

BMJ Open Ethiopian women's sexual experiences and coping strategies for sexual problems after gynaecological cancer treatment: a qualitative study

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ABSTRACT

Objective This study explored women's sexual experiences and coping strategies for sexual problems after gynaecological treatment.

Setting The research was carried out at Tikur Anbessa Specialized Hospital, one of the two cancer centre hospitals in the country.

Study design A phenomenological qualitative study design was employed in this study.

Study participants Participants were recruited using purposeful sampling. Thirteen eligible study participants were interviewed face to face. Data were collected from 2 February to 15 March 2019 and analysed at the same time. For data analysis, thematic analysis was used, which comprises three stages: data reduction, data display and data conclusion.

Results Four themes resulted from the analysis of individual interview data, including treatment side effects, sexual issues following radiation therapy, lack of awareness regarding cancer treatment and sexual dysfunction, and coping strategies for sexual dysfunction following gynaecological cancer treatment. Three subthemes emerged as coping mechanisms for managing sexual issues and dysfunction among Ethiopian women with gynaecological cancer: avoiding sexual intercourse, praying for healing and seeking professional help. These themes were identified as the rich and detailed account of the experiences of sexually active women who have received treatment for their cervical cancer.

Conclusion This study has broadened the perspectives on sexuality in the setting of gynaecological cancer and challenged certain commonly held beliefs about sexuality after treatment. Researchers should look into how inclusive sexuality education and training may be better integrated into the training programmes of healthcare workers. More research is needed to learn how partners of women with gynaecological cancer cope with sexual changes after treatment, how the couple as a partnership negotiates changes after treatment, and the facilitators and barriers that healthcare providers face when discussing sexuality issues with patients.

BACKGROUND

Sexuality is typically overlooked in clinical settings when it comes to gynaecological cancer treatment because it has little to do

Strengths and limitations of this study

- The researchers were self-conscious and aware of their immersion in the study process to ensure that it was as objective as possible.
- The information obtained from study participants could be subject to recall bias.
- The findings of this research applied to a similar population in the study area.

with the cure of the disease.^{1 2} The WHO's 2010 definition of sexuality is used as the underlying understanding of sexuality in this article. Sexuality encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy, and reproduction, and is characterised as the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors.^{2 3}

Patients with cancer are frequently asexualised because they do not fit into traditional notions of sexuality. Nonetheless, for many people, sexual well-being is a significant aspect of their overall quality of life.^{2 4} According to research, 40%–100% of women with gynaecological cancer will experience sexual problems following treatment.^{5 6} According to research studies, women with cervical cancer endure a variety of physical alterations to their vaginal anatomical structure and size. These alterations can cause them to have distorted body images and have conflicts with their partners.⁷ For instance, sexual dysfunction, such as low libido and dyspareunia, often persists after other aspects of health, such as mental health and social adjustment, have returned to normal.⁸

Population-based screening in the form of free Papanicolaou smears has been the focus of cervical cancer prevention.⁹ Most women, unfortunately, seek medical help when they are symptomatic and in advanced stages of

cancer, most typically stage IIIB, where definitive radiation is the preferred treatment.¹⁰ When compared with adjuvant radiotherapy, the higher doses administered are likely to cause more sexual dysfunction.¹¹ After breast cancer, gynaecological cancer is the leading cause of illness and mortality in women. Gynaecological cancer is the world's fourth most common type of cancer.¹² In Ethiopia, cervical cancer is the second most common malignancy among women,⁴ and there is a rising number of long-term survivors for whom quality of life is a top priority, despite a dearth of rehabilitation support tailored to their needs and interests.¹³

Patient-centred care and comprehensive support programmes in Ethiopia require a thorough understanding of women's lived experiences of sexuality after treatment. However, there is a scarcity of research on women's sexual experiences and adjustment after cervical cancer treatment in Ethiopia. Little is known about how women with gynaecological cancer deal with changes in their sexuality as a result of treatment, what kinds of sexual issues they have, how distressing they are or how they deal with them. The purpose of this study was to explore women's sexual experiences and coping strategies for sexual problems after undergoing gynaecological cancer therapy at Tikur Anbessa Specialized Hospital (TASH) Oncology Center.

RESEARCH METHODS

Research design

A phenomenological qualitative study design was employed in this study. The argument for employing qualitative research was that it is best suited for comprehending phenomena in their context, as well as analysing their feelings, opinions, suggestions, beliefs and behaviours.¹⁴ The study's main goal was not to extrapolate the findings to other situations because they were unique to the situation.

Study setting

The research was carried out at TASH, one of the two cancer centre hospitals in the country. Five senior oncologists, 2 palliative care experts, 33 residents, 4 radiotherapists, 3 medical physicists and 23 nurses worked at the TASH oncology unit. Breast, cervical and colorectal cancers were the most prevalent cancers seen in this institution. This research took place from 2 February to 15 March 2019.

Participants and sampling method

The participants were recruited using purposeful sampling, a non-random selection approach in which participants are chosen because they have experience with a phenomenon of interest and can thus contribute rich information to the problem.¹⁵ Women who had gynaecological cancers treated at TASH were chosen from the radiation oncology unit's weekly follow-up clinic. To be eligible for the study, participants had to be 18 years

old and above and have had therapy for cervical, uterine, vulvar or ovarian cancer, or a combination of these, in the previous 6–12 months. The radiation oncologist and gynaecologist involved in the follow-up clinic looked through their hospital files to find women who satisfied the inclusion criteria. Eligible women were notified about the study after their follow-up session and those who were interested were directed to the principal researcher. The principal researcher provided additional details about the study and those who wanted to continue completed the informed consent form. This procedure was carried out in the participant's native tongue. When information redundancy was achieved, recruiting came to an end following recognised qualitative research standards.¹⁶

Data collection and analysis

Indepth face-to-face interviews were done by the lead author and one female research assistant. An interview guide was used to outline the open-ended topics in English and Amharic. The interview guide used in this study is provided as online supplemental annex 1. Pilot interviews and actual data collection were conducted in two stages. The data from the pilot interviews were not included in the final analysis because they were used to test the interview guide. The interviews were conducted in participants' local (Amharic) language in both cases. The key research topic was: how do women feel about their sexuality after undergoing gynaecological cancer treatment? The following were the subquestions: how do women feel about their sexual functionality after treatment? what effect has this had on their sexual self-perception? what effect has this had on their sexual relationships? what coping mechanisms did they use to get over sexual issues if they had them? what are their thoughts on how to best manage their sexual health needs while undergoing cancer treatment?

Indepth interviews were done until saturation was reached, which occurred after 13 interviews when more data failed to reveal any new emergent codes or themes.¹⁷ The interviews took place in a private room at selected medical facilities. With the participant's permission, the assistant researcher audio-recorded and took written notes during the interviews. The interviews were done in Amharic and lasted between 30 and 50 min.

Data were collected and analysed at the same time. After reading the transcribed data and sorting them into appropriate units, the principal researcher manually coded the data. For data analysis, thematic analysis was used, which comprises three stages: data reduction, data display and data conclusion. To ensure the study's dependability, the researcher communicated with the two senior research supervisors via email, personal contact and phone conversations frequently to track any changes made to the protocol and processes, such as reviewing, defining and labelling themes uncovered. Furthermore, verbatim quotes were identified and used to clarify study findings.

Trustworthiness of the study

Trustworthiness is the ability of researchers to convince participants and themselves that the findings of the enquiry are direct, truthful or reliable.¹⁴ Before the main study, a pretest was conducted to assess the instrument's trustworthiness and reliability to correct and make required changes before the study began. To assure the report's credibility, several procedures were used, including the use of the same interview guide throughout the investigation. An audit trail was kept for researchers to confirm the methodologies used in the study. To ensure the transferability of the research results to similar contexts, a detailed explanation of the study area, methods and sample history was provided. Data were returned to participants to cross-check and validate their responses to ensure legitimacy. By using bracketing, the researchers guaranteed that their attitudes, thoughts and experiences about the topic under enquiry had no bearing on data collection and analysis. The study's data gathering and analysis techniques were also unaffected by the researchers' backgrounds.

Consent to participate

The TASH administration granted permission to conduct the study. To conduct the interviews, the authors received written informed consent from all participants. The importance of the study's voluntary participation was emphasised. All respondents' identities and other personal information were kept confidential.

Patient and public involvement

Patients were not involved in this study.

RESEARCH FINDINGS

Participants' sociodemographic characteristics

A total of 13 participants were enlisted to take part in the study. The average age was 48, ranging from 25 to 55 years old. Majority of the women (10 of 13) were married, although the three women who were described as 'single' had a regular sexual relationship.

All of the study subjects were given radiation therapy. For treatment of their cervical cancer, eight clients had external beam radiation, two received a combination of external beam radiation and surgery, and the remaining three received external beam radiation plus brachytherapy. The average period after treatment was 5 months, with the majority of women being between 3 and 9 months after therapy.

Themes

Four themes resulted from the analysis of individual interview data, including treatment side effects, sexual issues following radiation therapy, lack of awareness regarding cancer treatment and sexual dysfunction, and coping strategies for sexual dysfunction following gynaecological cancer treatment. Three subthemes emerged as coping mechanisms for managing sexual issues and dysfunction

Table 1 Categories and themes of women's sexual experiences and coping strategies for sexual problems

Categories	Themes
<ul style="list-style-type: none"> ▶ Feeling discomfort and uneasy. ▶ No sexual desire due to treatment side effect. 	<ul style="list-style-type: none"> ▶ Treatment side effect.
<ul style="list-style-type: none"> ▶ Lack of desire and intimacy. ▶ Lose of orgasm during intercourse. ▶ Avoiding sexual intercourse due to treatment side effect. ▶ Sexual intercourse caused suffering. ▶ Radiation caused scar tissues and dryness. 	<ul style="list-style-type: none"> ▶ Sexual issues following radiation therapy.
<ul style="list-style-type: none"> ▶ Lack of information about treatment side effect. ▶ Providers do not give sexual education. ▶ Seeking assistance from providers. 	<ul style="list-style-type: none"> ▶ Lack of awareness regarding cancer treatment and sexual dysfunction.
<ul style="list-style-type: none"> ▶ Negotiating with a partner to avoid sexual intercourse. ▶ Praying for healing. ▶ Seeking professional help. 	<ul style="list-style-type: none"> ▶ Coping strategies for sexual problems following gynaecological cancer treatment.

among Ethiopian women with gynaecological cancer: avoiding sexual intercourse, praying for healing and seeking professional help (see [table 1](#)). These themes were identified as the rich and detailed account of the experiences of sexually active women who have received treatment for their cervical cancer.

Theme 1: treatment side effect

Majority (11 of 13) of the women who received treatment for gynaecological cancer reported a variety of therapeutic side effects (immediate and late) after treatment, causing sexual dysfunction. According to the data, women who received cervical cancer therapy had bleeding during intercourse, dryness, indigestion, vomiting, low appetite, pain, skin changes in texture and colour, burning sensation while urinating, and vaginal discharge. Sample responses included the following:

Three months after starting cancer therapy, I was uneasy because I experienced a burning feeling when urinating and vaginal discharge; as a result, your sexual being does not exist.

...everything I eat comes out, and I had to go to the bathroom now and then. So, how do you anticipate having sex with your husband?

Theme 2: sexual issues following radiation therapy

Cancer treatment procedures have a detrimental impact on women's physical, psychological, emotional and sexual concerns. Pain, vaginal bleeding and discomfort were reported by most participants in this study during

sexual intercourse, primarily due to vaginal dryness and tightness. Sample responses included the following:

During sexual intercourse, I felt dreadful because of excruciating pain and there was no climax.

So you're not a fan of sexual activity? I'm hopeful that after the treatment is over, things will improve.

...I believe I'm overly tight because of the scar tissue induced by the radiation. I believe the dryness is due to the treatment, and it is inconvenient. Sexual intercourse becomes a cause of suffering for me; I would be delighted if I could prevent such agony.

Theme 3: lack of awareness regarding cancer treatment and sexual dysfunction

The data analysis revealed a third theme: lack of awareness regarding cancer treatment and associated sexual dysfunction. One category within the theme is insufficient information received from health providers about cancer treatment and associated sexual dysfunction. According to the findings of the study, majority (10 of 13) of the women interviewed expressed a lack of understanding regarding the treatment procedure and associated sexual problems. Sample responses in this regard included the following:

I had never heard of cervical cancer treatment affecting sexuality until I was diagnosed with cervical cancer...We were kept in the dark about the treatment technique and the sexual concerns that came with it by health care providers. As a result, I was unsure whether or not to engage in sexual activity while undergoing treatment.

...No one ever asked me outright about my sexuality. And I'm embarrassed to bring up the issue of [sex]. It didn't seem essential to me.

Theme 4: coping strategies for sexual problems following gynaecological cancer treatment

Three key themes emerged as coping mechanisms for managing sexual issues and dysfunction among Ethiopian women with gynaecological cancer: avoiding sexual intercourse, praying for healing and seeking professional help. Many of the participants use various avoidance tactics to deal with sexual problems. Majority (10 of 13) of the participants emphasised the importance of having open and honest conversations with their husbands about their sexual relationships. They believe that alerting their husbands about the effects of cervical cancer on their sexual lives made them more thoughtful and understanding of the situation. In this context, the following quotations were included:

After my cervical cancer treatment, I respectfully asked my husband to halt sexual contact, and he agreed.

Following my cancer diagnosis, I agreed with him to stop sexual intercourse due to substantial pain

during sexual intercourse and the fear of the 'disease process returning'.

I had never heard of cervical cancer treatment affecting sexuality until I was diagnosed with cervical cancer...We were kept in the dark about the treatment technique and the sexual concerns that came with it by health care providers. As a result, I was unsure whether or not to engage in sexual activity while undergoing treatment.

According to the findings of this study, majority of the participants use prayer as a coping mechanism for dealing with the side effects of gynaecological cancer, such as sexual issues. Coping techniques included accepting the illness and praying for the strength to engage in sexual activity. Some women feel cancer is a test from God designed to test their faith and patience. These women stated that their bodies belong to God and that they must accept it if God chooses to cause cancer in their private regions (genitalia).

Any illness, I believe, is a gift from God, thus it is outside of my knowledge. But I need to keep praying and reminding myself that nothing is too difficult for God. Because my body is his, I can accept it if he [God] wishes to affect my private part [Genitalia].

On the other hand, one participant avoided discussing her concerns with her husband because sexuality in the form of penetrative intercourse was no longer a priority in their lives. This client's lack of desire and intimacy has a major influence as a woman.

I don't feel like a woman since I'm usually in bed, therefore I lose my desirability and my husband loses interest in me; he doesn't see anything in me because she's not putting herself up because of her health.

A few women in this study reported hearing about the potential sexual side effects of adjuvant therapy from healthcare practitioners. One woman attempted to return to normal life, including sexual activity, by following medical advice:

The oncology nurse recommended me to maintain normal activities, including intercourse, as a cancer patient. So, when I'm not in pain and have a sexual desire, I rarely have sex....

DISCUSSION

Understanding the sexuality of women who have undergone gynaecological cancer treatment is a crucial tool for improving their care. This study explored women's sexual experiences and coping strategies for sexual problems after undergoing gynaecological cancer therapy at TASH Oncology Center. As a result of their therapy, majority of the patients with cancer in this study report having sexual issues: physical (eg, vaginal dryness, discomfort during intercourse) and psychological/emotional (eg, anxiety

during intercourse, decreased sexual interest, body image distress, loss of femininity), all of which are consistent with previous research.¹⁸ Majority of the women in this study reported changes in their sexual functioning before and after therapy, including a significant disruption in their sexual lives as a result of severe symptoms and/or treatment side effects. For instance, symptoms such as heavy bleeding, unpleasant discharge and weariness are common in late-stage gynaecological cancers and might influence a woman's sexuality beyond the therapy and post-treatment periods.²

Gynaecological cancer, according to the participants in this study, can have a major impact on sexual self-esteem, sexual relationships and sexual functioning. Women's physical, psychological, emotional and sexual problems are negatively impacted by cancer treatment techniques. Most participants in this study reported pain, vaginal bleeding and discomfort during sexual intercourse, owing to vaginal dryness and tightness related to therapy. This finding is in line with Cleary *et al's*¹⁸ findings, which found that patients with gynaecological cancer reported detrimental alterations in sexual relationships and sexual performance, as well as sexual dysfunction at all stages of the sexual response in patients with cervical cancer receiving radiotherapy. According to a study by Karin Stinesen Kollberg,¹⁹ participants with irradiation cervical cancer reported decreased vaginal lubrication, loss of emotions, decreased desire and shortened vaginal length.²⁰

Patients with cervical cancer experience a variety of physical changes to their vaginal anatomical structure and size, according to research. Women may develop erroneous body images as a result of these changes, as well as experience problems with their spouses.⁷ Sexual dysfunction, such as low libido and dyspareunia, for example, frequently persists even when other areas of health, such as mental health and social adjustment, have returned to normal.⁸

In this study, we asked participants about sexual relationships and sexual functioning information they had received from healthcare practitioners. According to the findings, majority of the participants said they received no information concerning their sexual functioning after obtaining cancer therapy from a healthcare professional, and majority of them would prefer more information on these topics from their healthcare professionals. Pitcher *et al*² observed a similar conclusion in a South African study, where majority of the participants wanted additional information from their healthcare professionals as well as the ability to engage in a support group.

According to a previous study conducted by Afiyanti,⁸ over 85% of nurses believe that discussing sexuality with patients is a taboo and private topic. These improper attitudes and beliefs among nurses about the sexuality of their patients may become a barrier to assisting patients with cancer in managing the sexuality problems induced by cancer and therapy.⁸ As a result, healthcare personnel must overcome several challenges to improve the quality

of life of patients with cancer. Providing and discussing information regarding sexuality concerns with patients are among the most important steps that healthcare professionals, including nurses, should take.²⁰ Oncology nurses should be proactive in detecting and assisting patients with cancer with psychosexual issues. Nurses should also be aware of and comprehend psychosexual issues to offer good care to patients with cancer and survivors.

Healthcare providers may be able to assist patients with their psychosexual recovery, because when a healthcare expert legitimises sexuality themes in a therapy setting it allows individuals and couples to discuss them on their own. This could lead to more open discussions about sexual issues, as well as a reduction in marital conflict and sexual violence.² Healthcare workers who work with patients with gynaecological cancer should strive to improve their understanding of sexuality in the setting of cancer by reading relevant materials and attending workshops and conferences.^{2 21 22}

Three key themes emerged as coping mechanisms for managing sexual issues and dysfunction among Ethiopian women with gynaecological cancer: praying for healing, avoiding sexual intercourse and seeking professional help. Almost all of the participants in this study dealt with sexual concerns by taking the normal course of accepting changes and changing their sexual habits. These individuals used their spiritual beliefs to give positive meaning to their sexual problems; two coping techniques were accepting the illness and praying for healing and hoping for the strength to engage in sexual activity. Some women believe that cancer is a test from God, putting their faith and patience to the test, allowing them to embrace their illness. Some of them focus on solutions and use conforming tactics by changing their sexual habits to cope with their spouses' sexual needs. To deal with sexual problems, many of the participants adopt various avoidance techniques. Some women said they avoided tricking their husbands into penetrative sex by declining intercourse in subtle ways, such as having open and honest dialogues about their sexual relationships with their husbands. This finding is consistent with other non-Western literature that has described spirituality and religion as coping methods that allow patients to follow their illness's natural course.^{23 24}

This study has broadened the perspectives on sexuality in the setting of gynaecological cancer and challenged certain commonly held beliefs about sexuality after treatment. Researchers should look into how inclusive sexuality education and training may be better integrated into the training programmes of healthcare workers. More research is needed to learn how partners of women with gynaecological cancer cope with sexual changes after treatment, how the couple as a partnership negotiates changes after treatment, and the facilitators and barriers that healthcare providers face when discussing sexuality issues with patients. This study had some limitations. While the data acquired through individual interviews may not be generalisable, the findings may be transferable to other



contexts with similar characteristics. However, it should also be noted that the emerging themes were supported by local and international works. As the women's sexual experiences were only reported at one moment following therapy, no conclusions can be drawn about how they regarded their sexuality over time. The study was unable to analyse the experiences of younger unmarried women because the sample comprised mostly of heterosexual women in long-term relationships with men. Concerns about the small sample size, data interpretation and bias are common criticisms of qualitative research. The researchers in this study, on the other hand, were self-conscious and mindful of their immersion in the research process for the procedure to be as objective as feasible. The researchers believe that the study's translucent characteristics is revealed by the detailed explanation of the sample, data gathering methods and data processing procedure.

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Contributors Hundie, YG, designed the research topic, developed the methods and involved in data collection, and performed data analysis. Sendo, EG, and Habte, T were involved in the study design, data analysis, interpretation and presentation of the findings, and in the final revision of the manuscript. All authors approved the final version of the manuscript to be published.

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Patient consent for publication Consent obtained directly from patient(s).

Ethics approval This study involves human participants. Ethical clearance to conduct this research was sought from the Research and Ethical Review Committee (IRB) of the School of Nursing and Midwifery, College of Health Sciences, Addis Ababa University (ID: 12/2019). Participants gave informed consent to participate in the study before taking part.

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