**BARRIERS TO CARE-SEEKING AMONG WOMEN LIVING WITH CERVICAL CANCER IN TAMALE, GHANA**

**ABSTRACT**

**Background:** There is an upsurge of cervical cancer cases worldwide, of which Ghana is no exception. However, despite the growing population of women suffering from this disease, not much research has been done. According to studies undertaken in other countries, survivors of cervical cancer encounter a lot of challenges such as socio-economic, physical, and psychological. In Ghana the few studies on the disease do not address the experiences of women living with the disease. The study sought to assess the barriers to care and experience of women living with cervical cancer seeking care at Tamale Teaching Hospital.

**Methods:** The exploratory descriptive qualitative design was used for the study. The Study was conducted in the Tamale Metropolis, specifically targeting women who have been diagnosed with the disease and undergoing treatment at the Tamale Teaching Hospital. The purposive sampling technique was used to recruit participants for the study. A semi-structured interview guide was used to conduct face-to-face interviews with participants. The tape-recorded interviews were then transcribed verbatim and analysed manually with the content analysis approach. The results were analyzed using thematic analysis.

**Findings:** The study reveals that women living with cervical cancer in the Tamale Metropolis grief about the unfairness of life as to why this should happen to them. More, patients have lost hope in ever recovering from the disease, a situation which has led to further hopelessness and suicidal intent.

**Recommendations:** Practice the family centered approach in caring for women living with cervical cancer. This approach will ensure that the patient’s family members and even the community at large play an active role in caring for the patient. It will go a long way to reduce neglect and stigma. Organize refresher courses for health staff on how to relate and communicate with patients.

**Key Words:*****cervical cancer, human papilloma virus (HPV), vaginal bleeding, visual inspection with acetic acid (VIA), lived experiences***

**INTRODUCTION**

The World Health Organisation (WHO) states that non-communicable diseases, such as malignancies, are responsible for the majority of the worldwide burden of disease 1. Cancer is characterised by the abnormal proliferation of cells, which can manifest in various locations throughout the human body, hence its name. Cervical cancer (CC) refers to the uncontrolled proliferation of cells originating in the cervix, which is the bottom narrow portion of the uterus that extends into the upper section of the vagina 2. Cervical cancer is the most common type of cancer affecting the female reproductive system worldwide. Its occurrence remains high in many developing countries due to the lack or ineffective implementation of preventative initiatives 3,4,5. Cervical cancer is responsible for around 52% of all cancer-related fatalities worldwide, according to the World Health Organisation (2015). According to the World Health Organisation (WHO) in 2014, the sub-Saharan region of Africa has varying rates of cervical cancer. East Africa has the greatest prevalence at 42.7%, followed by Southern Africa at 31.5%, Middle/Central Africa at 30.6%, West Africa at 29.3%, and North Africa at 6.6%.

Cervical cancer patients have several problems in the realms of social, economic, psychological, and physical aspects 6. A study conducted in South Africa revealed that women suffering from cervical cancer faced challenges in their social lives due to their inability to fulfil their spouses' sexual requirements, which ultimately resulted in divorce 7. Some individuals seek financial assistance from external sources, such as grants or loans, in addition to the help they receive from their siblings, in order to cover the costs of their treatment 8. The social disturbance experienced by cervical cancer patients is a persistent cause of stress, isolation, and diminished self-esteem 9.

The data obtained from the Obstetrics and Gynaecology Department of the Tamale Teaching Hospital (TTH) indicates a significant increase in the incidence of cervical cancer, rising from 21 cases in 2017 to 81 cases by the conclusion of 2018 (Tamale Teaching Hospital, 2020). According to the October 2019 data, there have been 34 documented instances of cervical cancer. Despite an apparent decrease in the number of cases between 2018 and 2019, the figures remain notably elevated.

Research conducted in Ghana about cervical cancer has primarily been quantitative in nature, with a specific focus on determining the prevalence of the disease and evaluating screening methods 10–13. The limited number of research that investigated the experiences among patients were carried out in the Accra Metropolis and Battor, both located in Southern Ghana 6,14. This research aims to investigate the experiences of women residing in the Tamale metropolis, located in the Northern region of Ghana, who are affected by cervical cancer.

**METHODS**

Study design: The study employed an exploratory descriptive qualitative design. The research was carried out in the Tamale Metropolis, with a specific focus on women who have received a diagnosis of the condition and are now receiving treatment at the Tamale Teaching Hospital.

Setting: The research was carried out at the Tamale Teaching Hospital (TTH). It was inaugurated on February 2, 1974 by Lt. Col. I. K. Acheampong, the former Head of State of Ghana. It is the third most extensive educational hospital in Ghana and the sole tertiary healthcare facility among the five northern zones, as well as certain areas of the Bono Ahafo Region in Ghana. The TTH is responsible for referring and managing all specialised cases in these areas.

Target Population: The target population of the study consisted of all women who visited the gynaecology unit of the Tamale Teaching Hospital (TTH) and were diagnosed with cervical cancer, either in the early stages or had survived the disease.

Inclusion Criteria: Respondents who speak Gonja, Twi (local dialects the researcher is fluent in) or English. They must have been diagnosed of cervical cancer in its early stages or undergoing treatment (surgery or chemotherapy).

Exclusion Criteria: Women who are not resident in the Tamale Metropolis. Women who have psychiatric disorders.

Sampling Technique and Size: This study employed the purposive sampling technique. Participation in this research was limited to those who had survived cervical cancer or were in the early stages of the disease. To recruit participants, we examined the medical records of patients at the gynaecology unit of the Tamale Teaching Hospital to find individuals who had been diagnosed with the condition. The predicted sample size ranged from five (5) to fifteen (15) individuals, determined by data saturation.

Data Collection Instrument: A comprehensive semi-structured interview guide was utilised to gather data for the study. The data gathering tool consisted of two pieces. Section one encompassed participants' demographic information, including age, marital status, occupation, number of children, income, and education level. The second segment included inquiries regarding the psychological encounters, socio-economic encounters, and obstacles to receiving care encountered by cervical cancer patients. The duration of each interview session ranged from 30 to 50 minutes.

Data Collection Procedure: Participants were provided with consent forms and were encouraged to endorse them by signing or thumbprinting, therefore indicating their consent to participate in the study. Interviews were held either at a designated location that ensured safety and security or at the participant's residence upon their request. The participants were informed that the interviews would be recorded and got their consent to do so. Interviews were done proficiently to maintain the integrity of the data and without compromising ethical considerations.

Electronic version of the transcript of each interview was stored in the personal computer of the researcher. The audio files were labelled with a participant interview number to serve as pseudonym and stored in an identifiable folder and security code provided to make them inaccessible to any other person except the researcher and supervisors. The printed-out transcript, consent forms and field notes for each participant were kept in a well labelled file.

Methodological Rigour: Trustworthiness was ensured by adopting credibility, transferability, confirmability, and dependability. To enhance credibility, a member check was done by tracing some of the participants to confirm the accuracy of transcribed data and emerging themes. The purpose of dependability is to ensure the findings of a qualitative inquiry are repeatable and elicit the same response if the inquiry occurred within the same group of participants. Transferability was adopted with the results of a qualitative research that can be generalized or transferred to other contexts or settings with similar characteristics. The confidence that the results of a research would be confirmed or corroborated by other researchers. A reflexive journal was kept and weekly investigators meetings done.

The consent also covered permission for audio recording, transcribing, note taking and quoting participant’s descriptions. Anonymity of the participants was maintained by eliminating identifying personal information from the interview and allocating pseudonyms instead of names to the participants. Finally, there was no reference to any participant since data collected was reported as aggregate.

**STUDY FINDINGS**

The study primarily focused on evaluating the obstacles to receiving healthcare and providing suggestions for enhancing the quality of care. Collectively, four distinct themes were identified as impediments to care, whereas three topics were derived from the interview transcripts as recommendations for enhancing care delivery. The subjects are introduced and exact quotations are employed to support the assertions.

Demographics

The participants' ages ranged from 38 to 55 years. One person was younger than 40 years, two were between 40 and 45 years, and the other two were between 50 and 55 years. Regarding Religion, three individuals identified as Muslims, while the remaining two identified as Christians. In terms of education, two participants had no prior schooling experience, one had completed Junior High School, and the remaining two had tertiary education. Four-fifths of the participants were married, while the remaining one was a widow. Moreover, the participants consisted of 3 Muslims and 2 Christians, which highlights the overall multi-religious character of the Tamale metropolis. In general, the participants reported different time periods in which they began their treatment. However, the majority (3 out of 5) started treatment promptly.

**Barriers to Care**

**Care delivery issues**

One major theme identified as a barrier to care was at the situation at hospitals where either excessive administrative process hampers effective care delivery or inadequate health care personnel leads to frequent changing of doctors who attend to patients.

*The challenges I encountered mostly have to do with the delay in receiving care at the hospital. There is no sense of urgency among both nurses and doctors; all they do is to check my temperature….this attitude sometimes deters me from even going to the hospital* ***(Afia)***

*The problem is that every time you go to the hospital, you have to see a different doctor; they are always changing, so you have to narrate your problems again* ***(Akosua)***

*Oooii as for our hospitals hmmm. Even how to get your folder is not easy….. And sometimes when you come like that, because I was coming and going all the time before they realized what was wrong with me. And the go come, go come is just too much in the hospital, but there’s nothing I can do about it because I need their help* ***(Ama)***

**Language barriers**

Language barrier also came up as another theme hampering effective care for cervical cancer patients. One participant observed that the language used at the hospitals is predominantly English. Since her understanding and ability to express herself freely in the English language is limited, she finds it difficult to express herself. Her response is as follows:

*The major challenge has to do with language barrier, when you go to the hospital, they are always speaking English but I don’t understand English. It makes it difficult for me to tell them how I’m feeling so they always say I have malaria* ***(Akua)***

**Unavailability of medication**

Unavailability of medication also emerged as a barrier to care for cervical cancer patients. It emerged that some hospitals do not often have the prescribed medication, and patients have to go to either Kumasi or Accra to purchase them. This often delays treatment and is considered a major barrier to care. The responses of some participants are provided below:

*There is also a challenge of getting some of the drugs even when you have money. Sometimes you have to buy from Kumasi or Accra. This goes to delay treatment* ***(Abena)***

*Sometimes too they say you have to go to the big hospital. Even the medicine for the treatment, sometimes they don’t have it, so we have to buy from Kumasi or wait for some time before they bring it* ***(Akosua)***

**High cost of treatment**

The cost of treatment for cervical cancer is expensive, says the participants. Since the illness has reduced their ability to work thereby reducing their income and earnings, it is becoming increasingly difficult for them to keep up with the cost of treatment. As a result, cervical cancer patients interviewed expressed worry over the financial challenge that the situation presents. Their responses are provided below:

*Mmmmm, first and foremost treating cancer is not an easy thing….. Finances are a huge challenge, because the cost of treatment is not covered by the health insurance* ***(Abena)***

*The other problem is money, they always say you go to hospital for free but as for this disease, you have to buy most of the medicine…and now that I’m not able to go to the market I depend on my son and other relatives* ***(Akua)***

**Improving Care Delivery**

**Education/Awareness**

Education and awareness creation emerged as a theme on improving care delivery for cervical cancer patients. According to the participants, the level of knowledge about cervical cancer is very low compared to the education on other diseases. They have these to say:

*Awww now I think everybody is aware of HIV/AIDS, hypertension and the likes….so I think if they increase education on this disease it will help; because I didn’t know about it until I was diagnosed even though I’m educated so you can imagine the many that are not educated. Also if authorities can do routine tests for all women at a particular age for this disease, it will help with early detection and treatment* ***(Ama)***

**Check-up/screening**

Regular check-up and screening were also considered by participants as a means to improving care for cervical cancer patients. They recognized that regular check-up and screening makes it possible for the disease to be detected early to prevent complications. In this regard, Akua had the following to say:

*First of all, women need to take charge of their lives, go for regular check-ups so that any sickness or problem will be detected and treated early to prevent complications. And for those who have been diagnosed, they should accept ad start treatment very early. The more you delay, the more the problem gets bad* ***(Abena)***

**Reducing cost of care**

The participants lamented about the cost of treatment for cervical cancer. They pleaded for a reduction in treatment cost and called on government to intervene either to bring the cost of treatment under the health insurance or absorb the costs. The following responses suffice:

*For me I think that if government makes the cost of treatment for this disease free it will help….because you cannot work to even pay for the bills and if you cannot pay, you will die. The other thing is if it is possible for the government to send some of the ‘big’ doctors to other hospitals instead of keeping them at one place so that they can take care of those at the smaller towns too* ***(Akua)***

*I wish to appeal to everyone to be supportive of their neighbours and not treat them bad in trying times of need. I wish to also plead that our doctors and nurses add a bit of urgency to their work because they are dealing with human lives. I also appeal to the government to absorb the treatment of cancer as it is done for some diseases under the health insurance scheme* ***(Afia)***

*The cost of treatment is too high, if they can reduce or even make it free for us. Also, if they can stop changing the doctors so that you don’t have to be narrating your problem to everybody* ***(Akosua)***

**DISCUSSION**

The studied literatures contain the following findings, which are examined to determine their significance and level of support. The mentioned concerns encompass economic strain, care delivery challenges, language problems, lack of medication, and the exorbitant cost of therapy.

Economic strain

The financial ramifications of cervical cancer on patients are substantial. The study revealed that patients experienced financial distress due to their inability to engage in employment, as well as the allocation of their wages towards medical expenses. These findings align with previous research that indicated cervical cancer patients faced work-related challenges as a result of their inability to work 15. Additionally, these patients encountered a decrease in their income, substantial expenses for medical bills, loss of possessions, and the burden of being in debt 15. Although none of the participants explicitly mentioned being in debt or losing possessions, they did indicate experiencing a decrease in income and having to pay for medical expenses. Once again, the majority of the participants experienced business closures as a result of their inability to work and participate in physical activities.

According to a study conducted by 15, the participants' incapacity to engage in productive employment resulted in women having to cover healthcare expenses with an interrupted flow of revenue. The medical expenses incurred by the women varied from GHC 300.00 (equivalent to 75 USD) to GHC 10,000.00 (equivalent to 2500 USD) for their treatment. Therefore, from an economic standpoint, the study argues that the detection and treatment of cervical cancer among women residing in the Tamale Metropolis imposes a financial burden and causes stress for both patients and their families. Similar to 14 study, this research discovered that although the majority of employed women continued to receive their full salary, those who were self-employed experienced the closure of their enterprises, exacerbating their financial difficulties.

Obstacles to receiving medical treatment

The investigation identified many obstacles to receiving care, such as challenges in delivering care, language hurdles, limited access to medication, and the high expenses associated with treatment. 16 identified system and practitioner delays as the primary obstacles in the realm of healthcare problems. This finding is supported by the current study, in which participants recognised bureaucratic administrative purposes as a hindrance to providing care for patients with cervical cancer. Furthermore, the frequent turnover of medical practitioners attending to patients provided cause for concern. Participants perceived that being assigned to a primary care physician enhanced the rapport and the physician's comprehension of the patient's medical history, hence enabling them to provide optimal support.

Moreover, the matter of language was brought up. This has not been identified as a significant obstacle in earlier studies; however, it is the case in the Tamale Metropolis. The official language spoken at the hospital is English. However, there are instances where the nurses and carers may not comprehend the local dialect spoken by the patients, except for English. The language barrier has a negative impact on communication between the patient and healthcare professionals or other individuals providing care. A participant said that because of language hurdles and her limited proficiency in English, she was unable to adequately communicate her symptoms to the healthcare practitioner treating her. Consequently, the original diagnosis was malaria, relying on the symptoms provided. Her true ailment, cervical cancer, was revealed at a later stage.

The lack of access to cervical cancer treatment at the Tamale Teaching Hospital is a source of concern for numerous individuals. Consequently, patients must seek the medication in larger hospitals or pharmacies located in Kumasi and Accra. These delays hinder therapy and serve as a significant obstacle to healthcare access for people with cervical cancer. Furthermore, there is the exorbitant expense associated with the procedure. Previous research has observed that the economic impact of cervical cancer on the ordinary Ghanaian woman is significant, as reported by 14. External beam radiotherapy at the Korle-Bu Teaching Hospital, Accra costs approximately GH¢ 2,000.00, whereas chemotherapy costs nearly GH¢ 1,500.00 (KBTH Radiotherapy Centre, 2014 as stated in 14.

**CONCLUSION**

It is important to mention the limited awareness of the disease among the general community, which results in delayed reporting and treatment initiation. Nurses should actively strive to educate patients on their diseases, as doing so will significantly reduce their anxiety and improve their compliance with treatment.

Ultimately, it is imperative to employ the comprehensive approach to patient care when tending to all individuals. Engaging the patient's family and the wider community in their healthcare will significantly enhance patient outcomes. Certain survivors were forsaken by their wives and some were even labelled as witches or subjected to punishment for their transgressions; integrating these individuals in the provision of patient care can mitigate stigmatisation.

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