

Social support experiences of cervical cancer patients at tikur anbessa specialized hospital, addis ababa, ethiopia: a qualitative study

Abstract

Background: Cervical cancer diagnosis creates a stressful situation that influences women's life. Social support during a stressful experience may contribute to improved physical and mental well-being. Therefore, the objective of this study was to assess the social support experiences and needs of cervical cancer patients at Tikur Anbessa Specialized Hospital, Addis Ababa, Ethiopia.

Methods: A qualitative study was conducted among eleven purposively selected cervical cancer patients on follow-up treatment. In-depth interviews were used to collect data. Data were analyzed via thematic analysis.

Results: The study found that most of the women have experienced good social support. Women perceive that the most important source of social support was from family members that was captured in the themes 'family support was significant' and 'caring husband'. On the other hand, few of them experienced that both their relatives and their close friends tended to avoid them despite their need for care. The results of the qualitative analysis also revealed a theme 'the support I need' in which participants considered information and advice from health care professionals as the most vital support they need.

Conclusion: It was concluded that health care professionals together with social workers have to assign adequate time and have a relational tool that enables them to help patients have a successful and trusted health care follow-up.

Keywords: cervical cancer, social support, experiences, qualitative study, ethiopia

Introduction

The diagnosis and treatment of any kind of cancer can be a challenging and distressing experience for any woman. Researches have documented various physical, psychological, and social consequences as an effect of dealing with a life-threatening illness, undergoing painful and impairing treatments, and accepting of a new identity.¹⁻⁴

In several countries, cervical cancer also poses a substantial economic difficulty for families. This difficulty includes the inability to be productive because of the illness, high expenses related to medical care, and the need for caregivers to quit or reduce working hours to look after women suffering from cervical cancer.^{5,6}

Social support is linked to improved physical and mental well-being as the main effects model and the stress-buffering model.⁷ The main effects model maintains that support is beneficial to health and well-being irrespective of the amount of stress people are experiencing. The stress-buffering model indicates the belief that support buffers against the adverse effects of stressors under conditions of high stress.

Social support refers to "the function and quality of social relationships, such as perceived availability of help, or support received".⁸ Social support can be differentiated as emotional, informational, and instrumental support.⁹ Emotional support is considered the commonest recognized type and includes the provision of compassion, apprehension, considerate, love, and trust. The family and close friends are the sources of emotional support. Informational support may help the person to respond to personal or situational demands that come in the form of advice and suggestions from

members of a person's network. According to Cohen et al.⁹ assistance in the form of money, time, practical assistance, and other explicit interventions are considered instrumental support.⁹

Perceived availability of social support during a stressful experience may contribute to a less threatening appraisal of the stressor and bolster confidence in one's ability to cope, leading to lower perceived stress and more adaptive emotional, behavioral, and physiological responses.^{10,11} This was also reported in another study where perceived social support had a significant positive effect on female cancer survivor's quality of life.¹² Perceived social support is also associated with subjective well-being¹³ and is a significant factor for the reduction of stress.¹⁴

Although researchers frequently highlight the importance of social support in improving the wellbeing of cancer patients, studies assessing social support are lacking in Ethiopia. Thus, to address this limited information exploring the social support experiences and needs among cervical cancer patients in Ethiopia is timely.

Materials and methods

A qualitative approach was implemented to collect data on women social support experiences and needs. Data was collected using face-to-face in-depth interviews.

Participants

Eleven cervical cancer patients receiving follow-up treatment at Tikur Anbessa Specialized Hospital were purposively selected. This purposeful selection of participants was to ensure gaining access to the details of their individual experiences.

Data collection

Data were obtained using in-depth semi-structured interviews. An interview guide was developed using open-ended questions relating to participants' social support experiences and needs. All interviews were audio-recorded after getting permission from each interviewee. The duration of interviews ranged from approximately 40-60 minutes.

Data analysis

Interviews were transcribed verbatim. The data were analyzed through thematic analysis. The quotes included in the results were typical views expressed in each interview to exemplify emergent themes.

Ethical considerations

Before the beginning of the data collection, necessary approval was obtained from responsible bodies. All the study participants were informed about the purpose of the study. Written consent was obtained prior to conducting the interviews. Participants were assured that they could withdraw or refuse to answer questions at any time during the interview.

Result

The age of the women ranges between 39 and 62 (with a mean of 49 years). Most of them were married and urban residents. Of all the women, eight of them have got some form of schooling ranging from elementary to tertiary. At the time of the interview, four of them were housewives and three of them were self-employed. All women had primary non-metastatic cervical cancer at entry and had been diagnosed with cervical cancer from between six and twenty-four months (with a mean of 14.82 months) and five of them are in stage III. In terms of treatments, five of them did radiation therapy.

Participants discussed their experience of social support after the diagnosis and during follow-up treatment for cervical cancer. Regarding social support, six themes have emerged: family support was significant, caring husband, close friends were helpful, neighbors support was unbelievable, some relatives and friends distanced themselves, and the support I need. These themes are described in detail below.

Theme 1: Family support was significant

Women reported that the most important support they perceive was from their families. Women also expressed the importance of social support from close friends and neighbors. Most of the women described that they have good social support. Having social support from their family or friends and neighbors helped them a lot. As one woman described:

"If my family were not supportive, getting the treatment will not be possible. Especially, my brother helped with the money for travel and accommodation here in Addis Ababa during my follow-up treatment in this hospital (Tikur Anbessa Specialize Hospital)." (Participant 9)

Women also mentioned that their families accompany them during their stay here in this hospital for follow-up treatment. This is reflected in the following excerpt:

"My sisters are always with me during my stay here in this hospital, it will be a very difficult situation without them." (Participant 1)

For many women, having support to get relief from the daily household activity or pressure was very helpful. One of the women expressed her experience with this kind of support and how it helped her as:

"I constantly feel exhausted to perform household activities. It was my little sister who was living with us since my diagnosis to do all the household activities ... I don't know what I could do without her...I wish her to have a blessed life in the future." (Tear filled in her eyes) (Participant 7)

Theme 2: Caring husband

Participants expressed how the support from their husbands helped to deal with their illness stress. This is shown in the following statement:

I was repeatedly sick and was examined by local health care professionals. They told us to go to Tikur Anbessa for further investigation and treatment. I was not willing to come to this hospital. It was my husband who persuaded me to come, and he stayed with me until I get the treatment, and he is still here with me during my follow-up treatment. (Showed pointing at where her husband is standing) (Participant 2)

Another way of support described by one woman was the support with the sharing of household activities by her husbands.

"My husband performs all the household activities. We do not have a maid to support us with the housework. He is the one taking care of the children when I am here for follow-up treatment." (Participant 1)

Of the nine women who are currently married, six of them were happy with the support they received from their husbands. They reported that this kind of support from their husbands felt them so cared for. For instance, one woman stated that:

"I think my greatest support I received comes from my husband, he takes care of me and the children...he always tells me to concentrate on my cancer care...still he is a kind husband for me." (Participant 6)

Theme 3: Close friends were helpful

Some women gained support from close friends who were seen as important contributors in the follow-up treatment. In addition to being with them to support them emotionally, the women even received money for transportation from their close friends. As a woman mentioned:

"My friends in the neighborhood know that I am suffering from cancer and in follow-up treatment here in this hospital. They contribute and gave me money every time I have a treatment schedule for my stay here in Addis Ababa." (Participant 5)

Another woman reported that how this support helped her a lot:

"One day when I was preparing to travel here, my friends come to visit me and gave me 2000 ETB. I cried a lot since I do not have enough money on my hand. I feel good to have close friends who are helpful." (Participant 9)

The other way women felt supported was the reassurance they get from friends through phone calls. One woman described this:

"My friends and relatives give me a phone call. They ask me about my situation, my children and everything. It was helpful for me to talk to them and reminds me that I was not forgotten." (Participant 2)

Theme 4: Neighbors support was unbelievable

For women with cervical cancer, daily life was a double burden in addition to cancer treatment. There is still household work: cooking meals, caring for kids, cleaning, going to market. Getting help from other people (family members, friends, or neighbors) resulted in relief from this pressure.

One type of support expressed by women happened when neighbors brought them meals. Women were relieved from cooking for families. This was also helpful when women were in the hospital for follow-up treatment. A woman described it as:

"My neighbors take a turn and bring a meal to us when I feel sick and stay on a bed; it was such kind support I get from them. And you know, even though they don't have much, but they share with us whatever they have cooked." (Participant 8)

Women also described the other support they get was going to the market to buy foodstuffs for them. A woman expressed her relief of going to the market by saying:

"I have a close friend whom I consider her as my sister ... she is the one who always visits the market to buy everything essential for us. You don't know how much this relieved me from going to the market." (Participant 1)

The various ways of social support during this period of diagnosis and treatment helped women whether it is through helping financially, household daily activities, emotional or calling them on the phone was essential in relieving them from experiencing a load of stress helps them improve coping and adaptation. The women also described that they highly valued all types of social support.

Theme 5: Some relatives and friends distanced themselves

Unfortunately, three participants experienced that both their relatives and their close friends tended to avoid them despite their need for care. This resulted in feeling lonely and losing hope by participants. In contrast to becoming a good supporter, the women also mentioned how their previous good friends and relatives avoided themselves after their cancer diagnosis. One woman explained it as:

"I was surprised and sad at the same time to see my friends whom I thought would be supportive just let me down. Even some of them did change their way when they see me in the road ... they feel like I can transmit the disease to them ... It hurts a lot when they do that on me." (Participant 6)

Another woman explained how extended family members distanced themselves after their illness from the family:

"I haven't imagined my relatives will turn their back on me like this. They have not even asked me once when I was admitted to the hospital. I don't know their reason ... but it is good to know who they really are ... I will never forgive them for what they did to me" (Participant 10)

The women reported that when they expected support from family or friends is not present; it brought feelings of sadness and anger during this time of need. There are also participants who received overwhelming support at the beginning, but the support fades away as time goes. A woman described this as:

"During my diagnosis, there was plenty of support from my friends and relatives. As time passed, most of my friends and relatives were not able to continue their support. But I understand that they are struggling with their own life that they may not get time to visit me." (Participant 3)

As described above, even though the women find themselves being supported at the beginning and need this social support over the prolonged time of cancer treatment, as time goes on, this social support reduced significantly.

Theme 6: The support I need

The participants strongly stressed the importance of having support from health care professionals, but openly informing their concerns with them was difficult. They expressed that in their process of treatment, help should have to be offered respectfully and discussion should have to be there about their various concerns so that they can have a successful and trusted health care follow-up.

The participants also stressed that having complete and trusted information support that can be obtained through discussion with them should be well acknowledged by their caregivers. For instance, one woman describes the support from the health care professionals as:

"The doctors who treat me were not kind. I felt uncomfortable talking about my concerns. I don't see any caring behavior from them." (Participant 9)

When discussed their support need, participants considered information and advice from health care professionals as the most important support they need. After the diagnosis, they need information that is valuable in helping them to differentiate and clear out between rumors and reality regarding their illness and the treatment.

For instance, one of the women described her struggle in finding the support she needs:

"I had worries concerning my treatment to talk with the health personnel, I have experienced financial difficulties with the cost of travel and accommodation ... but it is very problematic for me to discuss with them or find an organization who can support me ..." (Participant 7)

In this regard, participants described that they did not receive any reading materials (leaflets, brochures) about cervical cancer from the hospital. Women also reported that there is no support provided from social services or voluntary organizations for helping them economically or psychologically during follow-up treatment for cervical cancer.

Discussion

The study found that most of the women have experienced good social support. The most common responses of experience of social support from family, friends, and significant others were the themes 'family support was significant', 'caring husband', 'close friends were helpful' and 'neighbors support was unbelievable' in which participants speak of help from friend or neighbors resulted in relieving them from housework related pressure. This finding is in line with other studies^{15,16} where family members are often evaluated as the main source of support.

The qualitative study had depicted that having social support from their family or friends and neighbors helped them a lot. Previous studies also reported higher social support level was helpful in helping women cope with their illness.^{17,18} Similarly, another study revealed that perceived social support reduces harm/loss appraisal of illness.¹⁹ This demonstrates that women with higher perceived social support found it easier to use several coping strategies to manage the strain. The finding supported the idea of Lazarus & Folkman (1984) that perceived high social support helped handle both the root cause of the stress and for regulating emotional stress.¹⁰

On the other hand, few of them experienced that both their relatives and their close friends tended to avoid them despite their

need for care in the subtheme ‘some relatives and friends distanced themselves’. It was also reported that women find overwhelming support at the beginning, but the support fades away as time goes. Limited awareness and misunderstanding among the respondents and the community could also be found, and this could be another way that cancer is stigmatized, resulting in women covering up their illness.

The results of the qualitative analysis identified a theme ‘the support I need’ in which participants strongly stressed the importance of having information support from health care professionals. They expressed that in their process of treatment, help should have to be offered respectfully and discussion should have to be there about their various concerns so that they can have a successful and trusted health care follow-up. Other support needs identified were the need for support from social services or voluntary organizations for helping them address the economical and psychological difficulties.

Previous studies conducted locally indicated that cancer patients are experiencing long waiting times to get curative treatment,^{20,21} repeated service interruption,²² and communication challenges between patients and health care professionals.^{23,24} After the diagnosis, patients need information that is valuable in helping them to differentiate and clear out between rumors and reality regarding their illness and the treatment. This could be the reason that the qualitative participants considered information and advice from health care professionals as the most important support they need. Therefore, service providers should have openly communicate with patients in addressing their concerns, which may enhance the relationship between the two and satisfaction with the service.

Conclusion

The study found that most of the women have experienced good social support. Women perceive that the most important source of social support was from family members that was captured in the themes ‘family support was significant’ and ‘caring husband’. On the other hand, few of them experienced that both their relatives and their close friends tended to avoid them despite their need for care. The results of the qualitative analysis also revealed a theme ‘the support I need’ in which participants considered information and advice from health care professionals as the most vital support they need. It was concluded that health care professionals together with social workers have to assign adequate time and have a relational tool that enables them to help patients have a successful and trusted health care follow-up.

Acknowledgments

The authors would like to thank Jimma and Addis Ababa Universities. The authors are also grateful for the cooperation of the study participants.

Conflicts of interest

The author declares no conflict of interest.

Funding

None.

References

1. Brandao T, Schulz M, Matos M. Psychological adjustment after breast cancer: a systematic review of longitudinal studies. *Psycho-Oncology*. 2017;26(7):917–926.
2. Craft. Exercise effects on depressive symptoms in cancer survivors: A systematic review and meta-analysis. *Cancer Epidemiology Biomarkers Prevention*. 2011;21(1):3–19.
3. Goncalves V. Long-term quality of life in gynecological cancer survivors. *Current Opinion in Obstetrics and Gynecology*. 2010;22:30–35.
4. Liao MN, Chen SC, Lin YC, et al. Education and psychological support meet the supportive care needs of Taiwanese women three months after surgery for newly diagnosed breast cancer: A non-randomized quasi-experimental study. *International Journal of Nursing Studies*. 2014;51:390–399.
5. Lipsy RJ. Assessing the short- term and long- term burden of illness in cervical cancer. *The American Journal of Managed Care*. 2008;14(6):177–184.
6. Tsu VD, Levin CE. Making the case for cervical cancer prevention. What about equity? *Reproductive Health Matters*. 2008;16(32):104–112.
7. Cohen S, Wills TA. Stress, social support, and the buffering hypothesis. *Psychological Bulletin*. 1985;98:310–357.
8. Schwarzer R, Knoll N. Functional roles of social support within the stress and coping process: A theoretical and empirical overview. *International Journal of Psychology*. 2007;42:243–252.
9. Cohen S, Underwood L, Gottlieb B. *Social Support Measurement and Intervention*. New York: Oxford University Press; 2000.
10. Lazarus RS, Folkman S. *Stress, Appraisal and Coping*. New York: Springer Publishing Company Inc; 1984.
11. Taylor SE. Social support: A review. *The handbook of health psychology*. 2011;189–214.
12. Lee I, Park C. The mediating effect of social support on uncertainty in illness and quality of life of female cancer survivors: a cross-sectional study. *Health and Quality of Life Outcomes*. 2020;18:143.
13. Ammar, Nauffal, Sbeity. The role of perceived social support in predicting subjective well-being. *Journal of Happiness and Wellbeing*. 2013;1(2):116–130.
14. Lyrakos. The impact of stress, social support, self-efficacy and coping in university students, a multicultural European study. *Psychology*. 2012;(3):143–149.
15. Ozdemir D, Tas Arslan F. An investigation of the relationship between social support and coping with stress in women with breast cancer. *Psych Oncology*. 2018;27(9):2214–2219.
16. Yağmur Y, Duman M. The relationship between the social support level perceived by patients with gynecologic cancer and mental adjustment to cancer. *International Journal of Gynecology & Obstetrics*. 2016;134(2):208–211.
17. Long XN, Ngoc NB, Phung TT, et al. Coping strategies and social support among caregivers of patients with cancer: a cross-sectional study in Vietnam. *AIMS Public Health*. 2020;8(1):1–14.
18. Roohafza HR, Afshar H, Keshteli AH, et al. What is the role of perceived social support and coping styles in depression and anxiety? *Journal of Research Medical Science of J Isfahan University Medical Science*. 2014;19:944–949.
19. Ben-Ezra M, Hamama-Raz Y, Palgi S, et al. Cognitive Appraisal and Psychological Distress among Patients with Irritable Bowel Syndrome. *Journal of Psychiatry Relative Science*. 2015;52(1):54–60.
20. Rick T, Habtamu B, Tigeneh W, et al. Patterns of Care of Cancers and Radiotherapy in Ethiopia. *Journal of Global Oncology*. 2019.
21. 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 Women's Health*. 2015;15(75).

22. Haileslassie W, Mulugeta T, Tigeneh W, et al. The Situation of Cancer Treatment in Ethiopia: Challenges and Opportunities. *Journal of Cancer Prevention*. 2019;24:33–42.
23. 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).
24. Sibeoni J, Picard C, Orri M, et al. Patients quality of life during active cancer treatment: a qualitative study. *BMC Cancer*. 2018;18:951.