

**HEALTH SEEKING BEHAVIOUR OF WOMEN WITH CERVICAL CANCER AT
GYNAECOLOGICAL WARD- ZOMBA AND QUEEN ELIZABETH CENTRAL
HOSPITALS, MALAWI**

MSC. (REPRODUCTIVE HEALTH) DISSERTATION

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**UNIVERSITY OF MALAWI
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CANCER AT GYNAECOLOGICAL WARD - ZOMBA AND QUEEN ELIZABETH
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MSC. (REPRODUCTIVE HEALTH: HIV AND AIDS) DISSERTATION

By

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Submitted to the Department of Maternal and Child Health, Faculty of Nursing

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DECLARATION

I he, Eleanor Thoko Chadza hereby declare that this dissertation is my original work and that I have not submitted it or any part of it for a degree at any other university within or outside Malawi. All the sources I have used or quoted have been acknowledged by means of references.

Eleanor Thoko Chadza

Signature

August, 2012

CERTIFICATE OF APPROVAL

The undersigned certify that this thesis represents the student's own work and effort and has been submitted with our approval.

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Member, Supervisory Committee

DEDICATION

This dissertation is dedicated to God Almighty for His mercy and love to me throughout the masters' programme and to my children Sunganani and Jessica for their perseverance and encouragement throughout the entire period of my studies.

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ABSTRACT

Worldwide cervical cancer is the second most common form of cancer in women and the leading female cancer in sub-Saharan Africa, South America and South East Asia. It causes an estimated 275,000 deaths in the world annually with the highest prevalence being in the developing countries. In Malawi, between 2001 and 2002, cervical cancer accounted for approximately 28% of all female cancers nationally.

Cervical cancer is preventable and Malawi is one of the African countries that has had the greatest success in introducing cervical cancer prevention and treatment. Despite the effort by the Malawi government to increase sites for cervical cancer screening, women still report late for cervical cancer services.

The study was conducted at Zomba and Queen Elizabeth Central Hospital gynaecological wards since these are tertiary health institutions which are also referral centres. It was done to explore health seeking behaviour of women with cervical cancer. The target population for this study was all women diagnosed with cervical cancer that had been admitted at the hospital at any stage but not terminally ill patients. The planned sample size was thirty but it reached saturation at twenty-four participants. Data collection was done using semi-structured interview guide and face to face in-depth interviews which were conducted in Chichewa. The data was analysed using content analysis. The study revealed that women have knowledge of symptoms and risk factors of cervical cancer.

However, they lacked knowledge of the causes of cervical cancer as such they thought the symptoms would stop or that they had been bewitched and first visited the traditional healer. The women also encountered a lot of challenges to access health care services. They reported challenges in terms of distance, transport, economic factors, family support and health care providers.

The women need to have information about cervical cancer by increasing awareness of the disease through using locally understood messages. Women should be empowered to make decisions about their health as well as financially. More nurses and clinicians should be trained on cervical cancer screening so that all districts and some selected health centres should be able to provide the service to women in order to prevent them from walking long distances. Ministry of Health should prioritize cervical cancer as a national problem and allocate substantial resources for national awareness. There is also need to address the challenges for the women to access the services in an operable state.

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ABBREVIATIONS AND ACRONYMS

HPV	Human Papillomavirus
MOH	Ministry of Health
QECH	Queen Elizabeth Central Hospital
ZCH	Zomba Central Hospital
HIV	Human Immunodeficiency Syndrome
AIDS	Acquired Immunodeficiency Virus
VIA	Visual Inspection of the cervix with acetic Acid
CECAP	Cervical Cancer Prevention
STI	Sexually Transmitted Infections
CIN	Cervical Intraepithelial Neoplasm
NSO	National Statistical Office
COMREC	College of Medicine Research Ethics Committee
BLM	Banja La Mtsogolo
SRHR	Sexual and Reproductive Health and Rights Policy
RHU	Reproductive Health Unit
UNICEF	United Nations International Children's Emergency Fund

DEFINITION OF CONCEPTS

Cervical cancer : Cervical cancer is a malignant change of the cervical epithelium, which usually starts at the squamocolumnar junction.

Human Papillomavirus: It is a virus that is sexually transmitted and is the cause of cervical cancer.

Visual Inspection of cervix with Acetic Acid: It is visual inspection of the cervix with a naked unaided eye to detect abnormalities after application of dilute (3.5%) acetic acid or vinegar.

Cervical Intraepithelial neoplasm : It is a precursor lesion to cervical cancer

CHAPTER 1

Introduction to the Study

Introduction

Managing patients with cervical cancer is still a challenge in most developing countries because most women seek medical care after they have developed signs and symptoms. 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 they were in the terminal stages of the disease when they reached the health facility. Only 15 % of the women sought help in early, treatable stages (National Cervical Cancer Coalition, 1997- 2007). Cervical cancer is primarily a disease found in low income countries. Of the nearly 500,000 new cases that occur annually, 83% are in the developing world, and of these, 85% of the 274,000 deaths are associated with cervical cancer. The South Asian region harbours one fourth of the burden of cervical cancer. In India alone there are an estimated 132,000 new cases and 74,000 deaths each year. Most women with cervical cancer in these countries present themselves at an advanced state, resulting in low cure rates (Ali, et.al 2010).

Malawi has a population of 3.72 million women who are aged above 15 years. This group is at risk of developing cervical cancer. Current estimates indicate that every year 2,316 women are diagnosed with cervical cancer and 1,621 of them die from the disease (WHO/ICO Information Centre on HPV and Cervical Cancer, 2010). Cervical cancer ranks the first most frequent cancer among women in Malawi, and the second most frequent cancer among women between 15 and 44 years.

In Eastern Africa, the region Malawi belongs to, about 33.6% of women in the general population are estimated to harbour cervical Human Papilloma Virus infection at a given time.

The incidence of invasive disease reaches a maximum when women are at around the age of 40 (Malawi Ministry of Health National Service Delivery Guidelines for Cervical Cancer Prevention, 2005). In addition, at least 80% of these cancer admissions present in inoperable stages II-IV, and nearly all of them die (MOH, 2005).

Case audit of cervical cancer was done at QECH to assess the trend of the gynaecological cancers for the first quarter of 2008, and the prevalence of HIV and syphilis among the cases. Cervical cancer cases accounted for 6% of gynaecological admissions at QECH between January and April 2008. The findings show that cervical cancer still remains the leading gynaecological cancer among women in the unit. Still more, majority of the cases of advanced cervical cancer had been sub-optimally managed by health workers at initial visit when the disease was at its early stage hence missing an opportunity for adequate treatment (Taulo, Malunga, & Ngwira, 2008).

The progression of cervical cancer can be reduced if timely identification of precancerous lesions is followed by effective treatment. In many developing countries, treatment of precancer is neglected because therapeutic services are unavailable, inaccessible, or inadequately linked to screening services. Women in many developing countries and particularly women in rural areas have limited access to health services because health centres are located far from their homes. The other reasons include; high transportation costs, family and work responsibilities.

In developing countries, the proportion of women who do not return for treatment after screening can be as high as 80%, severely jeopardizing the effectiveness of a cervical cancer prevention program.

In Malawi , the Ministry of Health started a national screening programme aiming at screening 80% of women in Malawi aged between 30 and 45 years over five years (approximately 668,668 women by 2010 ., MOH, 2005). Currently, cervical cancer screening and cryotherapy services are provided in 22 facilities. During this time, only 7,048 women were screened for cervical cancer. Of those, 778 tested positive for pre-cancerous lesions and 414 were treated with cryotherapy.

In 2005, the screening services were done at hospitals and health centres here in Malawi and 2,495 and 810 women were screened respectively. Likewise, 3,138 and 581 screening services were done in 2006 (Kyei & Nkhoma, 2008). There is still need to increase community awareness on cervical cancer screening and improve health care seeking behaviour for early management of cervical cancer in a state it can be operated. All patients with precancerous lesions should be treated to prevent progression to invasive cervical cancer. The purpose of this study is to explore the health seeking behaviour of women with cervical cancer.

Background

Approximately 500,000 new cases of cervical cancer are diagnosed worldwide every year. Over 250,000 women die every year from this disease and approximately 80% of this disease burden and mortality is in the developing countries. Some of the countries with the highest incidence rates (reported as age-standardized rates per 100,000 women) are 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 per 100,000 women in the US and Canada (Nkhoma, 2008).

A 2001 report revealed that each year there were 6,192 new cases of cervical cancer patients. Of these, 3,166 were died, accounting for 50% of the total patients (Khunmun, 2006).

Cervical cancer is caused by a virus called Human Papilloma Virus (HPV) genotypes 16, 18 and several other strains. The HPV enters the cells covering the cervix at the squamocolumnar junction and then slowly causes mutations that, with time, can result in cancer. Infection with HPV occurs early in life but invasive cancer may not develop for as long as 10-20 years after the initial infection. The virus is acquired mainly through sexual activity. In Malawi, between 2001 and 2002, cervical cancer accounted for approximately 28% of all female cancers nationally (JHPIEGO, 2007).

Cervical cancer progression can be reduced if detected early. It takes about ten years on average for the disease to progress from moderate to severe precancerous cells and finally to invasive cancer (National Cervical Cancer Coalition, 2007). It is now established that HPV is usually present in approximately 99% of cervical cancers. Worldwide, cervical cancer is the second most common form of cancer in women and the leading female cancer in sub-Saharan Africa, Central and South America and South East Asia (Kamphinda- Banda, 2009). It causes an estimated 275,000 deaths in the world annually with the highest prevalence being in the developing countries (Kamphinda- Banda, 2009).

Without access to viable programmes, women from poor communities will continue to seek care only when they have developed symptoms and advanced stages of cervical cancer which is difficult to treat. It is estimated that over 80% of women with cervical cancer in developing countries are diagnosed at advanced stages.

A study done by Kunda, et al. (2007) found that factors that determine when patients get hospital treatment vary from the patients' own reasons to those due to health

providers. Patient factors include expectations that the symptoms might improve, visit to local traditional healer and self medication from a nearby drug shop or private clinic.

Other factors that have been documented as causing delay in patients seeking health facilities' treatment include the distance to the nearest health facility and socio-economic status. Some households are far from hospitals and poor infrastructure make accessibility to health care difficult. In areas where there is easy transportation, affordability of the costs of transport sometimes made patients unable to present to hospitals in time. Factors related to health provider included poor referral system, high work load and diagnostic difficulties.

Several studies found that many cancer patients in Africa do not seek health care services until the disease has worsened and advanced to a critical condition too complex for treatment and prognosis. Possible reasons for late presentation include socio-demographic, economical and cultural factors such as age, ignorance and lack of information, especially about the disease, marital status, poverty, myths, taboos and many others (Kazaura, Kombe, Yuma, Mtiro & Mlawa, 2007).

Cervical cancer is 100% preventable and Malawi is one of the African countries that have had the greatest success in introducing cervical cancer prevention and treatment. 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 (VIA) and cryotherapy as appropriate approaches to cervical cancer prevention. Since 2004, JHPIEGO has worked in cervical cancer prevention (CECAP) in Malawi for five years. Currently, cervical cancer screening and treatment services have been introduced in twenty-two health facilities (JHPIEGO-RHU, 2004-2006).

From 2004 to 2006, 7,048 women were screened for cervical cancer. Out of these, 778 tested positive for precancerous lesions and 414 were treated with cryotherapy (Kyei & Nkhoma, 2008). However, despite all these efforts, still women report late for cervical cancer services.

Similarly, at Zomba Central Hospital from January, 2010 to August, 2010, 487 patients had VIA. Out of these 22 patients were suspected of cervical cancer, 14 had cryotherapy done on them and 53 were admitted to the gynaecology ward due to cervical cancer.

Problem statement

Lack of early detection of cancer of the cervix, means that women often access the health services when the disease is at an advanced stage.

There has been a constant increase in the number of women entering hospital settings when the disease is already in the invasive stage. Despite Malawi Government's efforts to introduce cervical cancer screening services in twenty-two health facilities, still more women seek cervical cancer health care services in inoperable state. Literature review indicates scanty information on health seeking behaviours of women with cervical cancer. Therefore, there is need to explore cervical cancer patients' behaviours in seeking health care services. This in turn will provide a useful background for developing strategies to increase the need for women to seek health care services in operable state.

Significance of the study

The findings will enable health personnel to understand and accept nature and emotional conditions of cervical cancer patients in seeking health care services to deal with

the disease. The findings can also be used as a guide to providing information and counselling on other suitable alternatives for the patients. The findings will be useful at the policy level to complement knowledge and awareness about this important public health issue. Furthermore, the results will add to the body of knowledge of research and patients will be receiving evidence based care.

Objectives of the study

The broad objective.

To explore health seeking behaviours of women with cervical cancer.

Specific Objectives.

- To assess the knowledge of women with cervical cancer on causes, symptoms and risk factors of cervical cancer.
- To explore cultural beliefs of women with cervical cancer related to causes, symptoms and risk factors of cervical cancer.
- To describe decision making process of women with cervical cancer as regards seeking health care services for cervical cancer.
- To explore challenges that women with cervical cancer encounter in their life concerning health care seeking.

CHAPTER 2

Literature Review

Introduction

This section presents literature related to health care seeking behaviour of patients with cervical cancer. It covers women's knowledge on causes, symptoms and risk factors of cervical cancer, cultural beliefs related to causes, symptoms and risks of cervical cancer, decision making processes as regards seeking health care services for cervical cancer and challenges that women with cervical cancer encounter in their lives concerning health care seeking. Systematic literature review has been used as the researcher wanted to understand the sequence of events of cervical cancer.

Knowledge on causes, symptoms and risk factors

In a study done in Jamaica by Bourne, Kerr-Campbell, Mc Growder & Beckford (2010) patients lacked basic knowledge and awareness of the disease as such patients first went to the traditional healers/herbalists to seek health services. They expected that the symptoms would improve. Similarly, a study done in Zimbabwe by Mangoma et al, (2006) found the following as the causes of cervical cancer: dirtiness of the womb, semen described as dirt accumulates in the woman's genital parts after sexual intercourse, use of vaginal preparations, multiple sexual partners, family planning contraceptives, cold weather and witchcraft. Khunmun (2006) found that cervical cancer patients delayed treatment because they were not aware of or did not perceive the abnormality. They believed that unusual menstruation was normal for women and was simply discharge of bad blood.

If treatment was carried out, traditional medical services were chosen. These studies by Mangoma et al, 2006 & Khunmun, 2006, reveals that women with cervical cancer have misconception of the causes.

In a study done by Yaren, Ozkilinc, Guler & Oztop(2008) in Turkey about awareness of breast and cervical cancer risk factors and screening behaviours among nurses, revealed that smoking, early age at first sexual intercourse, multiple sexual partners and history of sexually transmitted disease were risk factors of cervical cancer. These findings were similar to the results of a study done by Nakalevu 2009; Wong, Khoo & Shilib, 2009 also found that women who have had multiple partners or a high risk partner or who began having intercourse at an early age are more at risk of HPV infection than others, sexually transmitted infections (STI), smoking, multi-parity, use of birth control pills and family history are at risk of cervical cancer.

Contrary to the above findings, Hoque (2009) in his study found immunosuppressant as one of the risk factors to cervical cancer. On the other hand, other risk factors that were identified in a study done by Wong et al (2009) also found that failure to maintain hygiene or “dirtiness” was a risk factor for cervical cancer development. They referred to keeping the vaginal area clean, proper hygiene especially during menstruation and washing away the partner’s semen after sexual intercourse. Certain types of food, such as deep-fried food, canned food, preserved eggs and salted/dried fish, might trigger the development of cervical cancer.

The study by Yaren et al, (2008) revealed that symptoms of cervical cancer included pain in pelvic region, pain during sexual intercourse and vaginal bloody discharge. Wong et. al (2009) also found other signs and symptoms of cervical cancer, such as irregular or abnormal bleeding and foul smelling and excessive vaginal discharge. Furthermore, Mangoma, Chirenje & Chimbari (2006) also found lower abdominal pains,

continuous bleeding or postmenopausal bleeding, watery and smelly discharge, nausea, backache and painful legs as symptoms of cervical cancer. These studies reported that patients first seek traditional healing due to lack of knowledge and awareness of the disease. The studies showed that they had knowledge of risk factors and symptoms of cervical cancer.

Furthermore, a study conducted in Botswana showed limited knowledge among women of low socioeconomic status and the reasons for this included cultural norms of secrecy, providers not informing the public and policy-makers' limited attention to cervical cancer (Nakalevu, 2009).

Cultural beliefs related to causes, symptoms and risk factors to cervical cancer

Culture also plays a role in health seeking behaviour. When a woman is diagnosed with cancer and enters treatment, her role changes from someone who gives care to someone who needs care. In addition to keeping multiple appointments, the side effects from therapy such as nausea and fatigue may keep a woman from her established role in the family. She may be hospitalized for periods of time. For many women, this may seem disastrous.

Latino men may have little or no knowledge of household responsibilities such as cooking or caring for the children and may be resistant to helping with these for fear of being teased by family and friends for doing "women's work." (Ashing-Giwa, Kagawa-Singer, Padilla, Tejero, Hsiao & Chhabra, 2004). These role changes create stress in families. It is important for the provider to involve and inform a spouse and family about what the needs of the patient will be as she undergoes treatment and how they can help and support her (Kingsley, 2010).

Furthermore, cultural conceptualization of a woman's body as private leads to a pervasive feeling of embarrassment and hesitation and is a major deterrent for Vietnamese

women to seek breast and cervical cancer examination (Donnelly, 2006). These studies indicate that culture emphasises on gender roles as such women seek health care services very late in order to take care of the family.

Culture also conceptualises female body as private and mostly are embarrassed to seek cervical cancer services. Therefore, there is need to involve the spouse and family during treatment. The study by Anorlu, 2008, has also revealed that socio-cultural factors, socio-economic factors and biological factors which include polygamy, poverty, poor nutritional status and infections play a role in generation and progression of cancer. Therefore, in the management of women with cervical cancer, socio-cultural, socio-economic and biological factors need to be addressed.

Furthermore, Anorlu (2008) categorised the risk factors to cervical cancer in terms of socio-cultural factors, socio-economic and biological factors as follows:

Socio-cultural factors: Early marriage, polygamous marriages and high parity. Polygamy is accepted in many societies in sub-Saharan Africa. In some cultures very young girls, usually virgins, are given out to marry to older men, some of which have three or more wives. This increases the likelihood of a girl contracting HPV infection at first intercourse with her husband. Polygamy is reported to increase by twofold the risk of cervical cancer two-fold and the risk increases with increasing number of wives. High parity, which is the norm in some cultures in Africa, is also a recognised, independent and HPV-related co-factor for the development of cervical cancer.

Socio-economic factors: Poverty is endemic in sub-Saharan Africa. A study in Mali in West Africa showed that within a population widely infected with HPV, poor social conditions, high parity and poor hygienic conditions were the main co-factors for cervical cancer.

Biological factors: Poor nutritional status and infections, like malaria, HIV and TB, are ravaging sub-Saharan Africa and have made many people immuno-compromised. Reproductive tract infections are also endemic. Recent studies have linked sexually transmitted infections (STIs) other than HPV with cervical cancer.

Herpes simplex type 2 Chlamydia Trachomatis and Neisseria gonorrhoea have both been associated with an increased risk for cervical intraepithelial neoplasia (CIN) and invasive cervical cancer, after accounting for infection with high-risk types of HPV. These infections excite chronic inflammatory response which causes the generation of free radicals that are thought to play an important role in the generation and progression of cancers.

Decision making process as regards seeking health care services for cervical cancer

The World Development Report has cited education as an essential component to human health. It states, “Households with more education enjoy better health, both for adults and for children (a result that) is strikingly consistent with a great number of studies, despite differences in research methods, time periods and population samples”. Women in developing countries tend to be poorly educated, which has profound ramifications for the total quality of their lives, ranging from healthcare access, health-seeking behaviour, to the ability to generate income. In most societies they have a status subservient to men, with less control over family resources, minimal access to money and, in general, inferior social power (Denny, Quinn & Sankaranarayanan, 2006).

A study done in Australia by Shahid, Finn, Bessarab & Thompson (2009) indicated that misunderstanding, fear of death, fatalism, shame, preference for traditional healing, beliefs such as that cancer is contagious and other spiritual issues affected their decisions around accessing services.

These findings provide important information for health providers who are involved in cancer-related service delivery. In Malawi, decision making is influenced by a number of factors as well and that makes people delay in seeking health services.

A study done by Donnelly (2008) found that woman–physician hierarchical relationship is a barrier to seeking help for Vietnamese immigrant women. Clients’ understanding of health problems and the decisions that they make to engage in available programmes are shaped by the clients’ interaction with healthcare professionals. It is equally important for healthcare providers to recognize that unequal power relationships will lead to resistance and ineffectiveness in health-care.

In Ghana, women are commonly required to have permission from their husbands to seek health care. For a certain woman in Ghana, her husband’s approval and encouragement were the most influential factors on her decision to be screened, and when she announced that she was ready to attend the screening clinic, he gave her permission to go. Khunmun (2006) found that decisions to use a particular service depend on perceptions of illness, its severity, access to services, duration of access, factors supplementary to purchase power for example, health insurance, affordability of each individual and satisfaction with service.

Men are the breadwinners especially in rural areas; yet it is the women who know the priorities within the homes. This can be detrimental to women's health as they have more pressing issues within the homes on which to spend the little money available rather than on their own health needs thus decision making to seek medical help comes last (Mutuyaba, Faxelid, Mirembe & Weiderpass, 2007).

Challenges that women with cervical cancer encounter

Women with cervical cancer face a lot of problems. Studies done by Dabash, et. al ,2005; Bourne, Kerr- Campbell, McGrowder & Beckford, 2010, found that there were several factors affecting women's access to cervical cancer prevention and treatment services.

Where offered, the poor organization of services in the public sector (often depending on a single provider's presence), translated into women having to make numerous visits and increasing therefore the likelihood of loss to follow-up.

Furthermore, the costs of services varied considerably by site and sector but even in the public sector, consultation fees coupled with the often high indirect costs of having to seek services (for instance, transportation, lost wages, and long waits), were reported to negatively influence access.

Similarly, many patients experience negative psychosocial reactions, for example, fear, shock, denial, anxiety, depression, anger, and shame due to the perception that cervical cancer is associated with sexually transmitted diseases and promiscuity. These reactions may likely impact treatment-seeking behaviours (Ashing-giwa, et al, 2004).

Another challenge identified was the doctor-patient relationship. Informants reported that people of different ethnic group harboured substantial distrust of providers and the services due to their history, personal experiences and negative experiences. Communication barriers, lack of cultural sensitivity, and limited time spent with patients also created impediment to care and lack of treatment adherence for ethnic minority women (Ashing-giwa et al, 2004).

Other factors that have been documented as causing delay in patients seeking health facilities' treatment include the distance to the nearest health facility and socio-economic status. Some households are far from hospitals and poor infrastructure makes accessibility to health care difficult. In areas where there is transportation, affordability of the costs of transport makes patients unable to present to hospitals in time. Factors related to health providers include poor referral system, high work load and diagnostic difficulties (Kunda, Fitzpatrick, Kazwala, French, Shirima & MacMillan, 2007).

A study done by Kamphinda-Banda (2009) also found a number of factors that hinder cervical cancer patients access to services: Firstly, a limited number of highly centralized services were available and where they were offered, there was poor organization of the services in the public sector, which were often dependent on a single provider's presence, resulting in women having to make numerous visits and therefore increasing the likelihood of loss to follow-up. Secondly, costs of services, which varied considerably by site and sector, and in the public sector, consultation fees coupled with the often high indirect costs of having to seek services such as transportation, lost wages, and long waits were reported to negatively influence access. Thirdly, negative perceptions by the community and clients of the quality of the public sector services were also reported to discourage clients from attending, especially in the absence of symptoms. Fourthly, lack of confidentiality and privacy were not just barriers to women using screening services but also contributed to their loss of dignity when their diagnosis of cervical cancer was being discussed in the presence of other relatives such as their sons. All these studies imply that women with cervical cancer meet a lot of challenges ranging from transport, long waits at the hospital, poor patient-doctor relationship and lack of privacy and confidentiality.

Summary of literature review

The literature review has discussed issues on knowledge of cervical cancer in relation to causes, symptoms and risks, cultural beliefs, decision making process as regards seeking cervical cancer services and challenges that women with cervical cancer encounter in the course of seeking cervical cancer services. The review has revealed that there are a number of factors that influence cervical cancer patients' health seeking behaviour. One of the factors that have been highlighted is barriers in accessing health care services which include lack of knowledge and awareness, the costs of services and high indirect costs of having to seek services (such as transportation, lost wages, and long waits).

Other factors include expectations that the symptoms might improve, visit to local traditional healer and self medication from a nearby drug shop or private clinic, the distance to the nearest health facility and socio-economic status. Some studies have been done in Malawi on cervical cancer but none has been done on health care seeking behaviours. As a result, women continue to seek health care services when their condition is in an advanced state. Therefore, there is need to conduct this research to explore the womens' health care seeking behaviour so that lasting solutions can be identified.

CHAPTER 3

Methodology

Introduction

This section provides information on description of research design and methodology. Research design, setting, sampling and sample size, data collection, data management and analysis, ethical consideration and plan for dissemination have been presented in this section.

Research design

Research design is the end –result of a series of decisions made by the researcher concerning how the study will be implemented (Burns & Grove, 2001). The purpose of a design is to set up a situation that maximises the possibilities of obtaining accurate responses to objectives, questions or hypotheses. This study employed a qualitative technique to explore health seeking behaviour of women with cervical cancer since little is known about their health care seeking behaviour (LoBiondo-Wood & Haber, 2006).

Setting

The study was conducted at Zomba and Queen Elizabeth Central Hospitals. These hospitals admit patients from within the district and also districts around Zomba, Blantyre and even from the Central Region. Zomba District has a population of 539,176 people with 280,422 females (National Statistical Office, 2008). These sites were chosen because they are tertiary facilities which have health workers with expertise in the management of cancer patients at all stages.

Target population

Population is the entire aggregation of cases that meet a specified set of criteria (Polit, Beck & Hungler, 2001). The target population for this study was all women with cervical cancer at all stages who had been admitted to gynaecological ward at Zomba and Queen Elizabeth Central Hospitals but not terminally ill patients. This was important because the women had gone through all the stages of cervical cancer development and had vivid memories of what they were going through.

Sampling and sample size

Sampling was done using convenience sampling. Convenience sampling is the use of the most readily accessible persons or objects in a study (LoBiondo-Wood & Haber, 2006). This was done through approaching all eligible women who presented to the gynaecologic department during the months of sample collection for interview. The sample size was thirty women with cervical cancer at any stage but not terminally ill. Ten participants were from Zomba and twenty from Queen Elizabeth Central Hospital. However, the data reached saturation point at twenty-four. Consequently, there were ten participants from Zomba and fourteen from Queen Elizabeth central Hospital. On average, Zomba central hospital admits six patients with cervical cancer per month and Queen Elizabeth Central Hospital admits thirteen per month.

Inclusion Criteria

The inclusion criterion for this study was a woman diagnosed with cervical cancer in whose file the stage of the cervical cancer was indicated. She had to be admitted to the gynaecological ward.

Exclusion criteria

The exclusion criteria was all women suspected of having cervical cancer but investigations were still in process as such would not be able to explain their ordeal and the diagnosis had not been confirmed. Those women who were terminally ill were also not included in the study as they would not stand the length of the interviews.

Study period

The study period includes time from research proposal writing to dissemination of results which is from January to November, 2011. The actual data collection was done between July and September, 2011.

Pilot study

The researcher visited Ethel Mutharika – gynaecology department at Kamuzu Central Hospital on 7/07/11 after getting permission from the management. Two women who met the inclusion criteria were approached individually for their consent to participate in the pilot of the study tool. The purpose of the study and the process to be followed were explained to them. On the following day, the researcher conducted the in-depth interviews with the women. The interview was conducted in a private room which was offered by the nurse in-charge of the department. The results from the pilot study were used to refine the tool.

Data collection

Data for this study was collected using a semi-structured interview guide. The interview guide contained two sections. Section A, contained questions on demographic data and section B had questions on knowledge of cervical cancer, cultural belief in

relation to cervical cancer, decision making process and challenges that the women with cervical cancer encounter (Appendix H, I). Face-to-face in-depth interview was conducted in Chichewa and was tape recorded.

The women were identified by asking the nurse on duty about the women admitted to the ward due to cervical cancer at the stage indicated in the file. Then the woman was approached. Introductions were made and the aim of the study was explained to her and she was asked if she was interested to participate in the study. If interested, then she was taken into a vacant room at the same gynaecologic ward for the interviews. All interviews were conducted at Zomba and Queen Elizabeth Central Hospitals and were taking almost one hour for each woman. There was a break in between for relaxation and refreshments. Data collection took place in the month of July, August and September, 2011 after piloting the tool at Kamuzu Central Hospital.

Research instrument

A semi-structured interview guide was used to ensure that all question areas were covered (H, I). The women were encouraged to talk freely about all the topics on the interview guide. The instrument contained questions on demographic data, knowledge of cervical cancer, cultural beliefs related to cervical cancer, decision making process and challenges.

Credibility and Dependability

Credibility and dependability was used to capture the rigorous spirit of qualitative inquiry and evaluation of the data.

Credibility

This refers to confidence in the truth of the data (Polit, 2001). To ensure credibility, the researcher used an interview guide which was approved by the supervisor and the instrument was piloted before the actual study.

Researcher credibility is also important as such the researcher's training, qualifications and experience were included in order to establish confidence in the data.

Dependability

This refers to data stability over time and over conditions. This goes together with credibility as there can be no credibility in the absence of dependability. An inquiry audit was done by an external reviewer whereby scrutiny of the data and relevant supporting documents was done.

To ensure credibility and dependability of the research results, the instrument was first assessed by the supervisor to see if it met the criteria. Still more the instrument was piloted at Kamuzu Central Hospital to evaluate if it would solicit the required responses. The pilot study is typically a smaller scale of the parent study with similar methods and procedures that yield preliminary data which determines the feasibility of conducting a larger- scale study and establish that sufficient scientific evidence exists to justify subsequent, more extensive research (LoBiondo-Wood & Haber, 2006). After piloting the tool, changes were made to the instrument so that it was credible and dependable. The interview was done face-to-face and it was recorded. This helped ensure its credibility and dependability.

The women were also assured of their right to privacy, confidentiality, dignity and right to anonymity. Each woman signed a consent form to show her willingness to participate in the study after reading and understanding the participant's information sheet (Appendix G, H). Code numbers instead of names were used to ensure confidentiality. The

responses were kept at a place only accessible to the researcher. The researcher maintained human dignity and protected the participants' rights by minimizing harm and maximizing benefits through following all the required research guidelines.

Data management

Data management for qualitative data is reductionist in nature since they convert large masses of data into smaller, more manageable segments (Polit et al, 2001). The data were tape recorded and transcribed verbatim before the next interview. Then it was translated into English by an independent person soon after the interview. Data was coded manually and similar responses were grouped together to represent a theme.

Data analysis

Analysis of qualitative data is an active and interactive process (Polit et al, 2001). It is a process of fitting data together, of making the invisible obvious, and of linking and attributing consequences to antecedents. The data was organised and the content coded according to categorisation scheme. All participants were assigned code numbers from 01 to 24 to distinguish the participants from each other during the interviews. Then themes emerged. Collaizzi method of content analysis was used in this study. Content analysis is a process of organising and integrating narrative, qualitative information according to emerging themes and concepts; classically, a procedure for analysing written or verbal communication in a systematic fashion (Polit et al, 2001). Collaizzi method comprises seven steps as follows:

- Each research informant's verbatim transcript was read to acquire a sense of the whole.

- Significant statements and phrases pertaining to the phenomenon being studied were extracted from each transcript
- Meanings were formulated from the significant statements
- Meanings were organised into themes and these themes evolved into theme clusters and eventually into theme categories
- These results were integrated into a rich and exhaustive description of the lived experiences
- The essential structure of the phenomenon was formulated
- The transcribed data was translated back into English by an independent person for validation.

Ethical consideration

Ethical consideration is very vital in research in order to safeguard human rights and prevent the conduct of harmful and illegal research (LoBiondo-Wood & Haber, 2006). Clearance to conduct the study was obtained from College of Medicine Research Ethics Committee (COMREC) through Kamuzu College of Nursing (Appendix A). Consent to conduct the study was obtained from relevant authorities such as the Medical Director of Zomba and Queen Elizabeth Central Hospital (Appendices B and C). A letter for requesting permission to conduct the pilot study was submitted to the Hospital Director (Appendix D).

An informed consent was also obtained from the women after thorough explanation of the purpose of the study, methods and procedures of data collection, risks or discomforts such as breach of personal privacy and some psychological distress was minimised by using code numbers and keeping the transcripts under locked cupboard which were

accessible to the researcher only. No woman was distressed to require a clinical officer or doctor for counselling (Appendix E, F).

CHAPTER 4

Presentation of Results

Introduction

This chapter describes findings of a study conducted at Zomba and Queen Elizabeth Central Hospital gynaecological wards. Data was collected between 19th July and 19th September, 2011.

The final sample size was twenty-four and their responses have been presented in two sections; the demographic characteristics and the womens' health seeking behaviours in qualitative narration form.

Demographic characteristics of the women

The women's age ranged from 25-60 years, with the majority of them being between 41-45 years and 56-60 years (21%) and those in the 36-40 year category were few (17%). There were equal proportions (8%) of the women aged 25-30, 31-35 and 46-50 years old and only 1 woman was aged 66.

Marital status.

Majority of the women were married (58%), but 21% were divorced. Very few (13%) were widowed and those that had been separated were in minority and accounted for 8%. Most of the women (63%), regardless of the marital status at the time of the study had been married twice (63%) and only 29% had been married once to the current husband at the time of the study. However, 8% of the women had been married three times in their life time.

Number of children.

Most of the women had many children, with 46% of them having 4-6 children. A good number of them (25%) had very high number (7-9) of children and 8% of them had up to 10-12 children. Women with acceptable number of children (1-3 children) comprised 21%.

Family planning.

The majority of the women (54%) had never used any family planning method. However, 25% of them had used depo provera while 13% had used pills. Few women (4%) had used a combination of pills, depo provera, condoms and only 4% had tubal ligation done.

Sexually transmitted infections.

Most of the women (75%) had never suffered from any sexually transmitted infection (STI). The majority (71%) were tested for HIV out of which 13% tested positive. Most of the women (50%) were tested for HIV in 2010 while 17% in 2005-2007 and (8%) in 2000 – 2004. Those who were tested long time ago comprised 4% of the participants.

Most of the women after testing positive for HIV had been suffering from headache (21%), malaria (17%), and a few (8%) complained of abdominal pains and coughing. Those with pneumonia, Tuberculosis and leg pains were only 4%.

Religion.

The women belonged to different religions. The majority of them belonged to Roman Catholic Church (33%), Islam (21%), Church of Christ (13%), Seventh Day Adventist (8%), CCAP (4%) and other Christian churches accounted for 21%.

Sexual intercourse.

The majority of the women started engaging in sexual intercourse while they were married (42%) although some started at as early as 16 years of age (17%). The earliest age at first sexual intercourse was 13 years for one of the women. Some women (29%) could not remember the age at first sexual intercourse.

Education.

Majority of the women (67%) attended primary education and just few of them (4%) attended secondary education but (29%) of the women did not go to school.

The four themes that emerged were knowledge of cervical cancer, decision making process, and cultural beliefs in relation to health seeking behaviour and challenges the women encountered when accessing health care services.

Qualitative results

Knowledge of cervical cancer.

Causes

Majority of the women had limited knowledge on the causes of cervical cancer; instead they had their own explanations on the phenomenon. They attributed cervical cancer to genetics, sexually transmitted infections, and multiparity. The woman who associated cervical cancer with genetics had this to say;

The health care providers say that if you have many sexual partners you can later in life suffer from cervical cancer. I don't believe it because in our family five people died, one of them was a young boy and the other one was an old woman.

I think it is genetic; we inherit it from our ancestors through the blood because the problem also affected my family members before (participant #20)

Other women did not know the definition of cancer and gave explanations that were not related to the disease;

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, some 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 (participant #03).

A third woman, though unable to define the disease was able to mention the risk factors associated with the disease accurately; "I hear that people can get cervical cancer through

sexual intercourse and others through having many children closely spaced but I don't really know whether this is true (participant #23)."

Symptoms

The majority of the women recognized the symptoms of cervical cancer. This is expected because all the women had been diagnosed of the disease. Most of them were able to mention such symptoms as vaginal bleeding, smelly vaginal discharge, abdominal pains, pelvic pain, painful sexual intercourse and bleeding after vaginal intercourse. Furthermore, the experiences of the women show that vaginal bleeding was sudden in its onset. Some women experienced profuse while others continuous and prolonged menses. For some, the bleeding started after inserting fingers into the vagina during douching as narrated by one of the women;

I just saw that suddenly I have started vaginal bleeding in November, 2010. The problem has persisted up to now. At times I produce clots and stop. I went to Thyolo hospital where they conducted vaginal examination and the bleeding stopped temporarily. When I went back home the bleeding started again (participant #16).

The women had different experiences with the disease as narrated by one of them;

I started feeling chest pains and then started to menstruate. The following day I experienced heavy menses, it was as if I had aborted. This surprised me because I had already menstruated in the same month. I started drinking traditional medicine but it did not work because after two months I also started menstruating heavily (participant #06).

The experience of another woman was similar in terms of bleeding but different in terms of other signs and symptoms;

In June, 2010, I was taking a bath and after inserting a finger in the vagina, I saw blood coming out. This surprised me because it meant that I was having menses every other week which was followed by a backache. At the beginning, I used to stay for a week without bleeding but later it became continuous (participant # 01).

Normally a woman produces a small amount of vaginal discharge which is whitish in colour and not smelling. Sometimes the women do not even notice that they produce a vaginal discharge. However, as a sign that all was not well most of the women in this study, suddenly started noticing profuse, foul smelling vaginal discharge as narrated by one of the women;

I started producing watery vaginal discharge mixed with blood and it was so foul that when it dropped down flies rushed there. At times the bleeding stopped for two days, but was followed by foul smelling vaginal discharge. I started feeling colicky lower abdominal pains while still producing the smelly vaginal discharge (participant # 13).

Another woman narrated how she started experiencing foul vaginal discharge but related it to the family planning method she was using;

For me, I was producing a lot of vaginal discharge and felt abdominal pains. At times, during sexual intercourse, I could have vaginal bleeding and feeling pain in the vagina. These things started when I stopped using family planning methods. Initially yellow vaginal discharge was coming out so I thought it was candidiasis (participant # 14).

The other symptoms that were reported by the women included; dyspareunia (painful sexual intercourse); abdominal pains which were burning in nature; severe backache; pelvic pain and severe itching on the genitalia. These symptoms indicated the stage of the cervical cancer and whether it had invaded other body tissues. Pain during urination and defecation signified that the bladder and the rectum had been infected by the virus as well. The experiences from the narration of the women were as follows; “Aah! For me, I just started feeling pain on the vulva and during sexual intercourse also blood started coming from the vagina. At first I was having menses very frequently then it stopped (participant # 09)”.

Another woman shared as follows;

I just started feeling abdominal pains, which were burning in nature and suffered from backache for a week then in the second week I started menstruating, iiih! I wondered as to what was happening to me. Since I did not know what to do, I just stayed at home (participant # 18).

Regarding the progression of the cervical cancer to the vulva, one woman narrated as follows;

I was feeling pain when urinating, and then I developed sores on the genital area which showed that the cancer problem was worsening. At first I was producing a lot of white vaginal discharge then I started vaginal bleeding. This is the third month since I started bleeding but vaginal discharge started last year. I lose a lot of blood that can even go down the legs. When the blood oozes for two to three days, it stops and then I start producing a lot of vaginal discharge (participant # 17).

The experience by another woman was as follows;

I started feeling general body pains and had difficulty in passing stools and then I started vaginal bleeding. I was having heavy menses twice every month which have continued for a year. I had been going to private clinics where they gave me drugs. When taking the drugs the bleeding would cease but after finishing taking them the heavy bleeding would start again (participant # 24).

Risk factors

The women did not know most of the risk factors but were able to mention the most commonly known risk factors. The risk factors known to them included; multiple sexual partners, family planning methods and sexually transmitted diseases. Regarding multiple sexual partners, one woman had this to say; “Aah! A certain doctor said sometimes if you have slept with a number of men you are at risk of developing cervical cancer” (participant # 12).

Another woman got the information from a nurse and shared as follows; “I learnt a number of risk factors from a nurse. She mentioned to me a number of risks which included having sexual intercourse with many men” (participant # 03).

Some women explained that prolonged use of family planning methods (pills) for more than five years can predispose a woman to cervical cancer risk. One of the women narrated as follows; “Probably it is due to family planning methods especially depo provera or pills” (participant # 11).

Some women did not directly indicate that some family planning methods were risk factors for cervical cancer but they only suspected it to be a risk factor; “Some people say family planning methods but I don’t know how” (participant #14).

One of the women, however, did not doubt at all and attributed her condition to the family planning methods she had been using.

For me what I suspect are the family planning pills that I was receiving from Zomba Hospital. These are responsible for my condition. Most people that use or used the pill as a family planning method have this bleeding problem. Most people do not talk about it in the open but pills are giving women problems because most women who have been using them in my home area have been diagnosed with this same problem as mine. For me to start bleeding continuously, I have been taking pills for a long time because every time I went to Zomba hospital I was given pills. I thought the doctor was giving me drugs to assist me but did not know that they would give me problems in future. I was going there with a problem of not menstruating. When I was given pills, I started bleeding continuously until I was diagnosed as having cervical cancer (participant # 20).

Some women mentioned sexually transmitted infection as a risk factor for cervical cancer.

The information was obtained from the clinic. One of the women had this to say;

Mmh! When you have sexually transmitted infection, you can have cervical cancer and also if you have unprotected sex you can have cervical cancer.

Maybe my husband was promiscuous so he contracted the disease and in turn infected me (participant # 19).

Decision making process.

Majority of the women reported that they went to the hospital when the problem became worse and bleeding became severe. Most of them resorted to first taking traditional medicine and it was only after they did not notice any change that they sought assistance

from the hospital. Consequently, this practice delayed the women because they took a long time to decide when to start seeking medical care.

I was bleeding a lot and it was different from the time I was on family planning methods. When I started bleeding in April, I went to the hospital after 3 months that was in July, because I thought that the bleeding would eventually stop. At first I thought the excessive bleeding was due to the family planning method I was using so when the bleeding persisted I went to Fatima hospital. After hospitalization, I was discharged but I was still bleeding. The bleeding episodes were on and off every 2 minutes so the hospital gave me a blood transfusion. To make matters worse, sometimes the bleeding started right in the hospital immediately after the blood transfusion (participant # 13).

Realizing that the bleeding being experienced and the vaginal discharge were abnormal, the participants suspected that their lives could be in danger. As a result they made a decision to seek medical help, as narrated by one of the women;

I realised that what was happening to me was not according to God's creation. Naturally, after finishing menses a woman is supposed to be normal but in my case, I was producing a lot of vaginal discharges. This was abnormal so I decided to seek medical help (participant # 04).

The women mentioned that they consulted some people to help in decision making. Most of them consulted family members who included spouse, friends and children. Nevertheless, a few of them made decisions on their own. For those who consulted family members they expected to receive consent from them so that they could seek medical

assistance at a health facility. The majority of the women consulted their spouses because they were the closest friends most of the times.

I take my husband as myself and also as somebody whom I can tell everything that is happening in my body as compared to other people because he is the one I am staying with.

He is the one who has known the problem for a long time before other people knew it. Other people only knew about the problem after it became serious (participant # 20).

The role of husbands in the wife's decision making was also shared by another woman as follows;

Aah! Problems like these ones; the first person to know them is your husband. I told my husband that the way I was bleeding was not normal nor was it due to family planning but something might have gone wrong, so I suggested to him that I seek medical help at a health facility (participant # 13).

Apart from husbands some women consulted their children, friends and relatives before they made a decision regarding seeking medical assistance from a health facility. One of the women who sought advice from a friend shared;

Where I come from in Mchinji, there is a club on "stop gender based violence". At the club they told us to choose a friend in whom we can confide when there is a confidential matter. I told my friend at the club about my problem. She told me that it could be cervical cancer and that I should go to the hospital without delay (participant # 01).

Another woman was advised by her own son and had this to say;

I told my son that I had gone back to my girl child years, because I had started menstruating again. He told me that it was unusual for this to happen that way and advised that I should seek medical assistance at a health facility (participant # 10).

For some women, parents, especially mothers were important sources of advice for the decision to seek medical care at a health facility. One of the women shared as follows; “I told my mother and she told me to go to the hospital to be examined” (participant # 23).

Though most women are subservient to men, in this study some women had to make the decision on their own after the husband or the significant others were reluctant to make a decision for them. Such an experience was shared by one of the women as follows;

I told my husband but he was just listening and did not do anything about it, so I thought of going to the hospital. I also explained to my mother but she did not know cervical cancer, she thought it was candidiasis since the production of excessive vaginal discharge is also caused by candidiasis. She advised that I should use traditional medicine. Consequently, I went to a herbalist where I was given some traditional medicine. I also visited the hospital and was given some drugs. I have been taking both the traditional medicine and the drugs from the hospital. When I saw that there was no improvement I just thought of going back to the hospital (participant # 14).

A woman who took her own initiative to visit the hospital had this to say;

I made the decision on my own because I was feeling pain, “moyo sasungirana, literary meaning one takes care of his or her own life” I listened to a radio programme whose discussion centred on cervical cancer. I learnt something from the radio programme then I said ooh! If I just stay at home with this disease, it means that I am not thinking properly but let me go to the hospital (participant # 03).

Some of the responses from spouses, children and friends were not encouraging the women to go to the hospital but to go to herbalists where local medicine was prescribed. This disease traditionally is associated with witchcraft or the unknown incurable diseases which are collectively known as “likango or mwanamphepo” in the vernacular language. This fact was reflected from one of the womens’ responses; “I told my friend and she said that probably it’s “likango” an incurable disease. Though I took local medicine, the problem persisted” (participant #05).

Another woman narrated as follows;

I told a certain lady and she said she had the medicine to cure the problem. However, she gave me traditional medicine which did not cure the disease. I went to the hospital where they gave me three packets of tablets, but still there was no improvement. The problem has now reached this stage and I have been sent to this hospital (participant # 21).

The womens’ narration indicated that the major reason for seeking health facility care was that they did not initially know that it was cervical cancer. Most of the women indicated that they thought it was a problem which was going to be solved easily with available traditional or simple medication from the hospital.

It took me four years because I thought it was going to stop. I had been taking traditional medicine for one week but there was no improvement so I stopped. Then I was just staying at home. After three weeks I went to the hospital where they gave me some drugs but there was no improvement. Consequently, I resolved to stop taking the drugs hoping that the problem would stop on its own (participant # 21).

On the contrary, some thought that they had been bewitched and hence resorted to going to herbalists. There were some women who did not go to the hospital because they did not have money to pay for the treatment since their closest health facility was a paying private hospital. For other women, going to private paying hospital was another detour which just delayed them further from receiving appropriate assistance at the cervical cancer clinic as narrated by one of the women;

“All this time I had been visiting a hospital, only that it was a private clinic instead of coming here quickly. I was delaying at private clinics. I should have come here early” (participant # 24).

Cultural beliefs in relation to seeking health care.

Cultural beliefs have an effect on health seeking behaviour of women with cervical cancer. Majority of the women could not believe that problems of menstruation could be due to natural causes such as cervical cancer but that they were bewitched. As a result, they first went to herbalists before going to the hospital, which delayed them from accessing timely appropriate care.

Before I went to the hospital, people were saying that it's 'mwanamphepo' (the incurable disease) so I visited two traditional healers. This other traditional healer brought a plastic full of medicine and then I said iih! Is it relish that I will use for food? My husband was the one who was going to these traditional healers but I knew that the problem was in my body and it was not going to be dealt with by traditional healers (participant # 05).

One of the women who sought assistance from a herbalist had this to say;

I went to a herbalist because we Africans believe in traditional healers. I thought it would be better to go there so that probably the symptoms would reduce before going to the hospital. However, the problem persisted even after going to the herbalists. When I saw that there was no improvement, I decided to go to the hospital (participant # 14).

Herbalists were at times admitting patients to their premises, thus delaying those that needed immediate attention at a health facility.

I went to one of the herbalists and stayed there for three months, while there I was given drugs to drink. When I saw that there was no improvement I went back to Mkula Private Clinic for the second time, but there was still no improvement, hence I made up my mind to come here (participant # 24).

Experience by some women show that the seeking of medical assistance at a health facility was made in secrete due to some traditional beliefs.

We did not tell anybody because we were afraid of worsening the situation; we just sneaked and came here. My sister died of the same vaginal bleeding. Another woman had the same problem and she passed away. People were saying that her husband had bewitched her but I tell you we lost her anyway (participant # 16).

Late diagnosis of the disease also contributed to the seeking of traditional medicine by some women. Some of the women went to health centres or private clinics to seek medical care first before resorting to traditional medicine, but they were delayed because they were being given inappropriate drugs.

The health facilities did not diagnose the disease and hence the problem persisted. When the women saw that there was no improvement that is when they resorted to seeking traditional medicine.

When I was tired of going to the hospital, I went to two traditional healers where I took local medicine because people were saying its “libale” (the incurable disease). There was no improvement and I just decided to go back to the hospital (participant # 03).

Another woman had a similar experience and shared as follows;

I went to Mkwilula, Ntaja, and Banja La Mtsogolo private hospitals as well as Liwonde, a Government hospital, but I was not treated properly. I also went to herbalists’ iiih! Their medicine was expensive. I visited more than 20 herbalists and their charges ranged from K500 to K1, 500 but there was still no improvement. Other herbalists advised that I have been bewitched (participant #10).

One of the women who started visiting a health centre in her locality had this to share;

I first went to Makhanga health centre and I was given tablets. I went there because it was where I was getting family planning contraceptives. I told them that the contraceptives were responsible for my problem but they just gave me tablets. I also went to Fatima hospital and they gave me drugs which did not help.

Despite taking drugs from the hospital, the bleeding persisted therefore I went to so many herbalists where I was given local medicine “zithumwa” that the whole waist was full of ‘zithumwa’. Other herbalists were administering their drugs through cutting tattoos on my body and the whole body was full of tattoos but there was no improvement.

I went back to Fatima hospital where they diagnosed the cervical cancer and advised that I should have my uterus removed. When I went back home, my relatives did not believe because they thought I had been bewitched (participant # 13).

The study results show that there were misconceptions about cervical cancer among the women. The misconceptions came about due to cultural beliefs. Culturally, some of the women thought that it is normal for them to produce vaginal discharge as it was a way of removing dust from the uterus. This belief is held for women who reach menopause. It is believed that at that stage women produce foul vaginal fluid to remove some products of conception which during child birth are expelled together with the child during child birth.

I thought that I had developed sores because sometimes sores or dust can be found in the uterus. We learnt that in the uterus there can be sores or dust and I thought that by producing a lot of foul vaginal discharge that was dark in colour, I was removing the dust from my uterus (participant # 13).

A woman who linked continuous smelly vaginal discharge with stoppage in child bearing narrated as follows;

I used to think that when you stop bearing children early some things remain in the uterus but if you have delivered many children all these things are removed at child birth. For me I thought that since I did not bear many children, things that remained in my uterus were being removed but when I came here at the hospital they told me that it is cervical cancer (participant # 23).

Challenges encountered when accessing health care services.

Accessibility to services in this study depended upon a number of things such as distance, means of transport, number of visits to the health facility, source of income and the time taken to reach the health facility. The challenges were in terms of accessibility, economic factors, family support and health care providers.

Distance

Majority of the women stayed far from health facility and it took them an average of two hours to reach the facility. This had an impact on their access to health care coupled with other issues. “Iih! It is very far but we still walk. When we start off at 6 am we reach the health facility at 8am or 8.30am” (participant # 11).

Another woman from the Lower Shire shared; “From home to the nearest health facility which is Makhanga is a bit far. We start off at 6 am by bicycle and reach the facility around 7.30 am. When we walk, we reach the facility at 8 or 9am”.(participant no#14)

Another woman from a different area in the southern region had this to share;

From home to Namatapa health facility iih! It is very far. If you start off at 6 am you reach there at 8.30 or 9 am. In those days when I was strong, I could walk. When people are very sick, they are taken to the health facility on a stretcher and sometimes the sick are carried on the back (participant # 17).

Some women reported that they were coming from areas near the health facility and it did not take them time to reach the health facility. They however could not reach the facility when the illness intensified.

I go to a government health facility which is near. At first I could walk to the facility but since I started suffering from this disease, I feel pain in the legs so I hire a bicycle to travel to the hospital (participant # 5).

This situation was similar to another woman who narrated as follows;

From home to Matope is near and it is the same distance as from Queen Elizabeth Central Hospital to Kamba right here in Blantyre. I walk on foot and when I start off at 6 am I arrive at the hospital by 8 am. Sometimes I arrive at the hospital in the morning before it is open (participant # 21).

Transport

In the rural areas, people mostly use their own or hired bicycles. However, not all people access the bicycles. Some people even 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 Bingu health facility iii! It is very far and, the distance could be similar as that from here to Nguludi. We walk and when we start off at 6 am we arrive in the afternoon. A hired bicycle costs K150 or K200(participant # 18).

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 facility. 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. In the case of 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.

Iih! 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 for paying the medical services or for transport to a health facility, h or she just stays at home (participant # 01).

Another woman shared her experience as follows;

I used to face problems when I did not have money because I just stayed at home suffering. At times I borrowed money but this posed another problem for me because I did not have a sure source of income which I could use to pay back the debt. However, despite the means of travel, I continued to visit the hospital with a hope that one day I would meet a doctor who could assist me properly.(participant # 20).

Source of income

For most of the women, the sale of farm produce in the form of crops and livestock was a very important source of income. Some of the women were involved in small scale businesses which generated some cash income for them. Others received assistance from well wishers. In most cases, the women still faced problems when seeking care from paying health facilities because the income was small and could not suffice to cover the huge hospital bills. It was noted from the study that though the majority of the women went to government hospitals which are free still at one point or the other they wished to visit a private paying clinic because they anticipated better quality services than at government hospital.

Makhanga is a government health facility and is free of charge. However, I also went to Fatima Mission Hospital five times.

During the first three visits I paid K350 for treatment. However, during the fourth and fifth visits, the medical bills were high. The medication for the fourth visit included a bottle of intravenous fluid and a bottle of blood and I paid K5, 375. During the fifth visit, I was transfused two pints of blood and the bill was K4, 100. These bills were too high for me considering that I only grow maize as a source of my income (participant # 13).

Experiences for high hospital bills were also shared by other women as follows;

I didn't pay anything at Mangochi and Liwonde but I did in the private health facilities. At Mkwilula private I paid K1, 500. I also went to Ntaja where I paid K1, 200 and at Manesi private clinic I paid K1, 500 (participant # 10).

Another woman had this to share regarding high hospital bills; "Chikhwawa and QECH are government hospitals so I did not pay anything. I went to Mkula Private Clinic twice and there I paid K1, 000 during the first visit and K1, 400 during the second visit". (Participant # 24).

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 had expected they went to private clinics. It was after these attempts that the women were at last referred to a hospital. However, the women delayed in seeking and accessing appropriate care for cervical cancer due to the previous hospital visits..

I went to Ulongwe Health centre two times and I was given oral drugs. Then I went to a private clinic where they referred me to Liwonde hospital. I went to Liwonde hospital four times and I was just being given oral drugs and vaginal pessaries. I

was examined in the vagina (VIA) and was given an appointment date to meet the doctor on 23/07/11. When I went on 23/07/11, I was told that the doctor was unable to come that day, so I just decided to come here at Zomba 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 but these other doctors.....” Here at Zomba hospital, the nurse examined me by inserting her fingers into the vagina, and told me that I was bleeding a lot. She then referred me to ward 2 and 3 where 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 a hospital I was not just staying at home (participant #04).

The maternal seeking behaviours of the women suggest that the mothers intended to access appropriate medical care on time. However, delays were caused by the health facility’s inability to diagnose the cancer early. As a result, the women made several visits to several health facilities before they were finally diagnosed of cervical cancer.

I went to Ntaja private health facility three times and I was just being given drugs but they did not examine me. The drugs did not work so I went to Nambanje private clinic two times where I was also given some tablets that did not heal me after paying K1, 000. I went to Nsanama another private facility once and I was given oral drugs and I was told to go to BLM probably they thought I was using family planning methods. At BLM, they examined me 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 K2, 000. After three weeks the bleeding started again. I went to Ntaja health facility again where they referred me to Liwonde hospital.

At Liwonde they examined me and told me that I have cervical cancer. I made three visits before they referred me here at Zomba Central Hospital (participant #07).

The delay to diagnose the cervical cancer was also narrated by another woman as follows;

I went to Mangochi hospital three times and I was given Aspirin and ferrous sulfate. After that I went to Liwonde four times and I was given two injections. I also went to Mkwilula private facility once where I paid K1, 500 and then went to Ntaja where I paid K1, 200 and then to Manesi private clinic where I paid K1, 500. I was also told to pay extra K700 for one tablet which they said was going to heal me but I had no money. As a result, I went back to Mangochi hospital for free medication where they referred me to Liwonde. At Liwonde after examination they referred me here at Zomba Central Hospital (participant # 10).

Family support

The majority of the women in this study reported that their children were grown-up and they took care of themselves. There were however, a few women that had children that needed care and their husbands or relatives took care of them. It is a challenge when women are hospitalized for a long period of time and they do not have relatives to offer support especially in caring for their children back home. Usually the children are left alone at home but need somebody to take care of them during the time that the mother is in hospital.

I don't have small children, at this age, laughs! If you see my last born, you cannot believe it. All my children are married and have their own families. I stay with four grandchildren but now they are with their mother (participant # 17).

Some women had left the responsibility of caring for their children to their spouses. "My husband takes care of them". (Participant # 15).

The women reported that while in hospital they were being taken care of by their children, sisters, mothers, relatives and husbands but there were others who had nobody to take care of them. "My children take care of me especially the three children who did not go further with their education. They stay in Mchinji with their spouse". (Participant # 01).

Few of the women had nobody to take care of them while admitted at the hospital. This has an impact on seeking health care as the sick women needed a guardian to take care of them.

As you know nowadays things have changed. It seems only the close relatives are the ones who take care of the sick. Here I am always alone and at times my child comes to visit me. A nine year old girl came to be my guardian but it did not amuse the nurses and they shouted at me. My relatives know that I am here but they do not come to see me (participant # 11).

Some of the women explained that their relatives wanted to take care of them, but the prolonged illness made some guardians to go back home so that they can cultivate the gardens.

My sickness has taken a long time and you know life in the villages requires that people work in order to earn a living. My relatives need to work so that they support their families and that is why they are not here. It does not mean that they

don't love me. However, there are still other people who assist me like here I am with my sister and my daughter (participant # 20).

Health care provider

For the majority of the women, their interaction with health care providers at the cervical cancer clinics that are offered at the two central hospitals was good. They were able to explain their problems and they were properly examined in the vagina using instruments (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 delayed.

At Jali 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 (participant # 05).

The experience of another woman was as follows;

Iih! They welcomed me well. They examined my vagina visually using an electric lamp and also with the assistance of instruments. I don't know what exactly they did with the intestines then they told me that I have a small wound on the cervix. In the ward the nurse on night duty also assisted me. She gave me hot water to bath and she waited for me to go to the theatre before she went home. Unfortunately the operation was postponed (participant # 03).

Similarly, one of the women had this to say;

I arrived at OPD and the doctor examined me in the vagina and told me that there is a wound in my uterus. Then I was told to come on Thursday in order to meet a specialist. On Thursday I came and the doctor examined me in the vagina by inserting instruments and found that I had cervical cancer.

I was given an appointment date of 18/08/11 for hysterectomy. However, it was postponed to 12/09/11 thus I came here yesterday (participant # 22).

Another woman shared as follows;

When I went to Kapiri health facility the doctors did not examine me because if they had examined me they could have detected the problem right there. However, when I went there again to show them what the doctors at Zomba Central Hospital had written, they told me that I have cervical cancer and they encouraged me to go back for operation. Here at Zomba central hospital, they examined me by inserting fingers in the vagina and they identified the problem. The only problem is that I was sent back from the theatre (participant # 01).

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

At Malosa hospital, the doctor did not examine me he just prescribed panadol.

At Liwonde hospital, the doctor welcomed me and prescribed drugs for me then went back home. Here at Zomba central hospital, I went to the outpatient department and after explaining the doctor told me to go to Gynae 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 # 02).

Though women expected to be examined in the vagina, few felt that their privacy was breached when the examination was conducted in the presence of a number of people who were just observing the procedure. One woman said:

When I entered the room Eeh! There was one doctor together with more than five other trainee doctors.

Normally I was supposed to be seen by one doctor but here there were five or seven other people observing and since I needed help I just accepted but I was not happy because the genital area is a very secretive place. Moreover, the other people didn't help they were just observing the genital area and I was disappointed (participant # 20).

Some of the women reported that they were going to the health facility every two weeks or every month, when the drugs that they had been given had ran out and to check if cryotherapy machine was working.

I was going to the hospital when the drugs they gave me ran out. I went there twice in July, 2011 but the doctor was not there and 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 # 04).

For some women the return date was not given. They were advised to go to the central hospital when they run out of drugs so that they may be operated before it was too late.

I was not told the return date but I was going there when the drugs had finished. At Fatima I was just told to go to QECH because the cancer was just starting and the uterus could be removed (participant # 13).

Other women were visiting a health facility just to check if the machine for freezing the cervical cancer cells was working.

I was going there every month to check if the machine had been maintained so that they could freeze the cells. However, the machine was not working so they did not perform that procedure (participant # 03).

Conclusion

This chapter presented results according to the major themes that emerged from the data analysis.

CHAPTER 5

Discussion of findings

Introduction

This chapter presents a discussion of the study whose purpose was to explore health seeking behaviours of women with cervical cancer. Strengths, limitations and recommendations have also been presented.

Demographic characteristics

The age ranges of the women in this study signify that most women have cervical cancer in their middle age and are exposed to the risk factors at a young age. The results show that the virus is activated by various risk factors at a young age as it takes about ten to twenty years to develop into cancerous lesions. These results agree with those reported by Malawi Ministry of Health National Service Delivery Guidelines for Cervical Cancer Prevention (2005) that the incidence of invasive disease reaches a maximum at about the age of forty. Furthermore, the study has demonstrated that women aged from twenty years can also have cervical cancer which means that they are exposed to the HPV at a young age and the cancer develops early when the early exposure is coupled with other risk factors.

The age of sexual debut has a bearing on the development of cervical cancer in women. In this study, the majority of the women started engaging in sexual intercourse while they were married. However, the age at the first intercourse is very low for some of the women in this study. This finding is consistent with those obtained in a similar study conducted among female health workers at the University of Benin Teaching Hospital, where a minority (39.7%) of the respondents, had their sexual debut before the age of 20 years (Gharoro & Ikeanyi, 2006). Likewise, Taherian (2002) found that the younger the woman at first intercourse the higher the risk of developing cervical cancer. This is thought to be due to the mutation of metaplastic squamous cells which become dysplastic as a result of exposure to carcinogens through early sexual intercourse. In addition, since the carcinogens are likely to be transmitted sexually, risk for cervical cancer rises with an increase in the number of sexual partners. Similarly, in this study majority of the women were married and had married twice or more which also is a risk factor for cervical cancer.

The study results showed that majority of the women had never used any family planning method. However, few of them had used both depo provera and pills. Use of oral contraceptives for short durations implies that women had not been exposed to increased oestrogen levels which cause cervical cancer. It is believed that 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 (CCP, 2004).

Findings from other studies such as those by ACS, (2007) have suggested that the number of live births that a woman has is a consistent risk factor for cervical cancer. The current study also showed a relationship between numbers of deliveries and cervical cancer as majority of the women had delivered 4-6 children leading to higher exposure of HPV.

The majority of the women had gone for HIV test and few of them were positive. This would indicate that reduction in human immunity due to HIV infection enables the human Papilloma virus to invade the epithelium of the cervix, causing mutation of the squamous cells which are precursors of cancerous cells. Furthermore, this would imply that the prevalence of HIV in Malawi (12%) would serve to increase the already alarming rate of cervical cancer which is currently at approximately 28% of all female cancers nationally (Malawi HIV & AIDS Monitoring & Evaluation report, 2005).

The study also found that women in middle age (28- 44) were HIV positive which concurs with the National Action Framework (2010-2012) which stipulated that HIV prevalence among adults aged 15-49 years is still high though it has stabilised at around 12%. A study by Parham et.al (2006), found that HIV positive patients have higher odds for cervical cancer development than HIV negative people. However, in this study only a few were HIV positive showing that the problem affects even those that are negative if they have been exposed to other risk factors. The information about HIV from other sources or studies was included to back u the findings of this current study.

Majority of the women had primary school education, while a few had not attended any education and very few had secondary school education. Nationally, 19.9% of Malawian women are non-educated, 65.2% attained primary school education and 14.6% secondary education (NSO &UNICEF, 2008). The study population differed with national statistics in that the percentage of those who had primary school education and those who did not go to school was higher than those who attained secondary education. This showed that the level of education correlates with health seeking behaviour as those who attained secondary education were very few as compared to the women who did not go to school. A study done by Denny, Quinn & Sankaranarayanan(2006) reported that women in developing countries tend to be poorly educated, which has profound ramifications for the total quality of their lives, ranging

from health care access, to health – seeking behaviour, to the ability to generate income. In Malawi, improved educational status of women is associated with better access to health care (Geubbels, 2006). Education empowers people. People who have some education are in a better position to seek and comply with health care provider’s instructions. However, many women in this study did not go to school which meant that they were not empowered to seek health care on their own.

Majority of the women were Christians and most of them belonged to Roman Catholic Church. Members belonging to Islamic faith were few. The findings indicate that both Christians and Muslims are at risk of cervical cancer and they need information about prevention of cervical cancer as there are no restrictions in seeking health care services. Both Christian and Islamic faiths do not restrict their believers from seeking health care services. However, a study done in the United States of America revealed that conservative religious beliefs limit utilization of modern medical services (Geubbels, 2006).

Qualitative results

The findings of this study identified four major themes which have been discussed according to the results of the study.

Knowledge of cervical cancer.

Causes

The women in this study showed that they had limited knowledge about the causes of cervical cancer as mostly they were mentioning either the symptoms or the risk factors instead of the causes. Likewise, studies done by Bourne, Kerr-Campbell, Mc Growder & Beckford (2010) revealed that patients lack basic knowledge and awareness of the disease as such they would first go to the traditional healer or herbalists to seek health care services.

Similarly, a study by Mangoma et al, (2006) found the following as the causes of cervical cancer: dirtiness of the womb, semen described as dirt and accumulates in the woman’s

genital parts after sexual intercourse, use of vaginal preparations, multiple sexual partners, family planning contraceptives, cold weather and witch craft which showed that the participants lacked knowledge on causes of cervical cancer. Furthermore, a study done by Dabash, et al,(2005) found that women who were undergoing treatment for early and late stage cervical cancer were often unaware of their exact diagnosis or if aware, did not know the cause of the disease for which they were being treated. All these findings show that women have little knowledge about the cause of cervical cancer as a result they could be exposed to the virus in their early age.

Symptoms

The women had knowledge of the symptoms of cervical cancer and they cited vaginal bleeding, smelly vaginal discharge, abdominal pains, pelvic pain, painful sexual intercourse and bleeding after vaginal sexual intercourse. This is similar to what Yaren et al, (2008) found in their study. Their study revealed symptoms such as pain in the pelvic region, pain during sexual intercourse and vaginal bloody discharge. Similarly, Wong et al (2009) found symptoms such as irregular or abnormal bleeding, foul smelling and excessive vaginal discharge. Furthermore, Mangoma, Chirenje & Chimbiri (2006) also found the following: lower abdominal pains, continuous bleeding or postmenopausal bleeding, watery and smelly discharge, nausea, backache and painful legs. These studies show that women have knowledge of the symptoms of cervical cancer though they report late to the health facility for care.

Risk factors

The study findings on the risk factors that the women were exposed on agree with studies done by Yaren, Ozkilinc, Guler & Oztop (2008) in Turkey on awareness of breast and cervical risk factors and screening behaviour among nurses. The results showed that smoking, early age at first sexual intercourse, multiple sexual partners and history of sexually transmitted disease were risk factors of cervical cancer. Another study done by Nakalevu (2009); Wong, Khoo & Shilib,(2009) also found that women who have had multiple partners or a high risk partner or who began having intercourse at an early age, smoking, multi-parity, use of birth control pills and family history are at risk of cervical cancer. Similarly, the study's findings are consistent with findings obtained in a similar study conducted among female health workers at the University of Benin Teaching Hospital, where a minority (39.7%) of the respondents, had their sexual debut before the age of 20 years (Gharoro & Ikeanyi, 2006).

Decision making.

In this study decisions to use a particular service depended on perceptions of illness, its severity, access to services and duration of access. Majority of the women went to the hospital when symptoms became severe. These findings are similar to what Khunmun (2006) found in his study. He found that decisions to use a particular service system depended upon perceptions of illness, its severity, access to services, duration of access, factors supplementary to purchase power for instance, health insurance, affordability of each individual and satisfaction with service.

Most of the women had to consult family members, spouse, friends, and children to help them in decision making. Most women in Malawi especially those of low socio-economic status have poor social empowerment and are excluded from making their own decisions.

Usually they consult their husband to decide for them where and when to seek help including preventive health behaviour and permission is either granted or not. The findings of this study are in line with what Basu, et al (2006) found in their study. In the study, women felt that lack of approval by the husband to have a test to cervical cancer screening was a barrier. This would be due to rural women being less empowered than urban women to make own decisions including those pertaining to health seeking behaviour. This finding is also similar to findings from a study done in India whereby 26.5% of women failed to have cervical cancer screening test because their husbands would not allow them to go to the health facility. However, few of the participants in this study made decision on their own to go to the hospital which is not commonly done by women as most of the time they are subservient to men.

The study has also revealed that in some families decisions to seek health care were made by children, either a son or a daughter. Similarly, a study conducted by Villafuerte, et al (2007) found that daughters are the family members that play the most important role in recommending and encouraging their mothers to participate in cervical cancer screening.

Cultural beliefs in relation to seeking health care.

Witchcraft

A few women cited witchcraft as a reason for taking long time before going to seek care at a health facility. This finding is in line with what Cancer of the cervix in North American Indian Women (2006) found. They found that modesty, taboos and use of traditional healing practices are important elements among American Indians. “Witching, evil spirits and elements beyond one’s control were identified as possible etiological causes of cancer”.

Furthermore, Vorobiof, Sitas & Vorobiof (2001) in their study of Breast cancer Incidence in South Africa reported that many black patients from different cultural groups still believe that cancer is caused by a special witchcraft.

Few of the women also attributed some of the symptoms to witchcraft as they do not believe that issues of prolonged menstruation can be natural. Likewise, Vorobiof, et al, (2001) found that in some cultures, post-menopausal or inter-menstrual vaginal bleeding is viewed as a sign of witchcraft making many women who have ovarian cyst, cervical cancer or endometrial cancers delay seeking medical care.

The majority of the women in this study visited traditional healers because they thought that it was “mwanamphepo” that is, the incurable disease and that the symptoms would stop after taking the local medicine. This concurred with the findings of a study done by Bingham, et al (2003) on factors related to socio cultural norms, which found that people tend to seek allopathic health care as a last resort (for example when home based care or traditional interventions fail) due to limited understanding of beliefs and attitudes towards the concept of prevention. The results of this study are also similar to what Franco, Duarte-Franco & Ferenczy, (2001) found that the women consulted traditional healers after the health care system had failed them. Furthermore, a study by Shahid, Bleam, Bessarab & Thompson (2010) revealed that Aboriginal women acknowledged traditional healing practices and the use of bush medicines as important aspects of cancer treatment. They alluded that bush medicine has spiritual significance for Aboriginal people as it is natural, comes from the land, considered culturally safe and provides comfort from a cultural perspective. All these findings are explaining the cultural beliefs among women which have an impact on their health seeking behaviour.

Myths

The study findings indicated that when women stop bearing children early, they think that there were some products of conception that remained in their womb which needed to be removed through bearing children as such they now have symptoms of abnormal vaginal discharge and vaginal bleeding. The women also reported that women that take pills for family planning are exposed to cervical cancer.

However, they did not take into consideration the length of time that can predispose somebody to cervical cancer. A study done by Taherian, et al (2002) revealed that use of combined oestrogen and progesterone oral contraceptives (COC) for more than five years increases the risk of invasive cervical cancer.

Challenges encountered when accessing health care services.

Accessibility to services depend on a number of things such as distance, means of transport, number of visits to the health facility, source of income and length of time taken to reach the health facility.

Distance

In Malawi most people live far away from a health facility which is a challenge when a person is sick. Majority of the women stayed far from health facility and it took them an average of two hours to reach the facility. This had an impact on their access to health care coupled with other issues. This is in line with the findings of Kunda, et al (2007) who reported that some households are far from hospitals and poor infrastructure make accessibility to health care difficult. Furthermore, a study conducted in Latin America by Agurto, et al (2005), reported that one of the barriers related to the provision of health

services was accessibility to health care centres and availability of quality services for example, women living in rural areas complained about long distances to get to the facility.

Transport

The common transport that people in the villages use is a bicycle. However, some people even fail to access the bicycle even if the cost is lower than other means of transport. Consequently the majority of the women walk to the facility despite the long distance to the facility. Kunda, et al (2007) also found that in areas where there is easy transportation, affordability of the costs of transport made patients unable to present to hospitals in time. Likewise, the study by Kamphinda Banda (2009) found that cost of services varied considerably by site and sector. In the public sector, consultation fees coupled with the often high indirect costs of having to seek services such as transportation, lost wages, and long waits were reported to negatively influence access. Fitzpatrick et al, (2007) in their study also found distance to the health facility, transportation, and affordability of the cost of services as challenges to seeking health care.

A study done by Kingsley (2010) found that patients on Medicare do not get assistance with transportation and may find taking a bus to appointments nearly impossible when feeling ill. A study done by Franco, Duarte-Franco & Ferenczy, (2001) found that poor people wait longer before they seek health care as they have to travel longer distances to reach health care facilities and are exposed to long waiting periods in the public sector.

Source of income

The study results reported that majority of the women earned money through selling of farm produce, livestock, doing small scale businesses and assistance from well wishers which was not adequate to carter for the services.

This has an effect on their accessibility to health care since they also visit private clinics where they have to pay huge sums of money as compared to their source of income. A study done by Kingsley (2010) about cultural and socioeconomic factors affecting cancer screening, early detection and care in Latino population found that preventive care is viewed as a luxury and as one Latino health care provider stated “if you don’t have money for treatment, you don’t want to know if you are sick”. This was due to unavailability of financial resources in Latin America; health care was inaccessible and unaffordable.

The results that the majority of the women made many visits to the health facility show that seeking health care drained their limited financial resources further. This is similar to what Dabash, et al (2005) found in their study. They found that poor organisation of services in the public sector (often depending on a single provider’s presence), translated into women having to make numerous visits and increased the likelihood of loss to follow up and increased costs of services through transportation and long waits. The results show that rural women have inadequate resources to carter for their health care services.

Family support

It is a challenge to access health care services if a woman has no relatives who offer support. Children are left alone at home and need somebody to take care of them while the woman is hospitalized. The results that the majority of the women in this study had grown up children who took care of themselves and that few of them were taken care of by the husband and relatives are in contrast with what Ashing-Giwa, et al (2007) found in their study. They found that hospitalized women were worried as to who would take care and provide for their children and other dependents that totally looked up to them for support.

Majority of the women were taken care of by their children. This finding is congruent with the study results done by Villafuerte, et al (2007) which revealed that

daughters are the family members that play the most important role in recommending and encouraging their mothers to participate in cervical cancer screening on their own. However, the results that few of the women had nobody to take care of them may impact negatively on the mothers' health care seeking behaviour because the women need a guardian when they are hospitalized.

Health care provider

Health care providers also pose as a challenge to seeking health care services. The results in this study are similar to those reported by Villafuerte et al (2007) where the women graded the attention received as good and expressed the same opinion about the information received from the physicians and health workers.

Bingham, et. al (2003) 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.

The problem of cervical cancer was identified through vaginal examination, scanning and taking a biopsy. Majority of the women reported that they were examined in the vagina with instruments. In a similar study by Villafuerte et al (2007) different findings were reported. Some women stated that the doctors skipped examination during the first consultation although they had expected to be examined and neither told them what problem they had, but simply prescribed medication. Furthermore, Mosha et al, (2009) 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.

The findings indicated that women made a lot of visits in order to be examined or get biopsy results as such the condition was worsening. This is similar to what women in Kenya said in a study done by Bingham, et al (2003) that cervical cancer services around the world require multiple visits for screening, confirmatory diagnosis, treatment and follow-up, compounding both financial and opportunity costs to women and contributing to high attrition rates.

The number of health care service providers has an impact on the care that the women received. Few reported that they were examined by a doctor and in the presence of trainee doctors and their privacy was breached. A study done by Kamphinda-Banda(2009) found that confidentiality and privacy were not just barriers to women using screening services but also contributed to their loss of dignity when their diagnosis of cervical cancer was being discussed in the presence of other relatives such as their sons. In a study done by Bingham, et al (2003), women in several settings also suggested improving privacy by minimizing the number of people coming into the examination room, having a dead bolt on a door or having a screen set up during the examination.

Conclusion

This chapter has discussed results according to the major themes that emerged from the data analysis. The study findings have indicated that the women had limited knowledge on the cause of cervical cancer and they attributed it to genetics, sexually transmitted infections and multiparity. However, the women demonstrated knowledge on the symptoms of cervical cancer as they mentioned vaginal bleeding, foul smelling vaginal discharge, dyspareunia and abdominal pains. They also indicated that they had some knowledge on risk factors as they

mentioned multiple partners, family planning methods and sexually transmitted infections. As a result there is need for sensitization campaign on cervical cancer.

The results have also indicated that there is indeed a problem in decision making as regards seeking health care services. The women had to consult family members and significant others whose decisions were not towards accessing health care services.

They first visited traditional healers since they thought that they had been bewitched or that they were suffering from incurable disease “mwanamphepo or likango” still delaying in accessing appropriate care.

Cultural beliefs of the women also have an impact on health care seeking. The women seek health care late after they have failed at a traditional healer and they come to the health facility when the cervical cancer has reached an inoperable situation. The women had a belief that problems of menstruation could not be natural as a result they visited traditional healers and were even admitted there. Most women also delayed in seeking appropriate health care services because they were visiting health centres or private clinics which could not assist them properly.

Misconceptions also had a bearing on health seeking behaviour. The women thought that they had to produce the vaginal discharge as one way of removing ‘dust’ and products of conception which remained due to stopping bearing children early as such there is need to dispel those rumours and misconception.

The women encountered a lot of challenges ranging from family, economic, transport, distance, family support and health care providers. The results have shown that the women were walking long distances to reach the facility as they did not have enough money for

transport. In addition to that the source of income was not constant to cater for the many visits to the health facility in order to be reviewed or get medications.

The women also lacked support from family members and most of them were being taken care of by their children which had a bearing on seeking health care services. The women also reported that the interaction with health care providers was good. However, some of them complained that they were not examined in the vagina a procedure that they had expected. Those who were examined, their privacy was breached because there were many health care providers during the vaginal examination.

Lack of cervical cancer screening facilities in most of the health facilities contribute to delay in accessing appropriate diagnosis and treatment for cancer.

Most health centres and private hospitals in the rural areas prescribed drugs to the women without first undertaking appropriate screening in order to come up with the right diagnosis.

Strength of the study

The researcher was of same sex as the women as such they were able to participate freely without any problem. The study took place where they were admitted and that increased their ability to participate as they could not miss any drugs or other services while being interviewed. The study employed a qualitative technique to explore health seeking behaviour of women with cervical cancer. This enabled the researcher to get rich information about cervical cancer as the women had gone through the ordeal of cervical cancer.

Study limitations

The researcher encountered a number of limitations during this study. During data collection at Zomba Central Hospital, there was lack of supplies such as sutures for performing operations as such many patients with cervical cancer were not admitted to the ward and it took one full month to recruit ten women. Time for data collection was also limited. Furthermore, some of the women could not be recruited due to barriers in communication as some women could not communicate in Chichewa but in Yao only.

Recommendations

The recommendations have been grouped into sections in order to come up with appropriate strategies to address the condition. The sections are: Ministry of Health (Policy makers), training institutions, Health facilities (Health centres, private hospitals and referral centres) communities and their leaders, families and individuals.

Ministry of Health (Policy Makers).

Government must recognise cervical cancer as a serious public health problem and allocate adequate resources to district hospitals for its prevention, treatment and research. The Minister of Health together with management team at policy level should make sure that all health care facilities have the National Sexual and Reproductive Health and Rights (SRHR) Policy document and that it is being used.

Cervical cancer should be prioritised since it is the second killer disease from breast cancer as such it should have its own national commemoration day of cancer (Cancer Day) in Malawi for wider dissemination of cervical cancer information since many women are dying.

Cervical cancer is preventable and if identified early it can be treated, therefore, Ministry of Health should increase the number of cryotherapy machines in the country so that each district and some selected Health centres should have the machine.

A national awareness strategy should be developed and disseminated country wide.

Ministry of Health should collaborate with non Governmental organisations in management of women with cervical cancer

Training institutions.

Educational institutions should continue providing education to health professionals, especially health educators about cervical cancer. Cervical cancer should be included in health care training curriculums so that students should have the knowledge and skills in managing patients with cervical cancer as well as preventive services. Professional governing bodies (Nurses and Midwives Council and Medical Council) should take a leading role in incorporation of cervical cancer during curriculum development.

College of Medicine should have a special training package for physicians who would prefer to specialise in cervical cancer patients' management in order for the women to access quality care. The training should also focus on how providers can communicate most effectively with men to encourage them to support their partners to go through the process of cervical cancer screening and treatment, if needed.

Health care facilities.

An ongoing quality-of-care in service training for health care providers is essential for improving service delivery. The training can help health workers understand the importance of a satisfied client and develop goals for improving performance. Management team at hospitals should conduct in-service training for health care providers about cervical cancer.

There is a need to further sensitize providers about women's fears and the dialogues they have outside the health centres. The women get information from various spheres some of which is false. The health professionals need to give them the right information and dispel rumours. For effective cervical cancer programs, health care service providers need to work

with community leaders to develop innovative strategies (such as mobile campaigns) for delivery of services to hard-to-reach women. These measures will also reduce attrition, as strong follow-up protocols will be put in place that can track and effectively motivate women to return for follow-up care.

Health care providers in all hospitals, health centres and even private clinics should perform visual inspection of the vagina with acetic acid (VIA) to any woman who reports of vaginal bleeding of unknown cause, abnormal vaginal discharge and the other symptoms which have been highlighted in order to diagnose cervical cancer early and commence appropriate treatment as soon as possible.

All hospitals should include well women gynaecology services for early identification of cervical cancer and other gynaecological problems in order to assist the women promptly.

A referral system of women suspected of cervical cancer should be put in place in order to track down all women with cervical cancer for early treatment. Referral centres should treat women with cervical cancer or suspects with urgency in order to identify the problem quickly and assist promptly.

Experts in cervical cancer management should also have scheduled visits to district hospitals to assess those suspected of cervical cancer to prevent them from travelling long distances, further depleting their little financial resources.

All hospitals should conduct a survey of the health centres in their catchment area in order to identify health facilities that can provide VIA services so that women do not travel long distances.

Health management teams of all hospitals should organise in service education for health providers which must emphasise proper communication networks with elders about

cervical cancer screening and reporting early to the health facility when they observe the symptoms of cervical cancer

Health care providers should educate communities in their catchment area about cervical cancer such as church communities, the media, employers, and traditional healers about cervical cancer on the signs and symptoms of cervical cancer and to refer suspected cases early to the cervical cancer clinics.

Using locally understood messages, increase awareness about cervical cancer about cervical cancer and the need for women to be tested at least once in every five years for those women who are sero negative and every three years for those who are sero positive every three years. Cervical cancer progresses to advanced state quickly when the immunity is compromised as such there is need to encourage all sero positive women to go for cervical cancer screening.

Communities and their leaders.

The community need to be involved in planning and delivering cervical cancer prevention services for clear understanding of the needs, concerns, and beliefs of women to ensure that services will be accessible, acceptable, and utilized. A key step to achieving optimal coverage is to gain broad community support.

Communication strategies for raising awareness about services and encouraging participation need to be developed with community input by carrying out formative research during the planning stage of program initiatives. Messages need to use words and phrases that are understood locally. Messages also should reflect the real concerns that women have about services, how communities view preventive care in general, and local understanding of screening procedures and of cancer. Community surveys or focus groups with potential

clients and their male partners and meetings with key opinion leaders can assist in developing strategies to reach everybody in the community.

Local leaders and the community should have forums with traditional healers in order to share information about cervical cancer especially signs and symptoms of cervical cancer so that when women go there, the traditional healers should be able to encourage them to go to the hospital.

Families and individuals.

Families need to be included in cervical cancer services for support. During provision of cervical cancer services, the husband should be included for moral and financial support. Family members should encourage the client to go to the hospital in order to have thorough physical examination for early identification of the problem.

Encourage the client to disclose the problem to the significant others in the family for support throughout the process of cervical cancer services. The women should also be empowered to make decisions on their own to access health care services as soon as they notice any abnormal vaginal discharge or vaginal bleeding of unknown origin.

Women in the rural area should be supported with loans to boost up their small scale businesses in order to be economically independent for easy access to health care services.

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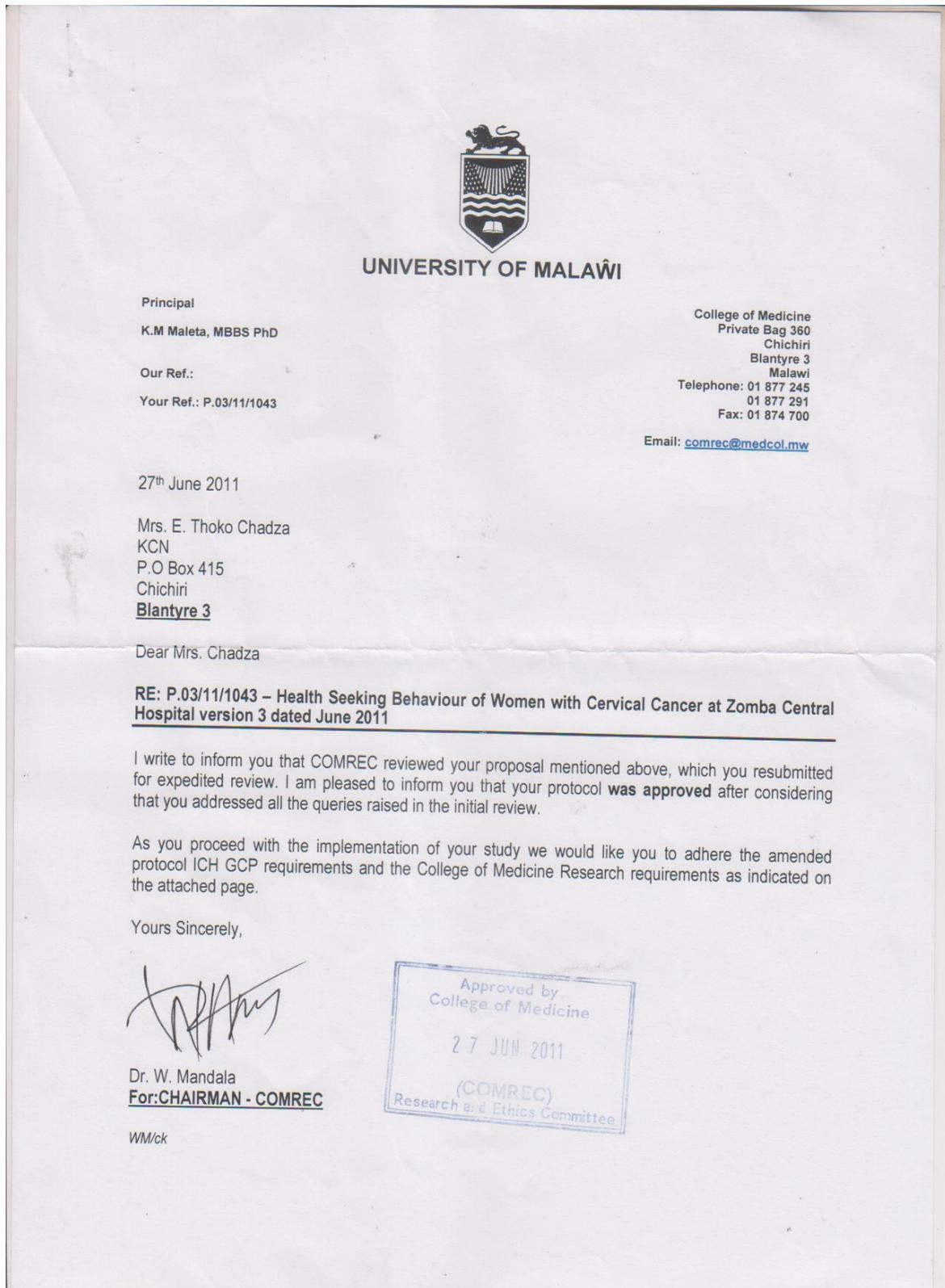
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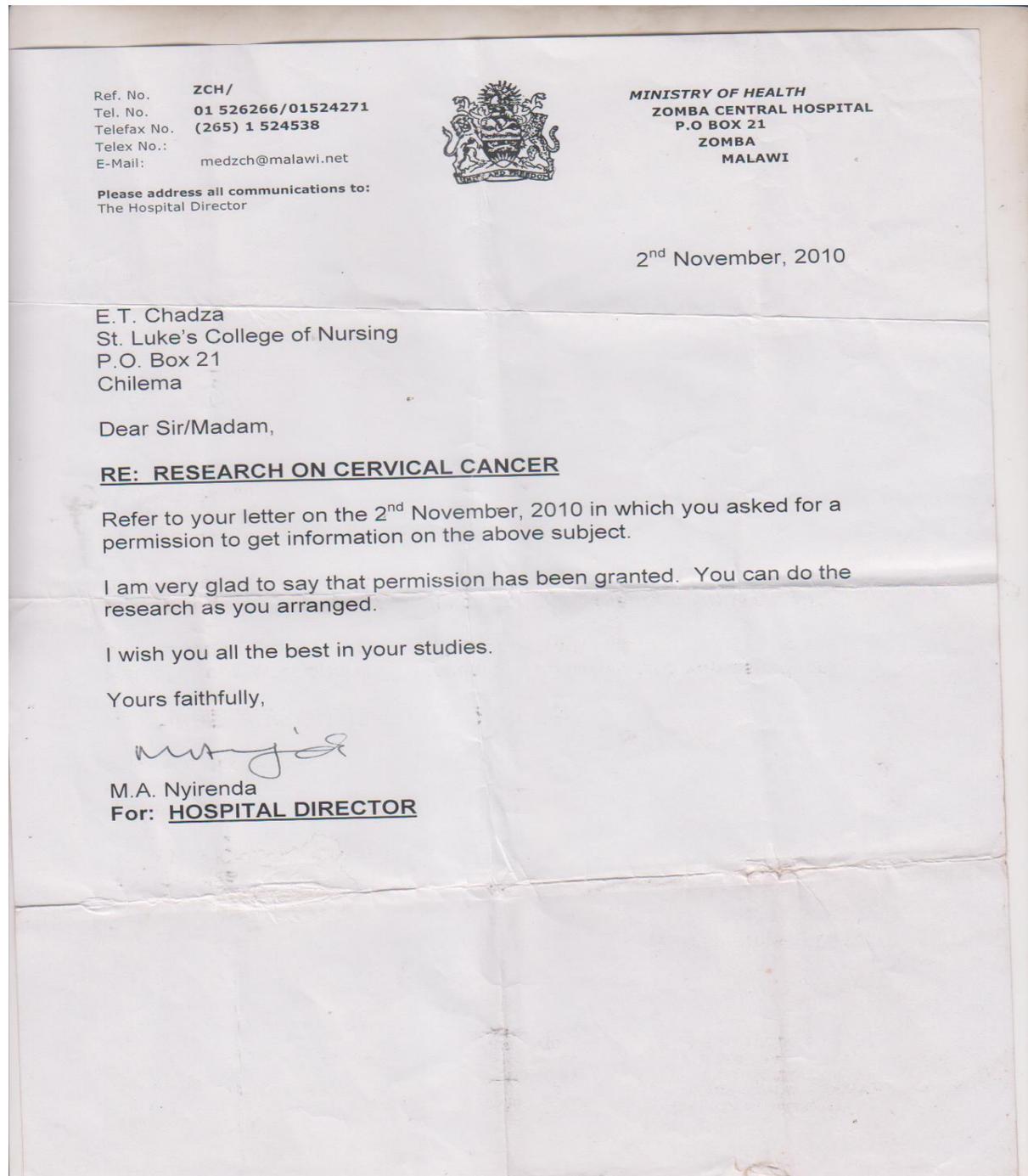
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Appendix A: Letter of approval from COMREC to conduct the study



Appendix B: Letter of approval from Zomba Central Hospital



Appendix C: Letter of approval from Queen Elizabeth Central Hospital

Telephone: (265) 01 874 333 / 677 333
Facsimile: (265) 01 876928
Email: queenshosp@globemw.net

All communications should be addressed to:
The Hospital Director



In reply please quote **No.**

QUEEN ELIZABETH CENTRAL HOSPITAL
P.O. BOX 95
BLANTYRE
MALAWI

Ref No. QE/10

20th June, 2011

Eleanor Thoko Chadza
Kamuzu College of Nursing
P.O. Box 415
BLANTYRE

Dear Sir/Madam

PERMISSION TO CONDUCT STUDY

This is to inform you that management has no objection for you to conduct a study on "**Cervical Cancer**" at Queen Elizabeth Central Hospital.

All the best in your studies.

Yours faithfully,

A handwritten signature in cursive script, appearing to read 'E. Nkangala'.

E. Nkangala
PRINCIPAL NURSING OFFICER
For: **HOSPITAL DIRECTOR**



Appendix D: Letter of approval from Kamuzu College Hospital

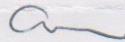
University of Malawi
Kamuzu College of Nursing
P.O. Box 415
Blantyre.
7th July, 2011.

The Hospital Director,
Kamuzu Central Hospital,
P.O.Box 149,
Lilongwe.
Attention: The Chief Nursing Officer
Dear Sir,

**REQUEST FOR CLEARANCE TO CONDUCT A PILOT STUDY ON
CERVICAL CANCER AT KAMUZU CENTRAL HOSPITAL**

I am a second year master of science in Reproductive Health student at the above college. In partial fulfilment of the program, a research project is required. I write to request for permission to conduct a pilot study at the hospital in July, 2011. The title of the study is: Health Seeking Behaviour of Women with Cervical Cancer. The results will assist the hospital's management team to devise measures in improving the services offered to patients with cervical cancer.

I am looking forward to hearing from you,
Yours faithfully,



Eleanor Thoko Chadza

CNO

COMREC review
done +
approved
given

Please assist her

Abide
1+1
7/7/11

Appendix E: Participants' information

Introduction

You are being asked to participate in a research study about 'Health Seeking Behaviours of women with cervical cancer who have been admitted at gynaecological ward. You are being requested to participate in this study because you are admitted here with cervical cancer. This study is important because it will enable health personnel to understand and accept nature and emotional conditions of cervical cancer patients in seeking health care services to deal with the disease. The results will also be used as a guide in providing information and counselling on other alternatives for patient care.

Procedure

As a participant of this study, you will meet the investigator at a place where there is audio-visual privacy. The investigator will audio tape you and take detailed notes later. This will only be done if you accept to take part in the study. You are free to tell the investigator to turn off the tape recorder at any point in the conversation if you are not comfortable with what we will be talking about. After the interview, the tape will be transcribed. You may see the transcript upon request and delete anything you do not want to be included in the report. You are free to withdraw at any time during the interview and that will not affect the care you are receiving at this hospital.

Risks

Your participation in this study will involve minimal risks. You may be uncomfortable with some questions. If you feel uncomfortable, you may decide not to answer those questions. If you become very distressed with some of the questions, you will be referred to Dr. Kabeya, head of gynaecology and obstetrics department at Zomba Central Hospital for counselling. His contacts are: 0995350606/ 088431484; e-mail address kabeyab@yahoo.fr. AT Queen Elizabeth Central Hospital, Dr Taulo, working in the gynaecology department will counsel the patients who will be distressed. His contacts are: 0999515304; e-mail address ftaulo@yahoo.com.

Benefits

There will be no direct benefits for your participation in this study. The potential benefit is that the information will assist health workers to improve in information giving and counselling of women with cervical cancer. This information is also helpful to policy makers for formulation of policies on management of women with cervical cancer.

Confidentiality

Confidentiality regarding your identity will be maintained throughout the research study. Before the results are out, only the researcher and her supervisor will see the results. However, the results will also be used for teaching, research, publications or presentations at conferences, only codes will be used and not individual names and other identifying information

Data collection

At the end of this information, if you can accept to participate in this study, then audiotape recordings of you will be done. The interviews will take one hour for each participant. There will be a break in between the interview for relaxing and refreshments. All recordings will be destroyed after analysis of data is completed.

Participant' rights

Your participation in this study is voluntary and you are free to withdraw at any time. Withdrawal from this study will not affect your treatment. You are free to choose not to respond to any particular questions if you do not want you may ask the tape recorder to be turned off at any point during the interview if there is something that you do not want to be recorded.

Contact persons

If you have any questions about this study you may call Eleanor Chadza on phone numbers 0888860017; 0995769738 or my supervisor, Dr E. Chirwa at Kamuzu college of Nursing on phone numbers 01873623 or 01880183 and the chairperson of COMREC 01871911

Participant's name.....

Signature..... Date.....

Name of person obtaining consent.....

Signature Date.....

Appendix F: Kalata yofotokozera anthu otenga nawo mbali mu kafukufuku

(Chichewa version)

Mau oyamba

Muli kupemphedwa kutenga nawo mbali mukafukufuku wofuna kudziwa ‘‘Zomwe amayi omwe ali ndi khansa yak homo lachiberekero amakumana nazo pofuna chithandizo ku chipatala chachikulu ku Zomba ndi ku Queen Elizabeth’’. Inuyo muli kupemphedwa kutenga nawo mbali mukafukufukuyi chifukwa munagonekedwa kuno chifukwa cha khansa yak homo la chiberekero. Kafukufukuyi ndiwofunika kwambiri chifukwa adzathandiza ogwira ntchito yothandiza amayi akhansa imeneyi moyenera powamvetsetsa zomwe zimawachitikira nthupi mwawo. Komanso zidzathandiza popeza njira zoyenera zowalangizira kuti adzibwera kuchipatala mwamsanga.

Ndondomeko

Inu monga m’modzi wotenga nawo mbali mukafukufukuyi, mudzakumana ndi amene akupangitsa kafukufukuyi pamalo poduka pempho. Wopangitsa kafukufukuyi adzakujambulani mawu ndikulemba zina papepala. zonsezi zizachitika pokha pokha inu mutavomereza kulowa nawo mukafukufukuyi. Inu muli wololedwa kuwawuza opangitsa kafukufukuyi kusiya kujambula ngati simuli wosangalatsidwa ndi zimene akukambazo. Akatha kukujambulani, adzathanthauzira zokambilanzozo ndi kuzilemba papepala. Muli womasuka kuwerenga zomwe atanthauzirazo ndikufufuta zomwe sizinakusangalatsane. Ngati mwasintha maganizo ndipo mukufuna kutuluka mukafukufukuyi muli wololedwa kutero.

Zovuta zomwe zingakhalepo

Mafunso ena akhoza kukhala opangitsa manyazi. Ngati mafunso ena atakhala wokusowetsani mtendere muli ndi ufulu kusayankha komanso kutuluka mukafukufukuyi. Komanso tidzakutailani nthawi yanu pang’ono poyankha mafunso. Ngati mafunso akukhudzani kwambiri mokudandaulitsani, tidzakuitanirani adokotala a Kabeya omwe amagwira mu wodi ku Zomba kuti akambe nanu za matendawa. Mungawapeze pa manambala awa: 0995350606/088431484; e-mail address kabeyab@yahoo.fr. Adokotala a Taulo omwe amagwira mu wodiku Queen Elizabeth ndi amene angakambe nanu modekha za matenda amanewa. Mungawapeze pa manambala awa: 0999515304; e-mail address ftaulo@yahoo.com.

Cholowa chomwe chingakhalepo

Palibe cholowa chili chonse chomwe mudzapeza potenga nawo mbali mukafukufuku ameneyu. Mukatenga nawo mbali zotsatirazo zizathandiza achipatala kudziwa momwe angathandizire amayi omwe ali ndi khansa yak homo lachiberekero, komanso kupereka uphungu woyenera wa khansa imeneyi kuti amayi azibwera kuchipatala kudzalandira thandizo mwamsanga. zizathandizanso omwe amakonza ndondomeko yothandizira amayi omwe ali ndi khansa yak homo lachiberekero.

Kusunga chinsinsi

Amene akupangitsa kafukufukuyi ndi aphunzitsi akulu amene akuyang’anira za kafukufuku ameneyi adzayesetsa kusunga chinsinsi posalemba maina anu papepala koma kugwiritsa ntchito nambala. Komabe, zotsatira zakafukufukuyi zidzagwiritsidwa ntchito pophunzitsira, kupangira kafukufuku wina, kulengezetsa mumapepala azasayansi komanso kumisonkhano yokambirana za sayansi, komabe dzina lanu silidzatchulidwa.

Malo osungira zofufuza

Ndikatha kukamba nanu zopempha chilolezochi, mupatsidwa mwai wosankha ngati mwavomera kutenga nawo mukafukufukuyi. Tikatha kugwiritsa nthito mapepala wonse ndi zomwe tinajambula tidzaziwononga.

Ufulu wanu wachibadwidwe

Mutenga nawo mbali mukafukufukuyi mosakakamizidwa pogwiritsa nthito ufulu wanu wachibadwidwe.kukana kutenga nawombali sikukhuzana ndichithandizo chomwe mukulandira mchipatala muno.Muli wololedwa kusankha kujambulidwa mawu kapena ayi mosakakamizidwa.

Anthu wofunika

Ngati muli ndimafunso okhudzana ndikafukufukuyi mutha kuyimba foni kwa a Eleanor Thoko Chadza pamanambala awa: 0888860017 kapena 0995769738; muthanso kuyimbira aphunzitsi anga a DR. E. Chirwa a ku Kamuzu College of Nursing pamanambala awa: 01873623 kapena 01880183.

Dzina la wotenga mbali.....saini.....Tsiku.....

Dzina la wopangitsa kafukufuku.....Saini.....Tsiku.....

Appendix G : Informed consent

University of Malawi
KAMUZU COLLEGE OF NURSING

Research Title : Health Seeking Behaviour of Women with Cervical Cancer at Zomba and Queen Elizabeth Central Hospital

Researcher : Eleanor Thoko Chadza

I have read and understood all the information concerning health seeking behaviour of women with cervical cancer. Clarifications have been made and that my participation is voluntary. The interview will take one hour and if I am very distressed the clinical officer or doctor will counsel me.

I..... voluntarily agree to participate in the above study. I understand that I can withdraw at any time. My refusal to answer some questions will neither affect my well being nor care I obtain in the hospital. If any problems or queries contact Eleanor Thoko Chadza (0888860017), Dr E. Chirwa (01873623) and Chairperson of COMREC (01871911).

Name of principal investigator.....	Signature.....
Name of participant.....	Signature.....
Date.....	Date.....

Appendix H: Kuvomereza kulowa nawo kafukufuku

University of Malawi
Kamuzu College of Nursing

Mutu wa kafukufuku : Kafukufuku wofuna kudziwa m'mene amayi womwe ali ndi khansa yakhomo la chiberekero amapezera chithandizo ku chipatala chachikulu cha Zomba ndi Queen Elizabeth.

Wopanga kafukufuku : Eleanor Thoko Chadza

Ndawerenga ndipo ndamvetsa bwino za kafukufuku ameneyi wa khansa yak homo lachiberekero. Andifotokozera bwino momveka ndipo ndikhonza kusiya nthawi ili yonse. Kafukufukuyi atenga ola limodzi ndipo ngati ndakhumudwa kwambiri ndi mafunso ena adzandiitanila adokotala kuti akambe nane modekha.

Ine..... mosakakamizidwa.ndavomereza kulowa nawo mukafukufuku ameneyi. Ndasankha ndekha mosaumirizidwa kulowa nawo kafukufukuyi ndipo ndikhoza kusiya nthawi ina ili yonse ngati ndasintho maganizo. Kulowa kafukufukuyi sikukhuzana ndi chithandizo chomwe ndikulandira muno mchipatala. Ngati ndapeza vuto kapena ndikukaika, ndingathe kuimba foni kwa adokotala amayi Chirwa pa nambala iyi: 01873623 kapena a pampando a COMREC 01871911.

Dzina lawopangitsa kafukufuku..... Saini.....Tsiku.....

Dzina la wolowa kafukufuku..... Saini.....Tsiku.....

Appendix I: Interview Guide

Code number :	<input type="text"/>
Name of interviewer :	<input type="text"/>
Date of interview :	<input type="text"/>
Section A: Demographic data	
Age	<input type="text"/>
How old are you?	
What is your marital status?	<input type="text"/>
Married	
Single	<input type="text"/>
Widowed	<input type="text"/>
Divorced	
Separated	<input type="text"/>
Living together	<input type="text"/>
Social history	
When did you get married?	<input type="text"/>
How many children do you have?	<input type="text"/>
How many other wives does your husband have?	<input type="text"/>
What family planning method have you been using?	<input type="text"/>
Have you ever suffered from sexually transmitted infection?	<input type="text"/>
Have you ever been tested for HIV?	<input type="text"/>
When did you get tested for HIV?	<input type="text"/>
what illnesses have been affecting you since you knew your sero status?	<input type="text"/>
At what age did you start to engage in sexual intercourse?	<input type="text"/>
Which denomination do you belong to?	<input type="text"/>
How far did you go with your education?	<input type="text"/>
Did not attend	
Primary	<input type="text"/>
Secondary	<input type="text"/>
Tertiary	<input type="text"/>

Section B

1. Knowledge about cervical cancer on causes, symptoms and risks

Now I am going to ask you questions concerning your knowledge of cervical cancer
How can you describe cervical cancer as regards

(a) Causes

Probes:

What is the cause of cervical cancer?

How does the cause of cervical cancer come about?

(b) Symptoms

Probes:

What symptoms of cervical cancer do you know?

How do those symptoms come about?

(c) Risk factors

What do you think are the risk factors for a woman to suffer from cervical cancer?

Probes:

Why are they risk factors?

(2) Decision making process

Now I would like to know as to what prompted you to seek health care services

Probes:

What made you to seek health care services?

Which of the symptoms were severe?

Whom did you consult first when the symptoms were worse?

Why did you choose to consult that person?

How long did it take for you to decide to seek health care?

Why did it take that long?

Who assisted you to come up with a decision to seek healthcare?

Who makes a final decision in your family?

Where else did you go for help?

What made you to decide on health care?

Cultural beliefs

Now, I am going to ask you questions in relation to cultural beliefs related to cervical cancer.

Probes:

How do people describe cervical cancer in your cultural context?

When you had the symptoms, what did you think was happening to you?

Culturally, what do people say about the origin of the symptoms?

Where do they go first to seek help?

Why do they do that?

How do they perceive the woman's body in relation to seeking health care?

What traditional treatment is given to a woman who has cervical cancer?

3. Challenges

Now I would like to know the challenges that you encountered in the course of seeking health care services

Probes

(a) Accessibility

How far is your home to the health facility?

How do you travel to the health facility?

How much do you pay for transport?

How many visits have you made to seek health care services?
What do you do when you do not have money, but you still need to visit the health facility?
How long does it take you to walk to the health facility?
How did the distance affect your visits to the hospital?
How long does it take for you to be assisted by the health service provider?
How did this affect you?

(b) Economic factors

How much do you pay for the services?
What is your source of income?
Who supports you financially?
How does that affect your health seeking behaviour?
What does your husband do to support the family?
What cash crops do you grow as a source of income?
What live stock do you have at home?
How did availability of financial resources affect your visits to the hospital or receiving treatment?

(c) Family support

What was the reaction of your relatives about the diagnosis and hospital visits?
How did the family support you when you were diagnosed with cervical cancer?
Probes:
Who assists you financially?
Who takes care of your children when you are sick?
Who helps you with household chores?
Who visits you at the hospital?
Health care providers
How was the interaction with the health care provider during yours to the health facility?
Probes:
How was the information about diagnosis and treatment given to you?
How were you assisted with your concerns?
How many times did the health care provider arrange for follow- up care?
How often were you coming to the health facility for review?
How many health service providers were available during your visit?
What did you like about your interaction with the health care providers?
What did you not like about your interaction with the health care providers?

Lastly, do you have any questions or comments?
Thank you for taking part in this study.

Appendix J : Mafunso akafukufuku

Nambala.....

Tsiku la kafukufuku.....

Dzina la wopanga kafukufuku

Gawo Loyamba

Ndikufunsani mafunso okhudzana ndi inuyo

Muli ndi zaka zingati?

Pankhani yabanja muli mbali iti?

Wokwatiwa

Mbeta

Ukwati unatha

Tayamba tapatukana kaye

Bambo akunyumba anamwalira

Kukhalira limodzi wosamanga banja

Za moyo wa m'banja

(a) Kodi munalowa m'banja liti?

(b) Kodi muli ndi ana angati?

(c) Kodi amuna anu ali ndi akazi ena angati?

(d) Kodi mumagwiritsa mankhwala anji olera?

(e) Ndi matenda ati opatsirana pogonana omwe munadwalapo?

(f) Kodi munayezetsapo za kachiroambo ka HIV?

(g) Munayezetsa liti?

(h) Mwakhala mukudwala matenda anji chiyezetsere?

(i) Munayamba zogonana muli ndi zaka zingati?

4. Mumapemphera mpingo wanji?

5. Malekezero a maphunziro

Sindinaphunzire sukulu

Ndinalekezera kupulaimale

Ndinalekezera kusekondale

Ndinafika ku koleji

Gawo Lachiwiri

1. Tsopano ndikufunsani za zomwe mukudziwa za matenda a khansa ya chiberekero

(a) Kodi chimene chimayambitsa khansa yakhomo la chiberekero ndi chiyani?

Kufunsitsitsa:

Kodi kamayambitsa bwanji khansayo?

Kodi kansayo imayamba bwanji?

(b) Tsopano ndikufunsani za zizindikiro za khansa yakhomo la chiberekero

Kufunsitsitsa:

Kodi ndi zizindikiro ziti za khansa zomwe mukudziwa?

Kodi zizindikiro zimenezi zimabwera bwanji?

Kodi zizindikiro zimenezi zimapitilira bwanji?

(c) Tsopano ndikufunsani za zomwe zingamupangitse munthu kuti adwale matendawa

Kodi zimene zingamupangitse munthu kuti adwale khansa yakhomo la chiberekero ndi chiyani?

Kufunsitsitsa:

Zimenezo zingapangitse bwanji munthu kudwala khansa?

2. Kupanga chiganizo chopita kuchipatala

Kodi chinakupangitsani ndi chiyani kuti muganize zopita ku chipatala?

Kufunsitsitsa:

Kodi chinakupangitsani ndi chiyani kuti mupite kuchipatala?

Kodi ndi zizindikiro ziti zomwe zinapitilira kwambiri?

Kodi mutaona kuti zizindikiro zikupitilira, woyamba kumuza anali ndani?

Chifukwa chiyani munasankha amenewo?

Zinakutengelani nthawi yayitali bwanji kuti mupange chiganizo chopita kuchipatala?

Kodi anakulimbikitsani ndani kuti mupite kuchipatala?

Chifukwa chiyani munatenga nthawi yaitali musanapite ku chipatala?

Kodi anakuthandizani ndani kuti mupange chisankho chopita kuchipatala?

Kodi amapanga chiganizo chomaliza kuti mupite kuchipatala ndi ndani?

Kodi ndi kutinso kwina komwe munapita kukafuna chithandizo?

Chinakupangitsani ndi chiyani kuti mupite ku chipatala?

Za miyambo yokhudzana ndi khansa

Tsopano ndikufunsani mafunso okhudzana ndi miyambo yakwanu pankhani ya khansa yakhomo la chiberekero

Kufunsitsitsa:

Pa miyambo yakwanu, anthu amati khansa yakhomo la chiberekero ndi chiyani?

Kodi mutaona zizindikiro za khansa inu mumaganizakuti chiyani?

Kodi anthu adera lanu amati matendawa amachokera kuti?

Amapita kukapeza chithandizo?

Chifukwa chiyani amapita kumeneko?

Kodi amayi akamadwala matenda amenewa, amaganiza zotani za thupi la mayiyo pankhani yopita kuchipatala?

Kodi wodwala matendawa amalandira chithandizo chotani kumudziko?

Tsopano ndikufunsani mafunso wofuna kudziwa zovuta zomwe mwakhala mukukumana nazo pofuna kupeza chithandizokuchipatala

Mayendedwe

Kufunsitsitsa:

Kodi kuchokera kwanu kufika kuchipatala, ndikotalikirana bwanji?

Kodi ndi njira yanji yamayendedwe yomwe mumagwiritsa nchito popita kuchipatala?

Mumalipira ndalama zingati?

Kodi mwayendera kangati kuchipatala kukafuna chithandizo asanakugonekeni kuno?

Kodi mukakhala kuti mulibe ndalama zolipilira mayendedwe mumatani?

Mumayenda nthawi yayitali bwanji kudzafika kuchipatalangati mwayenda pansi?

Kodi mukafika kuchipatala pamatenga nthawi yaitali bwanji kuti muthandizidwe?

Chifukwa chiyani pamatenga nthawi yaitali choncho?

Za chuma

Kodi mumalipira ndalama zingati mukalandira chithandizo?

Kodi ndalama mumazipeza bwanji?

Amakuthandizani ndani pankhani ya zachuma?

Ndiye zimenezi zimakhudzana bwanji ndi nkhani yopita kuchipatala?

Kodi amuna anu amakuthandizani bwanji pankhani ya ndalama?

Kodi mumalima mbewu zANJI zogulitsa kuti muzipeza ndalama?

Nanga mumaweta ziweto zANJI zokuti zizikuthandizani pa nkhani ya zachuma?

Chisamaliro cha abale

Kodi mukadwala amakusamalirani ndani?

Nanga amene amasamalira ana anu ndi ndani?

Kodi kuchipatala kuno amene amabwera kudzakuonani ndani?

Kodi abale ndi anansi anu atamva zamatendawa ndikugonekedwa mchipatala anati chiyani?

Kodi kuchipatala kuno amene amakusamalirani wochokera kwanu ndi ndani?

Anamwino kapena madokotala

Ndikufunsani mafunso wokhudzana ndi anamwino kapena madokotala omwe amathandiza wodwala khansa

Tandifotokozereni m'mene ankuilandilirani tsiku loyambakubwera kuchipatala ndi vuto lanu

Kodi vuto lanu la khansa analidziwa liti achipatala?

Kodi vuto limeneli analizindikira pogwiritsa njira yanji?

Kodi ndi ndaninso ena omwe anathandiza kuti vuto la khansa lizindikilike kuno kuchipatala?

Munayamba liti kumwa mankhwala a khansa?

Kodi kuchipatala kuno mumabwera pakapita nthawi yayitali bwanji kuti adzakuoneninso?

Kodi mukabwera anamwino kapena madokotala amakhalapo angati?

Kodi zimenezi zimakhudzana bwanji ndi nthawi yokuti muonedwe?

Kodi zimene munasangalatsidwa nazo pakukambirana kwanu ndi anamwino kapena adokotala ndi ziti?

Nanga zimene sizinakusangalatseni ndi ziti?

Pomaliza muli ndi mafunso kapena ndemanga.

Zikomo kwambiri potenga nawo mbali mukafukufukuyi.

