Factors that contribute to delay in seeking cervical cancer diagnosis and treatment among women in Malawi

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ABSTRACT

Cervical cancer is a curable disease if diagnosed early. However, many women in Malawi seek treatment when the disease has reached an inoperable stage. This study was conducted to explore factors that contribute to delay in seeking early diagnosis and treatment of cervical cancer among women in Malawi. The study was exploratory and utilized qualitative data collection and analysis method. In-depth interviews were conducted using a semi-structured interview guide on a purposive sample of 24 women who were diagnosed of cervical cancer at the gynaecological wards of Zomba and Queen Elizabeth Central Hospitals in Malawi between July and September, 2011. Thematic content analysis was used to analyze the qualitative data. Two major themes (individual and health facility) emerged from the participants’ narratives as factors that contributed to their delay in seeking early diagnosis and treatment. The individual factors included; limited knowledge on symptoms and signs and limited financial resources. The health facilities factors included; limited accessibility and unavailability of cancer screening facilities in the health centres. Results show that there is a need to strengthen the screening of cervical cancer among women in the country. In addition, there is a need to create community awareness of the signs and symptoms of cervical cancer and the merits of seeking early diagnosis and treatment.

Keywords: Cervical Cancer; Health Seeking Behaviour; Visual Cervix Inspection; Symptoms and Signs of Cervical Cancer; Cancer Screening Services

1. INTRODUCTION

Hospital management of women with cervical cancer remains a challenge in most developing countries because most women seek medical care after they have developed signs and symptoms. Almost all cervical cancers are caused by human papillomavirus (HPV), a common virus that can be passed from one person to another during sex [1]. There are many types of HPV. Some HPV types can cause changes on a woman’s cervix that can lead to cervical cancer over time, while other types can cause genital warts. HPV is very common and most people get it at some time in their lives. During the early stages of infection, HPV does not show any symptoms and signs, thus, the women do not know that they have been infected. For most women, HPV will go away on its own however, if it does not, over time, it causes cervical cancer [1]. When women develop cervical cancer, they present with various symptoms, the common ones being per vaginal discharge, lower abdominal pains, backache, post coital bleeding, postmenopausal bleeding, dyspareunia and vaginal bleeding [2].

Every year approximately 500,000 new cases of cervical cancer are diagnosed worldwide and over 250,000 women die [3]. Approximately 80% of the disease burden and mortality is in the developing countries where it is the second most common form of cancer in women and the leading female cancer in sub-Saharan Africa, Central and South America and Southeast Asia [4]. The higher incidence of cervical cancer in the developing countries compared to the developed countries is due to
lack of effective screening programs aimed at detecting precancerous conditions and treating them before they progress to invasive cancer [1]. In the developed countries, the incidence of cervical cancer and associated mortality rates has declined by 1.4% and 2.9% per year respectively since 1998. The decline is due to widespread, regular screening using papanicolaoua test which detects premalignant and malignant lesions and thereby facilitating early and timely treatment. It is anticipated that the incidence and mortality rates in the developed countries will be further reduced because school going girls are immunized with HPV vaccine [5]. In Malawi, cervical cancer is the second most frequent cancer especially among women aged between 15 and 44 years. The incidence of cervical cancer is highest among women aged around 40 years [6]. Cervical cancer accounted for approximately 28% of all female cancers nationally in Malawi between 2001 and 2002 [6].

Cervical cancer, if diagnosed early is treatable, but the challenge is that most rural women in the developing countries seek medical care after they have developed signs and symptoms. Literature show that over 80% of women with cervical cancer in developing countries are diagnosed at advanced stages [7]. A survey in Malawi on the cervical cancer morbidity showed that 80% of women who sought help between 2001 and 2002, were at an inoperable stage, thus in the terminal stages of the disease [1]. The delay is due to both the patients’ own reasons and those of the health providers. Consequently, every year, 2316 women are diagnosed with cervical cancer and 1621 die from the disease [1].

These statistics prompted the Malawi government to introduce free cervical cancer prevention and treatment services. In February, 2002, the Malawi Ministry of Health (MOH) incorporated cervical cancer in its National Reproductive Health Policy and endorsed visual inspection of the cervix using acetic acid and cryotherapy as appropriate approaches to cervical cancer screening leading to early initiation of treatment [6]. The policy also spells out preventive measures which include avoiding the following: cigarette smoking, long term use of oral contraceptives, early initiation of sexual intercourse, multiple sexual partners, giving birth to more children and contracting HIV and AIDS. The policy recommends vaccination of females aged 9 to 26 years [6]. However, these preventive measures target the women that are not yet infected by HPV. For those already infected, the policy recommends relatively simple and free of charge, outpatient procedures to destroy or remove the precancerous tissues depending upon the severity, size and location of the lesion [6]. The procedures are classified as ablative or excision. The ablative ones include; cryotherapy, cold coagulation, laser vaporization and electro surgery. Regarding excision, the women undergo a loop electrosurgical excision procedure [1]. Consequently, free cervical cancer screening and treatment services have been introduced in twenty-two health facilities of the country [8]. Despite these efforts, women are still diagnosed late with cervical cancer. The aim of this study was therefore to explore the factors that contribute to delay in seeking cervical cancer services by women in Malawi.

2. METHODS

The study was exploratory and utilized qualitative data collection and analysis method to explore factors that contribute to delay among women when seeking cervical cancer services. Little is known about the women’s cervical cancer care seeking behaviour in Malawi, therefore exploratory qualitative study was deemed appropriate [9].

2.1. Setting

The study was conducted at the gynaecological wards of Zomba and Queen Elizabeth Central Hospitals in Malawi from 19th July to 19th September, 2011. These hospitals are tertiary facilities which run cervical cancer clinics and admit patients within and outside the two districts.

2.2. Sample

The initial sample size was 30 women with cervical cancer but data saturation was reached after interviewing 24 women, ten from Zomba and 14 from Queen Elizabeth Central Hospitals.

2.3. Inclusion and Exclusion Criteria

To be recruited for the study women had to be diagnosed with cervical cancer regardless of stage and admitted at the gynaecological wards of the two hospitals. The study excluded all women that did not have cervical cancer or those with cervical cancer but were terminally ill.

2.4. Data Collection

A semi-structured questionnaire was used to guide face to face in-depth interview with the women that met the inclusion criteria and consented to the study. The discussions focused on demographic characteristics, knowledge of cervical cancer, socio-cultural beliefs and health facility challenges that the women encountered as they sought cervical cancer services. The interviews were conducted in the vernacular language and were audio recorded with a digital recorder.
2.5. Data Analysis

Demographic data was analyzed using SPSS version 16.0 and the results are presented as percentages. The participants were assigned code numbers from 01 to 24 to maintain confidentiality. The qualitative data was manually analyzed using thematic content analysis [10]. All the women that met the inclusion criteria consented to participate in the study and the interviews were transcribed verbatim and translated into English within 24 hours. Back translation by an independent person ensured that meanings of narrations were not lost during translation. The first stage of the analysis examined common repeated responses from each question. The second stage involved grouping similar responses into categories. The categories were validated with the participants. Themes and sub themes were developed and are reported as the study results.

3. TRUSTWORTHINESS

Four criteria [11] for enhancing rigor in qualitative research (credibility, confirmability, dependability, and transferability) were used to ensure trustworthiness of the results. The qualitative data was validated to ensure confirmability [12]. Credibility was guaranteed by using the member checking approach in which the researchers referred back to 8 selected participants to verify the data and interpretation of the findings. Transferability was established through collection of data that included field notes, together with a rich mix of participants’ narrations. Confirmability was ensured through the process of bracketing where by all previous knowledge, beliefs and common understanding about health seeking behaviours among women with cervical cancer were set aside.

3.1. Ethical Consideration

Permission to conduct the study was obtained from College of Medicine Research and Ethics Committee (COMREC) through Kamuzu College of Nursing. The Medical Directors of Zomba and Queen Elizabeth Central Hospitals granted permission for the study to be conducted at their respective hospitals. An informed consent was obtained from every participant and interviews were initiated after the participants had signed a consent form. Other ethical issues such as avoiding harm and maintaining confidentiality were strictly observed.

3.2. Findings

3.2.1. Demographic Characteristics of the Women

The women’s age ranged from 25 - 60 years, with 42% of them being between 41 and 60 years. Over half of them (58%) were married and 63% of the married women had been married twice. Parity was high and 46% of the women had 4 - 6 children. Regarding modern contraceptive use, 54% had never used any family planning method and only 25% of them had used depo-provera while 13% had used pills. The majority (71%) were tested for HIV and 13% of those tested were HIV positive. Of all the women, 42% had their first sexual intercourse experience while they were married and the earliest age at first sexual intercourse was 13 years for one of the participants.

3.2.2. Health Seeking Behaviour of the Participants

All the participants were diagnosed of cervical cancer late and were in the inoperable condition. Two themes (individual and health facility factors) emerged from the narrations of the participants regarding the factors that contributed to their delay in being diagnosed and commencing treatment for cervical cancer.

3.2.3. Individual Factors

Two sub themes emerged from the individual factors, which were; limited knowledge of cervical cancer and limited financial resources.

3.3. Limited Knowledge of Cervical Cancer

The participants’ narrations indicated that women had limited knowledge of cervical cancer and even failed to define it. They gave definitions that were not even related to the diseases as explained by participant #8.

“I was told that cervical cancer is in a group of syndromes of diseases that a person suffers before she gets tested for HIV. Since various viruses attack different organs in the body, others attack the brain, others weaken the body. There is now a cure for some of the viruses but it’s only the viruses that attack the uterus that are still causing problems.”

This limited knowledge contributed to delay in seeking health facility services. The women explained that they noticed unusual heavy and continuous bleeding but did not relate the symptoms to the disease. Consequently, they delayed in seeking health facility care as narrated by participant #12.

“I started feeling chest pains and then started to menstruate. The following day I experienced heavy menses, it was as if I had aborted. I was surprised because I had already menstruated in the same month. I did not know it was cervical cancer, the problem continued for 2 months.”

For some participants, the strange happening in their bodies were associated with other diseases and conditions that are not related to cervical cancer. One participant noticed heavy and continuous menses that were
accompanied by smelly virginal discharge but she attributed that to early stoppage in child bearing. Her narration was as follows;

“I was thinking that when you stop child bearing quickly some things remain in the uterus but if you have delivered many children all these things are removed at child birth. For me I was thinking that since I did not bear many children, then things remained in my uterus so I was removing them but when I came to the hospital they told me that it was cervical cancer.”—Participant #10.

The limited knowledge was also associated with traditional beliefs among rural communities. In the villages, cervical cancer is known as an incurable disease therefore most participants explained that they first sought traditional medicine before considering visiting hospitals, thus delaying in seeking appropriate care.

“Before I went to the hospital, people were saying that it is one of the incurable diseases, so I visited two traditional healers. I went to the traditional healers because culturally I believe in traditional medicine. I thought the herbs would heal the symptoms so that I could then go to the hospital. However the problem persisted after I went to the herbalists. When I saw that there was no improvement, I decided to come to the hospital.”—Participant #15.

3.4. Limited Financial Resources

The results show that some people in the villages did not have money and hence could not afford to hire a bicycle when they needed to go to a health centre. Those that were strong enough could walk but others who could not even walk waited to find money so that they could seek medical care at a health facility. For some women, they had to borrow money from a neighbour or friend but this is not an easy task in the villages where everyone has limited means of earning money. Participant #9 explained:

“Iiikh! It is a serious problem, when we have no money we just stay at home and people just die. When one does not have money to pay for the medical services at private hospitals or for transport to the free government hospitals, he/she just stays at home.”

3.5. Health Facility Factors

The participants had problems to access health facilities on time due to long distances to the health centres and high costs of transportation. In addition for those women that arrived at the health centres early, the dynamics of care delayed them and were referred for appropriate diagnosis and treatment at an advanced stage of the disease.

4. ACCESSIBILITY

Some participants had the desire to visit health facilities as soon as the symptoms and signs appeared however they were constrained by barriers to access the facilities. The barriers included; long distance to the facility and means of transportation to reach the health facility.

4.1. Distance

Majority of the women stayed far from health centres. The long distance had an impact on their access to health care. Participant #1 narrated as follows; “Iiikh! It is very far but we still walk. When we start off at 6 am we reach the health facility at 8 am or 8.30 am. The long distance is a deterrent to seek early medical attention at times”.

4.2. Transport

In the rural areas, people mostly use their own or hired bicycles. However, not all people access the bicycles. Some people fail to access the bicycles because they cannot afford the hiring costs. Consequently, the majority of the women go to the facility on foot despite the long distance. “From home to the nearest health centre, a hired bicycle costs MK160 (US$0.60) or MK270 (US$1.00), most of us cannot afford and so we walk on foot when we have the strength.”—Participant #6.

4.3. Dynamics of Care

The majority of the women made several visits to health facilities to seek care despite their limited resources. They first went to health centres where unfortunately drugs were prescribed without proper assessment. When they saw that their situation was not changing as they expected they went to private clinics. It was after these attempts that the women were at last referred to the central hospital. Thus the women delayed due to the previous hospital visits in seeking and accessing appropriate care for the cervical cancer.

“I went to the nearest health centre two times and I was given oral drugs. Then I went to a private clinic where they referred me to the district hospital. I went to this district hospital four times and I was just being given oral drugs and vaginal pessaries. I was examined in the vagina and was given an appointment date to meet the doctor on 23/06/11. When I went there on this date, I was told that the doctor was unable to come that day, so I just decided to come here at Zomba central hospital. The doctor who attended to me here was furious and said ‘you were just being delayed instead of the doctors referring you here; they were just giving you inappropriate drugs.’ I was told that I had cervical cancer which has been diagnosed late after staying with it for a long time. I replied that I had been seeking medical assistance at
different hospitals I was not just staying at home.”—Participant #18.

Narrations from several women suggest that some women had sought care early, but the lower levels of the health care (Health centres) did not diagnose the disease. Consequently, instead of referring the women to higher level facilities where they could be assisted the women were delayed with inappropriate drug prescriptions. The women made several visits to several health facilities before they were finally diagnosed of cervical cancer as narrated by participant #3.

“I went to a private hospital three times and I was just being given drugs but they did not examine me. The drugs did not work so I went to another private clinic two times where I was also given some tablets that did not heal me after paying MK1080 (US$4). I went to a third private hospital once and I was given oral drugs and I was told to go to another hospital that specializes in family planning because they thought I was using family planning methods. At the clinic I was examined in the vagina but they did not tell me anything. I was still bleeding. I was given an injection and tablets and they said probably the cause of my excessive bleeding was that I was approaching menopause. I paid MK2160 (US$8). After three weeks the bleeding started again. I went to a government health centre again where they referred me to my district hospital. Upon examination, they told me that I have cervical cancer. I made three visits before they referred me here at Queen Elizabeth Central Hospital”.

For the majority of the women, their interaction with health care providers at the two cervical cancer clinics was good. They were able to explain their problems and they were properly examined in the vagina using the speculum. In addition, appropriate drugs were provided to them. This is in contrast to the quality of services they had received at the health centre and private hospitals where they were just delayed as explained by participant #17.

“At the nearest health centre, they welcomed me well. I explained my problem to them but they did not examine me. They gave me very few drugs and told me that their supply of drugs from Government was limited due to lack of funds. I was referred to come here at Zomba hospital. Here they also welcomed me well. The doctor and nurse examined me in the vagina and found that I have cervical cancer”.

Another woman started from a mission health facility and then ended up getting the right diagnosis at the central hospital;

“At a mission hospital, the doctor did not examine me he just prescribed panadol. At my district hospital, the doctor welcomed me and he prescribed drugs for me then I went back home. Here at Zomba central hospital, I went to the outpatient department and after explaining the doctor told me to go to the gynaecological clinic where the doctor examined me in the vagina and said that I have cervical cancer and I was given drugs and went home.”—Participant #2.

Some of the women reported that they made hospital visits every two weeks or every month, but the cryotherapy machine was not working during most of the times.

“I was going to the hospital when the drugs they gave me run out. I went there twice in June, 2011 but the doctor was not there and the machine was not working. I was told to go again in August, 2011. I saw that I was being delayed and just decided to come here at Zomba hospital.”—Participant #15.

5. DISCUSSION

The age range of the women in this study of 25 - 60 years agrees with the range reported by Malawi Ministry of Health National Service Delivery Guidelines for Cervical Cancer Prevention [6] to be at a high risk of developing cervical cancer. Regarding the risk factors, results further show that the women were exposed to a diverse of risk factors of cervical cancer. For some women, onset of sexual intercourse at a young age was a risk factor. Early or teen age onset of sexual intercourse is common among girls in most of the Sub Sahara African countries. In a similar study conducted among female health workers at the University of Benin Teaching Hospital, over one third (39.7%) of the respondents, had their sexual debut before the age of 20 [13].

Results show that the participants were exposed to another risk factor for cervical cancer, which is multiple sexual partners as 65% of the women had been married more than once. HPV is transmitted sexually thus the risk for cervical cancer increases with an increase in the number of sexual partners [14]. The results that the majority of the women in this study were married more than once show that the participants had been exposed to this risk factor for cervical cancer.

The use of combined oral contraceptive pills for a long period of time increases the incidence of cervical cancer due to oestrogen which stimulates metaplasia [15]. The results show that only a few women in this study had used both depo-provera and pills. The women therefore used oral contraceptives for short durations which imply that they had not been exposed to increased oestrogen levels that would be a risk factor for cervical cancer. Regarding increased number of children as a risk factor, most of the participants in this study had 4 - 6 children. American Cancer Society, [16] reported a relationship between the number of live births that a woman has and incidence of cervical cancer. Results therefore show a relationship between the number of deliveries and cervi-
cervical cancer due to high exposure to HPV as the number of deliveries increase.

The results that 13% of the women in this study were HIV positive agree with the national HIV prevalence figures. According to the MDHS 2010 results [17] the national HIV prevalence rate for women in middle age (28 - 44 years) was 12%. Furthermore, the MDHS 2010 [17] stipulated that HIV prevalence among adults aged 15 - 49 years had stabilised at around 12%. The HIV positive status was also a risk for cervical cancer. A study by Khumnun [18], found that HIV positive patients have higher odds for cervical cancer development than HIV negative people. However, in this study, the proportion of HIV positive women was low, showing that cervical cancer affects even HIV negative women if they have been exposed to other important risk factors.

Majority of the women stayed far from health facility and it took them an average of two hours to reach the facility on foot. The long distance contributed to other factors that hindered women from accessing the free health care early when the symptoms and signs appeared as also reported by Kunda et al. [7]. Results show that households that live far from hospitals have difficulties to access the free health care. The situation in Malawi is exacerbated by poor road infrastructure that makes driving difficult. These results agree with those of a study conducted by Villafuerte et al. [19], who also found that one of the barriers related to the provision of free health services was long distance which limited women’s accessibility to health care centres.

Majority of the women walked to the facility despite the long distance. However, when they became weak, most of them were not able to walk to the health facility. Kunda et al. [7] reported similar results that patients and clients residing in areas where transportation was expensive and unaffordable, were unable to present to hospitals in time. Kamphinda-Banda [4] also reported that distance to the health facility and transportation were challenges for most people in the rural areas to seek health care.

The results further show that the health seeking behaviour of the women in this study was adversely affected by limited financial resources. The women in rural areas do not have adequate financial resources to enable them seek the free cervical cancer services on time. A study by Bourne et al. [20] reported that socio-economic factors delayed women from seeking cancer screening, early detection and care. In most developing countries, preventive care is not common because it is viewed as a luxury. The situation is different in the developed countries where women are screened for cervical cancer before symptoms and signs appear. As a result, in the developed countries cervical cancer incidence and mortality rates have been declining since 1998 [5]. When comparison is made between the developing and developed countries, the highest incidences (reported as age standardized rates per 100,000 women) in the developing countries are in Haiti (87.3), Tanzania (68.6), Zambia (53.7), Guinea (50.9), Rwanda (48.2) and Malawi (46.6) as compared to a rate of 7.7 in the USA and Canada [8].

The majority of the women made many visits to the health facility before they were properly diagnosed of the cervical cancer. Some participants even sought services from private health facilities several times where they paid bills for inappropriate treatment. Dabash, et al. [21] reported that poor services in the public facilities which often depended on a single provider’s presence resulted to women having to make numerous visits before they were assisted. Numerous visits may have been inevitable due to the nature of the diseases. Cervical cancer services around the world require multiple visits for screening, confirmatory diagnosis, treatment and follow-up which in the process compounds both financial and opportunity costs to women. These delays contribute to high attrition rates because appropriate treatment and care is not initiated on time [21].

Despite the delay, women described the care they received at the tertiary facility as being good and satisfactory. These results are similar to those reported by Villafuerte et al. [19] where women indicated that they received good and satisfactory care. Bourne et al. [20] in their study found that the client-provider relationship greatly affects client satisfaction, for example the conditions under which counselling takes place, how effectively and respectfully the provider communicates information to the woman, the woman’s ability to ask questions, the process of informed consent and the respect for privacy and confidentiality. Majority of the women in this study reported that they were examined in the vagina with instruments. In a similar study by Villafuerte et al. [19] different findings were reported. Some women stated that the doctor skipped examination during the first consultation and neither told them what they had found but simply prescribed medication. Furthermore, Mosha et al. [2] in their study found that per vaginal discharge was the clinical symptom reported by all patients followed by lower abdominal pain, backache and post coital bleeding. In view of these findings, clinicians need to at least perform a speculum examination as a primary screening tool in areas with limited resources for screening cervical cancer.

6. LIMITATION

This study was conducted at two tertiary hospitals in the Southern Region of Malawi. Consequently, the results may be limited in portraying the national picture in Malawi due to geographic and cultural differences among the different regions of the country.
7. CONCLUSION

There is limited knowledge about cervical cancer by most women in the country. The health workers at the lower health facility levels such as health centres are also constrained to diagnose the disease early. There is therefore a need to create awareness among women of all ages and health workers in all the hospitals to utilize the free cervical cancer prevention and screening services that are available in the 22 districts of the country. There is also a need for massive campaign to immunize all girls against HPV. For those already infected, when they present at any health facility with abnormal vaginal discharge that is followed by lower abdominal pain, backache and postcoital bleeding, they should immediately be referred to the cervical cancer clinics at the tertiary health facilities. Furthermore, there is a need for a multi-sectoral approach in addressing cervical cancer situation in Malawi, which should involve the Ministry of Health (Policy makers), training institutions, hospitals, communities and their leaders, families and individuals.

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