

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

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Abstract

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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,

56 lack of training and not having qualified professionals to organize and deliver psychosocial
57 services in those hospitals in Addis Ababa, Ethiopia.

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

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

63 **Background:**

64 Cancer is a devastating disease causing significant psychological problems among patients and
65 their caregivers [1]. Several studies revealed that cancer patients face emotional, social and
66 psychological difficulties, either in the form of anxiety or depressive disorders [2-5]. Piece of
67 evidence have also suggested that psychological disorders are significantly associated with
68 substantial functional impairment, fatigue, pain, poor quality of life [6, 7] and reduced survival
69 [8]. Particularly, patients with breast cancer who are in the midst of treatment have fear and
70 concerns regarding mortality, disease recurrence, and body image impairment, especially in
71 relation with mastectomy, hormonal treatment, and sexuality, as well as perceived attractiveness
72 with regard to spouses and loved ones [1, 9, 10].

73 Psychosocial services is one of the components of cancer care addressing the social, psychological,
74 emotional, spiritual, and functional aspects of the patient's journey with an interdisciplinary team
75 of care and service providers [11]. It includes a variety of psychological and educational
76 components, such as relaxation training, cognitive and behavioral coping strategies, cancer
77 education/information sessions, and group social support [12-14]. Provision of psychosocial
78 services revealed significant effects in the treatment of cancer patients in reducing emotional

79 distress, anxiety, and depression and also through improving adherence to treatment and enhancing
80 quality of life [15-18]. In addition to the listed benefits, recent studies have revealed that
81 psychosocial services can also improve survival of cancer patients [19, 20].

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

92 Nevertheless, cancer care systems in many low- and middle-income countries (LMICs) do not
93 even address the current burden of cancer due to poor screening services and poor development of
94 public health services. In addition, ignorance, unhealthy cultural and spiritual beliefs, and denial
95 of diagnosis are common problems that create many challenges in terms of fewer treatment
96 options, presentation at advanced stages of disease and pain management, resulting in a greater
97 need for psychosocial and palliative care. However, psychosocial services are not widely available
98 in LMICs, especially in Africa [24, 28]. One of the major challenges for not implementing existing
99 clinical practice guidelines for psychosocial care is most of these guidelines have been designed
100 primarily for well-resourced settings, considering their culture and local context [29, 30].

101 So far, few studies have been conducted on the implementation of psychosocial services in
102 LMICS. A qualitative study done in Indonesia reported that breast cancer patients obtained
103 information about their diagnosis and treatment from the doctors in the hospital. However, other
104 types of psychosocial services, such as counseling and emotional support, were not provided for
105 the patients [31]. According to a study done in Botswana, the majority of cancer patients received
106 social support from family members and friends. However, the study revealed that there is a gap
107 in the provision of psychosocial service due to understaffed facilities and both poor referral
108 communications and scheduling systems [32]. Similarly, our previous study in Ethiopia revealed
109 that breast cancer patients received social support from family members, friends and significant
110 others [33]. However, the provision of psychosocial services for breast cancer patients at the health
111 facility level has never been explored before. Therefore, this study will explore the availability and
112 receipt of psychosocial services for breast cancer patients in selected hospitals in Addis Ababa,
113 Ethiopia.

114 **Methods:**

115 **Study design and Place**

116 A sequential mixed study design [QUAN (qual)] was employed to assess the availability of
117 psychosocial services in seven hospitals in Addis Ababa, Ethiopia. In the first phase of the study,
118 a cross-sectional study design was used and quantitative data was collected from 428 breast cancer
119 patients between December 2017 and May 2018 at two large tertiary referral hospitals and five
120 private oncology clinics. Subsequently, a small scale qualitative approach was used to explore
121 more and supplement the quantitative information we gathered. Therefore, a total of nine IDIs
122 were conducted with breast cancer patients (n=4) and key informants (n=5) from July to September
123 2018.

124 Ethical clearance was obtained from the Research Ethics Committee (REC) of the School of Public
125 Health and Institutional Review Board (IRB) of the College of Health Sciences, Addis Ababa
126 University. Details about the facilities can be found in our previous paper [33].

127 **Study participants and sample size**

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

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

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

144 **Data collection and tools**

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

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

163 **Data analysis procedures**

164 The quantitative data was organized in Epi data software and analyzed using Statistical Package
165 for Social Sciences (SPSS) version 25. Bivariate logistic regression analysis was done for each
166 independent variable with receipt of psychosocial services. Those significant variables that had a

167 p value < 0.2 were included in the final multiple logistic regression model using the enter method.
168 The crude and adjusted odds ratios (COR and AOR) with 95% CI were presented.
169 The data analysis for the qualitative study was initiated in the field simultaneously with the data
170 collection process. All transcribed documents, field notes and reflexive memos were entered into
171 NVivo12 plus software. Each statement and word was coded line by line based on the stated
172 objectives. Thematic analysis was used to categorize and explain the emerging thematic areas
173 under each objective. The findings were guided and described using the tiered intervention model,
174 which provides a framework to review existing services within the community, identify gaps in
175 current service delivery, and for implementing psychosocial care using a community-based
176 approach. The model has five levels and the appropriate psychosocial intervention will be
177 administered based on the distress level of patients at different service delivery points. In this
178 study, we mainly focused on the first three levels. Provision of general information and advice
179 suitable for any cancer patient was considered as level one—universal care. Level two is called
180 supportive care, which focuses on provision of psychoeducation, emotional support and triage.
181 Level three is extended care and includes focused counseling, coping skills training, and
182 psychoeducation by trained health professionals. Level four (specialist care) and level five (acute
183 care) are the last two levels of care provided by skilled therapists and the multidisciplinary team
184 [35].

185 **Result**

186 The result of this study is organized and presented in three parts. The first section describes
187 findings from the qualitative study highlighting the types and location of psychosocial services
188 available for breast cancer patients from the perspective of both patients and health care providers.
189 Characteristics of patients and health care providers involved in qualitative interviews are
190 summarized in Tables 1 and 2. The second section deals with the findings from the quantitative

191 survey describing with the proportion of women who received psychosocial services in those
 192 health facilities. The analytic result of the survey was conducted among 428 patients, with a
 193 response rate of 96.4%. The sociodemographic and clinical characteristics of the participants are
 194 summarized in our previous study [33]. Table 4 identifies factors associated with psychosocial
 195 services use among breast cancer patients. The third section narrates the reasons for not providing
 196 psychosocial services and also suggestions and recommendations from providers/key informants
 197 towards psychosocial services needed among breast cancer patients.

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

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

199

200 **Section one: Qualitative study findings**

201 **Theme 1: Available psychosocial services**

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

205 **Subtheme 1.1: From the community**

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

213 **a) From family members**

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

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

217 **b) From close friends**

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

220 **c) From colleagues**

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

223 **Subtheme 1.2: From health professionals at the health facilities**

224 **a) Disclosure and counseling services**

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

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

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

232 On the other hand, there were breast cancer patients who accidentally got disclosed during the
233 waiting time or when they were linked to an oncologist. Sometimes cancer patients remained

234 undisclosed about their status. Respondents mentioned caregivers who informed the health
235 professionals not to tell the patient about cancer because of fear of discontinuing the treatment and
236 in order to prevent hopelessness.

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

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

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

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

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

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

256
257 In contrast, the health professionals reported that they were providing counseling services and
258 emotional support for cancer patients as much as the situation allowed them. However, they
259 mentioned that the service was not being provided for the patients in a structured and well-
260 organized manner. Except having short and brief discussions with each patient at the time of
261 diagnosis, all the key informants mentioned that there were no structured psychosocial services,
262 which included counseling, emotional support and discussion sessions with cancer patients either

263 individually or as a group. There was no assigned health professional who was responsible to
 264 provide such services in an organized way, but the physicians and nurses who were working in the
 265 oncology unit provided these services along with their other routine tasks.

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

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

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

Code	Profession	Year of experience	Year of experience at the oncology department	Type of the hospital
HP01	Oncologist	27 years	10 years	Government
HP02	Oncologist	15 years	11 years	Government
HP03	Clinical nurse	10 years	8 years	Private
HP04	Clinical nurse	5 years	4 years	Government
HP05	Health officer	2 years	2 years	Private

272
 273 **b) Provision of adequate information and brochures**

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

277 *“We provide all the necessary information to the patient and attendants.” (HP03: BSc nurse, private)*
 278 *“We inform the family members about the disease, stage and how to support the patient.” (HP04: BSc*
 279 *nurse, government)*

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

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

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

287 *“We usually talk among ourselves and get a lot of information from those patients who took the*
 288 *medication earlier.” (PO2: 35 years)*

289 It was also indicated that the main source of information for few groups of people (more educated)
290 was through the Internet, media and reading books.

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

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

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

300

301 **c) Concerning palliative care guidelines**

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

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

309

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

312 *"I have never seen the guideline and I don't know about it. I didn't receive any training on this" (HP03:
313 BSc nurse, private)*

314

315 **Section two: Quantitative study findings**

316 Concerning psychosocial services received, our quantitative study revealed that 57 (13.3%) breast
317 cancer patients ever received counseling services. Currently, only 47 (11.0%) of these patients
318 have received any kind of psychosocial service in the current health facility, either in the form of

319 counseling, emotional support or provision of information from health professionals. Out of these
320 patients, more than half 27 (57.6%) received information from the health professionals, while the
321 others received other forms of psychosocial services. Most 356 (83.2%) of the breast cancer
322 patients stated that they preferred to visit health facilities in order to receive psychosocial services,
323 70 (16.4%) of them preferred religious places and only 2 (0.5%) preferred traditional healers or
324 other people.

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

332 **Table 3: Type of psychosocial service received in selected health facilities in Addis Ababa, Ethiopia**

Variables	n	Percent (%)
Patients reaction at the time of diagnosis (n = 354)		
I was shocked & cried	207	58.5
Deep sadness	60	16.9
Hopelessness and fear of death	14	4.0
I didn't feel anything	50	14.1
Others*	23	6.5
Know about their disease status		
Breast cancer	354	82.9
Breast Tumor and inflammation	61	14.3
Don't know	12	2.8
Ever received counseling service		
No	384	86.7
Yes	57	13.3
Currently receiving any psychosocial service in this facility		
No	381	89.0
Yes	47	11.0
Type of psychosocial service received (n = 47)		
Counseling service	9	19.1
Emotional support	11	23.4
Provision of information	27	57.4
Participate in different gatherings		
No	28	6.5
Yes	400	93.5
Type of gatherings (n = 428 for each type)		
Spiritual	328	76.6
Only Funeral	323	75.5
Social	240	56.1
Women	125	29.2
Political	32	7.5
Challenges in relation to the disease		
No	353	82.5
Yes	75	17.5
Type of challenges encountered (n = 75 for each type)		
Problem on social activities	46	61.3
Problem on spiritual life	32	42.6
Problem with family	27	36.0
Problem with employer	22	29.3
Preferred place to receive psychosocial support		
Health facilities	356	83.2
Religious places	70	16.4
Traditional healers other people	2	0.5

333

334

335 According to the multivariate analysis, residence was one of the sociodemographic factors that
336 was significantly associated with receipt for psychosocial care. The odds of breast cancer patients
337 who live in Addis Ababa were 2.54 times more likely to receive any psychosocial services as
338 compared to those who came from outside of Addis Ababa [AOR = 2.54 (95% CI 1.30, 6.27)].
339 Clinical factors such as severity of pain and date of diagnosis, also had a significant association
340 with receiving psychosocial services. Breast cancer patients who had moderate pain were three
341 times more likely to receive psychosocial services as compared to those women without any pain.
342 [AOR = 2.84 (95% CI 1.02, 7.94)]. The odds of women who were diagnosed more than 1 year ago
343 were three times more likely to receive the service as compared to those who were recently
344 diagnosed (< 1 year) [AOR = 3.17 (95% CI 1.27, 7.89)]. Other sociodemographic and clinical
345 factors such as age, marital status, educational level, stage of cancer, and type of treatment were
346 not associated with receiving psychosocial services. In this study, we also couldn't find any
347 significant difference in provision of psychosocial services between private and government
348 hospitals [AOR = 1.67 (95% CI 0.46, 6.03)] (Table 4).

349 **Table 4: Multivariate logistic regression model for factors for receiving psychosocial service among**
 350 **Breast Cancer Patients in Addis Ababa, Ethiopia**

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

351

352 Section three: Qualitative study findings

353 Theme 2: Determinants of psychosocial services provision

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

358 *“The main problem is staff shortage and high patient flow...umm....we do not have a staff who is*
 359 *assigned for psychosocial activities...” (HP04: BSc nurse, government)*

360 In addition to this, there was high patient flow in these health facilities due to the limited number
361 of cancer centers in the country. Therefore, it was difficult for the health professionals to spend
362 more time with each patient and address their emotional and psychosocial needs.

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

366 *"...because of the high patients flow, doctors are forced to see many patients per day specially in*
367 *government hospitals."* (HP02: **Oncologist**)
368

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

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

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

376 **Theme 3: Suggestions about psychosocial services**

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

380 **Subtheme 3.1: General suggestion for cancer care**

381 Due to the increasing number of cancer patients in the country, the health professionals suggested
382 that the current cancer care should be improved in terms of medical supplies, diagnostic and
383 therapeutic machines, long- and short-term capacity buildings and expanding cancer centers in
384 different parts of the country. In addition, integration between different sectors and collaborative
385 approach should be well-established in order to improve the quality of care given for cancer
386 patients.

387 *“There is nothing more devastating than hearing there is no medication for heart disease or cancer*
388 *in the country. Therefore, training centers, pharmaceutical suppliers like PFSA and service providers*
389 *or hospitals should work together to improve quality of care.” (HPO1: Oncologist)*

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

393 **Subtheme 3.2: Specific to psychosocial services**

394 **a) For the community**

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

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

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

401 **b) For the Ministry of Health**

402 *Psychosocial support should be part of chronic disease care*

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

410 *“There are only short term trainings, but as a whole to say palliative care it must include palliative care*
411 *specialty nurses and physicians. If we have these facilities, those who need the service will be referred*
412 *to this unit and the service providers will give all the required support.” (HP02: Oncologist)*

413 *“I suggest assigning psychiatrist or trained personnel in addition to the doctors and nurses on palliative*
414 *care service. Therefore, it should be integrated in more organized and structured manner.” (HPO4: BSc*
415 *nurse, government)*

416 ***Establishing support groups in each department***

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

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

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

428 ***Psychosocial support should be included in the curriculum***

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

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

439 *“At some point clinical psychology was comprehended as an important issue but then it was*
440 *terminated. In the future, every Oncologist should work together with clinical psychologists.” (HPO1:*
441 *Oncologist)*

442 Not only was it the different components of the psychosocial services but it was also indicated that
443 other financial supports are needed for those patients who are coming from rural areas of the
444 country.

445 *“It’s good if financial support is given for such kind of patients who are coming from other parts of*
446 *Ethiopia.” (PO1: 36 years)*

447 **Discussion**

448 In this study, the majority of breast cancer patients received social support from their family
449 members, friends and colleagues. This finding is consistent with other studies conducted in China
450 [36], Turkey [37] and Botswana [32], which reported that cancer patients often received
451 psychosocial supports from their family members and friends.

452 Regarding disclosure of cancer diagnosis, several guidelines recommended that all cancer patients
453 should be well-informed about their diagnosis, treatment options and future prognosis of the
454 disease [23-25, 38]. However, the qualitative findings of our study found that there were some
455 breast cancer patients who were not even aware of their diagnosis. A previous study conducted in
456 Ethiopia also reported a similar finding concerning lack of disclosure of cancer diagnosis among
457 breast and cervical cancer patients [39]. This finding is not only in Ethiopia but also supported by
458 a quantitative study conducted in Egypt that revealed around 15% of cancer patients were not
459 aware of their diagnosis, and only their family members were aware of their diagnosis [40]. The
460 main reason assumed by interviewees for not disclosing to these patients was the pressure of
461 relatives on caregivers to prevent hopelessness and discontinuation of treatment. This reason is
462 also consistent with a study done in India, which reported that the majority of caregivers preferred
463 non-disclosure of cancer diagnosis and prognosis to their patients [41]. Poor disclosure of cancer
464 diagnosis in developing countries might be associated with poor educational attainment [40],
465 preference of traditional medicine, old age and having other chronic illnesses [42]. Even those

466 breast cancer patients who were informed of their diagnosis in this study perceived not being
467 properly approached and disclosed at the time of the diagnosis. This might be related to lack of
468 skill on how to break bad news to patients or due to a shortage of time to spend with each patient
469 in those health facilities. Further studies might be required to explore the reasons for not properly
470 disclosing cancer patients in developing countries.

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

488 with the perception of health professionals towards the capacity of mostly illiterate patients to
489 comprehend and appropriately interpret all these details.

490 Those patients who are residents of Addis Ababa were two times more likely to receive
491 psychosocial services compared to others who were residing outside of Addis Ababa. This finding
492 can be explained by the fact that people living in urban areas probably have better health
493 information and therefore insist on obtaining psychosocial services. This finding is supported by
494 a study conducted in Egypt, which revealed that educational level and place of residence were
495 significantly associated factors with regard to disclosure and provision of psychosocial services
496 [40]. The other associated factor with provision of psychosocial services was severity of pain. This
497 can be explained by the compassion of health professionals toward patients with severe pain. In
498 this study, those breast cancer patients who were diagnosed longer ago were more likely to receive
499 psychosocial services. This may be due to increased opportunities for service provision. It also
500 shows that, in contrary to high income settings, it is not standard to counsel patients at the time of
501 diagnosis.

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

510 nine interviews. By using the mixed study design, we helped to fill the limitation of each of the
511 approaches.

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

527 **Abbreviations**

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

532 **Declarations**

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

538 **Consent for publication:** Not applicable.

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

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

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544 interpretation of data and in writing the manuscript.

545 **Authors' contributions**

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

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