

Am I Dying Soon: Cervical Cancer Patient's Appraisal of their Diagnosis at Tikur Anbessa Specialized Hospital, Addis Ababa, Ethiopia

Anteneh Dirar^{1*} Wubegzier Mekonnen² and Zena Berhanu³

¹Department of Population and Family Health, Jimma University, Jimma, Ethiopia

²Department of Public Health, Addis Ababa University, Addis Ababa, Ethiopia

³Department of Social Work, Addis Ababa University, Addis Ababa, Ethiopia

Abstract

Background: Cervical cancer is a distressing disease with physical and psychosocial consequences that persisted beyond the period of diagnosis and treatments. Being diagnosed with cancer creates a stressful situation that influences both a person's personal and family life.

Objective: This study sought to explore appraisal of cervical cancer diagnosis among patients on follow-up treatment at Tikur Anbessa Specialized Hospital, Addis Ababa, Ethiopia.

Methods: Data were collected through in-depth interviews using a semi-structured interview guide with 11 purposively selected cervical cancer patients. The qualitative data were transcribed and analyzed via thematic analysis.

Results: The findings indicated that most women were found to appraise their illness negatively and had a strong emotional reaction as soon as they heard their diagnosis of cervical cancer. Most of the women have limited awareness and misunderstanding regarding their illness. These leads to utilizing traditional/religious practices, delay in seeking medical care, and experiencing stigma in the community.

Conclusion: It was concluded that enhancing cervical cancer awareness campaigns to alleviate knowledge gaps and misconceptions should be considered to help reduce delays in seeking medical care and stigmatization in the community.

Keywords: Cervical Cancer; Appraisal; Ethiopia

Introduction

Even though cervical cancer is a preventable disease and can be cured if noticed early and adequately treated, it is among the leading cause of death related to cancer among women living globally [1]. Cervical cancer affects women, including their families worldwide. The impacts (physical, psychological, social, and economic) of cervical cancer mortality in developing countries of the world are very high. Cervical cancer affects women at a relatively younger age of their life when they may be raising children, caring for the family, and contributing to the development of their community [2,3]. According to the World Health Organization, the death of a woman in her younger age as a result of cervical cancer is a tragic and unnecessary loss to her family and community that brings a massive consequence for the well-being of both. In Ethiopia, cervical cancer is the second commonly diagnosed cancer accounting for 9.6% of cancer cases, and it is the second cause of cancer death responsible for 10.3% of cancer mortality in 2020 [4]. In 2020 a total of 7445 women were diagnosed with cervical cancer and 5338 died as a result of cervical cancer. The age-standardized incidence rate was 21.5 per 100,000 and the age-standardized mortality rate was about 16.0 per 100,000. According to Lazarus and Folkman, stress is "a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and imperiling his or her well-being". For women who have experienced cervical cancer and who are the focus of this research, cancer diagnosis is the stressor. The experience

of the disease itself is stressful; particularly when at an advanced stage the treatment morbidity may be quite demanding and long-term [6,7]. The Theory of Stress, Appraisal and Coping (TSAC) proposed by Lazarus and Folkman illustrates that when people are faced with a stressor, such as cancer diagnosis, they experience a "cognitive appraisal process" which, in turn, directs their coping and ultimately their adaptation to the stressor. It is considered a "transactional" model because it not only depicts the individual as a mediator between the environmental stimuli and the response but also highlights the dynamic and reciprocal interactions between the person

***Corresponding author:** Anteneh Dirar, Department of Population and Family Health, Jimma University, Jimma, Ethiopia; E-mail: klagoro2@gmail.com

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and the environment [8]. Thus, according to this theory, an appraisal is a unique, dynamic, and relational process that is occurring constantly between the person and environment. According to Lazarus and Folkman (1984), a cognitive appraisal is understood as “the process of categorizing an encounter, and its various facets, with respect to its significance for well-being”. Cognitive appraisal has been categorized into primary and secondary appraisal. Primary appraisal involves evaluating whether an event is stressful. When an event is characterized as stressful (i.e., the outcome is viewed as resulting in harm/loss, threat, and challenge), secondary appraisal takes place. The secondary appraisal includes evaluating what can be done to deal with the stressor; it has a direct impact on coping strategies. This process does not necessarily enter conscious awareness. According to Hoffman, Lent, and, Raque-Bogadan, negative appraisal of illness results in “treatment that requires frequent medication appointment, pain or discomfort, disfigurement or loss of functions, a medication that impairs functioning, or traveling great distances may be viewed as exceeding one’s available resources” [9]. Studies conducted among different illnesses indicated that patient’s interpretation of their illness determines the reaction and behaviors of patients towards their illness. For instance, Esteva et al. found that colorectal cancer patients’ interpretation of illness determines delayed diagnosis [10]. Treatment adherence was also reported because of illness perception in rheumatoid arthritis [11]. Szymona-Pabkowska et al. had assessed the link between knowledge of the disease and disease-related appraisals among women with urinary incontinence. It was found that lack of knowledge could contribute to unfavorable patterns of disease related appraisals [12]. A qualitative study by among women with cervical cancer in Nepal indicated that patients had a lack of knowledge regarding cervical cancer and its causative agent and is also delayed seeking health care [13]. The studies mentioned above indicated the patients with different types of illnesses had different appraisals about their illness. Little is known about cervical cancer patients’ appraisal of their illness during their diagnosis in Ethiopia. Therefore, understanding the factors associated with the appraisal of cervical cancer is important in order to increase overall psychosocial adjustment and treatment outcome. This qualitative study enabled to gain an in-depth exploration that focuses on how cervical cancer patients on follow-up treatment at appraise their illness.

Literature Review

The study was conducted in Tikur Anbessa Specialized Hospital (TASH) oncology centre. TASH is a large referral teaching hospital, under the administration of Addis Ababa University, located in Addis Ababa, Ethiopia. The Oncology Centre of TASH is the only oncology referral and radiotherapy center in the country. The study was conducted on September 2020. A total of 11 purposively selected women who were receiving follow-up treatment for cervical cancer were recruited to participate in the qualitative study. A semi-structured interview guide was used to elicit responses related to participant’s appraisal experience with cervical cancer diagnosis. The data was collected through individual face-to-face in-depth interviews by the researcher. The interview guide was developed after reviewing pertinent literature in the area. The interview guide was evaluated by three experts (sociologist, health psychologist, and social worker). Modifications and corrections were made based upon the comment and suggestions. All interviews were audio-recorded and notes were taken. The audio data were then transcribed verbatim by the researcher. The dataset was analyzed *via* thematic analysis. Verbatim

quotes were also used in order to help ensure accurate representation of the data. Before the commencement of the data collection, necessary approval was obtained from responsible bodies. All study participants were briefed about the purpose of the study. Written informed consent was obtained from each participant.

Results

Socio-demographic characteristics of women

A total of 11 women participated in the qualitative study. An attempt was made to achieve the principle of maximum variation of participants by considering the socio-demographic and clinical characteristics (age, marital status, occupation, place of residence, duration of diagnosis, stage of cancer, and type of treatment). The age of the women ranges between 39 and 62 (with a mean of 49 years). Nine of the respondents are married and seven are urban residents. Of all the women, eight of them have got some form of schooling ranging from elementary to tertiary and the remaining three are illiterate. Concerning women’s occupations, four of them were housewives and three of them were self-employed at the time of the interview. 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. From the interview records, six themes have emerged regarding cervical cancer patient’s appraisal: initial reaction, awareness/understanding, seriousness, experiencing symptoms, treatment decision making, and delay to seek medical care. The themes and the various subthemes that emerged are described in detail below.

Initial reaction

Women tried to remember their reactions when they first heard about their diagnosis of cervical cancer. When women heard that they are diagnosed or learned they had cervical cancer, their initial reactions were wide-ranging. Four sub-themes about women’s initial reaction to the diagnosis were drawn from the data collected. These are: why this happened to me, am I dying soon, confusion, and hopelessness.

Why me?

Women do not expect that their illness will be cancer. It is clear that, for most women, it is not easy to admit to being diagnosed with cancer. They asked themselves repeatedly what could be the reason for having such kind of disease. Their initial reaction was shock and difficulty believing. The women reported a variety of reactions, as illustrated in the following quotation: “At that time, I couldn’t believe what I have heard ‘Cancer’, I asked myself why this happens to me, and I was shocked and felt numb for a long time.” (Participant 3). “In my lifetime I haven’t imagined I will be diagnosed with cancer at no time I have expected such tragedy will occur to me you know it is so painful to hear that.” (Participant 6). For most of the women, being diagnosed with cancer was an unexpected situation, and it was the first painful moment they experienced during the course of cancer.

Dying soon

When women are diagnosed with cancer, the first thing that comes to their mind was that they felt like they are dying soon. For some of them, their fear of death was anticipated as sadness and the feeling

that their kids might not be able to survive without them. This was evidenced in the following statement by one of the women. "I thought this was the end for me, so I felt sad. Soon I remember my children. I cried a lot for my children. I don't think they could survive if I am not around. Still, I cry whenever I think of that." (Her eyes filled with tears) (Participant 9). Another woman also described her feeling in the following statement: "I remember when the doctor told me that I have cancer; the first thing I asked him was 'am I going to die because I heard that people with cancer couldn't live' (Participant 11). As indicated by most of the women being diagnosed with cervical cancer was immediately related to the sense that they are going to die shortly.

Confusion

Women were also confused regarding the illness at the time of diagnosis of cervical cancer. They were confused about their disease, what type of disease it is, how to deal with it, and others were confused about treatment. These feelings of confusion are well described in the following statements by two women. "When he (the health care professional) told me about my illness, I became number I was confused I don't understand even what he was saying after that" (Participant 1). "After hearing that my disease is cancer, there were a lot of questions raising in my head that I couldn't get an answer, such as what is this diseases can I get cure how am I going to live" (Participant 10). For them, being diagnosed with cervical cancer was experienced by confusion regarding the illness itself and also about its treatment.

Hopelessness

Almost half of the women explained hopelessness about their fate after they were diagnosed with cervical cancer. They described a feeling of sadness and disappointment when they heard about their cancer. This was reported mostly because women expressed a lack of information regarding their illness and was unclear about the consequences. One woman showed this response by saying. "When I hear that I have cancer, I became so sad I didn't expect the result to be cancer, no one wants to hear that" (Participant 2). Another woman described experiencing hopelessness about her situation in this way. "During that time, I had a lot of customers and I was planning to expand further my business when I was diagnosed with cancer, I felt that it is not worth having hope about the business I was working on" (Participant 6). The reported reactions above indicated that women appraised their diagnosis as involving a stressful situation. They came to view their situation as harm, loss, threat when they think of their diagnosis and their follow-up treatment.

Awareness/Understanding

Almost all women do not have enough information and had a misunderstanding about cervical cancer. Two sub-themes about participants' awareness about their illness were drawn from the data collected. These are limited awareness about their illness and punishment from God.

Limited awareness: Women reported that they have a lack of awareness or understanding of issues related to cervical cancer. Even, for two women, they heard about cervical cancer for the first time during their diagnosis. Having an unexpected diagnosis of cervical cancer and having low awareness or understanding left women in a state of stress about their situation. The following quotations illustrate this point "I worried a lot I don't have information regarding the

disease I couldn't find someone with the disease in my area. But when I came here (Tikur Anbessa Specialized Hospital, I saw a lot of people having cancer and getting treatment." (Participant 5 "I am coming from a rural area, I didn't even hear what cervical cancer is, I thought of my disease as "mitch" (sun-stroke but when the health care professional told me they found it in me I asked him, 'what is that?' I felt worried." (Participant 8).

Punishment from God

Such lack of awareness or understanding of issues related to their illness made most of the women believe that the cause of their illness is some wrongdoing in their past life. And they believed that as a result of their wrongdoing, it is a punishment from God. Some of them also thought that their cancer was written for them. Two women explained it in this way "I didn't consider myself as a bad individual what did I do wrong in my life, I am struggling to raise my children. I thought this is a punishment from God." (Her eyes filled with tears (Participant 1. "I think I may have done something in the past that upset my God but I couldn't think of any wrong doing so I always think that this should not be my fate." (Struggling to control her tear (Participant 3 From the women's response, it is understood that most of them had very limited awareness and misunderstanding regarding cervical cancer and even some of them attributed the cause of their illness with some wrongdoing in the past and being punished by God. In order to alleviate this, they reported that some of them tried to search for information from different sources through asking the relatives, local health care professionals, and from mass media (radio and television health programs.

Seriousness

Women consider that cervical cancer is a serious illness. They reported that it has affected all aspects of their life. They explained this by stating the consequences they encounter. For instance, two women stated as:

"It is a very serious disease it makes me lose my strength...I am always fatigued...I can't move here and there as I do it in old days." (Participant 7) "The illness I have is very severe, it has changed everything in my life." (Participant 4).

Experiencing symptoms

Women with cervical cancer reported having experienced different symptoms. The most frequently reported symptom by women is having excessive bleeding, foul smell discharge coming out of their reproductive organ, and pain during intercourse. One of the women describes the symptoms she experienced as "I repeatedly had bled through my reproductive organ. I thought it was just a short-term conditio but it continued it was different from the menstrual bleeding I used to have when I tell my relative about the symptom, she told me it was 'mitch' (sun-stroke and I took some cultural treatment, but the bleeding didn't stop" (Participant 10 Another woman expressed how she experienced smelling discharge through her reproductive organ and the effect brought on her as "I have a discharge which has a bad smell coming out of my reproductive organ. I tried to clean it by water, and even I cleaned it with holy water, but still the bad smell couldn't disappear, I didn't know what is happening, for this reason, I always fear to be near to people" (Participant 4. In order to get relief from symptoms, women reported that they had taken different actions. Most of the women reported that they had used cultural medication

and holy water. They described that even though they have tried the above actions, the symptoms persist, and it became severe on most of the women.

Treatment decision making

Women explained various ways of treatment decision-making to seek care from health institutions. The decisions relied on their husbands or family/relatives or for a few through discussions with local health care professionals. One woman explained how her husband helped her in decision-making as: "It was my husband who heard about the treatment of cancer from the radio and believed that it will be good for me to get cured. Then we talked about it and decided that I have to get the treatment from health care institution, the hospital in our area referred me to this hospital (Tikur Anbessa Specialize Hospital)" (Participant 2). Few women reported that their relatives influenced the decision to seek treatment from health care institutions. The following statement evidences this "My nephew is a health care professional. We called him by phone and told him that I am diagnosed with cervical cancer. And he recommended that I should begin treatment as soon as possible from the hospital, so I began my treatment here (Tikur Anbessa Specialize Hospital)" (Participant 6).

Delay to seek medical care

There has been a delay in most women's decision-making to seek medical care. Some women reported that they did not consider seeking medical care, believing that the illness will heal by itself without treatment. One of the women reported this belief. "I didn't consider that the illness will be cancer I thought it will be healed by itself in a short period, so I waited a lot of time but as time goes it didn't disappear then I decided to seek care from a hospital." (Participant 7). Most of the women also reported that they have tried traditional practices for alleviating their illness. Even though women from urban areas have practiced traditional medicine before deciding on modern medicine, this was especially a case for all women coming from rural areas. One of them described the reality behind it as "I tried traditional herbal medicine before coming here. I tried the traditional herbs, going from place to place, but I was not cured. It was then that I tried to seek care from the hospital." (Participant 10). During the discussion, women also confessed that they had repeatedly tried cultural and religious practices before seeking care from health institutions. For some women, seeking care from a health institution was considered as the last option they had. One of the women evidenced this in the following statement: "Before I decide to seek medical care from a hospital, I have tried different kinds of traditional medicinal practice and also religious practice. However, I could not get relief, and even my illness gets worse. Then, I came here as the last choice after everything I tried failed" (Participant 5). Women who experienced delayed diagnosis reported that they regret not seeking care from health institutions early. They felt that their illness may not be like this if they have been diagnosed earlier. For example, a woman described her regret in this way "I think I should have decided to go to a health center when I experience the pain. I believe that the decision to go to the cultural practice was wrong, and I wish things will be different if I came here early." (Participant 8). From the above responses, it is clear that women decided to seek care from health institutions after the cultural practices or religious practices they have tried were not successful in bringing cures for them. It was also observed that women living in urban areas seek care from health institutions earlier. In

addition, most women stated that their limited understanding of cervical cancer resulted in the delayed health-seeking decisions.

Discussion

This study explores how cervical cancer patients on follow-up treatment at appraise their illness. The initial reaction or stressful appraisal of diagnosis and treatment of cervical cancer is indicated by the subthemes 'why this happened to me', 'am I dying soon', 'confusion', and 'hopelessness' in which most of the women were shocked and not daring to accept being diagnosed with cancer. Besides, patients experience confusion and hopelessness when they knew that they have cancer. Most of the women were shocked and not daring to accept being diagnosed with cervical cancer. In addition, most of them associated cancer as an incurable illness that leads to immediate death. Similar findings were reported from previous studies in Ethiopia. For example, a qualitative study done by Kaba et al. found that patients experienced feelings of confusion, anxiety, and fear during a cancer diagnosis [14]. Previous research in Kenya indicated that fear of death was the commonest reaction to the diagnosis of cervical cancer [15]. The result of the qualitative thematic analysis also added insight into the participant's need for proper counseling during disclosure of diagnosis results. In terms of causal attribution, the qualitative study revealed participants had very limited awareness and misunderstanding. This was captured in the subtheme 'punishment from God', where women attributed the cause of their illness with some wrongdoing in the past and being punished by God. This had been reported in previous studies. A qualitative study in China revealed that cancer patients attributed the cause of their cancer to sins committed earlier in life [16]. Likewise, another qualitative study in Palestine found that patients believed the cause of cancer was a test from God [17]. This limited awareness and misunderstanding among the respondents could also be found in the community, and this could be another way that cancer is stigmatized, resulting in women covering up their illness. The qualitative analysis also revealed a theme 'delay in seeking health care', which is reflected as a result of lack of awareness about cervical cancer symptoms and repeated practice of religious/traditional rituals. Similar to these findings, previous studies among cervical and other cancer patients in Ethiopia reported a lack of awareness of symptoms [18,19]. Financial problems [20]. Feeling no pain, seeking or reliance on cultural and/or religious treatment was stated as a reason for the delay to seek medical care. Thus, enhancing cervical cancer awareness campaigns to alleviate knowledge gaps and misconceptions should be considered to help reduce delays in seeking medical care and stigmatization in the community.

Conclusion

The findings indicated that most of the women have limited awareness and misunderstanding regarding their illness. The fact that women appraised their illness negatively and misconception regarding the illness by themselves and the community, leads to utilizing traditional or religious practices, delay in seeking medical care, and experiencing stigma in the community. Thus, enhancing cervical cancer awareness campaigns to alleviate knowledge gaps and misconceptions should be considered to help reduce delays in seeking medical care and stigmatization in the community.

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