral	Positive				
1. Type of Dx							
Breast ca	44	38	54	136			
Cervical ca	12	12	11	35			
Lung ca	4	1	4	9			
Intestinal ca	36	37	16	89	37.159	12	.000 → S*
Colorectal ca	8	3	5	16			
Prostate ca	7	10	8	25			
Others	24	43	8	75			
2. Duration of illness							
< 6 months	18	27	16	61			
6- month - 1 year	51	55	38	144			
1- 3 years	38	44	35	117	6.578	10	.765 → NS*
3 – 5 years	13	9	10	32			
> 5 years	14	9	6	29			

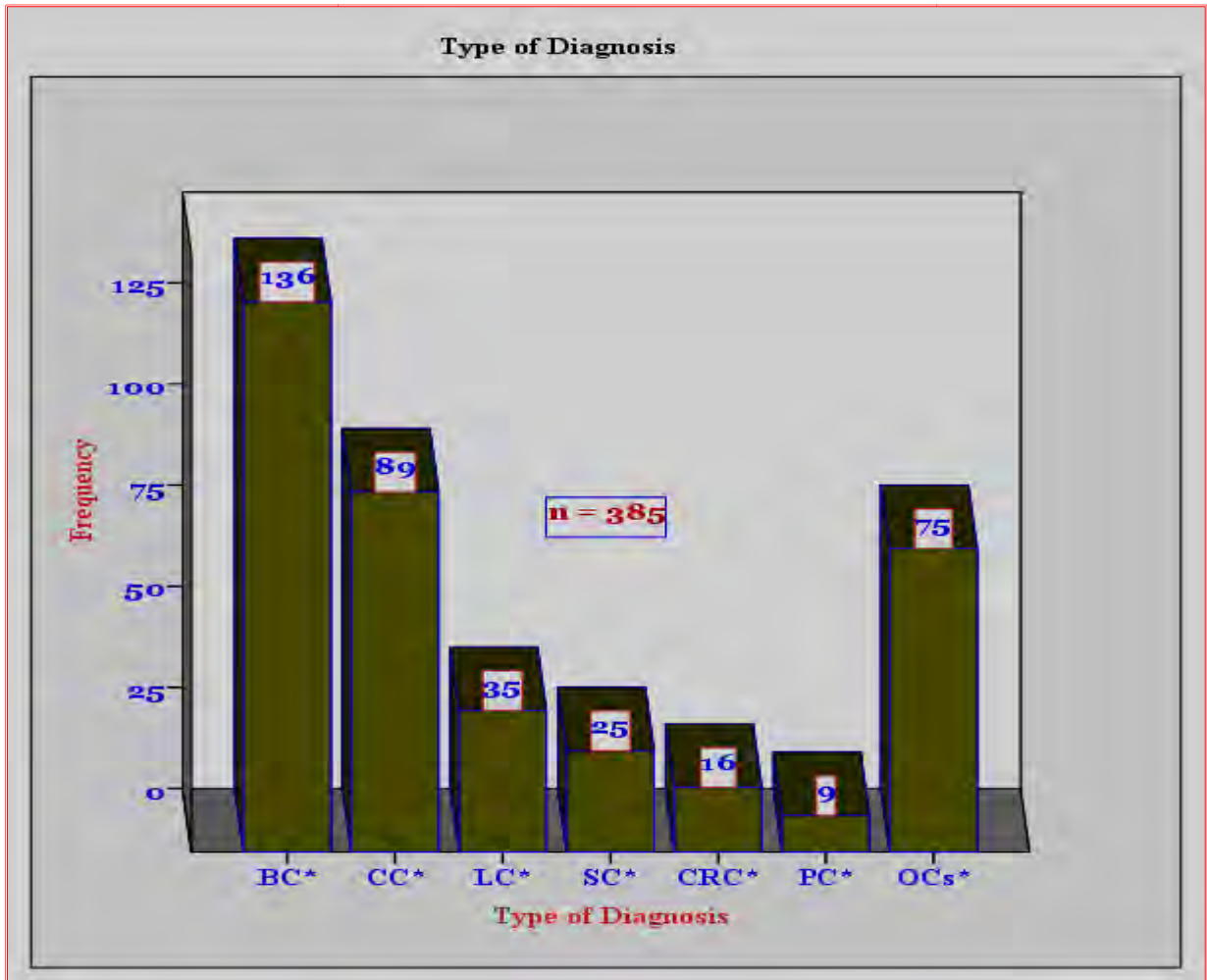
1. X² (12) = 37.159, P < 0.05 => S* = Significant

2. X² (10) = 6.578, P > 0.05 => NS* = Not significant

❖ While study participants' type of diagnosis had direct or indirect association with their opinion level, duration of illness had not found to have any direct or indirect association.

5.3 Study participants' Current Health Status

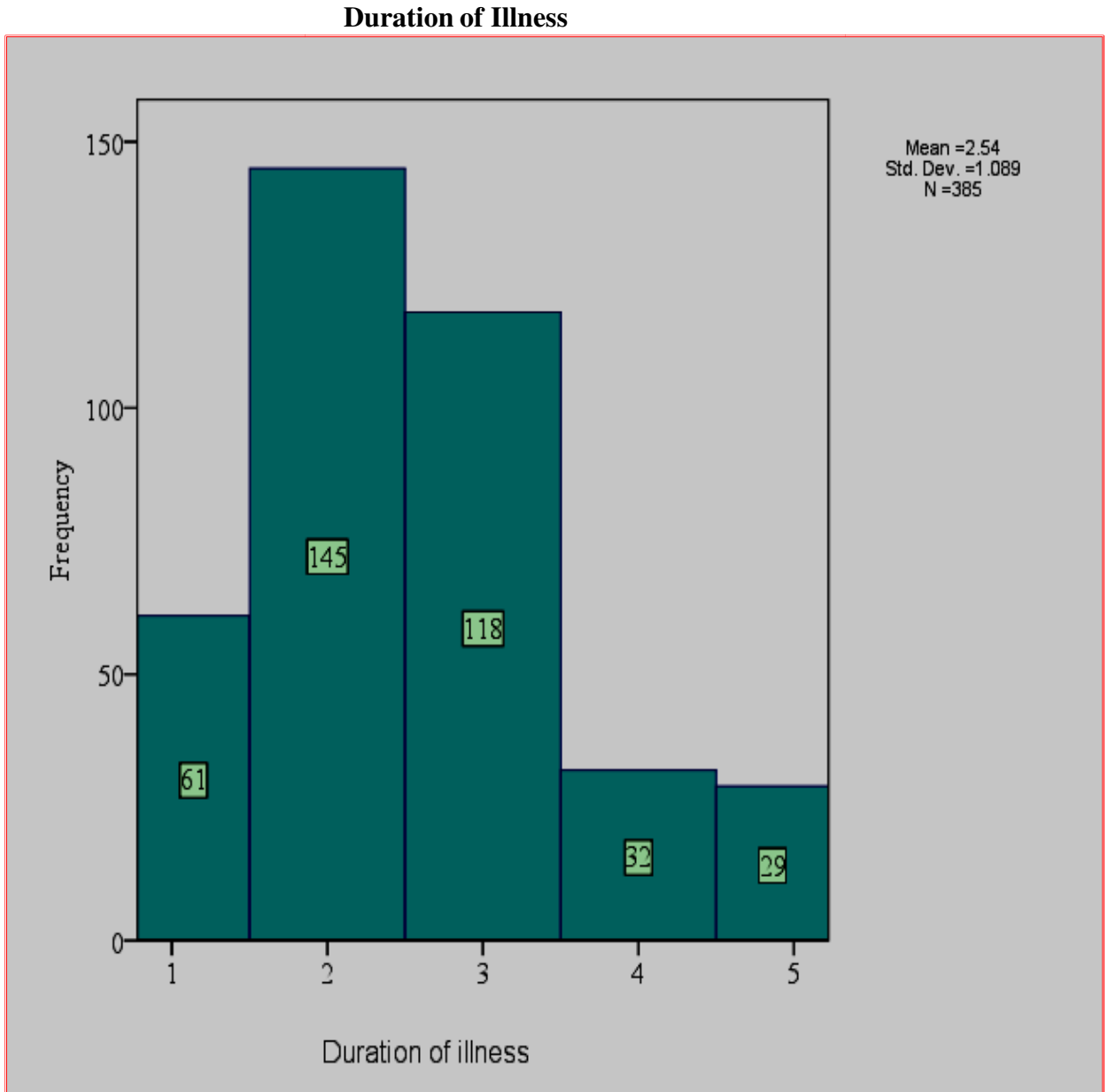
Concerning to current health status; 136 (35.3%) were diagnosed for breast cancer, 89 (23.1%) cervical cancer, 35 (9.1%) lung cancer, 25 (6.5%) stomach cancer, 16 (4.2%) colorectal cancer, 9 (2.3%) prostate cancer and the remaining 75 (19.5%) from other cancer types like malignant lymphoma, squamous cell carcinoma of oral mucosa, hepatoma and renal cell carcinoma.



BC* - Breast ca., CC* - Cervical ca., LC*- Lung ca., SC*- Stomach ca., CRC* - Colorectal ca., OCs* - Other cancers

Figure 2: Bar graph showing frequency of specific diagnosis of adult cancer patients in TASRH, AA, 2011.

As shown in figure 4 below, most of patients' duration of illness 37.7% (145) ranges from 6 month to 1 year and only 7.5% (29) were survive after 5 years of diagnosis.



1 = <6 month, 2 = 6 month – 1 year, 3 = 1-3 years, 4 = 3-5 years, 5 = >5years

Figure 3: A histogram showing frequency of adult cancer patients' duration of illness in TASRH, AA, 2011.

5.4 Type of Chemotherapeutic Agents and other Treatments taken by Study Participants

Surprisingly, half of the participants did not know the name of chemotherapy they have taken or currently taking. 106 (27.5%) were taking only chemotherapy while the rest 279 (72.5%) were under combination therapies.

5.5 Study Participants' opinion about chemotherapy related Information needs

From different questions presented to measure study participants' opinion towards various types of chemotherapy related information; question number 8 "Health professionals should discussed with patients about the probability of sterility and other reproductive system impairments, as appropriate" was very strongly believed with the mean score of 4.14. The mean score for question number 7 "Information about relaxation and imagery techniques before, during and after treatment as appropriate is very important to reduce drug induced body reactions and to have better disease outcome" was 3.02 and the mean score of question number 6 "Knowing about chemotherapy induced body reactions are not that much necessary to patients" was 2.6, which means majority of the participants response tends toward disagree for this particular statement. Details are show bellow by table 4.

Table 4:- Distribution of frequencies, percentages and mean scores of adult cancer patient's opinion towards chemotherapy related information in TASRH, AA, 2011.

Statements	SD	DA	UD	AG	SA	Mean
1. Health professionals assist patients to reduce or quit smoking, high calorie diets and to have active but not a sedentary life style as they attribute more for cancer risk.	42 (10.9%)	72 (18.7%)	37 (9.6%)	111 (28.8%)	123 (31.9%)	3.52
2. Health professionals provide general information about mechanisms of action or benefits of chemotherapy	69 (17.9%)	117 (30.4%)	46 (11.9%)	95 (24.7%)	58 (15.1%)	3.78
3. Knowing the benefits of chemotherapy is not that much important to patients?	119 (30.9%)	101 (26.2%)	31 (8.1%)	63 (16.4%)	71 (18.4%)	2.65
4. An invasive chemotherapeutic agent brings serious reactions to the body.	30 (7.8%)	123 (31.9%)	31 (8.1%)	89 (23.1%)	112 (29.1%)	3.69
5. Health professionals inform such drug induced body reactions before patients commence treatment.	58 (15.1%)	88 (22.9%)	32 (8.3%)	100 (26.0%)	107 (27.8%)	3.29
6. Knowing about such chemotherapy induced body reactions are not that much necessary.	127 (33.0%)	98 (25.5%)	31 (8.1%)	59 (15.3%)	70 (18.2%)	2.6
7. Information about relaxation and imagery techniques before, during and after treatment as appropriate is very important to reduce drug induced body reactions and to have better outcome of disease.	66 (17.1%)	90 (23.4%)	64 (16.6%)	101 (26.2%)	64 (16.6%)	3.02
8. Health professionals should discussed with patients about the probability of sterility and other reproductive system impairments, as appropriate.	22 (5.7%)	28 (7.03%)	24 (6.2%)	111 (28.8%)	200 (51.9%)	4.14

5.6 Study Participants' Opinion towards ways of Information Giving Approaches

The study participants were asked if “health professionals use different information giving approaches like charts, models, movies or oral information and written materials to provide the necessary information about chemotherapy” and “health professionals provide general cancer literatures or leaflets before the patient begins chemotherapy” and their response were disposed to disagree and uncertain with the mean score of 2.53 and 2.33 respectively. Whereas, for questions presented to ask if “oral information has always be supported with written materials to enhance understanding and remembering” and “Mass medias like radio, television and news papers, and internet are the major sources of chemotherapy related information” were believed very strongly agree by study participants with the mean score of 4.34 and 4.01 respectively as shown by table 5.

Table 5:- Distribution of frequencies, percentages and mean scores of adult cancer patient's opinion towards ways of information giving approaches in TASRH, AA, 2011.

Statements	SD	DA	UD	AG	SA	Mea
1. Health professionals use different approaches like charts, models, movies or oral information and written materials to provide the necessary information about chemotherapy.	113 (29.4%)	121 (31.4%)	36 (9.4%)	65 (16.9%)	50 (13.0%)	2.53
2. Oral information has always been supported with written materials to enhance understanding and remembering.	14 (3.6%)	22 (5.7%)	18 (4.7%)	98 (25.5%)	233 (60.5%)	4.34
3. Health professionals provide general cancer literatures or leaflets before the patient begins chemotherapy.	148 (38.4%)	103 (26.8%)	42 (10.9%)	43 (11.2%)	49 (12.7%)	2.33
4. Mass Medias like radio, television and news papers, and internet are the major sources of chemotherapy related information.	27 (7.0%)	31 (8.1%)	35 (9.1%)	112 (29.1%)	180 (46.8%)	4.01

5.7 Study Participants' Opinion towards Detailed Information Regarding Chemotherapy

The statement that “provision of detailed information related to cancer chemotherapy or increased openness towards their illness: 1 enhances satisfaction with communication and 2 are very important, fundamental and necessary” was strongly believed by Majority of the participants’ with the mean score of 4.26 and 4.37 respectively. On the other hand, great majority of the participants were strongly disagreed with the statements that “provision of detailed information and increased openness towards the disease without elements of counseling or psychotherapy is sufficient enough to improve psychological well-being and such an information should better to be withhold with the mean score of 2.4 and 2.02 respectively as its detailed shown from table 6 below.

Table 6:- Distribution of frequencies, percentages and mean scores of adult cancer patients’ opinion towards detailed information needs regarding chemotherapy in TASRH, AA, 2011.

Provision of detailed information related to chemotherapy or increased openness towards the disease: -	SD	DA	UD	AG	SA	Mea.
1. Enhances satisfaction with communication.	14 (3.6%)	14 (3.6%)	18 (4.7%)	150 (39.0%)	189 (49.1%)	4.26
2. Is more preferable, fundamental and necessary.	12 (3.1%)	7 (1.8%)	13 (3.4%)	146 (37.9%)	207 (53.8%)	4.37
3. Is sufficient to improve psychological well-being without elements of counseling or psychotherapy.	148 (38.4%)	87 (22.6%)	52 (13.5%)	44 (11.4%)	54 (14.0%)	2.4
4. Should better to withhold.	206 (53.5%)	75 (19.5%)	32 (8.3%)	35 (9.1%)	37 (9.6 %)	2.02
5. Improve anxiety, depression and quality of life.	30 (7.8%)	26 (6.8%)	33 (8.6%)	116 (30.1%)	180 (46.8%)	4.01

5.8 Study Participants' Level of Opinion

Majority of the participants (adult cancer patients in TASRH) had negative to neutral opinions towards chemotherapy related information. As shown in figure 4, 144 (37.40%) participants had neutral opinions and 135 (35.06%) had negative opinions. Whereas, only 106 (27.53%) of the participants had reported positive opinions.

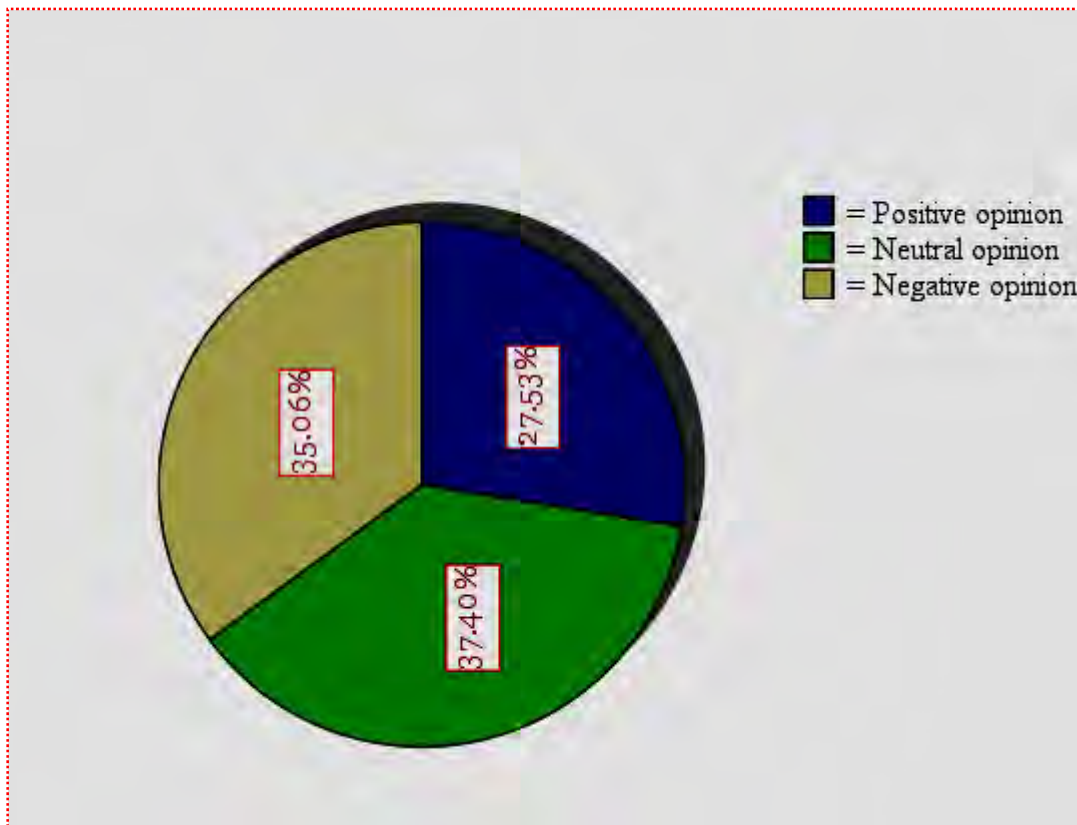


Figure 4: A pi-chart showing adult cancer patients' level of opinion towards cancer chemotherapy related information in TASRH, AA, 2011.

Part II Results for Qualitative Method

Table 7:- Distribution of frequencies and percentages of study participants involved in in-depth interview by socio-demographic data, in TASRH, AA, 2011.

Socio-demographic data		Frequencies	Percentage
Sex	Male	2	20
	Female	8	80
	Total	10	100
Age	30-44	7	70
	45-64	3	30
	Total	10	100
Marital status	Single	1	10
	Married	9	90
	Total	10	100
Religion	Orthodox	4	40
	Muslim	2	20
	Protestant	3	30
	Others	1	10
	Total	10	100
Education	Illiterate	1	10
	1 - 8	3	30
	9 - 10	1	10
	11- 12	2	20
	Others*	3	30
	Total	10	100
Occupation	Government employee	1	10
	Private employee	3	30
	Business	1	10
	Others	5	50
	Total	10	100
Income	< 420	3	30
	420-1000	4	40
	>1000	3	30
	Total	10	100
Ethnicity	Amhara	5	50
	Oromo	4	40
	Guraghea	1	10
	Total	10	100
Language	Amharic	5	50
	Oromifa	4	40
	Guraghegna	1	10
	Total	10	100

*Those study participants who can read and write without accessing formal education.

5.9 Study Participants' Opinion Obtained through In-Depth Interview

Difference Between Older and Younger Patients-Majority of the participants were believed that “there should be difference between older and younger patients regarding to proper understanding and utilization chemotherapy related information”. There suggestions were for youngsters; since they understand things quickly, no need of spending much time; simply telling them only oral information in a polite and relaxed a manner is enough to deliver information. Whereas, for elderly people frequency of things to be told, showing empathy, using different audio-visual aids and speaking in a very clear and simple language is of utmost important. However, there were very few discussants who believed “there should not be difference” by supporting their suggestion as the disease distresses all patients regardless of age differences, they understand fully even though the information was not given to the required level. The other supporting reason was that even if level of understanding is different, as long as the disease is the same; no need of separately viewing based on this biological difference.

Information and Support Needs-Majority of study participants involved in the qualitative part of this study, agreed with insufficient provision of basic chemotherapy related information. Affordability of treatment, characteristics of the drug like; side effects, mechanism of action and drug interactions and dietary and other supportive managements were among their priority needs.

Promote Understanding and Recalling-The common theme from participants' discussion on how to Promote understanding and recalling most important chemotherapy related information was that “giving information thoroughly by using leaflets or written materials, telling patients with warning and by emphasizing the magnitude of the associated problems and frequently inform patients with simple and understandable language”.

Study Participants' Perception toward Patient-Health Professional Communication-Most of the participants were agreed with the presence of poor patient to health professional communication due to balanced health professional to patient ratio; patients' behavioral problem; Professionals work overload or noncompliance to professional ethics; professionals failurity to understand patients' multi dimensional problems, patient dissatisfaction; and professionals' communication skill problem.

Study Participants' General Opinion towards Cost and Side-effect of Chemotherapeutic Agents in Comparison with other Treatment Options-Generally speaking the disease is for those only wealth people have got access to treatment. The cost of treatment did not consider lower economic groups; Government and voluntary organizations should work jointly with in order to make it available by optimum cost. The public as a whole have negative attitude towards chemotherapy due to its traumatic side effects. It is not only the cost, but it is not easily available for those able to afford. Even if the decision is for professionals patients prefer more surgery than chemotherapy. Some patients say "we afraid chemotherapy because it brings stigmatization from the community". Some says "by the way I didn't believe to get cure by chemotherapy. Because even professionals tell us surely as it does, cure is from God; simply I take it as God cure me by the reason of chemotherapy. Some says "chemotherapy should not be given at OPD level; by knowing how much it brings non tolerable problems to the patient, giving it and then discharge to home shows their negligence to others problem.

CHAPTER VI

DISCUSSION

This study aims to explore cancer patients' opinion towards chemotherapy related information needs at Tikur Anbessa Specialized Referral Hospital.

Collectively, findings obtained from majority of study participants to the quantitative method of this study showed that they had neutral and negative opinions towards chemotherapy related information as measured by Likert type attitude questions.

Information Giving Approaches

The study participants were asked if health professionals use different information giving approaches like charts, models, movies or oral information and written materials to provide the necessary information about chemotherapy. 113 (29.4%), 121 (31.4%), 36 (9.4%), 65 (16.9%), and 50 (13.0%) have replied strongly disagree, disagree, undecided, agree and strongly agree respectively with the mean score that tends to disagree (2.53). This did not mean that the study participants were not comfortable to the approaches, instead their desire was denied. In lined with this result, the findings of randomized controlled trials conducted in Spain and Italy produced similar idea that magnifies usefulness of the method. In Spanish, hospitalized breast cancer patients were given information booklets on surgical procedures 2–3 days before surgery and an additional booklet specific to adjuvant chemotherapy 1 month after surgery. Experimental group patients reported better adjustment in their working, domestic and sexual lives as time progressed compared with women who did not receive written information. The study from Italy assessed the impact of oral, written and video information about chemotherapy on cancer patients who were about to start treatment. At follow-up, before the following cycle of chemotherapy, the results demonstrated that significantly more patients in the oral, written and

video information group felt their QoL had improved as compared with those in the less intensive information groups. In addition, patients were positively disposed toward the provision of booklets and videotapes and reported high levels of utilization [36]. Again, for question presented to ask as 'oral information has always been supported with written materials to enhance understanding and remembering'. 14 (3.6 %) strongly agree; 22 (5.7%) disagree; 18 (4.7%) undecided; 98 (25.5%) agree and 233 (60.5%) strongly agree with the mean score which tends to strongly agree (4.34). similar to this, recent reviews of controlled clinical trials conducted on various methods of information-giving approaches to cancer patients have shown that the majority of patients receiving written information express favorable attitudes towards it and large part of this material has been devoted to prepare patients for cancer treatment [17, 27-31]. Furthermore, another observational study showed that Greek cancer patients reported a high need for factual information and expressed a strong preference for chemotherapy-related written material relevant to their condition and management [14].

The other question presented to ask was as health professionals provide general cancer literatures or leaflets before the patient begins chemotherapy. 148 (38.4%), 103 (26.8%), 42 (10.9%), 43 (11.2%), and 49 (12.7%) strongly disagree, disagree, undecided, agree and strongly agree respectively with the mean score that tends to disagree (2.33). This result showed that cancer patients in TASRH did not have the chance to understand chemotherapy and related information properly.

Detailed Information Needs:

Based on this information, the respondents were asked to give suggestions about the provision of detailed information regarding their chemotherapy or increased openness towards their disease, whether it: 1) enhances satisfaction to communication. 3) Is sufficient to improve psychological

well-being without elements of counseling or psychotherapy. 4) Should better to withhold and 5) Improves anxiety, depression and quality of life? For question number 1, the respondents replied as 14 (3.6%), 14 (3.6%), 18 (4.7%), 150 (39.0%), and 189 (49.1%) strongly disagree, disagree, undecided, agree, and strongly agree respectively with a mean score of 4.26 which tends to strongly agree. For the third question; percentage and frequency of the respondent suggestion on a Likert scale measurement were 148 (38.4%), 87 (22.6%), 52 (13.5%), 44 (11.4%), and 54 (14.0%) strongly disagree, disagree, undecided, agree, and strongly agree respectively with mean score of 2.4. Regarding to the 4th question; 206 (53.5%), 75 (19.5%), 32 (8.3%), 35 (9.1%), and 37 (9.6%) strongly disagree, disagree, undecided, agree, and strongly agree respectively with mean score tends to disagree (2.02). The last question presented to measure the respondents opinion towards the need of detailed information were suggested as follows; 7.8% (n = 30) strongly disagreed, 26 (6.8%) disagreed, 33 (8.6%) undecided, 116 (30.1%) agreed, and 180 (46.8%) respondents were strongly agreed with the statement with mean score that tends to agree (4.01). In contrast to single-center randomized trial conducted in southern and eastern European countries, this study revealed favorable attitude towards detailed information as it improves anxiety, depression and quality of life. Above all, comparing this finding with findings of strictly different populations and randomized controlled trials (experimental designs), because of lack of local findings with similar design was not statistically recommended, but it was found to agree with those findings. In contrast, the intervention produced no significant benefits in terms of anxiety, depression or quality of life. A qualitative research conducted in Netherlands reveals that the provision solely of information without elements of counseling or psychotherapy may not have been sufficiently powerful to improve psychological well-being. Both cognition and affect are known to be important in medical communications [42].

Strengthening the affective component of the intervention should have positive effects on mood, particularly for patients who are found on screening to experience severe levels of emotional distress. In fact, a recent meta-analysis of controlled clinical trials suggested that psychosocial interventions, including psycho-education, should be planned for at least 12 weeks if reliable benefits to quality of life are to emerge. Thus, the effectiveness of multi-component and more intensive, yet non-obstructive programs to the practice of oncology clinics needs to be addressed further [44].

Qualitative Study Discussion:

This section describes Study Participants' opinion obtained through an in-depth interview.

Difference between Older and Younger Patients:

Majority of the participants were believed that “there should be difference between older and younger patients regarding to proper understanding and utilization chemotherapy related information.” Whereas very few respondent suggested that “there should be no difference” by supporting their opinion as the disease distresses all patients regardless of age differences, they understand fully even though the information was not given to the required level. The other supporting reason was that even if level of understanding is different, as long as the disease is the same; no need of separately viewing based on this biological difference. According the findings obtained, for youngsters; since they understand things quickly, no need of spending much time simply tell them only oral information in a polite and relaxed a manner is enough to deliver information. Whereas, for elderly people frequency of things to be told, showing empathy, using different audio-visual aids and speaking in a very clear and simple language is of utmost important. Similar study conducted in University of Amsterdam, Amsterdam, Netherlands revealed that older patients may experience fewer cancer-related losses than younger patients due

to the age-associated reduction in the time left to live. For example, older patients may feel less disturbed in their future plans than younger patients do. Furthermore, for older patients, their illness may have less impact on their appreciation of life than for younger patients. Besides, older patients seem to need less support in coping with the disease and treatment than younger patients do. Therefore, younger people may need more information from the health care professional in order to cope with their disease and treatment; in contrast, older patients may be overwhelmed by the information [44].

Promote Understanding and Recalling:

The common theme of respondents' idea was "giving information thoroughly, give leaflets or written materials, tell patients with warning and by emphasizing the magnitude of the problem and try to address comprehensive information to all patients". A similar study conducted in University of Amsterdam, above mentioned, produced similar result as Information should be offered in a structured manner in which the most important, personally relevant information should be summarized and repeated [44]. Furthermore, information should be offered step-by-step, to enable patients to let the information sink in, to consider the personal relevance and make him- or herself familiar with it. Another key factor that affects comprehension of the information is the language level used to convey the message. Nurses should avoid using technical and jargon words. What is contradicting idea from this study was, patients him/herself brought a relative to the consultation, because patients and relatives both will remember different aspects of the information. For instance, let's state one study participant's quote from University of Amsterdam study findings. "I thought it was pleasant that I brought my children with me. In this way they knew what was going on". The other contradicting point seen to this study was instead of informing patients by warning and emphasizing the magnitude of the problem, distressing the

patient, showing empathy and support is an important aspect of patient education. It makes the patient (and relative) feel understood and creates a trustful environment, both during and after the consultation, which is a prerequisite for reflection on the information provided and the decision to undergo treatment [44].

Information Needs:

Majority of study participants involved in the qualitative part of this study, agreed with insufficient provision basic chemotherapy related information. Affordability of treatment, characteristics of the drug like; side effects, mechanism of action and drug interaction) and dietary and other supportive managements were among their priority needs. In line with this, study from the University of Amsterdam showed that information about their disease and treatment, like diagnosis, prognosis, complications and side-effects of treatments were patients' preference [44].

Strength and Limitation of the Study

Strength

The study considers both qualitative and quantitative methods (triangulation of designs) so; scope and depth of the study will be address.

Limitations

The study considers a non probable sampling technique, because of inaccessibility of sampling frame. Thus, it will be difficult to make inference to the source population. In availability of related local research made the discussion very challenging.

CHAPTER VII

CONCLUSION AND RECOMMENDATIONS

7.1 Conclusion

The study showed that majority of the study participants agreed with the poor provision of the most essential chemotherapy related information. Surprisingly, great majority of them did not know the name of chemotherapy they have taken or currently taking. In addition to this, as most of the participants' suggestion showed, they had neutral and negative opinions towards different chemotherapy related opinion questions.

Moreover, the study showed that most of the participants were disagreed with the use of different information giving approaches by health professionals. As the study indicated even if greatest number of study participants suggested as oral information has been supported with written materials to enhance understanding and remembering, most of them strongly disagreed with the statement that as "health professionals provide general cancer literatures or leaflets before the patient begins chemotherapy".

As the study revealed most of the study participants have a positive attitude to the provision of detailed information regarding their chemotherapy or increased openness towards their disease.

The result of the study also showed that age difference is the one which should be considered while health professionals try to give different health information to their patients; even if very few respondent stands to the other hand.

As of the study participants' point of view, imbalanced health professional to patient ratio, professionals' failurity to respect professional ethics and to understand multi dimensional patient problems were among the major causes of poor patients to health professionals communication in oncology unit.

7.2 Recommendations

Depending on the study findings, the researcher recommends the following:

1. To all nursing schools to: -
 - Bring a slight modification towards the curriculum, so that it will contain more details of currently prevailing chronic conditions with their specific nursing interventions.
 - Encourage academic staffs or nurse scholars to conduct related researches to fill visible knowledge-practice gaps and address multi-dimensional needs of the client.
2. To TASRH to whom it concerns to: -
 - Facilitate ongoing in-service training programs, communication training for nurses who are working at oncology unit to address their specific competencies and also to show empathetic behavior to the patient.
 - Adjust regular health education sessions for all clients in the oncology unit at least once a week; so that patients can get opportunity to learn from and to raise additional needs they want to have.
3. To MOH to: -
 - Establish one big cancer institution at national level that will serve as clinical and research center and in turn prevents patient crowding and delayed care at TASRH.
 - Seek alternatives to solve all patients' priority problem at the same time survival need, which is cost of chemotherapy (both availability and affordability).

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Part II: Questions related to patients' current health status and type of treatment taken:

1. What is the type of cancer you are diagnosed for?
 A. Breast cancer C. Prostate cancer E. Colorectal cancer G. I don't know
 B. Lung cancer D. Cervical cancer F. Stomach cancer H. Others (specify) _____
2. How long you are suffering from this illness? A. < 6 months B. 6 month to 1 year
 C. 1 -3 years D. 3-5 Years E. ≥ 5 years
3. Which type of chemotherapeutic agents you have been taking?
 A. Fluorouracil, B. Adriamycine C. Cyclophosphomide D. I don't know D. others (specify) _____
4. What are the other type of treatment(s) you have taken in addition to chemotherapy?
 A. Radiation therapy B. Surgery C. Others (specify) _____

Part III: Questions related to adult cancer patients' opinion towards cancer chemotherapy related information needs:

This section refers to issues related to cancer patients' opinion towards chemotherapy related information needs at TASRH. For each question bellow please indicate how strongly you agree or disagree, with the statements by putting 'X' under your choice.

1 = Strongly disagree 2 = Disagree 3 = Undecided 4 = Agree 5 = Strongly agree

No.	Statements	1	2	3	4	5
1.	Would you think health professionals assist patients to reduce or quit smoking, high calorie diets and to have active but not a sedentary life style as they attribute more for cancer risk?					
2.	Health professionals provide general information about mechanisms of action or benefits of chemotherapy.					
3.	Would you believe knowing the benefits of chemotherapy is not that much important to patients?					
4.	Would you think an invasive chemotherapeutic agent brings serious reactions to the body?					
5.	Did health professionals inform such drug induced body reactions before you commence the treatment?					
6.	Would you believe that knowing about such chemotherapy induced body reactions are not that much necessary?					
7.	Would you think that information about relaxation and imagery techniques before, during and after treatment as appropriate is very important to reduce drug induced body reactions and to have better outcome of disease.					
8.	Health professionals should discussed with patients about the probability of sterility and other reproductive system impairments, as appropriate.					

Part IV: Questions related to adult cancer patients opinion towards ways of information delivering approaches:

No.	Statements	1	2	3	4	5
1	Did health professionals use different approaches like charts, models, movies or oral information and written materials to provide the necessary information about chemotherapy?					
2	Would you think that oral information has always be supported with written material to enhance understanding and remembering					
3	Did health professionals provide general cancer information or leaflets before you commence chemotherapy?					
4	Would you think that mass medias like radio and television and internet are the major sources of chemotherapy related information					

Part V: Questions related to adult cancer patients' opinion towards cancer chemotherapy related information needs

No	Provision of detailed information related to chemotherapy or increased openness towards the disease: -	5	4	3	2	1
1.	Enhances satisfaction with communication.					
2	Is more preferable, fundamental and necessary.					
3.	Without elements of counseling or psychotherapy is sufficient to improve psychological well-being.					
4.	Should better to withhold.					
5.	Improve anxiety, depression and quality of life					

Part VI: In-depth Interview Checks Lists (for qualitative method):

Topic lists discussed with study subjects (patients)

1. The difference between older and younger patients regarding to information utilization capacity like understanding or recalling of information provided;
 - A. would you believe as there are differences between older and younger patients of which health professionals should take into account during patient education?
 - B. What is your suggestion to health professionals to take these differences into account?
2. Information and support needs of patients at the beginning of treatment;
 - A. Which one do you believe is the most important educational goals when preparing the patient for an invasive treatment like chemotherapy? Which type of chemotherapy related information needs do you believe is the most crucial to be given at the beginning of treatment for patients and families?
 - B. In what ways do you believe nurses or other health professionals should tailor education about chemotherapy to the individual needs and circumstances of younger and older cancer patients and their relatives?
 - C. Do you believe as there is any other important aspect that nurses should consider during patient education about chemotherapy?
3. Promote understanding and recall of the necessary chemotherapy related information;
 - A. Which information would you believe is considered most important to be remembered at the beginning of the treatment? Which information should be provided verbally (during consult) and which information can be provided in a written form?
 - B. In what ways do you believe nurses could inform patients and their relatives in order to enhance understanding and remembering relevant information to your treatments?
4. What are your perceptions toward causes of poor information communication between patients and health professionals?
5. What is your general opinion towards chemotherapeutic agents especially, with regard to cost, side effects and by comparing it with other treatment options?

Name of interviewer _____

Signature _____

Annex-II: Subject information sheet and consent form (English version)

Thesis Title: Assessment of Adult Cancer Patients' Opinion Towards Chemotherapy Related Information Needs in Tikur Anbessa Specialized Referral Hospital, Addis Ababa, Ethiopia.

1. Subject information sheet

Introduction

You are being invited to take part in this research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and decide whether or not you wish to take part.

Purpose of the study

High morbidity and mortality incidence associated with chronic illnesses especially cancer now a day's turns its burden from affluence nations to developing countries while they are not escape from the burden of numerous communicable diseases. Ethiopia as one of developing nation shares this burden and significant number of patients currently receive one of the most invasive treatment options, chemotherapy. Therefore the aim of this study is to explore cancer patients' opinion towards chemotherapy related information needs.

Procedure

If you are volunteer to participate in this study:-

1. You will be interviewed face to face by data collectors.
2. Data collectors will also ask you some more less structured questions to get your detailed individualized lived experience regarding to chemotherapy related information needs of cancer patients.

Risk and discomfort

By participating in this study, you are likely to spend your precious time during interview. Otherwise, this study will not introduce risks to the service that you are provided in this hospital.

Benefits from the study

If you are willing to participate in this study, you may not get direct benefit but you and other patients will benefited more especially on provision of information and support needs to your chemotherapy treatment but you will not be provided any incentives to take part in this study.

Confidentiality

The participants of this study will insure for preservation of confidentiality and anonymity. The information that you provide for this study will be kept confidential and will not be revealed to anyone except the principal investigator.

Right to refuse or withdrawal

You have full right to refuse from participating in this study and if you wish to do so, the health care that you get from the hospital will not be affected.

You have also full right to withdraw from this study at any time you wish, without losing any of the services you get from the hospital.

Whom to contact

If you have any further question and in case of urgency you can contact:-

Principal investigator: Mulugeta Belay

Address: mobile- 09-10-30-38-84

E-mail- muleb2003@gmail.com

Addis Ababa University, Faculty of medicine

Address: P.O.B. 9086

Phone: 011-551-28-76

2. Consent form

I have been informed verbally and in written form about this study that plans to investigate cancer patients' opinion towards chemotherapy related information needs surrounding chemotherapy treatment in TASRH, AA, Ethiopia. I understand what is involved and what I have been interviewed. I also know whom to contact if I need more information. I understand that confidentiality will be preserved. Moreover, I also understand that I have a right to withdraw from participating in this study at any time.

The investigator has briefed me that there are no major risks associated with being involved. I have been given enough time to think over before I signed this informed consent. It is therefore, with full understanding of the situation that I gave my consent and cooperate at my will to participate fully in the study.

_____	_____	_____
Name of study participant	date	signature
_____	_____	_____
Name of principal investigator	date	signature

*Annex- III: Personal data of principal investigator
Name: Mulugeta Belay Tiruneh (BSN, MSN fellow)*

Personal information	Place	Year
Birth	Wolabie Abo, W/Gojjam	Oct, 8,1987
Primary School	Dagi	1994-2001
High School	Merawi	2002-2003
Preparatory	Merawi	2004-2005
University, first degree	Haramaya University	2006-2008
Work experience	Wollo University	2008/09
Masters Student	Addis Ababa University	2009/10 till now

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Annex-VI: Declaration

This thesis is my original work, has not been presented for a degree in any other university and that all sources of material used for the thesis have been duly acknowledged.

Principal investigator

Name _____ Signature _____ Date _____

Advisor

Name _____ Signature _____ Date _____