Psychosocial challenges and available supportive care for cancer patients in Ethiopia

Thesis

to obtain the academic degree of

Doctor rerum medicarum (Dr. rer. medic.)
in the field of Epidemiology

submitted to the Faculty of Medicine of
Martin Luther University Halle-Wittenberg

By Abigiya Wondimagegnehu Tilahun

Supervisor: Prof. Dr. Eva Kantelhardt

Reviewers: Prof. Dr. Dirk Voldermark, Halle (Saale)

PD Dr. Kerem Böge, Berlin

Date of the defence: 25.11.2024

Referat (English)

This Ph.D. dissertation focused on psychosocial challenges and supportive care for cancer patients in Ethiopia. The study utilized a mixed methods approach, incorporating both quantitative (retrospective cohort and cross-sectional designs) and qualitative methods. We reviewed 1,298 patients' charts and conducted phone interviews with 365 cancer patients from eight rural hospitals in southwestern Ethiopia over 5 years to assess pathways to care. The qualitative data comprised 24 in-depth interviews and 16 focus group discussions to understand conceptions about cancer care among patients, family caregivers, health professionals, community representatives, and religious leaders. Findings revealed that most cancer patients were women in their 40s with late-stage breast (38%) or cervical (29%) cancers. Despite the predominantly available surgical services, one fifth of the patients did not undergo the recommended procedures due to patient refusal. Limited diagnostic and systemic treatment services were noted, resulting in patients visiting an average of three healthcare institutions before initiating treatment. The qualitative study identified reasons why elderly and very young women often refuse mastectomy, which included fear of surgery, religious beliefs, and desires to preserve breast tissue for breastfeeding. Lack of disease awareness, sociocultural influences, and having seen that women died despite mastectomy also contributed. Psychosocial challenges were summarized using the social-ecological model, revealing emotional distress, denial, and treatment refusal, along with ongoing feelings of hopelessness and fear throughout treatment. Family members' involvement in treatment decisions was revealed, along with the community's reliance on traditional medicine and religious practices as alternative treatments. Only a fraction of the breast cancer patients received psychosocial services, highlighting deficiencies in support systems within health facilities, including tertiary hospitals in Addis Ababa, attributed to heavy workloads, limited space, and a shortage of trained personnel. This contributed to a vicious cycle of negative and fatalistic attitudes, abandonment of care, and impaired outcomes among generations of cancer patients.

Innovative psychosocial services, potentially involving multiple professions, should be more seamlessly integrated into routine cancer care in Ethiopia. These services should be adapted to local contexts, considering sociocultural factors, community education levels, and available resources. By addressing individual psychosocial needs, we can significantly enhance patient retention in the healthcare system and improve outcomes. Educational initiatives should promote awareness of cancer as a treatable condition, leveraging support groups that include survivors and through collaboration with religious leaders and traditional healers. Expanding access to pathologic services, systemic treatments, and palliative care is crucial for facilitating early cancer detection and treatment in rural Ethiopia. Training healthcare professionals across various disciplines, including clinical psychology, palliative care, and social work, is vital for delivering comprehensive psychosocial support to cancer patients.

Wondimagegnehu, Abigiya: Psychosocial challenges and available supportive care for cancer patients in Ethiopia, Halle (Saale), Univ., Med. Fak., Diss., 24 pages, 2024.

Referat

Diese Dissertation fasst sechs Forschungspublikationen zusammen, die sich mit den psychosozialen Herausforderungen und der unterstützenden Betreuung von Krebspatienten in Äthiopien befassen. Hierfür wurden retrospektive Kohorten- und Querschnittsstudien durchgeführt, wobei quantitative und qualitative Methoden zum Einsatz kamen. Im Rahmen der Studie wurden die Krankenakten von 1298 Patienten geprüft und über einen Zeitraum von fünf Jahren Telefoninterviews mit 365 Krebspatienten aus acht ländlichen Krankenhäusern im Südwesten Äthiopiens geführt. Die qualitativen Daten umfassten 24 ausführliche Interviews und 16 Fokusgruppendiskussionen, an denen Krebspatienten, Pflege- und Gesundheitsfachkräfte, Gemeindevertreter und religiösen Oberhäupter teilnahmen. Die Ergebnisse zeigten, dass die meisten Krebspatienten Frauen in ihren 40ern waren und an Brust- oder Gebärmutterhalskrebs im Spätstadium erkrankt waren. Obwohl chirurgische Leistungen überwiegend zur Verfügung standen, unterzog sich ein Fünftel der Patienten nicht den empfohlenen Eingriffen, , zum größten Teil da sie Therapien ablehnten oder nicht in das Krankenhaus zurückkehrten. Die Möglichkeiten zur Diagnosestellung und systemischen Krebstherapie waren limitiert, was dazu führte, dass die Patienten im Durchschnitt drei Gesundheitseinrichtungen aufsuchten, bevor sie eine Behandlung begannen. In der qualitativen Studie wurden die Gründe untersucht, warum insbesondere ältere und sehr junge Frauen eine Mastektomie häufig ablehnten: Angst vor der Operation, religiöse Überzeugungen und der Wunsch, das Brustgewebe für das Kinderkriegen und Stillen bei jungen Patientinnen zu erhalten, waren häufig genannte Motive. Mangelndes Krankheitsbewusstsein, soziokulturelle Einflüsse und das Wissen um die negativen Folgen nach einer Mastektomie trugen ebenfalls dazu bei. Die psychosozialen Herausforderungen wurden anhand des sozio-ökologischen Modells zusammengefasst und zeigten emotionalen Stress, Verleugnung und Behandlungsverweigerung bei der Diagnose sowie anhaltende Gefühle der Hoffnungslosigkeit und Angst während der Behandlung. Es wurde festgestellt, dass die Familienmitglieder in die Behandlungsentscheidungen einbezogen werden und dass die Gemeinschaft auf traditionelle Medizin und religiöse Praktiken als alternative Krebsbehandlungen vertraut. Nur ein Bruchteil der Brustkrebspatientinnen erhielt psychosoziale Unterstützung, was auf die Mängel der Unterstützungssysteme in den Gesundheitseinrichtungen, insbesondere in den tertiären Krankenhäusern von Addis Abeba, hinweist, die auf die hohe Arbeitsbelastung, den begrenzten Raum und den Mangel an geschultem Gesundheitspersonal zurückzuführen sind. Innovative psychosoziale Dienste, an denen möglicherweise mehrere Berufsgruppen beteiligt sind, sollten nahtloser in die routinemäßige Krebsversorgung in Äthiopien integriert werden. Diese Dienste sollten an die lokalen Gegebenheiten angepasst werden, wobei soziokulturelle Faktoren, der Bildungsstand der Gemeinschaft und die verfügbaren Ressourcen zu berücksichtigen sind. Indem wir auf die individuellen psychosozialen Bedürfnisse eingehen, können wir die Patientenadhärenz im Gesundheitssystem deutlich erhöhen und die Behandlungsergebnisse verbessern. Aufklärungsinitiativen sollten das Bewusstsein für Krebs als behandelbare Krankheit fördern, durch den Einsatz von Selbsthilfegruppen für Krebsüberlebende und die Zusammenarbeit mit religiösen Oberhäuptern und traditionellen Heilern nutzen. Die Ausweitung des Zugangs zu pathologischen Diensten, systemischen Behandlungen und Palliativmedizin ist entscheidend für die Erleichterung der Krebsfrüherkennung und -behandlung im ländlichen Äthiopien. Die Ausbildung von medizinischem Fachpersonal aus verschiedenen Disziplinen, darunter klinische Psychologie, Palliativmedizin und Sozialarbeit, ist für die umfassende psychosoziale Unterstützung von Krebspatienten von entscheidender Bedeutung.

Wondimagegnehu, Abigiya: Psychosocial challenges and available supportive care for cancer patients in Ethiopia, Halle (Saale), Univ., Med. Fak., Diss., 24 pages, 2024.

Contents

Acronyms/Abbreviations

AOR: Adjusted Odds Ratio

BCS: Breast-Conserving Surgery

CCC: Comprehensive Cancer Centre

COR: Crude Odds Ratio

CPM: Contralateral Prophylactic Mastectomy

CT scan: Computed Tomography scan

CUP: Cancer of Unknown Primary

ER: Oestrogen Receptor

FGD: Focus Group Discussion

FNAC: Fine Needle Aspiration Cytology

GLOBOCAN: Global Cancer Incidence, Mortality, and Prevalence

HDA: Health Development Army

HEWs: Health Extension Workers

HMIS: Health Management Information System

IDI: In-Depth Interview

IPOS: International Psycho-Oncology Society

IRB: Institutional Review Board

LMICs: Low- and Middle-Income Countries

MCH: Maternal and Child Health

MRI: Magnetic Resonance Imaging

MRM: Modified Radical Mastectomy

NCCN: National Comprehensive Cancer Network

pET: Primary Endocrine Therapy

QCA: Qualitative Content Analysis

REC: Research Ethics Committee

RT: Radiotherapy

SEER: Surveillance, Epidemiology, End Results

SNNPR: Southern Nations, Nationalities, and People's Region

SSA: Sub-Saharan Africa

STSG: Split-Thickness Skin Grafting

WHO: World Health Organization

1. Introduction and objectives

1.1 Description of the problem

The burden of cancer globally is increasing, accompanied by immense physical, emotional, and financial challenges for individuals, communities, and healthcare systems (1,2). Cancer is a debilitating illness that leads to considerable psychosocial challenges for both patients and caregivers (3). Psychosocial challenges are the dynamic interactions among the physical, emotional, social, and cultural factors that come into play during the cancer trajectory (4). Several studies have revealed that psychosocial problems such as mood disturbance, hopelessness, psychological distress, anxiety, depression, cognitive problems, and fear of death or cancer recurrence, coping challenges, and interference with social relationships are commonly reported among cancer patients (5–8). Of these, anxiety emerges as a prominent psychological challenge for cancer patients, affecting all individuals at various stages of their illness. Over one third of cancer patients experience emotional distress, with approximately 1 in 5 expressing a need for psychosocial support (9–11). Another prevalent psychological problem is depression, which affects around 15–60% of cancer patients (12–15). The burden, severity, and types of psychological disorders vary significantly based on factors such as site of the cancer, stage of diagnosis, type and duration of treatment, geographic location, sociocultural context, and economic status of patients.

The effects of cancer on patients and survivors are always complex; both its diagnosis and treatment can be physically gruelling, disrupting all aspects of daily life and forcing patients to be dependent on caregivers and healthcare professionals (8,16). The primary triggers for psychological disorders among cancer patients often originate from the physical changes induced by the disease or its treatment. The multiple stages in the cancer journey include pre diagnosis, post diagnosis before treatment, during treatment, and short- and long-term after treatment, entailing different psychosocial problems and supportive care needs(8). For instance, typical chemotherapy side effects, such as hair loss, fatigue, and weight changes, have a huge psychological impact on cancer patients (17). The requirement to adjust to such changes can result in unforeseen consequences on body image and self-perception. Specifically, cancers demanding surgical removal of body parts may disrupt self-perception, appearance, physical capability, social interactions, and cognitive functioning (18,19). In general, several studies have shown that psychosocial problems are significantly associated with substantial functional impairment, fatigue, pain, low quality of life, poor adherence to treatment, and decreased survival rates among cancer patients (7,20).

Concerning the global burden of cancer and the demand for psychosocial support, the 2022 report from the International Agency for Research on Cancer (IARC) revealed a total of 19.98 million incident cases and close to 10 million deaths. The estimated number of people who were alive within 5 years following a cancer diagnosis was 53.5 million (21,22). It was also projected to cause 35.2 million new cases and 18.5 million deaths by 2050 (23). About 1 in 5 people develop cancer in their lifetime, and approximately 1 in 9 men and 1 in 12 women die from the disease (2). Although cancer detection rates and treatment successes continue to rise in high-income countries, many health systems in low- and middle-income countries (LMICs) are least prepared to manage this burden, and large numbers of cancer patients globally do not have access to timely quality diagnosis and treatment (24) which may contribute to the high psychosocial challenges and palliative care needs.

Most reported deaths in 2022 occurred in LMICs. Notably, Africa experiences a significant share of cancer-related deaths, comprising 7.8% of global cancer fatalities, exceeding its incidence rate of 5.9% of global cancer cases (21). This underscores cancer's disproportionate effect on marginalized populations and the pressing necessity to tackle cancer disparities globally (2). Limited diagnostic and treatment services in LMICs and advanced stage presentation can partly justify the poor prognosis of the disease and high mortality rate in those regions (25–27). Over the next decade, it is expected that more than 75% of cancer-related deaths will be concentrated in LMICs and Sub-Saharan Africa, where many of these nations are situated, presently facing a shortage of sufficient screening and detection methods, along with inadequate resources for treatment and psychosocial support (23,24). Given the scarcity of specialized diagnostic and treatment facilities in Sub-Saharan Africa, establishing efficient referral systems for cancer patients appears to be the most viable solution (24–26). Studies have shown how poor referral systems can hinder patients from accessing early diagnosis and treatment, which can significantly contribute to advanced stage presentation and poor outcomes (28–30). This may also directly influence the magnitude and severity of psychosocial challenges encountered by cancer patients in those settings.

In Ethiopia, cancer diagnoses are on the rise, accompanied by a high mortality rate. According to the Global Cancer Incidence, Mortality, and Prevalence (GLOBOCAN) 2022 report, the country recorded approximately 80,334 new cases and more than 54,698 deaths, with the majority (65.5%) affecting females (31). Cancers of the breast (32.1%) and cervix (15.5%) were the two most common cancers among females, while colorectal (12.1%) and leukaemia (9.5%) cancers were the most prevalent among males (31,32).

Like many other Sub-Saharan African nations, Ethiopians contend with a lack of diagnostic and treatment services. In fact, the number of specialists and essential equipment for cancer care in Ethiopia is among the most limited and constricted. Within the country's three-tier health system, oncologic care is predominantly centralized at tertiary referral centres (33). Primary level providers at health posts, health centres, and primary hospitals have a limited capacity for cancer diagnosis and often refer patients to general hospitals found at the secondary level (34). These hospitals provide diagnostic and surgical services, while some of them also provide endocrine therapy. At the tertiary level, specialized referral hospitals provide systemic oncology services, primarily situated in the capital or a few facilities at peripheral university hospitals (35,36). Consequently, surgery remains the only available service for many cancer patients at lower-level hospitals (34). Nevertheless, numerous cancer patients, especially those with breast cancer, do not receive even the most basic surgical care. This could stem from either operational challenges within the health facilities or patients' lack of psychological readiness, possibly due to the fear of complications and unforeseen sociocultural factors. Hence, some of these patients turn to alternative practitioners, such as herbalists, priests, and spiritual leaders (37,38) and only revisit healthcare facilities when complications and advanced-stage cancers arise (35,36,39).

For the past couple of decades, Tikur Anbessa Specialized Hospital (TASH) has been the only Ethiopian cancer centre offering comprehensive cancer care, including radiation treatment, until recently when Jimma and Hiwot Fana University Hospitals began offering the service (35,36,40). The government is actively pursuing the decentralization of oncology services, with systemic treatment available in over 24 hospitals, and plans are underway to introduce radiotherapy services in four additional cancer centres located in various geographic locations nationwide (34,35,41). Despite the encouraging efforts in expanding services and building capacity, various administrative and technical challenges have led to significant delays in accommodating and providing comprehensive cancer care including psychosocial support, especially in light of the increasing cases.

As integral components of cancer care, psychosocial services, including counselling, relaxation training, cognitive and behavioural coping techniques, cancer education/information sessions, and group social support are vital in addressing the social, psychological, emotional, spiritual, and functional needs of patients (42,43). The provision of these services has revealed significant effects on reducing emotional distress, anxiety, and depression (43,44). They have also improved adherence to treatment and enhanced the quality of and survival of cancer patients (42–45). As a result, these services are being integrated and delivered in routine cancer care in high-income countries (46–48). However, some studies have revealed a remaining gap in identifying the psychological, social, and spiritual needs of cancer patients in LMICs and properly addressing them through systematic and culturally tailored psychosocial services that benefit patient well-being (46,48).

In summary, cancer statistics in Ethiopia are predominantly confined to tertiary level hospitals or are restricted to the capital city, where the cancer registry is situated. However, the overall magnitude and pathway of cancer patients in the healthcare system, starting with symptom recognition to advanced care is not well documented. Although some studies have indicated that surgical treatment is the only available cancer treatment at the lower-level hospitals, patterns of surgical service utilization and refusal rate remained unstudied in peripheral sites of the country. Furthermore, the reasons for low uptake of surgical and other treatment options among breast cancer patients are not yet understood.

In addition, evidence suggests a difference in the psychosocial challenges faced and needs among cancer patients in Western countries and LMICs (19,48). Hence, recognizing the unique cultural, social, and emotional dynamics in LMICs is vital for enhancing the psychosocial and spiritual dimensions of supportive care. Nonetheless, detailed exploration of specific psychosocial challenges within these contexts, especially in Ethiopia, remains limited. Previous studies have been quantitative in nature, only highlighting unmet supportive care and information needs among cancer patients in Ethiopia (49–51). However, to the best of our knowledge, available psychosocial services for cancer patients at the health facility level had not been addressed before.

Therefore, in this study, we retrospectively assessed the magnitude of the most common cancers and surgical service utilization in eight rural hospitals over 5 years. Also, we sought to illustrate the entire pathway of cancer patients in those health facilities, which we believed to capture the barriers that hinder early cancer diagnosis and treatment in Ethiopia. Related to this, the reasons for refusing surgical services explicitly for mastectomy among breast cancer patients was qualitatively explored, and unique psychosocial challenges among cancer patients were identified using the social-ecological model. Finally, we applied a mixed methods design in order to assess the currently available psychosocial services that have been provided for cancer patients in the health facilities. It seemed beneficial to pinpoint gaps in the delivery of psychosocial services and develop suitable interventions by taking into account the socioeconomic and cultural context of the country. Utilizing knowledge of existing psychosocial services should allow for leveraging and expanding upon services rather than creating entirely new approaches and structures. This approach might also streamline the overall implementation process and strengthen the sustainability of these services within the healthcare system.

1.2 Research objectives

The research objectives were:

1. Determine the magnitude of frequently diagnosed cancers, describe the uptake of surgical services, and calculate the proportion of patients who refused surgical procedures in rural hospitals of Ethiopia from 2014 to 2019.
2. Describe pathways and referral patterns of patients with cancer diagnosed at primary and secondary hospitals in rural Ethiopia and identify contributing factors for successful completion of referrals.
3. Explore reasons for refusal of mastectomy and identify challenges in relation to having surgery among breast cancer patients in Ethiopia.
4. Explore the psychosocial challenges and needs of cancer patients in Ethiopia using a social-ecological model.
5. Assess the availability and receipt of psychosocial services for breast cancer patients in selected hospitals in Addis Ababa, Ethiopia.

The research findings were discussed through a review of literature in Africa and other regions. Recommendations for this study were formulated by accounting for the county context and these research findings. This dissertation employed retrospective cohort and cross-sectional study designs, incorporating both quantitative and qualitative approaches, as well as a mixed methods design, resulting in seven research publications (Wondimagegnehu et al. 2022, 2023, 2024).

2. Discussion

This doctoral thesis discusses the main findings of the research outputs concentrated on overall cancer burden and surgical service utilization among cancer patients in eight rural hospitals of Ethiopia over 5 years. We emphasized an exploration of the unique psychosocial challenges identified at individual, interpersonal, and community levels using the social-ecological model. In addition, an attempt was made to understand and articulate how institutional, personal, and sociocultural factors discourage women with breast cancer from receiving surgical treatment in rural communities of Ethiopia. The impact of traditional medicine and religious beliefs will also be discussed in detail. Moreover, the overall pathway of cancer patients starting from an initial consultation to receiving specialized cancer care is illustrated in the three-tier healthcare system of Ethiopia. Particularly, the status of psychosocial service provision for cancer patients and obstacles in integration of those services in the routine cancer care will be entertained at discussion's end.

2.1 Cancer is on the rise among young women

In this study, a total of 1,298 cancer cases were identified between 2014 and 2019, with an increasing pattern over the years. Breast (38%) and cervical (29%) cancers were the most frequently diagnosed among females, while prostate (19%) and oesophageal (16%) cancers were the most prevalent among males. Our findings highlight a concerning trend in rural Ethiopia, where cancer diagnoses among women occur at a young age, often coinciding with early motherhood and significant caregiving responsibilities for their children. This situation not only affects the women but also has repercussions on their children who may suffer due to the illness and the resulting caregiving challenges. A recent qualitative study provided valuable perspectives on the impact of maternal cancer on children, finding that many children are concerned about potentially losing their mother, and the challenges of being physically distanced from her during hospitalization suggested the emotional and practical hardships faced (52). Apart from its impact on children, maternal cancer adversely affects the entire family, with fathers frequently reporting increases in responsibilities and pressure due to prolonged physical, psychological, and financial demands of the course of treatment (53). According to the 2024 IARC report, maternal cancer deaths have intergenerational implications: 4.4 million women lost their lives to cancer in 2020, resulting in an estimated 1.04 million maternal orphans worldwide (54). More than a third (35%) of new maternal orphans are in Africa, with nearly half of the deaths attributed to breast cancer (25%) and cervical cancer (18%) (55). This underscores the critical need to decrease preventable deaths from these particular cancers through screening, vaccination, early detection, and treatment.

2.2 Pathways and referral of cancer patients in rural Ethiopia

The overall pathway of cancer patients was investigated among 365 eligible patients identified over a 3-year period. Our results revealed that, on average, the cancer patients sought care from three different healthcare institutions, from their initial encounter with a provider to their final treatment initiation. This finding is consistent with previous studies in Addis Ababa, which highlighted that cervical cancer patients visiting four health facilities from their first contact with primary healthcare units significantly contributed to delays in diagnosis and care (38,56). This suggests that the number of facilities visited has a direct time implication on early cancer diagnosis and treatment. This aligns with the WHO framework, which outlines three sequential steps: access to care, evaluation of the disease, and access to subsequent treatment. According to a recent systematic review, LMICs experience significantly longer access intervals, with a median of 6.5 months, compared to other countries (29). In Ethiopia, access to health facilities offering pathology services is limited, primarily found in urban areas. Consequently, patients are often referred to the private sector or comprehensive cancer centres for confirmatory diagnostic tests, leading to long travel distances and high expenses. Our 5-year review revealed that clinical diagnosis was predominant, with pathologic examination conducted for only 38.8% of the cases. Studies in Ethiopia and other LMICs have consistently shown that a significant proportion of cancer cases are diagnosed and treated clinically without undergoing pathologic examination for verification (25,27). The absence of pathology services, coupled with inadequate referral systems significantly contribute to delayed cancer diagnoses in Ethiopia (57,58). This issue was also evident in our study, where 65.4% of the cases were diagnosed at an advanced stage, highlighting the pressing need for pathologic services in Ethiopia. After diagnosis, only 26% received referrals for further cancer treatment, and yet, 21% of all the patients did not receive any treatment. These figures closely mirrored data from the population-based Addis Ababa Cancer Registry, revealing that one fifth of all cancer patients in the capital city remained untreated (36). This underscores a significant disparity in access to specialized tertiary care for certain cancer patients, potentially driving them to explore alternative treatments such as traditional remedies and religious rituals. In general, studies conducted in Sub-Saharan Africa have shown that inadequate referral systems impede patients' ability to access early diagnosis and treatment, resulting in advanced stage presentation and unfavourable outcomes, thus exacerbating the severity of psychosocial challenges for cancer patients in these regions (28–30).

2.3 Surgery: Sole option in rural hospitals with limited systemic treatment

Surgery stands as the primary cancer treatment widely offered in primary and secondary level hospitals of Ethiopia, with endocrine treatment being the only systemic option available. However, other systemic treatments like chemotherapy and radiotherapy services are rarely accessible at tertiary level hospitals.

This observation aligns with previous research in Africa, which noted that surgery is often the only feasible choice for numerous cancer patients on the continent due to constraints in systemic therapy and fragmented referral systems (59–63). Concurrent with the high prevalence of breast and cervical cancers, mastectomy (37.5%) and abdominal hysterectomy (20.4%) were the most frequently performed surgical procedures. Particularly, modified radical mastectomy was recommended for all breast cancer patients due to limited access to radiotherapy services required for breast conservation.

Although surgery was the sole treatment option in peripheral hospitals, nearly one fifth (18.5%) of scheduled surgeries were not carried out. Among these, half of the patients either declined treatment or failed to return to the hospital on their scheduled dates. Our qualitative study unveiled that many breast cancer patients in Ethiopia, particularly young and elderly women, often refused mastectomy and consequently returned to the health facilities much later, when surgery was no longer viable. Similarly in Northern Ethiopia, a study discovered that surgery was not pursued in 32% of breast cancer cases because of the disease's advanced stage (64). High refusal rates have been reported not only in Ethiopia but also in several other African nations, including Rwanda and Nigeria. In Rwanda, 15.7% of patients declined surgery (65), while in Nigeria, refusal rates reached 38% in two hospitals (66). In contrast, mastectomy is perceived as less impactful in developed countries, with a minimal refusal rate ranging between 0.64% and 3.56% (67–69). Let alone therapeutic breast surgery, contralateral prophylactic mastectomy (CPM) has become prevalent even among healthy women deemed at high risk of developing breast cancer (70).

The high refusal rate in Africa can be attributed to several factors, including distrust in medical treatment, availability of alternative treatments like traditional medicine, negative patient experiences, fear of complications, and prevalent misconceptions associating cancer with evil spirits, often requiring spiritual remedies only (60,61). Similar misconceptions about cancer causes were identified in another qualitative study we conducted, revealing that the rural community of Ethiopia perceives cancer as an incurable disease (71). Such deep-rooted beliefs also dictate that cancers should not be surgically interfered with, which can lead to delayed presentation and rejection of surgical interventions, ultimately contributing to high mortality rates. This cycle reinforces the belief that cancer is incurable, perpetuating reluctance to seek or accept medical intervention.

2.4 Reasons for refusal of mastectomy in Ethiopia

Our qualitative research further explored the various reasons for refusing mastectomy among breast cancer patients in Ethiopia. These included the fear of the surgical procedure and concerns about its success, compounded by scepticism about its effectiveness due to knowing someone who died even after breast removal. Lack of awareness, religious beliefs/practices, and reliance on traditional treatments were also identified as reasons for avoiding breast cancer surgery.

Desire to have a baby and breastfeed

The younger women and those with small, painless masses often preferred removing only the lump while preserving the surrounding breast tissue, a procedure commonly referred to as breast-conserving surgery (BCS). This problem was particularly pronounced among unmarried women who aspired to have children and breastfeed them. Previous studies have also associated refusal of surgery with being single or widowed, while expressing concerns that mastectomy at a young age might impact quality of life and overall achievements (67,72). A significant refusal rate for mastectomy among young women holds profound implications, given that most breast cancer patients in Ethiopia and Sub-Saharan Africa are of childbearing age (25,63). Evidence indicates that individuals who refuse mastectomy have a poorer prognosis in terms of overall survival compared to those who undergo surgery (68,69). Due to the scarcity of radiotherapy services in Ethiopia, mastectomy remains the primary surgical approach for breast cancer treatment across all stages (35,73). Nonetheless, BCS has emerged as an option in a few facilities within the capital city. This option is only offered if the surgeon confirms that the patient can access radiotherapy services, whether within private wings or elsewhere. Despite government efforts to expand radiotherapy services to five cancer centres in Ethiopia, the presence of only two radiotherapy machines for a population over 120 million falls short of the standard required to consider BCS a viable alternative for breast cancer patients in the country. Therefore, there is an urgent need to prioritize the expansion of radiotherapy services nationwide.

Poor success stories after mastectomy

Another notable finding was that some individuals refused mastectomy due to knowing someone who died after having the procedure. This might be attributed to a lack of clear communication about the intended purpose of the surgery, particularly for cases performed with palliative intent. For instance, our retrospective review revealed that 73.1% of surgeries performed for breast cancer patients were intended for palliation, potentially indicating a high mortality rate following mastectomy. Additionally, the high mortality rate after mastectomy could be attributed to the lack of systemic treatments; it is likely that these patients did not receive either chemotherapy or endocrine treatment following the operation. Our study in rural Ethiopia showed that nearly all patients died within 3 years after surgery without systemic treatment (74).

Unlike in developed countries, where cancer survivors often advocate openly for treatment, Ethiopia's cultural context poses unique challenges. Many cancer patients, particularly women, are hesitant to disclose their diagnosis or support newly diagnosed patients. Our qualitative investigation unveiled self-stigmatization among cancer patients, driven by negative societal pressures. While community members may not overtly stigmatize or discriminate against cancer patients, many individuals opted to withdraw from social engagements and refrained from discussing their illness with anyone beyond immediate family and close friends. Hence, engaging breast cancer survivors in advocacy could be impactful, offering powerful role models who demonstrate resilience and hope. By sharing their experiences, survivors can empower newly diagnosed women to make informed treatment decisions, including mastectomy. Professional counselling can further support individuals, providing tailored practical and emotional assistance.

Sociocultural factors and misconceptions

Another significant factor highlighted in our investigation was sociocultural influences, such as community advice, as breasts are perceived as symbols of femininity, beauty, and motherhood, which can impact women's decisions. In this study, certain breast cancer patients reported that community members advised and frightened them against surgery, suggesting that they would no longer be considered women after losing their breasts. Another qualitative study in Ethiopia also reported a similar finding and stated that the breasts symbolize women’s beauty and attraction. Additionally, some breast cancer patients expressed negative emotions regarding their body image and felt a sense of incompleteness following mastectomy (75). A qualitative study conducted in Nigeria investigated the belief that the removal of breasts leads to a loss of femininity and womanhood, sometimes resulting in women without breasts being perceived as men (72). Several studies have indicated that undergoing a mastectomy can have adverse effects on a woman's body image and her relationship with her husband (76,77).

2.5 Psychosocial challenges among cancer patients

Regarding psychosocial challenges among cancer patients, the social-ecological model was applied to summarize the main findings. Accordingly, the study identified that cancer patients face several unique psychosocial challenges at different stages of the disease’s trajectory. These challenges occur at individual and interpersonal levels, as well as in the relationship with communities and institutional systems of care. Right after diagnosis, numerous cancer patients experienced shock, fear, denial, and some even attempted suicide upon learning of their diagnosis. Depression, anxiety, hopelessness, and fear of death were identified as significant psychosocial challenges in this study, consistent with findings from multiple systematic reviews and explanatory studies (9,12,13,78). These symptoms are commonly reported among cancer patients, both at diagnosis and during treatment. Variations in symptom severity and frequency may be attributed to differences in cancer site and stage, treatment approaches, social dynamics, and access to psychosocial support. As proven by several studies, these psychosocial challenges hold significant clinical implications, leading to considerable functional impairment, diminished quality of life, reduced treatment adherence, and lower survival rates among cancer patients (7,20,79). With the anticipated rise in cancer cases and limited availability of specialized diagnostic and treatment centres in Sub-Saharan African countries over the next decade (24), unforeseen public health emergencies such as COVID-19 could potentially exacerbate economic, social, and psychological crises, amplifying psychosocial challenges among cancer patients (14,80). Therefore, healthcare systems should prepare to accommodate the influx of patients while also addressing their psychosocial needs through innovative approaches and collaborative efforts with other stakeholders and the community.

Suicidal risk: Perceiving cancer as a death sentence

A cancer diagnosis can profoundly unsettle one's sense of security, evoking deep-seated fears of pain, suffering, and mortality. Despite some cancers being treatable, the pervasive fear associated with cancer often leads to emotional distress and suicidal ideation upon diagnosis. In our study, some patients expressed attempting suicide upon receiving the diagnosis of breast cancer. Likewise, a recent meta-analysis that aggregated data from 28 studies found a significant increase in suicide mortality, nearly doubling compared to the general population. The risk fluctuates depending on factors such as cancer prognosis, stage, time since diagnosis, and geographic location (81). Numerous additional studies have also highlighted the prevalence of suicidal thoughts among cancer patients, particularly those undergoing chemotherapy, radiotherapy, and surgery (13,80–82). This indicates the importance of closely monitoring cancer patients for signs of suicidal behaviour and ensuring they receive specialized care to mitigate both short- and long-term suicide risks. Specifically, healthcare professionals should exercise caution and undergo thorough training when disclosing a cancer diagnosis to patients, ensuring they provide comprehensive emotional support before patients leave the medical facility. Our study also identified that even those who are diagnosed at an early stage considered cancer an untreatable disease, framing cancer as a death sentence.

This sentiment resonated with prior research, where cancer was often equated with death, evoking a primal fear response (16). Similarly, in Ethiopia, a widespread public perception of cancer as a deadly disease was reflected in previous studies (83,84). For this reason, both health professionals and family members tended to avoid using the term "cancer", opting for alternative language when discussing the illness with patients (39). The uneven perception may stem from high cancer mortality rates in Africa, including Ethiopia, where the lack of positive outcomes makes it difficult to convince people that cancer can be cured. Moreover, the reluctance of successfully treated individuals to share their stories publicly has hindered efforts to raise awareness in the community.

Treatment disruption due to financial hardship

One of the main psychosocial challenges identified in this study was financial strain, consistently mentioned by cancer patients, caregivers, and health professionals. Unlike other diseases, cancer demands prolonged local and systemic treatments, each posing a significant financial burden for many patients. Additionally, diagnostic procedures such as pathological tests and imaging are often unaffordable for cancer patients in Ethiopia, as these services are not widely available and require patients to travel long distances. As patients are required to visit more health facilities, their psychosocial challenges escalate, with the fear of recurrence and death heightened by the absence of recommended treatment. Furthermore, the patients often rely on caregivers to accompany them to various tertiary level hospitals, adding to the overall financial burden. In this study, the patients identified two primary obstacles to completing a referral: 73% cited financial difficulties in covering the costs of diagnostic tests and treatment, while 30% mentioned transportation issues. To gain insight into the barriers and facilitators of the referral system in rural Ethiopia, we conducted an additional qualitative study involving health professionals, hospital medical executives, and local health bureau representatives. We discovered that referred patients face challenges due to inadequate transportation systems, a lack of nearby accommodation close to specialized facilities, and difficulties navigating these facilities due to language barriers and illiteracy. This result is in line with a study conducted in Morocco, which found that cancer diagnosis and treatment frequently plunge households into poverty because patients must often travel long distances for diagnosis and treatment, with transportation and accommodation costs proving excessively expensive (85). The financial consequences of a cancer diagnosis on family members were similarly evident in other studies (53,56).

In contrast, many developed countries employ various mechanisms to alleviate the financial strain on patients, such as subsidizing medication costs, incorporating them into health insurance premiums, and connecting patients with supportive organizations. However, in Ethiopia and other LMICs, the lack of a comprehensive health insurance system means that cancer patients must bear the full burden of diagnostic and treatment expenses out of pocket. Although Ethiopia has been implementing community-based health insurance (CBHI) schemes as pilots since 2011, overall health insurance coverage remains only at 28.1%, indicating that further efforts are required. According to a recent study, 74.4% of cancer patients in Ethiopia experienced catastrophic health expenditure, with a mean overall cost of $2,366 per patient. Chemotherapy was one of the main reasons for such high expenditure(86). While Ethiopian health insurance covers costs for chemotherapy and related services, a significant barrier arises due to the shortage of medications at public hospitals. This frequently forces patients to seek costly alternatives at private pharmacies, which are often unaffordable for many cancer patients.

Family involvement in treatment decisions

Regarding the interpersonal level, respondents mentioned that the illness had adverse effects on both their family and their own social lives. In addition, the involvement of family members in major treatment decisions was mentioned. Our mixed methods study found that some breast cancer patients were unaware of their diagnosis and received treatment without proper disclosure. This finding is consistent with a previous study conducted in Addis Ababa that reported the lack of disclosure of a cancer diagnosis among breast and cervical cancer patients (87). The main reason given for not properly disclosing cancer patients was the pressure of relatives on health professionals to prevent hopelessness and discontinuation of treatment. Similarly, another study described the complexity of communication-related preferences regarding breaking bad news in oncology care in Ethiopia. While patients express a desire for information, the preferences of family caregivers create an ethical dilemma for healthcare providers regarding patient involvement in clinical decision-making; furthermore, due to the perceived fatality of the disease, the general public prefer discussions about poor life expectancy to be restricted to family members only (83). In our qualitative study, the breast cancer patients reported that their family discouraged them from undergoing mastectomy, despite medical recommendations. This highlighted a collective decision-making process within families, particularly among women with cancer who may have limited autonomy in choosing their treatment options. This may stem from lower levels of education and economic dependence on their husbands and the broader community (88). Similarly, another qualitative study described the paramount role of family in physician–patient communication in Ethiopia. The study revealed that family caregivers were often responsible for treatment decisions and avoided informing patients about a poor prognosis, believing that conveying such news may cause distress (83,84).

Perceived effectiveness of alternative treatments

Regarding the community and organizational levels, our study delved into external factors including community perceptions, norms, beliefs, cultural and religious practices, as well as traditional treatments and their impacts both positive and negative on the psychosocial well-being of cancer patients. Misconceptions about cancer's curability among patients, families, and communities led to scepticism towards conventional treatment, prompting the exploration of alternative approaches. The research uncovered that cancer patients frequently ceased medical treatment due to societal pressure to turn to traditional healers and religious practices, particularly prevalent in LMICs like Africa (27–30). Across the nation, studies have shown that many cancer patients resort to traditional remedies or religious rituals, resulting in delays in seeking treatment, refusal of conventional treatments, and discontinuation even after starting treatment (37,38,57,58).

Conversely, religion and spirituality have shown significant associations with cancer patients' adjustment and symptom management, and they are integral components of person-centred care, aiding patients in coping throughout the cancer journey, from diagnosis to treatment, survival, recurrence, and end-of-life care. Studies indicate that religious and spiritual coping are linked to lower levels of discomfort, as well as reduced hostility, anxiety, depression, and social isolation among cancer patients (89,90). Additionally, positive religious involvement and spirituality correlate with an enhanced quality of life and extended life expectancy (91). Therefore, it is crucial for healthcare professionals to recognize and support the spiritual needs of cancer patients, working together with religious leaders rather than disregarding religious rituals. This collaborative approach can complement medical care and lead to better prognoses.

2.6 Available psychosocial services

In our mixed methods study, only 47 (11.1%) of the breast cancer patients received psychosocial services either in the form of counselling, emotional support, or information provision. Counselling services and a provision of information about the types of tests as well as treatment details, including type, combination of treatments, duration, side effects, and regimen were reported parts of standard cancer treatment. However, some breast cancer patients in this study were unaware of their diagnosis and expressed not receiving sufficient information about their diagnosis and treatment, including the prescribed number of chemotherapy cycles. In a prior study conducted in Addis Ababa, breast cancer patients demonstrated a strong demand for information, especially concerning disease and treatment, with mean percentages of 94.8% and 93.7%, respectively. Moreover, two thirds of them indicated a preference for information from healthcare professionals (49). In addition to information needs, studies have shown a notable prevalence of unmet needs in cancer care across various domains in Sub-Saharan Africa. This included 63% for physical needs, 59% for health information and systems, 58% for psychological support, 44% for patient care and support, and 43% for sexual concerns (51,92). In our study, health professionals reportedly integrated such services into their routine activities, but there were no well-structured counselling services, information provision, emotional support, or group discussion sessions available for breast cancer patients in these health facilities. The primary reasons for not providing such psychosocial services for cancer patients were attributed to a high workload, inadequate space, and a shortage of trained health professionals. This is in line with another study in Addis Ababa which found that workload and time pressure, in combination with restricted space for privacy, limited the possibilities for physicians to deliver detailed information and provide emotional support (84). Likewise, numerous African countries lack the resources, including skilled personnel, infrastructure, and materials, to offer comprehensive psychosocial services (48,93,94).

Upon identifying the lack of psychosocial support for cancer patients within healthcare settings and recognizing the considerable psychosocial needs of these patients, we developed context-based psychosocial services. These services are intended for integration and delivery by healthcare providers both within health facilities and at the community level. Initially, we conducted a feasibility assessment to gain a thorough understanding of existing cancer services and determine the optimal approach for delivering these services using available human resources and infrastructure. Subsequently, we developed a psychosocial support package that encompasses counselling services, distribution of brochures, patient group discussions, and home visits facilitated by health extension workers (HEWs). In the preparation phase, we developed three audiovisual materials focusing on breast, cervical, and colorectal cancers, each lasting 5–8 minutes. Additionally, we produced two documentaries featuring real-life stories of survivors of breast and colorectal cancer. One survivor had prevailed over breast cancer and survived for 20 years, while the other had overcome colorectal cancer and lived for 12 years after diagnosis. Four brochures on breast, cervical, colorectal, and prostate cancers were prepared in two local languages, namely Amharic and Afaan Oromo. A total of 34 nurses and 15 HEWs were trained on how to deliver the designed psychosocial services. Five launching programs were held in five rural towns where the hospitals were situated. Community representatives, religious leaders, health professionals, and higher officials from zone/woreda health offices participated. To evaluate the impact of these services, a cluster randomized controlled trial was employed in 12 hospitals, two tertiary hospitals located in Addis Ababa and Hawassa city, and five rural hospitals; in each, a control and intervention wing were included. The intervention was designed to be administered for 6 months by trained nurses who worked at the oncology and surgical ward. As a result, 289 cancer patients were provided with counselling services and received brochures respective to their specific cancer type. Furthermore, 12 group discussion sessions were conducted, with 123 cancer patients actively participating. Three audiovisual materials were showcased across the six intervention sites. Additionally, the HEWs visited the homes of 72 cancer patients to provide emotional support. Currently, we are assessing the impact of the delivered psychosocial intervention at 6 and 12 months of follow up. Standard and validated measures like the European Quality of Life (EQoL) and Hospital Anxiety and Depression (HAD) tools were used to assess the outcomes of interest. Therefore, we conducted a validation study on the CR-29 EQoL tool, which had not been previously validated in Ethiopia. Our findings confirmed the reliability and validity of the Amharic version of the EORTC-QLQ-CR29 among colorectal cancer patients in Ethiopia (95).

2.7 Strengths and limitations

The main strength of this study was the inclusion of eight primary and secondary level hospitals located in Oromia and the SNNPR regions – the two largest regions in the country with considerable diversity of patient characteristics and health services. In addition, seven private and public hospitals in Addis Ababa, including TASH were included, enhancing the representativeness of our findings. Assessing the journey of cancer patients at primary and secondary healthcare levels, not done in previous studies, allowed us to compare the available diagnosis and treatment services for cancer and to capture the experiences of patients who may not have been represented in tertiary hospitals. Moreover, information collected over a 5-year period can illustrate the pattern of common cancers and surgical service utilization over time. A notable strength of our qualitative study lies in adhering to the principle of maximum variation and large sample size. The data were gathered from a diverse range of sources including cancer patients, their relatives, healthcare providers, community representatives, and religious leaders. This approach strengthened the comprehensiveness and inclusivity of the data. Particularly, the inclusion of breast cancer patients who actually refused mastectomy provided valuable insight into their reasons for refusal. Additionally, involving health professionals across various levels supported us in gaining comprehensive perspectives from both patients and healthcare providers. Employing both IDI and FGD for data collection further supported the triangulation of our findings. Additionally, the mixed methods study allowed for a comparison of psychosocial service availability between private and government hospitals.

Conversely, there were several limitations to the study. First, we missed data for important variables when the data were retrospectively reviewed from patient charts. Inadequate chart storage in hospitals may have also led to the omission of patient cards, resulting in an underestimation of the total number of cases. Moreover, only 58% of the patients listed in the logbook were contacted by phone, suggesting that individuals diagnosed late or with unsuccessful referrals may have passed away prior to data collection. We tried to interview relatives to account for this bias. The second limitation was recall bias, which we tried to mitigate by employing the calendar technique for date determination through cross-referencing with patient charts. One of the major limitations in our qualitative study was that the findings were confined to the studied geographic area, yet numerous themes aligned with the existing literature. In addition, all the interviews were conducted only in the official local language, whereas nuances present in other local languages might not have been captured. Another limitation was the predominance of breast and cervical cancer patients, resulting in a slight gender imbalance, with more females than males among the participants. In the mixed methods study, we solely conducted IDIs with health professionals and did not utilize validated questionnaires in the quantitative portion.

2.8 Conclusions

In Ethiopia, the increasing number of cancer diagnoses, particularly at advanced stages, presents significant psychosocial challenges, with a growing demand for supportive and palliative care services. Over a 5-year period, around 1,300 cancer cases were treated in eight rural hospitals in Ethiopia, with females bearing most of the burden. Clinical diagnoses were predominant, highlighting the urgent need for more pathology services. Surgery was the only available cancer treatment, yet one fifth of the needed surgeries were not performed due to patient refusal or patients not returning to the hospital. On average, cancer patients sought care from three different healthcare institutions, from their first visit to treatment initiation. Only one quarter of the cancer patients received referrals for further cancer treatment, and 1 in 5 patients went without any therapy. This was mainly due to financial hardship, transportation issues, and a lack of social support to complete their referrals. Hence, decentralizing oncology care into lower-level hospitals requires careful consideration, alongside improving linkages to higher-level services to both address issues of access, timeliness, quality, and affordability of care and break the cycle of late-stage presentation and high mortality rates. Many breast cancer patients in Ethiopia, especially young and elderly women, refused mastectomy for various reasons including fear of surgery, preferring mass excision over full breast removal, and sought alternative treatments like religious rituals and traditional remedies. Additionally, concerns about fertility and breastfeeding, limited awareness of disease severity, sociocultural beliefs, and negative survivorship narratives following mastectomy contributed to the high refusal rate, which directly impacted the increased breast cancer mortality in the country. In LMICs, most breast cancer patients are under 40 and of childbearing age, highlighting the significance of conception post-cancer treatment. Therefore, it is vital to address individual patient psychosocial needs and preferences to retain these patients in the health system. To combat disparities in breast cancer outcomes, the global breast cancer initiative prioritizes health promotion, early detection, timely diagnosis, and comprehensive management. Consequently, empowering women and bolstering capacity for care necessitate collaborative efforts among various stakeholders. It is crucial for the breast cancer guidelines in Ethiopia to recognize psychosocial care as an essential component, aligning Ethiopia with the global framework. Expanding BCS, particularly for young women with early-stage cancer, should coincide with efforts to introduce radiotherapy nationwide.

The main psychosocial challenges identified among cancer patients upon diagnosis include emotional distress, denial, suicidal attempts, and treatment refusal. Meanwhile, depression, hopelessness, and fear of death were prevalent challenges at the individual level during the course of treatment. At the interpersonal level, participants described the adverse impact of their illness on both the patients' family and their own social lives. Additionally, family members' involvement in critical treatment decisions was noted. For various reasons, including those mentioned, many cancer patients declined or discontinued treatment and returned to healthcare facilities at an advanced stage of the disease with various complications. Although the absence of stigma and discrimination in the community was encouraging, the study uncovered that most cancer patients still preferred to distance themselves from social gatherings, as they were hesitant to openly discuss their illness and wanted to avoid emotional distress. Hence, the study emphasizes the importance of developing comprehensive psychosocial services integrated into Ethiopia's routine cancer care. These services should be customized to the local context, considering sociocultural factors, community education levels, and available resources.

Despite the evident psychosocial challenges faced by cancer patients, there was a lack of structured support systems within health facilities, including tertiary hospitals in Addis Ababa. Our study revealed that only one tenth of breast cancer patients received psychosocial services like counselling, emotional support, or information provision in the health facilities. High workload, insufficient space, and a shortage of trained health professionals were the primary reasons for not providing these services. Therefore, there is a need to innovate psychosocial services, potentially through sharing tasks among different professions and aligning them more effectively into the standard cancer care. Also, involving cancer survivors can provide valuable support to newly diagnosed patients. Prioritizing the establishment of patient support groups and emphasizing these efforts might address their psychosocial needs and significantly improve clinical outcomes of cancer. Only this can stop the vicious cycle of the community's conception of cancer as a "death sentence", the fatalistic perception of patients with symptoms, late diagnosis, incomplete therapy, and the consequent very low survival rates which were again seen in the communities. Additionally, more emphasis should be given to delivering comprehensive palliative care, since most of the cancer patients were diagnosed at advanced stages, necessitating diverse psychosocial support services aligned with existing social frameworks. Implementing awareness programs in religious settings, schools, and media platforms is also crucial, possibly achieved by actively involving traditional healers, religious leaders, and influential figures. Overall, we recommend a large-scale interventional study that actually implements tailored psychosocial services in selected health facilities with an evaluation of its impact on improving quality of life, adherence to treatment, and the survival of cancer patients in Ethiopia. Also, to gain a complete picture of the problem, we recommend a qualitative study that includes traditional healers and patients with different cancer types who may have unique psychosocial problems depending on the anatomic site of origin. Also advisable are explorations of the lived experiences of breast cancer patients after having mastectomy and male breast cancer patients to uncover additional challenge dimensions per patients' own perspectives.

3. Reference

1. Sung H, Ferlay J, Siegel RL, et al. Global Cancer Statistics 2020: GLOBOCAN Estimates of Incidence and Mortality Worldwide for 36 Cancers in 185 Countries. CA Cancer J Clin. 2021;71(3): 209-249. https://doi.org/10.3322/caac.21660
2. World Health Organization (WHO). Global cancer burden growing, amidst mounting need for services. 2024. https://www.who.int/news/item/01-02-2024-global-cancer-burden-growing--amidst-mounting-need-for-services. Accessed March 15, 2024.
3. Grassi L, Spiegel D, Riba M. Advancing psychosocial care in cancer patients. F1000Res. 2017 Dec 4;6:2083. https://doi.org/10.12688/f1000research
4. Merighi JR. Handbook of oncology social work: Psychosocial care for people with cancer. Soc Work Health Care. 2016 ;55(6):481-4. https://doi.org/10.1080/00981389.2016.1162260
5. Yao G, Lai JS, Garcia SF, Yount S, Cella D. Positive and negative psychosocial impacts on cancer survivors. Sci Rep. 2023;13(1):14749. https://doi.org/10.1038/s41598-023-41822-x
6. Hung CT, Chen YJ, Chan JC, et al. Psychological distress, social support, self-management ability and utilization of social resources for female patients with cancer in Oncology Outpatient Settings in Taiwan. Support Care Cancer. 2020;28(7):3323-3330. https://doi.org/10.1007/s00520-019-05143-y
7. Van Beek FE, Wijnhoven LMA, Holtmaat K, et al. Psychological problems among cancer patients in relation to healthcare and societal costs: A systematic review. Psychooncology. 2021;30(11):1801-1835. https://doi.org/10.1002/pon.5753
8. Wang Y, Feng W. Cancer-related psychosocial challenges. Gen Psychiatr. 2022;35(5):e100871. https://doi.org/10.1136/gpsych-2022-100871
9. Naser AY, Hameed AN, Mustafa N, et al. Depression and Anxiety in Patients With Cancer: A Cross-Sectional Study. Front Psychol. 2021;12:585534. https://doi.org/10.3389/fpsyg.2021.585534
10. Radhakrishnan R, Selvaraj H, Chidambaram K, Kv A, James A, Thangavel S. Prevalence of Depression and Anxiety Disorders Among Cancer Patients: An Insight From a Single Institute. Cureus. 2023;15(8):e42831. https://doi.org/10.7759/cureus.42831
11. Van Oorschot B, Ishii K, Kusomoto Y, et al. Anxiety, depression and psychosocial needs are the most frequent concerns reported by patients: preliminary results of a comparative explorative analysis of two hospital-based palliative care teams in Germany and Japan. J Neural Transm (Vienna). 2020 ;127(11):1481-1489. https://doi.org/10.1007/s00702-020-02186-y
12. Mohammed A, Melak D, Demeke Bayou F, et al. Prevalence and associated factors of depression among breast cancer patients in Sub-Saharan Africa: A systematic review and meta-analysis. SAGE Open Med. 2024; 12:20503121241226897. https://doi.org/10.1177/20503121241226897
13. Ding X, Wu M, Zhang Y, et al. The prevalence of depression and suicidal ideation among cancer patients in mainland China and its provinces, 1994-2021: A systematic review and meta-analysis of 201 cross-sectional studies. J Affect Disord. 2023; 323:482-489. https://doi.org/10.1016/j.jad.2022.12.011
14. Adzrago D, Sulley S, Tagoe I, et al. Assessment of anxiety/depression among cancer patients before and during the COVID-19 pandemic. Psychooncology. 2022; 31(10):1681-1691. https://doi.org/10.1002/pon.6026
15. Mejareh ZN, Abdollahi B, Hoseinipalangi Z, et al. Global, regional, and national prevalence of depression among cancer patients: A systematic review and meta-analysis. Indian J Psychiatry. 2021; 63(6):527-535. https://doi.org/10.4103/indianjpsychiatry.indianjpsychiatry_77_21
16. Head KJ, Iannarino NT. "It Changed Our Outlook on How We Want to Live": Cancer as a Transformative Health Experience for Young Adult Survivors and Their Family Members. Qual Health Res. 2019; 29(3):404-417. https://doi.org/10.1177/1049732318800674
17. Rosa, WE., and Ferrell, BR. The Nature of Suffering and the Goals of Nursing, 2nd edn (New York, 2023; online edn, Oxford Academic), https://doi.org/10.1093/oso/9780197667934.001.0001. Accessed April 18, 2024.
18. Brierley ME, Sansom-Daly UM, Baenziger J, McGill B, Wakefield CE. Impact of physical appearance changes reported by adolescent and young adult cancer survivors: A qualitative analysis. Eur J Cancer Care (Engl). 2019 ;28(4):e13052. https://doi.org/10.1111/ecc.13052

19. Hubbeling HG, Rosenberg SM, González-Robledo MC, Cohn JG, Villarreal-Garza C, Partridge AH, Knaul FM. Psychosocial needs of young breast cancer survivors in Mexico City, Mexico. PLoS One. 2018; 13(5):e0197931. https://doi.org/10.1371/journal.pone.0197931
20. Essue BM, Iragorri N, Fitzgerald N, de Oliveira C. The psychosocial cost burden of cancer: A systematic literature review. Psychooncology. 2020; 29(11):1746-1760. https://doi.org/10.1002/pon.5516
21. International Agency for Research on Cancer, World Health Organization. Global cancer statistics, cancer today. 2022. https://gco.iarc.fr/today/en. Accessed March 16, 2024.
22. World Health Organization. Cancer. https://www.who.int/news-room/fact-sheets/detail/cancer. Accessed March 16, 2024.
23. International Agency for Research on Cancer, World Health Organization. Global cancer statistics, cancer tomorrow. 2022. https://gco.iarc.who.int/tomorrow/en/about. Accessed March 16, 2024.
24. Anandasabapathy S, Asirwa C, Grover S, Mungo C. Cancer burden in low-income and middle-income countries. Nat Rev Cancer. 2024; 24(3):167-170. https://doi.org/10.1038/s41568-023-00659-2
25. Martei YM, Pace LE, Brock JE, Shulman LN. Breast Cancer in Low- and Middle-Income Countries: Why We Need Pathology Capability to Solve This Challenge. Clin Lab Med. 2018; 38(1):161-173. https://doi.org/10.1016/j.cll.2017.10.013
26. LaVigne AW, Triedman SA, Randall TC, Trimble EL, Viswanathan AN. Cervical cancer in low and middle income countries: Addressing barriers to radiotherapy delivery. Gynecol Oncol Rep. 2017; 22:16-20. https://doi.org/10.1016/j.gore.2017.08.004
27. Jedy-Agba E, McCormack V, Adebamowo C, Dos-Santos-Silva I. Stage at diagnosis of breast cancer in sub-Saharan Africa: a systematic review and meta-analysis. Lancet Glob Health. 2016; 4(12):e923-e935. https://doi.org/10.1016/S2214-109X(16)30259-5
28. Gbenonsi G, Boucham M, Belrhiti Z, Nejjari C, Huybrechts I, Khalis M. Health system factors that influence diagnostic and treatment intervals in women with breast cancer in sub-Saharan Africa: a systematic review. BMC Public Health. 2021; 21(1):1325. https://doi.org/10.1186/s12889-021-11296-5
29. Brand NR, Qu LG, Chao A, Ilbawi AM. Delays and Barriers to Cancer Care in Low- and Middle-Income Countries: A Systematic Review. Oncologist. 2019; 24(12):e1371-e1380. https://doi.org/10.1634/theoncologist.2019-0057
30. Martins T, Merriel SWD, Hamilton W. Routes to diagnosis of symptomatic cancer in sub-Saharan Africa: systematic review. BMJ Open. 2020; 10(11):e038605. https://doi.org/10.1136/bmjopen-2020-038605
31. International Agency for Research on Cancer, World Health Organization.Cancer fact sheets, Ethiopia 2022. GLOBOCAN (2022). https://gco.iarc.who.int/media/globocan/factsheets/populations/231-ethiopia-fact-sheet.pdf. Accessed April 26, 2024.
32. Timotewos G, Solomon A, Mathewos A, et al. First data from a population based cancer registry in Ethiopia. Cancer Epidemiol. 2018; 53:93-98. https://doi.org/10.1016/j.canep.2018.01.008
33. Federal Ministry of Health. Ethiopia Health Sector Development Program IV 2010-2015 | Country Planning Cycle Database. 2010. https://extranet.who.int/countryplanningcycles/planning-cycle-files/ethiopia-health-sector-development-program-iv-2010-2015. Accessed March 18, 2024.
34. Federal Ministry of Health. National Cancer Control Plan 2016-2020. 2015. https://cancerinethiopia.org/ethiopias-national-cancer-control-plan/. Accessed March 18, 2024.
35. Rick T, Habtamu B, Tigeneh W, et al. Patterns of Care of Cancers and Radiotherapy in Ethiopia. J Glob Oncol. 2019; 5:1-8. https://doi.org/10.1200/JGO.19.00129
36. Feuchtner J, Mathewos A, Solomon A, et al. Addis Ababa population-based pattern of cancer therapy, Ethiopia. PLoS One. 2019; 14(9):e0219519. https://doi.org/10.1371/journal.pone.0219519
37. Gebremariam A, Addissie A, Worku A, Assefa M, Kantelhardt EJ, Jemal A. Perspectives of patients, family members, and health care providers on late diagnosis of breast cancer in Ethiopia: A qualitative study. PLoS One. 2019; 14(8):e0220769. https://doi.org/10.1371/journal.pone.0220769
38. Dereje N, Addissie A, Worku A, eta l. Extent and Predictors of Delays in Diagnosis of Cervical Cancer in Addis Ababa, Ethiopia: A Population-Based Prospective Study. JCO Glob Oncol. 2020; 6:277-284. https://doi.org/10.1200/JGO.19.00242
39. Abebe E, Abebe H. Types of Cancers Diagnosed and the Preference of Families of Adult Patients with Cancer about Disclosing Diagnosis to the Patients. Ethiop J Health Sci. 2017; 27(3):255-262. https://doi.org/10.4314/ejhs.v27i3.7

40. World Nuclear News. Ethiopia makes progress in cancer treatment provision : Regulation & Safety - World Nuclear News. 2019. https://www.world-nuclear-news.org/Articles/Ethiopia-makes-progress-in-cancer-treatment-provis. Accessed January 12, 2024.
41. Das M. Expansion of radiotherapy access in Ethiopia. Vol. 25, The Lancet. Oncology. 2024. p. 542. https://doi.org/10.1016/S1470-2045(24)00194-3
42. Hwang KS, Lee KH, Yang CM, Lee HJ, Lee SY. Effects of Psychosocial Interventions for Patients with Breast Cancer: A Meta-analysis. Clin Psychopharmacol Neurosci. 2023; 21(1):118-125. https://doi.org/10.9758/cpn.2023.21.1.118
43. Xiao F, Song X, Chen Q, et al. Effectiveness of Psychological Interventions on Depression in Patients After Breast Cancer Surgery: A Meta-analysis of Randomized Controlled Trials. Clin Breast Cancer. 2017; 17(3):171-179. https://doi.org/10.1016/j.clbc.2016.11.003
44. Guo Z, Tang HY, Li H, Tan SK, Feng KH, Huang YC, Bu Q, Jiang W. The benefits of psychosocial interventions for cancer patients undergoing radiotherapy. Health Qual Life Outcomes. 2013; 11:121. https://doi.org/10.1186/1477-7525-11-121
45. Mirosevic S, Jo B, Kraemer HC, Ershadi M, Neri E, Spiegel D. "Not just another meta-analysis": Sources of heterogeneity in psychosocial treatment effect on cancer survival. Cancer Med. 2019; 8(1):363-373. https://doi.org/10.1002/cam4.1895
46. Grassi L, Watson M; IPOS Federation of Psycho-Oncology Societies' co-authors. Psychosocial care in cancer: an overview of psychosocial programmes and national cancer plans of countries within the International Federation of Psycho-Oncology Societies. Psychooncology. 2012; 21(10):1027-33. https://doi.org/10.1002/pon.3154
47. Recklitis CJ, Syrjala KL. Provision of integrated psychosocial services for cancer survivors post-treatment. Lancet Oncol. 2017; 18(1):e39-e50. https://doi.org/10.1016/S1470-2045(16)30659-3
48. Travado L, Bultz BD, Ullrich A, et al. 2016 President's Plenary International Psycho-Oncology Society: challenges and opportunities for growing and developing psychosocial oncology programmes worldwide. Psychooncology. 2017; 26(9):1231-1238. https://doi.org/10.1002/pon.4471
49. Legese B, Addissie A, Gizaw M, Tigneh W, Yilma T. Information Needs of Breast Cancer Patients Attending Care at Tikur Anbessa Specialized Hospital: A Descriptive Study. Cancer Manag Res. 2021; 13:277-286. https://doi.org/10.2147/CMAR.S264526
50. Amane HY, Tessema AM, Seid KA, et al. Factors associated with unmet supportive care needs of oncology patients at Dessie Referral Hospital, 2020. Ecancermedicalscience. 2021; 15:1300. https://doi.org/10.3332/ecancer.2021.1300
51. Afework T, Wondimagegnehu A, Bogale AS, Kantelhardt EJ, Addissie A. Predictors of unmet supportive care needs of adult cancer patients in Ethiopia. Eur J Cancer Care (Engl). 2022; 31(6):e13694. https://doi.org/10.1111/ecc.13694
52. Almulla HA, Lewis FM. Losing Her: Children's Reported Concerns in the First 6 Months of Their Mother's Breast Cancer Diagnosis. Cancer Nurs. 2020; 43(6):514-520. https://doi.org/10.1097/NCC.0000000000000763
53. Inhestern L, Bergelt C. When a mother has cancer: strains and resources of affected families from the mother's and father's perspective - a qualitative study. BMC Womens Health. 2018; 18(1):72. https://doi.org/10.1186/s12905-018-0562-8
54. Guida F, Kidman R, Ferlay J, et al. Global and regional estimates of orphans attributed to maternal cancer mortality in 2020. Nat Med. 2022; 28(12):2563-2572. https://doi.org/10.1038/s41591-022-02109-2
55. Galukande M, Schüz J, Anderson BO, et al. Maternally Orphaned Children and Intergenerational Concerns Associated With Breast Cancer Deaths Among Women in Sub-Saharan Africa. JAMA Oncol. 2021; 7(2):285-289. https://doi.org/10.1001/jamaoncol.2020.6583
56. Tadesse SK. Socio-economic and cultural vulnerabilities to cervical cancer and challenges faced by patients attending care at Tikur Anbessa Hospital: a cross sectional and qualitative study. BMC Womens Health. 2015; 15:75. https://doi.org/10.1186/s12905-015-0231-0
57. Tesfaw A, Getachew S, Addissie A, et al. Late-Stage Diagnosis and Associated Factors Among Breast Cancer Patients in South and Southwest Ethiopia: A Multicenter Study. Clin Breast Cancer. 2021; 21(1):e112-e119. https://doi.org/10.1016/j.clbc.2020.08.011

58. Gebremariam A, Addissie A, Worku A, et al. Time intervals experienced between first symptom recognition and pathologic diagnosis of breast cancer in Addis Ababa, Ethiopia: a cross-sectional study. BMJ Open. 2019; 9(11):e032228. https://doi.org/10.1136/bmjopen-2019-032228
59. Sullivan R, Alatise OI, Anderson BO, et al. Global cancer surgery: delivering safe, affordable, and timely cancer surgery. Lancet Oncol. 2015; 16(11):1193-224. https://doi.org/10.1016/S1470-2045(15)00223-5
60. Moran B. Primacy of surgery in cancer care: a global situation. Lancet Oncol. 2015; 16(11):1188-9. https://doi.org/10.1016/S1470-2045(15)00282-X
61. White RE. Cancer surgery in Africa: if all you have is a hammer…. Lancet Oncol. 2015; 16(11):1190-1. https://doi.org/10.1016/S1470-2045(15)00289-2
62. Lukong KE, Ogunbolude Y, Kamdem JP. Breast cancer in Africa: prevalence, treatment options, herbal medicines, and socioeconomic determinants. Breast Cancer Res Treat. 2017; 166(2):351-365. https://doi.org/10.1007/s10549-017-4408-0
63. Sutter SA, Slinker A, Balumuka DD, Mitchell KB. Surgical Management of Breast Cancer in Africa: A Continent-Wide Review of Intervention Practices, Barriers to Care, and Adjuvant Therapy. J Glob Oncol. 2016; 3(2):162-168. https://doi.org/10.1200/JGO.2016.003095
64. Deressa BT, Cihoric N, Badra EV, Tsikkinis A, Rauch D. Breast cancer care in northern Ethiopia - cross-sectional analysis. BMC Cancer. 2019; 19(1):393. https://doi.org/10.1186/s12885-019-5612-6
65. O'Neil DS, Keating NL, Dusengimana JMV, et al. Quality of Breast Cancer Treatment at a Rural Cancer Center in Rwanda. J Glob Oncol. 2018; 4:1-11. https://doi.org/10.1200/JGO.2016.008672
66. Foerster M, Anderson BO, McKenzie F, et al. Inequities in breast cancer treatment in sub-Saharan Africa: findings from a prospective multi-country observational study. Breast Cancer Res. 2019; 21(1):93. https://doi.org//10.1186/s13058-019-1174-4
67. Gaitanidis A, Alevizakos M, Tsalikidis C, Tsaroucha A, Simopoulos C, Pitiakoudis M. Refusal of Cancer-Directed Surgery by Breast Cancer Patients: Risk Factors and Survival Outcomes. Clin Breast Cancer. 2018 ; 18(4):e469-e476. https://doi/10.1016/j.clbc.2017.07.010
68. Xie N, Hu X, Tang Y, Tian C, He Y, Hu ZY, Hu C, Wang X, Liu X, Liu L, Xiao H, Peng W, Zhou H, Ouyang Q. Impact of surgical management of primary tumors in stage IV breast cancer patients: a retrospective observational study based on SEER database. BMJ Open. 2022; 12(2):e054135. https://doi.org/10.1136/bmjopen-2021-054135
69. Wang S, Chen S, Huang Y, et al. Refusal of cancer-directed surgery in male breast cancer. Medicine (Baltimore). 2021; 100(13):e25116. https://doi.org/10.1097/MD.0000000000025116
70. Scheepens JCC, Veer LV', Esserman L, Belkora J, Mukhtar RA. Contralateral prophylactic mastectomy: A narrative review of the evidence and acceptability. Breast. 2021; 56:61-69. https://doi.org/10.1016/j.breast.2021.02.003
71. Wondimagegnehu A, Gizaw M, Genene Abebe L, Teka B, Kaufmann AM, Abebe T, et al. Perceived causes of cancer in a rural community of Ethiopia: a qualitative study. Glob Health Action. 2024 Dec 31;17(1):2401862. https://doi.org/10.1080/16549716.2024.2401862
72. Olasehinde O, Arije O, Wuraola FO, et al. Life Without a Breast: Exploring the Experiences of Young Nigerian Women After Mastectomy for Breast Cancer. J Glob Oncol. 2019: 1-6. https://doi.org/10.1200/JGO.18.00248
73. Bawoke G, Kejela S, Alemayehu A, Bogale GT. Experience with modified radical mastectomy in a low-income country: a multi-center prospective observational study. BMC Surg. 2021; 21(1):371. https://doi.org/10.1186/s12893-021-01374-1
74. Eber-Schulz P, Tariku W, Reibold C, et al. Survival of breast cancer patients in rural Ethiopia. Breast Cancer Res Treat. 2018 ; 170(1):111-118. https://doi.org/10.1007/s10549-018-4724-z
75. Teshome MH, Atinafu NT, Bekele YA, Tolera BD. The Lived Experience of Ethiopian Women After Mastectomy due to Breast Cancer: A Qualitative Study. Asian Pac J Cancer Prev. 2024; 25(1):103-108. https://doi.org/10.31557/APJCP.2024.25.1.103
76. Abebe E, Demilie K, Lemmu B, Abebe K. Female Breast Cancer Patients, Mastectomy-Related Quality of Life: Experience from Ethiopia. Int J Breast Cancer. 2020; 2020:8460374. https://doi.org/10.1155/2020/8460374
77. Lundberg PC, Phoosuwan N. Life situations of Swedish women after mastectomy due to breast cancer: A qualitative study. Eur J Oncol Nurs. 2022; 57:102116. https://doi.org/10.1016/j.ejon.2022.102116
78. Guo YQ, Ju QM, You M, Liu Y, Yusuf A, Soon LK. Depression, anxiety and stress among metastatic breast cancer patients on chemotherapy in China. BMC Nurs. 2023; 22(1):33. https://doi.org/10.1186/s12912-023-01184-1

79. Walker J, Hansen CH, Martin P, et al. Prevalence, associations, and adequacy of treatment of major depression in patients with cancer: a cross-sectional analysis of routinely collected clinical data. Lancet Psychiatry. 2014; 1(5):343-50. https://doi.org/10.1016/S2215-0366(14)70313-X
80. Ma Z, Mao Y, Wang Y, et al. Suicidal ideation and attempted suicide among cancer patients during the COVID-19 pandemic. J Med Virol. 2022; 94(12):5827-5835. https://doi.org/10.1002/jmv.28076
81. Heinrich M, Hofmann L, Baurecht H, et al. Suicide risk and mortality among patients with cancer. Nat Med. 2022; 28(4):852-859. https://doi.org/10.1038/s41591-022-01745-y
82. Zaorsky NG, Zhang Y, Tuanquin L, Bluethmann SM, Park HS, Chinchilli VM. Suicide among cancer patients. Nat Commun. 2019; 10(1):207. https://doi.org/10.1038/s41467-018-08170-1
83. Woldemariam AA, Andersson R, Munthe C, Linderholm B, Berbyuk Lindström N. Breaking Bad News in Cancer Care: Ethiopian Patients Want More Information Than What Family and the Public Want Them to Have. JCO Glob Oncol. 2021: 1341-1348. https://doi.org/10.1200/GO.21.00190
84. Kebede BG, Abraha A, Andersson R, et al. Communicative challenges among physicians, patients, and family caregivers in cancer care: An exploratory qualitative study in Ethiopia. PLoS One. 2020; 15(3):e0230309. https://doi.org/10.1371/journal.pone.0230309
85. Sauvaget C, Boutayeb S, Bendahhou K, Selmouni F, Belbaraka R, Muwonge R, Hassouni K, Lucas E, Alaoui L, Ibrahim Khalil A, Bennani M, Chami Y, Bekkali R. The journey of cancer patients and the quest to equity: findings from Morocco. Public Health. 2023;223:33-41. https://doi.org/10.1016/j.puhe.2023.07.015
86. Kasahun GG, Gebretekle GB, Hailemichael Y, Woldemariam AA, Fenta TG. Catastrophic healthcare expenditure and coping strategies among patients attending cancer treatment services in Addis Ababa, Ethiopia. BMC Public Health. 2020; 20(1):984. https://doi.org/10.1186/s12889-020-09137-y
87. Gebremariam A, Yalew AW, Hirpa S, et al. Application of the rapid ethical assessment approach to enhance the ethical conduct of longitudinal population based female cancer research in an urban setting in Ethiopia. BMC Med Ethics. 2018; 19(1):87. https://doi.org/10.1186/s12910-018-0328-8
88. Cain CL, Surbone A, Elk R, Kagawa-Singer M. Culture and Palliative Care: Preferences, Communication, Meaning, and Mutual Decision Making. J Pain Symptom Manage. 2018;55(5):1408-1419. https://doi.org/10.1016/j.jpainsymman.2018.01.007
89. Connolly M, Timmins F. Spiritual Care for Individuals with Cancer: The Importance of Life Review as a Tool for Promoting Spiritual Well-Being. Semin Oncol Nurs. 2021;37(5):151209. https://doi.org/10.1016/j.soncn.2021.151209
90. Cheng Q, Chen Y, Duan Y, Xie J, Zhang Q, Zheng H. Exploring the spiritual needs of patients with advanced cancer in China: a qualitative study. Sci Rep. 2024;14(1):4009. https://doi.org/10.1038/s41598-024-54362-9
91. National Cancer Institute. Coping – Faith and Spirituality. https://www.cancer.gov/about-cancer/coping/day-to-day/faith-and-spirituality. Accessed April 1, 2023.
92. Bore MG, Dadi AF, Ahmed KY, et al. Unmet Supportive Care Needs Among Cancer Patients in Sub-Saharan African Countries: A Mixed Method Systematic Review and Meta-Analysis. J Pain Symptom Manage. 2024;67(3):e211-e227. https://doi.org/10.1016/j.jpainsymman.2023.11.023
93. Ashley L, Lawrie I. Tackling inequalities in cancer care and outcomes: psychosocial mechanisms and targets for change. Psychooncology. 2016;25(10):1122-1126. https://doi.org/10.1002/pon.4278
94. Grassi L, Fujisawa D, Odyio P, et al. Disparities in psychosocial cancer care: a report from the International Federation of Psycho-oncology Societies. Psychooncology. 2016 ; 25(10):1127-1136. https://doi.org/10.1002/pon.4228
95. Abebe LG, Wondimagegnehu A, Woldemariam AA, Gelaye B, Kantelhardt EJ, Addissie A. Validity and Reliability of the Amharic Version of EORTC-QLQ-CR29 Among Colorectal Cancer Patients in Ethiopia. Cancer Manag Res. 2021;13:9287-9295. https://doi.org/10.2147/CMAR.S343127

4. Thesis

1. In primary and secondary level hospitals of Ethiopia, surgery was the only available treatment option for cancer patients, as systemic treatments were scarce. Consequently, most patients visited approximately three healthcare institutions from their initial encounter with a provider until their final treatment initiation.
2. Despite predominantly available surgical services, one-fifth of cancer patients did not undergo recommended procedures, partly due to patient refusal or failure to return back to the hospital on the scheduled date. Our qualitative study revealed that elderly and very young women with breast cancer were particularly incline to refuse mastectomy.
3. Primary reasons for refusal include fear of surgery and concerns about its success, compounded by knowing someone who died after mastectomy. Younger women often opt for breast-conserving surgery, particularly unmarried women aspiring to have children and breastfeed. Lack of awareness, religious beliefs, traditional treatments and sociocultural influences, regarding breasts as symbols of femininity, beauty, and motherhood, further impact women's decisions.
4. Psychosocial challenges were summarized using the social-ecological model, revealing emotional distress, denial, suicidal risk and treatment refusal upon diagnosis, while hopelessness, feeling depressed and fear of death were commonly reported problems during the course of treatment. At interpersonal level, the illness has had adverse effects on both the family members and the social lives of the patients. In addition, involvement of family members in major treatment decisions was also recognized. In the community, traditional medicine and religious rituals were considered as an alternative treatment for cancer.
5. In Addis Ababa, only ten percent of breast cancer patients received psychosocial support services, including counselling, emotional assistance, or informational guidance. Health professionals were reported to offer these services alongside their regular duties, without a formalized support system in place within health facilities. The primary obstacles to providing psychosocial support included heavy patient flow/workload, insufficient space, inadequate training, and a shortage of qualified professionals to organize and deliver such services within hospitals.

Publications

1. **Publication One: <u>Abigiya Wondimagegnehu</u>**, et al. (2022). Burden of cancer and utilization of local surgical treatment services in rural hospitals of Ethiopia: A retrospective assessment from 2014 to 2019. *Oncologist, 27*(11), e889-e898. https://doi.org/10.1093/oncolo/oyac127

   I conceived the idea, crafted the proposal, and developed the extraction tool. I led the recruitment and training of data collectors at study sites, supervised data processes, and conducted analysis. Additionally, I drafted the original manuscript, integrating feedback from coauthors and journal reviewers during publication.

   (Article Open Access CC BY-NC)

2. **Publication Two:** Josephin Trabitzsch, **<u>Abigiya Wondimagegnehu,</u>** et al. (2023). Pathways and Referral of Patients with Cancer in Rural Ethiopia: A multi-center retrospective cohort study. *Oncologist*, *28*(6), e359-e369. https://doi.org/10.1093/oncolo/oyad032

   I participated from study inception, designing the protocol and obtaining ethical approval. I recruited and trained data collectors, supervised data collection, contributed to analysis and interpretation, and reviewed manuscript drafts and provided feedback.

   (Article Open Access CC BY-NC)

3. **Publication Three:** Josephin Trabitzsch, … **<u>Abigiya Wondimagegnehu</u>** (2024). Understanding referral of patients with cancer in rural Ethiopia: A qualitative study. *BMC Cancer, 24*(1), 553. https://doi.org/10.1186/s12885-024-12294-7

   I participated from study inception, designing the protocol and obtaining ethical approval. I recruited qualitative data collectors, supervised data collection, contributed in the interpretation, and reviewed manuscript drafts and provided feedback.

   (Article Open Access CC BY-NC)

4. **Publication Four: <u>Abigiya Wondimagegnehu</u>**, et al. (2024). "How can a woman live without having a breast?": challenges related to mastectomy in Ethiopia. *BMC Cancer, 24*(1), 60. https://doi:org/10.1186/s12885-023-11801-6

   As the primary investigator, I conceived the idea, wrote the proposal and interview guides, recruited participants, and trained research assistants. I conducted interviews and group discussions, coded transcripts, and led data analysis and interpretation. Additionally, I authored the original manuscript, incorporating feedback from coauthors and journal reviewers, and served as the corresponding author during publication.

(Article Open Access CC BY-NC)

5. **Publication Five: <u>Abigiya Wondimagegnehu</u>,** et al. (2024). A Qualitative Study on Psychosocial Challenges of Patients With Cancer in Ethiopia Using the Social-Ecological Model. *Qual Health Res*, *34*(8-9), 828-841. https://doi.org/10.1177/10497323231219409 .

   I initiated the study, overseeing its conception, proposal writing, and participant recruitment. I conducted interviews, facilitated discussions, coded transcripts, analyzed data, and authored the manuscript. Additionally, I managed feedback incorporation from coauthors and journal reviewers, serving as the corresponding author during publication.

   (Article Open Access, use in dessertation granted by journal)

6. **Publication Six: <u>Abigiya Wondimagegnehu</u>**, et al (2023). Availability and Utilization of Psychosocial Services for Breast Cancer Patients in Addis Ababa, Ethiopia: A mixed method study. *Eur J Cancer Care (Engl),* 1-12. https://doi.org/10.1155/2023/5543335

   As the primary investigator, I designed the study protocol, trained data collectors, supervised quantitative analysis, conducted interviews, and analyzed qualitative data. I authored the manuscript and managed feedback from coauthors and reviewers as the corresponding author during publication.

   (Article Open Access CC BY-NC)

7. **Publication Seven:** Lidiya Genene, **<u>Abigiya Wondimagegnehu</u>**, et al (2021). Validity and Reliability of the Amharic Version of EORTC-QLQ-CR29 Among Colorectal Cancer Patients in Ethiopia. *Cancer Manag Res, 13*, 9287-9295. https://doi.org/10.2147/CMAR.S343127

   I participated from study inception, designing the protocol and obtaining ethical approval. I contributed to data analysis and interpretation, and reviewed draft manuscripts and provided comments.

   (Article Open Access CC BY-NC)

The Oncologist, 2022, **27**, e889–e898
https://doi.org/10.1093/oncolo/oyac127
Advance access publication 6 July 2022
Original Article

Burden of Cancer and Utilization of Local Surgical Treatment Services in Rural Hospitals of Ethiopia: A Retrospective Assessment from 2014 to 2019

Abigiya Wondimagegnehu[1,2], Fekadu Negash Bereded[3], Mathewos Assefa[4], Solomon Teferra[5], Bradley Zebrack[6], Adamu Addissie[1,2], Eva J. Kantelhardt[2,7,*]

[1]Department of Preventive Medicine, School of Public Health, College of Health Sciences, Addis Ababa University, Addis Ababa, Ethiopia
[2]Institute of Medical Epidemiology, Biometrics and Informatics, Martin-Luther-University, Halle, Saale, Germany
[3]Department of Surgery, St Paul's Hospital Millennium Medical College, Addis Ababa, Ethiopia
[4]Department of Oncology, School of Medicine, College of Health Sciences, Addis Ababa University, Addis Ababa, Ethiopia
[5]Department of Psychiatry, School of Medicine, College of Health Sciences, Addis Ababa University, Addis Ababa, Ethiopia
[6]University of Michigan, School of Social Work, Ann Arbor, MI, USA
[7]Department of Gynaecology, Martin-Luther-University, Halle (Saale), Germany

*Corresponding author: Eva J. Kantelhardt, MD, Institute of Medical Epidemiology, Biostatistics and Informatics, Martin-Luther-University, Halle, Germany. Email: eva.kantelhardt@uk-halle.de

Abstract

Background: Global cancer estimations for Ethiopia announced 77 352 new cases in 2020 based on the only population-based registry in Addis Ababa. This study characterizes cancer patients in rural Ethiopia at 8 primary and secondary hospitals between 2014 and 2019.

Patients and Methods: All clinically or pathologically confirmed cancer cases that were diagnosed between 1 May 2014 and 29 April 2019 were included. A structured data extraction tool was used to retrospectively review patients' charts and descriptive analysis was done.

Results: A total of 1298 cancer cases were identified, of which three-fourths were females with a median age of 42 years. Breast (38%) and cervical (29%) cancers were the most common among females, while prostate (19%) and oesophageal cancers (16%) were the most common among males. Only 39% of tumors were pathologically confirmed. Nearly two-thirds of the cases were diagnosed at an advanced stage. Surgery was the only accessible treatment option for more than half of the cancer patients, and systemic treatment (except endocrine) was rarely available. One in 5 patients did not receive the recommended surgical procedure, half due to patient refusal or lack of the patient returning to the hospital.

Conclusion: The pattern of cancer diagnoses in rural hospitals shows an exceptionally high burden in women in their middle-ages due to breast and cervical cancers. Advanced stage presentation, lack of pathology services, and unavailability of most systemic treatment options were common. The surgery was offered to nearly 60% of the patients, showing the significant efforts of health workers to reduce sufferings.

Key words: cancer; rural hospitals; treatment pattern; surgical services; Ethiopia.

Implications for Practice

In rural hospitals of southern Ethiopia, two-thirds of cancer patients are women in their 40s with late-stage breast or cervical malignancies. Surgery is the only treatment available and offered to nearly two-thirds of all patients, while endocrine treatment is the only systemic option available. High refusal rates for surgery may reflect the perception of cancer as a "death sentence" due to the lack of cancer survivors who encourage others to utilize oncology services early. Focusing on improving such basic services, involving the surgeons, and offering referral pathways for these patients can be the first steps to integrating oncology services into the lower levels of the health care system.

Introduction

Cancer accounted for almost 10.0 million deaths in 2020[1] and is projected to cause 16.2 million deaths by 2040.[2] More than half of the reported deaths occurred in low- and middle-income countries (LMICs); particularly, Africa has a high proportion of cancer deaths (7.2% of global cancer deaths) compared with its incidence (5.7% of global cancer incidence).[2,3] The majority of cancer patients in LMICs present at an advanced stage of the disease, which contributes to a poor prognosis of the disease and a high mortality rate.[4-6]

In Ethiopia, cancer is becoming a frequently diagnosed disease with a considerably high mortality rate. The increased

---

Received: 14 December 2021; Accepted: 18 May 2022.

incidence is due to aging and lifestyle changes. According to the Global Cancer Incidence, Mortality and Prevalence (GLOBOCAN) 2020 report, an estimated 77 352 new cases, and over 51 865 deaths were reported in the country, with the majority (50 598; 65.4%) occurring in females.[7] During 2012-2013, a total of 4139 newly diagnosed cases were recorded in the population-based cancer registry of Addis Ababa, with age-standardized rates per 100 000 inhabitants of 136 for females and 70 for males.[8] Similar to other LMICs, there are limited diagnostic and treatment services in Ethiopia, and the three-tier health system in the country positions oncologic care mainly at tertiary referral centers. In fact, the number of specialists and essential equipment for cancer care in Ethiopia is among the most limited and constricted in the world. Therefore, the only available service for most cancer patients at lower-level hospitals is surgery.[9,10] Systemic treatment is limited mainly to the only cancer center in Addis Ababa and a few facilities at peripheral university hospitals. However, many cancer patients do not even receive basic surgical services. This could either be due to a lack of surgical capacity or organizational problems. On the other hand, the patients may not be psychologically ready to receive the necessary surgical procedures with perceived unacceptable bodily mutilation or fear of systemic therapy for unknown reasons. As a result, these patients may seek help from alternative healers, such as herbalists, priests, and spiritual leaders,[11,12]and return to health facilities once complications and advanced-stage cancer occur.[13-15]

Even though there are studies about cancer care in Ethiopia, cancer statistics are either limited to tertiary level hospitals or only in the capital city where the cancer registry is based. However, to the best of our knowledge, the magnitude of cancer patients and reasons for non-uptake of surgical and other treatment options are not well documented in Ethiopia, particularly at lower-level rural hospitals. Therefore, this study is intended to determine the magnitude and characterize frequently diagnosed cancers, describe the uptake of surgical services, and calculate the proportion of patients who refused surgical procedures in rural hospitals in Ethiopia from 2014 to 2019.

Materials and Methods

Study Design and Area

The study was conducted in 8 rural hospitals in southern and southwestern Ethiopia: 6 secondary level hospitals—St. Lukas Catholic Hospital, Butajira General Hospital, Dubo St. Mary Hospital, Negist Elleni Hospital, Durame General Hospital, and Wollayta Teaching and Referral Hospital; and 2 primary level hospitals—Attat our First Lady of Lourdes Catholic Primary Hospital and Aira General Hospital. The majority (6) of them are located in the Southern Nations, Nationalities, and Peoples' Region (SNNPR), while St. Lukas Catholic Hospital and Aira General Hospital are situated in the Oromia region. These hospitals were chosen based on a preliminary assessment of their ability to provide cancer diagnostic and treatment services, as well as their relatively large rural catchment populations of 0.8-2.5 million people. The hospitals have 4 major inpatient departments (medical, surgical, pediatric, and gynecology/obstetrics) with a total of 100-350 beds. Diagnostic services such as common laboratory tests, X-ray and ultrasound are widely available in these hospitals. However, other imaging services such as computed tomography (CT scan) and magnetic resonance imaging (MRI) and pathologic tests like fine needle aspiration cytology (FNAC) and biopsy are provided through referral linkage with higher-level hospitals in Addis Ababa. A 5-year retrospective patient file data review was done from May 2019 to June 2019.

Study Participants

All clinically certain and/or pathologically confirmed cancer cases who were above 18 years old and who were diagnosed and possibly treated in those 8 hospitals between 1 May 2014 and 29 April 2019 were included.

Data Collection and Analysis

The diagnoses and treatments of patients at the included hospitals within the study period were ascertained from the admissions and outpatient logbooks of the hospitals. Subsequently, the cards of patients with an assessment of any type of cancer or suspected cancer were extracted from the database using the medical registration number. A structured data extraction tool was prepared based on the objective of the study and important variables, such as sociodemographic characteristics, clinical features, and type of treatment received (including reasons for non-uptake) were included. Eight health management information system (HMIS) focal persons who were working in those hospitals were involved in screening the logbooks and tracing all the files of patients who were diagnosed and treated in the past 5 years. A total of 16 data collectors (2 per site) who had BSc degrees in nursing were recruited to extract all the important information from the cards of patients. All collected data forms were assessed for data quality, completeness, and consistency and descriptive statistics were done using SPSS software version 25.

Ethical Clearance

Ethical clearance was obtained from the Addis Ababa University, College of Health Sciences, Institutional Review Board. Individual informed consent was waived due to the retrospective nature of the study.

Result

Sociodemographic Characteristics

During the study period, a total of 1511 cancer cases were identified in the 8 rural hospitals. Of those, the actual diagnosis was neither confirmed pathologically nor clinically for 213 (14.1%) cases, and no additional information was recorded for these cases, except stating that to "rule out a specific cancer." Therefore, a total of 1298 cancer patients either clinically or pathologically confirmed were included in our final analysis. The median age of participants was 42 years, with an interquartile range of 17 years. Three-fourths of all cases were females and more than half (52.9%) of them were married. Regarding their religious views, one-quarter (25.3%) of them were Protestants, while nearly one-fifth (17.3%) of them were Orthodox Christians. Even though educational status was not recorded for almost half (49%) of the cases, one-quarter were known to be illiterate and only one-tenth had attended formal education. More than one-third (35.5%) of cases were housewives and one-eighth were farmers. The majority of cases were identified at St. Lukas Catholic Hospital and Aira General Hospital, each accounting for one-fifth of the total cases (Table 1).

Table 1. Sociodemographic characteristics of cancer patients diagnosed in 8 rural hospitals of Ethiopia between 2014 and 2019.

Variables	*n* = 1, 298	Percent (%)
Sex		
Male	304	23.4
Female	983	75.7
Not recorded	11	0.8
Age		
18-29	167	12.9
30-44	520	40.1
45-59	386	29.7
60-74	189	14.6
>75	36	2.8
Name of the hospitals (catchment population in million)		
St Lukas (1.3)	267	20.6
Aira[+](1.3)	254	19.6
Durame (1)	156	12.0
Atat[+] (0.8)	150	11.6
Negest Elleni (2.5)	136	10.5
Ottana (2)	135	10.4
Dubo (0.8)	110	8.5
Butajira (1.3)	90	6.9
Origin of patients (region)		
Oromia	470	36.2
SNNPR	800	61.6
Others[*]	4	0.3
Not recorded	24	1.8
Religion		
Orthodox	224	17.3
Muslim	148	11.4
Protestant	328	25.3
Catholic and traditional	5	.4
Not recorded	593	45.7
Education		
Illiterate	331	25.5
Read and write	191	14.7
Primary education	72	5.5
Secondary education	40	3.1
Higher education	28	2.2
Not recorded	636	49.0
Marital status		
Single	60	4.6
Married	686	52.9
Divorced/separated	18	1.4
Widowed	31	2.4
Not recorded	503	38.8
Occupation		
Housewife	461	35.5
Farmer	176	13.6
Civil servant	21	1.6
Student	38	2.9
Others [a]	19	1.5
Not recorded	583	44.9

[+] Primary hospitals.
[*] Others include Amhara and Addis Ababa.
[a] Others include factory, merchant, and private.
Abbreviation: M, million.

Concerning the distribution of cases over the past 5 years, the number of cancer cases has been persistently increasing throughout these years from 97 (7.5%) cases in 2014 to 409 (31.8%) cases in 2018. Even though the data collected in 2014 was only for 8 months, the total cases reported was still far lower compared to the other years. In 2019, a total of 139 (10.7%) cases were identified from January to April, suggesting that the total number of cases at the end of the year might even be higher than the previous year (Fig 1).

Types of Cancer

Out of the total 1298 cancer patients who visited those 8 hospitals between 2014 and 2019, almost one-third of them were diagnosed with breast cancer. Cervical cancer was the second most common type of cancer, accounting for 22% of total cases. Oesophageal (9.5%), endometrial (5.5%), colorectal (5.2%), gastric (4.9%), and prostate (4.5%) were the other frequently diagnosed cancers during the stated period. The five most common cancers among females were breast, cervical, oesophageal, endometrial, and gastric, while prostate was the most common cancer among males, followed by oesophageal cancer, colorectal cancer, cancer of unknown origin (CUP), and gastric cancer (Table 2). Breast cancer was leading cancer in all rural hospitals, except for St. Lukas Catholic Hospital and Aira General Hospital (Table 3).

Medical and Clinical Characteristics

In this study, most (785; 60.5%) of the cases were diagnosed clinically, while only 503 (38.8%) of the cases were pathologically confirmed. Out of those cases with pathological confirmation, the histologic type was not recorded for 41.6%. Squamous cell carcinoma (44.6%) was the most common type of cancer, of which 80.9% were reported among cervical cancer patients, while ductal cell carcinoma (25.2%) and adenocarcinoma (12.2%) were the second and third common types of cancer with known histology, respectively. Out of the total of pathologically confirmed cancer cases, tumor grade was recorded only for 144 (28.6%) cases, of which 13.9% were grade III and 9.7% were grade II cancers. Concerning the stage of cancer, nearly two-thirds (65.4%) of the patients with a known stage were diagnosed at an advanced stage of cancer, either at stage III (37.4%) or stage IV (28.0%) (Table 4).

Treatment Options and Outcome

Surgical interventions were the most common cancer treatments in those rural hospitals, and surgery was planned for more than half (756; 58.2%) of the total cases. The major reasons why surgery was not planned for the remaining (519; 40.0%) cases were as follows: firstly, patients were directly referred to the next level health facility for further investigations (350; 67.4%) and secondly, patients with advanced cancer at the time of diagnosis (18; 3.5%) were not operated on. Out of a total of 756 planned surgical procedures, the majority (81.0%) were performed in those hospitals, while the rest (18.5%) were not done due to several factors. One of the major reasons was either patient refusal, or patients' not returning to the hospital after having an appointment. This accounted for almost half (49.3%) of the planned procedures. The rest of the patients were referred to the next level (32.1%) or planned in the future at the time of data collection (11.4%) (Table 4). With regard to the type of surgery, mastectomy was the most frequently performed

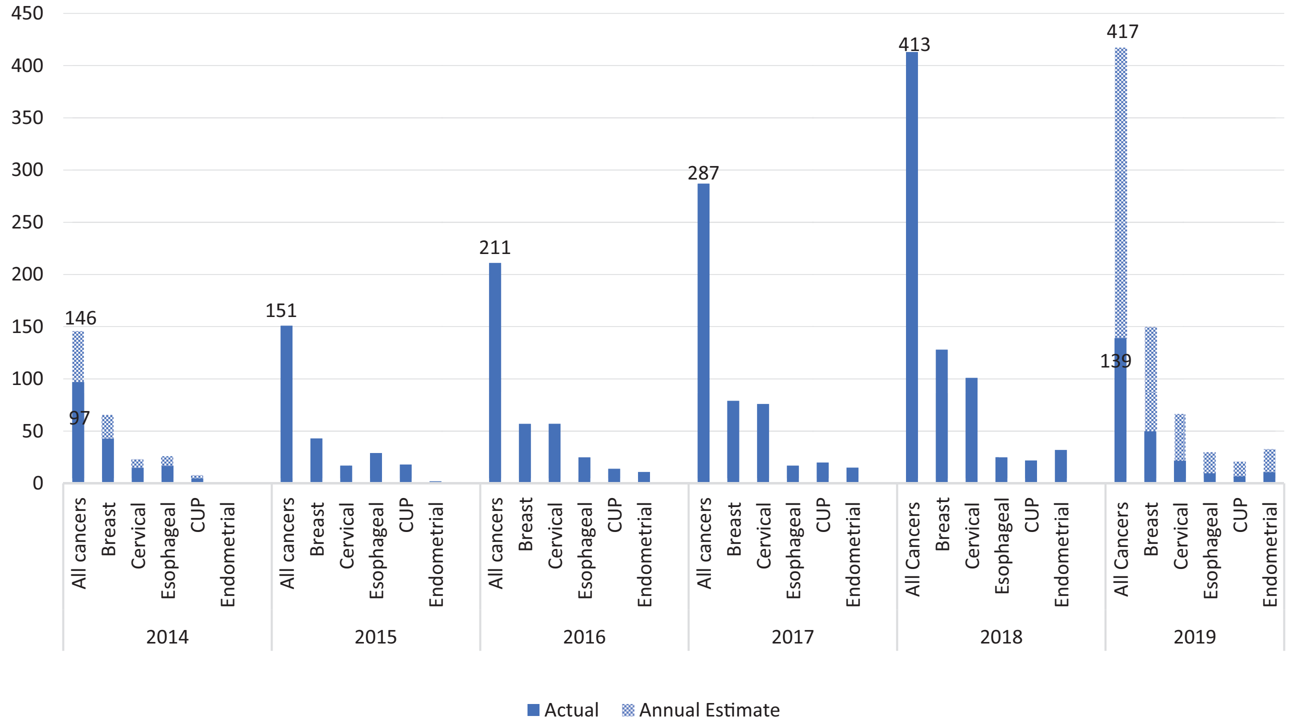


Figure 1. Types of cancer cases diagnosed in 8 rural hospitals of Ethiopia from 2014 to 2019 (*n* =1298). Actual data was collected for 8 complete months in 2014 and 4 months in 2019. Based on that, it's extrapolated for the whole year.

surgical procedure, concurrent with the high prevalence of breast cancer in those hospitals. Abdominal hysterectomy was the second most common surgical procedure, which accounted for 20.4% of the total surgeries performed during the study period (Fig 2). Out of the total of 612 surgeries performed in those hospitals, the intent of the surgery was mentioned to be curative for only 12.1% of the patients, whereas palliative surgery was performed for almost two-thirds (66.3%) of the patients. However, the intention of the surgery was not specified for the remaining 21.6% of patients (Table 5).

Concerning other types of cancer treatment, hormonal therapy was given to almost one-third (29.8%) of breast cancer patients. Out of these, 83.2% of them were taking tamoxifen; the type of drug was not recorded for the remaining 16.8% of cases. More than half (54.6%) of these patients were taking hormonal treatment for less than a year. However, none of the prostate cancer patients received hormonal treatment. According to the medical records, chemotherapy and radiotherapy (RT) services were not available in those hospitals, and only 1.4% and 0.7% of the total patients reported having ever received chemotherapy and RT, respectively (Table 4). It's also indicated that they have received these services at Tikur Anbessa Specialized Hospital, which is the largest hospital providing comprehensive cancer care in Ethiopia.

In relation to the referral system, around one-third (33.1%) of total cancer patients were referred to the next high-level health facility for either of the following reasons: immediately after diagnosis for additional investigations or for further systemic treatments such as chemotherapy and RT after receiving surgical treatment. Even though the exact referral sites were not recorded for 27.0% of these patients, nearly half (49.9%) of them were referred to the comprehensive cancer center in Addis Ababa. Based on the information documented in the charts of patients, 5.6% of in-hospital deaths were recorded, while the status of the remaining 94.4% of cases was unknown at the time of data collection (Table 4).

Discussion

This study described the overall burden of cancer cases in 8 rural hospitals in Ethiopia from 2014 to 2019. Our results revealed that the number of diagnosed cancer cases had been remarkably increasing over the years, and three-fourths of the cases were reported among females. Breast and cervical cancers were the most frequently diagnosed cancers among females, while prostate and oesophageal cancers were the most frequently diagnosed cancers among males. The majority of the cancer cases were diagnosed clinically, and pathologic evaluations were done only for one-third of the total cases.

More than 80% of the cancer cases in this study were in individuals below the age of 60 years. This finding is consistent with the population-based cancer registry in Addis Ababa, which stated that 72% of total cancer cases diagnosed from 2012 to 2014 were below the age of 60 years.[8] According to a recent study in 2020, 65% of total cases were below the age of 60 years,[16] and others reported that the median age of cancer patients ranged from 48 to 52 years.[12-14] Not only in Ethiopia but also in several LMICS, cancer is more common among individuals below 65 years of age.[17,18] This variation is mainly due to the young population structure in Ethiopia and in most low-income countries.

In this study, three-fourths (75.7%) of the total cancer cases were females, and a similar (72.8%) figure was reported from a record review done at the only oncology center in the country from 1998 to 2010.[19] Previous hospital-based and population-based studies also stated that more than 60%

Table 2. Types of cancer diagnosed in men and women.

Primary site of cancer	Males *n* (%)	Females *n* (%)	Unknown *n* (%)	Total *n* (%)	Pathologically confirmed *n* = 503
Breast	23 (7.6)	372 (37.8)	5 (45.5)	400 (30.8)	221 (55.3)
Cervical	0 (0)	289 (29.4)		289 (22.3)	141 (48.8)
Esophageal	49 (16.1)	74 (7.5)		123 (9.5)	5 (4.1)
CUP	37 (12.2)	46 (4.7)	3 (27.3)	86 (6.6)	24 (27.9)
Endometrial	0 (0)	71 (7.2)		71 (5.5)	30 (42.3)
Colorectal	45 (14.8)	19 (1.9)		67 (5.2)	12 (18.8)
Gastric	33 (10.9)	33 (3.4)	1 (9.1)	64 (4.9)	9 (13.4)
Prostate	58 (19.1)	0 (0)		58 (4.5)	15 (25.9)
Ovarian	0 (0)	30 (3.1)		30 (2.3)	11 (36.7)
Soft tissue	9 (3.0)	15 (1.5)	1 (9.1)	24 (1.8)	13 (54.2)
Bladder	10 (3.3)	2 (0.2)		13 (1.0)	0 (0)
Liver	7 (2.3)	3 (0.3)		10 (0.8)	1 (10.0)
Lung	3 (1.0)	5 (0.5)	1 (9.1)	9 (0.7)	2 (22.2)
Hematologic	3 (1.0)	5 (0.5)		8 (0.6)	0 (0)
Testicular	7 (2.3)	0 (0)		7 (0.5)	1 (14.3)
Thyroid	1 (0.3)	7 (0.7)		8 (0.6)	8 (100.0)
Pancreatic	3 (1.0)	2 (0.2)		5 (0.4)	2 (40.0)
Others*	16 (5.3)	10 (1.0)		26 (2.0)	8 (30.8)
Total	304 (100)	983 (100)	11 (100)	1298 (100)	503 (38.8)

Others: include inguinal, cholangial, renal, laryngeal, vulvar, penis, skin, and tongue cancer.
Abbreviation: CUP, cancer of unknown origin.

of cancer cases in Ethiopia occur among females.[8,13,16] This can be explained by the fact that breast and cervical cancers are the 2 most frequently diagnosed cancers occurring mainly/only in females. Our study also confirms that, in rural Ethiopia, cancer is a diagnosis in women who are very young, often have children at an early age, and are responsible for looking after their children (who likewise suffer).[20]

Our results suggest that the number of cancer cases presenting at hospitals is increasing over time, up to 4 times, between 2014 and 2018. This reflects the aging of the population, an increase in service uptake, and possibly lifestyle changes. Our findings support the global burden of cancer increases over time and is projected to be 29.5 million over the next 2 decades,[4] and by 2035, it's estimated that two-thirds of these new cancer diagnoses will occur in developing countries.[2]

Our results showed that breast and cervical cancers were the 2 leading cancers for both sexes, each accounting for 30.8% and 22.3% of total cancer cases, again showing the huge burden for women. Similar figures were reported from 2013 Addis Ababa population-based cancer registry data, in which 31.4% and 14.1% of total cancer cases were due to breast and cervical cancers, respectively.[8] In the tertiary cancer center in Addis Ababa, gynaecological malignancies (predominantly cancer of the uterine cervix) were found to be leading cancer, followed by breast cancer based on the retrospective review done from 1998 to 2010.[19] The University of Gondor Hospital also reported that cervical cancer was the most common cancer, accounting for 16.1% of total cases diagnosed and treated within a 1-year duration.[21] This might be due to the unavailability of RT services at lower-level hospitals and all cervical cancer cases ending up in a tertiary hospital, whereas breast cancer cases can receive surgical and other treatment options at primary or secondary level hospitals. In summary, these 2 cancers are the most prominent cancers in tertiary hospitals, in lower-level hospitals and also among the population, accounting for the lion's share of cancer deaths among females. The discrepancy in cervical cancer incidence and mortality between developed and developing nations is striking.[1,3] In 2020, Africa contributed to 19.4% of all incident cases worldwide,[1] and East Africa has the highest subregional incidence of cervical cancer.[5,22] This tragedy is due to a lack of screening services and human papillomavirus (HPV) vaccination in the region.

During the stated period, prostate (19.1%) cancer was the first cancer among males, followed by oesophageal (16.1%) and colorectal (14.8%) cancers. This differs slightly compared to findings in the Addis Ababa population-based cancer registry, showing that the three most common cancers among males were colorectal, non-Hodgkin's lymphoma, and prostate cancer.[23] However, leukaemia and non-Hodgkin's lymphoma were rarely found in our study. The main reason for this might be the lack of advanced diagnostic services and specialists, and thus a lack of detection of these cases in lower-level hospitals. The other possible explanation for this could be physicians considering such cases as HIV or other diseases and never suspecting a malignancy.

Out of the total 1298 cancer cases identified in our study; oesophageal cancer (9.5%) was the third most common cancer. Previous studies from other geographic areas reported it as the ninth most incident and the eighth leading cause of mortality in Ethiopia, contributing to less than 3% of total cases.[8,13,16,23] We found Aira General Hospital to be a hotspot in our study, and it is located in West Wellega zone of the Oromia region. Out of the total of 123 oesophageal cases reported within a

Table 3. Five top cancers diagnosed in 8 rural hospitals of Ethiopia between 2014 and 2019.

Top 5 cancers	Name of the hospitals							
	SNNPR region Primary and secondary level hospitals						Oromia region primary level hospitals	
	Attat (150)	Negest E. (136)	Dubo(110)	Durame (156)	Ottana (135)	Butajira (90)	St. Lukas (267)	Aira (254)
1st	Breast (84)	Breast (52)	Breast (33)	Breast (51)	Breast (60)	Breast (17)	Cervical (99)	Esophageal (79)
2nd	CUP (43)	Cervical (44)	CUP (22)	Cervical (17)	Cervical (32)	CUP (15)	Endometrial (38)	Breast (69)
3rd	Esophageal (10)	Gastric (9)	Cervical (14)	Prostate (17)	Colorectal (10)	Gastric (13)	Breast (34)	Cervical (68)
4th	Cervical (5)	Colorectal (8)	Endometrial (13)	Gastric (16)	Soft Tissue (6)	Esophageal (12)	Prostate (17)	Colorectal (12)
5th	Prostate (5)	Ovarian (6)	Gastric (10)	Esophageal (15)	Gastric (6)	Cervical (10)	Ovarian (6)	Endometrial (11)

Note: the values in bracket are actual number of cases.
Abbreviation: CUP, cancer of unknown primary.

5-year duration, nearly two-thirds (79; 64.2%) were reported from this hospital. Several studies conducted in Ethiopia also revealed certain hotspots in the Oromia region, particularly in the Arsi and West Wellega zones.[24-26] Consumption of hot beverages and porridge in these places has recently been identified as a risk factor for oesophageal cancer, along with other environmental factors.[27,28]

The majority of our cases were diagnosed clinically, and pathologic examination was done only for one-third (38.8%) of total cases, of which the histologic type and tumour grade were recorded only for 209 (41.6%) and 144 (28.6%) of cases, respectively. Several studies both in Ethiopia and other LMICs have highlighted that the majority of cancer cases were often diagnosed and treated clinically without verification through biopsy or other pathologic examination.[4,6,12] In Ethiopia, health facilities with FNAC and biopsy services are rare and mainly concentrated in urban areas. Therefore, patients are forced to travel long distances and spend a lot of money, especially for private services. Lack of pathology has many implications in terms of the provision of standard cancer care relying on histologic type, grade, and immunohistochemistry for breast cancer. The unavailability of local pathologic services is one of the main contributing factors to the late diagnosis of cancer in Ethiopia, together with weak referral systems and extended waiting periods for consultation.[11,29,30]

In LMICs, the majority of cancer patients are diagnosed at an advanced stage of the disease, which contributes to a high mortality rate and poor prognosis of the disease.[4-6,17] In this study, nearly two-thirds (238; 65.4%) of the total cases were diagnosed at an advanced stage of the disease. The majority of Ethiopian studies found that more than 70% of cancer cases in Ethiopia were diagnosed at stages III and IV.[13,14,16,23,25,31] According to a multicentre study in southern Ethiopia, 72.5% of breast cancer patients were diagnosed at an advanced stage of the disease.[29] Age above 40 years, lower educational levels, rural residence, visiting traditional healers and religious places, lack of awareness about cancer (including its risk factors), screening techniques, and severity of the disease were some of the identified factors associated with late-stage presentation.[6,12,30,31] Moreover, negative perceptions toward medical treatment,[23,32] low screening service uptake, and poor health-seeking behaviors[32-34]were the other reasons for the late presentation of cancer in the country.

Surgery is essential for global cancer care in all resource settings.[35,36] It's shown to be a vital method in the management of most patients with cancer.[37] Out of the 15.2 million new cases of cancer in 2015, over 80% of individuals with cancer required a surgical procedure, yet only 25% of cancer patients worldwide and less than 5% in low-income countries get timely, affordable, and safe surgery.[35] Our results showed that surgery is the most widely available cancer treatment option in the primary and secondary rural hospitals of Ethiopia, since systemic treatments, such as chemotherapy and RT services, are scarcely available at tertiary level hospitals. Studies also reported that, for most patients with cancer in Africa, surgery alone is the only realistically available option because of disorganized referral and treatment patterns.[37] Additionally, in many cases, the cost of neoadjuvant chemotherapy and RT is 2 to 3 times higher than the cost of all surgical care.[35,36]

Mastectomy was the most frequently performed surgical procedure, followed by total abdominal hysterectomy. Modified radical mastectomy is the recommended surgical

Table 4. Medical and clinical characteristics of participants.

Variables	*n* = 1, 298	Percent (%)
Method of diagnosis		
Clinically	785	60.4
Pathologically	503	38.8
Not recorded	10	0.8
Histologic type (*n* = 294)		
Squamouscell carcinoma	131	44.6
Ductal cell carcinoma	74	25.2
Adeno carcinoma	36	12.2
Adeno squamous cell carcinoma	21	7.1
Other types[*]	32	10.9
Tumor grade (*n* = 144)		
Grade I	25	17.4
Grade II	49	34.0
Grade III	70	48.6
Stage (*n* = 364)		
Stage I	16	4.4
Stage II	110	30.2
Stage III	136	37.4
Stage IV	102	28.0
Why surgery not planned (*n* = 519)		
Advanced cancer	18	3.5
Referred	350	67.4
Not recorded	151	29.1
Why surgery was not done (*n* = 140)		
Refused/patient did not return back	69	49.3
Planned in the future	16	11.4
Referred	45	32.1
Other reasons [c]	10	7.1
Hormonal treatment for breast cancer (*n* = 400)		
Yes	119	29.8
No	258	64.5
Not recorded	23	5.7
Duration of hormonal treatment (*n* = 119)		
1-3 months	27	22.7
4-6 months	17	14.3
7-9 months	6	5.0
10-12 months	15	12.6
>1 year	20	16.8
Not recorded	34	28.6
Chemotherapy		
Yes	18	1.4
No	1,062	81.8
Not recorded	218	16.8
Radiotherapy		
Yes	9	0.7
No	1,058	81.5
Not recorded	231	17.8
Total patients referred (*n* = 429)		
Immediately after diagnosis	350	81.6
After surgery planned	45	10.5
For further treatment	34	7.9

Table 4. Continued

Variables	*n* = 1, 298	Percent (%)
Name of health facility referred (*n* = 429)		
Tikur Anbessa specialized hospital	214	49.9
Hospital in Addis Ababa	36	8.4
Hawassa referral hospital	29	6.8
Hossana referral hospital	20	4.7
Wolayta teaching and referral hospital	11	2.6
Other hospitals[b]	3	0.7
Not recorded	116	27.0
Patient status mentioned in the patient file		
Died in hospital	73	5.6
Not recorded	1228	94.4

[*] Other types include—lobular, papillary, and basal cell carcinoma.
[c] Other reasons include poor medical condition, respiratory distress, and to resuscitate patients.
[b] Other hospitals include—Durame and Nekemete hospitals

procedure for all breast cancer patients in Ethiopia due to the low capacity for RT services that would be needed for breast conservation. This might have a lot of implications in terms of refusal and discontinuation of treatment. In this study, 49.3% of planned surgical procedures were not performed because either the patient refused or did not return to the hospital for follow-up on the appointed date. The most obvious reasons for not having surgery could be financial problems,[36,37] fear of the surgical procedure, or complications after the operation.[36] The other possible explanation is in association with visiting traditional healers and religious places.[11,12,29,30] In many parts of Africa, there are well-entrenched beliefs that cancers should not be touched and, furthermore, touching them through surgical resection or biopsy will lead to the acceleration of an already fatal disease. This belief frequently leads to very late presentation and refusal of surgical procedures[37] and eventually a high mortality rate, which is a vicious cycle will confirm the belief that cancer cannot be cured anyway. In addition, the lack of any systemic treatment for the rural population by itself already leads to fatal outcomes. Endocrine treatment may be an option to task-share with oncology services at lower-level hospitals.

Strengths and Limitations

One of the strengths of this study was the inclusion of patients from 8 primary and secondary hospitals selected from the Oromia and SNNPR regions; the 2 largest regions in the country with considerable diversity of patient characteristics and health services. Having both primary and secondary hospitals in our study also enabled us to compare the disease pattern and provision of cancer care at different health tiers. Five-year data can reflect the trend in the uptake of cancer services over the years. However, since the data were retrospectively reviewed from the charts of patients, missing data for important variables was one of the limitations of the study. In addition, there was a chance of missing the cards of patients because of poor storage of charts in those hospitals, which might have underestimated the total number of cases diagnosed and treated in these hospitals during the stated period. Due to the lack of awareness and shortage of accurate diagnostic services, certain cancers probably never reached

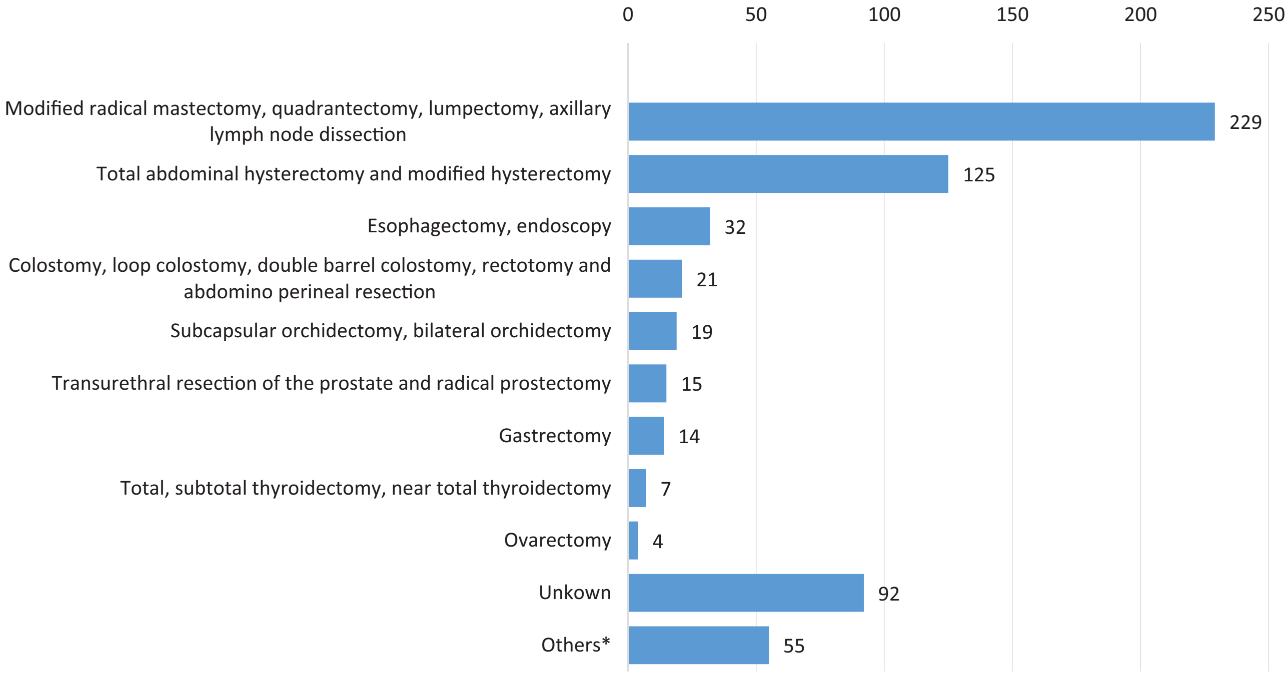


Figure 2. Types of surgery done for cancer patients in 8 rural hospitals of Ethiopia from 2014 to 2019 (*n* = 612). *Others—include laparotomy, local excision, tracheostomy, amputation and split-thickness skin grafting (STSG).

Table 5. Site of tumor and intention of surgery.

Primary site of cancer	Surgery planned *n* = 756 (% of total within entities)	Surgery performed *n* = 612 (% of total within entities)	Curative surgery *n* = 74 (% of total within entities)	Palliative surgery *n* = 406 (% of total within entities)	Intent not specified *n* = 132 (% of total within entities)
Breast	319 (79.8)	271 (85.0)	30 (11.1)	198 (73.1)	43 (15.9)
Cervical	96 (33.2)	82 (85.4)	10 (12.2)	67 (81.7)	5 (6.1)
Esophageal	47 (38.2)	38 (83.0)	0 (0)	3 (7.7)	36 (92.3)
CUP	46 (53.5)	29 (63.0)	3 (10.3)	16 (55.2)	10 (34.5)
Endometrial	57 (80.3)	50 (87.7)	19 (38.0)	27 (54.0)	4 (8.0)
Colorectal	39 (60.9)	32 (82.1)	2 (6.3)	23 (71.9)	7 (21.9)
Gastric	39 (58.2)	20 (51.3)	0 (0)	13 (65.0)	7 (35.0)
Prostate	47 (81.0)	41 (87.2)	3 (7.3)	29 (70.7)	9 (22.0)
Ovarian	18 (60.0)	16 (88.9)	1 (6.3)	14 (87.5)	1 (6.3)
Others*	14 (53.8)	10 (71.4)	2 (20.0)	5 (50.0)	3 (30.0)
Soft tissue	14 (53.3)	11 (78.6)	3 (27.3)	3 (27.3)	5 (45.5)
Bladder	6 (46.2)	1 (16.7)	0 (0)	0 (0)	1 (100)
Liver	2 (20.0)	2 (100)	0 (0)	2 (100.0)	0 (0)
Lung	2 (22.2)	0 (0)	NA	NA	NA
Hematologic	0 (0)	NA	NA	NA	NA
Testicular	4 (57.1)	2 (50.0)	0 (0)	1 (50.0)	1 (50.0)
Thyroid	6 (75.0)	6 (100)	1 (16.7)	5 (83.3)	0 (0)
Pancreatic	0 (0)	NA	NA	NA	NA
Total	756 (58.2)	612 (81.2)	74 (12.1)	406 (66.3)	132 (21.6)

*Others include inguinal, cholangial, renal, laryngeal, vulvar, penis, skin, and tongue cancer.
Abbreviation: CUP, cancer of unknown primary.

the rural hospitals or, if they did, they were not identified clinically without advanced imaging or other services.

Conclusion

Nearly 1300 total cancer cases were diagnosed and treated in 8 rural hospitals in Ethiopia, showing an increment over a 5-year duration. The majority of the burden of more than three-fourths of cancers was weathered by females. Breast and cervical cancers were the most common cancers among females, while prostate and oesophageal cancers ranked first and second among males, respectively. The majority of the cancer cases were diagnosed clinically, and pathologic tests were done only for one-third of the total cases, showing an urgent need for more pathology services. Given the lack of pathologists in the country, innovative strategies, such as sample collection services or telepathology, should be considered. Surgery is the predominantly available cancer treatment in these hospitals and is offered to 60% of the patients, showing the considerable efforts of the local surgeons. Of these surgeries, one-fifth were not performed due to patient refusal or patients not returning for appointments. This clearly shows the need to better understand the concepts and beliefs of patients within the community. Interdisciplinary research is required to find a way to talk about medical treatment options for rural populations and their concepts of health. Nearly none of the patients had records of receiving chemotherapy or RT at cancer centers, pointing to a lack of clear patient navigation and possibly the absence of reporting back from higher-level hospitals. In summary, we found considerable efforts by health workers, including surgeons, in remote areas to treat cancer patients with mainly late-stage diseases. Integrating oncology care into lower-level hospitals needs careful consideration for task-sharing, in addition to improving the linkage to higher-level services. Access, timeliness, quality, and affordability of the service need to be considered, and only then can the vicious circle of late-stage presentation, resulting in high mortality despite treatment and the perception of cancer as "a death sentence anyway" in the population, be broken.

Acknowledgment

The authors would like to thank the data collection nurses and HMIS focal persons who are working in those hospitals. We would also like to thank the administrators of the 8 health facilities for granting us permission to conduct the study.

Ethics Approval and Consent to Participate

Ethical clearance for this study was obtained from the Research Ethics Committee of the School of Public Health and the Institutional Review Board of the College of Health Science, Addis Ababa University. Informed consent is not applicable for this study, as the data were extracted from charts. The confidentiality and anonymity of the data were maintained, and all analysis methods were performed in accordance with the Declaration of Helsinki.

Funding

This work was supported by Else-Kroener-Foundation through Martin-Luther-University, Halle-Wittenberg, Germany, grant No. 2018_HA31SP.

Conflict of Interest

The authors indicated no financial relationships.

Author Contributions

Conception/design: A.W., F.N.B., M.A., S.T., B.Z., A.A., E.J. K. Provision of study material/patients: A.W., A.A., E.J.K. Collection and/or assembly of data: A.W., A.A., E.J.K. Data analysis and interpretation: A.W., F.N.B., E.J.K. Manuscript writing: A.W., M.A., S.T., B.Z., E.J.K. Final approval of manuscript: All authors

Data Availability

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

References

1. Sung H, Ferlay J, Siegel RL, et al. Global Cancer Statistics 2020: GLOBOCAN Estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA: Cancer J Clin*. 2021;71(3):209-249. Epub 2021/02/05. 10.3322/caac.21660
2. International Agency for Research on Cancer, World Health Organization. Global cancer statistics, cancer tomorrow. https://gco.iarc.fr/tomorrow/en. Accessed November 7, 2021.
3. Bray F, Ferlay J, Soerjomataram I, et al. Global cancer statistics 2018: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA Cancer J Clin*. 2018;68(6):394-424. https://doi.org/10.3322/caac.21492.
4. Martei YM, Pace LE, Brock JE, Shulman LN. Breast cancer in low- and middle-income countries: why we need pathology capability to solve this challenge. *Clin Lab Med*. 2018;38(1):161-173.
5. LaVigne AW, Triedman SA, Randall TC, Trimble EL, Viswanathan AN. Cervical cancer in low and middle income countries: addressing barriers to radiotherapy delivery. *Gynecol Oncol Rep*. 2017;22:16-20. https://doi.org/10.1016/j.gore.2017.08.004.
6. Jedy-Agba E, McCormack V, Adebamowo C, dos-Santos-Silva I. Stage at diagnosis of breast cancer in sub-Saharan Africa: a systematic review and meta-analysis. *The Lancet Global Health*. 2016;4(12):e923-ee35.
7. International Agency for Research on Cancer, World Health Organization. Cancer fact sheets, Ethiopia 2020. GLOBOCAN (2020). https://gco.iarc.fr/today/data/factsheets/populations/231-ethiopia-fact-sheets.pdf. Accessed August 12, 2021.
8. Timotewos G, Solomon A, Mathewos A, et al. First data from a population based cancer registry in Ethiopia. *Cancer Epidemiol*. 2018;53:93-98. https://doi.org/10.1016/j.canep.2018.01.008.
9. Federal Ministry of Health Ethiopia. National cancer control plan 2016–2020. Addis Ababa, Ethiopia, 54P.
10. Telos Consulting. The Ethiopian cervical cancer prevention program: evaluation report for pink ribbon red ribbon, Addis Ababa, April 2018, 31P.
11. Gebremariam A, Addissie A, Worku A, Assefa M, Kantelhardt EJ, Jemal A. Perspectives of patients, family members, and health care providers on late diagnosis of breast cancer in Ethiopia: a qualitative study. *PloS One*. 2019;14(8):e0220769. Epub 2019/08/02.
12. Dereje N, Addissie A, Worku A, et al. Extent and predictors of delays in diagnosis of cervical cancer in Addis Ababa, Ethiopia: a population-based prospective study. *J Global Oncol*. Feb 2020;6:277-284.
13. Abebe E, Abebe H. Types of cancers diagnosed and the preference of families of adult patients with cancer about disclosing diagnosis to the patients. *Ethiopian J Health Sci*. 2018;27(3):255-262.
14. Muluken G, Addissie A, Getachew S, et al. Cervical cancer patients' presentation and survival in the only oncology referral hospital,

Ethiopia: a retrospective cohort study. *BMC Infectious Agents Cancer*. 2017;12(61).

15. Eber-Schulz P, Tariku W, Reibold C, et al. Survival of breast cancer patients in rural Ethiopia. *Breast Cancer Res Treat*. 2018;170(1):111-118.
16. Feuchtner J, Mathewos A, Solomon A, et al. Addis Ababa population-based pattern of cancer therapy, Ethiopia. *PLoS One*. 2019;14(9):e0219519. Epub 2019/09/20.
17. Magrath I. Cancer in low and middle income countries. *Health G20*. 2010;20:58-68.
18. Knaul FM, Arreola-Ornelas H, Rodriguez NM, et al. Avoidable mortality: the core of the global cancer divide. *J Global Oncol*. 2018;4:1-12.
19. Tigeneh W, Molla A, Abreha A, Assefa M. Pattern of cancer in *Tikur anbessa* specialized hospital oncology center in Ethiopia from 1998 to 2010. *Int J Cancer Res Mole Mech*. 2015;1(1).
20. Galukande M, Schuz J, Anderson BO, Zietsman A, Adisa C, Anele A, et al. Maternally orphaned children and intergenerational concerns associated with breast cancer deaths among women in Sub-Saharan Africa. *JAMA Oncol*. 2021; 7(2):285-289. Epub 2020/12/24. https://doi.org/10.1001/jamaoncol.2020.6583
21. Tefera B, Assefa M, Rauch D. Patterns of cancer in University of Gondar Hospital: North-West Ethiopia. *J Oncol Med Practice* 2016;2(1)
22. World Health Organization. WHO leads the way towards the elimination of cervical cancer as a public health concern; 2018. https://www.who.int/reproductivehealth/cervical-cancer-public-health-concern/en/. Accessed November 7, 2021.
23. Memirie ST, Habtemariam MK, Asefa M, et al. Estimates of cancer incidence in Ethiopia in 2015 using population—based registry data. *J Global Oncol*. 2018;4:1-11. https://doi.org/10.1200/JGO.17.00175
24. Hassen HY, Teka MA, Addisse A. Survival status of esophageal cancer patients and its determinants in Ethiopia: a facility based retrospective cohort study. *Front Oncol*. 2020; 10:594342. Epub 2021/03/05. https://doi.org/10.3389/fonc.2020.594342
25. Wondimagegnehu A, Hirpa S, Abaya SW, et al. Oesophageal cancer magnitude and presentation in Ethiopia 2012-2017. *PLoS One*. 2020;15(12):e0242807. Epub 2020/12/02. https://doi.org/10.1371/journal.pone.0242807
26. Deybasso HA, Roba KT, Nega B, Belachew T. Clinico-pathological findings and spatial distributions of esophageal cancer in Arsi Zone, Oromia, Central Ethiopia. *Cancer Manag Res*. 2021;13:2755-2762. Epub 2021/04/02. 10.2147/CMAR.S301978
27. Deybasso HA, Roba KT, Nega B, Belachew T. Dietary and environmental determinants of oesophageal cancer in Arsi Zone, Oromia, Central Ethiopia: a case-control study. *Cancer Manag Res*. 2021; 13:2071-2082. Epub 2021/03/06. https://doi.org/10.2147/CMAR.S298892
28. Chen Y, Tong Y, Yang C, et al. Consumption of hot beverages and foods and the risk of esophageal cancer: a meta-analysis of observational studies. *BMC Cancer*. 2015; 15:449. Epub 2015/06/03. https://doi.org/10.1186/s12885-015-1185-1
29. Tesfaw A, Getachew S, Addissie A, et al. Late-stage diagnosis and associated factors among breast cancer patients in South and Southwest Ethiopia: a multicenter study. *Clin Breast Cancer*. 2021;21(1):e112-e119. Epub 2021/02/05. 10.1016/j.clbc.2020.08.011
30. Gebremariam A, Addissie A, Worku A, et al. Time intervals experienced between first symptom recognition and pathologic diagnosis of breast cancer in Addis Ababa, Ethiopia: a cross-sectional study. *BMJ Open*. 2019;9(11):e032228. Epub 2019/11/14. https://doi.org/10.1136/bmjopen-2019-032228
31. Hassen AM, Hussien FM, Asfaw ZA, Assen HE. Factors associated with delay in breast cancer presentation at the only oncology center in North East Ethiopia: a cross-sectional study. *J Multidiscipl Healthcare*. 2021;14:681-694. Epub 2021/03/30. https://doi.org/10.2147/JMDH.S301337
32. Chaka B, Sayed AR, Goeieman B, Rayne S. A survey of knowledge and attitudes relating to cervical and breast cancer among women in Ethiopia. *BMC Public Health*. 2018;18(1):1072. https://doi.org/10.1186/s12889-018-5958-8.
33. Abeje S, Seme A, Tibelt A. Factors associated with breast cancer screening awareness and practices of women in Addis Ababa, Ethiopia. *BMC Womens Health*. 2019;19(1):4. https://doi.org/10.1186/s12905-018-0695-9.
34. Habtu Y, Yohannes S, Laelago T. Health seeking behavior and its determinants for cervical cancer among women of childbearing age in Hossana Town, Hadiya zone, Southern Ethiopia: community based cross sectional study. *BMC Cancer*. 2018;18(1):298. https://doi.org/10.1186/s12885-018-4203-2.
35. Sullivan R, Alatise OI, Anderson BO, et al. Global cancer surgery: delivering safe, affordable, and timely cancer surgery. *Lancet Oncol*. 2015;16(11):1193-1224.
36. Moran B. Primacy of surgery in cancer care: a global situation. *Lancet Oncol*. 2015;16(11):1188-1189. https://doi.org/10.1016/S1470-2045(15)00282-X.
37. White RE. Cancer surgery in Africa: if all you have is a hammer. *Lancet Oncol*. 2015;16(11):1190-1191. https://doi.org/10.1016/S1470-2045(15)00289-2.

The Oncologist, 2023, **28**, e359–e368
https://doi.org/10.1093/oncolo/oyad032
Advance access publication 20 March 2023
Original Article

Pathways and Referral of Patients with Cancer in Rural Ethiopia: A Multi-center Retrospective Cohort Study

Josephin Trabitzsch[1,2], Abigiya Wondimagegnehu[1,2,3], Tsion Afework[1,3], Ole Stoeter[1,2], Muluken Gizaw[1,2,3], Sefonias Getachew[1,2,3], Jilcha Diribi Feyisa[1,4], Lesley Taylor[5], Andreas Wienke[2], Adamu Addissie[1,2,3], Eva Johanna Kantelhardt[*,1,2,3,6]

[1]Global Health Working Group, Martin-Luther-University Halle-Wittenberg, Halle (Saale), Germany
[2]Institute of Medical Epidemiology, Biometrics, and Informatics, Martin-Luther-University Halle-Wittenberg, Halle (Saale), Germany
[3]Department of Preventive Medicine, School of Public Health, Addis Ababa University, Addis Ababa, Ethiopia
[4]Department of Oncology, Saint Paul's Hospital Millennium Medical College, Addis Ababa, Ethiopia
[5]Department of Surgery, City of Hope National Medical Center, Duarte, Los Angeles, CA, USA
[6]Department of Gynaecology, Martin-Luther-University Halle-Wittenberg, Halle (Saale), Germany

[*]Corresponding author: Eva Johanna Kantelhardt, MD, Global Health Working Group, Martin-Luther-University Halle-Wittenberg, Magdeburgerstraße 8, 06112 Halle (Saale), Germany. Tel: +49 (0)345 557 4166/557 1891; Email: eva.kantelhardt@uk-halle.de

Abstract

Introduction: Well-organized patient pathways are essential to achieve early diagnosis and timely treatment of patients with cancer in Sub-Saharan Africa. This retrospective cohort study describes pathways and referral patterns of cancer patients in rural Ethiopia.

Patients and Methods: The retrospective study took place from October to December 2020 at 2 primary- and 6 secondary-level hospitals in southwestern Ethiopia. Of 681 eligible patients diagnosed with cancer between July 2017 and June 2020, 365 patients were included. Structured interviews on the patients' pathways were conducted by telephone. The primary outcome was successful referral, which was defined as occurring when the intended procedure was initiated at the receiving institution. Logistic regression was used to assess factors associated with successful referrals.

Results: Patients visited on average 3 health care institutions from their first encounter with a provider until their final treatment initiation. After diagnosis, only 26% (95) of patients were referred for further cancer treatment, of which 73% were successful. Patients referred for diagnostic tests were 10 times more likely to complete referrals successfully than patients referred for treatment. Overall, 21% of all patients remained without any therapy.

Conclusion: We found that referral pathways of patients with cancer in rural Ethiopia were largely cohesive. The majority of patients referred for diagnostic or treatment services followed the advice. Nevertheless, an unacceptable number of patients remained without any treatment. Capacity for cancer diagnosis and treatment at primary- and secondary-level health facilities in rural Ethiopia must be expanded to enable early detection and timely care.

Key words: cancer; health system; Sub-Saharan Africa; patient pathways.

Implications for Practice

This study on patient pathways highlights the experiences of patients with cancer diagnosed at primary- and secondary-level hospitals in rural Ethiopia. It includes patients who never reach specialized tertiary care and are therefore missed in studies at specialized cancer centers. An average of 3 care-nodes during the patients' journey is encouraging. Expanding public pathology services and treatment capacity remain fields of action to enable early cancer diagnosis and treatment for the rural population of Ethiopia.

Introduction

Advanced stages at diagnosis and long intervals between first symptoms and treatment initiation are causing cancer mortality rates in Sub-Saharan Africa to rank among the highest worldwide.[1] Disorganized patient pathways have been thought to prevent patients from receiving early diagnosis and treatment.[2,3] As specialized diagnostic and treatment options are only available in few facilities in Sub-Saharan African countries, efficient referral systems for patients with cancer are of particular importance.

Recent reports on pathways of patients with cancer in Sub-Saharan Africa have largely focused on breast and cervical cancer.[2] The experiences of patients with less common cancers are not well described. In addition, most data have been collected from tertiary hospitals.[4,5] Those studies do not describe the unknown proportion of patients who are diagnosed

Received: 8 July 2022; Accepted: 27 January 2023.

with cancer in peripheral hospitals but never appear in tertiary hospitals to receive treatment. Moreover, there are few detailed studies on referral pathways for patients with suspected cancer.

In Ethiopia, as in many other countries in Sub-Saharan Africa, the health care system is divided into 3 tiers or levels. At the primary level are health posts, health centers, and primary hospitals. At the secondary level are general hospitals, of which larger ones can be affiliated with universities and serve as regional referral hospitals or "secondary referral hospitals." At the tertiary level are specialized referral hospitals.[6] In terms of cancer care, primary- and secondary-level hospitals have capacity for diagnosis but limited capacity for general surgical and systemic oncology services. Specifically for breast cancer treatment, endocrine therapy is available at some. For further diagnostics or treatment, such as chemotherapy, patients are mostly referred to one of 7 specialized tertiary referral hospitals around the country, which serve as comprehensive cancer centers. All 7 centers are now equipped with radiation machines and will soon offer treatment to patients. At the time of data collection, Tikur Anbessa Specialized Hospital, located in the capital city Addis Ababa was the only hospital in the country providing radiotherapy.

In this study, we aimed to describe pathways and referral patterns of patients with cancer diagnosed at primary and secondary hospitals in southwestern rural Ethiopia. In addition, we assessed which factors contributed to patients successfully completing referrals. We identify opportunities for future work to increase early cancer diagnosis and treatment.

Patients and Methods

Study Design, Setting, and Population

This retrospective cohort study was conducted between October and December 2020 at 8 hospitals in the rural Southwest of Ethiopia (Supplementary Table S1). Two hospitals were primary hospitals, while 3 hospitals were general and secondary referral hospitals. In all hospitals, cancer diagnosis mostly relied on clinical findings or biopsies evaluated at private pathology facilities or specialized hospitals. In terms of treatment, all the hospitals provided basic surgery for common cancers. Endocrine treatment (Tamoxifen) for breast cancer was available at all 8 sites, while only 1 secondary-level referral hospital (Assela University Teaching Hospital) provided chemotherapy.

We compared patient experiences across the primary- and secondary-level of the health-care system. Due to their size and smaller catchment area primary and general hospitals see substantially less patients with cancer compared with secondary referral hospitals. To achieve equal numbers of patients across the 3 groups, the study population consisted of patients aged 18 years or older who were diagnosed with cancer between July 2017 and June 2020 at primary and general hospitals, or between January 2018 and December 2019 for those diagnosed at secondary referral hospitals.

The primary outcome measured in this study was the successful completion of referring patients with cancer for further diagnostics or care. Referrals were defined to be successful when a patient initiated the diagnostic or treatment procedure at the receiving institution. When these procedures were still planned, or could not be determined to have been initiated, we defined the outcome of these referrals as "not determinable."

Data Collection

To identify eligible patients, nurses trained in data collection conducted a retrospective case note audit at all sites. The nurses were trained and supervised by our principal data collectors, who were masters-level graduates from the Addis Ababa School of Public Health.

Within the preliminary case note audit, we identified 681 patients diagnosed with cancer, of which 65.3% (445) patients had a morphologically verified diagnosis, while 24% (163) patients had been diagnosed clinically only. For 10% (71) the method of diagnosis was not documented within the case notes. Our principal data collectors reached 370 patients or their relatives via phone to conduct a structured interview about the patient's referral pathway. The questionnaire was adapted from a validated tool on delay in treatment for breast cancer.[7] It was discussed with an Ethiopian senior-oncologist in advance to ensure validity in the Ethiopian setting. After pretesting the tool with 40 patients at Tikur Anbessa University Hospital few changes were made for contextualized understanding of the questions (Supplementary Table S2). As suggested by Unger-Saldana et al. an algorithm was adapted to the Ethiopian calendar and applied to determine past dates using the calendar technique. If patients were too ill to participate personally or deceased, close relatives were interviewed on their behalf.

Socio-demographic data and clinical data from the study site were cross-checked between patients charts and interviews: For socio-demographic information, the interview data were preferred, and for the patients' clinical history data from case notes were preferred for accuracy. Of the 370 patients or patients' relatives interviewed, we excluded 5 patients from further analysis due to incohesive data.

Patient Pathway Definitions and Referral Processes

We defined patient pathways to comprise broadly of all health care providers the patients saw between their first recognition of cancer symptoms until the completion of their treatment: these included both traditional or spiritual healers and formal health care providers in private or government health care institutions. When a patient accessed a healthcare institution in their pathway, we defined this encounter as a "care node." When the patient received a diagnosis at a hospital, we defined the location a "study site." When a patient was referred to another hospital for further diagnostic tests or treatment, we defined that location as the "receiving institution."

We categorized the reasons for patient referral into 3 groups—for diagnostic tests only, for treatment, or unknown. Patients referred for treatment might also have received diagnostic tests at the receiving institution, however, we assumed treatment to have been the primary objective of the referral. Treatments included surgery, endocrine treatment, chemotherapy, radiation, and radiochemotherapy.

Data Analysis

Data were entered into EpiData Version 4.6.0.2 and transferred to R Version 4.0.4 for statistical analysis. Descriptive analyses were applied to assess referral patterns as well as diagnostic and treatment initiation intervals.

The influence of predictors on the success of referral was assessed using a logistic regression model. As some patients were referred multiple times, we assessed each referral individually. This way we could include patients who had experienced successful as well as unsuccessful referrals. We used multi-level regression models to investigate cluster effects due to several referrals of one patient, as well as several patients coming from one site. Models were compared using Akaike and Bayesian Information Criteria (AIC and BIC). Both multi-level regression models did not improve the model fit and were therefore discarded.

Predictors were chosen based on literature.[8-10] Their influence was first checked in univariable regression models. Sex was excluded from the multivariable model, as it was closely correlated with cancer entity and therefore judged to be colinear. Results from the univariable regression are presented as crude odds ratios (COR), those from the multivariable model as adjusted odds ratios (AOR)—both with 95% CIs. Cases where the success of referral was not determinable were excluded from this analysis. However, as they still added valuable data to the descriptive parts of the analysis, we did not remove them from analysis completely.

Ethical Considerations

This study is part of a project aiming to design, implement, and evaluate decentralized cancer care in Ethiopia. It was approved by the Institutional Review Board of the Addis Ababa University College of Health Science (ref: 041/20/SPH). An ethical protocol regarding interviews with critically ill patients or relatives of deceased patients was implemented and discussed in detail with all members of the data collection team. Study participants gave their oral informed consent before each interview and were offered the investigators´ contact details. All data was handled confidentially and participants´ data were pseudonymized after the phone-calls.

Results

Of the 365 patients included in the study, 58% answered the phone-call interviews themselves, while 42% of the interviews were conducted with relatives. The main reason why patients did not take part in the interviews themselves, was their death prior to our study: at the time of data collection 31% (113) patients were already deceased. Other reasons for relatives to answer the interview included language barriers as well as the patients' weak conditions. Patients were predominantly female and breast and cervical cancer made up almost two-thirds of all cancer entities (Table 1). The prevalence of other cancer entities differed strongly between hospitals. Of the total 20 patients with stomach cancer, 90% came from Dubbo St. Mary's Catholic Hospital (a primary-level hospital site). Also, of the 10 patients with prostate cancer, 50% were diagnosed at Butajira Hospital (a secondary-level general hospital site). Only one hematologic cancer was registered in the cohort.

A morphologically verified diagnosis was available in the medical records of 69% (252) patients. At primary-level hospitals, most pathology review was performed in the private sector. Cancer stage at time of diagnosis was documented for 55.3% (202) patients. Almost 3 quarters of those patients had been diagnosed with cancer stages III or IV.

At hospitals where patients were diagnosed with cancer (the study sites), 49% (180) of patients received surgery, 27% (98) endocrine treatment, and 14% (53) chemotherapy. When doctors at study sites made treatment recommendations, the majority of patients accepted endocrine and chemotherapy, and 89% of patients accepted surgery.

Patient Pathways

Table 2 shows that 220 (60%) patients went to a primary level health center when first seeking help for their cancer symptoms. On average, patients visited 1.2 health-care facilities before their diagnosis at the study site. The average number of care nodes visited throughout the entire patient pathway (from first seeking medical advice until final treatment initiation) was 3. Only 35 (10%) patients reported visiting a traditional or spiritual healer after their first cancer symptom recognition.

Referral Patterns

After patients were diagnosed with cancer at study sites, 250 (68%) were referred once to another facility, and 50 (14%) were referred twice (Table 3). At both primary level and general hospital study sites, first referrals were mostly for diagnostic tests only, and second referral were for treatment. At secondary-level referral hospital sites, the reasons for referrals were evenly distributed between diagnostic tests and treatment. A second referral hardly ever occurred. All in all, after diagnosis 26% (95) of patients were referred for any further cancer treatment.

Success rates of referrals differed strongly between the reason for the referral. The referral was more successfully completed for diagnostic tests than for initiation of treatment. While 96% (161) of the referrals for diagnostic procedures were successful, only 73% (72) of referrals for treatment resulted in treatment initiation at the receiving institutions.

Figure 1 shows the patient experience of referrals after receiving a cancer diagnosis at study sites. At primary-level hospital study sites, patients were first referred to the private sector usually for additional diagnostic services. Often a second referral was then made to receive care at a comprehensive cancer center. By contrast, at secondary-level hospitals, 65% (50) of patients were referred directly to a comprehensive cancer center. Only one primary hospital site referred patients to a secondary referral hospital.

Perceived Challenges and Enablers to Completing a Referral

Patients identified two major challenges to completing a referral: 73% (268) reported financial hardship in affording diagnostic tests and treatment; 30% (110) reported transportation issues. While 11% (41) described a lack of social support, most patients (76%, 279) stated that family support enabled them to complete their referrals. Perceptions of challenges and enablers did not substantially differ between patients who had been referred successfully and patients whose referral had not been successful.

Predictors of Successful Referral

Patients were 10 times more likely to complete the referral successfully when the reason was for diagnostic tests rather than treatment (Table 4). The trend increased in the multivariable model to an odds ratio of 13.3 (CI 4.12–42.92). In univariable regression, the other factors associated with successful referrals were being female, referral from a general hospital, and being diagnosed with breast or cervical cancer. These factors were not confirmed in the multivariable model. The remaining tested predictors (age, religion, occupation, education, and stage) did not show any association with successful referral.

Table 1. Socio-demographic and clinical characteristics of study participants at time of data collection by health-care level of study site.

Variable	All sites (%[a]) n = 365	Primary hospital sites (%) n = 116	General hospitals sites (%) n = 95	Referral hospital sites[b] (%) n = 154
Age (in years, median (IQR))	40 (15)	40 (15)	44.3 (15)	40 (18.8)
Sex				
Female	283 (77.5)	76 (65.5)	81 (85.3)	126 (81.8)
Male	82 (22.5)	40 (34.5)	14 (14.7)	28 (18.2)
Religion				
Orthodox	155 (42.5)	51 (44)	42 (44.2)	62 (40.3)
Protestant	125 (34.2)	46 (39.7)	25 (26.3)	54 (35.1)
Muslim	80 (21.9)	18 (15.5)	25 (26.3)	37 (24)
Other[c]	5 (1.4)	1 (0.9)	3 (3.2)	1 (0.6)
Educational level				
No formal education	187 (51.2)	80 (69)	39 (41.1)	68 (44.2)
Primary	107 (29.3)	26 (22.4)	42 (44.2)	39 (25.3)
Secondary or above	65 (17.8)	9 (7.8)	14 (14.7)	42 (27.3)
Unknown	6 (1.6)	1 (0.9)	0 (0)	5 (3.2)
Occupation				
Housewife	216 (59.2)	64 (55.2)	64 (67.4)	88 (57.1)
Farmer	82 (22.5)	38 (32.8)	20 (21.1)	24 (15.6)
Civil servant	32 (8.8)	6 (5.2)	8 (8.4)	18 (11.7)
Other[d]	33 (9)	8 (6.9)	2 (2.1)	23 (14.9)
Unknown	2 (0.5)	0 (0)	1 (1.1)	1 (0.6)
Marital status				
Married	312 (85.5)	110 (94.8)	73 (76.8)	129 (83.8)
Single	26 (7.1)	5 (4.3)	4 (4.2)	17 (11)
Widowed	20 (5.5)	0 (0)	13 (13.7)	7 (4.5)
Divorced/separated	7 (1.9)	1 (0.9)	5 (5.3)	1 (0.6)
Cancer entity				
Breast	166 (45.5)	44 (37.9)	45 (47.4)	77 (50)
Cervix	65 (17.8)	9 (7.8)	30 (31.6)	26 (16.9)
Colorectum	32 (8.8)	13 (11.2)	4 (4.2)	15 (9.7)
Stomach	20 (5.5)	18 (15.5)	2 (2.1)	0 (0)
Other[e]	82 (22.5)	32 (27.6)	14 (14.7)	36 (23.4)
Stage				
I	10 (2.7)	2 (1.7)	3 (3.2)	5 (3.2)
II	44 (12.1)	10 (8.6)	14 (14.7)	20 (13)
III	99 (27.1)	15 (12.9)	47 (49.5)	37 (24)
IV	49 (13.4)	7 (6)	17 (17.9)	25 (16.2)
Not documented	163 (44.7)	82 (70.7)	14 (14.7)	67 (43.5)
Method of diagnosis as documented on site				
Clinically	78 (21.4)	49 (42.2)	11 (11.6)	18 (11.7)
Morphologically verified	252 (69)	60 (51.7)	73 (76.8)	119 (77.3)
Not documented	35 (9.6)	7 (6)	11 (11.6)	17 (11)
Place of morphological verification[f]				
Study site	74 (29.4)	4 (6.7)	36 (49.3)	34 (28.6)
Private sector	159 (63.1)	54 (90)	32 (43.8)	73 (61.3)
Other[g]	18 (7.1)	2 (3.3)	4 (5.5)	12 (10.1)
Unknown	1 (0.4)	0 (0)	1 (1.4)	0 (0)
Therapy on study site[h]				
Surgery suggested	203 (55.6)	50 (43.1)	72 (75.8)	81 (52.6)
Surgery performed	180 (88.7)	42 (84)	65 (90.3)	73 (90.1)
Endocrine treatment suggested	101 (27.7)	38 (32.8)	39 (41.1)	24 (15.6)
Endocrine treatment initiated	98 (97)	37 (97.4)	37 (94.9)	24 (100)

Table 1. Continued

Variable	All sites (%[a]) n = 365	Primary hospital sites (%) n = 116	General hospitals sites (%) n = 95	Referral hospital sites[b] (%) n = 154
Chemotherapy suggested	53 (14.5)	0 (0)	0 (0)	53 (34.4)
Chemotherapy initiated	53 (100)	0 (0)	0 (0)	53 (100)
Therapeutic intent				
Curative	102 (27.9)	9 (7.8)	50 (52.6)	43 (27.9)
Palliative	110 (30.1)	30 (25.9)	23 (24.2)	57 (37)
Not determinable[i]	153 (41.9)	77 (66.4)	22 (23.2)	54 (35.1)
No. of patients deceased	113 (31)	55 (47.4)	29 (30.5)	29 (18.8)

[a] Column wise percentage unless otherwise specified.
[b] Referral hospitals on the secondary-level of the health-care level.
[c] Other religions include catholic religion and atheists.
[d] Other occupations include student, teacher, factory worker, merchant, day labourer, machine operator.
[e] Other cancer entities include prostate cancer, esophageal cancer, thyroid cancer, ovarian cancer, liver cancer, bladder cancer and others.
[f] Percentages are in relation to number of patients with morphologically verified diagnosis.
[g] Other place of morphological verification includes primary, secondary, and tertiary health care facilities.
[h] Percentages for performed/initiated procedures are in relation to number of suggested procedures.
[i] If therapeutic intent was not documented, stage I was estimated curative, stage IV palliative, stages II and III were rated not determinable.

Extent of Overall Cancer Treatment

Figure 2 shows how the referral patterns impacted the patient's initiation of treatment.

On the study sites (primary or secondary hospitals) 63% (221) of patients initiated some form of treatment. After referrals, this number increased to 76% (269). We found that 21% of patients remained without any treatment—even after referrals.

Overall, treatment differed between cancer entities and study sites. At primary and secondary general hospitals, 75% (67) of patients with breast cancer received surgery and non-surgical treatment without referral. At secondary-level referral hospitals only 29% (21) received surgery and non-surgical treatment on-site. Across all levels, only 5% of all patients with breast cancer did not receive any therapy at a study site, which was reduced to 3% after referrals.

By contrast, only 15% (9) of all patients with cervical cancer across all study sites received any form of treatment on-site, regardless of where they received their diagnosis. After referrals, 72% (43) of the patients with cervical cancer received some sort of treatment, however, 28% (17) remained untreated.

For other cancers (n = 131) only 56% (73) of patients received any form of therapy, even after referral. In these cases, the initiation of treatment strongly depended on the health-care level at where patients received their diagnosis. For patients diagnosed at primary-level hospital sites, 23% (14) of patients initiated any form of treatment after referral. When patients were diagnosed at general and secondary referral hospital study sites, those numbers were higher: 74% (14) and 88% (45), respectively.

Discussion

In this study, we described pathways and referral patterns of patients diagnosed with cancer at primary- and secondary-level hospitals in the rural southwestern region of Ethiopia. We found fewer than one-third of patients were referred for treatment from the study sites—however, those patients who were referred largely followed the referral advice. One-fifth of all patients remained without any cancer treatment.

As the Ethiopian government has been investing in developing the primary health care level for the last 2 decades, it was satisfactory to find referral pathways at this level are working as intended.[11] More than 80% of patients in our cohort accessed the health-care system at the primary level. After having addressed a health post or health center with their cancer symptoms, most patients were referred directly to a primary- or secondary-level hospital. The average number of care nodes visited before diagnosis at study sites ranged between 1 when patients were seen at primary and general hospitals, and 1.4 at secondary referral hospitals. The observation that 60% of all patients first sought assessment for cancer symptoms at a health center highlights the importance of primary level facilities in early detection of cancer.

In contrast to previous claims about disorganized referral pathways, we found cohesive referral patterns after patients received clinical or pathological diagnosis at the primary- or secondary-level health care sites.[2,5] Most patients were either referred to the private sector for confirmatory diagnostic tests or to a comprehensive cancer center directly. On average, patients visited 3 facilities (care nodes), consistent with findings from a mixed-method study on cervical cancer patients conducted at Tikur Anbessa Specialized Hospital in 2013.[12] This suggests that most patients followed pathways along the 3-tier health care system, largely bypassing multiple referrals within one health care level or counter-referrals.

The strongest predictor for a successful referral in our model was the referral objective. Patients were greater than 10 times more likely to complete the referral successfully when the reason was for diagnostic tests rather than treatment. Diagnostic services for cancer patients in this rural region of Ethiopia are offered by private clinics or hospitals situated in small towns. This keeps additional indirect costs for diagnostic procedures (transport, being away from work, and accommodation) lower than seeking diagnostic services in distant larger cities. Moreover, diagnostic tests are cheaper than total treatment costs. Patients may be more likely to compete for their referral for diagnostic tests than

Table 2. Characteristics of patients' with cancer pathways by health-care level of study site.

	All (%[a]) *n* = 365	Primary hospital sites (%) *n* = 115	General hospital sites (%) *n* = 95	Referral[b] hospital sites (%) *n* = 154
First health care provider visited with cancer symptoms				
Traditional or spiritual healer	31 (8.5)	6 (5.2)	2 (2.1)	23 (14.9)
Health post	21 (5.8)	4 (3.4)	4 (4.2)	13 (8.4)
Health center	220 (60.3)	77 (66.4)	53 (55.8)	90 (58.4)
Primary hospital	60 (16.4)	23 (19.8)	20 (21.1)	17 (11)
Other[c]	19 (5.2)	3 (2.6)	9 (9.5)	7 (4.5)
Unknown	14 (3.8)	3 (2.6)	7 (7.4)	4 (2.6)
No. of care nodes visited[d,e] (mean (SD))				
Before diagnosis at study site	1.2 (0.66)	1 (0.76)	1 (0.49)	1.4 (0.58)
After diagnosis at study site	0.8 (0.68)	1.2 (0.73)	0.8 (0.51)	0.5 (0.52)
During total pathway	3 (0.85)	3.2 (0.97)	2.8 (0.76)	2.9 (0.76)
Distribution of total care nodes				
1–2 care nodes	89 (24.4)	24 (20.7)	22 (23.2)	43 (27.9)
3–4 care nodes	230 (63)	77 (66.4)	65 (68.4)	88 (57.1)
5–6 care nodes	12 (3.3)	10 (8.6)	0 (0)	2 (1.3)
Pathway not finished	13 (3.6)	2 (1.7)	3 (3.2)	8 (5.2)
Unknown	21 (5.8)	3 (2.6)	5 (5.3)	13 (8.4)
Patients ever visiting a traditional or spiritual healer since first symptom recognition	35 (9.6)	13 (3.6)	2 (0.5)	20 (5.5)

[a] Column wise percentage unless otherwise specified.
[b] Referral hospitals on the secondary-level of the health-care level.
[c] Other includes secondary-level hospitals or private health care facilities.
[d] Care nodes are defined as formal health care facilities patients addressed on their pathway.
[e] Patients whose pathway was not known to be finished are excluded (*n* = 13).

for treatment because of these financial considerations. Although access to diagnostic services is more broadly available than treatment, patients still experience significant delays between their clinical presentation and obtaining a morphological diagnosis.[2] A study about patients with breast cancer in rural Ethiopia confirmed our finding, that most patients had to be referred for a morphologically verified diagnosis—prolonging time to diagnosis.[13] Establishing pathology services at primary- and secondary-level hospitals or a well-defined collaboration within the private sector could cut referrals for diagnostic services and therefore shorten time to diagnosis. Implementation of such an intervention would align with the World Health Organization (WHO) Global Breast Cancer Initiative to decrease diagnostic time intervals to <60 days.[14]

Overall, we found higher than expected success rates of patients following through with referrals. Referrals for treatment were successful in 73% of cases. In a WHO trial evaluating referral of women after a positive visual inspection with acetic acids in Tanzania, rates of successful referrals only ranged between 36% and 56%.[15] Similar to our findings, that study did not show a significant impact of sociodemographic characteristics on the successful completion of referrals.[16] However, we did not include the impact of the patient´s financial situation in the regression model due to low response rates. Considering almost 3 quarters of all respondents had reported cost barriers associated with the referrals, the influence of the patient's economic status on successful referrals was notable.

Opportunities exist to increase the rate of referrals, as less than a third of patients reported a referral for treatment after receiving a cancer diagnosis. This might be explained by the patients' mostly advanced cancer stage at time of diagnosis. However, reasons why health care professionals at primary- and secondary-level hospitals do not refer in the first place remain to be investigated for opportunities in education and areas of improvement.

We found 21% of rural patients with cancer received no treatment even after referrals. This is in line with data from the population-based Addis Ababa Cancer Registry where one-fifth of all patients diagnosed with cancer between 2012 and 2014 remained without any therapy even in the capital city, with presumed access to care.[17]

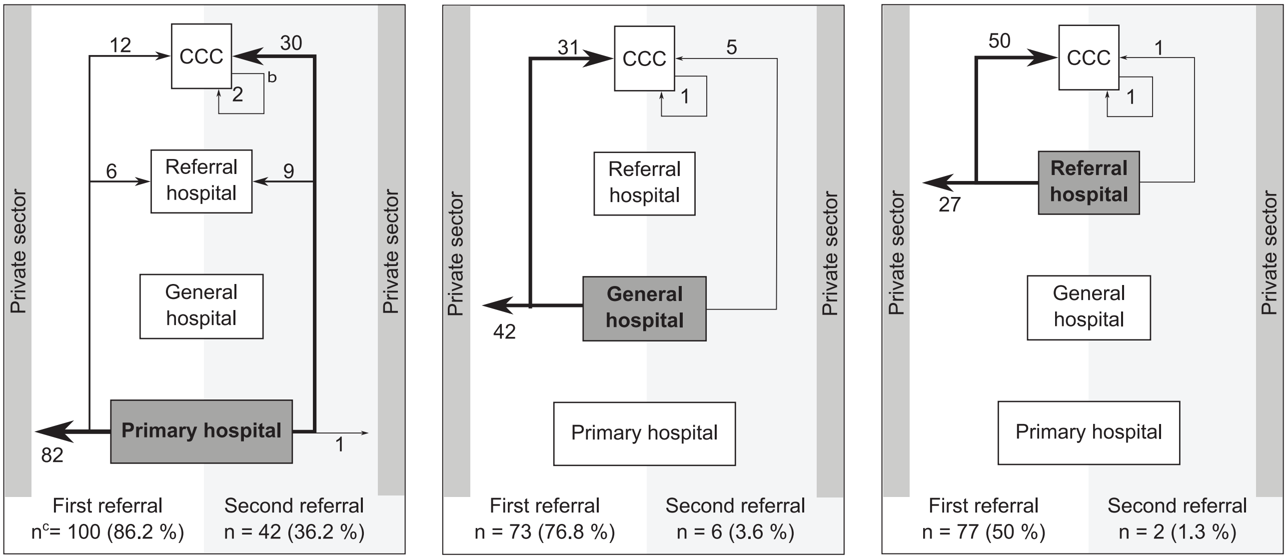
Patients with malignancies other than cervical or breast cancer seem to face significant hardship when seeking care. Multiple cancers, such as blood cancers were greatly underrepresented within our study cohort compared to relevant incidence rates reported from Addis Ababa.[18] This suggests that certain patients might not receive a cancer diagnosis in the first place. Of those who were diagnosed, chances of receiving any therapy were low at primary-level hospital study sites, where almost 70% of all patients diagnosed with cancer other than breast or cervical cancer remained untreated. Even though the current focus on breast and cervical cancer seems justified due to their absolute numbers, awareness, and education about other cancer entities at primary and secondary health-care levels must increase urgently.

We consider it a great strength of this study to have assessed pathways of cancer patients registered at the primary and secondary health-care levels, enabling us to describe the experiences of patients who might never have been included in patient cohorts at tertiary hospitals.

Table 3. Primary objectives and success of referrals from study site by health-care level of study site.

	All sites (%) *n* = 365	Primary hospital sites (%) *n* = 116	General hospital sites (%) *n* = 95	Referral[a] hospital sites (%) *n* = 154
Primary objectives of referral (% of all first or second referrals)				
First referral (*n* = 250)				
Diagnostics only	167 (66.8)	87 (87)	44 (60.3)	36 (46.8)
Treatment	72 (28.8)	8 (8)	28 (38.4)	36 (46.8)
Objective unknown	11 (4.4)	5 (5)	1 (1.4)	5 (6.5)
Second referral[b] (*n* = 50)				
Treatment	27 (54)	20 (47.6)	5 (83.3)	2 (100)
Objective unknown	23 (46)	22 (52.4)	1 (16.7)	0 (0)
Referrals'' success by primary objective (% of all referrals for given objective)				
Diagnostics only (*n* =167)				
Successful	161 (96.4)	86 (98.9)	42 (95.5)	33 (91.7)
Not successful	4 (2.4)	1 (1.1)	1 (2.3)	2 (5.6)
Success not determinable [c]	2 (1.2)	0 (0)	1 (2.3)	1 (2.8)
Treatment (*n* = 99)				
Successful	72 (72.7)	21 (75)	26 (78.8)	25 (65.8)
Not successful	19 (19.2)	7 (25)	6 (18.2)	6 (15.8)
Success not determinable	8 (8.1)	0 (0)	1 (3)	7 (18.4)
Objective unknown[d] (*n* = 34)				
Not successful	32 (94.1)	25 (92.6)	2 (100)	5 (100)
Success not determinable	2 (5.9)	2 (7.4)	0 (0)	0 (0)

[a] Referral hospitals on the secondary-level of the health-care level.
[b] No referrals for diagnostics only among second referrals.
[c] Success of referral was classified "not determinable" if treatment initiation was pending or unknown at time of data collection. The number of patients referred for diagnostics only with pending referral status was 0, the number of patients referred for treatment with pending referral status was 8. There were no pending referrals among patients with unknown referral objective.
[d] No successful referrals among referrals with unknown objective.



a) Referral from primary hospitals (n^a = 116)

b) Referral from general hospitals (n = 95)

c) Referral from secondary referral hospitals (n = 154)

Figure 1. Referral pathways of patients with cancer along the 3-tier health care system in Ethiopia. Patients were diagnosed (and included into the study) at (**a**) primary hospital, (**b**) general hospital, or (**c**) secondary referral hospital level and then referred for diagnostic tests or treatment. CCC, comprehensive cancer center (tertiary specialized hospital). [a] *n* corresponds to total number of patients in study cohort registered on specific health care level. [b] Arrow corresponds to referrals within health-care level. [c] *n* corresponds to number of patients referred of all patients in study cohort registered on specific health-care level.

Table 4. Crude odds ratio (COR) and adjusted[a] odds ratio (AOR) with 95% CIs for successful referral in study cohort.

	Referrals[b] *N* = 288	Successful referrals (%)	COR (CI)	*P*-value[c]	AOR (CI)	*P*-value[d]
Sex						
Male	71	51 (71.8)	Reference	—	—	—
Female	217	182 (83.9)	2.04 (1.08, 3.83)	.03	—	—
Age (in years)						
>40	134	102 (76.1)	Reference	—	—	—
≤40	154	131 (85.1)	1.79 (0.99, 3.24)	.06	1.74 (0.68, 4.44)	.25
Religion						
Protestant	106	83 (78.3)	Reference	—	—	—
Orthodox	129	102 (79.1)	1.05 (0.56, 1.96)	.89	—	—
Other[e]	53	48 (90.6)	2.66 (0.95, 7.45)	.06	—	—
Occupation						
Farmer	65	47 (72.3)	Reference	—	—	—
Housewife	170	141 (82.9)	1.86 (0.95, 3.66)	.07	—	—
Civil servant	29	24 (82.8)	1.84 (0.61, 5.56)	.28	—	—
Other[f]	24	21 (87.5)	2.68 (0.71, 10.1)	.14	—	—
Marital status						
Not married	35	30 (85.7)	Reference	—	—	—
Married	253	203 (80.2)	0.68 (0.25, 1.83)	.44	—	—
Education						
No formal education	152	120 (79)	Reference	—	—	—
Primary	86	71 (82.6)	1.26 (0.64, 2.49)	.5	—	—
Secondary or higher	50	42 (84)	1.4 (0.6, 3.28)	.44	—	—
Health care level of study site						
Primary hospital	140	107 (76.4)	Reference	—	—	—
General hospital	77	68 (88.3)	2.33 (1.05, 5.17)	.04	0.76 (0.22, 2.63)	.67
Secondary referral hospital	71	58 (81.7)	1.38 (0.67, 2.82)	.38	0.71 (0.22, 2.26)	.56
Cancer entity	—	—	—	—	—	—
Other[g]	119	84 (70.6)	Reference	—	—	—
Breast	108	97 (89.8)	3.67 (1.76, 7.68)	<.01	1.38 (0.44, 4.33)	.58
Cervix	61	52 (85.2)	2.41 (1.07, 5.41)	.03	2.92 (0.83, 10.33)	.1
Stage	—	—	—	—	—	—
I—II	39	34 (87.2)	Reference	—	—	—
III—IV	96	86 (89.6)	1.26 (0.4, 3.97)	.69	—	—
Unknown	153	113 (73.9)	0.42 (0.15, 1.14)	.09	—	—
Primary objective of referral						
Treatment	91	72 (79.1)	Reference	—	—	—
Diagnostics only	165	161 (97.6)	10.62 (3.5, 32.34)	<.01	13.3 (4.12, 42.92)	<.01
Unknown[h]	32	0 (0)	—	—	—	—

[a] Adjusted for age, health-care level of study site, cancer entity and objective of referral.
[b] Referrals where procedures were still planned or not known to have been initiated were excluded (*n* = 12).
[c] *P*-value for crude odds ratio.
[d] *P*-value for adjusted odds ratio.
[e] Other religions include catholic religion and atheists.
[f] Other occupations include student, teacher, factory worker, merchant, day labourer, machine operator.
[g] Other cancer entities includes prostate cancer, oesophageal cancer, thyroid cancer, ovarian cancer, liver cancer, bladder cancer and others.
[h] Unknown objectives were not included into regression models due to no successful referrals.

The study has several limitations. First is the retrospective, hospital-based sampling method. Only 58% of the patients identified in the chart note audit could be reached via telephone and more than a third of all interviews were conducted with relatives. It is possible patients diagnosed at advanced stages or patients with unsuccessful referrals resulting in less treatment had higher likelihood of severe disease or death before the time of data collection. Such patients were therefore likely not included and underrepresented in this study.

Second, this study may have recall bias. To reach adequate sample size, we had to create a 3-year eligibility period for diagnosis at primary and general hospitals and 2 years

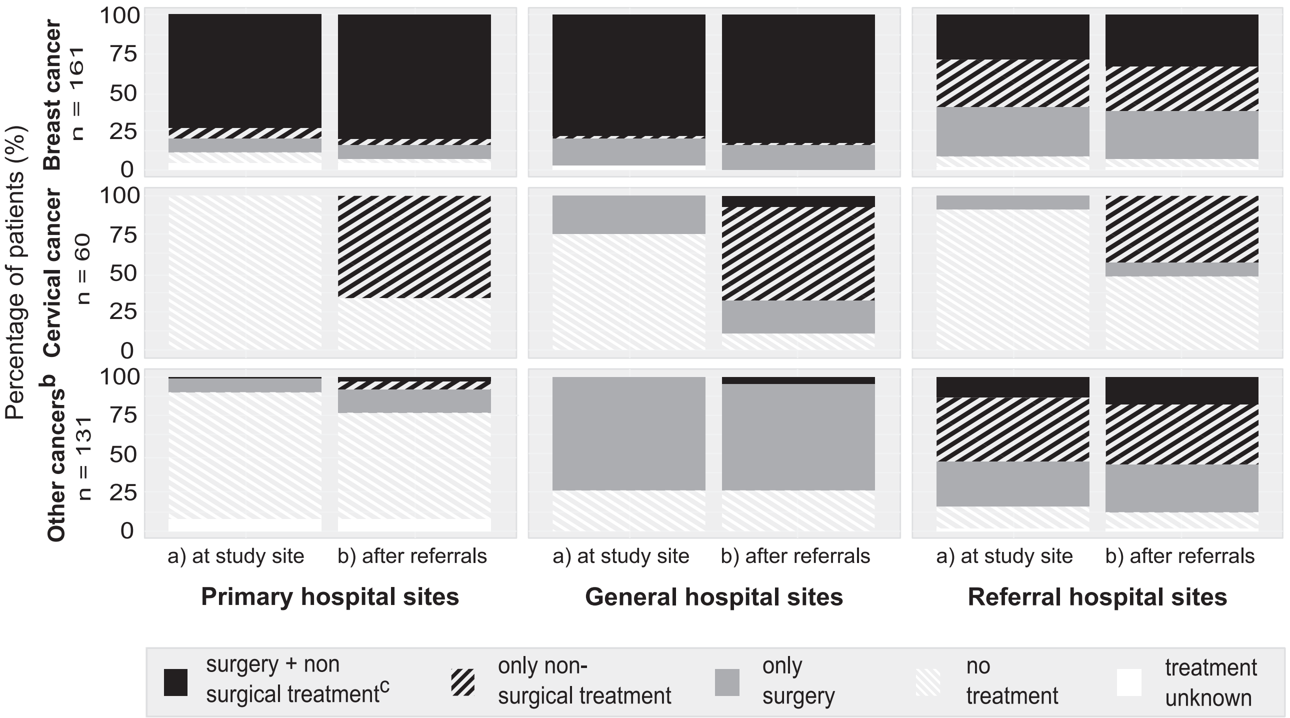


Figure 2. Treatment received by patients[a] with cancer (**a**) at study site and (**b**) after referrals in Ethiopia. [a]Excluding patients whose pathway was not finished or not known to be finished (n = 13). [b]Other cancers include prostate cancer, oesophageal cancer, thyroid cancer, ovarian cancer, liver cancer, bladder cancer, and others. [c]Non-surgical treatment includes hormonal treatment, chemotherapy, radiochemotherapy, and radiotherapy.

eligibility period at secondary referral hospitals. We tried to minimize the resulting recall-bias by using the calendar technique for determination of dates and cross-checking with patient charts wherever possible.

Third, we did not ask patients whether they received any treatments before diagnosis at the study site. Therefore, the described extent of treatment received at secondary-level referral hospitals might be incomplete. This might explain the low numbers of patients with breast cancer at secondary referral hospitals receiving surgery and non-surgical treatments.

Lastly, the number of patients with incomplete pathways in this study (n = 13) seems small, considering the long waiting times for treatment at secondary and tertiary referral hospitals.[19] Some pathways might have ended prematurely due to the patient's death and should not have been counted as "not successful." We were unable to inquire the direction of causality between non-referral and death from relatives. Also, we could not entirely rule out the possibility that patients might have received further treatment after the time of data collection, even though no further treatment had been planned at that time.

Conclusions

Pathways of patients with cancer in rural Ethiopia followed a largely cohesive pattern from the primary and secondary levels to tertiary level care—which points toward considerable awareness among patients and health workers in that region. While the number of patients referred for treatment is low, those patients who are referred mostly follow the referral advice.

It was encouraging to find the majority of patients with breast cancer being offered and accepting surgery and systemic treatment at primary and secondary health care level. Expanding capacity in diagnosis and treatment for other cancer entities could reduce the considerable number of patients still remaining without any cancer treatment. While diagnostic and treatment services are expanding to all health-care levels, barriers preventing health care providers in peripheral hospitals from referring patients for specialized cancer treatment need to be identified and addressed.

Funding

This work was supported by Else Kroener-Fresenius Foundation through Martin-Luther-University, Halle-Wittenberg, Germany, grant No. 2018_HA31SP. The study was also supported by a grant from Hospital Partnership through Deutsche Gesellschaft für Internationale Zusammenarbeit funded by the Ministry for Economic Cooperation and Development (ID 81281315).

Conflict of Interest

The authors indicated no financial relationships.

Author Contributions

Conception/design: J.T., A.W., J.D.F., A.A., E.J.K. Provision of study material or patients: J.T., A.W., M.G., S.G. Collection and/or assembly of data: J.T., T.A., M.G., S.G. Data analysis and interpretation: J.T., O.S., A.W. Manuscript writing: J.T., L.T., E.J.K. Final approval of manuscript: All authors.

Data Availability

The data underlying this article will be shared on reasonable request to the corresponding author.

Supplementary Material

Supplementary material is available at *The Oncologist* online.

References

1. Sung H, Ferlay J, Siegel RL, et al. Global cancer statistics 2020: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA Cancer J Clin*. 2021. https://doi.org/10.3322/caac.21660
2. Brand NR, Qu LG, Chao A, Ilbawi AM. Delays and barriers to cancer care in low- and middle-income countries: a systematic review. *Oncologist*. 2019;24(12):e1371-e1380. https://doi.org/10.1634/theoncologist.2019-0057
3. Martins T, Merriel SWD, Hamilton W. Routes to diagnosis of symptomatic cancer in sub-Saharan Africa: systematic review. *BMJ Open*. 2020;10(11):e038605e038605. https://doi.org/10.1136/bmjopen-2020-038605
4. Foerster M, McKenzie F, Zietsman A, et al. Dissecting the journey to breast cancer diagnosis in sub-Saharan Africa: findings from the multicountry ABC-DO cohort study. *Int J Cancer*. 2021;340:351. https://doi.org/10.1002/ijc.33209
5. Dye TD, Bogale S, Hobden C, et al. Complex care systems in developing countries: breast cancer patient navigation in Ethiopia. *Cancer*. 2010;116(3):577-585. https://doi.org/10.1002/cncr.24776
6. Ministry of Health E. *Health Sector Transformation Plan II: 2020/21-2024/25*; 2021.
7. Unger-Saldaña K, Peláez-Ballestas I, Infante-Castañeda C. Development and validation of a questionnaire to assess delay in treatment for breast cancer. *BMC Cancer*. 2012;12:626. https://doi.org/10.1186/1471-2407-12-626
8. Foerster M, Anderson BO, McKenzie F, et al. Inequities in breast cancer treatment in sub-Saharan Africa: findings from a prospective multi-country observational study. *Breast Cancer Res*. 2019;21(1):93. https://doi.org/10.1186/s13058-019-1174-4
9. Dereje N, Addissie A, Worku A, et al. Extent and predictors of delays in diagnosis of cervical cancer in Addis Ababa, Ethiopia: a population-based prospective study. *JCO Glob Oncol*. 2020;6:277-284. https://doi.org/10.1200/JGO.19.00242
10. Oliveria SA, Yood MU, Campbell UB, Yood SM, Stang P. Treatment and referral patterns for colorectal cancer. *Med Care*. 2004;42(9):901-906. https://doi.org/10.1097/01.mlr.0000135820.44720.89
11. Teklu AM, Alemayehu YK, Medhin G. *National Assessment of the Ethiopian Health Extension Program: Final Abridged Report*. Ethiopia: Addis Ababa; 2020.
12. Tadesse SK. Socio-economic and cultural vulnerabilities to cervical cancer and challenges faced by patients attending care at Tikur Anbessa Hospital: a cross sectional and qualitative study. *BMC Womens Health*. 2015;15:75. https://doi.org/10.1186/s12905-015-0231-0
13. Getachew S, Tesfaw A, Kaba M, et al. Perceived barriers to early diagnosis of breast Cancer in south and Southwestern Ethiopia: a qualitative study. *BMC Womens Health*. 2020;20(1):38. https://doi.org/10.1186/s12905-020-00909-7
14. Anderson BO, Ilbawi AM, Fidarova E, et al. The Global Breast Cancer Initiative: a strategic collaboration to strengthen health care for non-communicable diseases. *Lancet Oncol*. 2021;22(5):578-581. https://doi.org/10.1016/S1470-2045(21)00071-1
15. Lavelle AE, Su D, Kahesa C, Soliman AS. Needs for professional education to optimize cervical cancer screenings in low-income countries: a case study from Tanzania. *J Cancer Educ*. 2019;34(1):124-129. https://doi.org/10.1007/s13187-017-1276-6
16. Yim ET, Rogers TB, Msami K, et al. Factors related to completion of referral among women with suspected cervical cancer and dysplasia in Tanzania. *Int J Gynaecol Obstet*. 2021;152(1):88-95. https://doi.org/10.1002/ijgo.13412
17. Feuchtner J, Mathewos A, Solomon A, et al. Addis Ababa population-based pattern of cancer therapy, Ethiopia. *PLoS One*. 2019;14(9):e0219519. https://doi.org/10.1371/journal.pone.0219519
18. Timotewos G, Solomon A, Mathewos A, et al. First data from a population based cancer registry in Ethiopia. *Cancer Epidemiol*. 2018;53:93-98. https://doi.org/10.1016/j.canep.2018.01.008
19. Teshome B, Trabitzsch J, Afework T, et al. Perceived barriers to timely treatment initiation and social support status among women with breast cancer in Ethiopia. *PLoS One*. 2021;16(9):e0257163. https://doi.org/10.1371/journal.pone.0257163

Trabitzsch *et al. BMC Cancer* (2024) 24:553
https://doi.org/10.1186/s12885-024-12294-7

BMC Cancer

RESEARCH Open Access

Understanding referral of patients with cancer in rural Ethiopia: a qualitative study

Josephin Trabitzsch[1], Morena Marquardt[1], Sarah Negash[1], Winini Belay[1,2], Yonas Abebe[2,3], Edom Seife[4], Kunuz Abdella[3], Muluken Gizaw[1,2], Sefonias Getachew[1,2], Adamu Addissie[1,2], Eva Johanna Kantelhardt[1,5]* and Abigiya Wondimagegnehu[1,2]

Abstract

Background Cancer incidence is increasing in Ethiopia mainly due to increased life expectancy, while oncological capacities remain limited. Strong referral linkages between different levels of the healthcare system are key to provide timely access to cancer care. In this qualitative study, we assessed limitations and potential of cancer patient referral in the rural Southwest of Ethiopia.

Methods We held four focus group discussions (FGD) with health professionals at one primary and three secondary hospitals and conducted eight in-depth interviews (IDI) with the hospitals´ medical executives and local health bureau representatives. Data was analysed inductively using thematic analysis and emerging themes were categorized within the revised concept of access by Penchansky and Saurman.

Results The inevitable referral of patients with cancer in the rural Southwest of Ethiopia is characterized by the absence of clear communication protocols and the lack of formal referral linkages. The newly implemented hub-system has improved emergency referrals and could be expanded to non-emergency referrals, sensitive to the needs of advanced oncological care. Liaison officers can pave the way but need to be trained and equipped adequately. Referred patients struggle with inadequate transportation systems, the lack of accommodation close to specialized facilities as well as the inability to navigate at those sites due to language barriers, illiteracy, and stigmatization. Few Non-Governmental Organizations (NGOs) help but cannot compensate the limited governmental support. The shortage of medications at public hospitals leads to patients being directed to costly private pharmacies. In the light of those challenges, cancer remains to be perceived as a "death sentence" within the rural communities.

Conclusions Standardized referral linkages and a multi-faceted support network throughout the cancer care continuum are necessary to make oncology care accessible to Ethiopia´s large rural population.

Keywords Cancer, Healthcare system, Sub-Saharan Africa, Patient pathways

*Correspondence:
Eva Johanna Kantelhardt
eva.kantelhardt@uk-halle.de
[1] Global Health Working Group, Institute of Medical Epidemiology, Biometrics, and Informatics, Martin-Luther-University Halle-Wittenberg, Magdeburgerstraße 8, 06112 Halle (Saale), Germany
[2] Department of Preventive Medicine, School of Public Health, Addis Ababa University, Addis Ababa, Ethiopia
[3] Federal Ministry of Health, Addis Ababa, Ethiopia
[4] Department of Oncology, College of Health Science, Tikur Anbessa Specialized Hospital, Addis Ababa University, Addis Ababa, Ethiopia
[5] Department of Gynaecology, Martin-Luther-University Halle-Wittenberg, Halle (Saale), Germany

Introduction

Referral of cancer patients between healthcare levels in Sub-Saharan Africa has often been described to be poorly coordinated, resulting in extended time to diagnosis and treatment initiation and contributing to the region´s high cancer mortality [1–3]. In 2015, Ethiopia launched its first National Cancer Control Plan aiming to reduce cancer mortality in the country by 15% by 2020. Since then, the Ethiopian government has invested heavily into oncology services, implementing prevention and screening initiatives as well as expanding diagnostic and treatment capacities. However, the availability of advanced oncology services remains limited to tertiary-level specialized hospitals located in the larger cities. Considering that 80% of the Ethiopian population are living in rural areas, strong referral linkages between rural primary and general hospitals and tertiary specialized hospitals in the cities are of particular importance to provide access to oncology care to Ethiopia´s large rural population [4, 5].

Ethiopia´s healthcare system is divided into three tiers: Health posts, health centres and primary hospitals on the lowest level, general hospitals on the secondary level and specialized hospitals on the tertiary healthcare level [1]. In terms of cancer care, at primary- and secondary-level hospitals, cancer diagnosis mostly relies on clinical findings. An affirmative diagnosis is often only possible in cooperation with pathology facilities or specialized hospitals. Primary- and secondary-level hospitals provide basic surgery for common cancers, and some offer hormonal therapy (Tamoxifen) for breast cancer patients. For advanced surgery or chemotherapy patients have to be referred to tertiary-level specialized hospitals. At time of data collection, there was only one hospital (Tikur Anbessa Specialized Hospital) providing radiotherapy.

While literature on access to oncology care in Ethiopia is increasing, referral linkages specifically have rarely been studied [6]. Furthermore, most studies addressing access to cancer care in Ethiopia have been conducted at tertiary-level cancer centres, missing out on perspectives of primary and secondary level healthcare institutions [7].

In this study we aimed to achieve a comprehensive understanding of factors influencing referral of cancer patients from primary and secondary hospitals in the rural Southwest of Ethiopia. We included healthcare professionals and representatives from local health bureaus to capture their perceptions on the existing referral system and assessed their ideas for its development in the future.

Methods

Study design and ethical approval

This qualitative study was conducted in December 2020 at primary and secondary hospitals in the rural Southwest of Ethiopia. It is part of a larger project aiming to design, implement, and evaluate decentralized cancer care in Ethiopia. In the writing of this manuscript we followed the Consolidated criteria for reporting qualitative research (COREQ) [8].

The study was approved by the Institutional Review Board of the Addis Ababa University College of Health Science (ref: 041/20/SPH). Study participants gave their written informed consent before each interview or discussion. All data were handled confidentially and participants´ data were pseudonymized within the transcripts.

Participant selection and setting

The study took place at one primary and three secondary hospitals in the region of Southern Nations, Nationalities, and Peoples (Table 1).

On each site, we conducted one focus group discussions (FGD) among health professionals. Participants were sampled purposefully, based on their involvement into oncology care and patient referral. Six to ten healthcare professionals participated in each FGD. In addition, we conducted in-depth interviews (IDIs) with the medical executives of each hospital, as well as with representatives from the affiliated health bureaus. Participants were approached via phone-calls prior to the interviews. All but one of the priorly arranged discussions and interviews took place; one medical executive dropped out just before the interview due to time constraints. His deputy took part in the in-depth interview instead. The FGDs took place in selected rooms within the hospital compounds while the IDIs were conducted in the participants´ private offices.

Data collection

Discussions and interviews were conducted by two well-trained and experienced data collectors, who were one female and one male masters-level graduates. During the interviews one principal data collector acted as interviewer and moderator, while the other quietly observed the discussion taking notes.

Individualized topic guides were used to conduct interviews and focus group discussions (see Additional file 1). They were partially adapted by the data collectors to capture emerging themes as the process of data collection evolved. Interview guides were designed in English. They were translated and back translated to Amharic to ensure coherence. All interviews were conducted in Amharic. After four focus group discussions and eight in-depth interviews with key informants, data saturation was judged to have been reached. All discussions and interviews were audio-recorded, and those recordings were transcribed and translated into English by the two principal data collectors.

Table 1 Capacity, staff, and equipment available at study sites at time of data collection (December 2020)

	Attat Our First Lady of Lourdes Catholic Primary Hospital, Wolisso	**Butajira General Hospital, Butajira**	**Negist Elleni Mohamed Memorial Referral Hospital, Hossana**	**Wolaita Sodo University Teaching and Referral Hospital, Sodo**
Hospital level	Primary hospital	Secondary hospital	Secondary hospital	Secondary hospital
Region	Gurage Zone	Gurage Zone	Hadiya Zone	Wolaita Zone
Catchment population	800,000	1,300,000	3,000,000	2,000,000
No. of beds	65	190	220	200
Staff				
No. of doctors	6	31	108	134
No. of oncologists	0	0	0	1
No. of pathologists	0	0	1	1
Diagnostics				
X-ray	yes	yes	yes	yes
CT	no	no	no	yes
MRI	no	no	no	on installation
FNAC	no	no	yes	yes
Biopsy	no	no	on installation	no
Therapy				
Chemotherapy	no	no	no	no
Hormonal Therapy	Tamoxifen	Tamoxifen	Tamoxifen	Tamoxifen
Pain medication	yes	yes	yes	yes
Referral				
Distance to Addis Ababa (km)	175	130	230	365
Referral hub hospital	Alert Hospital, TASH	SPMH	TASH	Hawassa Hospital, TASH

FNAC fine needle aspiration cytology;Alert Hospital Alert Comprehensive Specialized Hospital, Addis Ababa;TASH Tikur Anbessa Specialized Hospital, Addis Ababa;SPMH St. Paul´s Millenium Hospital, Addis Ababa;Hawassa Hospital Hawassa University Comprehensive Specialized Hospital

Data analysis

We applied thematic framework analysis to analyse the data [9]. As suggested by Ritchie et al. we followed five analytical steps during analysis: (1) familiarisation, (2) constructing an initial framework, (3) indexing and sorting, (4) data summary and display and (5) abstraction and interpretation. We judged this to be the best suitable approach to analysis as it had been developed to be used in healthcare policy development and has since then become an often referred to approach in healthcare research. The initial framework was designed by the first author based on emerging themes and then applied parallelly by two authors to the same three transcripts. Results were discussed and the framework was adapted accordingly to ensure similar indexing and sorting. The finalized framework was then applied to all transcripts. MAXQDA 2023 was used for software support during analysis.

We used the modified "Concept of Access" to categorize our emerging findings [10, 11]. The concept was originally designed by Penchansky et al. in 1981 to describe access to healthcare within five dimensions (availability, accessibility, accommodation, affordability and acceptability) [10]. As suggested by Saurman we added awareness as a sixths dimension to mirror the total width of our data [11].

Results

Socio-demographics

Thirty-eight medical professionals and four health bureau representatives took part in our interviews and focus group discussions. FGDs took between 50 and 60 min, while IDIs lasted between 22 and 46 min. Participants in the FGDs were mostly nurses (15) and physicians (7). More than half of the participants had been working at the hospital for less than five years, there were 18 women and 16 men (Table 2). Participants in IDIs were predominantly male and all but one below the age of forty years. Among the medical executives were two general practitioners, one surgeon and one gynaecologist. Health bureau representatives were two non-communicable diseases focal persons, one medical service coordinator and one disease prevention team leader (Table 3).

Perceptions on cancer patient referrals

Across all interviews and focus group discussions, participants described the need to strengthen referral linkages between primary and secondary as well as tertiary

Table 2 Participants of focus group discussions

	No. of participants (%) (*n* = 34)
Interview duration (in minutes, mean (range))	57 (50–60)
Study site	
Attat Primary Hospital	10 (29.4)
Butajira General Hospital	9 (26.5)
Negest Elleni Memorial Hospital	9 (26.5)
Wolayta Sodo Hospital	6 (17.6)
Age (years)	
< 30	18 (52.9)
30–39	10 (29.4)
40–49	4 (11.8)
≥ 50	2 (5.9)
Gender	
female	18 (52.9)
male	16 (47.1)
Job title	
nurse	11 (32.4)
physician	7 (20.6)
midwife	6 (17.6)
health officer	5 (14.7)
nurse in leadership position	4 (11.8)
pharmacist	1 (2.9)
Working experience (years)	
< 5	19 (55.9)
5–10	7 (20.6)
11–15	2 (5.9)
> 15	6 (17.6)

Table 3 Participants of in-depth interviews

	Medical executives (*n* = 4)	**Health bureau representatives[a] (*n* = 4)**
Interview duration (in minutes, mean (range))	32 (22–45)	40 (28–46)
Age (years)		
< 30	1	2
30–39	2	2
40–49	0	0
≥ 50	1	0
Gender		
Female	1	1
Male	3	3
Speciality		
General practitioner	2	-
Surgery	2	-
Gynaecology and obstetrics	1	-
Job title		
NCD focal person	-	2
Medical service coordinator	-	1
Disease prevention team leader	-	1
Working experience (years)		
< 5	3	2
5–10	0	2
11–15	0	0
> 15	1	0

NCD: non communicable diseases

[a] Health bureau representatives were from the following health bureaus: Gurage Zonal Health Bureau, Hadiya Zonal Health Bureau, Wolaita Sodo Zonal Health Bureau, Hawassa Regional Health Bureau.

healthcare institutions. Acknowledging the major challenges referred cancer patients faced at time of this study, perceptions on the patients´ determination to overcome those barriers differed: Some participants reported that most cancer patients refused referral, while others stated patients mostly accepted the advice, eager to follow referral. Participants ideas on how to improve the referral for patients with cancer in the rural Southwest of Ethiopia are presented in the Additional file 2.

The reason [for refusing referral] is mainly the low economical capacity of these patients and also, once they know it is cancer, they get discouraged because of what they heard about the disease. They claim that they have almost no time left to live, and it is [therefore] no use to go to the referral hospitals or it [following the referral advice] has no advantage over staying here. (FGD participant, female, nurse, age group 30–39 years)

It is a life and death condition for them, therefore they will go. As long as they have money, they will go. (FGD participant, female, health officer, age group 40–49 years).

Availability of oncology service

Limited oncological capacities at all levels of the healthcare system

Participants consistently identified the limited oncological capacities at all levels of the healthcare system as a major barrier to successful referral. At most sites, patients had to be referred upon suspected diagnosis or after surgery and morphological cancer verification. However, referring hospitals struggled to fulfil the receiving hospitals´ referral criteria, such as prior advanced diagnostics, that often were not available at their institution. Organizing the diagnostic workup via private diagnostic services was reported to increase costs for the patients as well as time to referral.

Regarding capacities at tertiary specialized hospitals, participants reported of patients who waited in the capital city for weeks for a preliminary appointment and were then sent back home to await their treatment initiation, which could take months.

Sometimes they come back because the appointment for radiation is in six months, seven months or more... And they are discouraged by going up and down and I put them on my palliative care list. I just give them anti-pain.

You know until then [until the reception of an appointment for treatment] they are already dead. (Hospital executive, age group ≥ 50 years)

Lack of oncology specialists and training

Participants also mentioned the lack of oncology specialists at primary and secondary healthcare level. Next to the call for increased speciality and subspecialty training in oncology, health bureau representatives repeatedly mentioned the inability of rural facilities to bind trained specialists. Medical staff and health bureau representatives alike experienced that once trained adequately, oncology specialists would move to the larger cities and specialized cancer centres. Participants suggested to address the lack of oncological expertise in rural areas by establishing formal teachings from specialists to healthcare professionals from lower-level hospitals.

Accessibility

Road infrastructure and transport

Due to the limited number of cancer centres throughout the country, referred patients often had to travel far to receive adequate treatment. Ethiopia´s road infrastructure was perceived to challenge patients substantially, hindering them to receive services and travel back home in one day.

Most cancer cases were non-emergency referrals and therefore patients had to organize their own transport. Besides the associated costs, patients weakened by the disease and associated treatment often were too sick to endure travelling with public transport.

Accommodation

Protocols and communication within referring hospitals

In all settings, medical seniors were the ones deciding to refer patients. They would also be the ones writing the referral letter or communicating with the liaisons´ office in case of emergencies. Even though health bureau representatives highlighted the sites´ obligation to have appropriate protocols in place, formal referral protocols were only implemented at one site.

In two FGDs, the topic of unclear communication among professionals within the hospital emerged. This could lead to different parties making differing referral arrangements and resulted in patients being referred inadequately.

Liaisons and the hub-system for emergency referrals

At all sites, emergency referrals were organized via the formal liaison system. Nurses designated as liaisons were in charge of calling the receiving hospital in advance to check for availability of beds and announce the patients´ arrival. Even though participants agreed that the implementation of liaisons had brought major improvements to the system of emergency referrals, shortcomings of the system were discussed across all interviews and focus group discussions:

Liaisons, both at the referring as well as at the receiving institution, were perceived as not well trained to fulfil their responsibilities. They often did not grasp the urgency of the referral, or in case of cancer patient referrals, would refer patients to sites that did not offer cancer treatment.

Another perceived barrier to efficient referral of cancer patients was the newly implemented “hub system”. All primary and secondary hospitals had predefined “hub hospitals”, which were tertiary specialized hospitals acting as the first site to address when referring emergencies to a higher level. However, many of those hub hospitals did not offer oncology services, resulting in referring hospitals omitting the hub system to find adequate care for their patients with cancer. However, patients would often be rejected from hospitals other than the official hub hospital. One positive aspect of the system was the establishment of command posts: Those were interposed, site-independent units facilitating emergency referrals from lower-level hospitals to specialized facilities. Their implementation was perceived to have smoothened communication between referring and receiving hospitals.

Most of the cancer referrals at the study sites were non-emergencies. The extent to which the liaisons´ office was involved into their organization differed between hospitals. Two sites did not involve liaisons into non-emergency referrals at all. Referral letters were written by a senior doctor and patients had to organize their travels by themselves. At other sites referral letters written by doctors had to be signed and registered by the liaisons office who then supported patients in organizing their travels. In some cases, prior phone-calls were made by the health professionals to receiving institutions checking for capacities. However, this was not the norm. Participants consented that non-emergency referral via a well-equipped liaisons office, with the referring site checking for capacity and communicating the referral to the receiving site, would have a substantial impact on cancer patient referral.

Data management

Data management was perceived to play another important role in cancer patient referral. At time of data collection, patients carrying a referral letter were often the only form of communication between hospitals. However, professionals generally judged hand-written referral letters to be an unreliable source of data transmission. Participants from one hospital reported, that the strengthening of the liaison system had improved referral writing practices at their institution, because liaisons would no longer accept imprecise entries on the referral letter. Furthermore, there was a collective call for digital data management between hospitals, allowing for the transfer of patient data.

Participants also hoped that a digital form of data management would improve the feedback system regarding referred patients. Even though health bureau representatives described an official feedback system to be in place, currently hospitals only heard back from referred patients, when they had relatives working in the hospitals or if patients came back for further treatment. Health bureaus stated to be aware of the problem regarding the management of data and highlighted the governments ambitions to improve data quality in health facilities.

If you would only know how people for example get a chance for radiation. Like a feed-back of how meaningful this referral was, whether it makes sense to refer people or whether they are just spending their money and time for nothing…so just simple feed-back on what is possible and what is not possible, would be nice. (Hospital executive, age group ≥ 50 years)

Communication between hospitals

Poor communication between primary- and secondary-level hospitals on one side and tertiary hospitals on the other side was consistently lamented. The formal line of communication via liaisons offices was described to be unreliable due to lack of equipment and congestion.

Informal communication on the other side mostly relied on personal connections between health professionals: At referring sites where professionals knew staff from receiving sites personally, communication worked better than at sites without personal connection.

Besides communication, participants repeatedly regretted the lack of a formal way of receiving updates on services offered at receiving institution. For instance, one medical director did not know about a second hospital having recently started chemotherapy in the capital city. Health bureau representatives confirmed this observation, adding that even in health bureaus they often were not up-to-date regarding services being offered in their catchment area. As a result, patients were referred to hospitals with inadequate treatment capacities.

In the absence of well-functioning formal referral linkages, at some sites a non-governmental cancer organisation acted as the major link between the hospitals. They ensured patients met all the requirements for acceptance at the receiving institution and communicated with receiving hospitals about the referred patients. Multiple participants suggested panel discussions with members from all healthcare levels to establish personal connections and improve communication between hospitals.

And nationally, it would be better if there was a forum prepared for hospitals to exchange their experience and discuss ways to ease treatment for referral patients. For example, a forum between our hospital and TASH [Tikur Anbessa Specialized Hospital]. I believe the health system has many stakeholders such as government organizations, government bodies and so on, so there needs to be a regular forum which includes all the stakeholders. (FGD participant, female, midwife, age group < 30)

Patient navigation

Across all interviews and discussions participants highlighted, that patients with cancer were often severely ill and therefore needed much support with the facilitation of their referral. Existing projects proving the success of "patient navigators" assisting patients throughout their pathways were discussed: At one hospital site a "cancer nurse" was responsible for accompanying patients with cervical cancer to the receiving institutions. Other participants reported of an NGO providing similar services for patients with cancer. Besides establishing skilled hospital personnel or volunteers from NGOs as patient navigators, one participant suggested the introduction of so called "case managers" (former cancer patients) accompanying patients throughout their journey. In the past, this approach had proven to be successful in the context of the referral of patients with HIV.

If the patient links with Mathiwos Wondu Ethiopian Cancer Society then things going smoothly because they receive the patient [in Addis Ababa] and facilitate processes, including cost coverage. But this association cannot reach to all cancer patients, so it is better to expand such kind of program. (Health bureau representative, age group 30–39)

Reception at receiving institutions

Finding the correct services at the receiving institution could be a challenge to referred patients. Many patients were not able to read and could therefore not follow signs at the receiving institution. Furthermore, some patients did not speak Amharic, the language spoken in the capital city.

At the time of the study, patients that were not referred by ambulance had to go through the receiving hospital´s OPD before getting connected to the oncology unit. A fast-track system, channelling referred patients with cancer directly to the oncology unit was thought to decrease waiting times at the receiving institution.

Finding the unit at the hospital compound is also other challenge. I heard there was a patient who came back from the hospital, where he had been referred to, without getting the investigation and management, because he did not find the exact room. So, it's better to modernize the reception and assign individuals to show the way to the units to which they [the patients] were referred to. (Hospital executive, age group < 30 years)

Affordability

Patients handling of costs

Participants discussed how the patients' economic status directly affected their ability to follow the referral advice. It determined not only where they would be referred to (more costly private institutions offered treatment with substantially shorter waiting times), but also whether they could follow the referral at all. Healthcare workers emphasized the efforts patients made to comply with the referral. Because of the disease, patients often were unable to work and cover the costs themselves. Mostly, costs were arranged with the family or within the communities. Some patients rented their land or sold their property. However, facing the uncertainty of surviving the disease even if they followed the referral, many patients refused referral. Those patients then turned to cultural healers or went back home, possibly preparing for death.

Governmental support

In the absence of universal health insurance, the Ethiopian government provides free cancer treatment at public hospitals for patients with a low economic background. However, participants reported regular shortages of medications at tertiary public hospitals. In those occasions, even patients eligible for free treatment were told to buy medication at private pharmacies – leading to them having to pay for treatment which was supposed to be free. In addition, the governments´ support did not cover expenses for food and accommodation before and during the treatment. Patients relied on having relatives in the city. Participants agreed that those factors often resulted in patients not being able to afford following the referral advice, even though they were eligible for free treatment.

Non-governmental support

Compensating for the lack of governmental aid, all study sites had support mechanisms in place trying to enable patients financially to follow the referral advice. Those mechanisms included social workers assisting the patients in raising the necessary money as well as the provision of free transport. However, the hospital´s ability to support was perceived to be insufficient, often resulting in staff personally donating money for patient referrals. Again, NGOs were also perceived to play an important role in decreasing direct and indirect costs for patients. They paid for travel expenses and offered food and accommodation in staying houses close to the receiving hospitals.

Awareness

Health education

There was large consent on the importance of educating patients about their cancer disease. Participants highlighted, that patients would only follow the referral advice, if they were informed properly about their disease and its possible outcomes. The provision of health education was described to take place on different levels: On community-level (health extension workers, public gatherings, and mass media), hospital-level (lectures on health-related topics in the waiting areas each morning) as well as on a one-on-one level during appointments. There was a general perception, that educated and well-informed patients were more likely to follow the referral advice. Uneducated and uninformed patients would often turn to traditional medicine instead.

Most of the time people tend to do what they believe. So, if they understand well, they don't hesitate to follow a referral process unless they may have financial problem. (Hospital executive, age group < 30 years)

Availability of public information on services

In addition to information about the cancer disease, participants agreed on the importance of providing patients with information on costs and waiting times. They regretted not being able to give patients the numbers on how much money they needed at the receiving institution. This led to referred patients having to return home without any treatment, because they ran out of money while waiting.

Acceptability

Trust in the health system

The patients´ perception of referral as a "death sentence" was one more emerging theme. Even though, knowledge about cancer in rural communities was perceived to have increased over the last years, cancer was still reported to have a fatal reputation. Rumors of rejection and long waiting times at the specialized hospitals added to the patients´ believe that once referred, they would never come back alive.

Healthcare professionals suggested to learn from the countries´ experiences with HIV which also used to be perceived as "death sentence". Participants suggested to extend existing cancer awareness campaigns and include education about cancer into the curriculum of health extension workers. Establishing cancer as a treatable disease in communities and families was felt to be essential to convince patients of the significance of following the referral.

So likewise, when we come to cancer, it follows a similar pattern as when HIV first came to Ethiopia. HIV patients used to feel hopeless and likewise cancer patients are feeling like that now. Secondly, the status of HIV reached what *it has today due to integrated relent less effort, so if we do the same with cancer, I bet we could save lots of lives. (FGD participant, female, nurse, age group 40–49 years)*

Stigmatization

One more barrier to successful referral was reported to be the stigmatization patients from rural areas experienced at tertiary hospitals. Patients often returned to referring hospitals complaining of having been handled badly at the receiving institution. Establishing a welcoming environment at receiving hospitals was regarded to contribute to the patients´ successful treatment initiation at the tertiary healthcare level.

They [referred cancer patients] come [back] and complain "We would rather die here than go there [again], they don't accept us as you do, they don't talk to us as you do, they harass us saying 'people who come from rural areas,' the place they give [us] is not good.' They also complain like 'they host those who come from near that area, and they only give distant appointments to us.' (FGD participant, female, nurse in a leadership position, age group<30).

Discussion

Patients with cancer referred from primary and secondary hospitals to tertiary specialized care face challenges in all dimensions of Penchansky´s revised concept of access. We found a broad range of experiences among medical and local health bureau representatives on how to address those challenges aiming to provide access to cancer care in rural Ethiopia.

Participants felt strongly about the need to increase oncological capacities throughout the country as a foundation for successful referral. Expanding specialized training and connecting specialists in oncological societies are tools to strengthen a nation´s expertise in oncology care [12]. Ethiopia´s first clinical oncology residency program was initiated at Tikur Anbessa Hospital in 2013. Since 2019, the "Ethiopian Society of Haemato-Oncology" serves as a national platform for knowledge exchange. One intervention suggested by participants of the study was the training of non-oncology-specialists to provide oncological diagnostics and treatment. Experiences with this task shifting model from other countries in Sub-Saharan Africa are promising: An example could be the training of non-oncologists (internists, paediatricians, general practitioners, and nurses) in delivering cancer care, as it has been successfully done in Rwanda over the past year [13].

We identified three possible ways patients with cancer were referred: non-emergency referral via referral letter only, non-emergency referral via the liaisons´ office and emergency referrals. Most cancer patients were non-emergencies and mostly referred via referral letters only. Standardized referral letters had been introduced by the Ministry of Health in 2010 and were used in all four hospitals [14].

While oncological emergency referrals were organized via the official hub-system, for non-emergency referrals there were no inter-hospital referral protocols. An intra-institutional protocol for cancer patient referral was in place at only one of our study sites. Knowledge on where to refer patients with cancer relied on the health professionals´ personal experiences and expertise. Even though the hub-system for emergency referrals was perceived to be a barrier to the referral of patients with cancer, participants consented, that having a set system defining where to refer patients had improved emergency referrals in general. Expanding the system to include non-emergency referrals, sensitive to the availability of advanced oncological care, could improve referral of patient with cancer substantially.

In its "Guideline for implementation of a patient referral system" the Ethiopian Ministry of Health foresaw a "referral coordinator" at each hospital - responsible for the facilitation of emergency as well as non-emergency referrals [14]. In our study, only one hospital reported organizing non-emergency referrals via the liaisons´ office (which served as referral coordinator). Training and equipping designated personnel at the liaisons´ office, enabling them to organize both emergency and non-emergency referrals in a reliable manner emerged to be of substantial significance when improving cancer patient referral.

An important aspect in strengthening the referral linkage between healthcare levels is the standardization of data management. At the time of our study, patient data was collected in paper files and referral-letters were hand-written. Currently the Ministry of Health is developing a standardized electronic health record system to "strengthen digitization of routine and non-routine data collection, management, analysis and use" [15].

To enable patients to follow referral advice, participants also suggested the implementation of patient navigators. In high-income countries patient navigation programs are a well-established tool to promote access to cancer care [16]. Nurses or lay persons, who have been trained to be "patient navigators", accompany patients with cancer throughout their diagnostic and treatment journey. Depending on the extent of the program, patient navigators provide patients with health education, facilitate appointments, and arrange linkages to follow-up services. In countries without universal health coverage, the navigation services often also include stipends for transport, accommodation, and treatment [17, 18]. In the past years, the concept of patient navigation has been increasingly adapted in low- and middle-income countries, showing positive effects on outcomes like treatment initiation and adherence [19]. Initiatives such as the BEACON Initiative (Building expertise, advocacy, and capacity for oncology navigation) launched by the American Cancer Society implementing patient navigation programs at national referral hospitals in Uganda and Kenya serve as examples [20].

Furthermore, a smooth reception of referred patients at the receiving institutions was identified to be key for a successful referral. Participants suggested to address the patients´ difficulties in finding the correct units at the receiving hospitals by establishing an easy-to-follow signposting, as well as staffed info-points. Such low-cost concepts, sensitive to the patients´ different language and educational backgrounds, have previously shown to improve the patients´ experiences at receiving institutions substantially [21].

A current project addressing the need for "fast-track" pathways for patients with cancer at receiving institutions is the "Walk-in-Clinic" at the Else-Kroener-Center for Cancer Care in Addis Ababa. In collaboration with the surgical and oncology units at Tikur Anbessa Hospital the centre enables women with suspected cancer to omit the usual out-patient department pathways and be directly seen by gynaeco-oncologists and breast surgeons [22].

Direct and indirect costs were perceived to be a major barrier to successful referral. Patients with sufficient financial means could visit private hospitals or receive care in countries with better access to high-quality healthcare. However, with an income per capita of 940$ and approximately one quarter of the population living below the international poverty line, most patients in Ethiopia rely on the public healthcare sector [23, 24]. Ethiopia aims to establish a universal health coverage by 2030 [1]. To reach this ambitious goal, the government has established multiple channels to increase access to healthcare for its population: Social health insurance is currently being implemented for people working in the formal sector, while community-based health insurance schemes are successfully expanded within the large informal sector [1]. In addition, certain oncology-associated interventions were recently added to the "Essential Health Services Package", guaranteeing their provision free of charge, or with cost-sharing and cost-recovery mechanisms in place at public hospitals [25]. Patients who cannot afford care are eligible for free treatment, provided they receive a "fee waiver" from their local health bureau [1, 26].

Nevertheless, the multitude of unofficial financial support mechanisms in place at all study sites demonstrates that patients with cancer in rural Ethiopia still face substantial financial challenges. Unavailability of necessary medications in public institutions (resulting in patients having to buy treatment at private pharmacies) as well as the costs for transport and accommodation associated with the treatment, emerged to be major barriers to oncology care. These findings are confirmed by previous studies [26–29]. Reliable mechanisms for the procurement and financing of cancer drugs at public hospitals are needed to decrease direct costs of treatment. Indirect costs could be tackled by the provision of governmental travel stipends for those in need as well as the establishment of staying houses close to the cancer centres.

We found high awareness regarding the significance of health education in the provision of cancer care among health professionals and health bureau representatives. This mirrors the governments´ focus on health education since the launch of Ethiopia´s Health Extension Program in 2003. Core of the program are health extension workers who promote primary healthcare on the community level. A study by Funga et al. found health extension workers to be the main source of information on cancer for most of the rural population [30]. However, even though the Health Extension Program has proven to be highly successful in providing health education to Ethiopia´s rural population, awareness on cancer is still insufficient and the perception of cancer as a "death sentence" common [30–33]. Expansion of existing and initiation of new cancer awareness programs is therefore essential to increase knowledge about cancer in rural communities. In addition, the implementation of survivor groups could contribute to change the patients´ attitude towards cancer and improve trust into the healthcare system [34]. Establishing cancer as a curable disease is important to convince patients to follow the referral advice.

Interestingly, while much reported previously in the context of access to cancer care, stigmatization of patients in their community did not emerge to be a major barrier to successful referral in our study [35]. This might be explained by the healthcare professionals´ and health bureau representatives´ perspective of the study. A recent study on the perceptions of cervical cancer care among Ethiopian women and their providers supports this explanation: While patients discussed the role of stigmatization within their communities vividly, providers did not mention stigma as a major barrier to care [35]. On the other hand, participants did report about patients feeling stigmatized at receiving institutions due to their rural background. While we could not find any literature on stigmatization of rural patients in specialized hospitals in Ethiopia, poor handling and disrespectful communication at tertiary hospitals has been described before [35, 36]. Further research on patients´ experiences at tertiary hospitals as well as health professionals´ training is needed to guarantee culturally sensitive access to cancer care.

We believe it a great strength of this study to have captured a broad variety of perspectives of healthcare professionals and health bureau representatives who are involved into cancer care at the primary and secondary level of the healthcare system. However, our study has certain limitations: First and foremost, our results are limited by the participants´ provider perspective. To receive a comprehensive understanding of the cancer patient referral in rural Ethiopia, perspectives of referred patients have to be considered. In terms of sample size, the number of IDIs and FGDs conducted for this study falls within the lower end of what is typically considered adequate in qualitative research. However, while we cannot exclude the possibility that an increased sample size would have contributed new data, after four FGDs and eight IDIs we felt we had reached data saturation. Working with a small sample size increases the importance of thorough purposive sampling. Following the guidance of Ritchie et al., we ensured best possible representation and diversity within the sample with regards to variables such as age, years of experience, field of expertise, healthcare level, and hospital size [9]. This approach also helped to minimize, however not eliminate, a potential sampling bias.

Furthermore, we did not use a formal protocol regarding the triangulation of data collected by different methods and from different participant groups. However, in the final phases of analysis we did colour-code different origins of elements within themes and subthemes to be aware of consent and contradictions between the different participant groups.

Conclusions

In the rural Southwest of Ethiopia, decision makers are aware of multi-factorial challenges cancer patients face when being referred from lower-level hospitals to tertiary-level oncology care. A way forward requires a multi-faceted approach involving capacity building, improved coordination between different levels of the healthcare system, standardized protocols and data management, financial and social support mechanisms, as well as awareness programs. Lay persons as patient navigators could be involved. Establishing an environment for inter-institutional exchange and integrating stakeholders´ broad experiences from the primary and secondary healthcare level into future policy making is a key to reduce disparities in cancer care and make oncology care available to Ethiopia´s large rural population.

Abbreviations

COREQ	Consolidated criteria for reporting qualitative research
FGD	focus group discussion
IDI	in-depth interview
NGO	non-governmental organization
OPD	outpatient department
FNAC	fine needle aspiration cytology
NCD	non-communicable diseases

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12885-024-12294-7.

Supplementary Material 1

Supplementary Material 2

Acknowledgements
Not applicable.

Author contributions

JT: conception and design of study, collection and assembly of data, analysis and interpretation of data, drafting of the work; MM: analysis and interpretation of data, drafting of the work; SN: conception and design of study, revision of the manuscript; WB: collection and assembly of data, analysis and interpretation of data; YA: collection and assembly of data, analysis and interpretation of data; ES: analysis and interpretation of data, revision of the manuscript; KA: analysis and interpretation of data, revision of the manuscript; MG: conception and design of study, revision of the manuscript; SG: conception and design of study, revision of the manuscript; AA: conception and design of study, revision of the manuscript; EJK: conception and design of study, revision of the manuscript; AW: conception and design of study, collection and assembly of data, revision of the manuscript. All authors read and approved the final manuscript.

Funding
Funding was provided by Else-Kroener-Fresenius-Foundation (HA18_31SP), Bundesministerium für Bildung und Forschung Germany (01KA2220B), and the Wellcome Trust (Del-22-008). The Funders had no role in the design and conduct of the study, collection, management, analysis, and interpretation of the data; preparation, review, or approval of the manuscript; and decision to submit the manuscript for publication.
Open Access funding enabled and organized by Projekt DEAL.

Data availability

The datasets used and analysed during the presented study are available from the corresponding author on reasonable request.

Declarations

Ethics statement

This study is part of a project aiming to design, implement, and evaluate decentralized cancer care in Ethiopia. It was approved by the Institutional Review Board of the Addis Ababa University College of Health Science (ref: 041/20/SPH).
Study participants gave their written informed consent before each interview.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

Received: 7 February 2024 / Accepted: 19 April 2024

References

1. Ministry of Health E. Health Sector Transformation Plan II: 2020/21-2024/25. 2021. https://extranet.who.int/countryplanningcycles/sites/default/files/public_file_rep/ETH_Ethiopia_Health-Sector-Transformation-Plan-II_2021-2026.pdf. Accessed 23 Jan 2024.
2. Brand NR, Qu LG, Chao A, Ilbawi AM. Delays and barriers to cancer care in low- and middle-income countries: a systematic review. Oncologist. 2019;24:e1371–80. https://doi.org/10.1634/theoncologist.2019-0057

3. Martins T, Merriel SWD, Hamilton W. Routes to diagnosis of symptomatic cancer in sub-saharan Africa: systematic review. BMJ Open. 2020;10:e038605. https://doi.org/10.1136/bmjopen-2020-038605
4. The World Bank Group. Rural population (% of total population) - Ethiopia | Data. 2023. https://data.worldbank.org/indicator/SP.RUR.TOTL.ZS?locations=ET. Accessed 2 Mar 2023.
5. Federal Ministry of Health, Ethiopia. National Cancer Control Plan: 2016–2020. 2015. https://www.iccp-portal.org/system/files/plans/NCCP%20Ethiopia%20Final.pdf. Accessed 23 Jan 2024.
6. Trabitzsch J, Wondimagegnehu A, Afework T, Stoeter O, Gizaw M, Getachew S, et al. Pathways and referral of patients with cancer in rural Ethiopia: a multi-center retrospective cohort study. Oncologist. 2023;23:e359–68. https://doi.org/10.1093/oncolo/oyad032
7. Dye TD, Bogale S, Hobden C, Tilahun Y, Deressa T, Reeler A. Experience of initial symptoms of breast cancer and triggers for action in Ethiopia. Int J Breast Cancer. 2012. https://doi.org/10.1155/2012/908547
8. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care. 2007;19:349–57. https://doi.org/10.1093/intqhc/mzm042
9. Ritchie J, Lewis J, editors. Qualitative research practice: a guide for social science students and researchers. 2nd ed. London: SAGE; 2014.
10. Penchansky R, Thomas JW. The concept of access: definition and relationship to consumer satisfaction. Med Care. 1981;19:127–40. https://doi.org/10.1097/00005650-198102000-00001
11. Saurman E. Improving access: modifying Penchansky and Thomas's theory of Access. J Health Serv Res Policy. 2016;21:36–9. https://doi.org/10.1177/1355819615600001
12. Al-Ibraheem A, Abdlkadir AS, Mohamedkhair A, Mikhail-Lette M, Al-Qudah M, Paez D, Mansour AH. Cancer diagnosis in areas of conflict. Front Oncol. 2022;12:1087476. https://doi.org/10.3389/fonc.2022.1087476
13. Rubagumya F, Greenberg L, Manirakiza A, DeBoer R, Park PH, Mpunga T, Shulman LN. Increasing global access to cancer care: models of care with non-oncologists as primary providers. Lancet Oncol. 2017. https://doi.org/10.1016/S1470-2045(17)30519-3
14. Federal Ministry of Health, Ethiopia. Guideline for Implementation of a Patient Referral System. https://www.medbox.org/document/ethiopia-guideline-for-implementation-of-a-patient-referral-system#GO. Accessed 20 Jan 2023.
15. Federal Ministry of Health, Ethiopia. Standard for electronic health records system (EHRs) in Ethiopia. https://e-library.moh.gov.et/library/wp-content/uploads/2022/02/Standard-for-Electronic-Health-Record-System-EHR-in-Ethiopia.pdf. Accessed 23 Jan 2024.
16. Moy B, Chabner BA. Patient navigator programs, cancer disparities, and the patient protection and affordable care act. Oncologist. 2011;16:926–9. https://doi.org/10.1634/theoncologist.2011-0140
17. Collier S, Semeere A, Byakwaga H, Laker-Oketta M, Chemtai L, Wagner AD, et al. A type III effectiveness-implementation hybrid evaluation of a multicomponent patient navigation strategy for advanced-stage Kaposi's sarcoma: protocol. Implement Sci Commun. 2022;3:50. https://doi.org/10.1186/s43058-022-00281-7
18. Ibbotson JL, Luitel B, Adhikari B, Jagt KR, Bohler E, Riviello R, Ibbotson GC. Overcoming barriers to accessing surgery and rehabilitation in low and middle-income countries: an innovative model of patient navigation in Nepal. World J Surg. 2021;45:2347–56. https://doi.org/10.1007/s00268-021-06035-1
19. Dalton M, Holzman E, Erwin E, Michelen S, Rositch AF, Kumar S, et al. Patient navigation services for cancer care in low-and middle-income countries: a scoping review. PLoS ONE. 2019;14:e0223537. https://doi.org/10.1371/journal.pone.0223537
20. Knudsen KE, Wiatrek DE, Greenwald J, McComb K, Sharpe K. The American cancer society and patient navigation: past and future perspectives. Cancer. 2022;128(Suppl):2673–7. https://doi.org/10.1002/cncr.34206
21. Raut A, Thapa P, Citrin D, Schwarz R, Gauchan B, Bista D, et al. Design and implementation of a patient navigation system in rural Nepal: improving patient experience in resource-constrained settings. Healthc (Amst). 2015;3:251–7. https://doi.org/10.1016/j.hjdsi.2015.09.009
22. Else Kröner Center for Cancer Care Halle-Wittenberg/Addis Ababa. Ethiopia | Else Kröner-Fresenius-Stiftung. 02/03/2023. https://ekfs.de/en/humanitarian-funding/center-special-projects/else-kroener-center-addis-abeba-ethiopia. Accessed 2 Mar 2023.
23. The World Bank Group. Country Profiles. 2022. https://pip.worldbank.org/country-profiles/ETH. Accessed 27 Feb 2023.
24. The World Bank Group. GNI per capita, Atlas method (current US$) - Ethiopia | Data. 2023. https://data.worldbank.org/indicator/NY.GNP.PCAP.CD?locations=ET. Accessed 27 Feb 2023.
25. Eregata GT, Hailu A, Geletu ZA, Memirie ST, Johansson KA, Stenberg K, et al. Revision of the Ethiopian essential health service package: an explication of the process and methods used. Health Syst Reform. 2020;6:e1829313. https://doi.org/10.1080/23288604.2020.1829313
26. Alebachew A, Hatt L, Kukla M, Nakhimovsky S. Universal health coverage measurement in a low–income context: an Ethiopian case study. Bethesda, MD; 2014.
27. Ali EE. Health care financing in Ethiopia: implications on access to essential medicines. Value Health Reg Issues. 2014;4:37–40. https://doi.org/10.1016/j.vhri.2014.06.005
28. Damte Tegegn B, Negeri KG. Assessment of utilization of health care services and the associated factors among adult fee-waiver beneficiaries in Hawassa, southern Ethiopia: a community based cross sectional study. J Public Health Res. 2022;11:1–11. https://doi.org/10.1177/22799036221139940
29. Chote T, Tushune K, Yitbarek K, Woldie M. The utilization of health services among poor households with user fee payment waiver certificate in Gamo Gofa zone, Southern Ethiopia. Divers Equal Health Care. 2017;14:243–8. https://doi.org/10.21767/2049-5471.1000117
30. Funga ML, Dilebo ZD, Shuramo AG, Bereku T. Assessing breast cancer awareness on reproductive age women in West Badewacho Woreda, Hadiyya zone, South Ethiopia; Community based cross- sectional study. PLoS ONE. 2022;17:e0270248. https://doi.org/10.1371/journal.pone.0270248
31. Ayele W, Addissie A, Wienke A, Unverzagt S, Jemal A, Taylor L, Kantelhardt EJ. Breast awareness, self-reported abnormalities, and breast cancer in rural Ethiopia: a survey of 7,573 women and predictions of the national burden. Oncologist. 2021;26:e1009–17. https://doi.org/10.1002/onco.13737
32. Getachew S, Tesfaw A, Kaba M, Wienke A, Taylor L, Kantelhardt EJ, Addissie A. Perceived barriers to early diagnosis of breast cancer in south and southwestern Ethiopia: a qualitative study. BMC Womens Health. 2020;20:38. https://doi.org/10.1186/s12905-020-00909-7
33. Chaka B, Sayed A-R, Goeieman B, Rayne S. A survey of knowledge and attitudes relating to cervical and breast cancer among women in Ethiopia. BMC Public Health. 2018;18:1072. https://doi.org/10.1186/s12889-018-5958-8
34. Kantelhardt EJ, Assefa M, McCormack V, Cubasch H, Jemal A, Pace LE. Expert discussion: breast Cancer in low-resource countries. Breast Care (Basel). 2020;15:310–3. https://doi.org/10.1159/000508693
35. Burrowes S, Holcombe SJ, Leshargie CT, Hernandez A, Ho A, Galivan M, et al. Perceptions of cervical cancer care among Ethiopian women and their providers: a qualitative study. Reprod Health. 2022;19:2. https://doi.org/10.1186/s12978-021-01316-3
36. Dirar A, Mekonnen W, Berhanu Z. The experiences of cervical cancer patients during follow-up care in Ethiopia: a qualitative study. Cancer Manage Res. 2022;14:2507–18. https://doi.org/10.2147/CMAR.S373379

Publisher's Note

Wondimagegnehu *et al. BMC Cancer* (2024) 24:60
https://doi.org/10.1186/s12885-023-11801-6

BMC Cancer

RESEARCH Open Access

“How can a woman live without having a breast?”: challenges related to mastectomy in Ethiopia

Abigiya Wondimagegnehu[1,2*], Solomon Teferra[3], Mathewos Assefa[4], Bradley Zebrack[5], Adamu Addissie[1,2] and Eva J. Kantelhardt[2,6]

Abstract

Background Although mastectomy is the standard treatment modality for breast cancer patients in Ethiopia, our previous study revealed that one in five patients do not receive the recommended procedure, half due to patient refusal or lack of returning to the hospital. Therefore, this study aimed to explore reasons for refusing mastectomy and identify challenges among breast cancer patients in Ethiopia.

Methods An explorative qualitative study was conducted in four hospitals located in the towns of Woliso, Butajira, Hossana, and Assela. A total of 14 in-depth interviews (IDIs) and eight focus group discussions (FGDs) were held with breast cancer patients, patient relatives, and health professionals. Four semi-structured interview guides were used to facilitate the IDIs and FDGs. All recorded IDIs and FGDs were transcribed and translated verbatim and entered in NVivo 12 software. Emerging ideas were categorised and explained using an inductive content analysis approach.

Results Our participants reported that particularly elderly and very young women refuse to have mastectomy. The main reasons identified in this study were summarised into six themes: (i) fear of the surgical procedure, (ii) religious beliefs and practice, (iii) utilisation of traditional treatments, (iv) in relation to having a baby and breastfeeding their children (young patients often request to remove only the lump, leaving their breast tissue intact), (v) lack of awareness about the disease, and (vi) sociocultural factors and advice from the community that influence women, since breasts are considered an attribute of femininity, beauty, and motherhood. In addition, knowing someone who died after mastectomy emerged as a main reason for not having breast cancer surgery.

Conclusions High refusal rate for mastectomy has direct implication on increased breast cancer mortality. Hence, expansion of radiotherapy service is instrumental to initiate breast-conserving surgery as an alternative surgical procedure, especially for young women with early-stage breast cancer. Involving religious leaders, traditional healers, and breast cancer survivors could be an effective strategy to persuade newly diagnosed breast cancer patients. Addressing individual patient psychosocial needs and preferences may substantially improve retention of breast cancer patients in the health system.

Keywords Breast cancer, Breast surgery, Mastectomy, Refusal, Reasons, Ethiopia

---

*Correspondence:
Abigiya Wondimagegnehu
abitowon@gmail.com

Full list of author information is available at the end of the article

Background

Surgery is an important part of breast cancer treatment along with radiation and systemic treatments such as endocrine therapy, cytotoxic chemotherapy, targeted therapy, and immunotherapy [1]. Mastectomy and breast-conserving surgery (BCS) represent the two primary surgical options used to treat invasive breast cancer [2]. The survival benefit for undergoing surgery remains a well-known fact, as several studies found breast cancer patients who refused surgery had higher risk of mortality compared with those who had surgical treatment [3, 4].

In developed countries, having breast surgery is standard and according to a study done in the United States of America (USA), 95% of breast cancer patients underwent surgical treatment [5]. Not only therapeutic breast surgery, but contralateral prophylactic mastectomy (CPM) has also increased steadily over the last twenty years in women of all age groups and breast cancer stages [6, 7]. Genetic testing, pathogenic mutation of BRCA, strong family history, and suspicious findings on breast MRI were identified as the main reasons for its increment. As a result, most patients with unilateral breast cancer or even healthy women with high risk of breast cancer underwent CPM followed by immediate breast reconstruction [6, 7].

In contrast, frequency of breast cancer surgery in low- and middle-income countries (LMICs) remained very low even though it is the only treatment option available in most countries [8]. In Africa, limited resources for systemic therapy have contributed to the application of surgery as the primary modality for the management of resectable breast cancer [9, 10]. Even in some countries like Uganda, large areas of the country have no breast surgery at all and most of the surgical procedures are still being performed at the national referral hospital [11].

Among the various types of breast cancer surgeries, modified radical mastectomy (MRM) is the most common procedure in many African countries [8, 9]. According to a continent-wide review, about 85% of breast cancer patients undergo mastectomy because of the advanced stage of the disease [10] and reports from east Africa indicate that up to 99% of patients undergo mastectomy due to unavailability of other treatment modalities [9, 10]. Lack of or poor access to radiation facilities is the rate-limiting step for breast conservation in many African countries [8–10]. In sharp contrast, BCS is the preferred surgical procedure in developed countries and the percentage of breast cancer patients who had a mastectomy is often below 30% in most European countries [12] and 22.4% in the USA [13].

Nevertheless, mastectomy is considered culturally objectionable in sub-Saharan Africa (SSA), and let alone to choose CPM, the decision to have therapeutic unilateral mastectomy remains a big challenge for many breast cancer patients in the region. Therefore, compliance by patients vary from country to country and the refusal rates in countries like Eritrea and Cameroon are lower compared to Nigeria [10]. Inversely in western countries, refusal for further surgery such as breast reconstruction and oncoplastic surgery might be more common than refusing therapeutic mastectomies [12].

In Ethiopia, breast cancer is the leading cancer with an estimated 16,133 (20.9%) new cases and 9, 061 (17.5%) new deaths in 2020 [14]. Like other LMICs, there are limited diagnostic and treatment services in the country and the only available service for most breast cancer patients at lower-level hospitals is surgery [15]. Except endocrine treatment, systemic treatments are limited only in tertiary-level hospitals, which are mainly located in the capital or a few big cities [16, 17]. For instance, Tikur Anbessa Specialized Hospital was the only cancer centre that provided comprehensive cancer care including radiation treatment for the last couple of decades [17]. Recently, Jimma university hospital initiated radiotherapy services but still fell short of the international atomic agency recommendations of four machines per 1 million population [18]. There are only two radiotherapy machines for a population of 125 million, which makes breast-conserving surgery inaccessible and the standard for breast cancer in Ethiopia is MRM [16, 19].

Even though surgery is the only accessible treatment option in most peripheral hospitals of Ethiopia, many breast cancer patients do not even receive this service for several reasons [20, 21]. According to a study conducted in North Ethiopia, surgery was omitted in 32% of breast cancer patients because of an advanced stage of the disease with initial metastasis. MRM was the most common surgical procedure performed for 91% of breast surgeries done in Gondor Hospital [22]. Recently, a multicentre study in Ethiopia revealed that one in five patients did not receive the recommended surgical procedure, half due to patient refusal or lack of the patient returning to the hospital [16]. This is one of the missed opportunities leading to poor treatment outcomes and high mortality from breast cancer in the country.

Therefore, this study aimed to explore main reasons for refusing mastectomy and identify challenges in relation to having surgery among breast cancer patients in Ethiopia. Identifying those factors may enable the design of effective strategies to retain breast cancer patients in the health care system, which potentially improves adherence to subsequent treatments, enhance quality of life, reduce mortality, and improve overall survival. In addition, the economic benefit is far from reach compared to costs incurred to treat advanced cancer cases and through improving survivorship and productivity of breast cancer patients.

Methods

Study design and place

Exploratory qualitative study was employed to identify reasons for refusing mastectomy among breast cancer patients in Ethiopia. The study was conducted in four hospitals: St. Lukas Catholic Hospital Woliso, Negist Elleni Mohammed Referral Hospital Hossana, Butajira General Hospital, and Assela University Teaching and Referral Hospital. The hospitals are situated within a 130–250 km radius from the capital city, Addis Ababa. These hospitals and towns were purposively selected based on the different geographic directions from Addis; southwest, south, southeast, and east, and due to their potential for representing several Ethiopian populations located in two large regions, namely Oromia and Southern Nations, Nationalities, and Peoples' Region (SNNPR).

Study participants and sample size

In this study, fourteen in-depth interviews (IDI) and eight focus group discussions (FGDs) were conducted with a total of 70 participants (18 males and 52 females). We used a purposive sampling strategy to assure a broad variety of information. With regard to the actual participants recruited in our study, we intentionally selected both health professionals and cancer patients in order to gain the two different perspectives and also triangulate our findings. Even among the health professionals, we included clinical staffs working at the different levels of the health care system. Three IDIs with patient relatives and three IDIs with breast cancer patients who refused to have a mastectomy were held. Out of these three women whom we interviewed, one of them was 90 years old while the other two were 37 and 42 years of age. Of this, two of the women were married and had children but the other woman who was 37 years of age was not married and did not have children at the time of interview. In each town, two IDIs with health extension workers (HEWs) (community workers providing primary health care service at health post level which is the lowest health facility in the three health care tier system of Ethiopia) and two FGDs with breast cancer patients who had undergone surgery and health professionals (surgeons, oncology residents, head nurse, oncology nurse, midwife, maternal child health (MCH), gynaecologist, pathologist, general practitioner, and health officer) were conducted separately (Table 1). The participants were purposely selected, and an attempt was made to achieve the maximum variation of participants by including different age groups, rural and urban residency, gender, educational attainment, and interaction and provision of care for breast cancer patients.

Data collection tools and procedures

Based on the objective of the study, four semi-structured interview guides were prepared to facilitate the IDIs and FGDs. Initially, all the interview guides were prepared in English and translated to Amharic (local language). The data was collected by two well-trained data collectors who had ample experience in facilitating qualitative data. On average, each IDI took around 21 to 49 min, while the FGDs stayed for a minimum of 58 min to a maximum of 103 min. Detailed field notes were taken during IDIs and one of the data collectors was taking notes while the other is moderating the group discussions. In addition, data collectors wrote reflexive memos immediately after completing each IDI and FGD. Daily debriefings on emerging thematic areas were done with the entire research team and the data was collected until we reached the theoretical saturation level. All FGDs and IDIs were audio-recorded, and notes were taken during the interviews and discussions. The data were organised and appropriately labelled immediately after each session. Subsequently, all recorded IDIs and FGDs were transcribed and translated verbatim after repeatedly listening to the recordings.

Table 1 Characteristics of study participants, Ethiopia

Name of towns	No of IDI*	No of FGD[a]	Age range of participants	Male	Female	Role
Assela	2 IDI_with HEW[b]	2 (1 with HP[c] & 1 with BCa[d] patients	30–50	5	8	Surgeon, GP[e], Oncology resident, oncology and psychiatry nurse, nurse head
Woliso	2 IDI_with HEW 1 IDI_with patient relative	2 (1 with HP & 1 with BCa patients	27–60	4	8	Surgeon, clinical nurse, surgical ward head nurse, psychiatric nurse
Hosanna	2 IDI_with HEW 1 IDI_ refused BCa pt	2 (1 with HP & 1 with BCa patients	35–55	4	12	Surgeon, Pathologist, Surgical ward nurse, Psychiatric nurse MCH[f] focal, Midwife
Butajira town	2 IDI_with HEW 2 IDI_Refused BCa pt 1 IDI_Patient relative 1 IDI_Patient relative_refused	2 (1 with HP & 1 with BCa patients	27–90	5	14	Surgeon, pathologist, gynaecologist, surgical ward nurse, midwife, health officer
Total	**14**	**8**	**27–90**	**18**	**52**	

* IDI: in-depth interview, [a] FGD: focus group discussion, [b] HEW: health extension workers, [c] HP: health professionals, [d] BCa: breast cancer patients, [e] GP: general practitioner, [f] MCH: maternal and child health

Data analysis procedures

The data analysis was initiated simultaneously with the data collection process and a qualitative content analysis technique was employed. Daily debriefings on the newly emerging ideas were held with the entire research team, along with insiders who lived in those selected towns for a long period of time and who knows the community very well including the culture, language and social structure. All recorded observations and events during data collection were discussed and involvement of insiders in our debriefing sessions enabled us to verify the emerging ideas and properly interpreted the findings. It also supported us to understand the unique wordings, expressions and idioms revealed in our study. Once all transcripts were prepared by the data collectors, the principal investigator checked whether all IDIs and FGDs were properly transcribed and translated through listening to the audio recordings. All the recorded audios and transcripts were repeatedly reviewed to obtain an overall sense for and get familiarised with the data. Then, all transcribed documents, field notes, and reflexive memos were entered into NVivo 12 plus software. The analysis began by highlighting sentences of importance and dividing them into meaning units. Each document was coded line by line and the meaning units were condensed and labelled with short codes. Subsequently, similarities and differences between the codes were identified and categories were developed. Data triangulation was used to identify convergence of data obtained through IDIs and FGDs. Also through comparing and contrasting the reasons given by the patients themselves and their relatives and health professionals. Finally, emerging themes and subthemes were tested and revised through discussion with the team members and appropriate interpretations were given.

Ethical clearance

Ethical clearance was obtained from the Research Ethics Committee of the School of Public Health and Institutional Review Board of College of Health Sciences, Addis Ababa University. Informed consent was obtained from all participants. Confidentiality and anonymity of the data was kept during data analysis and presentation of the findings. All methods were carried out in accordance with relevant guidelines and regulations in the Declaration of Helsinki.

Results

The main findings of this study are organised into two themes. The first theme discusses refusal of mastectomy through given actual experiences of health professionals and patients. In the second theme, we identified several reasons why breast cancer patients refuse mastectomy, and these factors are further categorised in to six sub themes: (a) in relation to the surgical procedure, (b) due to religious beliefs and practices, (c) traditional medicine, (d) in relation to having a baby, (e) lack of awareness, and (f) sociocultural factors. The details of each theme and subthemes are described below.

Women refusing mastectomy

Our results found that breast cancer patients in Ethiopia refuse to have a mastectomy for several reasons. This idea was reflected in all FGDs and IDIs conducted with both cancer patients and health professionals. Most of the health professionals involved in the FGDs reported that many breast cancer patients refuse to have a mastectomy and they usually struggle to convince them. For example, a surgeon at Hosanna hospital mentioned that *"…there is resistance to have the surgery. Most of the time, they [breast cancer patients] accept the surgery after having two or more visits. For that matter, there are also others who refuse at all and return back to their home.* (FGD_HP_Surgeon_Hossana)

> *"The challenge starts during admission. Since it is removing a body organ, most women do not accept this. They are afraid of hearing about mastectomy, they do not accept it easily. They often agree after taking much time and through several attempts to convince them. Most of the time, they went back to their home and spent several months until they return back to us." (FGD_HP_Nurse_Woliso).*

Some of the patients confessed that they refused initially and later decided to have the surgery. We also encountered breast cancer patients who still continue to resist surgery.

> *"No way, I am not going to be operated. Oooo, ere ete I do not want to be operated. I have St. Michael. SIBHAT LAB! In the name of the father, the son and the holy spirit. May you forgive me St. Gebriel. I will never be operated!" (IDI_Refused BCa_Butajira).*

Even though the challenge was expressed in all study sites, the extent of refusal varies from place to place. For instance, in Woliso, the surgeon reported that most of the patients resist or totally refuse to have the surgery and return back to the health facility at an advanced stage where only supportive care is given.

> *"A lot of patients refuse mastectomy and usually get lost and will never come back. For example, last week, I sent one woman to Addis Ababa for diagnosis and came with her result. I was waiting for her and preparing a place to do the surgery, but she disappeared. So, we do not know where she is now. She*

> *is lost! Umm… from all diagnosed cases only less than 50% had mastectomy. But most discharged refusing it." (FGD_HP_Surgeon_Woliso).*

> *"Most of the women who refused the surgery returned back to us after the disease advanced with a fungated breast and those women have died by now and only few are surviving." (FGD_HP_Surgeon_Woliso).*

On the other hand, the surgeon from Butajira reported that patients often do not refuse to have surgery, rather they request to get priority. *"This was actually the only woman who refused surgery, but most patients want to have the surgery immediately after diagnosis. They prefer to get priority for surgery and do not refuse so far."* (FGD_HP_Surgeon_Butajira) However, two of the three patients interviewed in this study for refusing mastectomy were from Butajira town.

Who most refuses

Concerning specific subgroups who most refuse, the health professionals reported that young women (mostly referring to those who are below 40 years of age) who are not married and do not have children or with small babies often refuse mastectomy. Again, very old people also refuse to have the surgery due to hopelessness and fear of the procedure.

> *"…the most resistance is coming from either very old or very young women. Especially those who are below 30 refuse to have mastectomy. There is such a kind of resistance from them. It is psychologically difficult to accept mastectomy for the younger ones. It would have been good if we have breast conserving surgery for them." (FGD_HP_Surgeon_Hossana).*

Reasons for refusal—afraid of the surgical procedure

In this study, several factors were identified for not having a mastectomy and a major one was fear of the surgical procedure. Many patients mentioned that they are afraid of the surgery, assuming that the anaesthesia or the surgery itself may kill them. This reason was mainly reflected from elderly people, and health professionals also reported trying to convince such patients through counselling.

> *"I was simply afraid of it and never thought that I will be healthy after having a surgery." (FGD_Refused BCa_Butajira).*

> *"But for few of the patients the reason is due to fear of the surgery. They think they may die from the surgery. For those who are afraid of surgery, it is possible to advise them for a short period of time and convince them." (FGD_HP_Nurse_Woliso).*

Knowing someone who died after mastectomy

In addition to fear of the procedure, some participants also mentioned that they do not trust in the effectiveness of the surgery and have encountered some patients who died even after breast removal.

> *"I am afraid because I know a woman whose breast was removed and died after one year with a lot of pain. It has been so long since this happened, but I always remember her. She always comes into my mind whenever they advise me to be operated. I am not afraid of surgery since I was operated before for another problem. But since I saw that woman who died after her breast was removed, I consider that my fate will also be like her. I will die if I am operated. That's why I am afraid of the surgery." (IDI_Refused BCa_Hossana).*

Some of the participants mentioned that they prefer to take oral medications and only treat the cancer with medications rather than being operated. Surgery is considered the last option after exhausting other treatments. They have also reflected that they are willing to take any form of medication (tablets or injections) in lieu of the operation.

> *"Whatever it takes, I can take that kind of drug. I do not care whether it will be taken for a short or long time. But if I get it, I will use it, but I do not want to be operated." (IDI_Refused BCa_Butajira).*

Why the whole breast?

The surgeons in our FGDs reported that patients usually resist having a mastectomy because they request to remove only the mass and it is difficult to convince them why the whole breast should be removed. Especially younger women and those with a painless small mass do not agree to remove the whole breast.

> *"The challenge is not with totally refusing the surgery. They choose among the types of surgery to be done. They want you to remove only the diseased part or the mass/lump which means breast conservative therapy. So, after agreeing to have the surgery, they consult you "Why don't you only remove the cancer/lump rather than removing the whole breast?"" (FGD_HP_Suregon_Butajira).*

Due to religious beliefs and practices

This study revealed that there is a belief in the community that cancer cannot be cured by medical treatment. Due to this and hopelessness, cancer patients prefer to visit religious places. Then, after spending several months in those places, they will return to the health facilities at such an advanced stage that they can not receive curative service, only supportive care.

> *"For example, there was a woman here who refused to have a mastectomy and she went to a religious place. She thought that she would be cured by religious things/faith. Therefore, there is such a belief in this area." (FGD_HP_Nurse_Butajira).*

Almost all the cancer patients involved in this study mentioned that they have visited religious places and tried different religious rituals to get cured. Some of the patients mentioned that they are simultaneously using both the medical treatment and religious practices, while others totally disagree with the medical plan and only took religious treatments such as prayers, holy water, emnet (some powder to be applied on their body), and duwa (prayer in Islam religion). Especially among those breast cancer patients who refused to have a mastectomy, agreeing to remove their breast demonstrates a lack of faith in God or the angels. Going to the health facility and removing their breast means not trusting God and going above His supernatural power. For instance, one of the women who refused to have a mastectomy said:

> *"I prefer to die now rather than losing my breast. I have the word of God and I promised to God that " You are the one who created all my body parts, and you will give me back my body as it used to be. I will not be operated unless it is difficult for you [referring God]" I have a strong faith in God. So, I believe that there is nothing above the power of Him. I have told them [referring to the health professionals] this from the beginning and they were telling me to think about it. But I told them as I have already decided a long time ago and there is nothing that I am going to think about anymore." (IDI_Refused BCa_Butajira).*

A very old breast cancer patient who refused to have a mastectomy even described it as a sin to agree to have the surgery at this age.

> *"For what reason? No way, I do not want to have surgery on any part of my body. hoooo, I will never be operated as long as St George is alive, St, Mary and St. Michael are alive. I already decided on this. I swear to myself. My sisters also advised me to be operated but I gave my witness to God. I am going to be a Monk so I can not be operated. In the name of the father, the son and holy spirit (saying it with sign). Oooo, ere ete I do not want to be operated..... It is a sin. I do not know whether I will die now or tomorrow. May you forgive me St. Gabriel. I will never be operated!" (IDI_Refused BCa_Butajira).*

Our results also identified pressure from religious leaders and community members to stick to religious practices rather than medical care. Moreover, it is highlighted that while there are many religious places nearby, cancer patients tend to travel very far to get healed, and spend a lot of money and time visiting different monasteries.

> *"One of the major challenges these days is, there are several religious practices, especially prayer is very common around here. There are a lot of prayer houses everywhere. They [religious leaders] even order them [the patients] to stop their medication and follow only the religious activity. Umm... the other woman also said, " I am not going to have the surgery. The servant of God told me that God will remove this disease from me, and I should not allow a knife to be put on my body" Therefore, she refused to have the surgery." (FGD_HP_Nurse_Hossana).*

Due to traditional medicine

One of the identified reasons women refuse to have surgery was a strong belief in the community; that traditional medicine is more effective than medical care or surgery. Most people in the community believe that cancer can be cured by different herbals and the patient can survive without losing their breast or other body parts.

> *"The community perceives that cancer cannot be cured by medical treatment. Yaw... they say, it can only be cured by traditional medicine." (FGD_BCa_Assela).*

With few exceptions, most patients we interviewed tried different traditional medicines suggested by community members. Even those who already started medical care mentioned that many people were advising them to take traditional medicine rather than strictly following medical care.

> *"Traditional medicine is available anywhere. At the beginning, people were advising me to use traditional medicine and not to go to the health facility. A lot of people were advising me this in my village, but I came to the hospital without accepting their idea." (FGD_BCa_Hossana).*

Because they want to have a baby

The other interesting finding of this study is that women will refuse to have a mastectomy if they want to have a baby and breastfeed their child. This problem is more prominently reflected among young women who are not married and want to have a baby. Health professionals reported that they face challenges in convincing this particular age group to have surgery, and the greatest challenge is the financial constraint of formula milk for their baby.

> *"About the mastectomy, especially for the young women, it is very difficult to accept the surgery since it has its own effect on having a baby. It is totally challenging and has a lot of problems. That could also be one of their reasons for refusal." (FGD_HP_Nurse_Hossana).*

> *"Actually, those women who are in the childbearing age are afraid of having the surgery since they want to breastfeed their kids. But still, we advise them to have the surgery because they can use one breast for breastfeeding. Once, I was in a dilemma since she cannot afford to buy formula for her baby. So, it is difficult to advise her not to breastfeed and only give formula." (FGD_HP_Nurse_Woliso).*

Additionally, a few participants mentioned that breasts have a strong meaning for women and is a representation of their femininity. One of the breast cancer patients said about losing her breast, *"So I always say to God, 'You created me with full body parts and please do not make my breast diseased before I give birth and before I breast feed my children. You are the one who gave me my breast, it is my feminine symbol."* (IDI_Refused BCa_Butajira).

Similarly, another woman who refused to have a mastectomy described her feelings on the relationship between her breasts and the bond with her children. *"Wuyyyyyyyyyyy (shouted) Gebriel help me please!! How can I remove my breast which nine of my children fed? Never! It is better to remain sick and die with it rather than losing my breast".* (IDI_Refused BCa_Butajira)

Due to lack of awareness

In general, lack of awareness about breast cancer, particularly in relation to its clinical manifestation, treatment modalities, and prognosis was one of the main reasons why many women refuse to have a mastectomy. Especially at the early stage, where it mainly presents with a small painless mass, many women consider it a simple illness that will subside by itself. Therefore, many women prefer to keep the mass, as long as it is not painful and does not hinder their routine life. For instance, a surgeon from Hosanna hospital said:

> *"Its presentation is usually small breast mass/ lump. The scenario for prostate, gastric and colonic cancer is totally different in which most patients present with obstruction. So, they are not in a position to refuse the surgery since they need relief. But this does not apply for breast cancer. A small painless mass is a concern for us, but most patients do not realize this at the beginning. To be honest, most of these patients return back and beg us to do the surgery after the swelling is burst and fungated." (FGD_HP_Surgeon_Hossana).*

Sociocultural factors and misconceptions

Many respondents mentioned that they were advised by community members not to have surgery. Even those who already had a mastectomy stated that they were told by their family members and neighbours not to have surgery, and even went so far as to advise them not to visit hospitals anymore but rather take traditional medicine or go to religious places.

> *"As for me, I went back to my home fully convinced to be operated on Monday. But all of my family members and neighbours were not happy about it. None of them were willing to have the surgery, none of them. People around me were telling me not to have the surgery. They said, "How can you live without having a breast? How can a woman live without having a breast? She can not live at all, she will die" So, it's better not to have the surgery and stay alive. A looottt... of people were warning me as I will die if my breast is removed. (FGD_BCa_Woliso)*

The caregivers we interviewed also stated that they faced such challenges from community members while they were struggling to convince their relatives. For instance, a son of a breast cancer patient who refused to have a mastectomy said:

> *"She is really afraid of the operation. Because the community advised her not to be operated and as she may die if the surgery is done at this age. Since she is very old, she accepts what people said." (IDI_Son of Refused BCa pt_Butajira).*

The other interesting findings of this study were community misperceptions about having a mastectomy. For instance, some people assume that cutting their breast might aggravate the illness and disseminate the cancer to other parts of the body and cause death. Others consider this surgical procedure as disability and prefer to die having all their body parts.

> *"So, God created me with full body parts, so I do not want to miss any of my body parts while observing with my naked eyes." (IDI_Refused BCa_Butajira).*

> *"They think that the disease may reoccur if the surgery is done. People assume that, if this organ is removed, there is a probability of refilling it. Because of this, they say, "It is better if I die as I am complete rather than having the surgery."" (IDI_HEW_Woliso).*

Discussion

This study revealed that many breast cancer patients in Ethiopia refuse to have a mastectomy, especially young and very old women, and often return to the health facility much later, when surgery is impossible. This finding is consistent with a study conducted in Rwanda that reported that 15.7% of breast cancer patients either refused the surgery or disappeared without receiving the recommended operation [23]. Similarly, a prospective multi-country study revealed that treatment refusal contributed to not initiating the recommended treatment. A high refusal rate (38%) was reported in two Nigerian hospitals, while almost all (98.7%) women in Namibia had initiated the treatment within one year of diagnosis [24]. Another study from Nigeria reported a high refusal rate, with only 32% of breast cancer patients having had the recommended operation [10]. Previous study conducted in eight hospitals located in southwestern Ethiopia also revealed that one in five cancer patients did not receive the reccomended surgical treatment; half due to refusal while the remaining did not return back to the health facility on their appointments [16].

In contrast, removing the breast is not considered as impactful in developed countries and the refusal rate is minimal. A study from the USA reported that out of 531,700 breast cancer patients identified in the Surveillance, Epidemiology, and End Results (SEER) database, only 0.64% refused surgery [25]. Another study using the same database from 2010 to 2015 found that 3.56% of a total 13, 618 patients with stage IV breast cancer refused the recommended primary tumour surgery [26], and of the 5,860 male breast cancer patients identified, only 0.9% refused surgery [3]. This huge difference in refusal rate between high- and low-income countries could be explained by lack of knowledge about the disease, low educational and economic status, and difficulty in accessing health services in LMICs [4]. On the other hand, availability of immediate breast reconstruction, improvement of postoperative aesthetic results, and reimbursement plays an important role in whether patients have therapeutic or prophylactic mastectomy in western countries [6, 7].

Our results identified that young women who are not married and do not have children often refuse mastectomy. Similarly, a qualitative study in Nigeria revealed that undergoing mastectomy at a young age may interfere with quality of life and overall accomplishment. These ideas may be responsible for fearing mastectomy, which makes young women delay or refuse treatment [27]. In previous studies, single or widowed marital status were found to be associated with refusal of surgery [4, 25]. The desire for future marriage, pregnancy, and breast feeding their children influence the treatment decision of many young women. In contrast, around one-third of patients in Uganda who received surgical treatment was below the age of 40 years and more than half of them were below 50 years [11]. This variation could be explained by the fact that the study did not report the refusal rate and only described the age of breast cancer patients who underwent mastectomy within one year, and it is known that most breast cancer patients in SSA are below the age of 40.

A high refusal rate for mastectomy among young women has a great implication since most breast cancer patients in Ethiopia and SSA are of childbearing age [8, 10, 16]. Basically, BCS is recommended as a local treatment for young women with early-stage breast cancer [28]. Given the absence of survival difference between MRM and BCS, the patients in developed countries are ultimately the ones who decide their preferred surgery, barring any contraindication [7]. For this reason, many patients who want to preserve their breast tissue decide to have BCS since radiation treatment is widely available in developed countries [29]. But the situation in LMICs does not allow young women to choose among the two surgical procedures and it is mainly the decision of the surgeon. In Ethiopia, most surgeons are forced to avoid BCS and instead perform mastectomy in most breast cancer patients, regardless of the stage at diagnosis [30]. Scarcely available radiotherapy services, with more than a year wait time, increases the risk of tumour recurrence and threatens the life of patients who have BCS. For this reason, MRM remains the standard surgery in Ethiopia today [17, 19]. This challenge was clearly reflected in our study, as many young breast cancer patients requested to have only the lump excised—not the entire breast—and this was one of their reasons for refusal and seeking alternatives. As evidence shows, the refusal group was associated with a poorer prognosis in overall survival compared to the surgery group [3]. This indicates that availing BCS should not be considered a luxury, but rather a mandatory alternative treatment option for young breast cancer patients in Ethiopia. Despite the administrative and technical challenges causing delay in the expansion of radiotherapy service in seven cancer centers in Ethiopia, Jimma university hospital recently started the service and became the second cancer center next to Tikur Anbessa Specialized Hospital [19]. However, having only two radiotherapy machines for a population of 125 million is still below the standard to consider BCS as an alternative surgical procedure for breast cancer patients in Ethiopia. Hence, efforts in expanding radiotherapy services all over the country requires due attention.

Our results identified that not only young women refused mastectomy, but older women also refused for various reasons. One of our participants who resisted having a mastectomy after repeated advice from health professionals and family members was over 90 years old. This finding is in line with a review of 22 studies done in USA, Asia, and Europe, which reported that breast cancer patients older than 70 years were more likely to refuse treatment, with the main factors including unmarried status, non-white race, female gender, and having government or no insurance [4]. Another quantitative study also identified that older age (≥65 years) was one of factors for refusal of mastectomy among male breast cancer patients [3]. In contrast, women undergoing mastectomy in China were older and more likely to be married and have at least one child [31].

Interestingly, all the refusal patients we interviewed were willing to take alternative treatments, either in the form of tablets or injections. Similarly, a case study of a 74-year-old woman in South Korea who refused mastectomy reported that a modified treatment process, including non-surgical primary therapies, minimised surgery, and close follow-up was successful, without signs of recurrence or metastasis after eight years from diagnosis [32]. In such conditions, endocrine and radiation therapy were chosen as treatment alternatives. A meta-analysis demonstrated that primary endocrine therapy (pET), even as monotherapy, has comparable response rates to neoadjuvant chemotherapy in patients with oestrogen receptor (ER) positive tumours, and with considerably lower toxicity [33]. Consistently, a retrospective study in South Africa revealed that pET can be a viable alternative for those patients over 70 years of age [34]. Not having an alternative modified treatment in LMICs is one of the missed opportunities to address those elderly patients who want to optimise all medical treatments except the surgery. Given considerably lower toxicity and relative ease of administering oral therapies in comparison with other systemic treatments, pET can be considered an effective approach in LMICs [1], particularly in a country like Ethiopia where radiation treatment is limited and more than 65% of breast cancer tumours are ER positive [35].

Knowing someone who died after having a mastectomy was one of the reasons identified in this study. This is probably because the actual intent of the performed surgical procedure was not properly communicated to patients and relatives, particularly for those procedures done with the intention of palliation. The other possible explanation could be, as with other surgical procedures, the community may expect total cure following surgery, even without receiving other systemic treatments. According to the Cochrane review, it is not possible to make definitive conclusions on the benefits and risks of breast surgery associated with systemic treatment for women diagnosed with metastatic breast cancer, and it was recommended that the discussion and decision to perform breast surgery should be individualised and shared between the physician and the patient [36]. Therefore, it is unknown whether surgeons were performing operations without ruling out distant metastasis since imaging and other diagnostic modalities are limited in peripheral sites of Ethiopia. The other reason for high mortality after mastectomy could be due to lack of systemic treatments; most likely these patients did not receive either chemotherapy or endocrine treatment after having the operation. Our study from rural Ethiopia showed that nearly all patients died within three years after surgery without systemic treatment [37]. Therefore, as is clearly shown in a Nigerian study [27] involving breast cancer survivors, this could play an important role in convincing newly diagnosed women to accept mastectomy in addition to professional counselling.

One of the important issues that emerged in refusal of mastectomy among breast cancer patients was seeking alternative treatments such as traditional medicine and religious practices. A previous study among breast cancer patients in Addis Ababa also identified that utilisation of traditional medicine was a significant factor in advanced stage presentation [38]. A similar finding was reported by a multicentre study conducted in three sub-Saharan countries wherein women who believed in traditional medicine and spiritual healings were eight times more likely not to have received conventional breast cancer treatment, including surgery [24]. Not only in African countries, but traditional medicine was also mentioned as one of the factors for delay in presentation in Singapore [39]. The easy accessibility of traditional and alternative medicine locally is a double-edged sword. Patients often choose to subscribe to alternative medicine, believing in its curative effect, thus delaying presentation and also initiation of treatment.

Patients perceive and experience illness, care, and death according to their culture, values, beliefs, life experiences, and meaning of life. Thus, it is argued that spirituality, culture, and the socioeconomic status may influence patients' healthcare decision-making [4]. In this study, some breast cancer patients mentioned that people in the community were advising and frightening them against surgery, saying that they will not be considered a woman after losing their breasts. This is because breasts are presumed to be an attribute of femininity, maternity, and sexuality [30]. A qualitative study in Nigeria explored the perception that breast removal results in loss of femininity and womanhood, and that a woman without breasts is considered a man [27]. These community perceptions uniquely expressed in Africa can be partly explained by low disease awareness, women's lack of economic dependence and decision making power, and strong attachments to motherhood and breastfeeding.

Our study reflected that breasts have special meaning, especially for elderly women in relation to motherhood and expression of attachment with their children. Therefore, they refused to have a mastectomy because of fear of losing this bond and considered it abandonment of their children. Similarly, a qualitative study in Sweden reported that breasts mean femininity, beauty, attraction, and motherhood [40]. After mastectomy, it was difficult for some women to accept the situation, as they felt they lost their femininity and considered themselves disabled or incomplete. Some studies showed that a mastectomy negatively affected a woman's body image, as well as the relationship with their husband [27, 30, 41].

Strengths and limitations

One of the strengths of this study is the inclusion of breast cancer patients who refused to have a mastectomy, which enabled us to understand their actual reasons for refusal. Use of both IDI and FGD data collection techniques enhanced the triangulation of our findings. Moreover, inclusion of health professionals ranging from community health workers to specialists supported us in capturing the whole situation and realising the different perspectives from both patients and health professionals. The findings of this study are limited to the geographic area covered, but we see that there are many themes also found in other literature. All interviews were conducted in the official local Amharic language, so possible nuances present in other local languages were not captured. Due to the rareness of the case, we could not include male breast cancer patients in our study and the health professionals reported as they didn not observe major challenges or resistent from male patients.

Clinical significance

First, to meet more patients' needs, especially young women with early-stage breast cancer, BCS should be made more available. Expansion of radiotherapy services is already ongoing, with a second site providing this service. Clear guidelines for BCS are needed to justify the additional radiation time to ensure BCS for those patients who have curative options and would otherwise abandon therapy altogether.

Second, in case of elderly patients who are not suitable for surgery, effective non-surgical primary therapies such as a combination of endocrine and radiation therapy should be considered.

Third, concepts and information must be tailored to the patient´s understanding. Fear about surgery, not understanding the reasons for mastectomy, and lack of awareness about disease severity are important points of agreement for undergoing such complex treatment modalities. Addressing individual patient psychosocial needs and preferences is also a key element for the retaining them in the health system.

Fourth, a high proportion of patients in LMICs are below the age of 40 and still of childbearing age. Conception following anticancer therapies is a key component to be considered. Therefore, health professionals should be conscious of this and try to build trust with these patients to facilitate open discussion about their personal life, future plans, and family size. Training on onco-fertility counselling might be useful.

Fifth, awareness creation programs are crucial in both religious places and through collaborative efforts with traditional healers, religious leaders, and influential people. Involving breast cancer survivors could also play an important role in persuading newly diagnosed breast cancer patients. Bringing these to the forefront and establishing patient support groups may have substantial impact. Guidelines on how to manage young breast cancer patients in Ethiopia may assist surgeons in decision-making, to include accessible adjuvant treatment. It is also recommended for future researchers to explore the lived experience of breast cancer patients after having mastectomy and involve male breast cancer patients in order to see the other dimension of the challenge from their own perspective.

Conclusion

Many breast cancer patients in Ethiopia, especially young and elderly women, refuse to have a mastectomy. In this study, six main reasons for refusal of mastectomy were identified. These include fear of the surgical procedure itself, arguing for excision of just the mass and not the whole breast, and searching for alternative treatments such as religious rituals and traditional treatments. Particularly for young women, they often refuse in relation to having a baby and breastfeeding. Low awareness about the disease, especially its severity and prognosis, also emerged as a primary reason for mastectomy refusal. Moreover, sociocultural factors in the community, especially that of considering breasts a symbol of femininity and motherhood, influence women not to have the surgery. Poor survivorship stories after mastectomy also contributed to high refusal rate in the country.

Abbreviations

BCS	Breast-conserving surgery
CPM	Contralateral prophylactic mastectomy

ER	Estrogen receptor
FGD	Focus group discussion
GP	General practitioners
HEW	Health extension workers
HP	Health professionals
IDI	In-depth interview
LMICs	Low- and middle-income countries
MRM	Modified radical mastectomy
PET	Primary endocrine treatment
QCA	Qualitative content analysis
SEER	Surveillance, Epidemiology, and End Results
USA	United States of America

Acknowledgements
The authors would like to thank Addis Ababa University, College of Health Sciences for the ethical review process. They would also like to thank the study participants, health facilities, and the funding organisation.

Author contributions
All authors conceived and designed the study. AA prepared the interview guides and conducted the IDIs and moderated the FGDs. Data analysis and interpretation of the findings was performed by AW, ST, and MA. AW and EJK drafted the manuscript and AA, MA, and ST were actively involved in data interpretation and rewriting the manuscript. BZ and EJK critically reviewed the different versions of the manuscript. All authors read and approved the final manuscript.

Funding
This work was supported by Else-Kroener-Foundation through Martin-Luther-University, Halle-Wittenberg, Germany, Grant No. 2018_HA31SP. The work was also supported through the German Ministry of Research and Education, Grant 01KA2220B. The funding bodies were not involved in the study design, collection, analysis, and interpretation of the data, or writing of the manuscript.
Open Access funding enabled and organized by Projekt DEAL.

Data availability
The datasets used and/or analysed during the current study are available from the corresponding author upon reasonable request.

Declarations

Competing interests
The authors declare no competing interests.

Ethics approval and consent to participate
Ethical clearance of this study was obtained from the Research Ethics Committee of School of Public Health and Institutional Review Board of College of Health Science, Addis Ababa University. Oral informed consent was taken from all participants and it was approved by the Institutional Review Board of College of Health Science, Addis Ababa University with an approval number 041/20/SPH. Confidentiality and anonymity of the participants was maintained. All methods were carried out in accordance with relevant guidelines and regulations in the Declaration of Helsinki.

Consent for publication
Not applicable.

Author details
[1]Department of Preventive Medicine, School of Public Health, College of Health Sciences, Addis Ababa University, Addis Ababa, Ethiopia
[2]Global Health Working Group, Institute of Medical Epidemiology, Biostatistics and Informatics, Martin-Luther-University, Halle, Germany
[3]Department of Psychiatry, 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]School of Social Work, University of Michigan, Ann Arbor, USA
[6]Department of Gynecology, Martin-Luther-University, Halle (Saale), Germany

Received: 13 July 2023 / Accepted: 27 December 2023

References

1. Mutebi M, Anderson BO, Duggan C, Adebamowo C, Agarwal G, Ali Z, et al. Breast cancer treatment: a phased approach to implementation. Cancer. 2020;126(Suppl 10):2365–78. Epub 2020/04/30.
2. Kaidar-Person O, Offersen BV, Boersma LJ, de Ruysscher D, Tramm T, Kuhn T, et al. A multidisciplinary view of mastectomy and breast reconstruction: understanding the challenges. Breast. 2021;56:42–52. Epub 2021/02/22.
3. Wang S, Chen S, Huang Y, Hu D, Zeng W, Zhou L, et al. Refusal of cancer-directed surgery in male breast cancer. Medicine. 2021;100(13):e25116. Epub 2021/04/01.
4. Dias LM, Bezerra MR, Barra WF, Rego F. Refusal of medical treatment by older adults with cancer: a systematic review. Annals of Palliative Medicine. 2021;10(4):4868–77. Epub 2021/04/10.
5. Siegel RL, Miller KD, Jemal A. Cancer statistics, 2015. CA Cancer J Clin. 2015;65:5–29.
6. Aniela Nodiåi GC, Smaranda, Stoleru. Alexandru Blidaru, Cristian Ioan Bordea. Contralateral Prophylactic Mastectomy in Patients with Breast Cancer. 2021;116:11.
7. Scheepens JCC, Veer LV, Esserman L, Belkora J, Mukhtar RA. Contralateral prophylactic mastectomy: a narrative review of the evidence and acceptability. Breast. 2021;56:61–9. Epub 2021/02/24.
8. Martei YM, Pace LE, Brock JE, Shulman LN. Breast Cancer in low- and Middle-Income countries: why we need Pathology Capability to solve this challenge. Clin Lab Med. 2018;38(1):161–73.
9. Lukong KE, Ogunbolude Y, Kamdem JP. Breast cancer in Africa: prevalence, treatment options, herbal medicines, and socioeconomic determinants. Breast Cancer Res Treat. 2017;166(2):351–65. Epub 2017/08/05.
10. Stephanie A, Sutter AS, Balumuka DD, Mitchell KB. Surgical management of breast Cancer in Africa: a continent-wide review of intervention practices, barriers to care, and adjuvant therapy. J Global Oncol April 2017;3(2).
11. Ekdahl Hjelm T, Matovu A, Mugisha N, Lofgren J. Breast cancer care in Uganda: a multicenter study on the frequency of breast cancer surgery in relation to the incidence of breast cancer. PLoS ONE. 2019;14(7):e0219601. Epub 2019/07/12.
12. Delphine Héquet KZ, Couturaud SDBenoît, Ngô C, Fourchotte V, De La Rochefordière A, Féron J-G, Fitoussi A, Bélichard C, Reyal F, Laki F, Hajage D. Brigitte Sigal, Bernard Asselain, and Séverine Alran, Institut Curie Breast Cancer, Group, Roman Rouzier. Reasons of not having breast reconstruction: a historical cohort of 1937 breast cancer patients undergoing mastectomy. SpringerPlus 2013, 2:325. 2013;2(325):10.
13. Anna Schoenbrunner JU, Anne M, Wallace JP, Einck LK, Mell. and James D. Murphy. The impact of surgeons on the likelihood of mastectomy in breast Cancer. Annals of surgery. May 01, 2019;269(5).
14. International Agency for Research on Cancer WHO. Cancer fact sheets, Ethiopia 2020. GLOBOCAN (2020). 2020. International Agency for Research on Cancer, World Health Organization. Cancer fact sheets, Ethiopia 2020. GLOBOCAN (2020). https://gco.iarc.fr/today/data/factsheets/populations/231-ethiopia-fact-sheets.pdf. Accessed April 7, 2023.
15. Federal Ministry of Health Ethiopia. National cancer control plan 2016–2020. Addis Ababa, Ethiopia, 54P.
16. Wondimagegnehu A, Negash Bereded F, Assefa M, Teferra S, Zebrack B, Addissie A, et al. Burden of Cancer and Utilization of Local Surgical Treatment Services in Rural hospitals of Ethiopia: a Retrospective Assessment from 2014 to 2019. Oncologist. 2022;27(11):e889–e98. Epub 2022/07/07.
17. Tara Rick YvN, Habtamu B, Grover S, Tigeneh W, Assefa M. Aynalem Abreha, and Luca Incrocci patterns of care of cancers and Radiotherapy in Ethiopia. J Global Oncol. 2019.
18. Ethiopia makes progress in cancer treatment provision. World Nuclear News. Available online Ethiopia makes progress in cancer treatment provision: Regulation & Safety - World Nuclear News (world-nuclear-news.org). Accessed on April 12 2023.
19. Bawoke G, Kejela S, Alemayehu A, Bogale GT. Experience with modified radical mastectomy in a low-income country: a multi-center prospective observational study. BMC Surg. 2021;21(1):371. Epub 2021/10/22.
20. Timotewos G, Solomon A, Mathewos A, Addissie A, Bogale S, Wondemagegnehu T, et al. First data from a population based cancer registry in Ethiopia. Cancer Epidemiol. 2018;53:93–8.

21. Tefera BB, Assefa M, Abebe B, Rauch D, editors. Patterns of cancer in University of Gondar Hospital: North-West Ethiopia. 2018.
22. Deressa BT, Cihoric N, Badra EV, Tsikkinis A, Rauch D. Breast cancer care in northern Ethiopia - cross-sectional analysis. BMC Cancer. 2019;19(1):393. Epub 2019/04/27.
23. Daniel S, O'Neil NLK, Jean Marie V, Dusengimana V, Hategekimana A, Umwizera T, Mpunga LN, Shulman, Lydia E. Pace. Quality of breast Cancer Treatment at a Rural Cancer Center in Rwanda. J Global Oncol. 2017:11.
24. Foerster M, Anderson BO, McKenzie F, Galukande M, Anele A, Adisa C, et al. Inequities in breast cancer treatment in sub-saharan Africa: findings from a prospective multi-country observational study. Breast cancer Research: BCR. 2019;21(1):93. Epub 2019/08/15.
25. Gaitanidis A, Alevizakos M, Tsalikidis C et al. Refusal of Cancer-Directed Surgery by Breast Cancer Patients: Risk Factors and Survival Outcomes. Clin Breast Cancer. 2018;18:e469-76. https://www.clinical-breast-cancer.com/article/S1526-8209(17)30381-6/fulltext.
26. Xie N, Hu X, Tang Y, Tian C, He Y, Hu ZY, et al. Impact of surgical management of primary tumors in stage IV breast cancer patients: a retrospective observational study based on SEER database. BMJ Open. 2022;12(2):e054135. Epub 2022/02/03.
27. Olalekan Olasehinde TA, Kingham TP, Arije O, Arowolo O, Wuraola FO. Carla Boutin-Foster, Marguerite Samson, Olusegun Isaac Alatise, Olawumi Olajide. Life without a breast: exploring the experiences of young Nigerian women after mastectomy for breast Cancer. J Global Oncol. 2019.
28. Sinnadurai S, Kwong A, Hartman M, Tan EY, Bhoo-Pathy NT, Dahlui M, et al. Breast-conserving surgery versus mastectomy in young women with breast cancer in Asian settings. BJS Open. 2019;3(1):48–55. Epub 2019/02/09.
29. Gu J, Delisle M, Engler-Stringer R, Groot G. Mastectomy versus breast-conservation therapy: an examination of how individual, clinicopathologic, and physician factors influence decision-making. Curr Oncol. 2019;26(4):e522–e34. Epub 2019/09/25.
30. Abebe E, Demilie K, Lemmu B, Abebe K. Female breast Cancer patients, mastectomy-related quality of life: experience from Ethiopia. Int J Breast Cancer. 2020;2020:8460374. Epub 2020/04/25.
31. Liu J, Guo D, Hunter S, Lee RLT, Zhu J, Chan SW. The uptake and Factors Associated with mastectomy among Chinese women with breast Cancer: a retrospective observational study. Asian Pac J Cancer Prevention: APJCP. 2021;22(5):1599–606. Epub 2021/05/29.
32. An JK, Woo JJ, Kwak HY. The 8-Year management of an older breast Cancer patient by non-surgical primary therapies and minimized surgery: a Case Report. Annals of Geriatric Medicine and Research. 2020;24(3):218–22. Epub 2020/08/28.
33. Spring LM, Gupta A, Reynolds KL, Gadd MA, Ellsen LW, Isakoff SJ, et al. Neoadjuvant endocrine therapy for estrogen receptor-positive breast cancer: a systematic review and meta-analysis. JAMA Oncol. 2016;2:1477–86. https://doi.org/10.1001/jamaoncol.2016.1897.
34. Benn CA, Ramdas Y, Smit T, Shaw V, Rapoport BL. Analysis of primary endocrine therapy in patients older than 70 years with breast cancer rejecting surgery from a single unit in South Africa including COVID-19 issues. J Geriatric Oncol. 2021;12(7):1118–21. Epub 2021/03/13.
35. Desalegn Z, Yohannes M, Porsch M, Stückrath K, Anberber E, Santos P, et al. Intrinsic subtypes in Ethiopian breast cancer patient. Breast Cancer Res Treat. 2022;196:495–504. https://doi.org/10.1007/s10549-022-06769-z.
36. Tosello G, Torloni MR, Mota BS, Neeman T, Riera R. Breast surgery for metastatic breast cancer. Cochrane Database Syst Rev. 2018;3(3):CD011276. Epub 2018/03/16.
37. Eber-Schulz P, Tariku W, Reibold C, Addissie A, Wickenhauser C, Fathke C, et al. Survival of breast cancer patients in rural Ethiopia. Breast Cancer Res Treat. 2018;170(1):111–8.
38. Gebremariam A, Addissie A, Worku A, Assefa M, Kantelhardt EJ, Jemal A. Perspectives of patients, family members, and health care providers on late diagnosis of breast cancer in Ethiopia: a qualitative study. PLoS ONE. 2019;14(8):e0220769. Epub 2019/08/02.
39. Ng CWQ, Lim JNW, Liu J, Hartman M. Presentation of breast cancer, help seeking behaviour and experience of patients in their cancer journey in Singapore: a qualitative study. BMC Cancer. 2020;20(1):1080. Epub 2020/11/11.
40. Lundberg PC, Phoosuwan N. Life situations of Swedish women after mastectomy due to breast cancer: a qualitative study. Eur J Oncol Nursing: Official J Eur Oncol Nurs Soc. 2022;57:102116. Epub 2022/03/11.
41. Restrepo DJ, Sisti A, Boczar D, Huayllani MT, Fishe J, Gabriel E, et al. Characteristics of breast Cancer patients who refuse surgery. Anticancer Res. 2019;39(9):4941–5. Epub 2019/09/15.

Publisher's Note

Qualitative Health Research
2024, Vol. 0(0) 1–14
© The Author(s) 2024
Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/10497323231219409
journals.sagepub.com/home/qhr
Sage

A Qualitative Study on Psychosocial Challenges of Patients With Cancer in Ethiopia Using the Social-Ecological Model

Abigiya Wondimagegnehu[1,2], Mathewos Assefa[3], Solomon Teferra[4], Eva J. Kantelhardt[2,5], Bradley Zebrack[6], and Adamu Addissie[1,2]

Abstract

Cancer diagnosis and treatment can be physically arduous, disrupting patients' social and work lives. Understanding the extent of these problems is key to addressing patients' needs, but specific psychosocial challenges have not yet been well studied in resource-limited settings. A qualitative study was conducted in the capital and two regions of Ethiopia with the aim of exploring psychosocial challenges among cancer patients. A total of 14 in-depth interviews (IDIs) and 16 focus group discussions (FGDs) were done with cancer patients, health professionals, community representatives, and religious leaders. Four separate interview guides were used to facilitate the interviews and discussions. All transcribed documents, field notes, and reflexive memos were entered into NVivo 12 software, and deductive thematic analysis using the social-ecological model was applied to summarize the main findings. At an individual level, emotional distress, suicidal risk, denial, and refusal of treatment were identified immediately after diagnosis while hopelessness, feeling depressed, and fear of death were commonly reported psychosocial challenges during the course of treatment. Involvement of family members in major treatment decisions was recognized at an interpersonal level. Our result also revealed that cancer patients had strong social support from family members and close friends. In the community, traditional medicine and religious rituals were considered an alternative treatment for cancer. The findings indicate that counselling and psychoeducation are crucial for cancer patients, family members, and close friends. Awareness creation programmes should be delivered through collaboration with religious leaders and traditional healers.

Keywords
cancer patients; psychosocial challenges; social-ecological model; Ethiopia

Introduction

A cancer diagnosis may threaten one's physical, emotional, and social existence (Emory Winship Cancer Institute, 2019; Gorman, 2003). Psychosocial challenges are the dynamic interactions among the physical, emotional, social, and cultural factors that come into play during the cancer trajectory (Merighi, 2016). The physical changes that arise from cancer or its treatment are the most common causes of psychological disorders among cancer patients. For instance, common chemotherapy side effects, such as hair loss, fatigue, and weight changes, have a huge psychological impact on cancer patients (Nikbakhsh et al., 2014; Rosa & Ferrell, 2023; Zainal et al., 2013). The need to adapt to hair loss, cognitive issues, and fluctuations in weight may have unexpected consequences on body image and self-perception (Emory Winship Cancer Institute, 2019; Fingeret et al., 2014). In particular, the type of cancers that require surgical removal of body parts may lead to disruptions in self-

---

[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 Oncology, School of Medicine, College of Health Sciences, Addis Ababa University, Addis Ababa, Ethiopia
[4] Department of Psychiatry, School of Medicine, College of Health Sciences, Addis Ababa University, Addis Ababa, Ethiopia
[5] Department of Gynecology, Martin-Luther-University, Halle, Germany
[6] School of Social Work, University of Michigan, Ann Arbor, MI, USA

Corresponding Author:
Abigiya Wondimagegnehu, Department of Preventive Medicine, Addis Ababa University, College of Health Sciences, Sefere Selam Campus, Off # 501, PoBox 26421 Code 1000, Addis Ababa, Ethiopia.
Email: abigiya.wondimageg@aau.edu.et

perception, appearance, physical ability, social relationships, and cognition (Brierley et al., 2019; Fingeret et al., 2014; Hubbeling et al., 2018).

In addition to its physical implications, some cancer treatments affect cognitive functioning: thinking, memory, word retrieval, problem-solving, executive function, and multitasking (Merighi, 2016). For this reason, many people living with cancer lose their independence and autonomy, as cognitive functioning may decrease over time and cancer affects every aspect of daily life. Therefore, they are forced to rely on family, friends, and health care professionals to perform everyday tasks (Head & Iannarino, 2019; Merighi, 2016; Wang et al., 2015).

Moreover, symptoms of depression, anxiety, and hopelessness are frequent among patients with cancer (Doherty et al., 2019). More than one-third of cancer patients are emotionally distressed and about one in five cancer patients express the need for psychosocial support (Bergerot et al., 2016). Anxiety is one of the leading psychological challenges associated with cancer, and all cancer patients undergo a level of anxiety at some point in their disease trajectory. This level of concern increases as patients identify how severe their condition is with the stage of presentation and how the treatment progresses (Saleh Baqutayan, 2012). Depression is another common disabling disorder that affects approximately 15%–25% of cancer patients (Nikbakhsh et al., 2014; Wondimagegnehu et al., 2019; Zainal et al., 2013).

The overall burden, severity, and type of psychological disorders vary hugely depending on the stage of cancer, type of treatment received, duration and cost of treatment, and availability of psychosocial support (Doherty et al., 2019; Emory Winship Cancer Institute, 2019; Merighi, 2016). The cancer site also plays a major role in the distinct challenges confronted by cancer patients, reflected by isolation, stigmatization, and loss of autonomy (Gorman, 2003; Merighi, 2016; Zebrack et al., 2007). Some studies identified that breast and cervical cancer patients have a higher prevalence and a severe form of these disorders. For instance, symptomatic anxiety and depression among breast cancer patients were reported as high as 32% and 28%, respectively, while among patients with other types of cancer (such as esophageal, colorectal, and thyroid), it was ranging between 3% and 15% for both disorders (Alemayehu et al., 2018; Nikbakhsh et al., 2014).

Not only clinical factors but also external environmental factors such as geographic setting, sociocultural context, and socio-economic status of the patients play a major role in the variation across the continents (Doherty et al., 2019; Grassi & Watson, 2012). Particularly in low- and middle-income countries (LMICs), the majority of cancer patients are diagnosed at an advanced stage of the disease, which contributes to the high mortality rate and poor prognosis of the disease (Martie et al., 2018; World Health Organization [WHO], 2018). According to a systematic review in sub-Saharan Africa, the percentage of patients diagnosed at Stage IV cancer ranges from 4% to 70% (Jedy-Agba et al., 2016). This may have direct implications for the type and severity of psychosocial challenges faced by cancer patients in those settings. However, the number of studies conducted in LMICs is very minimal, and the available evidence suggests that there is a difference in the psychosocial challenges and needs among cancer patients in Western countries and LMICs (Herce et al., 2014; Hubbeling et al., 2018; Travado et al., 2017). This variation might be due to differences in medical decision-making, pressure for collusion, extreme poverty, and cultural expectations about emotional and spiritual responses to severe illness (Ahmadi et al., 2019; Cain et al., 2018). In addition, differences in levels of education, occupation, values, and religious beliefs among low-income populations have been observed to influence patients' greatest fears and concerns at the end of life (Elsner et al., 2012).

Understanding the cultural, social, and emotional experiences in LMICs is critical for improving the psychosocial and spiritual aspects of palliative care; however, specific psychosocial challenges have not been well studied in these settings, particularly in Ethiopia. Previous studies of cancer in Ethiopia were more quantitative, focusing on stage of diagnosis and survival (Abebe & Abebe, 2017; Eber-Schulz et al., 2018; Gizaw et al., 2017), awareness of cancer (Aweke et al., 2017; Chaka et al., 2018), health-seeking behaviour (Habtu et al., 2018), and screening service uptake (Geremew et al., 2018). However, the psychosocial challenges experienced by cancer patients were not well explored in a qualitative study looking at the social, cultural, and religious structure of the community. Therefore, the aim of this study is to explore the psychosocial challenges among cancer patients in Ethiopia, an LMIC with very limited structures and resources to support the identification of and clinical response to cancer patients' psychosocial needs. The social-ecological model was used to explore the multiple levels of psychosocial challenges. This model is a theory-based framework emphasizing the interactive effects of personal and environmental factors at individual, interpersonal, organizational, community, and public policy level (Bronfenbrenner, 1977; Bronfenbrenner & Ceci, 1994). Hence, realizing the magnitude and depth of unique psychosocial challenges from different sociocultural perspectives may have paramount importance. We believe that the current study will generate evidence on how to address these specific needs of cancer patients and can be used as an input for designing context-based, effective, and applicable supportive care in resource-limited settings.

Methods

Study Design and Place

We conducted a qualitative study in four rural and two urban hospitals located in Addis Ababa, Oromia, and the Southern Nations, Nationalities, and Peoples' Region (SNNPR) of Ethiopia. These four rural hospitals (St. Lukas Catholic Hospital, Negist Elleni Mohammed Referral Hospital, Butajira General Hospital, and Assela University Teaching and Referral Hospital) and two urban hospitals (Bete Zata Hospital and Tikur Anbessa Specialized Hospitals) were purposively selected.

Study Participants and Sample Size

Focus group discussions (FGDs) were conducted with cancer patients, health professionals, community representatives, and religious leaders in each study site, totalling 16 FGDs. On average, five to nine participants were included in each FGD, amounting to 121 participants: 31 from Butajira, 28 from Hossana, 27 from Weliso, 26 from Assela, and 9 from Addis Ababa city. Cancer patients above 18 years of age and on follow-up during the data collection period were included in the FGDs. In addition, 14 in-depth interviews (IDIs) were conducted with six cancer patients, five health professionals, and three patient relatives. Purposive sampling and theoretical saturation techniques were used and a maximum variation of participants was achieved by recruiting patients with different types of cancer and health professionals from various specialties. An attempt was also made to achieve diverse perspectives by recruiting participants from different religious denominations (Pariona, 2017) and by considering the community role, place of residence, age, and gender of the participants.

Data Collection and Tools

Four separate interview guides (for IDI/FGDs conducted with cancer patients, health professionals, community representatives, and religious leaders) were prepared based on the study objective. We purposively used both IDI and FGD data collection techniques in order to complement and triangulate our findings. The FGDs enabled us to explore the overall psychosocial challenges observed/recognized at community and organizational levels while the IDIs were very crucial to understand the situation from patients' perspective through freely discussing any psychosocial challenges including sensitive issues.

Questions about any form of psychosocial challenge that cancer patients face throughout the disease trajectory were included. We asked whether the diagnosis or the medical treatment affected their social, financial, spiritual, and family life. Questions about personal feelings, challenges in relation to their interaction with community members, and the presence of stigma or discrimination were included in the interview guide. We also asked about the presence and utilization of alternative treatment options, such as traditional healers and religious places in their village. In addition, religious leaders were asked if cancer patients often visit their institution, how long they stay, what specific needs they have, and what kind of care or support do they offer to cancer patients. A principal investigator and research assistant conducted all the FGDs and IDIs. On average, IDIs were held for 21–47 min and FGDs took 65–102 min. The FGDs and IDIs with health professionals, cancer patients, and relatives were held in their respective hospitals while FGDs with community representatives and religious leaders were done in the compound of kebele offices (the smallest administrative unit in Ethiopia). After conducting the preliminary analysis and summarizing the main findings, the research team decided to use the social-ecological model (Bronfenbrenner, 1977; Bronfenbrenner & Ceci, 1994) to deductively explore the psychosocial challenges at individual, interpersonal, and community/organizational levels. This model is a theory-based framework for understanding the multifaceted and interactive effects of individual, interpersonal, and community/organizational factors that determine behaviours and for identifying behavioural and organizational leverage points and intermediaries for health promotion within organizations (Akinyemiju et al., 2022; Bronfenbrenner & Ceci, 1994). Daily debriefings were held on emerging thematic areas and the data collection continued until we reached the theoretical saturation level particularly through comparing and contrasting emerging ideas from each participant categories in the different study sites. All the interviews were audio-recorded, and notes were taken during the interviews and discussions. Subsequently, all recorded interviews were transcribed and translated verbatim after repeatedly listening to the recorded audios.

Data Analysis Procedures

Data analysis started in the field while conducting the first nine IDIs in Addis Ababa. Based on the daily debriefing held among the research team, it was possible to identify emerging thematic areas that require further exploration. All transcribed documents, field notes, and reflexive memos were entered into NVivo 12 software. A principal investigator and research assistant coded each document line by line, and deductive thematic analysis (Bingham & Witkowsky, 2022; Caulfield, 2019) was used to categorize and explain the emerging thematic areas under each level in the social-ecological framework. At the beginning, sentences of importance were highlighted and divided into meaning units. Then, the meaning units were condensed and labelled with short codes; all codes were compared to identify similarities and differences. Connections between codes were searched and categories were developed based on the codes' manifest content. As we recruited participants from various categories, they may look at the situation from different perspectives, depending on their age, type of cancer, profession, role in the community, and so on; therefore, we attempted to check similarities and differences in the emerging categories across these subgroups. Finally, emerging categories and concepts identified at individual, interpersonal, organizational, and community levels in the social-ecological model were constantly compared, tested, and revised to be fitted in their respective themes and sub-themes. At the individual level, we identified various psychosocial challenges experienced by cancer patients and expressed at different phases of the disease trajectory. Therefore, we further subcategorized into two sub-themes, whereas we merged the identified sub-themes under organizational and community levels into one theme. The findings were discussed, re-categorized, and modified to ensure reliability and better explanation. Disagreements were discussed until consensus was reached.

Ethics

Ethical clearance of this study was obtained, and written informed consent was taken from all participants. Confidentiality of the data was maintained.

Results

A total of 28 cancer patients, 3 patient relatives, 31 health professionals, 32 community representatives, and 27 religious leaders participated in this study (Table 1). Informed by the social-ecological model, the main findings were categorized into three levels: (i) individual level, (ii) interpersonal level, and (iii) community and organizational level (Figure 1). The themes and sub-themes presented under each level of the model were identified to be similar across the different subgroups included in this study.

Theme 1: Psychosocial Challenges at Individual Level

This theme describes the psychosocial problems that each cancer patient feels about themselves, influenced by the knowledge, attitude, perception, and sociodemographic characteristics of the patient. We further subcategorized these problems into two sub-themes: (a) challenges immediately after diagnosis and (b) challenges during the course of treatment.

Sub-Theme 1: Immediately After Diagnosis

(a) Emotional distress:

Our participants mentioned that many cancer patients became very emotional when they were first informed as having cancer. This is related to their perception of the disease in a way that many patients directly associate cancer with death. Furthermore, many cancer patients, especially breast cancer patients, did not expect to have a serious illness because most of the time they presented with a small, painless lump. They reported being shocked by the news, as illustrated by the following quote:

> The name by itself is very scary … I was shocked, cried … I felt so bad ummm … different feelings at the same time. (IDI-P01: age 36 years, BC patient, AA)

(b) Suicidal risk:

Some of the patients who had received a diagnosis of breast cancer reported attempting suicide after receiving the news of their diagnosis, as demonstrated by the following quotes:

> It really damages your mind when you are told as having breast cancer for the first time … my brother was with me and I just ran away from him and tried to commit suicide. I wanted to be hit by a car. (IDI-P04: age 35, BC patient, AA)

> … we were forced to hide sharp materials from her since she wanted to kill herself. We were even considering it as evil spirit. (FGD-CR06: community representative, Hossana)

(c) Denial:

Denial was one of the major problems observed among cancer patients at the time of diagnosis. Both health professionals and the patients reported that it is very difficult for the majority of cancer patients to accept the diagnosis immediately. For this reason, those patients who were diagnosed in a government hospital went to private clinics and those who were diagnosed in rural areas usually travelled to Addis Ababa or a nearby city in order to repeat the tests and confirm the diagnosis.

> Since I didn't believe the result, I requested the doctor to give me another prescription to repeat the test. Then, the result was the same. (IDI-P04: age 35, BC patient, AA)

Denial was a very common problem not only at the time of diagnosis but even during the course of treatment. The health professionals mentioned that some patients, especially those with advanced cancer, still remained in a fluctuating state of denial even after they were convinced

Table 1. Characteristics of Participants Involved in the IDIs and FGDs in Five Towns in Ethiopia, 2019.

Data collection method	No. of IDIs/ FGDs	No. of participants	Gender	Age range (years)	Type of cancer or role of participant
FGD with cancer patients (Code P)	4	22	All females	20–70	18 breast cancers, 1 gastric cancer, 3 cervical cancers
FGD with health professionals (Code HP)	4	26	12 males, 14 females	28–60	4 surgeons, 1 pathologist, 2 gynaecologists, 1 oncology resident, 2 general practitioners, 3 psychiatry nurses, 8 surgical ward nurses, 5 midwives (cervical cancer screening)
FGD with religious leaders (Code RL)	4	27	25 males, 2 females	37–68	9 priests (Orthodox), 9 sheiks (Muslim), 7 pastors (Protestant), 2 Catholic leaders
FGD with community representatives (Code CR)	4	32	13 females, 19 males	38–74	8 HDAs, 7 kebele leaders, 6 eder leaders, 7 women representatives, 4 community leaders
IDI with health professionals (Code HP)	5	5	3 females, 2 males	27–60	2 oncologists, 2 nurses, 1 health officer
IDI with cancer patients (Code P)	6	6	All females	30–51	5 breast cancers, 1 endometrial cancer
IDI with patient relatives (Code R)	3	3	2 males, 1 female	31–45	Husband, son, and daughter

FGD, focus group discussion; HDA, Health Development Army (lowest-level health workers in the village); IDI, in-depth interview.

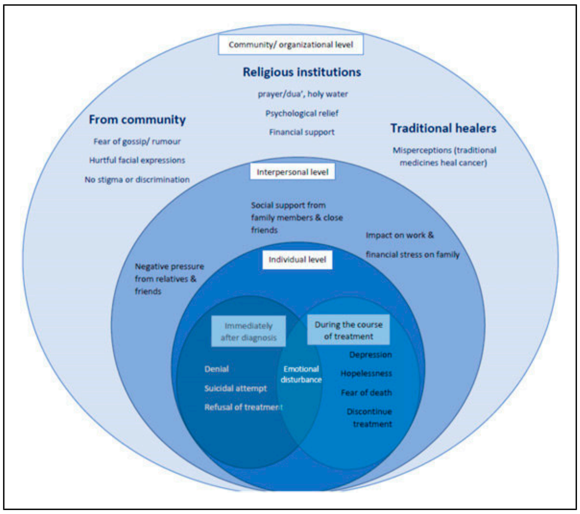


Figure 1. The social-ecological model of psychosocial problems among cancer patients in Ethiopia.

and started the treatment. Health professionals reported their observation in the following quote:

> They are in denial and do not want to hear any negative outcome or progress. Some patients want to go to private facility because they want to listen something promising. (IDI-HP04: nurse, government, AA)

(d) Refusal of treatment:

Surgeons who were interviewed reported that many cancer patients refused surgical treatments specifically for total removal of the breast (mastectomy) because it is the most common surgical procedure offered for breast cancer patients in Ethiopia.

> … when they hear the word cancer, the first thing which comes into their mind is death. So they immediately want to go home refusing surgery. (FGD-HP04: surgeon, Hossana)

Sub-Theme II: During the Course of Treatment

(a) Emotional disturbance:

At the time of diagnosis, cancer patients also reported that the treatment and its side effects brought emotional instabilities that might have serious psychological implications in their life, as illustrated by the following quote:

> Umm … it's hard … you feel so tired, you don't have hair, and your emotion is fluctuating. Even sometimes, you become irritable to those people who are taking care of you. Crying … (IDI-P01: age 36, BC patient, AA)

(b) Hopelessness, feeling depressed, and fear of death:

In this study, the other most commonly mentioned psychological problem among cancer patients was feeling sad/depressed. As the health professionals reported, many cancer patients feel depressed from the date of diagnosis and while receiving treatment. These patients perceive that the disease will not be cured and assume they will die immediately. The hopelessness observed is demonstrated in the following quote:

> Cancer kills the hope of living both the patient and their family. Even HIV patients do not lose hope as cancer patients do. Because they know that they can survive long taking the ART drugs. (FGD-CR02: community representative, Hossana)

(c) Non-adherence to treatment:

Our participants reported that many cancer patients discontinue treatment because of financial constraints (transport cost, medication, accommodation, etc.). Most cancer patients in peripheral sites needed to travel to Addis Ababa or nearby cities in order to obtain treatment. Another reason was that some patients assumed that the disease was cured after having surgery and the wound was healed without receiving systemic treatment. On the other hand, there were patients who expected a fast recovery after taking the medication, and when they did not observe any improvement in their health, they became discouraged and searched for alternatives such as traditional medicines. Giving late appointments and a lack of adequate information were other reasons for discontinuation of treatment among cancer patients. The following quote illustrates this:

> Usually, patients go to the health center then, they will be referred to hospital and again to Addis Ababa. In between, the patients spend a lot of money without getting any treatment and they suffer a lot. (FGD-CR08: HDA, Hossana)

Theme 2: Psychosocial Challenges at Interpersonal Level

In this study, we observed the relationship between cancer patients and their family members and close friends in two directions: from family members and close friends to the cancer patient (both positive and negative sides); and how the disease affected family members and also the work and social life of the cancer patient.

Sub-Theme I: Social Support From Family Members and Close Friends to Cancer Patients. Despite several psychosocial challenges identified in this study, we identified that almost all the cancer patients received strong social support from family members and close friends, starting from diagnosis until the end of treatment, as illustrated by the following quotes:

> My families are very supportive. They sacrificed and invested a lot for my treatment. (FGD-P02: age 33, BC patient, Woliso)

> My children, my husband and all my neighbors encourage and support me. (FGD-P02: age 50, BC patient, Hossana)

It is revealed that there is a strong social support in the community even after the patients died. Health professionals we interviewed stated that cancer patients often receive support from family members and the general community.

> Diseases like cancer, HIV, cardiac and kidney illnesses are chronic debilitating diseases which we have to start the supportive care immediately after diagnosis. The level of care continues even after the patient dies, which includes supporting the family after their loss. This is called Bereavement stage. The good thing in our country, our community has a very good social structure. In Ethiopia, people support each other for 3 or more days after death. People still go there for support even after 7 or 8 days especially relatives from far stay with them. Regarding cancer, patients usually feel better emotionally when being exposed to religious urge. (IDI-HP01: oncologist, AA)

In addition, the importance of psychosocial support was acknowledged by most of our participants and suggested different mechanisms on how best to involve different stakeholders and capitalize on the already existing social structure and health care system. For instance, community representatives from Butajira stated as follows:

> Counseling and education about cancer should be given by health care providers, while the edir (small supporting social structure) and religious leaders will mobilize the people to participate as the community strictly abide to edir rules and will not be absent. It will also be good if religious leaders are involved because they have great acceptance and respect by the people. In collaboration with the kebele (small administration unit) and edir leaders and with that of health extension workers and health development armies. (FGD-CR03: community representative, Butajira)

> I think psyhcosocial support should be part of the care. Intensive counseling plus bringing similar cases together and talking about the disease is very useful. We need to arrange a room for such kind of session to learn from each other, as it will be better than given by the health care provider. So

> psychosocial service is important especially for cancer patients, it is very essential. (FGD-HP07, health officer, Butajira)

Sub-Theme II: Impact of the Disease on Family Members and the Work/Social Life of Patients. All the participants, including patients' relatives, health professionals, and community representatives, reported that the disease had a negative impact on the family members and the work and social life of the patients, as demonstrated by the following quotes:

> …. she was a merchant and very active to do any kind of work. But as you can see her now, she is very weak and someone needs to take care of her at home. (IDI-R01: son, Assela)
>
> … all the family members will be negatively affected. Cancer makes the whole family very poor and to be dependent on others. (FGD-CR02: community representative, Hossana)

Theme 3: Psychosocial Challenges at the Community/Organizational Level

This theme encompasses the existing external factors that had a positive or negative influence on the psychosocial health of cancer patients in the community. These factors include community perceptions, norms/beliefs, and cultural/religious practices; therefore, we categorized them into three levels: (i) from the general community; (ii) religious institutions; and (iii) traditional treatment.

Sub-Theme I: From the Community. Concerning stigma and discrimination, we found contradictory findings reflecting the presence of self-stigma due to negative pressures coming from the community. Even though the community members do not instantly stigmatize or discriminate cancer patients, many patients preferred to isolate themselves from different social gatherings and did not want to talk about their disease to anyone other than their family members and close friends, as illustrated by the following quote:

> To tell you the truth, it's very difficult to talk about this issue in our community. Nobody knows that I have cancer except my family and few friends. I don't want to talk about it. Because people's reaction is psychologically touching. So, I don't want to be emotionally disturbed. The society is very challenging and I need to live carefully. (FGD-P05: age 33, BC patient, Waliso)

In this study, we tried to explore the reasons why patients want to hide their diagnosis and isolate themselves from the community. Among the several reasons they mentioned, fear of rumour or gossip and fear of being very emotional were the most commonly mentioned reasons. In some cases, the attendants were the ones who forced cancer patients to be isolated or not to actively engage in social gatherings due to the sickness itself and the weariness of such events. Our participants reported that community members assume that all cancer patients will die immediately and they often show them pity when sharing their sadness. In addition, some patients stated that they feel very emotional when people talk about their disease and whenever someone comes to their house to visit them. The following quotes support these findings:

> People usually talk behind your back and gossip each other when they see you from far. I feel so bad whenever people act like this. They always remind me my illness. (FGD: P02, age 27, BC patient, Waliso)
>
> Our community assume that cancer patients will die immediately. So, I don't want people to show me pity face and say "emtse." I don't want that; it reminds me as I will die soon. (IDI-P01: age 36, BC patient, AA)

In contrast, our results revealed that community members believe that cancer will not be transmitted from person to person despite their low awareness level about the disease. Thus, stigma and discrimination towards cancer patients did not emerge as one of the psychosocial challenges in the community, and the health professionals also commented that they never encountered this kind of complaint from their patients.

> We feel so sad for cancer patients and there is no stigma and discrimination on these patients. We have never seen such kind of thing until now. (FGD-CR02: kebele leader, Butajira)
>
> Here our community is integrated by a number of social activities. The society provides support for patients, do not discriminate or stigmatize them. However the patients usually hide their problem and they do not want to talk or have contact with other person. (FGD-RL: priest, Butajira)

Sub-Theme II: Religious Institutions. In this study, we discovered that there were different religious places that provide spiritual support for cancer patients in the community. Many cancer patients practice their own religious rituals, such as praying, dua (prayer in the Muslim community), and drinking holy water.

> I can say almost all cancer patients come to our monasteries and historical religious places especially for holy water. Umm … there are patients who are totally cured and there are also others who passed away in those places. This depends on the strength of their faith. (FGD-RL08: priest, Hossana)

Among the several reasons why cancer patients visited religious places, cost and extended duration of medical treatment and pressure from community members were identified. However, the main reason was due to the strong perception in the community: people believed that cancer is a dangerous disease that requires God's/Allah's intervention in order to survive after being diagnosed with the disease. Therefore, many patients visited those places to be cured from the disease and gain psychological relief.

> Most of the time cancer patients come to our church for three main reasons, first for prayer (to be healed), second for financial support, and third to get psychological relief since most of them are hopeless. (FGD-RL06: pastor, Butajira)

Our results also identified that many cancer patients refused or discontinued medical treatment and stayed in religious places for an extended duration. Afterwards, they returned back to the health facilities with complications and at an advanced stage of the disease in which there was no option to provide curative treatment other than giving supportive care.

> Some people prefer to visit other places like religious places. I personally met many patients who refused the treatment and they returned back after the disease is metastasized. (IDI-HP02: oncologist, AA)

Sub-Theme III: Traditional Healers

(a) Community perception:

The community believes that traditional medicines can heal any lumps/tumours. They assume that local herbal treatments applied on a swelling can help to burst the wound and dry it immediately. In addition, the community perceives that cancer cannot be cured by medical treatment. For these reasons, there are several herbalists/traditional healers in the community that provide herbal medicines for cancer and other chronic illnesses.

> The community believe that cancer cannot be cured by medical treatment. So, people always advise us to take her to a herbalist. (IDI-R02: husband, Assela)

(b) Practice:

Some patients reported that they took traditional medicine either before coming to the health facility or even after they started the medical treatment. Some of these patients stated that they do not believe that traditional medicine can cure cancer, but they tried these treatments because of a lack of other alternatives and because of pressure from the community. On the other hand, few patients believed that traditional medicine could totally cure cancer and even shared their experience.

> Sister told me as I have to take the tablet for 5 yrs. But I took some herbal medicine in between and I am fine now. (FGD-P05: age 44, BC patient, Butajira)

Discussion

This study revealed that cancer patients face several unique psychosocial challenges at different stages of the disease trajectory. These challenges occur at individual and interpersonal levels, as well as in the relationship with communities and institutional systems of care. Immediately after diagnosis, many cancer patients expressed shock, fear, and even attempted suicide when they were informed that they had cancer.

A cancer diagnosis can create a threat to one's general sense of security and orderliness in life (Gorman, 2003). Even for early-stage treatable cancers, many people retain deep-seated fears that any cancer represents pain, suffering, and death. The emotional disturbance is highly associated with the awareness within the community, which is why it is important to differentiate and understand the prognosis of the different types of cancer. In our study, the majority of participants were breast cancer patients, with some diagnosed at an early stage of the disease. However, all of them were extremely shocked at the time of diagnosis. This might be because of lack of adequate knowledge and the perceived severity of the disease in the community (Chaka et al., 2018; Geremew et al., 2018). The majority of people are not aware of treatable cancers and assume that cancer cannot be cured even if it is diagnosed at an early stage and treatment is given to the patient: they directly link the word 'cancer' with death, which is why many patients suffer from severe emotional distress when they hear the word 'cancer'. Similar findings were reported from a study conducted among adolescent cancer patients in the United States (Head & Iannarino, 2019). Another study also stated, "For many, cancer is synonymous with death, and fear is a rational and primal response" (Penson et al., 2005). This is consistent with a previously conducted study on the disclosure of cancer diagnosis in Ethiopia, which reported that both health professionals and family members tried to avoid the word 'cancer' and preferred to use other similar words to talk about the illness with the patient (Abebe & Abebe, 2017).

A similar type of perception towards cancer treatment was also reported from other African countries, such as Nigeria (Jedy-Agba et al., 2017), Cameroon (Kaninjing et al., 2018), Botswana (Anakwenze et al., 2018), and

Ghana (Gyedu et al., 2018). This unbalanced perception might be attributed to high cancer mortality rates in Africa (American Cancer Society [ACS], 2022; Bray et al., 2018), including Ethiopia (Eber-Schulz et al., 2018; Gizaw et al., 2017). In particular, a lack of good success stories makes the situation more difficult to persuade the community that cancer patients can be cured and live longer. In addition, there is no patient support group organized by survivors, and those patients who were treated and cured from cancer usually do not go public to increase public awareness (Wondimagegnehu et al., 2023). In contrast, a large-scale study conducted among advanced cancer patients in 11 countries across the world reported that 55% of patients receiving palliative care inaccurately perceive that their cancer is curable (Yennurajalingam et al., 2018); this huge variation in perception towards the curability of cancer might be due to geographical differences (the majority of the data in the above-mentioned study was from developed countries), methodological differences, and the fact that it was hospital-based with only advanced cancer patients, compared to our study that included community representatives and religious leaders.

Depression, hopelessness, and fear of death were the other identified psychosocial challenges in this study. Several systematic reviews and explanatory studies reported that these symptoms are very common among cancer patients, either at the time of diagnosis or during the course of treatment (Doherty et al., 2019; Saleh Baqutayan, et al., 2012; Wondimagegnehu, et al., 2019; Zainal et al., 2013). However, the reported variation in the percentage and severity of symptoms might be explained by the difference in the site and stage of cancer, the type of treatment received, the social structure, and the psychosocial support received.

Although the magnitude of refusals for medical treatment was not determined in this study, our results suggested that several cancer patients refused surgical or any kind of treatment immediately after diagnosis. This finding is in line with a previous quantitative study stating that one in five cancer patients refuse surgery or discontinue medical treatment in peripheral hospitals of Ethiopia (Wondimagegnehu et al., 2022). Conversely, a study in the United States reported that only .4% and .9% of cancer patients refused surgical and radiation therapy, respectively (Aizer et al., 2014). The main reasons for refusal should be explored further, but possible explanations might include lack of trust in the medical treatment, bad experience of other patients, fear of complications, and also false beliefs (the cause of cancer is an evil spirit that should be treated with spiritual customs only).

We also found that some cancer patients discontinued medical treatment for several reasons. Financial constraint was one of the major reasons explored in this study. Due to the complex nature of the disease, cancer requires local and systemic treatment for an extended duration of time, and it is known that each type of treatment is expensive and not affordable for many cancer patients. For this reason, many developed countries use different mechanisms to minimize the financial burden on patients: subsidizing the medication cost, including it in health insurance fees or linking patients with different supporting organizations, and other means. However, in Ethiopia and other LMICs, the absence of a health insurance system (Travado et al., 2017) means that cancer patients have to pay all the diagnostic and treatment costs from their own pockets. According to a study in Cameroon, only 1% of cancer patients used private insurance and 1% received support from the government to pay for treatment (Price et al., 2012). In addition, because of the limited number of cancer centres in Ethiopia, the majority of cancer patients and their caregivers need to travel to the capital city, which exposes them to additional transport and accommodation costs. Such extra costs exacerbate the financial stress on the whole family and can even make treatment impossible. The above-mentioned study found that 23% of patients travelled more than 7 hours to reach a cancer centre and that 40% of patients spent more than $200 on a single round of chemotherapy (Price et al., 2012). Similarly, a study in Ethiopia found that 74.4% of patients experienced catastrophic health expenditure, with a mean overall cost of $2366 per patient. Chemotherapy was one of the main reasons for such high expenditure (Kasahun et al., 2020). Another study in Malawi reported that around two-thirds of cancer patients frequently request financial and food support, suggesting a high prevalence of economic and psychosocial needs in such settings (Herce et al., 2014).

This study also identified that cancer patients discontinue medical treatment because of pressure from the community to visit traditional healers and religious places. Traditional treatment is still considered to be one of the effective treatment options for many chronic illnesses in LMICs, especially in Africa. Several studies conducted in different parts of the continent reported that many cancer patients took traditional medicine or at least tried it once (Anakwenze et al., 2018; Jedy et al., 2017; Kaninjing, 2018).

Even though spirituality is one of the components of psychosocial support recommended for patients with chronic illness, our study found that religious beliefs and practices may negatively influence cancer patients either to accept and start treatment immediately after diagnosis or to discontinue medical treatment. Similar studies in Nigeria and Ghana reported that there is a significant association between religion and late-stage diagnosis among breast cancer patients (Gyedu et al., 2018; Jedy et al., 2017). These studies revealed the impact of religion on screening practice, early diagnosis, and adherence to treatment in cancer care. Another qualitative study from India described the link between cancer care and religion from a different angle, looking at the impact of cancer on religion. The participants reported that cancer affected their faith and even changed their religion while few became closer to God due to their illness (Elsner, 2012). Similar findings were reported from Malaysia, with cancer considered to be a lesson from God and suffering seen as educational theodicy: getting closer to God (Ahmadi et al., 2019). Our study also explored the link between faith and the curability of cancer and found that the Ethiopian community strongly believed that someone can be cured from cancer if he/she has a strong faith in God/Allah and properly practices the religious rituals. Previous studies conducted in different parts of the country also came up with similar findings concerning religious practices and the utilization of traditional medicine among cancer patients (Chaka, 2018; Dereje et al., 2020; Gebremariam et al., 2019). The misconception by patients, their family, and community that cancer is not curable negatively affected patients' acceptance of treatment and, as a result, caused the patients to look for alternative approaches.

Nevertheless, cancer patients in Ethiopia receive social support from family, friends, and significant others; our results also revealed that they are forced to hide themselves from social activities due to peoples' reaction around them. The community members are unintentionally disrupting patients' emotional well-being assuming that they are providing social care. Similarly, a qualitative study done in Liberia narrated about the wholistic nature of cancer patients and how the interaction of various environmental, social, and interpersonal factors attribute the psychosocial well-being of cancer patients (Lusaka et al., 2023).

The findings of this study suggest the need to design, integrate, and provide culturally acceptable psychosocial services in the routine cancer care of Ethiopia. Challenges identified at individual, interpersonal, and community levels may offer guidance on how and where to intervene and who to involve in the establishment and implementation of a supportive care system in the continuum of cancer care. Therefore, an educational session on how to approach and provide emotional and other supportive care should be given for family members/care givers and the general community at large. According to a recent scoping review, providing different types of supportive services in less-resourced settings, even when health systems are fragmented and fragile, can improve mental health, physical health, and the quality of life of cancer patients (Cabanes et al., 2022). Even though the importance of psychosocial services for cancer patients has been well proven, previous study in Ethiopia showed there are no structured psychosocial services for cancer patients (Wondimagegnehu et al., 2023). The need for increased community engagement, primary palliative care capacity development, and the support of local and national decision-makers is also emphasized to expand supportive care through considering the various dimensions of patients (Lusaka et al., 2023). Similarly in Ethiopia, attention should be given for provision of comprehensive palliative care as majority of cancer patients are diagnosed at advanced stage of the disease and require various form of psychosocial services that should be integrated in the routine cancer care and existing social structure.

One of the strengths of this study is fulfilling the principle of maximum variation, in that the data were collected from cancer patients, patients' relatives, health professionals, community representatives, and religious leaders, which enhanced the completeness and representativeness of the data. The other strengths of the study are the large sample size, the use of a mixed data collection technique (both IDIs and FGDs), and the study being conducted in both urban and rural areas.

One limitation of this study is that the majority of the participants involved in this study were breast cancer patients, which slightly skewed our participants to more females than males. However, an attempt was made to include other types of cancers, such as gastric, endometrial, and cervical cancer. Another limitation of the study is that traditional healers were not included, even though we initially planned to involve them; we approached two herbalists in Butajira, but they were not willing to be interviewed.

Conclusion and Recommendation

In this study, at an individual level, emotional distress, denial, and suicidal attempts were the most common challenges immediately after diagnosis, while depression, hopelessness, and fear of death were identified as problems during the course of treatment. At an interpersonal level, we found that cancer patients had strong social support from family members and close friends. However, the involvement of family members in major decisions had a negative influence on adherence to treatment.

Due to this and several other reasons, many cancer patients refused or discontinued treatment and visited religious places or traditional healers, returning back to the health facility at an advanced stage of the disease. Even though there was no stigma or discrimination in the community, this study also revealed that the majority of cancer patients isolated themselves from social gatherings because they did not want to talk about their disease.

Therefore, psychosocial services that include individual counselling and psychoeducation should be provided for cancer patients in health facilities. Health professionals need to routinely screen cancer patients for comorbid diseases such as depression and anxiety and provide appropriate emotional support as needed. Importantly, family and close friends need to be supported and counselled about the treatment in order to avoid contradictory advice being given to the patients. Health education programmes should be organized to improve patient and public awareness that cancer is a curable/treatable disease, using a patient support group, such as cancer survivors, to improve the emotional, psychosocial, and clinical outcomes of cancer. Religious leaders and traditional healers should be involved and work collaboratively with health professionals in the provision of psychosocial services for cancer patients; they should also be informed about the treatment concepts of common cancers and the importance of timely management. In order to gain a complete picture of the problem, we recommend a larger study that includes traditional healers and patients with different cancer types who may have unique psychosocial problems depending on the anatomic site of origin.

Acknowledgments

The authors would like to thank the College of Health Sciences, Addis Ababa University, for the ethical review process. They would also like to thank the study participants, health facilities, and the funding organization.

Author Contributions

All authors conceived and designed the study. A.W., A.A., and E.J.K. prepared the interview guides and A.W. conducted the IDIs and moderated the FGDs. Data analysis and interpretation of the findings was performed by A.W., who also drafted the manuscript. A.A. and B.Z. were actively involved in data interpretation and rewriting the manuscript. M.A., S.T., and E.J.K. critically reviewed the different versions of the manuscript. All authors read and approved the final manuscript.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by the Else-Kroener-Fresenius Foundation through Martin Luther University, Halle-Wittenberg, Germany, Grant No.: 2018_HA31SP. This study was also supported by a grant from the German Academic Exchange Service to Martin Luther University, Halle-Wittenberg, Germany (ID: 57216764), and a grant from the Hospital Partnerships programme through the Deutsche Gesellschaft für Internationale Zusammenarbeit, funded by the Ministry for Economic Cooperation and Development (ID: 81281315).

Ethical Statement

Ethical Approval

Ethical clearance of this study was obtained from the Research Ethics Committee of School of Public Health and Institutional Review Board of College of Health Science, Addis Ababa University (approval number: 041/20/SPH).

Informed Consent

Written informed consent was taken from all participants. Confidentiality and anonymity of the participants was maintained.

ORCID iD

Abigiya Wondimagegnehu https://orcid.org/0000-0002-1491-0959

References

Abebe, E., & Abebe, H. (2017). Types of cancers diagnosed and the preference of families of adult patients with cancer about disclosing diagnosis to the patients. *Ethiopian Journal of Health Sciences*, *27*(3), 255–262. https://doi.org/10.4314/ejhs.v27i3.7

Ahmadi, F., Mohamed Hussin, N. A., & Mohammad, M. T. (2019). Religion, culture and meaning-making coping: A study among cancer patients in Malaysia. *Journal of Religion and Health*, *58*(6), 1909–1924. https://doi.org/10.1007/s10943-018-0636-9

Aizer, A. A., Chen, M. H., Parekh, A., Choueiri, T. K., Hoffman, K. E., Kim, S. P., Martin, N. E., Hu, J. C., Trinh, Q. D., & Nguyen, P. L. (2014). Refusal of curative radiation therapy and surgery among patients with cancer. *International Journal of Radiation Oncology, Biology, Physics*, *89*(4), 756–764. https://doi.org/10.1016/j.ijrobp.2014.03.024

Akinyemiju, T., Ogunsina, K., Gupta, A., Liu, I., Braithwaite, D., & Hiatt, R. A. (2022). A socio-ecological framework for cancer prevention in low and middle-income countries. *Frontiers in Public Health*, *10*(10), 884678. https://doi.org/10.3389/fpubh.2022.884678

Alemayehu, M., Deyessa, N., Medihin, G., & Fekadu, A. (2018). A descriptive analysis of depression and pain complaints among patients with cancer in a low income country. *PLoS One*, *13*(3), Article e0193713. https://doi.org/10.1371/journal.pone.0193713

American Cancer Society. (2022). *Breast cancer facts and figures 2022-2024*. American Cancer Society. https://www.cancer.org/research/cancer-facts-statistics/breast-cancer-facts-figures.html

Anakwenze, C., Bhatia, R., Rate, W., Bakwenabatsile, L., Ngoni, K., Rayne, S., Dhillon, P., Narasimhamurthy, M., Ho-Foster, A., Ramogola-Masire, D., & Grover, S. (2018). Factors related to advanced stage of cancer presentation in Botswana. *Journal of Global Oncology*, *4*(2018), 1–9. https://doi.org/10.1200/JGO.18.00129

Aweke, Y. H., Ayanto, S. Y., & Ersado, T. L. (2017). Knowledge, attitude and practice for cervical cancer prevention and control among women of childbearing age in Hossana Town, Hadiya zone, Southern Ethiopia: Community-based cross-sectional study. *PLoS One*, *12*(7), Article e0181415. https://doi.org/10.1371/journal.pone.0181415

Baqutayan, S. M. S. (2012). The effect of anxiety on breast cancer patients. *Indian Journal of Psychological Medicine*, *34*(2), 119–123. https://doi.org/10.4103/0253-7176.101774

Bergerot, C. D., Philip, E. J., Schuler, T. A., Clark, K. L., Loscalzo, M., Buso, M. M., de Matos Neto, J. N., Pinto Neto, J. V., Nonino, A., & de Araujo, T. C. C. F. (2016). Development and implementation of a comprehensive psychosocial screening program in a Brazilian cancer center. *Psycho-Oncology*, *25*(11), 1343–1349. https://doi.org/10.1002/pon.4275

Bingham, A. J., & Witkowsky, P. (2022). Deductive and inductive approaches to qualitative data analysis. In C. Vanover, P. Mihas, & J. Saldaña (Eds.), *Analyzing and interpreting qualitative data: After the interview* (1st ed., pp. 133–146). SAGE Publications, Inc. https://books.google.de/books/about/Analyzing_and_Interpreting_Qualitative_R.html?id=QqwFEAAAQBAJ&redir_esc=y

Bray, F., Ferlay, J., Soerjomataram, I., Siegel, R. L., Torre, L. A., & Jemal, A. (2018). Global cancer statistics 2018: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA: A Cancer Journal for Clinicians*, *68*(6), 394–424. https://doi.org/10.3322/caac.21492

Brierley, M. E., Sansom-Daly, U. M., Baenziger, J., McGill, B., & Wakefield, C. E. (2019). Impact of physical appearance changes reported by adolescent and young adult cancer survivors: A qualitative analysis. *European Journal of Cancer Care*, *28*(4), Article e13052. https://doi.org/10.1111/ecc.13052

Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. *American Psychologist*, *32*(7), 513–531. https://doi.org/10.1037/0003-066X.32.7.513

Bronfenbrenner, U., & Ceci, S. J. (1994). Nature-nurture reconceptualized in developmental perspective: A bioecological model. *Psychological Review*, *101*(4), 568–586. https://doi.org/10.1037/0033-295X.101.4.568

Cabanes, A., Taylor, C., Malburg, C., & Le, P. T. (2022). Supportive care interventions for cancer patients in low- and middle-income countries (LMICs): A scoping review. *Supportive Care in Cancer*, *30*(11), 9483–9496. https://doi.org/10.1007/s00520-022-07319-5

Cain, C. L., Surbone, A., Elk, R., & Kagawa-Singer, M. (2018). Culture and palliative care: Preferences, communication, meaning, and mutual decision making. *Journal of Pain and Symptom Management*, *55*(5), 1408–1419. https://doi.org/10.1016/j.jpainsymman.2018.01.007

Caulfield, J. (2019, September 9). How to*Do Thematic A*nalysis | Step-by-Step Guide & Examples. https://www.scribbr.com/methodology/thematic-analysis/

Chaka, B., Sayed, A., Goeieman, B., & Rayne, S. (2018). A survey of knowledge and attitudes relating to cervical and breast cancer among women in Ethiopia. *BMC Public Health*, *18*(1), 1072. https://doi.org/10.1186/s12889-018-5958-8

Dereje, N., Addissie, A., Worku, A., Assefa, M., Abraha, A., Tigeneh, W., Kantelhardt, E. J., & Jemal, A. (2020). Extent and predictors of delays in diagnosis of cervical cancer in Addis Ababa, Ethiopia: A population-based prospective study. *JCO Global Oncology*, *6*(6), 277–284. https://doi.org/10.1200/JGO.19.00242

Doherty, M. E., Power, L., Rahman, R., Ferdous, L., Akter, K. M., Quadir, S. S., Sharmin, S., Evans, E., & Khan, F. (2019). The psychosocial and spiritual experiences of patients with advanced incurable illness in Bangladesh: A cross-sectional observational study. *Indian Journal of Palliative Care*, *25*(4), 487–493. https://doi.org/10.4103/IJPC.IJPC_113_19

Eber-Schulz, P., Tariku, W., Reibold, C., Addissie, A., Wickenhauser, C., Kantelhardt, E. J., Fathke, C., Hauptmann, S., Jemal, A., & Thomssen, C. (2018). Survival of breast cancer patients in rural Ethiopia. *Breast Cancer Research and Treatment*, *170*(1), 111–118. https://doi.org/10.1007/s10549-018-4724-z

Elsner, F., Schmidt, J., Rajagopal, M., Radbruch, L., & Pestinger, M. (2012). Psychosocial and spiritual problems of terminally ill patients in Kerala, India. *Future Oncology*, *8*(9), 1183–1191. https://doi.org/10.2217/fon.12.97

Emory Winship Cancer Institute. (2019). Emotional and psychosocial effects of cancer. *Cancer Quest*. https://www.cancerquest.org/patients/psychosocial-problems

Fingeret, M. C., Teo, I., & Epner, D. E. (2014). Managing body image difficulties of adult cancer patients: Lessons from available research. *Cancer*, *120*(5), 633–641. https://doi.org/10.1002/cncr.28469

Gebremariam, A., Addissie, A., Worku, A., Assefa, M., Kantelhardt, E. J., & Jemal, A. (2019). Perspectives of patients, family members, and health care providers on late diagnosis of breast cancer in Ethiopia: A qualitative study. *PLoS One*, *14*(8), Article e0220769. https://doi.org/10.1371/journal.pone.0220769

Geremew, A. B., Gelagay, A. A., & Azale, T. (2018). Comprehensive knowledge on cervical cancer, attitude towards its screening and associated factors among women aged 30-49 years in Finote Selam town, northwest Ethiopia.

Reproductive Health, *15*(1), 29. https://doi.org/10.1186/s12978-018-0471-1

Gizaw, M., Addissie, A., Getachew, S., Ayele, W., Mitiku, I., Moelle, U., Yusuf, T., Begoihn, M., Assefa, M., Jemal, A., & Kantelhardt, E. J. (2017). Cervical cancer patients presentation and survival in the only oncology referral hospital, Ethiopia: A retrospective cohort study. *Infectious Agents and Cancer*, *12*(61), 61. https://doi.org/10.1186/s13027-017-0171-4

Gorman, L. M. (2003). *The psychosocial impact of cancer on the individual, family, and society psycho nursing care* (2nd ed.). Oncology Nursing Society. https://www.ons.org/sites/default/files/publication_pdfs/Sample/Chapter/0554/PsyNsgCare2nd.pdf

Grassi, L., & Watson, M. (2012). Psychosocial care in cancer: An overview of psychosocial programmes and national cancer plans of countries within the International Federation of Psycho-Oncology Societies. *Psycho-Oncology*, *21*(10), 1027–1033. https://doi.org/10.1002/pon.3154

Gyedu, A., Gaskill, C. E., Boakye, G., Abdulai, A. R., Anderson, B. O., & Stewart, B. (2018). Differences in perception of breast cancer among Muslim and Christian women in Ghana. *Journal of Global Oncology*, *4*(4), 1–9. https://doi.org/10.1200/JGO.2017.009910

Habtu, Y., Yohannes, S., & Laelago, T. (2018). Health seeking behavior and its determinants for cervical cancer among women of childbearing age in Hossana town, Hadiya zone, Southern Ethiopia: Community based cross sectional study. *BMC Cancer*, *18*(1), 298. https://doi.org/10.1186/s12885-018-4203-2

Head, K. J., & Iannarino, N. T. (2019). It changed our outlook on how we want to live": Cancer as a transformative health experience for young adult survivors and their family members. *Qualitative Health Research*, *29*(3), 404–417. https://doi.org/10.1177/1049732318800674

Herce, M. E., Elmore, S. N., Kalanga, N., Keck, J. W., Wroe, E. B., Phiri, A., Mayfield, A., Chingoli, F., Beste, J. A., Tengatenga, L., Bazile, J., Krakauer, E. L., & Rigodon, J. (2014). Assessing and responding to palliative care needs in rural sub-Saharan Africa: Results from a model intervention and situation analysis in Malawi. *PLoS One*, *9*(10), Article e110457. https://doi.org/10.1371/journal.pone.0110457

Hubbeling, H. G., Rosenberg, S. M., González-Robledo, M. C., Cohn, J. G., Villarreal-Garza, C., Partridge, A. H., & Knaul, F. M. (2018). Psychosocial needs of young breast cancer survivors in Mexico city, Mexico. *PLoS One*, *13*(5), Article e0197931. https://doi.org/10.1371/journal.pone.0197931

Jedy-Agba, E., McCormack, V., Adebamowo, C., & Dos-Santos-Silva, I. (2016). Stage at diagnosis of breast cancer in sub-Saharan Africa: A systematic review and meta-analysis. *Lancet Global Health*, *4*(12), 923–935. https://doi.org/10.1016/s2214-109x(16)30259-5

Jedy-Agba, E., McCormack, V., Olaomi, O., Badejo, W., Yilkudi, M., Yawe, T., Ezeome, E., Salu, I., Miner, E., Anosike, I., Adebamowo, S. N., Achusi, B., Dos-Santos-Silva, I., & Adebamowo, C. (2017). Determinants of stage at diagnosis of breast cancer in Nigerian women: Sociodemographic, breast cancer awareness, health care access and clinical factors. *Cancer Causes and Control*, *28*(7), 685–697. https://doi/10.1007/s10552-017-0894-y

Kaninjing, E., Lopez, I., Nguyen, J., Odedina, F., & Young, M. E. (2018). Prostate cancer screening perception, beliefs, and practices among men in Bamenda, Cameroon. *American Journal of Men's Health*, *12*(5), 1463–1472. https://doi.org/10.1177/1557988318768596

Kasahun, G. G., Gebretekle, G. B., Hailemichael, Y., Woldemariam, A. A., & Fenta, T. G. (2020). Catastrophic healthcare expenditure and coping strategies among patients attending cancer treatment services in Addis Ababa, Ethiopia. *BMC Public Health*, *20*(1), 984. https://doi.org/10.1186/s12889-020-09137-y

Lusaka, J., Kpoeh, J. D., Crowell, J. P., Gowa, M. S., Hardy, D. M., Karanja, V., & Rosa, W. (2023). "I am a human": A process evaluation of a nurse-led community-based, palliative care program in Liberia, West Africa. *Journal of Hospice and Palliative Nursing*, *25*(3), 137–145. https://doi.org/10.1097/NJH.0000000000000944

Martei, Y. M., Pace, L. E., Brock, J. E., & Shulman, L. N. (2018). Breast cancer in low- and middle income countries: Why we need pathology capability to solve this challenge. *Clinics in Laboratory Medicine*, *38*(1), 161–173. https://doi.org/10.1016/j.cll.2017.10.013

Merighi, J. R. (2016). Handbook of oncology social work: Psychosocial care for people with cancer. *Social Work in Health Care*, *55*(6), 481–484. https://doi.org/10.1080/00981389.2016.1162260

Nikbakhsh, N., Moudi, S., Abbasian, S., & Khafri, S. (2014). Prevalence of depression and anxiety among cancer patients. *Caspian Journal of Internal Medicine*, *5*(3), 167–170. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4143739/pdf/cjim-5-167.pdf

Pariona, A. (2017, April 25). Religious beliefs in Ethiopia. *World atlas*. https://www.worldatlas.com/articles/religious-beliefs-in-ethiopia.html

Penson, R. T., Partridge, R. A., Shah, M. A., Giansiracusa, D., Chabner, B. A., & Lynch, T. J. (2005). Update: Fear of death. *The Oncologist*, *10*(2), 160–169. https://doi.org/10.1634/theoncologist.10-2-160

Price, A. J., Ndom, P., Atenguena, E., Mambou Nouemssi, J. P., & Ryder, R. W. (2012). Cancer care challenges in developing countries. *Cancer*, *118*(14), 3627–3635. https://doi.org/10.1002/cncr.26681

Rosa, W. E., & Ferrell, B. R. (2023, July 20). *The nature of suffering and the goals of nursing*. Oxford University Press. https://academic.oup.com/book/46614?login=true

Travado, L., Bultz, B. D., Ullrich, A., Asuzu, C. C., Turner, J., Grassi, L., & Jacobsen, P. (2017). 2016 president's plenary international psycho-oncology society: Challenges and opportunities for growing and developing psychosocial oncology programmes worldwide. *Psycho-Oncology*, *26*(9), 1231–1238. https://doi.org/10.1002/pon.4471

Wang, J. W., Shen, Q., Ding, N., Zhang, T. R., Yang, Z. Q., Liu, C., Chen, S., Berry, H. L., Yuan, Z., & Yu, J. (2015). A qualitative exploration of the unmet psychosocial rehabilitation needs of cancer survivors in China. *Psycho-Oncology*, *25*(8), 905–912. https://doi.org/10.1002/pon.4023

Wondimagegnehu, A., Abebe, W., Abraha, A., & Teferra, S. (2019). Depression and social support among breast cancer patients in Addis Ababa, Ethiopia. *BMC Cancer*, *19*(1), 836. https://doi.org/10.1186/s12885-019-6007-4

Wondimagegnehu, A., Abebe, W., Hirpa, S., Kantelhardt, E. J., Addissie, A., Zebrack, B., & Teferra, S. (2023). Availability and utilization of psychosocial services for breast cancer patients in Addis Ababa, Ethiopia: A mixed method study. *European Journal of Cancer Care*, *2023*(12), 5543335. https://doi.org/10.1155/2023/5543335

Wondimagegnehu, A., Negash Bereded, F., Assefa, M., Teferra, S., Zebrack, B., Addissie, A., & Kantelhardt, E. J. (2022). Burden of cancer and utilization of local surgical treatment services in rural hospitals of Ethiopia: A retrospective assessment from 2014 to 2019. *The Oncologist*, *27*(11), 889–898. https://doi/10.1093/oncolo/oyac127

World Health Organization (WHO). (2018, September 11). *WHO leads the way towards the elimination of cervical cancer as a public health concern*. https://www.who.int/news/item/11-09-2018-who-leads-the-way-towards-the-elimination-of-cervical-cancer-as-a-public-health-concern

Yennurajalingam, S., Rodrigues, L. F., Shamieh, O., Tricou, C., Filbet, M., Naing, K., Ramaswamy, A., Perez-Cruz, P. E., Bautista, M. J., Bunge, S., Muckaden, M. A., Sewram, V., Fakrooden, S., Noguera-Tejedor, A., Rao, S. S., Liu, D., Park, M., Williams, J. L., Lu, Z., & Bruera, E. (2018). Perception of curability among advanced cancer patients: An international collaborative study. *The Oncologist*, *23*(4), 501–506. https://doi.org/10.1634/theoncologist.2017-0264

Zainal, N. Z., Nik-Jaafar, N. R., Baharudin, A., Sabki, Z. A., & Ng, C. G. (2013). Prevalence of depression in breast cancer survivors: A systematic review of observational studies. *Asian Pacific Journal of Cancer Prevention*, *14*(4), 2649–2656. https://doi.org/10.7314/APJCP.2013.14.4.2649

Zebrack, B. J., Yi, J., Petersen, L., & Ganz, P. A. (2007). The impact of cancer and quality of life for long-term survivors. *Psycho-Oncology*, *17*(9), 891–900. https://doi.org/10.1002/pon.1300

Hindawi
European Journal of Cancer Care
Volume 2023, Article ID 5543335, 12 pages
https://doi.org/10.1155/2023/5543335

Research Article

Availability and Utilization of Psychosocial Services for Breast Cancer Patients in Addis Ababa, Ethiopia: A Mixed Method Study

Abigiya Wondimagegnehu,[1,2] **Workeabeba Abebe**,[3] **Selamawit Hirpa**,[1,4] **Eva J. Kantelhardt**,[2,5] **Adamu Addissie**,[1,2] **Bradley Zebrack**,[6] **and Solomon Teferra**[7]

[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 (Saale), Germany*
[3] *Department of Pediatrics and Child Health, School of Medicine, College of Health Sciences, Addis Ababa University, Addis Ababa, Ethiopia*
[4] *Medical Faculty of the Martin-Luther-University Halle-Wittenberg, Institute for General Practice and Family Medicine, Halle (Saale), Germany*
[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*

Correspondence should be addressed to Abigiya Wondimagegnehu; abitowon@gmail.com

Received 5 April 2023; Revised 22 August 2023; Accepted 30 August 2023; Published 12 September 2023

Academic Editor: Sourav Panja

The provision of psychosocial services has a substantial impact on cancer care by reducing emotional distress and improving both the quality of life and survival of patients, but the availability and utilization of such services have not been well studied in developing countries, particularly, Ethiopia. Therefore, we explored the types of psychosocial services available for breast cancer patients in Addis Ababa, Ethiopia. A mixed method study was conducted using a cross-sectional survey involving 428 breast cancer patients, followed by a qualitative study. A total of nine in-depth interviews (IDIs) were conducted with four breast cancer patients and five key informants using two separate interview guides. In addition to descriptive statistics, logistic regression was performed to identify factors associated with the provision of psychosocial services. Thematic analysis was used for the qualitative data, using NVivo 12 plus software. Only 47 (11.1%) patients received psychosocial services in the form of counselling, emotional support, or information provision. 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 were no well-structured counselling services, emotional support, or group discussion sessions for breast cancer patients in these health facilities. The main reasons for not providing these services were high patient flow/workload, inadequate space, lack of training, and not having qualified professionals to organise and deliver psychosocial services in these hospitals. Only one in ten breast cancer patients received psychosocial services from health professionals, and the services were not delivered in a structured way. Therefore, psychosocial services should be integrated in both private and government health facilities in Ethiopia.

1. Introduction

Cancer is a devastating disease causing significant psychological problems among patients and their caregivers [1]. Several studies have revealed that cancer patients face emotional, social, and psychological difficulties in the form of either anxiety or depressive disorders [2–5]. Evidence has also suggested that psychological disorders are significantly associated with substantial functional impairment, fatigue, pain, poor quality of life [6], and reduced survival [7]. Particularly, patients with breast cancer who are in the midst of treatment experience fear and concerns regarding mortality, disease recurrence, and body image impairment, especially in relation to mastectomy, hormonal treatment, and sexuality [1, 8, 9]. For this reason, the National Comprehensive Cancer Network (NCCN) Distress Management Panel guideline indicates the importance of assessing the physical, psychological, social, and spiritual needs of cancer patients and recommends regular screening for any form of distress, anxiety, and other common mental illnesses using appropriate and validated tools [10, 11].

Psychosocial services are one of the components of cancer care addressing the social, psychological, emotional, spiritual, and functional aspects of the patient's journey, requiring an interdisciplinary team of care and service providers [12]. These services include a variety of psychological and educational components, such as relaxation training, cognitive and behavioural coping strategies, cancer education/information sessions, and group social support [13–15]. Provision of psychosocial services to cancer patients in treatment revealed significant effects on reducing emotional distress, anxiety, and depression [16, 17]; it also improved adherence to treatment and enhanced the quality of life [18, 19] and survival of cancer patients [20, 21].

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 comorbid psychiatric disorders in cancer and other chronic illnesses [22–26]. For instance, the primary vision of the International Psycho-Oncology Society (IPOS) in collaboration with the World Health Organization (WHO) is to improve the quality of cancer care and cancer policies through the provision of psychosocial care globally [27].

Due to their positive impacts on several treatment outcomes, psychosocial services are being integrated and delivered in routine cancer care in high-income countries [9, 20, 23, 28]. However, some studies revealed that there is still a gap in identifying the psychological, social, and spiritual needs of cancer patients and properly addressing them through systematic and culturally tailored psychosocial services that can benefit patient well-being [29–31].

Particularly, 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 [26, 32]. One of the major challenges in the implementation of existing clinical practice guidelines for psychosocial care is that most of these guidelines have been designed primarily for well-resourced settings, considering their culture and local context [33, 34].

So far, few studies have been conducted on the implementation of psychosocial services in LMICs. A qualitative study conducted in Indonesia reported that breast cancer patients obtained information about their diagnosis and treatment from the doctors at the hospital. However, other types of psychosocial services, such as counselling and emotional support, were not provided for the patients [35]. According to a study conducted in Botswana, the majority of cancer patients received social support from family members and friends. However, the study revealed a gap in the provision of psychosocial services due to understaffed facilities and poor referral communications and scheduling systems [36]. Similarly, our previous study in Ethiopia revealed that breast cancer patients received social support from family members, friends, and significant others [37]. A few studies conducted in different parts of the country also found that the unmet supportive care and information needs of cancer patients are high, and sociodemographic, clinical, and information-related factors were identified as factors in the unmet needs of cancer patients in Ethiopia [38–40].

However, the provision of psychosocial services for breast cancer patients at the health facility level has never before been explored. Therefore, this study explored the availability and receipt of psychosocial services for breast cancer patients in selected hospitals in Addis Ababa, Ethiopia. The findings of this study may be helpful to identify gaps in the provision of psychosocial services and design appropriate psychosocial services by considering the socioeconomic and cultural context of the country.

2. Materials and Methods

2.1. Study Design and Research Environment. A sequential mixed study design (QUAN (qual)) was employed; in the first phase of the study, a cross-sectional study design was used, and quantitative data were collected from 428 breast cancer patients. In Ethiopia, there is a three-tier healthcare system, in which comprehensive cancer care is available at tertiary-level hospitals and some cancer treatments, such as surgical and chemotherapy services, are provided at secondary-level hospitals. This study was conducted at two large tertiary referral hospitals and five private oncology clinics in Addis Ababa. Based on the preliminary analysis conducted on the quantitative data, a small-scale qualitative approach was used for further exploration and validation of the quantitative findings by interviewing a few more breast cancer patients. In addition, the findings were triangulated by looking at the availability of the service from the perspective of health professionals as well. This also enabled us to identify barriers to the provision of psychosocial service in these health facilities. Ethical clearance was obtained from the Research Ethics Committee (REC) of the School of Public Health and the Institutional Review Board (IRB) of the College of Health Sciences, Addis Ababa University.

2.2. Study Participants and Sample Size. The sample size for the quantitative part of the study was calculated using the following assumptions: 95% confidence interval (CI), margin of error (d) = 5%, 40.3% prevalence of depression [41], and 20% nonresponse rate. The final calculated sample size was 444. The eligibility criteria were all pathologically confirmed breast cancer patients above 18 years of age who were undergoing treatment at the selected health facilities.

In the qualitative part of the study, in-depth interviews (IDIs) were conducted with four purposively selected breast cancer patients and five health professionals (two oncologists, two BSc nurses, and one health officer) who were working in the respective oncology departments. Psychologists and psychiatrists are not available in most of the private cancer clinics and are not involved in cancer care in the two tertiary hospitals. Therefore, we purposively selected these nurses as they have a close attachment with cancer patients. An attempt was made to achieve the principle of maximum variation of participants by considering the type of health facility, duration of diagnosis, age, and place of residence.

2.3. Data Collection and Tools. For the quantitative part of the study, a structured questionnaire was developed and adapted to our context after reviewing the literatures. The questionnaire has a total of 26 multiple choice and yes/no questions organised into three subsections: sociodemographic characteristics (8), clinical characteristics (8), and types of psychosocial services received (10). At the end of the questionnaire, two open-ended questions were included in order to give the patients a chance to describe in more detail any related services they have received in those facilities. Breast cancer patients were considered to have received psychosocial services if they reported having received any kind of counselling service, emotional support, or information/educational materials from health professionals working at the current health facility. The quantitative data were collected through face-to-face interviews since a considerable proportion of women were expected to have little formal education. Therefore, seven data collectors (one at each site) were recruited and trained on the objective of the study, data collection tools, and interview techniques by the principal investigator.

For the qualitative study, two separate interview guides were prepared for IDIs with patients and key informants. The interview guide for the patients has seven main and probing questions about psychosocial problems encountered, methods of disclosure, types of information received, and counselling and other psychosocial supports received at the health facilities. Similarly, the interview guide for the health professionals has eight open-ended questions focusing on psychosocial challenges observed among breast cancer patients, available psychosocial services at their facility, how they are delivered, and their perception of psychosocial support and why it is not being provided. The principal investigator and a research assistant who has experience in qualitative research conducted all the interviews. Daily debriefings were held on emerging thematic areas, and all the information we gathered from these additional four patients was consistent and in support of our quantitative findings. Therefore, we did not continue interviewing more patients as we reached the theoretical saturation level. All the interviews were audio recorded and notes were taken during the interviews. The data were organised and appropriately labelled immediately after each interview. Subsequently, all recorded interviews were transcribed and translated verbatim.

2.4. Data Analysis Procedures. The quantitative data were organised using Epi data software and analysed using Statistical Package for Social Sciences (SPSS) version 25. A bivariate logistic regression analysis was performed for each independent variable associated with the receipt of psychosocial services. 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 to the data collection process. All transcribed documents, field notes, and reflexive memos were entered into NVivo12 plus software. Each statement and word were coded line by line based on the stated objectives.

Inductive thematic analysis was applied in order to summarise and explain the emerging categories and themes 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 implement psychosocial care using a community-based approach [42]. The model has five levels, and the appropriate psychosocial intervention is administered based on patients' distress levels 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. The second level is known as supportive care, which focuses on the provision of psychoeducation, emotional support, and triage. Level three (extended care) includes focused counselling, coping skills training, and psychoeducation by trained health professionals. Level four (specialist care) and level five (acute care) are the final two levels of care provided by skilled therapists and multidisciplinary teams.

3. Results

The results of this study are organised and presented in two parts. The first section shows findings from the quantitative survey, describing the proportion of women who received psychosocial services in these health facilities. The analysis of the survey was conducted among 428 patients, with a response rate of 96.4%. The second section deals with the findings from the qualitative study, highlighting the types and locations of psychosocial services available for breast cancer patients. It also narrates the reasons for not providing psychosocial services for breast cancer patients in these facilities.

3.1. Section One: Quantitative Study Findings. The sociodemographic and clinical characteristics of the participants are summarised in Table 1. The majority of 354 (82.7%) of the study participants were aware of their diagnosis, while 61 (14.3%) believed that they had breast inflammation, and the remaining 13 (3.0%) did not know about their condition at all.

Concerning the psychosocial services received, our quantitative study revealed that only 47 (11.0%) of these patients had received any kind of psychosocial service at the current health facility, in the form of counselling, emotional

Table 1: Sociodemographic and clinical characteristics of participants in the quantitative study.

Variables		$n = 428$	Percentage (%)
Categorised age	20–29	41	9.6
	30–39	157	36.7
	40–49	113	26.4
	50–59	61	14.2
	≥60	56	13.1
Type of health facility	Government	363	84.8
	Private	65	15.2
Educational level	Illiterate	88	20.6
	Read and write	26	6.1
	Primary	83	19.4
	Secondary	129	30.1
	Tertiary	102	23.8
Religion	Orthodox	290	67.8
	Catholic	5	1.1
	Protestant	55	12.9
	Muslim	78	18.2
Residence	Inside Addis	203	47.4
	Outside of Addis	225	52.6
Marital status	Married	242	56.5
	Cohabiting	19	4.4
	Divorced	50	11.7
	Widowed	69	16.1
	Single	48	11.2
Occupation	Housewife	203	47.4
	Merchant	52	12.2
	Government employee	84	19.6
	Private/NGO[a]	50	11.7
	Farmer	18	4.2
	Other*	21	4.9
Stage of cancer ($n = 417$)	Stage I	32	7.7
	Stage II	163	39.1
	Stage III	184	44.1
	Stage IV	38	9.1
Type of breast cancer	ER −ve	47	11.0
	ER +ve	36	8.4
	Unknown	345	80.6
Severity of pain	None	76	17.8
	Mild	213	49.8
	Moderate	114	26.6
	Severe	25	5.8
Chemotherapy ($n = 422$)	No	63	14.9
	Yes	359	85.1
Surgery ($n = 422$)	No	45	10.7
	Yes	377	89.3
Radiotherapy ($n = 422$)	No	388	91.9
	Yes	34	8.1
Hormonal therapy ($n = 422$)	No	373	88.4
	Yes	49	11.6

[a] Non Governmental Organization, *daily laborer and student.

support, or the provision of information from health professionals. Out of these patients, more than half, 27 (57.6%), had received information from health professionals, while the others had received other forms of psychosocial services. Most of the 356 patients (83.2%) 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.

Although the majority of participants are still involved in different social activities, 75 (17.5%) of the total participants reported that the disease affected different aspects of their lives. Out of these, 46 (61.3%) and 32 (42.6%) of the patients stated that the disease affected their social and spiritual lives, respectively (Table 2).

According to the multivariate analysis, residence was one of the sociodemographic factors that were significantly associated with the receipt of psychosocial care. Breast cancer patients who live in Addis Ababa were 2.54 times more likely to receive any psychosocial services than those who came from outside of Addis Ababa (AOR = 2.54 (95% CI 1.30, 6.27)) (Table 3). Clinical factors such as pain severity and the date of diagnosis also showed a significant association with receiving psychosocial services. Breast cancer patients who had moderate pain were three times more likely to receive psychosocial services than women without any pain (AOR = 2.84 (95% CI 1.02, 7.94)). Women who had been diagnosed more than 1 year earlier were three times more likely to receive these services than those who had been recently diagnosed (<1 year) (AOR = 3.17 (95% CI 1.27, 7.89)) (Table 3).

3.2. Section Two: Qualitative Study Findings. The sociodemographic and clinical characteristics of breast cancer patients who were involved in the qualitative study are summarized in Table 4. Similarly, the qualifications of the included health professionals and their years of experience are described in Table 5.

4. Theme 1: Available Psychosocial Services

The psychosocial services available for breast cancer patients were described and categorised into two main subthematic areas: (i) from the community and (ii) from health facilities.

4.1. Subtheme 1.1: From the Community. Despite the fact that there is an awareness gap and the way that the community provides social support has its own limitations, most of the breast cancer patients who participated in this study testified that they received various types of emotional support from family members. For instance, a 36-year-old breast cancer patient said, "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." **(BCP, Age 36)**

In addition, cancer patients receive support from different groups of people in the community, such as close friends and colleagues.

> "*"My close friends know about it and we always discuss about everything. They comfort me a lot. . .they are very supportive."* **(BCP, Age 35)**"

> "*"Even at work, people usually support me. For example, they reduce workload and give me permission when I have an appointment."* **(BCP: Age 36)**"

4.2. Subtheme 1.2: From Health Professionals at Health Facilities

4.2.1. Disclosure and Counselling Services. In the health facilities visited, there was no structured way of disclosing a diagnosis to breast cancer patients. In most cases, the physician who made the diagnosis was the one who disclosed it to the patients, *"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 counselling service based on patient's knowledge and health condition."* **(HP: Health officer, private)**

The patients also confirmed that the diagnosis had been disclosed by doctors, *"There was a doctor who did the investigation and told me as I have cancer."* **(BCP, Age 35)**

On the other hand, there were breast cancer patients whose diagnosis had been accidentally disclosed while they were waiting for their turn at the hospital or when they were referred to an oncologist. Sometimes, cancer patients remained unaware of 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. . .Then, I heard from other patient who sited beside me as we are waiting for a cancer doctor."* **(BCP, Age 36)**"

> "*"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."* **(HP: BSc nurse, private)**"

All breast cancer patients who participated in the qualitative study reported that they did not receive any counselling services. They also mentioned that their diagnosis was not properly disclosed and that the health professionals did not provide any emotional support or counselling at the time of diagnosis.

> "*"The way he told 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."* **(BCP, Age 35)**"

Table 2: Type of psychosocial service received in selected health facilities in Addis Ababa, Ethiopia.

Variables		n	Percentages
Currently receiving any psychosocial service in this facility	No	381	89.0
	Yes	47	11.0
Type of psychosocial service received ($n = 47$)	Counselling service	9	19.2
	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

Table 3: Multivariate logistic regression model for factors associated with receiving psychosocial services among 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)
	Cohabiting	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 year	**1**	**1**
	More than 1 year	**2.95 (1.26, 6.86)***	**3.17 (1.27, 7.89)***

Factors with significant influence are shown in bold.

In contrast, the health professionals reported that they were providing counselling services and emotional support for cancer patients insofar as the situation allowed them to. However, except for brief discussions with each patient, there were no structured psychosocial services such as counselling, emotional support, and discussion sessions with cancer patients, either individually or as a group. 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 structured system, even the psychological support and counselling is not provided adequately. But we are trying our best and we need both*

Table 4: Characteristics of breast cancer patients involved in the qualitative study.

Code	Age	Place of residence	Time since diagnosis	Educational status	Occupation	Type of treatment received previously	Current treatment	Type of hospital
BCP[a]1	36	Addis Ababa[b]	4 years	First degree	Bank teller	Surgery (mastectomy of one breast) Chemotherapy Hormonal treatment for 3 years 4 months of radiotherapy	Second round of chemotherapy (6th cycle)	Private
BCP2	42	Debre Markos[c]	2 years	Unknown	Housewife	Surgery (partial excision) Chemotherapy Hormonal therapy (>1 year)	Second round of chemotherapy (8th cycle)	Government
BCP3	51	Addis Ababa	6 months	Unknown	Merchant	Surgery (mastectomy of both breasts)	First round of chemotherapy (2nd cycle)	Private
BCP4	35	Dire Dawa[d]	1 year	First degree	Bank branch manager	Surgery (mastectomy of one breast)	First round of chemotherapy (4th cycle)	Government

[a] BCP, breast cancer patient. [b] Addis Ababa is the capital city of Ethiopia. [c] Debre Markos, a city located 307 km Northwest of Ababa. [d] Dire Dawa, a city located 525 km away from Addis Ababa, Eastern Ethiopia.

Table 5: Characteristics of health professionals involved in the qualitative study.

Code	Profession	Years of experience	Years of experience in the oncology department	Type of 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

> *counsellors and clinical psychologists."* **(HP: Oncologist, government)**"

4.2.2. Provision of Adequate Information and Brochures. Some participants reported that they had received some information from health professionals about the treatment options, side effects, and duration of treatment.

> "*"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."* **(BCP: 42 years)**"

However, most of the patients indicated that the information provided by health professionals was not adequate, and the majority of breast cancer patients held discussions amongst themselves and accessed a lot of information from other patients who had been diagnosed previously.

> "*"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."* **(BCP: 35 years)**"
>
> "*"We usually talk among ourselves and get a lot of information from those patients who took the medication earlier."* **(BCP: 42 years)**"

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

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

5. Theme 2: Determinants of Psychosocial Service 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. These included a shortage of staff, a high workload, and not having an assigned person to deliver these services in an organised way.

> "*"The main problem is staff shortage and high patient flow…umm…. we do not have a staff who is assigned for psychosocial activities…"* **(HP: BSc nurse, government)**"

In addition, there was high patient flow in these health facilities due to the limited number of cancer centres 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."* **(BCP: 42 years)**"
>
> "*"…because of the high patient flow, doctors are forced to see many patients per day specially in government hospitals."* **(HP: Oncologist, government)**"

The other justification was a lack of skill/training on how to provide counselling and other professional support. They also stated that the set-up itself was not convenient for providing patients with individual counselling.

> "*"There are no trained personnel, which makes it difficult to provide counselling service."* **(HP: Health officer, private)**"
>
> "*"The patients are very eager to listen, but the issue is we do not have adequate room for counselling services."* **(HP: BSc nurse, government)**"

6. 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 those of other studies conducted in China [43], Turkey [44], and Botswana [36], which reported that cancer patients often received psychosocial support from their family members and friends.

6.1. Lack of Knowledge about the Diagnosis. Regarding disclosure of a cancer diagnosis, several guidelines recommend that all cancer patients should be well informed about their diagnosis, treatment options, and future prognosis of the disease [24–26, 45]. However, 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 the lack of disclosure of a cancer diagnosis among breast and cervical cancer patients [46]. This finding is not only seen in Ethiopia but also supported by a quantitative study conducted in Egypt that revealed that around 15% of cancer patients were not aware of their diagnosis, with only their family members being aware [47]. The main reason given by interviewees for not disclosing this 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 performed in India, which reported that the majority of caregivers preferred nondisclosure of a cancer diagnosis and prognosis to their patients [48]. Poor disclosure of a cancer diagnosis in developing countries may be associated with poor educational attainment [47], preference for traditional medicine, old age, and having other chronic illnesses [49].

6.2. Lack of Knowledge about the Planned Treatment. Several studies revealed that counselling services are one of the major components of psychosocial services that are being delivered in developed countries [12, 24–27, 50, 51]. However, breast cancer patients in this study reported that they did not receive counselling services at their current health facility. According to the cancer survivorship plan of the Institute of Medicine (IOM), the minimum level of care and information that should be given to each cancer patient includes the provision of information about the types of tests, results, and tumour characterization, as well as treatment details, including type, combination of treatments, duration, side effects, and regimen [33]. Nevertheless, patients in this study mentioned that they did not receive details about their diagnosis and treatment, including the number of chemotherapy cycles prescribed for them. They also stated that they never received educational materials in the form of brochures or leaflets. Similarly, many African countries do not provide comprehensive psychosocial services [27, 32, 52]. There is a lack of resources, including skilled people, infrastructure, and materials.

6.3. Rural-Urban Disparities in Access to Service. Patients who were residents of Addis Ababa were twice as likely to receive psychosocial services as those who were living 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 with disclosure and provision of psychosocial services [47]. This has implications for the importance of having daily coping mechanisms, involvement of community health, and establishing cancer support groups, particularly for those cancer patients who live further away from cancer centres, which are mostly concentrated in big cities.

6.4. Access to Counselling Services. The other factor associated with the provision of psychosocial services was having pain; the likelihood of breast cancer patients receiving psychosocial services was higher when they had moderate pain. This can be explained by the human nature of health professionals to feel sympathetic and provide more emotional or other psychosocial services for those with pain than stable patients. In this study, breast cancer patients who were diagnosed one and more years ago were more likely to receive psychosocial services as compared to those who were newly diagnosed. A possible explanation for this may be that, as the duration of stay in the health system increases, the chance of receiving these services will also be higher due to having repeated appointments with health professionals and receiving different types of treatment.

6.5. Strengths and Limitations. The main strength of this 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. The maximum variation of responses was achieved by including newly diagnosed and recurrent cases. During our qualitative study, collecting information from both patients and health professionals increased the generalizability of the study. The major limitation of this study was that we only conducted IDIs, and it may be helpful if other data collection techniques, such as focus group discussions (FGD), were used in order to confirm our findings. Another limitation of this study was that we did not use a validated questionnaire for the quantitative part and that the questionnaire was developed through a review of the literature and modified for the local context.

7. Conclusions

In this study, psychosocial services were found to be rarely available for breast cancer patients, whether in the form of counselling services, emotional support, or provision of information, and not in a structured way. A high workload, inadequate space, and a lack of trained health professionals were the major reasons for not providing these services. Therefore, innovative psychosocial services, possibly tasks shared through different professions, need to be better integrated into routine cancer care. The services need to be tailored to the local context through consideration of various sociocultural factors, the educational attainment of the community, and available resources. The Ministry of Health should expand the training of health professionals in different disciplines, including clinical psychology, palliative care, and social work. Palliative care units and patient support groups should be established to reach patients in rural and urban areas.

Abbreviations

AOR:	Adjusted odds ratio
IOM:	Institute of Medicine
IPOS:	International Psycho-Oncology Society
IRB:	Institutional Review Board

LMICs: Low- and middle-income countries
FSA: Food and Safety Authority
REC: Research Ethics Committee
WHO: World Health Organization.

Data Availability

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Ethical Approval

Ethical clearance for this study was obtained from the Research Ethics Committee of the School of Public Health and the Institutional Review Board of the College of Health Science, Addis Ababa University. All analytical methods were performed in accordance with the Declaration of Helsinki.

Consent

Written informed consent was obtained from all participants.

Disclosure

A preprint of this article has previously been published in research square [53]. The funding body was not involved in the study design; collection, analysis, and interpretation of the data; or writing of the manuscript.

Conflicts of Interest

The authors declare that they have no conflicts of interest.

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 contributed to 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 have read and approved the final manuscript.

Acknowledgments

The authors would like to thank Dr. Aynalem Abraha from the Department of Oncology and the Women's Health Research Working Group (WHRWG), especially Dr. Mitike Molla, for their additional ideas and suggestions at the inception of the study. We would also like to thank the seven health facilities, breast cancer patients, and key informants who were willing to participate in the study. This study was supported by the Department of Psychiatry, College of Health Sciences, AAU. AW, EK, and AA were supported by the Else Kröener-Fresenius Foundation through Martin-Luther-University, Halle-Wittenberg, Germany, grant no. 2018_HA31SP.

References

[1] L. Grassi, D. Spiegel, and M. Riba, "Advancing psychosocial care in cancer patients," *F1000Research*, vol. 6, p. 2083, 2017.

[2] N. Vin-Raviv, T. F. Akinyemiju, S. Galea, and D. H. Bovbjerg, "Depression and anxiety disorders among hospitalized women with breast cancer," *PLoS One*, vol. 10, no. 6, Article ID e0129169, 2015.

[3] A. Alacacioglu, E. Ulger, U. Varol et al., "Depression, anxiety and sexual satisfaction in breast cancer patients and their partners-Izmir oncology group study," *Asian Pacific Journal of Cancer Prevention*, vol. 15, no. 24, pp. 10631–10636, 2015.

[4] N. Nikbakhsh, S. Moudi, S. Abbasian, and S. Khafri, "Prevalence of depression and anxiety among cancer patients," *Caspian J. Intern. Med.*, vol. 5, no. 3, pp. 167–170, 2014.

[5] N. Z. Zainal, N. R. Nik-Jaafar, A. Baharudin, Z. A. Sabki, and C. G. Ng, "Prevalence of depression in breast cancer survivors: a systematic review of observational studies," *Asian Pacific Journal of Cancer Prevention*, vol. 14, no. 4, pp. 2649–2656, 2013.

[6] C. C. Reyes-Gibby, K. O. Anderson, P. K. Morrow, S. Shete, and S. Hassan, "Depressive symptoms and health-related quality of life in breast cancer survivors," *Journal of Women's Health*, vol. 21, no. 3, pp. 311–318, 2012.

[7] J. Walker, C. H. Hansen, P. Martin et al., "Prevalence, associations, and adequacy of treatment of major depression in patients with cancer: a cross-sectional analysis of routinely collected clinical data," *The Lancet Psychiatry*, vol. 1, no. 5, pp. 343–350, 2014.

[8] American Cancer Society, *Body Image and Sexuality after Breast Cancer 2009*, American Cancer Society, Atlanta, Georgia, USA, 2009.

[9] G. Christ, C. Messner, and L. Behar, *Handbook of Oncology Social Work: Psychological Care for People with Cancer*, Oxford University Press, Oxford, England, 2015.

[10] M. B. Riba, K. A. Donovan, B. Andersen et al., "Distress management, version 3.2019, NCCN clinical practice guidelines in oncology," *Journal of the National Comprehensive Cancer Network*, vol. 17, no. 10, pp. 1229–1249, 2019.

[11] P. Patterson, N. M. D'Agostino, F. E. J. McDonald et al., "Screening for distress and needs: findings from a multinational validation of the adolescent and young adult psycho-oncology screening tool with newly diagnosed patients," *Psycho-Oncology*, vol. 30, no. 11, pp. 1849–1858, 2021.

[12] G. T. Macdonald, F. Baldassarre, P. Brown et al., "Psychosocial care for cancer: a framework to guide practice, and actionable recommendations for Ontario," *Current Oncology*, vol. 19, no. 4, pp. 209–216, 2012.

[13] S. Daniels, "Cognitive behavior therapy for patients with cancer," *J. Adv. Pract. Oncol.*, vol. 6, no. 1, pp. 54–56, 2015.

[14] F. Xiao, X. Song, Q. Chen et al., "Effectiveness of psychological interventions on depression in patients after breast cancer surgery: a meta-analysis of randomized controlled trials," *Clinical Breast Cancer*, vol. 17, no. 3, pp. 171–179, 2017.

[15] C. Reese, J. Weis, D. Schmucker, and O. Mittag, "Development of practice guidelines for psychological interventions in the rehabilitation of patients with oncological disease (breast, prostate, or colorectal cancer): methods and results," *Psycho-Oncology*, vol. 26, no. 10, pp. 1513–1518, 2017.

[16] Z. Guo, H. Tang, H. Li et al., "The benefits of psychosocial interventions for cancer patients undergoing radiotherapy," *Health and Quality of Life Outcomes*, vol. 11, no. 1, p. 121, 2013.

[17] F. D'Abramo, U. Goerling, and C. Guastadisegni, "Targeted drugs and Psycho-oncological intervention for breast cancer patients," *Journal of Negative Results in BioMedicine*, vol. 15, no. 1, p. 6, 2016.

[18] K. Parahoo, S. McDonough, E. McCaughan et al., "Psychosocial interventions for men with prostate cancer: a Cochrane systematic review," *BJU International*, vol. 116, no. 2, pp. 174–183, 2015.

[19] L. S. Hoon, C. W. Chi Sally, and H. Hong-Gu, "Effect of psychosocial interventions on outcomes of patients with colorectal cancer: a review of the literature," *European Journal of Oncology Nursing*, vol. 17, no. 6, pp. 883–891, 2013.

[20] W. Fu, M. Marko Popovic, A. Agarwal et al., "The impact of psychosocial intervention on survival in cancer: a meta-analysis," *Annals of Palliative Medicine*, vol. 5, no. 2, pp. 93–106, 2016.

[21] S. Mirosevic, B. Jo, H. C. Kraemer, M. Ershadi, E. Neri, and D. Spiegel, ""Not just another meta-analysis": sources of heterogeneity in psychosocial treatment effect on cancer survival," *Cancer Medicine*, vol. 8, no. 1, pp. 363–373, 2019.

[22] B. L. Andersen and C. S. Dorfman, "Evidence-based psychosocial treatment in the community: considerations for dissemination and implementation," *Psycho-Oncology*, vol. 25, no. 5, pp. 482–490, 2016.

[23] G. Rubin, A. Berendsen, S. M. Crawford, R. Dommett, and C. Earle, "The expanding role of primary care in cancer control," *The Lancet Oncology*, vol. 16, no. 12, pp. 1231–1272, 2015.

[24] L. Grassi and M. Watson, "Psychosocial care in cancer: an overview of psychosocial programmes and national cancer plans of countries within the International Federation of Psycho-Oncology Societies," *Psycho-Oncology*, vol. 21, no. 10, pp. 1027–1033, 2012.

[25] J. Turner, B. McAvoy, K. Luxford, and J. Fletcher, "Clinical practice guidelines for the psychosocial care of adults with cancer. welcome support for gps," *Australian Family Physician*, vol. 33, no. 1-2, pp. 63–65, 2014.

[26] C. J. Recklitis and K. L. Syrjala, "Provision of integrated psychosocial services for cancer survivors post-treatment," *The Lancet Oncology*, vol. 18, no. 1, pp. e39–e50, 2017.

[27] L. Travado, B. D. Bultz, A. Ullrich et al., "2016 President's Plenary International Psycho-Oncology Society: challenges and opportunities for growing and developing psychosocial oncology programmes worldwide," *Psycho-Oncology*, vol. 26, no. 9, pp. 1231–1238, 2017.

[28] K. M. Fennell, D. A. Turnbull, N. Bidargaddi, J. L. McWha, M. Davies, and I. Olver, "The consumer-driven development and acceptability testing of a website designed to connect rural cancer patients and their families, carers and health professionals with appropriate information and psychosocial support," *European Journal of Cancer Care*, vol. 26, no. 5, Article ID e12533, 2017.

[29] C. Hung, Y. Chen, J. Chan et al., "Psychological distress, social support, self-management ability and utilization of social resources for female patients with cancer in oncology outpatient settings in Taiwan," *Supportive Care in Cancer*, vol. 28, no. 7, pp. 3323–3330, 2020.

[30] B. van Oorschot, K. Ishii, Y. Kusomoto et al., "Anxiety, depression and psychosocial needs are the most frequent concerns reported by patients: preliminary results of a comparative explorative analysis of two hospital-based palliative care teams in Germany and Japan," *Journal of Neural Transmission*, vol. 127, no. 11, pp. 1481–1489, 2020.

[31] E. O'Hea, A. Kroll-Desrosiers, A. S. Cutillo et al., "Impact of the mental health and dynamic referral for oncology (MHADRO) program on oncology patient outcomes, health care utilization, and health provider behaviors: a multi-site randomized control trial," *Patient Education and Counseling*, vol. 103, no. 3, pp. 607–616, 2020.

[32] L. Grassi, D. Fujisawa, P. Odyio et al., "Disparities in psychosocial cancer care: a report from the international federation of psycho-oncology societies," *Psycho-Oncology*, vol. 25, no. 10, pp. 1127–1136, 2016.

[33] B. L. Andersen, R. J. DeRubeis, B. S. Berman et al., "Screening, assessment, and care of anxiety and depressive symptoms in adults with cancer: an American Society of Clinical Oncology guideline adaptation," *Journal of Clinical Oncology*, vol. 32, no. 15, pp. 1605–1619, 2014.

[34] S. C. Lechner, N. Ennis-Whitehead, B. R. Robertson et al., "Adaptation of a psycho-oncology intervention for black breast cancer survivors: project CARE," *The Counseling Psychologist*, vol. 41, no. 2, pp. 286–312, 2012.

[35] A. Iskandarsyah, C. de Klerk, D. R. Suardi, M. P. Soemitro, S. S. Sadarjoen, and J. Passchier, "Psychosocial and cultural reasons for delay in seeking help and nonadherence to treatment in Indonesian women with breast cancer: a qualitative study," *Health Psychology*, vol. 33, no. 3, pp. 214–221, 2014.

[36] C. A. Brown, R. E. Kohler, O. John et al., "Multilevel factors affecting time to cancer diagnosis and care quality in Botswana," *The Oncologist*, vol. 23, no. 12, pp. 1453–1460, 2018.

[37] A. Wondimagegnehu, W. Abebe, A. Abraha, and S. Teferra, "Depression and social support among breast cancer patients in Addis Ababa, Ethiopia," *BMC Cancer*, vol. 19, no. 1, p. 836, 2019.

[38] B. Legese, A. Addissie, M. Gizaw, W. Tigneh, and T. Yilma, "Information needs of breast cancer patients attending care at Tikur Anbessa Specialized Hospital: a descriptive study," *Cancer Management and Research*, vol. 13, pp. 277–286, 2021.

[39] H. Y. Amane, A. M. Tessema, K. A. Seid et al., "Factors associated with unmet supportive care needs of oncology patients at Dessie Referral Hospital," *Ecancermedicalscience*, vol. 15, p. 1300, 2020.

[40] T. Afework, A. Wondimagegnehu, A. S. Bogale, E. J. Kantelhardt, and A. Addissie, "Predictors of unmet supportive care needs of adult cancer patients in Ethiopia," *European Journal of Cancer Care*, vol. 31, no. 6, Article ID e13694, 2022.

[41] A. O. Popoola and A. O. Adewuya, "Prevalence and correlates of depressive disorders in outpatients with breast cancer in Lagos, Nigeria," *Psycho-Oncology*, vol. 21, no. 6, pp. 675–679, 2012.

[42] S. D. Hutchison, S. K. Steginga, and J. Dunn, "The tiered model of psychosocial intervention in cancer: a community-based approach," *Psycho-Oncology*, vol. 15, no. 6, pp. 541–546, 2006.

[43] J. A. Su, D. C. Yeh, C. C. Chang et al., "Depression and family support in breast cancer patients," *Neuropsychiatric Disease and Treatment*, vol. 13, pp. 2389–2396, 2017.

[44] A. Bener, R. Alsulaiman, L. Doodson, and T. Agathangelou, "Depression, hopelessness and social support among breast cancer patients: in highly endogamous population," *Asian Pacific Journal of Cancer Prevention*, vol. 18, no. 7, pp. 1889–1896, 2017.

[45] A. Montazeri, A. Tavoli, M. A. Mohagheghi, R. Roshan, and Z. Tavoli, "Disclosure of cancer diagnosis and quality of life in

cancer patients: should it be the same everywhere?” *BMC Cancer*, vol. 9, no. 1, p. 39, 2009.

[46] A. Gebremariam, A. W. Yalew, S. Hirpa et al., “Application of the rapid ethical assessment approach to enhance the ethical conduct of longitudinal population based female cancer research in an urban setting in Ethiopia,” *BMC Medical Ethics*, vol. 19, no. 1, p. 87, 2018.

[47] S. A. Alsirafy, S. S. Abdel-Kareem, N. Y. Ibrahim, M. A. Abolkasem, and D. E. Farag, “Cancer diagnosis disclosure preferences of family caregivers of cancer patients in Egypt,” *Psycho-Oncology*, vol. 26, no. 11, pp. 1758–1762, 2017.

[48] L. Nyblade, M. Stockton, S. Travasso, and S. Krishnan, “A qualitative exploration of cervical and breast cancer stigma in Karnataka, India,” *BMC Women’s Health*, vol. 17, no. 1, p. 58, 2017.

[49] Z. Bruwer, M. Futter, and R. Ramesar, “Communicating cancer risk within an African context: experiences, disclosure patterns and uptake rates following genetic testing for Lynch syndrome,” *Patient Education and Counseling*, vol. 92, no. 1, pp. 53–60, 2013.

[50] A. Surbone, L. Baider, T. S. Weitzman, M. J. Brames, C. N. Rittenberg, and J. Johnson, “Psychosocial care for patients and their families is integral to supportive care in cancer: MASCC position statement,” *Supportive Care in Cancer*, vol. 18, no. 2, pp. 255–263, 2010.

[51] M. Eichler, M. Hechtner, B. Wehler et al., “Use of psychosocial services by lung cancer survivors in Germany: results of a German multicenter study (LARIS),” *Strahlentherapie und Onkologie*, vol. 195, no. 11, pp. 1018–1027, 2019.

[52] L. Ashley and I. Lawrie, “Tackling inequalities in cancer care and outcomes: psychosocial mechanisms and targets for change: tackling inequalities in cancer care and outcomes,” *Psycho-Oncology*, vol. 25, no. 10, pp. 1122–1126, 2016.

[53] A. Wondimagegnehu, *Availability and Utilization of Psychosocial Services for Breast Cancer Patients in Addis Ababa, Ethiopia: A Mixed Method Study*, Research Square, Durham, NC, USA, 2021.

Cancer Management and Research

Dovepress
open access to scientific and medical research

Open Access Full Text Article

ORIGINAL RESEARCH

Validity and Reliability of the Amharic Version of EORTC-QLQ-CR29 Among Colorectal Cancer Patients in Ethiopia

Lidya Genene Abebe[1]
Abigiya Wondimagegnehu[1,2]
Aynalem Abraha Woldemariam[3,†]
Bizu Gelaye[4,5]
Eva Johanna Kantelhardt[2,6]
Adamu Addissie[1,2]

[1]Department of Preventive Medicine, School of Public Health, College of Health Sciences, Addis Ababa University, Addis Ababa, Ethiopia; [2]Institute of Medical Epidemiology, Biometrics and Informatics, Martin-Luther-University, Halle-Wittenberg, Halle, Germany; [3]Department of Oncology and Radiotherapy, School of Medicine, College of Health Sciences, Addis Ababa University, Addis Ababa, Ethiopia; [4]Department of Epidemiology, Harvard. T. H. Chan School of Public Health, Boston, MA, USA; [5]The Chester M. Pierce, M.D. Division of Global Psychiatry, Massachusetts General Hospital, Boston, MA, USA; [6]Department of Gynaecology, Martin-Luther-University, Halle-Wittenberg, Halle, Germany

[†]Aynalem Abraha Woldemariam passed away on April 9, 2021

Background: The European Organization for Research and Treatment of Cancer – Quality of Life Questionnaire (EORTC-QLQ) developed to assess quality of life among colorectal cancer patients has not been translated into a local language or validated in the Ethiopian context. Therefore, this study aimed to examine the psychometric properties of the EORTC-QLQ-CR29 tool in Ethiopia among colorectal cancer patients.

Methods: A cross-sectional study was conducted in a major referral hospital in Addis Ababa, Ethiopia, from March to May, 2020. A total of 158 colorectal cancer patients were included. The validity of the tool was assessed using Multitrait Scale Analysis, Mann–Whitney test and Pearson correlation coefficient. The internal consistency was examined using Cronbach's alpha.

Results: Among the participants, 52.2% were men, with a median age of 46 years (IQR = 17.7 years). The item-total correlation alpha values ranged from 0.47 to 0.91. Multitrait Scale Analysis demonstrated convergent and divergent validity of the tool, except for the Blood and Mucus in Stool scale. All item correlations within their scales were greater than 0.4, except for the Blood and Mucus in Stool scale. The values of correlation coefficients between all items and their own domain were higher than other domains, except for the Blood and Mucus in Stool scale. The correlation between the core questionnaire and the colorectal tool ranged from −0.45 to 0.58. The tool showed a significant difference between stoma and non-stoma patients and between patients who had good physical function and those who did not.

Conclusion: The Amharic version of the EORTC-QLQ-CR29 tool can be used to assess the health-related quality of life in Ethiopian colorectal cancer patients.

Keywords: validity, EORTC-QLQ, colorectal cancer, Ethiopia

Introduction

Colorectal cancer is the third leading cause of cancer cases worldwide. In 2018, there were more than 1.8 million new cases and 881,000 deaths from colorectal cancer.[1] The incidence of colorectal cancer is higher in high-income countries, but the mortality is higher in low- and middle-income countries. In Eastern Africa, colorectal cancer was the fourth most frequently diagnosed cancer type.[2] In Ethiopia, the second most populous country in sub-Saharan Africa, colorectal cancer is the most common cancer diagnosis in males and it ranks fourth in females.[3] It is also responsible for 11.2% of cancer-related deaths in males and 4.8% of cancer-related deaths in females in Ethiopia.

Correspondence: Lidya Genene Abebe
Tel +251 912665940
Email lidyagenene@gmail.com

Received: 7 October 2021
Accepted: 1 December 2021
Published: 21 December 2021

Gastrointestinal cancer patients have been reported to suffer from problems that emerged as a consequence of both the disease and the treatments, which negatively affect their quality of life.[4] For instance, colorectal cancer symptoms and its treatments have several adverse effects and toxicity, which affect quality of life.[5,6] Colorectal cancer patients have significantly lower physical, role, cognitive and social function compared to the general public. Moreover, they have a higher frequency of constipation, diarrhoea and financial difficulties.[7–9] Thus, further research on health-related quality of life is recommended to guide decision making in treatment choice.[10]

The World Health Organization (WHO) defines "quality of life" as a broad concept that depends on a person's physical health, psychological state, level of freedom, social relationships, and personal beliefs.[11] Cancer treatments have started incorporating quality of life as an end point.[12] Thus, different sensitive, reliable and validated tools are available to assess quality of life among cancer patients. Frequently used tools are the core EORTC-QLQ, the Functional Assessment of Chronic Illness Therapy (FACIT) Measurement System, the Rotterdam Symptom Checklist (RSCL), and the Symptom Distress Scale (SDS).[13] Of these, the core EORTC-QLQ has been recommended to be used when the aim of the study is to assess disease-specific symptoms.[14,15] To complement the core EORTC-QLQ, different disease-specific modules have been developed, and the EORTC-QLQ for colorectal cancer patients (EORTC-QLQ-CR29) is one of these tools. This tool has been developed to be used alongside the core tool in colorectal cancer patients. This disease-specific tool has been validated in different countries such as Spain, Taiwan, Korea and China.[16–19] Even though the Ethiopian Federal Ministry of Health has developed a strategy to assess and treat distressing symptoms in cancer patients,[20] there are no validated tools to assess quality of life among colorectal cancer patients. Therefore, this study intended to examine the reliability and construct validity of EORTC-QLQ-CR29 tool among Ethiopian colorectal cancer patients.

Materials and Methods

Study Design, Area and Participants

A cross-sectional study was carried out at Tikur Anbessa Specialized Hospital (TASH) from March to May, 2020 in colorectal cancer patients. TASH is the largest referral and teaching hospital in Ethiopia, serving as the only radiotherapy centre in the country. In this oncology centre, there are two radiotherapy machines, 36 inpatient beds and 12 outpatient chemotherapy beds. There are also six clinical oncologists, who provide the oncology services.[21]

The sample size was calculated based on the recommendations of 5 to 10 participants /item for checking factor structure and validity of items given for scaling analysis.[22,23] The tool has 29 items; thus, a minimum sample size of 145 participant is required. However, within the study period, 160 participants were approached and 158 of them participated in the study. Since Amharic is the official working language of Ethiopia and is spoken by millions of Ethiopians as a second language, 158 pathologically-confirmed Amharic speaking colorectal cancer patients aged 18 years or older were included while being treated at the TASH oncology department.

Instrument

EORTC-QLQ-CR29 is a 29-item module developed to complement the core EORTC-QLQ. It comprises 19 single items and four scales to assess urinary frequency, blood or mucus in the stool, stool frequency, body image, and other problems faced by patients. The tool scales are generally classified as functional and symptom scales.[24] Since most patients do not have formal education, it may be difficult to use a self-administered questionnaire. Therefore, patients' socio-demographic, clinical characteristics, and quality of life data were collected using an interview-administered questionnaire.

The EORTC-QLQ-CR29 tool was translated into Amharic according to the EORTC translation guidelines.[25] Two native Amharic speakers independently translated the instrument from English to Amharic. These versions were discussed in the research group and a consensus was reached. After that, two proficient English speakers translated the Amharic version back to English. Then, it was sent to the EORTC translation group for reviewing and proofreading. After receiving the comments from the EORTC translation group, a pilot was conducted. The study was conducted to identify difficult, confusing and upsetting questions. None of the questions were found to be difficult, confusing or upsetting for the participants. Based on the recommendations from the pilot study,[25] ten colorectal cancer patients took part in the pilot, and these participants were excluded from the actual study.

After the completion of the pilot study, the data collection commenced. The data was collected by two nurses who have bachelor's degrees and work in the oncology centre.

Training on how to collect the data was given to the data collectors by the principal investigator for three days, focusing on the purpose of the study, contents of the questionnaire, and how to approach and get consent from patients. The principal investigator supervised the data collection process every other day to monitor the data collection procedure. Patients were approached in the waiting room while waiting for their turns. To ensure confidentiality and anonymity of the participants, code was used in the questionnaire instead of respondents' names.

Data Analysis

Descriptive statistics were used to assess the frequency distributions of socio-demographic characteristics and clinical data. Numbers and percentages were used for categorical variables and median, and interquartile range were used for continuous variables. The reliability was assessed using Cronbach's alpha. A value of Cronbach's alpha of 0.70 or greater was considered to be adequate.[23]

Convergent validity, the extent to which two measures are related to the same construct, was determined by employing Multitrait scaling analysis. Multitrait scaling analysis focuses on items as the unit of analysis.[23]

Known-groups validity was checked using the Mann-Whitney test to see whether the tool is able to detect differences between groups. The known groups that were used for comparison were treatment intent, physical function, and presence of stoma.[24] Based on the median value of the physical scale of the core EORTC-QLQ, patients were classified as having better or worse physical function. Those patients with a median score of ≥ 43.3 for the physical scale were considered to have better physical function whereas those below 43.3 were considered to have worse physical function.[26]

The correlations between the items of the colorectal cancer and core tools scales were determined using Pearson Correlation Coefficient. All scales and items were transformed into a 0–100 score as per the EORTC-QLQ scoring manual.[27] Statistical analyses were performed using SPSS, version 21.

Results

Socio-Demographic Characteristics of Respondents

A total of 158 participants were included in this study, with a median age of 46 (IQR =17.7). About 50 (32.3%) study participants had no formal education and were employed (32.3%) while 45 (28.5%) respondents had attended college. As presented in Table 1, the majority of the study participants were men (52.5%), married (63.3%), and residents of Addis (64.4%).

Clinical Characteristics of Respondents

85 of the respondents (53.8%) were treated for rectal cancer. Seventy-eight respondents (49.4%) were being treated with chemotherapy alone. About 120 respondents (75.9%) were treated with palliative intent. The majority of respondents (72.2%) were stage-four cancer patients (Table 2).

Reliability of EORTC-QLQ-CR29

The reliability of the tool was examined based on the value of Cronbach's alpha coefficients (alpha ≥ 0.70). As presented in Table 3, all of the scales had an alpha value of greater than or equal to 0.7, except for the Mucus and Blood in Stool scale (0.47). Urinary Frequency had the highest alpha value (0.91), followed by Stool Frequency (0.85).

Construct Validity

Convergent and Divergent Validity Results of Multitrait Scaling Analysis for EORTC-QLQ-CR29

Convergent and divergent validity were assessed in terms of item-own scale and item-other scale correlation, respectively. The item-own scale correlation was over 0.4 for all scales. Similarly, the item-own correlation for all scales was higher than the item-other scale correlation. As seen in Table 4, except for the Blood and Mucus in Stool scale, all scales have an item-own correlation of above 0.4 and an item-other scale correlation below the item-own scale correlation of 0.4.

The Correlation Between the Core EORTC-QLQ and CR29 Scales

The correlation between the core EORTC-QLQ and CR29 scales ranged from −0.45 to 0.58. The highest correlation was seen between the Body Image scale from the colorectal tool and the Emotional scale from the core questionnaire. The highest negative correlation was observed between Flatulence and Cognitive Function ($r = -0.45$). Most of the correlations between the core EORTC-QLQ and CR29 were below 0.4 (Table 5).

Known-Groups Validity of EORTC-QLQ-CR29

To assess the known-groups validity of the tool, comparisons of scores of multi-item scales and single items of

Table 1 Socio-Demographic Characteristics of Respondents at Tikur Anbessa Specialized Hospital, Addis Ababa, 2020

Variable	Category	Frequency (n = 158)	Percent (%)
Sex	Men	83	52.5
	Women	75	47.5
Educational status	No formal education	51	32.3
	Primary education	35	22.2
	Secondary education	27	17.1
	College and above	45	28.5
Occupation	Farmer	11	7
	Employed	51	32.3
	Housewife	51	32.3
	Retired	11	7
	Student	19	12
	Merchant	15	9.5
Region	Addis Ababa	102	64.6
	Oromia	27	17.1
	Amhara	17	10.8
	Others*	12	7.5
Marital status	Married	100	63.3
	Single	28	17.7
	Divorced	13	8.2
	Widowed	17	10.8
Age	18–45	132	41.8
	46–65	170	53.8
	>65	14	4.4

Notes: *Others = Tigray; Southern Nations, Nationalities and Peoples'; and Dire Dawa.

Table 2 Clinical Characteristics of Respondents in Tikur Anbessa Specialized Hospital, Addis Ababa, 2020

Variables	Category	Frequency (n = 158)	Percent (%)
Cancer site	Colon	73	46.2
	Rectum	85	53.8
Type of treatment	Chemotherapy only	78	49.4
	Surgery and radiotherapy only	16	10.1
	Chemotherapy and surgery only	34	21.5
	Chemotherapy and radiotherapy only	17	10.8
	CSR	12	7.6
	Radiotherapy only	1	0.6
Treatment intent	Curative	38	24.1
	Palliative	120	75.9
Cancer stage	Stage I	7	4.4
	Stage II	24	15.2
	Stage III	13	8.2
	Stage IV	114	72.2

Abbreviation: CSR, chemotherapy, surgery and radiotherapy.

Table 3 Cronbach's Alpha Values of EORTC-QLQ-CR29 Scales in Tikur Anbessa Specialized Hospital, Addis Ababa, 2020

Scale Name	Number of Items	Cronbach's Alpha Coefficients
Urinary Frequency	2	0.91
Mucus and Blood in Stool	2	0.47
Body Image	3	0.70
Stool Frequency	2	0.85

EORTC-QLQ-CR29 among three clinically-distinct groups were made. These three groups were treatment intent, presence of stoma and physical function. This study hypothesised that patients with a stoma had a higher symptom score for Embarrassment and a lower functional score for the Anxiety and Body Image items and scale. Similarly, patients with worse physical health and palliative patients were expected to have higher scores for the symptom items and scales and lower scores for functional scales and items.

The Mann-Whitney test revealed that there was no significant difference between the curative and the palliative treatment groups in any of the scores of the colorectal tool scales or items. In patients with and without a stoma, the presence of a stoma led to a deterioration in quality of life by increasing Urinary Frequency, Flatulence, Embarrassment and Anxiety.

Table 4 Construct Validity for EORTC-QLQ-CR29 Scales in Tikur Anbessa Specialized Hospital, Addis Ababa, 2020

Scale	Item Numbers	Item-Own Scale Correlation	Item-Own Scale Correlation After Correction Overlap	Item-Other Scale Correlation	P-value
Urinary Frequency	31, 32	0.94–0.96	0.81	−0.33–0.34	<0.001
Blood and Mucus in Stool	38, 39	0.74–0.79	0.24	−0.31–0.35	<0.001
Stool Frequency	52, 53	0.92–0.93	0.73	−0.33–0.35	<0.001
Body Image	45–47	0.75–0.81	0.51–0.55	-(0.4–0.19)	<0.001

Table 5 The Correlation Between the Core EORTC QLQ and CR 29 Scales in Tikur Anbessa Specialized Hospital, Addis Ababa, 2020

	PF	RF	PA	FA	NV	CF	EF	SF	QoL
Urinary Frequency	−0.04	−0.01	−0.01	0.01	0.01	0.11	−0.23[b]	−0.02[a]	0.12
Urinary Incontinence	−0.24[b]	−0.24[b]	0.17[a]	0.17[a]	0.14	−0.23[b]	−0.21[b]	−0.39[b]	0.09
Dysuria	−0.275[b]	−0.34[b]	0.30[b]	0.24[b]	0.43[b]	−0.210[b]	−0.33[b]	−0.32[b]	−0.13
Abdominal Pain	−0.14	−0.10	0.38[b]	0.36[b]	0.24[b]	−0.14	−0.08	−0.04	0.07
Buttock Pain	−0.13	−0.19[a]	0.09	0.02	0.24[b]	0.10	−0.14	−0.19[a]	−0.19[a]
Bloating	−0.27[b]	−0.23[b]	0.21[b]	0.25[b]	0.17[a]	−0.19[a]	−0.31[b]	−0.15	0.09
Blood and Mucus in Stool	−0.17[a]	−0.10	0.24[b]	0.35[b]	0.18[a]	−0.35[b]	−0.17[a]	−0.13	0.26[b]
Dry Mouth	−0.30[b]	−0.12	0.20[a]	0.33[b]	0.02	−0.25[b]	−0.21[b]	−0.17[a]	0.25[b]
Hair Loss	−0.35[b]	−0.27[b]	0.36[b]	0.30[b]	0.38[b]	−0.36[b]	−0.09	−0.20[a]	0.04
Taste	−0.31[b]	−0.32[b]	0.40[b]	0.44[b]	0.32[b]	−0.31[b]	−0.06	−0.19[a]	−0.03
Anxiety	0.29[b]	0.26[b]	−0.02	−0.05	−0.01	−0.07	0.33[b]	0.23[b]	0.10
Weight	0.31[b]	0.24[b]	−0.11	−0.15	−0.21[b]	0.21[b]	0.32[b]	0.333[b]	−0.05
Body Image	0.45[b]	0.26[b]	−0.30[b]	−0.29[b]	−0.22[b]	0.25[b]	0.58[b]	0.30[b]	0.00
Flatulence	−0.41[b]	−0.31[b]	0.37[b]	0.11	0.35[b]	−0.45[b]	−0.12	−0.28[b]	0.15
Faecal Incontinence	−0.32[b]	−0.43[b]	0.29[b]	0.17[a]	0.30[b]	−0.39[b]	−0.34[b]	−0.34[b]	0.04
Sore Skin	−0.20[a]	−0.37[b]	0.28[b]	0.04	0.37[b]	−0.11	−0.33[b]	−0.239[b]	0.08
Stool Frequency	−0.23[b]	−0.31[b]	0.17[a]	0.11	0.18[a]	0.06	−0.38[b]	−0.14	−0.07
Embarrassment	−0.12	−0.16[a]	0.03	0.09	0.08	0.06	−0.31[b]	−0.11	0.10
Stoma Care Problem	−0.15	−0.12	0.03	−0.08	−0.03	0.07	−0.26[b]	−0.14	−0.07
Sexual Interest Men	−0.14	−0.11	0.05	0.11	0.03	0.04	0.02	−0.16[a]	−0.12
Impotence	0.03	0.15	−0.09	−0.08	−0.17[a]	−0.02	−0.04	0.02	0.15
Sexual Interest Women	−0.09	−0.08	0.06	−0.09	−0.14	−0.04	−0.06	0.00	0.17[a]
Dyspareunia	0.08	0.11	−0.07	0.07	0.11	0.01	0.05	−0.06	−0.12

Notes: [b]Correlation is significant at the 0.05 level, [a]Correlation is significant at the 0.01 level.

Abbreviations: PF, physical function; RF, role function; PA, pain; FA, fatigue; NV, nausea and vomiting; CF, cognitive function; EF, emotional function; SF, social function; QoL, quality of life.

Patients with better physical function scored higher for functional items and scales and scored lower for symptom items and scales. This suggested the known-groups validity of the tool is fulfilled. (Details are presented in Table 6.)

Discussion

The purpose of this study was to examine the reliability and construct validity of the Amharic version of the EORTC-QLQ-CR29 among Ethiopian colorectal cancer patients. In our study, the tool was found to be reliable. Its internal consistency values ranged from 0.47 to 0.91. All scales had Cronbach's alpha values of above 0.7, except for the Blood and Mucus in Stool scale. This finding concurs with the Dutch and original studies.[24–28] However, this finding differed from Korean and Taiwanese studies,[17,18] which found Cronbach-alpha values of greater than 0.7 for all scales.

Table 6 Known-Groups Comparison: Scales and Items in the EORTC-QLQ-CR29 for Clinically-Distinct Groups in Tikur Anbessa Specialized Hospital, Addis Ababa, 2020

CR-29	Treatment Mean Rank Value			Presence of Stoma			Physical Function		
	Curative	Palliative	P value	Yes	No	P value	Worse	Better	p-value
	n = 38	n = 120		n = 60	N = 98		n = 79	n = 79	
BI	76.03	80.60	0.84	79.01	79.80	0.92	66.99	92.01	<0.001
AN	78.25	79.90	1.00	65.95	87.80	0.002	74.37	84.63	0.13
WET	76.22	80.54	0.99	80.73	78.74	0.78	73.11	85.89	0.07
SXM	34.65	44.33	0.10	47.27	38.70	0.87	16.67	45.67	0.25
SXW	36.28	38.54	0.64	39.18	37.30	0.49	43.13	31.81	0.07
UFR	79.53	79.49	1.00	89.78	73.21	0.02	80.06	78.94	0.87
BM	82.18	78.65	0.99	69.50	85.6	0.02	84.40	74.60	0.15
STF	78.59	79.79	0.98	86.78	75.04	0.11	83.23	75.77	0.30
URI	82.92	78.42	0.97	82.53	33.33	0.49	82.09	76.91	0.45
DY S	87.25	77.05	0.80	77.85	80.51	0.70	89.18	69.82	0.00
ABP	79.08	79.63	1.00	69.20	85.81	0.02	88.94	70.06	0.01
BTP	74.57	81.06	0.86	84.89	76.20	0.23	82.50	76.50	0.39
BLO	76.63	80.41	1.00	75.12	82.18	0.30	88.21	70.79	0.01
DRM	75.83	80.66	0.87	80.37	78.97	0.84	91.20	67.80	<0.001
HRL	87.16	77.08	0.60	66.35	87.55	<0.001	93.04	65.96	<0.001
TAT	75.39	80.80	0.99	68.37	86.32	0.01	90.32	68.68	<0.001
FLU	76.59	80.42	0.99	89.68	73.27	0.02	95.54	63.46	<0.001
FEI	74.55	81.07	1.00	88.01	74.29	0.05	87.53	71.47	0.02
SOS	77.55	80.12	0.96	80.12	79.12	0.89	84.40	74.60	0.16
EMB	83.78	78.15	0.96	108.25	61.90	<0.001	82.70	76.30	0.34
SCR	34.19	29.48	0.47	NA	NA	NA	35.05	25.95	0.03
IMP	35.58	44.04	0.16	48.77	37.75	0.16	45.12	39.37	0.12
DYS	43.47	36.27	0.64	34.91	39.84	0.37	35.57	40.93	0.23

Abbreviations: BI, body image; AN, anxiety; WET, weight; SXM, sexual interest (men); SXF, sexual interest (women); UFR, urinary frequency; BM, blood and mucus in stool; STF, stool frequency; URI, urinary incontinence; DYS, dysuria; ABP, abdominal pain; BTP, buttock pain; BLO, bloating; DRM, dry mouth; HRL, hair loss; TAT, taste; FLU, flatulence; FEI, faecal incontinence; SOS, sore skin; EMB, embarrassment; SCR, stoma care problem; IMP, impotence; DYP, dyspareunia; NA, not applicable.

All-items correlations within their scales were greater than 0.4, except for the Blood and Mucus in Stool scale. This is similar to the results seen in a Spanish study.[16] However, this is inconsistent with the previous findings where it was shown that the Blood and Mucus in Stool scale had convergent and divergent validity.[17–19,24,28] The different findings reveal that limited variability in item score has an effect on correlation.[29] Thus, lower variability in our study might explain the difference. In fact, the items that comprise the Blood and Mucus in Stool scale may not correlate with each other.

Known-group comparison was performed to check whether the tool was able to detect differences between distinct groups. Our findings are consistent with studies conducted in Spain, China and the Netherlands,[16,19,24,28] where the tool was found to differentiate between the groups. However, the Body Image and Sore Skin items did not discriminate between patients with and without stoma. This is inconsistent with previous findings where a difference was seen according to the presence of a -stoma.[16,19,24,28] This difference might be due to the fact that, in our study, there was an age difference between stoma and non-stoma patients. However, the previous studies did not report the age of stoma and non-stoma patients. In the current study, patients in the stoma groups were older than those in the non-stoma groups. Based on a study conducted in Australia, elderly patients have a greater appreciation for their function and body image.[30] Similarly, the scales and items did not differentiate curative and palliative patients. This could be explained by the fact that, in our study, the sample size is smaller in the curative group.

The correlation between the core EORTC-QLQ and CR29 ranged from "weak" to "moderate". The highest correlation was observed between the Emotional and Body Image scales. This agrees with studies conducted in Korea and Spain.[16,18] This result suggests that the tools are designed to cover different dimensions of health-related quality of life. Therefore, the core questionnaire should be used along the specific module.

In general, the original tool was made in English. English is not widely spoken in Ethiopia. Therefore, the tool may not be understood in the same way in Ethiopia. There are also cultural differences between Ethiopia and where the original tool was first developed. On top of all these, there is also a lack of studies on the validity of the tool in Africa. Thus, this study can fill the gaps observed in Africa.

Strengths and Limitation of the Study

While the translation of the tool was done, every step of the EORTC translation process was followed, under the supervision of the EORTC translation group. Nonetheless, this study had its own limitations. Even though patients were included irrespective of their place of residence, treatment and disease stage, most of them were in the final stages of cancer. This is because most cancer patients in Ethiopia come to hospital at the late stages of the disease.

Conclusion

The current study supported the reliability and validity of the Amharic version of the EORTC-QLQ-CR29 among Ethiopian colorectal cancer patients. We also recommend that researchers and clinicians use the core questionnaire alongside the disease-specific module while assessing health-related quality of life in colorectal cancer patients. Specific support for each patient should be focused on the individual domains and items which eventually contribute to lower quality of life.

Abbreviations

EORTC-QLQ, European Organization for Research and Treatment of Cancer Quality of Life questionnaire; EORTC-QLQ-CR29, European Organization for Research and Treatment of Cancer Quality of Life questionnaire for colorectal cancer patients; FACIT, Functional Assessment of Chronic Illness Therapy; GLOBOCAN, Global Organization Board of Cancer Association Network; PCA, Principal Component Analysis; QoL, Quality of life; SDS, The Symptom Distress Scale; WHO, World Health Organization.

Data Sharing Statement

The data are available from the corresponding author on reasonable request.

Ethics Approval and Consent to Participate

Ethical clearance was obtained from the Ethical Clearance Committee of Addis Ababa University (AAU) College of Health Science, School of Public Health Ethical Review Committee. Permission to use the questionnaires was secured from the EORTC research group using an online form at https://qol.eortc.org/form. Informed written consent was given by all participants. This study was conducted in accordance with the Declaration of Helsinki.

Acknowledgments

The authors would like to thank Addis Ababa University for funding this study. We would like to express our sincere gratitude to all participants and those who supported the study. In loving memory of our friend and colleague, Dr. Aynalem Abraha Woldemariam.

Funding

This study was funded by Addis Ababa University for partial fulfilment of a Master's degree in Public Health with a specialty in Epidemiology and Biostatistics by the first author.

Disclosure

The authors declare that they have no conflicts of interest for this work.

References

1. Bray F, Ferlay J, Soerjomataram I, Siegel RL, Torre LA, Jemal A. Global cancer statistics 2018: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA Cancer J Clin*. 2018;68:394–424. doi:10.3322/caac.21492
2. Ferlay J, Ervik M, Lam F, et al. *Global Cancer Observatory: Cancer Today*. Lyon, France: International Agency for Research on Cancer; 2020.
3. Memirie ST, Habtemariam MK, Asefa M, et al. Estimates of cancer incidence in Ethiopia in 2015 using population-based registry data. *J Glob Oncol*. 2018;1–11. doi:10.1200/JGO.17.00175
4. Numico G, Longo V, Courthod G, Silvestris N. Cancer survivorship: long-term side-effects of anticancer treatments of gastrointestinal cancer. *Curr Opin Oncol*. 2015;27:351–357. doi:10.1097/CCO.0000000000000203
5. Akhlaghi E, Lehto RH, Torabikhah M, et al. Chemotherapy use and quality of life in cancer patients at the end of life: an integrative review. *Health Qual Life Outcomes*. 2020;18(1):1–9. doi:10.1186/s12955-020-01580-0
6. Birgisson H, Påhlman L, Gunnarsson U, Glimelius B. Late adverse effects of radiation therapy for rectal cancer - a systematic overview. *Acta Oncol*. 2007;46(4):504–516. doi:10.1080/02841860701348670
7. Grosek J, Novak J, Kitek K, Bajric A, Majdic A, Kosir JA. Health-related quality of life in Slovenian patients with colorectal cancer: a single tertiary care center study. *Radiol Oncol*. 2019;53(2):231–237. doi:10.2478/raon-2019-0015
8. Arndt V, Merx H, Stegmaier C, Ziegler H, Brenner H. Quality of life in patients with colorectal cancer 1 year after diagnosis compared with the general population: a population-based study. *J Clin Oncol*. 2004;22(23):4829–4836. doi:10.1200/JCO.2004.02.018
9. Jansen L, Koch L, Brenner H, Arndt V. Quality of life among long-term (P 5 years) colorectal cancer survivors – systematic review. *Eur J Cancer*. 2010;46(16):2879–2888. doi:10.1016/j.ejca.2010.06.010
10. Blazeby JM, Avery K, Sprangers M, Pikhart H, Fayers P, Donovan J. Health-related quality of life measurement in randomized clinical trials in surgical oncology. *J Clin Oncol*. 2015;24(19):3178–3184. doi:10.1200/JCO.2005.05.2951
11. World Health Organization. *Division of Mental Health and Prevention of Substance Abuse. WHOQOL: Measuring Quality of Life*. World Health Organization; 1997.
12. Bonnetain F, Borg C, Adams RR, et al. How health-related quality of life assessment should be used in advanced colorectal cancer clinical trials. *Ann Oncol*. 2017;28(9):2077–2085. doi:10.1093/annonc/mdx191
13. Tamburini M. Health-related quality of life measures in cancer. *Ann Oncol*. 2001;12:8–10. doi:10.1093/annonc/12.suppl_3.S7
14. Pallis AG, Mouzas IA. Instruments for quality of life assessment in patients with gastrointestinal cancer. *Anticancer Res*. 2004;24(3b):2117–2121.
15. Luckett T, King MT, Butow PN, Heading G. Choosing between the EORTC QLQ-C30 and FACT-G for measuring health-related quality of life in cancer clinical. *Ann Oncol*. 2011;22(10):2179–2190. doi:10.1093/annonc/mdq721
16. Arraras JI, Suárez J, Arias de la Vega F, et al. The EORTC Quality of Life questionnaire for patients with colorectal cancer: EORTC QLQ-CR29 validation study for Spanish patients. *Clin Transl Oncol*. 2011;13(1):50–56. doi:10.1007/s12094-011-0616-y
17. Shen M, Chen L, Ho T, Shih Y, Huang C, Chie W. Validation of the Taiwan Chinese version of the EORTC QLQ-CR29 to assess quality of life in colorectal cancer patients. *BMC Cancer*. 2018;18:1–10. doi:10.1186/s12885-017-3892-2
18. Ihn MH, Lee S, Son IT, et al. Cultural adaptation and validation of the Korean version of the EORTC QLQ-CR29 in patients with colorectal cancer. *Support Care Cancer*. 2015;23:3493–3501. doi:10.1007/s00520-015-2710-0
19. Lin J, Zhang L, Wu D, et al. Validation of the Chinese version of the EORTC QLQ-CR29 in patients with colorectal cancer. *World J Gastroenterol*. 2017;23(10):1891–1898. doi:10.3748/wjg.v23.i10.1891
20. Kifle M, Abdella K, Moge T, Tsegaye T, Moges A. National cancer control plan of Ethiopia. 2015.
21. Deressa BT, Cihoric N, Tefesse E, Assefa M, Zemenfes D. Multidisciplinary cancer management of colorectal cancer in Tikur Anbessa Specialized Hospital, Ethiopia. *J Glob Oncol*. 2019;5:1–7. doi:10.1200/JGO.19.00014
22. Norman GR, Streiner DL. Biostatistics - the bare essentials. In: Mehta L, McKeon M, editors. *An Introductory Course in Statistics (Preferably, Applied Statistics)*. 4th ed. USA: People's Medical Publishing House; 2014:937.
23. Kyriazos TA. Applied psychometrics: sample size and sample power considerations in factor analysis (EFA, CFA) and SEM in general. *Psychology*. 2018;9(08):2207–2230. doi:10.4236/psych.2018.98126
24. Whistance RN, Conroy T, Chie W, et al. Clinical and psychometric validation of the EORTC QLQ-CR29 questionnaire module to assess health-related quality of life in patients with colorectal cancer. *Eur J Cancer*. 2009;45(17):3017–3026. doi:10.1016/j.ejca.2009.08.014
25. Dewolf L, Koller M, Velikova G, et al. *EORTC Quality of Life Group Translation Procedure*. 3rd ed. Brussels, Belgium: EORTC Quality of Life Group; 2009:32.
26. Koller M, Lorenz W. Quality of life: a deconstruction for clinicians. *J R Soc Med*. 2002;95(10):481–488. doi:10.1177/014107680209501002
27. Fayers PM, Aaronson NK, Bjordal K, Groenvold M, Curran D, Bottomley A; on behalf of the EORTC Quality of Life Group. *The EORTC QLQ-C30 Scoring Manual*. 3rd ed. EORTC Quality of Life Group: Brussels, Belgium; 2001.
28. Stiggelbout AM, Kunneman M, Baas-thijssen MCM, Neijenhuis PA. The EORTC QLQ-CR29 quality of life questionnaire for colorectal cancer: validation of the Dutch version. *Qual Life Res*. 2016;25:1853–1858. doi:10.1007/s11136-015-1210-5
29. Goodwin LD, Leech NL. Understanding correlation: factors that affect the size of r. *J Exp Educ*. 2006;74(3):249–266. doi:10.3200/JEXE.74.3.249-266
30. Tiggemann M, McCourt A. Body appreciation in adult women: relationships with age and body satisfaction. *Body Image*. 2013;10(4):624–627. doi:10.1016/j.bodyim.2013.07.003

Explanation of Previous dissertation attempt (Erklärung über frühere Dissertationsversuche und Selbstständigkeitserklärung):

I hereby declare that this work is the first attempt of writing a dissertation. I also declare that this work is exclusively submitted as a dissertation for the General Practice and Family Medicine of Martin Luther University Halle Wittenberg.

Halle (Saale), 09. April 2024

Ort und Datum

Unterschrift
(Abigiya Wondimagegnehu Tilahun)

Acknowledgment

First and foremost, I give glory to the almighty God, who has been faithful throughout the ages, especially in my life. I joyfully dedicate this Ph.D. thesis to my beloved parents, who selflessly sacrificed their own opportunities for the betterment of their children and have eagerly awaited the realization of their dreams through us. Words cannot express my gratitude; you are truly exceptional. Abaye, this is only the beginning. I promise to passionately pursue my career in cancer care and honour your name in the scientific community.

My sincere thanks go to my primary supervisor, Prof. Eva Kantelhardt, for her invaluable mentorship throughout this journey. I am deeply grateful for her unwavering guidance, encouragement, and comprehensive coaching. I also want to express my profound appreciation to my supervisors, Dr. Adamu Addissie, Prof. Solomon Teferra, Dr. Mathewos Assefa, and Prof. Bradley Zebrack, for their unreserved support throughout the process. It has been an honor and privilege to learn from them and acquire knowledge and skills under their supervision.

I am grateful to Else Kroner Fresenius Stiftung (EKFS) for funding the expenses associated with this research project. Additionally, I extend my thanks to Addis Ababa University, School of Public Health, for their continuous support, and to Martin Luther University for providing this opportunity. Special appreciation goes to Dr. Maria Eckenweber and Eva Hermann for their technical assistance in compiling this thesis.

Lastly, I wish to express my deep gratitude to my beloved siblings, close friends, and colleagues in Addis Ababa and Germany for their continuous encouragement and valuable scientific advice in each step.