

ADDIS ABABA UNIVERSITY



SCHOOL OF PUBLIC HEALTH

**Information needs of breast cancer patients attending care at
Tikur Anbessa Specialized Hospital, Addis Ababa Ethiopia,
2017**

Prepared by: Birhan Legese(Bsc)

Advisors: Adamu Addissie (MD, MPH,MA,PhD)

Muluken Gizaw (Bsc, MPH, PhD fellow)

Wondemagegnhu Tigne (MD, clinical oncologist)

A thesis submitted to the school of graduate studies in Addis Ababa university school of public health, in partial fulfillment of the requirements for the degree of masters' in public health, 2017, Addis Ababa, Ethiopia.

June, 2017

Addis Ababa, Ethiopia

Dedication

I dedicated this work to all the women who have lost their lives through breast cancer and those still suffering from this disease. Hopefully, an improved information provision about this disease may make women able to make informed decisions regarding their care, have increased quality of life, and cope better with their illness.

.....God, you are my everything.....

Acknowledgement

First of all I will give thanks to my God and words cannot explain his mercy, love and support that he is always offering me. Then I would like to thank Addis Ababa University, School of public health for being the reason to know more and providing the opportunity to develop this thesis. My Deepest and heartfelt appreciation goes to my advisors Dr. Adamu Addissie, Mr. Muluken Gizaw and Dr. Wondemagegnhu Tigneh for their valuable support and advise, starting from topic selection till the end of proposal development. I take this opportunity to extend my thanks for the Librarian & computer lab staffs of SPH for their support during my search for reference materials and other instructors who give me their support when I am in need.

Abstract

Background: Breast cancer is the leading cancer among women in Ethiopia worldwide. Cancer patients are always eager to have information about every topic related to their illness and having the information is helpful for them to cope and for a better quality of life. But little is known about the information needs of breast cancer patients. So this study will address that gap.

Objective: Assessing the information needs of breast cancer patients attending care at Tikur Anbessa Specialized Hospital, Addis Ababa Ethiopia, 2017

Methods: Hospital based cross sectional study and qualitative methods was used. Toronto informational needs questionnaire was used to address the information needs and data on sociodemographic factors was assessed using structured questionnaire from literatures. Semi-structured interviews were conducted with patients and their care givers to support the quantitative part. Likert scales to determine whether patients need to know more about 52 items of information categorized under five domains namely treatment, disease, and investigative tests, physical and psychosocial was used. High mean score show higher information needs. One way ANOVA and regression was done to see association of sociodemographic and clinical variables with information needs. All statistical analysis was performed using STATA (Version 14), and statistical significance was set at $P < 0.05$.

Result: The total mean score for overall information need among breast cancer patients is 238.7(22.5) which means 4.59 with a range scale of 156-260. Among the five subscales information on disease and information on treatment were the most highly needed areas with mean percentage of 94.8 and 93.7 respectively and 254(67%) of them preferred the information to come from health professionals. Diagnosing as stage IV ($p=0.02$) &Urban residence is associated with less and high information needs respectively when compared to other categories.

Conclusion and recommendation: The information needs of breast cancer patients were high. Determining what the patient's needs is an important aspect of providing health care especially in cancer care. The health care system should include a way of information provision for breast cancer patients based on their needs.

Table of contents

Acknowledgement.....	iii
Abstract	iv
Table of contents.....	v
List of Tables and Figures	vii
Abbreviations	ix
CHAPTER ONE.....	1
INTRODUCTION	1
1.1 Background.....	1
1.2 Statement of the problem.....	2
1.3 Significance of the study.....	3
CHAPTER TWO.....	4
2. LITERATURE REVIEW.....	4
2.1 Epidemiology of breast cancer	4
2.2 Information needs of breast cancer patients.....	5
2.3 Source and factors associated with information needs of breast cancer patients.....	7
CHAPTER THREE.....	9
3. OBJECTIVES.....	9
3.1 General Objective	9
3.2 Specific Objectives.....	9
CHAPTER FOUR.....	10
4. METHODS	10
4.1 Study area.....	10
4.2 Study design:	10
4.3 Source population	10
4.4 Study population	10
4.4.1 Inclusion and exclusion criteria	10
4.5 Sample size determination	11
4.6 Sampling procedures.....	12
4.7 Data collection procedures	12
4.7.1 Quantitative.....	12
4.7.3 Study variables	14

4.7.4 Operational definitions.....	14
4.7.5 Data quality management.....	14
4.7.6 Data analysis.....	15
4.8 Ethical consideration	16
4.9 Dissemination of results.....	16
CHAPTER FIVE.....	17
5. RESULTS.....	17
6. DISCUSSION	34
7. CONCLUSION	38
8. RECOMMENDATION.....	39
References.....	40
ANNEXS.....	45

List of Tables and Figures

List of Tables

Table 1: Socio-demographic characteristic of breast cancer patients attending care at TASH, Addis Ababa Ethiopia, 2017

Table 2: Clinical characteristics of breast cancer patients attending care at TASH, Addis Ababa Ethiopia, 2017

Table 3: Information need among breast cancer patients attending care at TASH, Addis Ababa Ethiopia, 2017

Table 4: Treatment, disease, tests, physical and psychosocial information needs of breast cancer patients attending care at TASH, Addis Ababa, Ethiopia, 2017

Table 5: Preferable source and time of information among breast cancer patients attending care at TASH Addis Ababa Ethiopia, March-May 2017

Table 6: Associations between sociodemographic and clinical variables with information need of breast cancer patients at TASH, Addis Ababa Ethiopia, 2017

List of figures

Figure 1: Conceptual framework

Figure 2: preferred sources of information needs of breast cancer patients attending care at TASH Addis Ababa Ethiopia, 2017

Fig 3: Preferred time to have information mentioned by breast cancer patients attending care at TASH Addis Ababa Ethiopia, 2017

Abbreviations

ANOVA	Analysis of variance
ASI	Age specific incidence
ASMR	Age specific mortality rate
CDC	Centers for disease control and prevention
DALYs	Disability adjusted life years
FMOH	Federal ministry of health
HICs	High income countries
NCDs	Non communicable diseases
SSA	Sub-Saharan Africa
TASH	Tikur Anbesa Specialized Hospital
TINQ-BC	Toronto information need questionnaire of breast cancer
UK	United Kingdome
USA	United States of America

CHAPTER ONE

INTRODUCTION

1.1 Background

Breast cancer starts when cells in the breast begin to grow out of control and its impact is substantial with different experience from women to women [1, 2]

In Sub Saharan Africa, breast cancer is the most common cancer in women with poor survival rates [3] and in Ethiopia cancer has been gradually recognized as a critical public health problem but it continues to get low public health priority including on research activities in many area [4] and breast cancer is one of the leading cancer types which is capable of taking away the life of our poor women [5].

Information need is information that persons may need to enhance physical and psychological health [2] and patients with cancer are always eager to have information about different topics since diagnosing with cancer is stressful experience [6]

Information provision to the patient is one of the most important supportive cancer cares. It helps them to prepare for the treatment, increase their strength to deal with their illness and it helps them to adhere to their therapy [7, 8]. It also has a positive impact on feelings and attitudes, which allow the patient to prepare for the future [9].

A breast cancer patient's ability can be improved by giving them relevant information, in order to cope with the disease and overcome the adverse effects of the treatment process. With the provision of such information, patients may be prepared for the forthcoming trials of treatment and rehabilitation, reducing their possible anxiety, and mood disturbances through these phases. In addition, providing relevant information to breast cancer patients according to their actual needs can also help to improve communication with others [10-12].

1.2 Statement of the problem

In Ethiopia breast cancer is one of the leading cause of cancer related morbidity and mortality in women[13] Analysis of a 16 years breast cancer trend shows a non-declining pattern and most of the patient diagnosed with late stage [14].Breast cancer patients may experience depression or anxiety at any stage of their illness from pre diagnosis to the final stage, and the association of the body part of the cancer with the gender may even worsen the result [15,16] They also suffers from problems like pain and fatigue; psychological problems, as well as psychosocial problems such as family worries and sexual problems. Hence there is a need to provide education, information and support over time [17].

In Ethiopia cancer patients are not satisfied with the potentials of acquiring information [18]. Health professionals often lack time to discuss the questions that women might have and there is no formal form of information provision system for cancer patients. Not only that there is no patient information leaflet or it is not on circulation.

But it is known that treatment for breast cancer is prolonged and complex and it need the active involvement of the patients themselves so information about the general situation of their illness and health is necessary for patients, to make the information to be relevant and useful, knowing the position of women towards receiving this information is necessary. So this study addressed this gap.

1.3 Significance of the study

The finding from this study will give information to critically evaluate the existing information needs of breast cancer patients. Generally the finding from this study can give insight for researchers, health care providers and policy makers to plan a better information provision system for breast cancer patients attending care so that it makes their life easier adhere to their treatment and they become advocator when they communicate with other women with or without breast cancer.

CHAPTER TWO

2. LITERATURE REVIEW

2.1 Epidemiology of breast cancer

In 2013, breast cancer caused 1.8 million incident cases and 464 thousand deaths worldwide. It caused 13.1 million DALYs, 63% of breast cancer occurs in developing countries [19].

Breast cancer incidence is also characterized by a marked age-specific variation worldwide. In western countries, the rate increases rapidly before the menopause, and increases gradually afterward. But in low incidence countries the increase after the menopause is low or even negative [20]. Belgium, Denmark and France are the top countries with ASIR of breast cancer and Fiji, Bahamas and Nigeria has the highest ASMR from breast cancer [21].

Due to population growth and aging, the incidence in breast cancer rates is rapidly increasing in Africa. In Uganda, for example, breast cancer incidence rate has doubled from 11 per 100,000 in 1961 to 22 per 100,000 in 1995 and increased from 18 per 100,000 to 31 per 100,000 in the period between 1991 and 2006 [22]. Cancer survival data are extremely scarce for developing countries, but the few data available are in line with the observed incidence/mortality differences [22]

The 5-year survival rates for breast cancer are much worse for low- and low-middle income countries such as Gambia (12%), Algeria (38.8%), India (52%) and Brazil (58.4%) in comparison to HICs such as the United States of America (83.9%), Sweden (82.0%), Japan (81.6%) and Australia (80.7%) [23, 24]. Ethiopia is the top 9th country worldwide by death rate with age standardized mortality rate of 23 per 10⁵ [26].

2.2 Information needs of breast cancer patients

Nowadays considering communication and information as important entity in helping people to cope with cancer is increasing. Research has indicated that the vast majority of cancer patients want to be informed about their illness. But it is also recognized that patients vary in how much information they want and that this may change during their illness [25].

Due to advancements in modern medicine survival from cancer is increasing and cancer is considering a curable disease. Patients are actively involving in making decisions about their care which result in improved quality of life [26].

Patients' knowledge influences their ability to actively participate in decision-making about their medical care and treatment choices as well as their ability to manage their condition and which improve their own medical outcome [27]. Patients should have accurate knowledge of their own disease state to make educated treatment decisions and be actively engaged in decision-making processes [27].

Many previous studies have shown consistently that there is a high need for information among breast cancer patients about illness and most importantly regarding their general condition and their treatment options [28].

Breast cancer patients need information, not only to help them to understand the disease and its treatment, but also to allow them to interpret the aversive events and action taken, so that the threat from the diagnosis becomes lesson by inherent [29].

On study of South Africa revealed that even though patients expressed as they want information, there is also unexpressed and dormant information needs in them. They also expressed different fluctuating level of information need [30].

The need for accurate information on cancer and treatment options, the role of food in cancer and the need for nutritional information, and the role of Chinese medicine in cancer treatment

is the most information needed by cancer patients according to the study done in USA on immigrant Chinese women with cancer [31].

The study done in USA at Chicago metropolitan area to dig out patients' recommendation to improve access shows many women's wanted health providers to give them information about their health condition relaying information about their diagnosis and prognosis more honestly [32].

In Canada women with cancer suggest that they want detailed information from their doctor or in a written material [33].

A study done in England asked women if they had received enough information regarding their illness and its treatment, and a high proportion would have liked to have had more information on the after-effects of the operation, including physical, sexual and emotional aspects [34].

Many of the younger women would have liked their partner to have been included in the discussions and 25% of the partners who responded to the questionnaire would have liked more information on the illness and its treatment [35].

Nowadays health Information needs and seeking behavior is widely viewed as the ways by which individuals obtain information about health, illness and any health related issues [36].

In a study done in USA on cancer patients to assess their information seeking style both before and after treatment and in the pretreatment, 17% reported an active information-seeking style, 69% were moderately active, and 14% were passive [37].

An information seeking behaviour survey of 968 in Korean cancer women comes with the finding that 404 (41.7%) had sought cancer information. When patients felt a need for information, their information-seeking behaviour increased [28].

In Ethiopia cancer patients have high need of information on specific type of cancer like the name and the stage, side effect of chemotherapy and their management, survival or prognosis [18].

2.3 Source and factors associated with information needs of breast cancer patients

Research findings suggest that most patients prefer to have and use information which comes from their clinician and preferred information from this source but about half of them checked internet before nearsighted their physician [38,39]

In Hawaii doctors, family members, nurses, friends, the Internet, other medical personnel, and other patients are the most important information sources respectively. Individuals, however, were most satisfied with family and friends as sources of information, followed by nurses, other patients, and doctors [40].

Books, brochures, and pamphlets (98%); doctor or other health professionals (97%); and spouse or partner, family members, friends, or all of these (62%) are the top health information sited by women with cancer in California according to a study [41].

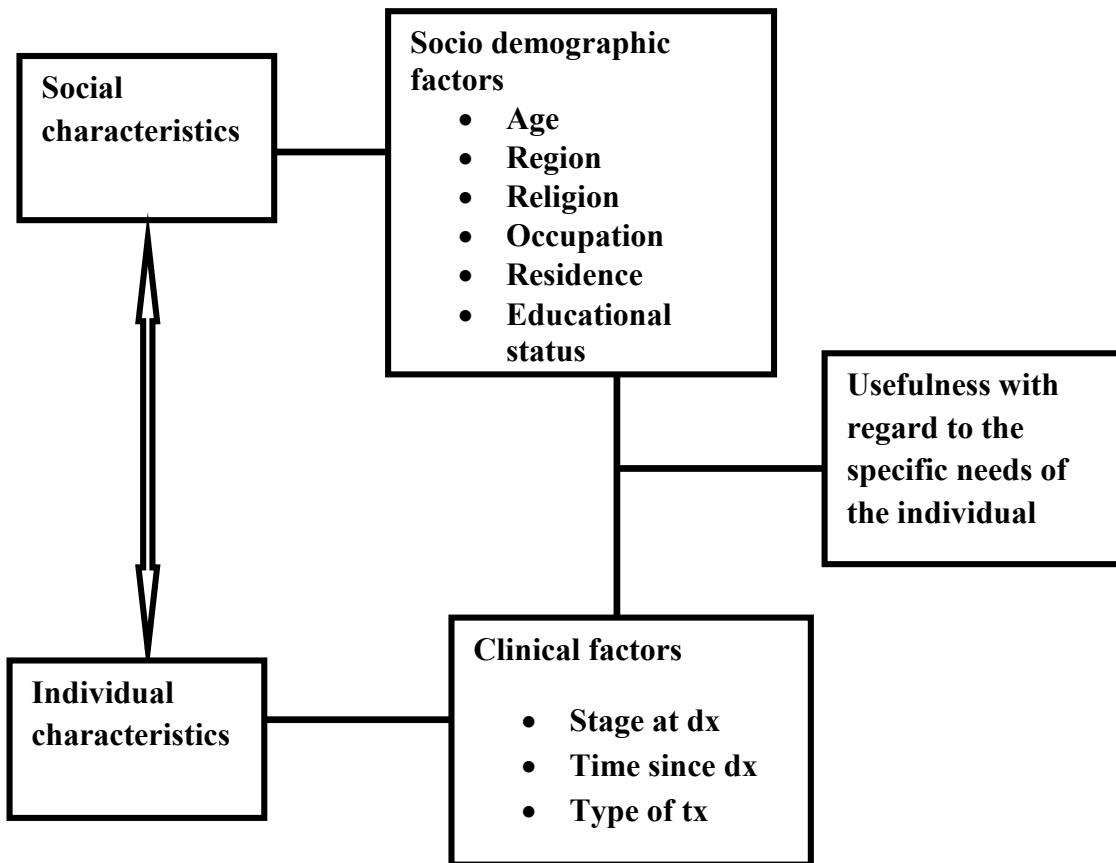
In a study done in USA on minority groups of Hispanic groups revealed that respondents preferred receiving health care and cancer care information from the television, the radio, billboards, the Internet, and print media. More specifically, Hispanic participants stated that they preferred to have cancer care information which is cultural sensitive and preferably their own language using lay terms rather than medical jargons [42].

In a study of UK the finding suggest that age and women's main source of information are significant predictors of perceived informational shortage and this shortage brings dissatisfaction with the health care program. Always wanting information is predictable from subject characteristics [43]. Patient-provider language difference may block the communication between them and it creates a problem for proper information exchange [44].

Information and knowledge is an important issue in cancer control but there is a gap in cancer seeking between cancers patients with high and low socioeconomic status. Also, when information was sought from mass media, education had a greater association with treatment information seeking [45].

Most of cancer patients want information from doctors in Ethiopia, whereas others want from nurses [18].

Fig 1: Conceptual framework



CHAPTER THREE

3. OBJECTIVES

3.1 General Objective: Assessing the magnitude of information needs and factors associated with the information needs of women with breast cancer attending TASH, 2017, Addis Ababa, Ethiopia.

3.2 Specific Objectives:

- ✓ Describing the information needs on treatment, disease, tests, physical and psychosocial information needs of breast cancer patients attending TASH.
- ✓ Assessing socio demographic and some clinical factors which are associated with needs of information
- ✓ Describing the preferred sources and time of breast cancer patients to need information.

CHAPTER FOUR

4. METHODS

4.1 Study area

This study was conducted in Tikur Anbessa Specialized Hospital (TASH), Addis Ababa Ethiopia.

Tikur Anbessa Hospital is serving people who comes from all parts of the country through referral and offers diagnosis and treatment for approximately 370,000- 400,000 patients per year. The hospital has 600 beds, of which only 18 are allocated for cancer treatment. Of the 201 physicians at the hospital, only two are hematologists, four are medical oncologists, four are radiotherapists, two are surgical oncologists, and one is a pediatric oncologist. Three palliative pain specialists also work at the hospital. Only 26 of the Black Lion's 627 nurses are dedicated oncology nurses. The hospital has one CT scanner and one MRI scanner. Treatments offered at the Black Lion Hospital cancer center include anticancer drugs, surgery, and radiotherapy [46].

4.2 Study design: Hospital based Cross sectional study which supported by qualitative.

4.3 Source population: Breast cancer patients who visit the oncology department of Tikur Anbessa Hospital.

4.4 Study population: Patients with clinically diagnosed and histological confirmed cancer of breast will be enrolled in to the study.

4.4.1 Inclusion and exclusion criteria

Inclusion criteria

- Adult women with confirmed cancer of the breast
- Who are on care in Tikur Anbessa Hospital

Exclusion Criteria:

- Patients with neurological disorders, causing cognitive impairment and hence preventing the comprehension of study purposes and questionnaires.

4.5 Sample size determination

Sample size:

Sample size is calculated using a formula for single population proportion and taking 63% of patients on chemotherapy want information on chemotherapy and their management [19] at 95% confidence level the sample size become **358** when calculated and after adding 10% none respondent rate it adjusted to be **394**.

So the equation is as the following

$$n = z^2 p (1-p) / d^2$$

$$= (1.96)^2 (0.63 \times 0.37) / (0.05)^2$$

$$= 358.18$$

$$= (358.18 + 10\% \text{ non-response rate})$$

$$= (358.18 + 35.8)$$

$$= 393.98 \approx \mathbf{394}$$

Where

n= number of the study subjects (sample size)

Z= is standardized normal distribution curve for the 95% confidence level

p= 63% of population proportion who want information about chemotherapy and its management [18].

d= the margin of error taken 5% = 0.05

So the study will be conducted on **394** breast cancer patients.

4.6 Sampling procedures

Tikur Anbessa Specialized Hospital was selected because it is currently the only referral hospital which provides different types of therapy including radiation therapy for cancer patients in Ethiopia.

Since there is no sampling frame individual participant with breast cancer were selected sequentially or consecutively within the time of data collection.

4.7 Data collection procedures

4.7.1 Quantitative

Structured questionnaire from literatures was used for the assessment of socio demographic data of the patients and clinical information. For the assessment of informational needs Toronto informational needs questionnaire for breast cancer (TINQ-BC) [47] was used trying to adopt after pretesting on 20 patients. This tool is not used in Ethiopia before but used in many countries other including Egypt [48] and it is a widely used instrument and has the potential to assess the informational needs of women with breast cancer on an international basis [49].

The tool was translated in to Amharic and then it was back translated to English by different individuals to check consistency and conceptual equivalence. After pretesting of the questionnaire for simplicity and ease of administration it used for its primary purpose. Three oncology nurses for data collection and one supervisor were selected with previous experience of data collection and training was given on data collection technique.

The Toronto Informational Needs Questionnaire of Breast Cancer (TINQ-BC)

The TINQ-BC was developed to assess specific informational needs of breast cancer populations, such as patients being treated by surgery, chemotherapy or radiation therapy [47, 50, 51].

The development and initial testing of the instrument were outlined by Galloway et al (1997) To elicit women's perception of their informational needs related to their experience of breast cancer and despite the ceiling effect of the instrument [47], it was applied effectively to other cancer patients such as those with prostate cancer [52].

TINQ-BC contains 52 item scales, measuring the following five subscales of informational need: Disease, Treatment, Investigative Tests, Physical and Psychosocial needs(Annex 1) Total score with minimum of **52** and maximum of **260**, the mean score to represent higher information needs is 200 and above.

The five subscales of TINQ-BC

- ✓ **Treatment** (16 items): assess information need about various treatments, how they work, performed, sensations that may be experienced and possible side effects.
- ✓ **Disease** (9 items): assess information need about the nature, process and prognosis of the disease.
- ✓ **Investigative tests** (8 items): assess information need about procedures used to assess the extent of disease, how, why they are done and sensations that may be experienced.
- ✓ **Physical** (11 items): assess information need about the preventive, restorative and maintenance care that may be needed as a result of the disease and treatments.
- ✓ **Psychosocial** (8 items): assess information need about how to handle the patients' or their families' feelings.

So this instrument selected to use in this study because it is a widely used tool in many countries to measure the information needs of breast cancer patients.

4.7.2 Qualitative

Purposive sampling method was employed and depending on theoretical saturation or when the data collection is not bringing the desirable information on the objective any more was the sample size determination. In-depth interview with patients and their caregivers was conducted. The discussions was carried out by principal investigator and interviews was audio recorded and transcribed then translate into English for data analysis.

4.7.3 Study variables

Dependent variables

- Information needs

Independent variables

Sociodemographic factors

Age
Region
Religion
Residence
Marital status
Educational status
Occupation

Clinical factors

Stage at diagnosis
Time since diagnosis
Type of therapy

4.7.4 Operational definitions

Information needs: - recognition that breast cancer patient's knowledge is inadequate to satisfy a goal in relation to health/disease issue [45].

High information needs: - patients who score above mean value which is 200[47].

Preferred Source of information: - source through which breast cancer patients want information to come [53].

4.7.5 Data quality management

Each data collector was checked the questionnaires for completeness before leaving the study participant and supervisor was visit in between randomly to cross-check the proper filling of questionnaire. One in three questionnaires was cross-checked by principal investigator to increase data quality.

All filled questionnaires were reviewed at the end of the day by the supervisor and investigator before preparing for the entry and analysis. The tools for information need was pretested on 20 patients prior to the actual data collection to check for the reliability, accuracy of responses, language clarity, and appropriateness of the tools since no one uses it in Ethiopia before. And the necessary changes on wording were done based on the findings of the pretest.

4.7.6 Data analysis

Statistical analysis: - Quantitative

The data collection instruments were coded and data was checked and entered using EpiData version 3.1 software a must enter command were activated for every single item to minimize missing during data entry and checked repeatedly for the eligibility before it exported. It was exported to STATA version 14 and it was checked for missing values before analysis by commanding to tabulate and list the missing value for each variable list then it checked from questionnaire to fill. For the study population descriptive statistics i.e. mean, frequency and percentage was computed. One way ANOVA analysis was used to examine mean differences in dependent and independent variables among the groups. The independent effect of socio demographic and clinical factor on information need was determined using multiple regressions. Variables which have significant association with the outcome were entered into multivariable models. All statistical analysis was performed using STATA (Version 14), and statistical significance was set at $P \leq 0.05$.

Qualitative

Iterative content analysis of the verbatim transcripts of the audio recorded interviews with patients and caregivers was carried out to identify the importance, area, enabler or barrier factors on information need as stated by them. The investigator was identify and highlighted every codable unit of text in the transcripts that represent a singular idea. A list of themes was then created from each transcript.

4.8 Ethical consideration

First permission to undertake the study was obtained from Ethical Review Committee of Addis Ababa University College of Health Science School of public health. All participants were get information about the purpose of the study, confidentiality of the information, and the right not to be participated or withdraw at any time. Participants were informed that participating in the study will not harm anyone rather the evidence obtained from their participation will bring an improvement on the implementation for the health of general population.

4.9 Dissemination of results

The results of the study were presented in Addis Ababa University School of Public Health as partial fulfillment of master degree in public health after completing the research. In addition the final result document will be presented to responsible bodies working in the area. Beside to this, the findings of the study will be published through peer reviewed journals as scientific outputs which will be additional asset of the health research.

CHAPTER FIVE

5. RESULTS

5.1 Socio-demographic characteristics of the participants

The final sample size for obtaining data for this study was 375 with response rate of 95.2%. The majority (80.53%) of participants in the study was between the age of 20 and 51 and the median age was 40. Those who follow Orthodox Christianity were (70.7%) and urban dwellers were 303 (80.8%), Addis Ababa is the living place for 167(44.5%) of them. High school was the most frequently reported (29.9%) level of education. A large portion 280 (74.7%) of the women indicated that they are married and over half of them 212(56.5) were of housewives (Table 1).

Table 1: Socio-demographic characteristic of breast cancer patients TASH, Addis Ababa Ethiopia, March-May 2017 (n=375)

Characteristics	Frequency (in number)	Percent
Participants age (years)		
20-35 years	113	30.13%
36-51 years	189	50.40%
52-67 years	62	16.53%
>67	11	2.93%
Current Marital Status		
Married	280	74.67%
Single	39	10.40%
Widowed	35	9.33%
Separated	21	5.60%
Religion		
Orthodox	265	70.67%
Muslim	62	16.53%
Protestant	36	9.60%
Others	12	3.2%
Region		
Addis Ababa	167	44.53%
Oromia	127	33.87%
Amhara	37	9.87%
SNNPR	24	6.40%

Other	20	5.33%
Participants education		
No formal education	80	21.33%
Read & write	55	14.7%
Elementary	71	18.93%
High school	112	29.87%
Above high school	57	15.2%
Participants living environment		
Urban	303	80.8%
Semi-Urban	29	7.73%
Rural	43	11.47%
participants occupation status		
Housewife	212	56.53%
Employed	85	22.67%
Unemployed	27	7.2%
Farmer	25	6.67%
Merchant	14	3.73%
Other ^{occ}	12	3.2%

Rel^{Rel} Catholic, Jehovah Witness, Wake feta. ^{occ} private work
 Reg^{Reg} Tigray, Diredawa, Somali, Hareri, Benishangul, Gambella

5.2 Clinical characteristics of the participants

The majority of the patients 160(42.9%) are diagnosed as stage III and only below 5% of them were diagnosed as early as stage I. 70% of the women had diagnosed within a period two years. Majority of the participants 244 (65.1%) who are placed on chemotherapy were also took surgery or radiation treatments, 22.4% were on hormonal therapy.

Table 2: Clinical characteristics of breast cancer patients attending care at TASH, Addis Ababa Ethiopia, March-May 2017 (n=375)

Characteristics	Frequency	Percent
-----------------	-----------	---------

Time since diagnosis		
3months-1yr	150	40.00%
1yr-2yr	139	37.07%
2yr-3yr	43	11.47%
3yr-4yr	29	7.73%
4yr-5yr	14	3.73%
Stage at diagnosis		
Stage I	17	4.535
Stage II	115	30.67%
Stage III	161	42.93%
Stage IV	82	21.87%
Type of treatment		
Chemotherapy	87	23.2%
Radiotherapy	19	5.07%
Surgery	21	5.6%
Hormonal	84	22.4%
Chemo & surgery	139	37.07%
Chemo & radio	18	4.8%
Radio & surgery	7	1.87%

5.3 Descriptive statistics of information needs among breast cancer patients

The Toronto Information Needs Questionnaire (TINQ-BC) was used to assess the information need of breast cancer patients on 52 items with 5 subscale namely treatment, disease, diagnostic tests, physical and psychosocial needs.

It used a likert scale with five subscale starting from not important (rated 1) to extremely important (rated 5). per item very important (rated 4) and above is rated as high information need.

Mean score above 4.75 was rated as extremely important for single item (47) in this study every item scored above 4 mean score showing high needs of information. The minimum mean score when compared to others are “what to do if I become concerned about dying” (M=4.05 with scale 1-5) and “Where I can get help if I have problems feeling as attractive as I

did before” (M=4.1 with scale of 1-5) but it still rated as very important which is high information need11.

Whereas about 8 items scored mean above 4.75 including “If there is cancer anywhere else in my body”(M=4.81 with scale of 2-5) , “If the breast cancer will come back”(M=4.80 with scale of 2-5) and “If my illness is hereditary” (M=4.80 with scale of 2-5). All are shown on Table 3.

The total mean score for overall information need among breast cancer patients is 238.7(22.5) with a range scale of 156-260 so the proportion of participants with score above mean value were 92.7%.

Table 3: Information need among breast cancer patients attending care at TASH, Addis Ababa Ethiopia, March-May 2017

Items(question1-52) n=375	Mean (S. D.)	Range
What types of treatment are available	4.52(.88)	1-5
Who to talk with if I hear about treatments other than the available	4.44(.97)	1-5
How to prepare for my Treatment	4.74(.58)	2-5
If I have side effects, how to deal with them	4.76*(.53)	2-5
How I will feel after my Treatment	4.71(.56)	2-5
Who I should call if I have questions while I am still getting treatment	4.68(.60)	3-5
How my treatment is done	4.66(.65)	1-5
How long I will be receiving Treatment	4.74(.55)	2-5
Why the doctor suggest this treatment for me	4.67(.63)	2-5
The possible side effects of my treatment	4.76*(.53)	2-5
If there are ways to prevent treatment side effects	4.78*(.51)	1-5
What side effects I should report to the doctor/nurse	4.76*(.52)	3-5

Who should I call if I have questions after all the treatments are over	4.70(.61)	2-5
If the treatment will alter the way I look	4.68(.61)	2-5
If I am prone to infection to because of my treatment	4.75(.53)	3-5
How the treatment works against cancer	4.63(.69)	1-5
If it is known what causes breast cancer	4.72(.60)	1-5
If the breast cancer will come back	4.80* (.52)	2-5
If there is cancer anywhere else in my body	4.81* (.48)	2-5
How the illness may affect my life over the next few months	4.76(.52)	2-5

How breast cancer acts in the body	4.71(.54)	2-5
If my illness is hereditary	4.80* (.51)	2-5
How the illness may affect my life in the future	4.79* (.49)	3-5
The medical name for my type of breast cancer	4.54(.78)	1-5
How to know if the cancer has come back	4.65(.72)	1-5
How I will feel during the test	4.64 (.65)	1-5
How the tests(e.g. x-ray, bone scans) are done	4.43(.86)	1-5
The meaning of the result of the test	4.47(.81)	1-5
Why the doctor suggest this test and if there are other ways of tests	4.51(.73)	2-5
Why they need to test by blood	4.46(.78)	2-5
How I will feel after the tests	4.47(.76)	2-5
What is the result of blood test mean	4.44(.83)	1-5
When to have a mammogram	4.60(.68)	2-5
If there are any physical things I should not do	4.55(.71)	2-5

How long my wound/incision will take to heal	4.61(.67)	2-5
If I can wear brassiere or if there is change in my wearing style	4.48(.83)	1-5
Which foods I can or cannot Eat	4.71(.68)	1-5
How to care for my wound or incision	4.71(.58)	2-5
If I can continue my usual hobbies and sports	4.53(.68)	2-5
If I'm going to need help taking care of myself	4.40(.86)	1-5
Where to examine my breasts	4.64(.65)	2-5
If I can take a bath or a shower	4.53(.72)	1-5
How to tell if the cancer has come back	4.73(.53)	3-5
If there is special exercise I have to do	4.63(.62)	2-5
If there are groups where I can talk with other people with cancer	4.36(.89)	1-5
Where can I get help if I have problems feeling as attractive as I did before	4.11(1.03)	1-5
What to do if I feel uncomfortable in social situations	4.33(.89)	1-5
If I can continue my usual social activities	4.38(.89)	1-5
If there will be changes in the usual things I can do with and for my family	4.37(.88)	1-5
Where I can get help to deal with my feelings about my illness	4.39(.89)	1-5
What to do if I become concerned about dying	4.05(1.26)	1-5
Where my family can go if they need help dealing with my illness	4.49(.82)	1-5

*items with mean score of above 3.75

An in-depth interview was also conducted to supplement the finding of the quantitative data and the majority of the participants were care givers. Most of the in depth interview respondents also stressed about the importance of information.

43 years old who come from Bale Robe underlined the importance of information for breast cancer as the unquestionable necessity.

“...I want information so much. I want to know about every single entity which is related to my current health condition... I want to thank you that you really start to think for us if you ask us about our need... Provide us with important information soon... we really want to know....”

Patients want the truth about everything. A 51 years old breast cancer patient who comes from Addis said...

“...I want information ...I want the truth. It is better to know the truth than living in a fear and suspicious state. Doctors shouldn't hesitate to tell everything for a patient...”

A 20 year daughter was a care giver for her mother. She was really serious about information provision for breast cancer patients.

“...having appropriate information is the right of patients. They should be provided with information along with treatment...It is the right of them...”

A 29 years old lady from Addis was giving care for her breast cancer patient mom. According to her...

“.....information is very important the fear or threat of dying highly echoed not only among patients but also among people around her..... the women wanted to be told that the diagnosis was not a death sentence. They wanted to be supplied with necessary information and we also want to get it because we treat her at home.....”

Cancer patients have many queries about different concerned their illness and illness related issues and being informed is advantageous not only for them but also for others. This is also stressed by a 32 years lady who is giving care for her sister with breast cancer.

“...breast cancer patients have many questions running in their mind. They have cancer it is not a simple condition to accept easily. Their life changed since they first listen that they have cancer so information related to treatment, disease and anything related to health is important for them more than ever... let alone for them it is necessary for their care giver, family as a whole and even to the society...”

There were five subscales that were scored from the Toronto information needs questionnaire of breast cancer, because of the number of items in each subscale is not the same, mean percentage were used to identify the areas of highest information need between subscales.

5.4 Information needs on Treatment

This subscale has 16 items to assess information need about various cancer treatments, how they work, performed, sensations that may be experienced and possible side effects [47]. The descriptive statistics along with the reliabilities generated from the five TINQ subscales are shown in Table 4.

The standardized mean of this subscale was 4.68 and it was rated between “very important to extremely important” (M=75 on a scale from 48 to 80) with mean percentage of 93.7%

A 21 years old daughter said the following when she asked about information need

“...There should be information provision for both patients and care givers. For example when my mom takes chemotherapy at the first time she just lost her hair she we shocked... We were arguing that was that happening because of the disease itself or the side effect of the treatment...”

This 27 years old guy from Addis was helping her mother. According to him..

“...Information about everything related to health issue is important. Cancer patients should believe in their therapy before they start it otherwise it is unworkable. They should also be given information about side effects. If they know it prior to starting they will not be harmed since they are ready. The degree of suffering is lower in those who know than those who don't know...”

Are all patients are coming on their day of appointment for a therapy? A 38 years old lady who lost her older sister because of breast cancer was caring for her younger sister with breast cancer, the second breast cancer in the siblings.

“... My older sister lost her life because of breast cancer. At that time we heard rumor that surgery would facilitate the metastasize of breast cancer then we absented on a day of appointment and we went to traditional healer but the herb worsen the wound and burst her breast you see this all happened because of lack of enough information at hospital about modern treatment...”

5.5 Information needs on Disease

Disease subscale has 9 items to assess information need about the nature, process and prognosis of disease [47]. It was also rated between “very important and extremely important” with standardized mean of 4.73 (M=42.6 on a scale of 23-45) with mean percentage of 94.8%.

The participants of the in-depth interview also claimed on the importance of the information needs on diseases.

53 years old patients who come from Arsi, Oromia pronounced on the essential of having information on disease for her saying

“...I want to know about the behavior of the disease...what it hates and what it loves I will act accordingly if I know it...”

A 35 years old male was a care giver husband of lactating mother. He is from Addis Ababa. Information all area is necessary specially...

“...if breast cancer is transmissible from mother to child and foods, activities anything else that prevent wound and that makes it the cancer recur...” and another husband say *“...for me knowing the cause of breast cancer is very important more than anything else..”*

5.6 Information needs on Investigative test

This is an 8 item subscale to assess information need about procedures used to assess the extent of disease, how, why they are done and sensations that may be experienced [47]

The women rated knowledge that they needed to know about investigative tests were “very important to extremely important” (M=36 on a scale from 21 to 40). With 90 mean percentage and standardized mean of 4.5.

5.7 Information needs on physical

Physical information needs subscale assess information need about the preventive, restorative and maintenance care that may be needed as a result of the disease and treatments. It has 11 items [47]

The standardized mean for physical subscale was 4.59 and 90.8 mean percentage. It was between “very important to extremely important” (M=50.5 on a scale from 33 to 55).

Participants state many areas of information needs. A 44 years old male from Addis Ababa was giving care for his wife. According to him...

“...information on physical needs such as sleep, activity levels, pain control, and nutritional way are the most important aspects of information for a patient with breast cancer...”

5.8 Information needs on Psychosocial

Information need about how to handle the patients' or their families' feelings assessed by an 8 item subscale for psychosocial information needs [47]

It itemized as “very important” (M=34.5 on a scale of 16 to 40) with mean percentage of 88 and standardized mean of this subscale is 4.3.

The area of information need mostly cited by in-depth interview participants was psychosocial. Most of them were stressing how cancer is fearful and dangerous which change the feeling state of the women completely.

35 years old was telling how the behavior of his wife changed since she diagnosed with cancer.

“...the behavior of my wife changed completely since she knows that she has breast cancer...she become bad tempered ...I want information how to treat her during this time...”
and 24 years old female also said

“...I don't know whether it is because of the disease or the treatment the behavior of my sister was changed...her mood is disturbed...there would be so helpful if there is working body to deal with such like condition ...”

A 34 years participant from Adama said....

“...breast cancer patients should get information since it may help them to be hopeful, for good communication styles, and preferred shared decision-making process...”

In Ethiopia there are no associations of breast cancer in. A 48 years old husband said...

“...there should be an association or a group of survived breast cancer patients to share information and experiences, expresses feelings... it would be helpful for reassurance...”

Descriptive and reliability Statistics of the TINQ Subscales

Table 4 : Treatment, disease, tests, physical and psychosocial information needs of breast cancer patients attending care at TASH, Addis Ababa Ethiopia, 2017.

Subscale	Mean(S.D)	Mean %	Range	No items	Cronbach's Alpha
Information on treatment(Q1-16)	75(7.46)	93.7	48-80	16	0.94
Information on disease(Q17-25)	42.69(3.82)	94.8	23-45	9	0.88
Information on investigative test(Q26-33)	36(5.07)	90	21-40	8	0.93
Physical information need(Q34-44)	50.5(5.35)	91.8	33-55	11	0.89
Psychosocial information need(Q45-52)	34.5(5.7)	86.2	16-40	8	0.89
Overall information need(Q1-52)	238.7(22.5)	92	156-260	52	0.96

5.9 Preferable source and time to have information

The participants have been questioned what their preferred time and source to have information was using one item for each question which is designed after literature review. 254(67%) of them want health professionals i.e. Doctors and nurses to be their source of information whereas 97(25.87%) of them want the information by any means. 284 (75.73%) of the participants said that the appropriate time to have the information is before starting the treatment and any time was cited by 75(20%) of them.

The finding of an in-depth interview was also similar with the quantitative. Most of the participants narrate health professionals particularly Doctor should be the source of information for breast cancer patients.

For example a 34 years old patient said...

“...my doctor should be my principal information source he knows me more than any one...I can say am on his hand next to God...”

Table 5: Preferable source and time of information among breast cancer patients attending care at TASH Addis Ababa Ethiopia, March-May 2017 (n=375)

Item	Frequency	Percent
Preferable source of information		
Health professionals	254	67.73%
Media	9	2.4%
Leaflet	1	0.27%
Health education in health institution	14	3.73%
By any way/means	97	25.87%
Preferable time to have the information		
Before starting the treatment	284	75.73%
After starting the treatment	11	2.93%
After finishing the treatment	5	1.33%
Any time is possible	75	20%

Preferred source of information of breast cancer patients

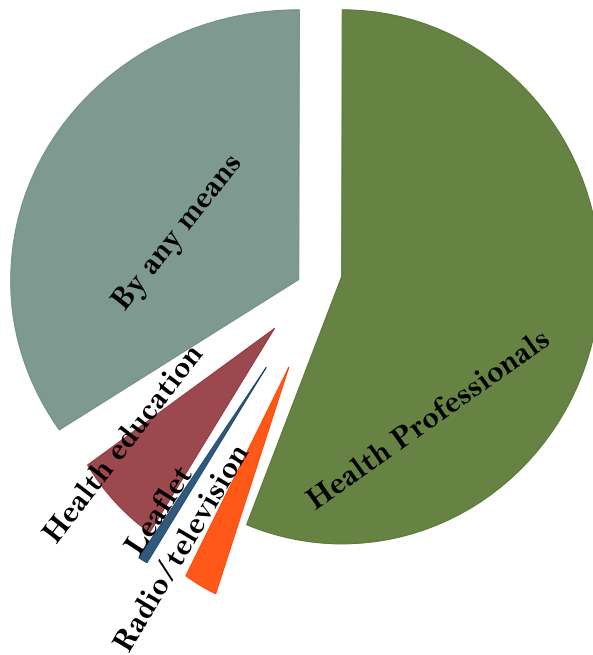


Figure 2: preferred sources of information needs of breast cancer patients attending care at TASH Addis Ababa Ethiopia, 2017

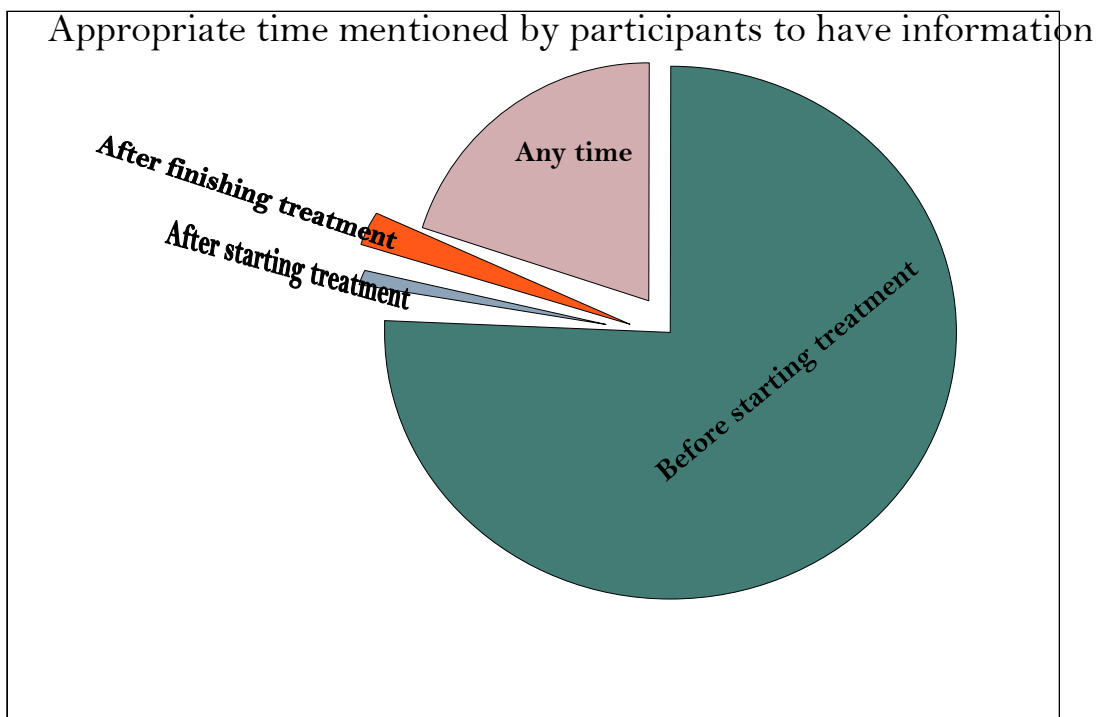


Fig 3: Preferred time to have information mentioned by breast cancer patients attending care at TASH Addis Ababa Ethiopia, 2017

Association of information needs with sociodemographic and clinical variables

To eliminate categorical variables from the regression procedures that did not show any significant relationships with the dependent variable, informational needs (TINQ), one-way analysis of variance (ANOVA) was conducted with the demographic variables age, marital status, religion, region, education, occupation, living location, time of diagnosis, stage at diagnosis, first degree relative with breast and type of therapy cancer, and tumor stage at time of diagnosis prior to the generation of the multiple regression analysis,

The only differences revealed by ANOVA were living locations and stage at diagnosis. Urban group (M=240.2) was significantly different ($F_{(2,372)}=3.55, p=0.02$) from the other groups semi-urban(M=232.7) and rural(M=232.1) and being diagnosed as stage IV(M=230) was significantly different($F_{(3,371)}=6.03, p=.0005$) from the other group stage I (M=235.4) , stage II(M=243) and stage III(M=240).Table 6 show the one way ANOVA result.

Table6: Association of sociodemographic and clinical variables with information needs of breast cancer patients attending care at TASH, Addis Ababa Ethiopia, 2017

Characteristics	Mean(S.D)	Frequency (in no)	Df	F	Pr>F
Participants age (years)					
20-35 years	239.08(24.19)	113	3,371	0.7	0.5
36-51years	239.65(22.47)	189			
52-67 years	236.27(19.55)	62			
>67	231.81(22.8)	11			
Current Marital Status					
Married	238.5(23.45)	280	3,371	0.3	0.7
Single	241.5(17.36)	39			
Widowed	239.5(23.2)	35			
Separated	236.11(20.1)	21			
Religion					
Orthodox	238.89(22.5)	265	2,372	0.08	0.924
Muslim	237.7(21.23)	62			
Others	238.11(25.6)	48			
Region					
Addis Ababa	240.3(21.65)	167	3,371	2.05	0.1
Oromia	236.(22.7)	127			
Amhara	244.64(20.6)	37			
Other	235.47(26.4)	44			
Participants education					
Illiterate	233.68(24.28)	80	4,370	1.81	0.13
Read & write	237.54(18.8)	55			
Elementary	238.5(24.3)	71			
High school	240.72(23.4)	112			
Above high school	243.08(18.7)	57			
Participants living environment					
Urban	240.2(21.6)	303	2,372	3.55	0.02**
Semi-Urban	232.7(26.6)	29			
Rural	232.16(24.7)	43			
participants occupation status					
Housewife	237.2(22.6)	212	4,370	1.73	0.1
Employed	242.8(22)	85			
Unemployed	242.3(18.8)	27			
	231.88(27.84)	25			
Farmer					
Others	239.6(21.4)	31	14		

Characteristics		Frequency	Df	F ratio	Prob>F
Time since diagnosis					
3months-1yr	238.7(23.1)	150	4, 370	0.49	0.7
1yr-2yr	237.9(23.9)	139			
2yr-3yr	240.5(18.7)	43			
3yr-4yr	236.2(23)	29			
4yr-5yr	245.1(18.3)	14			
Stage at diagnosis					
Stage I	235.35(26.6)	17	3, 371	6.03	0.0005**
Stage II	243.07(20.55)	115			
Stage III	240.26(22.15)	161			
Stage IV	230.12(23.1)	82			
Type of treatment					
Chemotherapy w surgery	238.7(25.27)	87	4, 370	0.33	0.86
Chemotherapy	236.57(21.5)	19			
Hormonal	239.09(21.02)	21			
Surgery	241.57(28.8)	84			
Radio with surgery or chemo	240.47(20.6)	139			

** Significant association

Tests for the assumptions for multiple regression analysis interpretation normality, linearity and non-multicollinerarity of the data were conducted and results of the analysis indicated that the assumptions for multiple regressions had been met.

Both urban and stage IV were significant as we see from the finding of the coefficient. Urban ($\beta= 6.7$, $t=2.32$ with $p=0.02$) and stage IV ($\beta= -10.3$, $t=-3.7$ with $p=0.000$).See table 7

	R	R-squared	Df	F	Sig
Model	0.05	0.04	2,372	10.66	0.0000
Regression coefficient					
	Coeff.	Std.err.	T	P > t	[95% Conf. Interval]
Urban	6.7	2.89	2.32	0.021	1.015 12.41
Stage	-10.31	2.76	-3.74	0.000	-15.74 -4.88
Cons	235.5	2.72	86.43	0.000	230.16 240.88

Pearson correlation was calculated to determine the correlation between urban locations and stage IV and urban is positively correlated with Toronto information needs total score ($r= 0.14$) whereas stage IV correlate negatively ($r= -0.2$)

6. DISCUSSION

To start from sociodemographic part the majority (80.53%) of participants in this study was between the age of 20 and 51 which shows breast cancer is affecting women at early age in contrast to developed countries which was more than two-thirds of breast cancer cases are diagnosed in women aged 50 years and older (54). Again 80.53% of the participants were living in urban area which is similar with the study of India, the finding stated that large number of breast cancer patients was living in urban areas[55]. This might be due to the presence of high risk factors in urban area or women with breast cancer are not coming to health facilities.

These days considering communication and information as important entity in helping people to cope with cancer is increasing and patients are actively involving in making decisions about their care for improvement of their quality of life. It is obvious that they will decide when they know well about their medical care and treatment options. Breast cancer patients have high need for information not only to help them to understand the disease and its treatment, but also to allow them to interpret the aversive events and action taken, so that the threat from the diagnosis becomes lesson by inherent [25-29].

This study will add some knowledge about the information needs of breast cancer patients who attend care in hospital. In terms of specific information, the participants need information extremely about some items in treatment and disease including if there is cancer anywhere else in their body and how to know if breast cancer has comeback which were congruent with different previous studies [47, 49, 50].

The overall information need is high with mean total score of 238.7(S.D 22.5, ; range, 156–260) out of 260 which was higher than the study of Korea which brought mean total score of 203.61 (standard deviation, 34.43; range, 109–255) and study of Graydon et al [47,49] .This can be because cancer patients in Ethiopia rely only on hospital environment and have no any alternative to get information since they are not educated and have no access.

Participants revealed that gaining information about the disease process (94.8%) as well as why and how treatments were performed (93.7%) were main areas of concern this is consistent with many studies that there is a high need for information among breast cancer

patients about illness and most importantly regarding their general condition and their treatment options [28]. But different from a study done in Egypt on breast cancer patients on surgical therapy majority (88%) of them expressed high and moderate importance for physical informational needs compared to other subscales[48] and this difference can be because of the type of treatment they were on which is cutting parts of the physical. But it is similar on psychosocial information needs which is among the least in both studies when compared to other subscales even though still high in current study.

When we relate with the only study regarding information needs of cancer patients in Ethiopia it is congruent in terms of type and higher in terms of amount which was 67.3% of the participants need information about the stage and type of cancer and 63.29% need about side effects of chemotherapy and their management[18]. The research conducted on specific type of cancer i.e. Breast cancer may makes to detect high information need since breast cancer patients are at their young age as well as the place of the cancer is sensitive to gender.

Even though it is still highly needed in this study information needs on psychosocial ranked the least in terms of score when compared to other subscales like many other studies [47-49].

The use of qualitative and quantitative approaches provides greater understanding of patients' information needs reported by patients [28].

This study also tried to gather data through in-depth interview to support the findings of the quantitative part and most participant expressed that diagnosing with breast cancer have traumatic effect on a general wellbeing of a woman.

Women need to be aware of the procedure and the side effects of the treatment, the behavior and the condition of the disease and the feelings and social concerns that may arise as a result of the disease. Information on how to receive help or referral to support groups can be beneficial in assisting women to deal with feelings and concerns after a breast cancer diagnosis. This is true since study shows information can ease uncertainty, fear, and loss that is created by the diagnosis of cancer [26]

Knowing the sources to which breast cancer patients turn for information would be helpful to a better information provision technique. Fisher et al also suggested that programs that use culturally acceptable information sources or that address key barriers to information seeking are more likely to be effective [56].

Participants of this study also asked to choose their preferred sources of information and most (67.7%) of them expressed that they want to have information which comes through health professionals of them want health professionals i.e. Doctors and nurses to be their source of information this is similar with the study of Mekuria et al which were Doctors and nurses were the preferred sources of cancer patients [18] and other many studies also suggest that the preferred source of information for breast cancer patients [8, 39]

Participants also asked the appropriate time that they prefer to have information and most(75.73%) of the participants suggested that the appropriate time to have the information was before starting the treatment and any time was cited by 20% of them.

In this study the only association found between sociodemographic and clinical variables were being stage IV at diagnosis and living in urban area. Living in urban area is associated with high information needs ($p=0.02$) compared to living in semi-urban or rural area which is similar with the finding of information needs of breast cancer in which there was association between residence and high information needs [48] whereas diagnosing as stage IV is associated with low information need ($p=0.000$) compared to diagnosing as other stage. This finding was different from Galloway et al. which was the only factor associated with information needs was age i.e. young age was associated with high information needs [47] the low information needs of patients with stage IV compared to other stage might be due to hopelessness. Unlike other studies [47-48, 58] Age and education is not associated with information needs in this study, this might be due to the high proportion of young age i.e. >50 t and similar educational status i.e. majority are high school and elementary which hide the mere difference among other statuses.

6.1 Limitation of this study

This study presented limitations, in that it was cross-sectional and included cancer patients exclusively in ambulatory treatment. The sample contained both early and advanced breast cancer patients, preventing a clear separation among people in different disease stages and such, together with the fact that a longitudinal approach was not carried out, hinders the possibility of an assessment of the information need of breast cancer patients throughout the disease process from diagnosis to cure or end of life.

It was also a single-institution study and may therefore not represent the reality of day Hospital patients' of other institutions and also other regions even though patients come from all parts of Ethiopia. So generalization is difficult.

The instrument used to assess patients' information needs, the TINQ-BC, is not validated in Ethiopia even though it was used in almost similar countries like Egypt.

7. CONCLUSION

Patients attending care at TASH present a higher overall information need. They reported high needs of information on each domain but especially on disease and treatment. The open questions also revealed these patients would like to receive more information about treatment side effects and be given detailed results of the tests they pass. They would also appreciate more information on long-term outcome, nutrition and recurrence symptoms.

Unlike other studies, the education level was not found to be associated with the level of information received because this sample was composed of similar educational attainments i.e. elementary and high school and because of that and such known effect was lost. Patients diagnosed as stage IV has less information need when compared to others. Patients living in urban area have more needs for information than patients living in semi-urban and rural area, so the information given requires tailoring.

Generally this study has aided knowledge by determining what areas are important in assisting women to be informed .It has contributed to research in the area of overall information need of breast cancer patients specifically in the area of treatment, disease and diagnostic tests, physical and psychosocial as reported by patients. The in-depth interview with patients and caregivers have supplied with valuable information about the specific needs and components necessary to assist women in treatment considerations, psychosocial wellbeing and decision making by learning about the impact of the fear of death, need for hope, importance of emotional feelings, and good communication between and with health care providers as well as with their surrounding as a whole.

8. RECOMMENDATION

- Breast cancer patients should get information about their illness along with the full range of treatment options and side effects.
- They should be a body who listens breast cancer patients' thoughts, preferences, and personal feelings to include these concepts into the presentation of information, scope of options, and recommended treatments and plan of care.
- There should be enough discussion time and conversation time with the patient should not be rushed realizing Patient's feelings, desires, and needs is an important aspect of providing care and information.
- Associations of breast cancer patients should be formed in an effort to provide support for and among breast cancer survivors. These sites also may provide a beneficial connection for women with newly diagnosed breast cancer, who are on treatment and have completed breast cancer treatments.

Future Research

- This study needs replication in a variety of settings using a nationally validated tool to include a greater diversity of cultures, educational levels, and geographical location.
- Communication patterns and partnerships with health care providers also needs further study in women diagnosed with breast cancer
- A qualitative approach solely to get more in-depth insights or possibly to elicit new or different findings about the information behavior of breast cancer patients
- A longitudinal approach is necessary to detect change on information needs of breast cancer patients throughout the disease process from diagnosis to cure or end of life.
- A longitudinal approach to detect the effect of having information on quality of life and survival
- Examining the availability of information provision system in Ethiopia and developing culturally and socially sound information provision system.
- Validating TINQ-BC in Ethiopia for a cross-cultural adoption.

References

1. American cancer society, what is cancer? Last Medical Review: 9/19/2014 and last revised: 1/29/2016, page 1.
2. Gray, R. E., Fitch, M., Greenberg, M., Hampson, A., Doherty, M., & Labrecque, M. (1998) information need of well, longer-term survivors of breast cancer. *Patient education and counseling*, 33(3), 245-255.
3. Ferlay J, Shin HR, Bray F, Forman D, Mathers C, Parkin DM. GLOBOCAN 2008 v1.2. Cancer incidence and mortality worldwide: IARC Cancer Base No. 10. Lyon: International Agency for Research on Cancer; 2010
4. Tigeneh W (2015) Pattern of Cancer in Tikur Anbessa Specialized Hospital Oncology Center in Ethiopia from 1998 to 2010. *Int J Cancer Res Mol Mech* Volume 1.1: doi <http://dx.doi.org/10.16966/2381-3318.103>
5. Ethiopian Cancer Association. Fight against tobacco to reduce the risk of cancer through anti-tobacco youth clubs in Ethiopia. Available at <http://www.yeeca.org>
6. Cassileth BR, Zupkis RV, Sutton-Smith K, March V. Information and participation preferences among cancer patients. *Ann Intern Med* 1980;92:832-6.
7. Andy S.L. Tan, Mihaela Moldovan-Johnson et al. An analysis of the association between cancer-related information seeking and adherence to breast cancer surveillance procedures. , 2012; DOI: 10.1158/1055-9965.EPI-12-0781.
8. vander Meulen N, Jansen J, van Dulmen S et al. Interventions to improve recall of medical information in cancer patients: A systematic review of the literatures. *Psychooncology* 2008;17:857-868.
9. Sainio C, Eriksson E. Keeping cancer patients informed: a challenge for nursing. *Eur J Oncol Nurs* 2003;7:39-49
10. Harrison-Woermke DE, Graydon JE. Perceived informational needs of breast cancer patients receiving radiation therapy after excisional biopsy and axillary node dissection. *Cancer Nurs* 1993;16:449-55
11. Meredith C, Symonds P, Webster L, Lamont D, Pyper E, Gillis CR, et al. Information needs of cancer patients in west Scotland: Cross sectional survey of patients' views. *BMJ*. 1996;313:724-6.

12. Reynolds PM, Sanson-Fisher RW, Poole AD, Harker J, Byrne MJ. Cancer and communication: Information-giving in an oncology clinic. *Br Med J (Clin Res Ed)* 1981;282:1449–51
13. Ethiopian Cancer Association, “Breast cancer,” [http://www.yeeca.org/Learn about Cancer.htm](http://www.yeeca.org/Learn%20about%20Cancer.htm)
14. Abate SM, Yilma Z, Assefa M, Tigneh W (2016) Trends of breast cancer in Ethiopia. *Int J cancer Res Moi Mech* 2(1): doi <http://dx.doi.org/10.16966/2381-3318.121>
15. Srivastava V, Mumtaz Ahmad Ansari, Anand Kumar et al. Study of anxiety and depression among breast cancer patients from North India. 2016, Vol.2 No.1: 4
16. Cheryl ann Spittler. Exploration of how women make treatment decisions after a breast cancer diagnosis. 2011. Available at <https://kuscholarworks.ku.edu/>.
17. RK Grover, N Kaur, R Miglani. Information and rehabilitation needs of Indian breast cancer patients: report of a cross sectional study. *Indian journal of cancer* vol. 51, no. 3 July-September, 2014, pp. 262-266
18. Abebe Basaazim Mekuriya, Daniel Asfaw Erku, Sewnet Admasu Belachew. Preferred information sources and needs of cancer patients on disease symptom and management: A cross sectional study. *Patient preference and adherence* , Dove press 2016: 10 1991-1997
19. Mohsen Naghavi et al. Global burden of cancer 2013. *JAMA Oncology*. 2015 July 1; 1(4): 505–527. doi:10.1001/jamaoncol.2015.0735.
20. Yasuhiro Toyoda, Takahiro Tabuchi et al. Past trends and future estimation of annual breast cancer incidence in Osaka, Japan. *Asian Pac J Cancer Prev*, 2016, 17 (6), 2847-2852
21. Karla Unger-Saldaña. Challenges to the early diagnosis and treatment of breast cancer in developing countries. *World Journal of Clinical Oncology*. 2014 No 8721, issue 2.
22. Parkin DM, Namboozee S, Wabwire-Mangen F, Wabinga HR: Changing cancer incidence in Kampala, Uganda, 1990-2006, *Int J cancer* 2010, 126(5):1187–1195.
23. Coleman et al. Cancer survival in five continents: a worldwide population-based study (CONCORD). *Lancet Oncology* 2008; 9: 730-756
24. Sankaranarayanan et al. Cancer survival in Africa, Asia, and Central America: a population-based study. *Lancet Oncol* 2010; 11: 165-173

25. Unger-Saldana K. Challenges to the early diagnosis and treatment of breast cancer in developing countries (2014). *World journal of clinical oncology*, volume 5, issue 3.
26. Geraldine M Leydon, Mary Boulton, Clare Moynihan, et al. Cancer patients information' needs and information seeking behavior: in-depth interview study. April, 2000. *BMJ VOLUME 320*.
27. Shim H-Y, Park J-H, Kim S-Y, Shin DW, Shin J-Y, et al. (2014) Discordance between Perceived and Actual Cancer Stage among Cancer Patients in Korea: A Nationwide Survey. *PLoS ONE 9(5): e90483*. doi:10.1371/journal.pone.0090483.
28. Finney Rutten LJ, Arora NK, Bakos AD, Aziz N, Rowland J: Information needs and sources of information among cancer patients: a systematic review of research (1980–2003). *Patient Educ Couns 2005, 57:250–261*.
29. Yik Mun Lee, Jayne Francis, Kare Walker, Sze Ming Lee. What are the information needs of Chinese breast cancer patients receiving chemotherapy. *Asian pacific journal of cancer*. 2007 April . Vol 51, issue 2.
30. Ina Fourie. Information needs information behaviors of patients and their family members in a cancer palliative care setting: An exploratory study of an existential context from different context. December 2008. *iR information research*. Vol. 13, No.4.
31. Leng J, Lee T, Sarpel U, Lau J, Li Y, Cheng C, Chang MD, Gany F. Identifying the information and psychosocial needs of Chinese immigrant cancer patients. A focus group study. PubMed - indexed for MEDLINE.
32. Ragas et al. What Women Want: Patient Recommendations for Improving Access to Breast and Cervical Cancer Screening and Follow-up. PMC. *Women Health Issues*. 2014 ; vol 24, issue 5.
33. MacCallum M, Jolicoer L, Lefebvre M, Babchishin LK, Robert Chauret S, Le T, Lebel S. Supportive care needs after gynecologic cancer: where does sexual health fit in? 2008 PMC. *J of women's*. Vol 14, issue 3.
34. Corney R, Everett H, Howells A, Crowther M. The care of patients undergoing surgery for gynecological cancer: the need of information, emotional support and counseling. 1992 June. Vol 17, issue 6.
35. Lambert, S. D, Loisele, C. G. (2007). Health information – seeking behavior. *Qualitative Health Research*, 17(8), 1006-1019.

36. Eheman et al. Information seeking styles among cancer patients before and after treatment by demographics and use of information sources. *J Health Commun.* 2009 ; 14(5)
37. Thorburn et al. Sources of breast and cervical cancer information for Hmong women and women.PMC. *Women Health.* 2013 ; 53(5).
38. Parker PA, Davison BJ, Tishelman C, Brundage MD. What do we know about facilitating patient communication in the cancer care setting? *Psychooncology.* 2005;14:848-858.
39. Hesse BW, Nelson DE, Kreps GL, et al. Trust and sources of health information: the impact of the Internet and its implications for health care providers: findings from the first Health Information National Trends Survey. *Arch Intern Med.* 2005;165:2618-2624
40. Talosig-Garcia M, Davis SW. Information seeking behaviors of minority breast patients. An exploratory study. 2005 10, suppl 1.
41. David K.Whyntes, Katherine Clarke, Zoë Philips, Mark Avis,"Cervical cancer screening and perceived information needs", *Health Education*,2006. Vol. 105 Issue: 4.
42. Munoz-Antonia et al. African Americans' and Hispanics' information needs about cancer care. *J Cancer Educ.* 2015 June; 30(2):PMC.
43. Simon et al. Perception of patient provider communication in breast and cervical related care. A qualitative study of low income English and Spanish speaking women. *J Community Health.* 2013 August ; 38(4).
44. Lee et al. Looking beyond the internet; Examining socioeconomic inequalities in cancer information seeking among cancer patients. *Health Commun.* 2012;27(8).PMC.
45. Case, D.O. (2007). *Looking for information: a survey of research on information seeking, needs and behaviour.* 2nd ed. Amsterdam: Elsevier.
46. Woubshet Y. ,Girma B. ,Teklu M. A. Cancer in Ethiopia. *Lancet Oncology.*2013.Vol 14. DOI: 10.1016/S1470-2045(12)70399-6 · Source: PubMed
47. Galloway, S., Graydon, J., Harrison, et al. (1997). Informational needs of women with a recent diagnosis of breast cancer: development and initial testing of a tool. *Journal of Advanced Nursing.* 25, 1175-1183.

48. Labiba Abd El-kader Mohamed, Hanan Ahmed El-Sebaee. Comparison of informational needs among newly diagnosed breast cancer women undergoing different surgical modalities. *Journal of Biology, Agriculture and Healthcare* ISSN 2224-3208 (Paper) ISSN 2225-093X (Online) Vol.3, No.13, 2013
49. Myungsun Yi, Juhee Cho, Dong-Young Noh. Informational needs of Korean women with breast cancer: cross-cultural adaptation of the Toronto informational needs questionnaire of breast cancer. *Asian nursing research*, 2007. Vol 1.no 3
50. Harrison, D. E., Galloway, S., Graydon, J. E., Palmer-Wickham, S., & Rich-van der Bij, L. (1999). Information needs and preference for information of women with breast cancer over a first course of radiation therapy. *Patient Education and Counseling*, 38, 217–225.
51. Lee, Y. M., Francis, K., Walker, J., & Lee, S. M. (2004). What are the information needs of Chinese breast cancer patients receiving chemotherapy? *European Oncology Nursing Society*, 8, 224–233.
52. Templeton, H. R. M., & Coates, V. E. (2001). Adaptation of an instrument to measure the informational needs of men with prostate cancer. *Journal of Advanced Nursing*, 35, 357–364.
53. . Wilson TD. *Human Information Behavior*. University of Sheffield, UK. 2000; vol.3:2.
54. Coughlin SS, Cypel Y (2013) Epidemiology of Breast Cancer in Women. In: Ahmed A (eds) *Breast Cancer Metastasis and Drug Resistance*. Springer, New York
55. Pakseresht, S., Ingle, G. K., Bahadur, A.K., Ramteke, V. K., Singh, M.M., Garg, S. & Agarwal, P.N. (2009).
56. Risk factors with Breast Cancer among Women in Delhi. *Indian Journal of Cancer*, 46 (2): pp. 132-138..
57. Fisher TL, Burnet DL, Huang ES, Chin MH, Cagney KA. Cultural leverage: Interventions using culture to narrow racial disparities in health care. *Med Car Res Rev*. 2007; 64(5 Suppl):243S–82S.
58. Ankem K. Factors influencing information needs among cancer patients: A meta-analysis. *Library & Information Science Research* 28 (2006) 7–23

ANNEXS

Annex I

Information sheet

Greeting: Good morning/afternoon!

Hello. My name is _____. I am data collector for master of public health student project in Addis Ababa University. I am conducting a study with the aim of assessing the information needs of breast and cancer patients in Tikur Anbessa hospital. The information I collect will help to you and the government at large to plan a better information provision system for patients in general and for breast cancer patients in particular. Now you are randomly selected for the survey. The questions usually take about 20 to 25 minutes.

Objective of the study: Assessing the information needs of breast cancer patients in Tikur Anbessa Specialized hospital.

Benefit of the study: The participants will have long and short term benefits. The long term benefit would be, the result of the study will be useful to expand and implement a good information provision system on breast cancer which could be very beneficiary for the participants and also for the overall community.

Risk of the study: Participating in this study will not have any risk or harm.

Rights of Participants: You have full right either to participate or refuse as well as to quit at the middle or at any time you want after you start the participation in this study. You may respond to all the questions or you may not answer to questions you don't want to answer. You can ask any question which is not clear for you.

Confidentiality: Any information forwarded will be kept confidential and names will not be written or specified.

Annex II

Informed consent

As to the information given on the above, Participating in this study has no any harm or risk. Your name will not be written on this form and the information you give will never be shared to anyone. It is possible not to answer any questions that you don't want to answer and you may end this interview at any time you want .You are selected by chance to participate in this study and your sincere response to the interview will be very valuable for the achievement of the study.

At the same time we would like to appreciate your voluntarily participation in the study after a thorough understanding of the information given to you.

I have read this form or it has been read to me in the language I comprehend and understand all conditions stated above.

Then are you willing to participate in this study?

1- No (say thank you)

2- Yes (continue interviewing)

Name of principal investigator: Birhan Legese

Cell phone No – 0910796908

E-mail: birhan4j@gmail.com.

Name of interviewer _____ signature _____

Date of interview (Ethiopian calendar) ____/____/____

Result of interview:

1- Completed..... 2- Refused

3- Respondent not available..... 4- Partially completed

Checked by supervisor;

Name Signature Date

Annex III Questionnaire

Information regarding socio-demographic factors

No	Question	Answer	Skip
101	How old are you (in years)?	
102	Sex	F.....1 M.....2	
103	What is your Religion?	Orthodox.....1 Muslim.....2 Protestant.....3 Catholic.....4 Other.....5	
104	Where is your living Region?	Oromia.....1 Addis Ababa....2 Amhara.....3 SNNPR.....4 Other.....5	
105	What type of living environment are you from	City.....1 Countryside.....2 Periurban.....3	
106	What is your marital status?	single...1 Married.....2 Divorce.....3 Widowed.....4 separated.....5	
107	What is your educational status?	illiterate.....1 primary.....2 secondary.....3	

		college.....4 Other.....5	
108	What is your Occupation?	House wife.....1 Private employee.....2 Farmer.....3 Government employee... 4 Daily laborer.....5 Merchant..... 6 Student.....7 Others (specify)..... 8	
To be filled from patient card			
109	Type of cancer?	Breast cancer.....1 Other.....2	
110	Stage of cancer?	Stage I.....1 Stag II.....2 Stage III.....3 Stage IV.....4	
111	Date of diagnosis?/...../.....	
112	Type of treatment?	Chemotherapy.....1 Radiotherapy.....2 Surgery.....3 Hormonal.....4 Other.....5	

II. Questionnaire for information needs

Questionnaire

I am interested in learning about the types of information women with breast cancer need.

How important it is/was for you to have this information?

1. Information need on treatment

		Not important	Slightly important	Moderately important	Very important	Extremely important
1	What types of treatment are available	1	2	3	4	5
2	Who to talk with if I hear about treatments other than the available	1	2	3	4	5
3	How to prepare for my Treatment	1	2	3	4	5
4	If I have side effects, how to deal with them	1	2	3	4	5
5	How I will feel after my Treatment	1	2	3	4	5
6	Who I should call if I have questions while I am still getting treatment	1	2	3	4	5
7	How my treatment is done	1	2	3	4	5
8	How long I will be receiving Treatment					
9	Why the doctor suggest this treatment for me	1	2	3	4	5
10	The possible side effects of my treatment	1	2	3	4	5
11	If there are ways to prevent treatment side effects	1	2	3	4	5
12	What side effects I should report to the doctor/nurse	1	2	3	4	5
13	Who should I call if I have questions after all the treatments are over	1	2	3	4	5
14	If the treatment will alter the way I look	1	2	3	4	5
15	If I am prone to infection to because of my treatment	1	2	3	4	5
16	How the treatment works against cancer	1	2	3	4	5

2. Information need on the disease

		Not important	Slightly important	Moderately important	Very important	Extremely important
17	If it is known what causes breast cancer	1	2	3	4	5
18	If the breast cancer will come back	1	2	3	4	5
19	If there is cancer anywhere else in my body	1	2	3	4	5
20	How the illness may affect my life over the next few months	1	2	3	4	5
21	How breast cancer acts in the body	1	2	3	4	5
22	If my illness is hereditary	1	2	3	4	5
23	How the illness may affect my life in the future	1	2	3	4	5
24	The medical name for my type of breast cancer	1	2	3	4	5
25	How to know if the cancer has come back	1	2	3	4	5

3. Information about Investigative test

		Not important	Slightly important	Moderately important	Very important	Extremely important
26	How I will feel during the test	1	2	3	4	5
27	How the tests(e.g. x-ray, bone scans) are done	1	2	3	4	5
28	The meaning of the result of the test	1	2	3	4	5
29	Why the doctor suggest this test and if there are other ways of testing.	1	2	3	4	5
30	Why they need to test by blood	1	2	3	4	5
31	How I will feel after the tests	1	2	3	4	5

32	What is the result of blood test mean	1	2	3	4	5
33	When to have a mammogram	1	2	3	4	5

4. Information needs on Physical

		Not important	Slightly important	Moderately important	Very important	Extremely important
34	If there are any physical things I should not do	1	2	3	4	5
35	How long my wound/incision will take to heal	1	2	3	4	5
36	If I can wear brassiere or if there is change in my wearing style	1	2	3	4	5
37	Which foods I can or cannot Eat	1	2	3	4	5
38	How to care for my wound or incision	1	2	3	4	5
39	If I can continue my usual hobbies and sports	1	2	3	4	5
40	If I'm going to need help taking care of myself	1	2	3	4	5
41	Where to examine my breasts	1	2	3	4	5
42	If I can take a bath or a shower	1	2	3	4	5
43	How to tell if the cancer has come back	1	2	3	4	5
44	If there is special exercise I have to do	1	2	3	4	5

5. Psychosocial information need

		Not important	Slightly important	Moderately important	Very important	Extremely important
45	If there are groups where I can talk with other people with cancer	1	2	3	4	5
46	Where can I get help if I have problems feeling as attractive as I did before	1	2	3	4	5
47	What to do if I feel uncomfortable in social situations	1	2	3	4	5
48	If I can continue my usual social activities	1	2	3	4	5
49	If there will be changes in the usual things I can do with and for my family.	1	2	3	4	5
50	Where I can get help to deal with my feelings about my illness	1	2	3	4	5
51	What to do if I become concerned about dying	1	2	3	4	5
52	Where my family can go if they need help dealing with my illness	1	2	3	4	5

53. What is your preferable source to get information?

- | | |
|----------------------------|--|
| 1. Doctor | 5. Health education in health institution |
| 2. Nurse | 6. By any way/means |
| 3. Radio/television | 7. Other specify |
| 4. Leaflet | |

54. When is your preferable time to get information?

- 1. Before starting the treatment**
- 2. After I start the treatment**
- 3. After the treatment is over**
- 4. Any time is possible**

Questions for qualitative data

Hello Dear!

I am doing a research with the aim of assessing information needs of breast cancer patients. So I want to carry out an in-depth interview with you because it is important for the study. And an idea that gathered from you is very useful to plan a better information provision for breast cancer patients. During this interview, I will raise some question regarding the needs of information among breast cancer patients for the purpose of grasping the main idea and analysis I will record your voice but I will remove it completely after I take the idea from it . Thank you for your time and help.

Discussion points

	Regarding Information needs	
1	First what is your opinion regarding the importance of information? Have you a desire for information?	
2	What type of information do you think most importantly required by breast cancer patients?	
3	When is the information required?	
4	What do you think the possible reasons for needing information are?	
	Regarding Information sources	
5	What do you think that the most Preferable information sources are? Why	
6	Do you think patients are Willing to ask any question related to their health?	
7	Do you think other people should be informed other than patient too?	
	Regarding Influencing factors	
8	What do you think the possible factors that affect information flow?	

9	What sort of things should be improved for smooth and strong provision of information for breast cancer patients?	
---	---	--

የመረጃ መስጫ

የጥናቱ ርዕስ:- በጥቁር አንበሳ ሆስፒታል የሚገኙትን የጡት ካንሰር ያለባቸውን አዎቂ ሴቶችን መረጃ የማግኘት ፍላጎታቸውን መጠየቅ/ማጥናት

ጤና ይስጥልኝ እባላለው። እኔ ዛሬ እዚህ የተገኘሁት በአዲስ አበባ ዩኒቨርሲቲ የህብረተሰብ ጤና ተማሪ የሆነችውን ብርሃን ለገሰ በመወከል ሲሆን በጥቁር አንበሳ ሆስፒታል ከላይ በተጠቀሰው ርዕስ ላይ ጥናት እያደረገች ሲሆን ጥናቱም የማስትርስ ዲግሪ ለማግኘት የሚያስችላት ነው። በጥናቱ ላይ ለመሳተፍ ከመወሰንም በፊት የጥናቱን አላማ ፣ ጥናቱ ላይ በመሳተፍ የሚያገኙት ጥቅም እና ጉዳት እንዲሁም ደግሞ ከእርስዎ የሚጠበቀውን ሁኔታ እንደሚከተለው እገልጻለሁ።

አላማ:- በጥቁር አንበሳ ሆስፒታል የሚገኙትን የጡት ካንሰር ያለባቸውን ሴቶች መረጃ የማግኘት ፍላጎታቸውን ማጥናት

ቅደም ተከተል:- የስምምነት ወረቀቱን ከፈረሙ በኋላ የተዋቀሩና አግባብ ያላቸውን ጥያቄዎች መረጃ ሰብሳቢው ይጠይቅታል ምላሽም ወረቀቱ ላይ ይሰፍራል መጠየቁም ቢበዛ ከ20-25 ደቂቃ ይወስዳል።

ለተጠያቂው የሚሰጠው ጥቅም: ተጠያቂው ሆነ ሌሎች ህሙማን ብሎም ማህበረሰቡ ዘላቂነት ያለው ጥቅም ያገኛል ይህም የጥናቱ ውጤት በህሙማን ፍላጎት ላይ የተመሰረተ ትክክለኛ የሆነ የመረጃ አቅርቦትና ዝርጋታን ለማስፈጸም እንደ ግብአት የሚረዳ ሲሆን ይህም የጡት ካንሰር ያለባቸውን ሰዎችም ሆኑ ሌሎች ስለ አጠቃላይ የጤና ሁኔታቸው እና አጠባበቅ ይረዱ ዘንድ የሚያስችል ነው።

የሚያስከትለው ጉዳት:- በዚህ ጥናት ላይ መሳተፍ የሚያስከትለው ምንም አይነት ጉዳት የለም

የተጠያቂው መብቶች:- ለመሳተፍ ሆነ ላለመሳተፍ ሙሉ መብት አለው፤ መጠየቁን ጀምረው ከመሀል የማቆምም ሆነ ያልፈለጉትን ጥያቄ ያለመመለስ ሙሉ መብት አለው

ሚስጥራዊነት:- ሁሉም መረጃ ሚስጥራዊነቱ የተጠበቀ ሲሆን የዕርሶ ስም በመጠየቁ ላይ አይሰፍርም የምንጠቀመው የሚስጥ ቁጥር ነው

የስምምነት ቅፅ

ከላይ የጥናቱ አላማ፣ ጥቅሙ ፣ ጉዳቱ፣ እንዲሁም ሚስጥራዊነቱ በሚገባኝ እና በምረዳው ቋንቋ ተገለጻል። በጥናቱ ላይ ያለመሳተፍም ሆነ ከጀመርኩ በኋላ በፈለኩት ጊዜ አቋርጬ የመሄድ ሙሉ መብት አለኝ።

በዚህ ጥናት ላይ ተሳትፎዬ ፈፅሞ በፍላጎት ላይ የተመሰረተ ነው

በዚህ ጥናት ላይ ለመሳተፍ ፍቃደኛ ንዎት?

- 1. አይደለሁም (አመሰግናለሁ)
- 2. አዎ (እንቀጥል)

የጥናት አድራጊዎ ስም:- ብርሀን ለገሰ

ስልክ ቁጥር:- +251910796908

ኢ-ሚይል:- birhan4j@gmail.com

የተጠያቂው ስም ፊርማ

የተጠየቀበት ቀን/...../.....

የጥናቱ ውጤት:

- 1. ተጠናቋል
 - 2. መጠየቅ አልፏለትም
 - 3. በከፊል ተጠናቀቀ
 - 4. ተጠያቂው አልተገኘም
- በተቆጣጣሪ ተረጋግጧል ስም ፊርማ ቀን

101	ዕድሜዎት ስንት ነው? (በአመት)ዓመት
-----	-------------------------	----------

102	የምን ሐይማኖት ተከታይ ነዎት?	አርቶዶክስ1 ሙስሊም2 ፕሮቴስታንት3	ካቶሊክ4 የባህልአምልኮ5 የተለየ ከሆነ ይጠቀስ6
103	ከምን አይነት አካባቢ ነው የመጡት?	ከተማ1 ከተማ ቀመስ ገጠር3	ገጠር2
104	ከየትኛው ክልል ነው የመጡት?	አሮሚያ1 አዲስ አበባ2 አማራ3	ትግራይ4 ሶማሊ5 ሌላ6
105	የጋብቻ ሁኔታ ?	ያገቡ1 ያላገቡ2 የተፋቱ3	ባል የሞተባቸው4 ያላገቡ አብረው ሚኖሩ5
106	የትምህርት ሁኔታ?	ያልተማሩ1 ማንበብና መጻፍ የሚችሉ2 አንደኛ ደረጃ3 ሁለተኛ ደረጃ4 ቴክኒክ እና ሙያ የተማሩ5 ከፍተኛ ትምህርት (ይገለፁ)6	
107	የእርስዎ ስራ ሁኔታ? (መረጃ ሰብሳቢ፣ከአንድ በላይ መልስ ሊኖር ይችላል)	የቤት እመቤት1 አርሶ/አርብቶ አደር2 ነጋዴ3 የመንግስት/የሙያ ደ. ተቀጣሪ4 የጉልበት ስራተኛ5 ተማሪ6 የተለየ ከሆነ ይጥቀሱ7	
ክሊኒካል መረጃ (ከካርድ የሚሞላ)			
108	የካንሰር አይነት?	
109	የካንሰር ደረጃ?	
110	ካንሰር መቼ ነው የተገኘው (የተረጋገጠበት ቀን)?/...../.....	
110	እየወሰዱ ያሉት የህክምና አይነት	ኬሞ1 ጨረር2 ቀዶ ጥገና3 ሆርሞናል4 ሌላ5	

ክፍል 2: ስለ ጡት ካንሰር መረጃ የማግኘት ፍላጎትን በተመለከተ መጠይቅ

ህክምናውን በተመለከተ						
ተ.ቁ		አያስፈልግም	በመጠኑ ያስፈልጋል	ያስፈልጋል	በጣም ያስፈልጋል	እጅግ በጣም ያስፈልጋል
1	ለዚህ በሽታ የሚሆኑ የህክምና አይነቶች ምን ምን እንደሆኑ ማወቅ	1	2	3	4	5
2	አሁን ካሉት የህክምና አማራጮች ውጪ ሌላ እንዳለ ብሰማ ለማን ማሳወቅ እንዳለብኝ ማወቅ	1	2	3	4	5
3	ለህክምናው እንዴት መዘጋጀት እንዳለብኝ ማወቅ	1	2	3	4	5
4	በህክምናው ምክንያት የጉንዳኝ ጉዳት ሲያጋጥመኝ ምን ማድረግ እንዳለብኝ ማወቅ	1	2	3	4	5
5	ከህክምና በኋላ እንዴት እንደማስማኝ ማወቅ	1	2	3	4	5
6	ህክምና ላይ እያለው ጥያቄ ቢኖርብኝ ለማን መናገር እንዳለብኝ ማወቅ	1	2	3	4	5
7	ህክምናዬ እንዴት እንደሚከናወን ማወቅ	1	2	3	4	5
8	ለምን ያህል ጊዜ ህክምና ላይ እንደምቆይ ማወቅ	1	2	3	4	5
9	ዶክተሩ ይህን አይነቱን የህክምና አይነት ለምን እንዳዘዘለኝ ማወቅ	1	2	3	4	5
10	ህክምናው ሊያስከትለው የሚችለውን የጉንዳኝ ጉዳት ማወቅ	1	2	3	4	5
11	የጎንዳኝ ጉዳት እንዳይመጣ የምከላከልበት መንገድ ካለ	1	2	3	4	5
12	ምን አይነት የጎንዳኝ ጉዳት ሲደርስብኝ ለዶክተር /ካርስ መንገር እንዳለብኝ ማወቅ	1	2	3	4	5

13	ህክምናዬን ሁሉ ከጨረስኩ በኋላ ጥያቄ ቢኖርብኝ ለማን መንገር እንዳለብኝ ማወቅ	1	2	3	4	5
14	ህክምናው በአካሌ ላይ የተለየ እይታ የሚያመጣብኝ ከሆነ ማወቅ	1	2	3	4	5
15	በህክምናው ምክንያት በቀላሉ ለበሽታ የምጋለጥ ከሆነ ማወቅ	1	2	3	4	5
16	ህክምናው እንዴት ካንሰሩን ለማጥፋት እንደሚሰራ ማወቅ	1	2	3	4	5
በሽታውን በተመለከተ						
		አያስፈልግም	በመጠኑ ያስፈልጋል	ያስፈልጋል	በጣም ያስፈልጋል	እጅግ በጣም ያስፈልጋል
17	የጡት ካንሰር የሚያመጣ ነገር ከታወቀ እሱን ማወቅ	1	2	3	4	5
18	የጡት ካንሰር ተመልሶ የሚመጣ ከሆነ ማወቅ	1	2	3	4	5
19	ከጡቴ ውጪ ሌላ ቦታ ካንሰር ካለብኝ ማወቅ	1	2	3	4	5
20	በሚቀጥሉት ጥቂት ወራት ውስጥ በሽታው እንዴት ሊጎዳኝ እንደሚችል ማወቅ	1	2	3	4	5
21	የጡት ካንሰር ሰውነትን እንዴት እንደሚያደርግ ማወቅ	1	2	3	4	5
22	በሽታው ከዘር ወደ ዘር የሚተላለፍ ከሆነ ማወቅ	1	2	3	4	5
23	ወደፊት በሽታው ህይወቴን እንዴት ሊጎዳው እንደሚችል ማወቅ	1	2	3	4	5
24	የእንደኔ አይነቱ የጡት ካንሰር በህክምናው ምን ተብሎ እንደሚጠራ ማወቅ	1	2	3	4	5
25	ካንሰሩ ተመልሶ ቢመጣ እንዴት ማወቅ	1	2	3	4	5

	እንደሚቻል ማወቅ					
ምርመራውን በተመለከተ						
26	ምርመራው በሚከናወንበት ጊዜ ሊሰማ የሚችለውን ስሜት ማወቅ	1	2	3	4	5
27	ምርመራው እንዴት እንደሚካሄድ ማወቅ	1	2	3	4	5
28	የምርመራው ውጤት ምን ማለት እንደሆነ ማወቅ	1	2	3	4	5
29	ሀኪሙ ይህን አይነቱን ምርመራ ለምን እንዳዘዘ ማወቅ እና ሌላ አማራጭ ካለ ማወቅ	1	2	3	4	5
30	የደም ምርመራ ለምን እንዳስፈለገ ማወቅ	1	2	3	4	5
31	ከምርመራው በኋላ ምን አይነት ስሜት ሊሰማኝ እንደሚችል ማወቅ	1	2	3	4	5
32	የደም ምርመራው ምን ማለት እንደሆነ ማወቅ	1	2	3	4	5
33	የጡት ራጂ መነሳት ያለብኝ መቼ እንደሆነ ማወቅ	1	2	3	4	5
አካላዊ ጤናን በተመለከተ						
34	ማድረግ የሌለብኝ የእንቅስቃሴ ወይም አካላዊ ድርጊት ካለ ማወቅ	1	2	3	4	5
35	በህክምናው ምክንያት የሚመጣው ቁስል ለመዳን የሚፈጅበት ጊዜ ምን ያህል እንደሆነ ማወቅ	1	2	3	4	5
36	የጡት ማስያዣ ማድረግ እችል እንደሆነ እና በአለባበሴ ላይ ለውጥ ማድረግ ካለብኝ ማወቅ	1	2	3	4	5
37	መብላት ያለብኝ እና የሌለብኝ የምግብ አይነት ካለ ማወቅ	1	2	3	4	5
38	ቁስሌ ቶሎ እንዲድን	1	2	3	4	5

	ምን አይነት እንክብካቤ ማድረግ እንዳለብኝ ማወቅ					
39	በፊት አደርጋቸው የነበሩት ድርጊቶችና ልምዶችን መቀጠል እችል እንደሆነ ማወቅ	1	2	3	4	5
40	ራሴን ለመንከባከብ የሌላው እርዳታና ድጋፍ የሚያሻኝ ከሆነ ማወቅ	1	2	3	4	5
41	የጡት ምርመራ የት ማድረግ እንዳለብኝ ማወቅ	1	2	3	4	5
42	ሰውነቴን መታጠብ እችል እንደሆነ ማወቅ	1	2	3	4	5
43	በሽታው ተመልሶ ቢመጣበኝ ምን ማድረግ እንዳለብኝ ማወቅ	1	2	3	4	5
44	እጄን በተለየ መልኩ ማንቀሳቀስ ካለብኝ ማወቅ	1	2	3	4	5

የሰነ-አእምሮ እና ማህበራዊ ጉዳዮችን በተመለከተ

		አያስፈልግም	በመጠኑ ስፈልጋል	ያስፈልጋል	በጣም ስፈልጋል	እጅግ በጣም ያስፈልጋል
45	ሌላ ካንሰር ያለባቸው አብሬ ልወያይ የምችልባቸው ቡድኖች ካሉ ማወቅ	1	2	3	4	5
46	ልክ እንደድሮው የሴትነት ውበት እንዳለኝ የማይሰማኝ ከሆነ ዕርዳታ ከየት ማግኘት እንደምችል ማወቅ	1	2	3	4	5
47	በማህበራዊ እንቅስቃሴ ጊዜ ምቹኝ ካልተሰማኝ ምን ማድረግ እንዳለብኝ ማወቅ	1	2	3	4	5
48	ከጋደኞቹም ጋርም ሆነ ከቤተሰቦቹ ጋር ስለበሽታይ እንዴት ማውራት እንዳለብኝ ማወቅ	1	2	3	4	5
49	ከቤተሰቦቹ ጋር በማደርገው እና	1	2	3	4	5

	በማደርግላቸው ነገር ላይ ለውጥ የሚኖር ከሆነ ማወቅ					
50	በበሽታው ምክንያት ለሚፈጠርብኝ ስሜት እርዳታ ብፈልግ ከየት ማግኘት እንደምችል ማወቅ	1	2	3	4	5
51	ስለ ሞት እሰብኩ ብጨነቅ ምን ማረድግ እንዳለብኝ ማወቅ	1	2	3	4	5
52	ህመሜን አስመልክቶ ቤተሰቦቼ እርዳታ ቢፈልጉ ወይም መሄድ እንዳለባቸው ማወቅ	1	2	3	4	5

53. መረጃው በማን በኩል ቢደርሰ/ቢሰጥዎ ይመርጣሉ?

- | | |
|-----------------|----------------------|
| 1. በነርስ | 4. በበራሪ ወረቀት |
| 2. በዶክተር | 5. በጤና ተቀም በሚሰጠው ት/ት |
| 3. 2.በሬዲዮ/ቴሌቪዥን | 6. በየትኛውም መንገድ |
| | 7 ሌላ ይጠቀስ..... |

54. መረጃ መስጠት ያለበት መቼ ነው?

- | | |
|----------------------|----------------------|
| 1. ህክምናው ከመጀመሩ በፊት | 3. ህክምናውን ሲጠናቀቅ |
| 2. ህክምናው ከተጀመረ በኋላ | 4. በየትኛውም ጊዜ ቢሆን ይሁን |
| 5. ሌላ ካለ ይጥቀሱልን..... | |

ጤና ይስጥልኝ

ስሜ.....ይባላል

የመወያያ ነጥቦች

1. በመጀመሪያ መረጃ ምን ያህል አስፈላጊ ነው ትላለህ/ትያለሽ የአንተ/ቼ መረጃ የማግኘት ፍላጎትህ/ሽ እንዴት ነው?
2. የጡት ካንሰር ያለባቸው ሴቶች ማግኘት ያለባቸው መረጃዎች ምንድናቸው ብለህ/ሽ ታስቢያለሽ/ታስባለህ?
3. መቼ ነው መረጃ ማግኘት ያለባቸው?
4. ስለበሽታው መረጃ ማግኘት ያለባቸው ምክንያቱ ምንድ ነው?
5. መረጃውን ማግኘት ያለባቸው ከማን ወይም ከምንድነው ?ለምን
6. የጡት ካንሰር ያለባቸው ሴቶች ከጤናቸው ጋር በተያያዘ ማንኛውንም ጥያቄ ለመጠየቅ ፍቃደኛ ናቸው ብላችሁ ታምናላችሁ?
7. ከህመማት ውጪ ሌሎች በዙሪያቸው ያሉ ሰዎች መረጃ ማግኘት አለባቸው?
8. መረጃ ወደፊላጊው በአግባቡ እንዳይደርስ የሚያደርጉ መሰናክሎች ምንድናቸው?
9. በጠንካራ መልኩ በቂ መረጃ ለህመማት እንዲደርስ የማድረግ ፕሮግራም ለመዘርጋት ምን መደረግ አለበት ትላላችሁ?