The availability and utilization of psychosocial services for breast cancer patients in Addis Ababa, Ethiopia: a mixed method study

Abigiya Wondimagegnehu1, 2*, Workeabeba Abebe3, 8, Selamawit Hirpa1, Aynalem Abraha4, Eva J. Kantelhardt2, 5, Adamu Addissie1, 2, Bradley Zebrack6, Solomon Teferra7, 8

Affiliation:

1 Department of Preventive Medicine, School of Public Health, College of Health Sciences, Addis Ababa University, Addis Ababa, Ethiopia.
2 Institute of Medical Epidemiology, Biostatistics and Informatics, Martin-Luther-University, Halle, Germany.
3 Department of Pediatrics and Child Health, School of Medicine, College of Health Sciences, Addis Ababa University, Addis Ababa, Ethiopia.
4 Department of Oncology, School of Medicine, College of Health Sciences, Addis Ababa University, Addis Ababa, Ethiopia.
5 Department of Gynecology, Martin-Luther-University, Halle (Saale), Germany.
6 University of Michigan, School of Social Work, Ann Arbor, MI, USA.
7 Department of Psychiatry, School of Medicine, College of Health Sciences, Addis Ababa University, Addis Ababa, Ethiopia.
8 Harvard T.H. Chan School of Public Health, Harvard University, Boston, MA, USA.

Corresponding Author: Abigiya Wondimagegnehu Tilahun (AW)
E mail: abitowon@gmail.com
Cell phone: +251913955333
Abstract

Background: Provision of psychosocial services has substantial impact in cancer care by reducing emotional distress and improving both the quality of life and survival of patients, but the availability and utilization of the services have been not well-studied in developing countries, particularly in Ethiopia. The aim of this study was to explore the types of psychosocial services available for breast cancer patients and utilization in selected health facilities in Addis Ababa, Ethiopia.

Methods: A mixed method study was conducted using a cross-sectional survey involving a sample of 428 patients with breast cancer, followed by a qualitative study in seven health facilities in Addis Ababa, Ethiopia. A total of nine in-depth interviews (IDIs) were conducted with purposefully selected four breast cancer patients and five key informants using two separate interview guides. Descriptive statistics were calculated using SPSS software, and both bivariate and multivariate logistic regressions were done to identify factors associated with provision of psychosocial services. Thematic analysis was used for the qualitative data using NVivo 12 plus software.

Result: Only 47 (11.1%) patients received psychosocial services, either in the form of counseling, emotional support or provision of information. Addis Ababa residency, severity of pain and longer duration since diagnosis were factors associated with provision of psychosocial services. Health professionals reportedly provided such services along with their routine activities, and patients predominantly received social/emotional support from family members, friends and colleagues. There was no well-structured counseling service, emotional support or group discussion sessions for breast cancer patients in these health facilities. The main reasons reported by health professionals for not providing these services were high patient flow/workload, inadequate space,
lack of training and not having qualified professionals to organize and deliver psychosocial services in those hospitals in Addis Ababa, Ethiopia.

Conclusion: This study revealed that very few breast cancer patients received psychosocial services from health professionals, and the services were not integrated and delivered in a structured way. Therefore, integrating and implementing psychosocial services in cancer care is recommended both in private and government health facilities in Ethiopia.

Key words: psychosocial services, breast cancer, mixed design, Ethiopia

Background: Cancer is a devastating disease causing significant psychological problems among patients and their caregivers [1]. Several studies revealed that cancer patients face emotional, social and psychological difficulties, either in the form of anxiety or depressive disorders [2-5]. Piece of evidence have also suggested that psychological disorders are significantly associated with substantial functional impairment, fatigue, pain, poor quality of life [6, 7] and reduced survival [8]. Particularly, patients with breast cancer who are in the midst of treatment have fear and concerns regarding mortality, disease recurrence, and body image impairment, especially in relation with mastectomy, hormonal treatment, and sexuality, as well as perceived attractiveness with regard to spouses and loved ones [1, 9, 10].

Psychosocial services is one of the components of cancer care addressing the social, psychological, emotional, spiritual, and functional aspects of the patient’s journey with an interdisciplinary team of care and service providers [11]. It includes a variety of psychological and educational components, such as relaxation training, cognitive and behavioral coping strategies, cancer education/information sessions, and group social support [12-14]. Provision of psychosocial services revealed significant effects in the treatment of cancer patients in reducing emotional
distress, anxiety, and depression and also through improving adherence to treatment and enhancing quality of life [15-18]. In addition to the listed benefits, recent studies have revealed that psychosocial services can also improve survival of cancer patients [19, 20].

The significant advances in the effectiveness of psychosocial interventions have encouraged different health organizations, associations, and committees to develop, implement, and disseminate psychosocial guidelines and evidence-based treatments for several co-morbid psychiatric disorders in cancer and other chronic illnesses [21-25]. For instance, the primary vision of the International Psycho-Oncology Society (IPOS) in collaboration with World Health Organization (WHO) is improving the quality of cancer care and cancer policies through provision of psychosocial care globally [26]. This can be achieved through bringing psycho-oncology training programs to developing countries and regions [26]. Due to its positive impacts on several treatment outcomes, psychosocial services are integrated and being delivered in routine cancer care in high-income countries [10, 21, 22, 27].

Nevertheless, cancer care systems in many low- and middle-income countries (LMICs) do not even address the current burden of cancer due to poor screening services and poor development of public health services. In addition, ignorance, unhealthy cultural and spiritual beliefs, and denial of diagnosis are common problems that create many challenges in terms of fewer treatment options, presentation at advanced stages of disease and pain management, resulting in a greater need for psychosocial and palliative care. However, psychosocial services are not widely available in LMICs, especially in Africa [24, 28]. One of the major challenges for not implementing existing clinical practice guidelines for psychosocial care is most of these guidelines have been designed primarily for well-resourced settings, considering their culture and local context [29, 30].
So far, few studies have been conducted on the implementation of psychosocial services in LMICS. A qualitative study done in Indonesia reported that breast cancer patients obtained information about their diagnosis and treatment from the doctors in the hospital. However, other types of psychosocial services, such as counseling and emotional support, were not provided for the patients [31]. According to a study done in Botswana, the majority of cancer patients received social support from family members and friends. However, the study revealed that there is a gap in the provision of psychosocial service due to understaffed facilities and both poor referral communications and scheduling systems [32]. Similarly, our previous study in Ethiopia revealed that breast cancer patients received social support from family members, friends and significant others [33]. However, the provision of psychosocial services for breast cancer patients at the health facility level has never been explored before. Therefore, this study will explore the availability and receipt of psychosocial services for breast cancer patients in selected hospitals in Addis Ababa, Ethiopia.

Methods:

Study design and Place

A sequential mixed study design [QUAN (qual)] was employed to assess the availability of psychosocial services in seven hospitals in Addis Ababa, Ethiopia. In the first phase of the study, a cross-sectional study design was used and quantitative data was collected from 428 breast cancer patients between December 2017 and May 2018 at two large tertiary referral hospitals and five private oncology clinics. Subsequently, a small scale qualitative approach was used to explore more and supplement the quantitative information we gathered. Therefore, a total of nine IDIs were conducted with breast cancer patients (n=4) and key informants (n=5) from July to September 2018.
Ethical clearance was obtained from the Research Ethics Committee (REC) of the School of Public Health and Institutional Review Board (IRB) of the College of Health Sciences, Addis Ababa University. Details about the facilities can be found in our previous paper [33].

**Study participants and sample size**

The sample size for the quantitative part of the study was calculated using these assumptions: 95% confidence interval (CI), margin of error (d) = 5%, 40.3% prevalence of depression [34] and 20% non-response rate. The final calculated sample size was 444. The eligibility criteria were all pathologically confirmed breast cancer patients above 18 years of age and who were undergoing treatment in those selected health facilities in Addis Ababa, Ethiopia.

In the qualitative part of the study, both in-depth and key informant interviews were employed with a convenience sample of breast cancer patients and health professionals. A total of four IDIs were conducted with purposively selected breast cancer patients from two hospitals. An equal number of participants was recruited from private and government hospitals. An attempt was made to achieve the principle of maximum variation of participants by considering type of health facility, duration of diagnosis, age and place of residence.

Similarly, the key informant interviews were done with five health professionals (two oncologists, two BSc nurses and one health officer) who were working in the respective oncology departments for at least 2 years. These health professionals were purposively selected from both private and government hospitals in order to observe potential variation in the available psychosocial services between the two categories.
Data collection and tools

For the quantitative part of the study, a structured questionnaire was developed and adapted to our context after reviewing literature; sociodemographic information was included. Breast cancer patients were considered as receiving psychosocial services if they reported having received any kind of counseling service, emotional support or information/educational materials by health professionals working in the current health facility.

Based on the preliminary analysis done on the quantitative data, the research team became more interested in further exploration and validation of the findings by conducting a few more IDIs with breast cancer patients who were not included in the survey. In addition, the finding was triangulated through interviewing health professionals who were providing services in those health facilities. Therefore, two separate interview guides were discussed and prepared by the team for IDIs with patients and key informants. The principal investigator and a research assistant who has experience in qualitative research conducted all the interviews. Participants were recruited gradually and IDIs with breast cancer patients were conducted initially, followed by key informant interviews. Daily debriefings were held on emerging thematic areas, and the data collection continued until the theoretical saturation level was reached. All the interviews were audio recorded, and notes were taken during the interviews. The data was organized and appropriately labeled immediately after each interview. Subsequently, all recorded interviews were transcribed and translated verbatim.

Data analysis procedures

The quantitative data was organized in Epi data software and analyzed using Statistical Package for Social Sciences (SPSS) version 25. Bivariate logistic regression analysis was done for each independent variable with receipt of psychosocial services. Those significant variables that had a
p value < 0.2 were included in the final multiple logistic regression model using the enter method. The crude and adjusted odds ratios (COR and AOR) with 95% CI were presented.

The data analysis for the qualitative study was initiated in the field simultaneously with the data collection process. All transcribed documents, field notes and reflexive memos were entered into NVivo12 plus software. Each statement and word was coded line by line based on the stated objectives. Thematic analysis was used to categorize and explain the emerging thematic areas under each objective. The findings were guided and described using the tiered intervention model, which provides a framework to review existing services within the community, identify gaps in current service delivery, and for implementing psychosocial care using a community-based approach. The model has five levels and the appropriate psychosocial intervention will be administered based on the distress level of patients at different service delivery points. In this study, we mainly focused on the first three levels. Provision of general information and advice suitable for any cancer patient was considered as level one—universal care. Level two is called supportive care, which focuses on provision of psychoeducation, emotional support and triage. Level three is extended care and includes focused counseling, coping skills training, and psychoeducation by trained health professionals. Level four (specialist care) and level five (acute care) are the last two levels of care provided by skilled therapists and the multidisciplinary team [35].

Result
The result of this study is organized and presented in three parts. The first section describes findings from the qualitative study highlighting the types and location of psychosocial services available for breast cancer patients from the perspective of both patients and health care providers. Characteristics of patients and health care providers involved in qualitative interviews are summarized in Tables 1 and 2. The second section deals with the findings from the quantitative
survey describing with the proportion of women who received psychosocial services in those health facilities. The analytic result of the survey was conducted among 428 patients, with a response rate of 96.4%. The sociodemographic and clinical characteristics of the participants are summarized in our previous study [33]. Table 4 identifies factors associated with psychosocial services use among breast cancer patients. The third section narrates the reasons for not providing psychosocial services and also suggestions and recommendations from providers/key informants towards psychosocial services needed among breast cancer patients.

Table 1: Characteristics of participants involved in the qualitative study.

<table>
<thead>
<tr>
<th>Code</th>
<th>Age</th>
<th>Place of residence</th>
<th>Time since diagnosis</th>
<th>Educational status</th>
<th>Occupation</th>
<th>Type of treatment received before</th>
<th>Current treatment</th>
<th>Type of hospital</th>
</tr>
</thead>
<tbody>
<tr>
<td>P01</td>
<td>36</td>
<td>Addis Ababa</td>
<td>Four years ago</td>
<td>First degree</td>
<td>Bank teller</td>
<td>Surgery (mastectomy, I breast)</td>
<td>Second round chemo (6th cycle)</td>
<td>Private</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Chemotherapy, Hormonal 3 yrs 4 months Radiotherapy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>P02</td>
<td>42</td>
<td>Debre Markos</td>
<td>Two years ago</td>
<td>Unknown</td>
<td>House wife</td>
<td>Surgery (partial excision) Chemotherapy, Hormonal therapy (&gt;1 yr)</td>
<td>Second round chemo (8th cycle)</td>
<td>Government</td>
</tr>
<tr>
<td>P03</td>
<td>51</td>
<td>Addis Ababa</td>
<td>Six months ago</td>
<td>Unknown</td>
<td>Merchant</td>
<td>Surgery (Mastectomy both breasts)</td>
<td>First cycle chemo (2nd cycle)</td>
<td>Private</td>
</tr>
<tr>
<td>P04</td>
<td>35</td>
<td>Dire Dawa</td>
<td>One year ago</td>
<td>First degree</td>
<td>Bank branch manager</td>
<td>Surgery (Mastectomy 1 breast)</td>
<td>First cycle chemo (4th cycle)</td>
<td>Government</td>
</tr>
</tbody>
</table>

Section one: Qualitative study findings

Theme 1: Available psychosocial services

One of the major thematic areas identified was the availability of psychosocial services. The psychosocial services available for breast cancer patients were described and further categorized in to two main sub thematic areas: i) from the community and ii) from the health facilities.

Subtheme 1.1: From the community
The IDIs conducted with both patients and key informants revealed that many cancer patients received different kinds of psychosocial support from their close friends, family members and the community. Respondents also indicated that the social structure by itself had a great contribution in minimizing the risk of having depression and other psychosocial problems. Despite the fact that there is an awareness gap and the way the community provides social support has its own limitations, the breast cancer patients who participated in this study testified that they received various types of emotional support from different groups of people in the community.

a) From family members

“The good thing, I receive a lot of support from my family. My husband is very supportive, my sisters, my mother and friends. All are very supportive.” (P01: 36 years)

“...my brother was with me and he was the only one who comforted me.” (P02: 42 years)

b) From close friends

“My close friends know about it and we always discuss about everything. They comfort me a lot...they are very supportive.” (P04: 35 years)

c) From colleagues

“Even at work, people usually support me. For example, they reduce workload and give me permission when I have an appointment.” (P01: 36 years)

Subtheme 1.2: From health professionals at the health facilities

a) Disclosure and counseling services

In the health facilities that were visited, there was no structured way of disclosing breast cancer patients. But most of the time, the physician who made the diagnosis was the one who disclosed the diagnosis to patients; this was also reported by patients.

“There was a doctor who did the diagnosis and disclosed me as I have cancer.” (P04: 35 years)

“The doctor is the one who handles most of these issues using the short time he has for examining all the patients. He provides the counseling service based on patient’s knowledge and condition.” (HP04: Health officer, private)

On the other hand, there were breast cancer patients who accidentally got disclosed during the waiting time or when they were linked to an oncologist. Sometimes cancer patients remained
undisclosed about their status. Respondents mentioned caregivers who informed the health professionals not to tell the patient about cancer because of fear of discontinuing the treatment and in order to prevent hopelessness.

“They didn’t tell me anything about the disease except telling me that I will be linked to another doctor who will come to this facility on Saturday...Then, when I came on Saturday, I heard from other patient beside me that we are waiting for a cancer doctor.” (P01: 36 years)

“Sometimes, patients bring their pathology result without being informed about their diagnosis...the family members insist us not to tell them and the doctor will not say anything.” (HP03: BSc nurse, private)

All breast cancer patients who participated in the qualitative study reported that they did not receive any counseling services at the time of diagnosis. They even mentioned that they were not properly disclosed and the health professionals didn’t provide any emotional support or counseling at the time of diagnosis.

“The way he disclosed me was really shocking. Then, I isolated myself from any kind of medical treatment. The doctor told me as its breast cancer, and as there is no option other than removing my breast. I even asked him about the cause and he said we don’t have time to discuss about this; rather we have to focus on the solution. That’s all what he said to me.” (P04: 35 years)

However, one patient reported that she received emotional support and encouragement from her doctor at the time of diagnosis.

“...the doctor supported me a lot. He told me as it’s diagnosed at early stage and as I can survive... he said, there are lots of medications and even if you lose your hair, it will be replaced to its normal condition.” (P01: 36 years)

In contrast, the health professionals reported that they were providing counseling services and emotional support for cancer patients as much as the situation allowed them. However, they mentioned that the service was not being provided for the patients in a structured and well-organized manner. Except having short and brief discussions with each patient at the time of diagnosis, all the key informants mentioned that there were no structured psychosocial services, which included counseling, emotional support and discussion sessions with cancer patients either
individually or as a group. There was no assigned health professional who was responsible to provide such services in an organized way, but the physicians and nurses who were working in the oncology unit provided these services along with their other routine tasks.

“We do not have such system even the psychological support and counseling is not provided adequately because of high workload. But we are trying our best. We need both counselors and clinical psychologists.” (HP01, Oncologist)

“There is no unit which provides counseling service in structured system. Most of the time, the oncologists teach the patients about the choice of treatment.” (HP02: Oncologist)

Table 2: Characteristics of key informants participated in the qualitative study

<table>
<thead>
<tr>
<th>Code</th>
<th>Profession</th>
<th>Year of experience</th>
<th>Year of experience at the oncology department</th>
<th>Type of the hospital</th>
</tr>
</thead>
<tbody>
<tr>
<td>HP01</td>
<td>Oncologist</td>
<td>27 years</td>
<td>10 years</td>
<td>Government</td>
</tr>
<tr>
<td>HP02</td>
<td>Oncologist</td>
<td>15 years</td>
<td>11 years</td>
<td>Government</td>
</tr>
<tr>
<td>HP03</td>
<td>Clinical nurse</td>
<td>10 years</td>
<td>8 years</td>
<td>Private</td>
</tr>
<tr>
<td>HP04</td>
<td>Clinical nurse</td>
<td>5 years</td>
<td>4 years</td>
<td>Government</td>
</tr>
<tr>
<td>HP05</td>
<td>Health officer</td>
<td>2 years</td>
<td>2 years</td>
<td>Private</td>
</tr>
</tbody>
</table>

b) Provision of adequate information and brochures

In this study, the participants reported that they received some information about the treatment options, side effects and duration of treatment. Not only the patients but also the health professionals mentioned that they also had provided this information for the caregivers.

“We provide all the necessary information to the patient and attendants.” (HP03: BSc nurse, private)

“We inform the family members about the disease, stage and how to support the patient.” (HP04: BSc nurse, government)

“When I start chemotherapy, the doctor told me that the treatment has an effect on my hair and as I should not be worried about it.” (PO2: 42 years)

However, the patients indicated that the information provided by health professionals was not adequate and the majority of breast cancer patients discussed matters among themselves and got a lot of information from other patients who were diagnosed earlier.

“No, I was not even informed about the no. of cycles prescribed for me. On the third cycle, I asked the nurse and told me as its six cycles.” (PO4: 35 years)

“We usually talk among ourselves and get a lot of information from those patients who took the medication earlier.” (PO2: 35 years)
It was also indicated that the main source of information for few groups of people (more educated)
was through the Internet, media and reading books.

“...educated people usually Google about their cases, stage of the disease and laboratory results.”
(HP04: Health officer, private) “...I start reading on the Internet and become more aware of the
disease, steps and further treatments.” (PO1: 36 years)

Concerning the provision of leaflets and brochures, none of the participants mentioned that they
received such kind of educational materials. The health professionals also reported that they did
not usually give those materials to their patients.

“No, no no one gave me such kind of materials.” (PO1: 36 years)
“We try our best to help the patients with what we can but we do not provide educational materials
or other supports.” (HP01: Oncologist)

c) Concerning palliative care guidelines

One of the categories explored under the broader thematic area of provision of psychosocial
services was palliative care guidelines, which were endorsed by the Ethiopian Federal Ministry of
Health in 2017. Few questions about its implementation were asked, and only the two oncologists
who participated in this study were aware of the guidelines. They also mentioned that they were
involved in cascading the program in different health facilities.

“...Currently there is a department at the MoH which is responsible for this service and we also gave
the training for professionals from different hospitals.” (HP01: Oncologist)

However, the other health professionals mentioned that they were not even aware of the
guidelines, and it was not being implemented.

“I have never seen the guideline and I don’t know about it. I didn’t receive any training on this” (HP03:
BSc nurse, private)

Section two: Quantitative study findings

Concerning psychosocial services received, our quantitative study revealed that 57 (13.3%) breast
cancer patients ever received counseling services. Currently, only 47 (11.0%) of these patients
have received any kind of psychosocial service in the current health facility, either in the form of
counseling, emotional support or provision of information from health professionals. Out of these
patients, more than half 27 (57.6%) received information from the health professionals, while the
others received other forms of psychosocial services. Most 356 (83.2%) of the breast cancer
patients stated that they preferred to visit health facilities in order to receive psychosocial services,
70 (16.4%) of them preferred religious places and only 2 (0.5%) preferred traditional healers or
other people.

In association to their involvement in the social activities, the majority 400 (93.5%) of the
participants still participated in social gatherings in their community. Among the different types
of gatherings, a similar proportion of breast cancer patients were involved in spiritual gatherings
328 (76.6%) and attended funerals 323 (75.5%), while more than half of the patients 240 (56.1%)
participated in other social activities. However, 75 (17.5%) of the total participants reported that
the disease affected different aspects of their life. Out of these, 46 (61.3%) and 32 (42.6%) of the
patients stated that the disease affected their social and spiritual life respectively (Table 3).
Table 3: Type of psychosocial service received in selected health facilities in Addis Ababa, Ethiopia

<table>
<thead>
<tr>
<th>Variables</th>
<th>n</th>
<th>Percent (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients reaction at the time of diagnosis (n = 354)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I was shocked &amp; cried</td>
<td>207</td>
<td>58.5</td>
</tr>
<tr>
<td>Deep sadness</td>
<td>60</td>
<td>16.9</td>
</tr>
<tr>
<td>Hopelessness and fear of death</td>
<td>14</td>
<td>4.0</td>
</tr>
<tr>
<td>I didn’t feel anything</td>
<td>50</td>
<td>14.1</td>
</tr>
<tr>
<td>Others*</td>
<td>23</td>
<td>6.5</td>
</tr>
<tr>
<td>Know about their disease status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breast cancer</td>
<td>354</td>
<td>82.9</td>
</tr>
<tr>
<td>Breast Tumor and inflammation</td>
<td>61</td>
<td>14.3</td>
</tr>
<tr>
<td>Don’t know</td>
<td>12</td>
<td>2.8</td>
</tr>
<tr>
<td>Ever received counseling service</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>384</td>
<td>86.7</td>
</tr>
<tr>
<td>Yes</td>
<td>57</td>
<td>13.3</td>
</tr>
<tr>
<td>Currently receiving any psychosocial service in this facility</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>381</td>
<td>89.0</td>
</tr>
<tr>
<td>Yes</td>
<td>47</td>
<td>11.0</td>
</tr>
<tr>
<td>Type of psychosocial service received (n = 47)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Counseling service</td>
<td>9</td>
<td>19.1</td>
</tr>
<tr>
<td>Emotional support</td>
<td>11</td>
<td>23.4</td>
</tr>
<tr>
<td>Provision of information</td>
<td>27</td>
<td>57.4</td>
</tr>
<tr>
<td>Participate in different gatherings</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>28</td>
<td>6.5</td>
</tr>
<tr>
<td>Yes</td>
<td>400</td>
<td>93.5</td>
</tr>
<tr>
<td>Type of gatherings (n = 428 for each type)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spiritual</td>
<td>328</td>
<td>76.6</td>
</tr>
<tr>
<td>Only Funeral</td>
<td>323</td>
<td>75.5</td>
</tr>
<tr>
<td>Social</td>
<td>240</td>
<td>56.1</td>
</tr>
<tr>
<td>Women</td>
<td>125</td>
<td>29.2</td>
</tr>
<tr>
<td>Political</td>
<td>32</td>
<td>7.5</td>
</tr>
<tr>
<td>Challenges in relation to the disease</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>353</td>
<td>82.5</td>
</tr>
<tr>
<td>Yes</td>
<td>75</td>
<td>17.5</td>
</tr>
<tr>
<td>Type of challenges encountered (n = 75 for each type)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Problem on social activities</td>
<td>46</td>
<td>61.3</td>
</tr>
<tr>
<td>Problem on spiritual life</td>
<td>32</td>
<td>42.6</td>
</tr>
<tr>
<td>Problem with family</td>
<td>27</td>
<td>36.0</td>
</tr>
<tr>
<td>Problem with employer</td>
<td>22</td>
<td>29.3</td>
</tr>
<tr>
<td>Preferred place to receive psychosocial support</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health facilities</td>
<td>356</td>
<td>83.2</td>
</tr>
<tr>
<td>Religious places</td>
<td>70</td>
<td>16.4</td>
</tr>
<tr>
<td>Traditional healers other people</td>
<td>2</td>
<td>0.5</td>
</tr>
</tbody>
</table>
According to the multivariate analysis, residence was one of the sociodemographic factors that was significantly associated with receipt for psychosocial care. The odds of breast cancer patients who live in Addis Ababa were 2.54 times more likely to receive any psychosocial services as compared to those who came from outside of Addis Ababa [AOR = 2.54 (95% CI 1.30, 6.27)].

Clinical factors such as severity of pain and date of diagnosis, also had a significant association with receiving psychosocial services. Breast cancer patients who had moderate pain were three times more likely to receive psychosocial services as compared to those women without any pain. [AOR = 2.84 (95% CI 1.02, 7.94). The odds of women who were diagnosed more than 1 year ago were three times more likely to receive the service as compared to those who were recently diagnosed (< 1 year) [AOR = 3.17 (95% CI 1.27, 7.89)]. Other sociodemographic and clinical factors such as age, marital status, educational level, stage of cancer, and type of treatment were not associated with receiving psychosocial services. In this study, we also couldn’t find any significant difference in provision of psychosocial services between private and government hospitals [AOR = 1.67 (95% CI 0.46, 6.03)] (Table 4).
Table 4: Multivariate logistic regression model for factors for receiving psychosocial service among Breast Cancer Patients in Addis Ababa, Ethiopia

<table>
<thead>
<tr>
<th>Variables</th>
<th>Crude OR (95% CI)</th>
<th>Adjusted OR (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health facilities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Government</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Private</td>
<td>1.57 (0.58, 4.13)</td>
<td>1.67 (0.46, 6.03)</td>
</tr>
<tr>
<td>Age</td>
<td>1.04 (1.01, 1.08)</td>
<td>1.04 (0.99, 1.08)</td>
</tr>
<tr>
<td>Residence</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Outside Addis</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Inside Addis</td>
<td>1.87 (0.97, 3.52)</td>
<td>2.54 (1.30, 6.27)</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Married</td>
<td>2.00 (0.87, 4.62)</td>
<td>2.35 (0.91, 6.08)</td>
</tr>
<tr>
<td>Cohabitated</td>
<td>0.87 (0.23, 3.24)</td>
<td>1.53 (0.25, 9.52)</td>
</tr>
<tr>
<td>Divorced</td>
<td>2.70 (0.76, 9.30)</td>
<td>2.61 (0.63, 10.91)</td>
</tr>
<tr>
<td>Widowed</td>
<td>3.01 (0.92, 9.56)</td>
<td>2.05 (0.49, 8.62)</td>
</tr>
<tr>
<td>Severity of pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>None (0)</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Mild (1-3)</td>
<td>2.09 (1.02, 4.28)</td>
<td>1.93 (0.82, 4.53)</td>
</tr>
<tr>
<td>Moderate (4-6)</td>
<td>3.21 (1.29, 7.99)</td>
<td>2.84 (1.02, 7.94)</td>
</tr>
<tr>
<td>Severe (7-10)</td>
<td>2.78 (0.59, 13.12)</td>
<td>2.44 (0.46, 12.92)</td>
</tr>
<tr>
<td>Final stage of cancer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stage I</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Stage II</td>
<td>0.62 (0.13, 2.81)</td>
<td>0.88 (0.17, 4.49)</td>
</tr>
<tr>
<td>Stage III</td>
<td>0.42 (0.09, 1.89)</td>
<td>0.65 (0.13, 3.29)</td>
</tr>
<tr>
<td>Stage IV</td>
<td>1.20 (0.16, 9.04)</td>
<td>1.18 (0.14, 10.17)</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Yes</td>
<td>0.53 (0.18, 1.52)</td>
<td>0.34 (0.076, 1.57)</td>
</tr>
<tr>
<td>Duration of Dx</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than 1 yr</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>More than 1 yr</td>
<td>2.95 (1.26, 6.86)</td>
<td>3.17 (1.27, 7.89)</td>
</tr>
</tbody>
</table>

Section three: Qualitative study findings

Theme 2: Determinants of psychosocial services provision

Reasons for not providing psychosocial services in these health facilities were also explored in the qualitative part of the study, and several justifications were given by the key informants we interviewed. These included shortage of staff, high workload and not having an assigned person who will deliver these services in an organized way.

“The main problem is staff shortage and high patient flow...umm....we do not have a staff who is assigned for psychosocial activities...” (HP04: BSc nurse, government)
In addition to this, there was high patient flow in these health facilities due to the limited number of cancer centers in the country. Therefore, it was difficult for the health professionals to spend more time with each patient and address their emotional and psychosocial needs.

“I don’t know the reason, but I think it’s because of high patient flow. Let alone to spend some time with you and discuss about your disease condition, the medication by itself is given in hurry.” (PO2: 42 years)

“...because of the high patient flow, doctors are forced to see many patients per day specially in government hospitals.” (HP02: Oncologist)

The other justification given by the nurses was lack of skill / training on how to provide counseling and other professional supports. They also stated that the setup by itself was not convenient to provide individual counseling for the patients.

“There is no trained personnel on this issue, which makes it difficult to provide the counseling.” (HP05: Health officer, private)

“The patients are very eager to listen. But the issue is we do not have adequate room for these services” (HP04: BSc nurse, government)

Theme 3: Suggestions about psychosocial services

Subsequently, the participants forwarded some suggestions on how psychosocial services should be delivered for cancer patients in these health facilities. All the forwarded suggestions were categorized into two subthemes.

Subtheme 3.1: General suggestion for cancer care

Due to the increasing number of cancer patients in the country, the health professionals suggested that the current cancer care should be improved in terms of medical supplies, diagnostic and therapeutic machines, long- and short-term capacity buildings and expanding cancer centers in different parts of the country. In addition, integration between different sectors and collaborative approach should be well-established in order to improve the quality of care given for cancer patients.
“There is nothing more devastating than hearing there is no medication for heart disease or cancer in the country. Therefore, training centers, pharmaceutical suppliers like PFSA and service providers or hospitals should work together to improve quality of care.” (HPO1: Oncologist)

“...In bigger hospitals including regional hospitals, palliative care should be found in organized way as a department to provide counseling service, psychosocial support and ensure drug availability.” (HPO2: Oncologist)

Subtheme 3.2: Specific to psychosocial services

a) For the community

It was indicated that creation of awareness programs should be organized for the general community, since some of the psychosocial challenges were coming from the community.

“In my opinion, the awareness creation should be more focused on the other members of the community even in a good way than the patients.” (P01: 36 years)

“Awareness creation is the first thing then implementing what someone knows will come next.” (HPO2: Oncologist)

b) For the Ministry of Health

Psychosocial support should be part of chronic disease care

The health professionals who participated in this study shared their experiences in other countries and how the service should be integrated into the routine care for chronic diseases. It was indicated that a separate palliative care unit should be established and included in the structure of the health care system with the required skilled professionals who are capable of delivering all the necessary components of the psychosocial services at all levels. Therefore, trained health professionals from different disciplines should be assigned to work collaboratively in order to deliver this service in an organized and structured manner at all levels of the health care system.

“There are only short term trainings, but as a whole to say palliative care it must include palliative care specialty nurses and physicians. If we have these facilities, those who need the service will be referred to this unit and the service providers will give all the required support.” (HPO2: Oncologist)
“I suggest assigning psychiatrist or trained personnel in addition to the doctors and nurses on palliative care service. Therefore, it should be integrated in more organized and structured manner.” (HPO4: BSc nurse, government)

Establishing support groups in each department

In addition to establishing palliative care units at the institutional level, the vital contribution of small support groups in each department was also described in details. The health professionals reported that the counseling services and other psychosocial services should be tailored in the country’s context and depend on the knowledge and capacity of the community.

“The issue of counseling depends on the specific society, culture and awareness of the community. So we need to be wise on how to approach patients by considering the local situation.” (HPO1: Oncologist)

“In other countries, there are support groups for each type of disease. This means, in addition to what they get from health professionals, breast cancer patients get most of the information related to breast cancer from those who get cured from the disease. So, these groups are very important.” (HPO2: Oncologist)

Psychosocial support should be included in the curriculum

The other key point raised by health professionals concerning future directions and improvement in cancer care was adding psychosocial services as part of the curriculum of health professionals. It’s suggested that this component of care should be given either as a course or subtopics depending on the length of stay with patients in each specificity track. In relation to this, it’s also recommended to reopen the “clinical psychology” specialty field due to the high demand for the service in the current health care system.

“We health professionals should use a holistic approach to address patients’ need. We have to assess the social, financial and spiritual challenges of the patient. To achieve this, newly graduates should be taught in this manner and this should be incorporated in the health policy and the medical or nursing school curriculum.” (HPO1: Oncologist)

“At some point clinical psychology was comprehended as an important issue but then it was terminated. In the future, every Oncologist should work together with clinical psychologists.” (HPO1: Oncologist)
Not only was it the different components of the psychosocial services but it was also indicated that other financial supports are needed for those patients who are coming from rural areas of the country.

"It's good if financial support is given for such kind of patients who are coming from other parts of Ethiopia." (PO1: 36 years)

Discussion

In this study, the majority of breast cancer patients received social support from their family members, friends and colleagues. This finding is consistent with other studies conducted in China [36], Turkey [37] and Botswana [32], which reported that cancer patients often received psychosocial supports from their family members and friends.

Regarding disclosure of cancer diagnosis, several guidelines recommended that all cancer patients should be well-informed about their diagnosis, treatment options and future prognosis of the disease [23-25, 38]. However, the qualitative findings of our study found that there were some breast cancer patients who were not even aware of their diagnosis. A previous study conducted in Ethiopia also reported a similar finding concerning lack of disclosure of cancer diagnosis among breast and cervical cancer patients [39]. This finding is not only in Ethiopia but also supported by a quantitative study conducted in Egypt that revealed around 15% of cancer patients were not aware of their diagnosis, and only their family members were aware of their diagnosis [40]. The main reason assumed by interviewees for not disclosing to these patients was the pressure of relatives on caregivers to prevent hopelessness and discontinuation of treatment. This reason is also consistent with a study done in India, which reported that the majority of caregivers preferred non-disclosure of cancer diagnosis and prognosis to their patients [41]. Poor disclosure of cancer diagnosis in developing countries might be associated with poor educational attainment [40], preference of traditional medicine, old age and having other chronic illnesses [42]. Even those
breast cancer patients who were informed of their diagnosis in this study perceived not being properly approached and disclosed at the time of the diagnosis. This might be related to lack of skill on how to break bad news to patients or due to a shortage of time to spend with each patient in those health facilities. Further studies might be required to explore the reasons for not properly disclosing cancer patients in developing countries.

Concerning counseling services, the majority of breast cancer patients who participated in the quantitative part of this study reported that they didn’t receive such kinds of service in their current health facility. However, counseling services were one of the major components of psychosocial services that are being delivered in developed countries [11, 23-26, 43, 44]. According to the cancer survivorship plan of the Institute of Medicine (IOM), a minimum of care and information that should be given for each cancer patient includes provision of information about the type of tests, results, tumor characterization, and treatment details, including type, combination of treatment, duration, side effects, regimen and so on [10]. Nevertheless, patients from the IDIs in this study mentioned that they didn’t get all the necessary details about their diagnosis and treatment, including the number of chemotherapy cycles prescribed for them. They also stated that they never received educational materials, either brochure or leaflet form. Similarly, many African countries do not provide such comprehensive psychosocial services, including counseling and provision of information materials for cancer patients [26, 28, 45]. The possible explanation for this variation in the provision of psychosocial services between developed and developing countries is lack of resources, whether it be skilled man power, infrastructure, materials and so on. The other reason might be due to the high patient flow, which makes it difficult for health professionals to spend enough time with each patient. Furthermore, this might also be associated
with the perception of health professionals towards the capacity of mostly illiterate patients to comprehend and appropriately interpret all these details.

Those patients who are residents of Addis Ababa were two times more likely to receive psychosocial services compared to others who were residing outside of Addis Ababa. This finding can be explained by the fact that people living in urban areas probably have better health information and therefore insist on obtaining psychosocial services. This finding is supported by a study conducted in Egypt, which revealed that educational level and place of residence were significantly associated factors with regard to disclosure and provision of psychosocial services [40]. The other associated factor with provision of psychosocial services was severity of pain. This can be explained by the compassion of health professionals toward patients with severe pain. In this study, those breast cancer patients who were diagnosed longer ago were more likely to receive psychosocial services. This may be due to increased opportunities for service provision. It also shows that, in contrary to high income settings, it is not standard to counsel patients at the time of diagnosis.

A main strength of the quantitative study is the large sample size and inclusion of private and government hospitals in Addis Ababa, leading to a broad picture of the situation. Maximum variation of responses was achieved through including newly diagnosed and recurrent cases. During our qualitative study, collecting information from patients and also health professionals increased the generalizability of the study. The major limitation of this study was that we only conducted IDIs, and it might be helpful if other data collection techniques, such as focus group discussion (FGD) were used in order to triangulate our findings. Our quantitative approach was limited by the lack of detailed questions. Our qualitative approach was limited by only conducting
nine interviews. By using the mixed study design, we helped to fill the limitation of each of the
approaches.

**Conclusions:** In this study, psychosocial services were barely found for breast cancer patients,
either in the form of counseling services, emotional support or provision of information. Except
provision of irregular type of emotional support and counseling services for the patients, there was
no structured and well-organized psychosocial services in those health facilities. High patient flow,
workload, inadequate space and lack of trained health professionals were the major reasons for not
providing psychosocial services. The key informants mentioned that psychosocial services are one
of the neglected areas in cancer care, which requires due attention. It’s recommended that
psychosocial services should be integrated in routine cancer care, at least at secondary and tertiary
hospitals in the country. It’s also indicated that the service should be tailored in the local context
through considering various sociocultural factors, educational attainment of the community and
available resources in the country. The Ministry of Health should expand the training of health
professionals in different disciplines, including clinical psychology, social work and palliative
care. Further studies are required to identify other barriers in provision of this service and in order
to explore the psychosocial challenges and needs among all cancer patients in different parts of the
country.

**Abbreviations**

AOR, Adjusted Odds Ratio; IOM, Institute of Medicine; IPOS, International Psycho-Oncology
Society; IRB, Institutional Review Board; LMICs, Low- and Middle-Income Countries; PFSA,
Food and Safety Authority; REC, Research Ethics Committee; WHO, World Health
Organization.

**Declarations**
Ethics approval and consent to participate: Ethical clearance of this study was obtained from the Research Ethics Committee of the School of Public Health and Institutional Review Board of the College of Health Science, Addis Ababa University. Written informed consent was obtained from all participants. The confidentiality and anonymity of the participants was maintained. All analysis methods were performed in accordance with the Declaration of Helsinki.

Consent for publication: Not applicable.

Availability of data and material: The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Competing interests: The authors declare that they have no competing interests.

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Authors’ contributions
All authors conceived and designed the study. AW and SH conducted the IDIs. AW, SH, WA and AA performed the data analysis and interpretation of the findings. AW and WA drafted the manuscript. BZ, EK, AA and ST were actively involved in data interpretation and critically reviewed the manuscript. All authors read and approved the final manuscript.

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References


