

**BARRIERS AND FACILITATORS TO UPTAKE OF CERVICAL CANCER
SCREENING AMONG WOMEN ACCESSING MATERNAL AND CHILD HEALTH
SERVICES IN KAMPALA, UGANDA.**

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Key Words: Uptake, Cervical Cancer, Screening, Challenges, Strategies, Knowledge,
Availability, Affordability, Nsambya Hospital, Uganda

ABBREVIATIONS

- ACCP:** Alliance for Cervical Cancer Prevention
- AIDS:** Acquired Immunodeficiency Symptoms
- DNA:** Deoxyribonucleic Acids
- HIV:** Human Immunodeficiency Virus
- HPV:** Human Papilloma Virus
- IARC:** International Agency for Research on Cancer
- LEEP:** Loop Electrosurgical Excision Procedure
- MOH:** Ministry of Health
- PATH:** Program for Appropriate Technology in Health
- PNFP:** Private Not for Profit
- STI:** Sexual Transmitted Infection
- UNCR:** Uganda National Council Registry
- UNCST:** Uganda National Council of Science and Technology
- VIA:** Visual Inspection with Acetic Acid
- VILI:** Visual Inspection with Lugol's Iodine
- WHO:** World Health Organization



DECLARATION

I, Lydia Atuhaire, hereby declare that this mini thesis research titled: *Barriers and facilitators to Uptake of Cervical Cancer Screening Services among Women Accessing Maternal and Child Health Services in Kampala, Uganda*, is my own work except where acknowledged in the text. No portion of this work has been submitted for any degree or any other qualification in this or any other university and all sources used have been acknowledged and adequately referenced.



Lydia Atuhaire

2nd Sept 2013

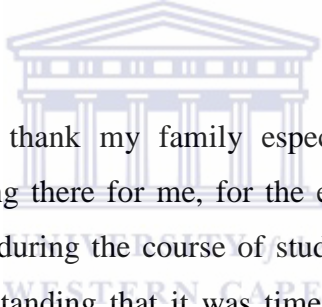


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ABSTRACT

Background

Cervical cancer continues to pose a huge challenge on women's health worldwide especially in the poorest countries, with more than 500,000 new cases and 270,000 deaths annually. By 2008, cervical cancer was the most common female cancer in East Africa affecting 44 per 100,000 women and the highest female cancer related mortality accounting for 35 per 100,000 women. In Uganda, cervical cancer accounts for 40 percent of all cancers and is the leading gynaecological cause of death among women. More than 80 percent of women are diagnosed with late-stage disease, when it is problematic or impossible to treat.

Aim

The aim of the study was to explore the challenges to uptake of cervical cancer screening among women accessing maternal and child health services at Nsambya Hospital in Kampala, Uganda.

Methodology

An exploratory and descriptive qualitative study was conducted in Nsambya Hospital, Kampala. Purposive sampling of 25 women accessing maternal and child health care services was applied. Qualitative data was collected using semi-structured interviews and thematic content analysis was done.

Results

Three broad themes emerged from the study namely: knowledge and awareness about cervical cancer; barriers; and facilitating factors to cervical cancer screening. Generally, knowledge and awareness about cervical cancer was very low although the risk perception was very high. Barriers to cervical cancer screening included fear of positive results, absence of pain, busy work schedules, unfriendly screening procedures, and long waiting times at the health services. Availability of free screening services, availability and affordability of cervical cancer drugs and integrated services were reported as facilitating factors.

Conclusion

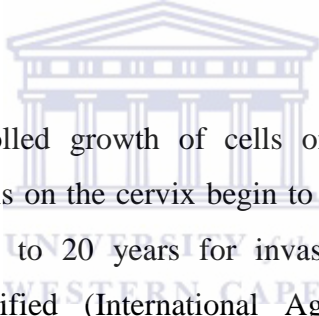
Most women have limited awareness about cervical cancer and are unable to differentiate with other cancers such as breast cancer and uterine cancer. Although a few women perceive screening as important for cervical cancer prevention, some associate screening with pain, and an embarrassing procedure, while others are hindered from screening due to fear of the outcome (positive results). The main socio economic factors that influence uptake to cervical cancer screening are male partner support and busy work schedules while culture does not have any influence on uptake of cervical cancer screening.



CHAPTER 1: INTRODUCTION

1.1 Background

Cervical cancer has continued to pose a huge challenge on women's health worldwide especially in the poorest countries (Ferlay *et al.*, 2002). The World Health Organisation (WHO) (2009) reported that cervical cancer is the second most common cancer in women, with more than 500,000 new cases occurring annually and 270,000 lives lost due to cervical cancer every year. By the year 2009, the worst hit regions were parts of Asia, Sub Saharan Africa, the Caribbean, and Central and South America with the rate of more than 40 cases per 100,000 women; compared with less than 10 per 100,000 women in North America and Europe (WHO, 2009). Cervical cancer was also reported to be the most common female cancer in East Africa affecting 44 per 100,000 women and the highest female cancer related mortality accounting for 35 per 100,000 women (WHO, 2009).



Cervical cancer is the uncontrolled growth of cells on the cervix (the mouth of the uterus/womb) (WHO, 2006). Cells on the cervix begin to grow slowly and abnormally over several years usually taking 10 to 20 years for invasive cancer to develop after the precancerous lesions are identified (International Agency for Research on Cancer Organization (IARCO) (2003). Cervical cancer is sexually transmitted and is caused by the human papilloma virus (HPV). Thus there is a strong link between cancer of the cervix and sexually transmitted infections (STIs). According to Bosch (2002) and WHO (2008), the risk factors for cervical cancer development include frequent births, early sexual debut before age of 16 years, and presence of other sexually transmitted infections such as Herpes Simplex and Human Immune deficiency Virus (HIV) infection. One of the most effective ways of preventing and controlling cervical cancer is screening which contributes to early diagnosis (WHO, 2008). Success of cervical cancer screening initiatives depends on high participation of the target population, which in turn is determined by the women's knowledge and perceptions, cultural and other socio-economic issues (WHO, 2006; Mutyaba *et al.*, 2007; Cann, 2008; Katahoire *et al.*, 2008; Nakalevu, 2009; Satija, 2009).

1.2 The burden of cervical cancer in Uganda

Uganda has one of the world's highest cervical cancer incidence rates of 45.6 per 100,000 women and cervical cancer deaths at 25 per 100,000 women (WHO, 2009). According to WHO (2010), cervical cancer continues to be the leading gynaecological cause of death among Ugandan women. 80% of women with cervical cancer are diagnosed with late-stage disease that is difficult to treat. Cervical cancer accounts for 40% of all cancers in Uganda (WHO, 2010). However, the actual magnitude of this type of cancer for Uganda might be higher since most of the cases are never reported or registered. For example, the Uganda National Cancer Registry (UNCR) covers only one county within Kampala district in Central Uganda, out of over 100 districts in the country. The Uganda Ministry of Health (MOH) policy and regulations on cervical cancer recommend that all women aged 25–49 years should have cervical cancer screening, and girls aged 10-14 years should be vaccinated against human papilloma virus (HPV). This vaccination and screening campaign is aimed at achieving 80% coverage by 2015 (MOH, 2010). The Uganda Ministry of Health (MOH) in partnership with Non-Governmental Organizations (NGOs) such as PATH Uganda, the World Health Organization (WHO), and private not for profit (PNFP) hospitals have established organized cervical cancer screening programmes and have set up screening centres in some regions of the country. These centres provide health education, screening, advocacy and treatment for cervical precancerous lesions (MOH, 2010). However, these efforts do not meet overall demand since they are only found in a few selected areas of the country.

1.3 Problem statement

There is very low uptake of cervical cancer screening in Uganda, and the few screening services available are not fully utilized by women (Mutuyaba *et al.*, 2007; Katahoire, 2008). Given the small number of cervical cancer screening centres, it was expected that they would be overwhelmed by the large numbers of women who come to seek the service. However, this is not the case; the numbers of women who seek the screening services are low (Mutuyaba *et al.*, 2006). The underlying reasons for the low uptake of cervical cancer screening in this hospital had not been established. Although several studies have been done on the uptake of cervical cancer screening services (Katahoire, 2008; Mutuyaba *et al.*, 2007; Nakalevu, 2009), there was no study that elucidated the low usage of the existing cervical cancer screening services.

1.4 Outline of thesis

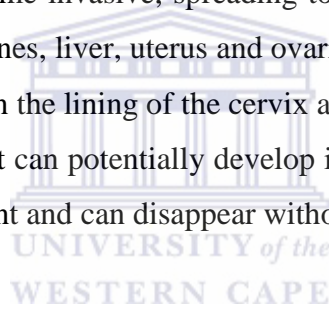
This thesis presents a background and review of the literature on cervical cancer in Chapters one and two giving an analysis of the global and local situation as well as risk factors. Chapter three is the author's presentation of the methodology while Chapter four shows the results of the study. Chapter five is a discussion of the study findings while in Chapter six, the author concludes and presents several recommendations in view of the study findings on cervical cancer.



CHAPTER 2: LITERATURE REVIEW

2.1 Cervical cancer and screening

The cervix is the bottom part of the uterus, which connects the uterine body to the vagina or the birth canal (WHO, 2006). The part of the cervix that is closest to the uterine body is known as the endocervix and the part of the cervix that is next to the vagina is called the ectocervix. Most of the cervical cancer lesions begin in the junction where the endocervix and ectocervix meet. Cancers can be caused by DNA (Deoxyribo-Nucleic Acids) mutations (gene defects) that activate cells promoting cell division (oncogenes). Sometimes this could be caused by inactivation of tumour suppressor genes, resulting to abnormal proliferation of cervical cells (IARCO, 2003). Cancer of the cervix occurs when the cells of the cervix grow out of control where malignant cancer cells continue to divide until they form a growth or tumour that may appear as a cauliflower-like growth that bleeds easily on contact. If left undetected, the cancer cells become invasive, spreading to tissues and organs outside of the cervix such as the bladder, intestines, liver, uterus and ovaries (Smeltzer & Bare, 2004). Most cervical cancers develop slowly in the lining of the cervix as pre-cancerous changes known as pre cancer lesions (dysplasia) that can potentially develop into cancer if not treated early, but some lesions may not be malignant and can disappear without treatment (IARCO,2003).



Screening for cervical cancer is the most preventive measure and the purpose of the screening is to detect the early pre-cancerous lesions and treat them before they can develop into invasive cervical cancer (Bosch *et al.*, 2002). Among all the cancers, cervical cancer is the only type that can be totally prevented if there is regular screening and treatment of its pre-cancerous lesions (MOH, 2006; Bosch *et al.*, 2002). There are several methods available for detection of several forms of pre cancers and these include direct visual inspection of the cervix aided by chemicals like 5 percent acetic acid and iodine (visual inspection with acetic acid [VIA] and visual inspection with Lugol's iodine [VILI]), which cause recognisable colour changes. Other screening techniques, like cytology (conventional Pap smears, liquid-based cytology) and HPV DNA testing, and treatment of pre-cancer using cryotherapy or the loop electrosurgical excision procedure (LEEP), are helpful in reducing the burden of cervical cancer (Bosch *et al.*, 2002; Smeltzer & Bare, 2004). Every woman should be screened at every opportunity of contact with a health professional, at postnatal clinics, STI clinics and gynaecological clinics. For women who are sexually active, annual screening

from age 18 to 35 years is advised; thereafter every 3 to 5 years, provided the test results remain negative (WHO, 2006). In developed countries where resources are allocated to prevention initiatives, the prevalence and mortality of cervical cancer has fallen between 30% and 75% (Clifford *et al.*, 2005). However, the success of cervical cancer screening initiatives depend on high participation of the targeted group, which is also determined by the women's knowledge, perceptions, attitudes and other socio-cultural issues.

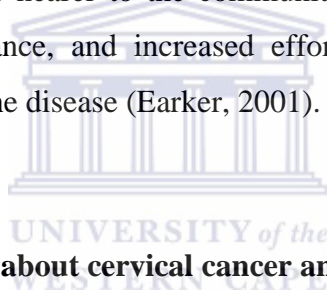
2.2 Risks of cervical cancer

HPV is the most important risk factor for cervical cancer and persistent infection with HPV types 16 and 18, which causes the majority of cervical cancer cases increase the risk of disease development (Gharoro & Ikeanyi, 2006; WHO, 2006). HPV is sexually transmitted therefore risk of acquiring HPV infection is highest soon after sexual activity begins, and in some cases, it has a second peak amongst women at menopause. However penetrative sex is not required for transmission. Skin-to-skin genital contact is a well-recognised mode of HPV transmission (Clifford *et al.*, 2005). The risk of HPV exposure appears to increase with the number of lifetime sexual partners of women (Winer *et al.*, 2003). Therefore, women who have had multiple partners or a high risk partner or who began having intercourse at an early age are more at risk for HPV infection than others. Sexual intercourse without condom use increases the risk of becoming infected with HPV but not all the women infected with HPV will eventually develop cervical cancer. Research shows that women with HPV who smoke or have a weakened immune system have an increased risk of developing cervical cancer (Gharoro & Ikeanyi, 2006). HIV-infected individuals are at higher risk of HPV infection, and persistence of the infection, even when they are on antiretroviral therapy (Blossom *et al.*, 2007). There is currently no cure for HPV infection apart from management of lesions or growths caused by HPV infection (American Cancer Society, 2009).

2.3 Socio-economic factors that influence uptake of cervical cancer screening

The decision to have cervical cancer screening has been shown to be mainly influenced by socioeconomic factors. Qualitative studies conducted in India, South Africa and Uganda found that older women who were of low socio economic status and unemployed, were less likely to participate in cervical cancer screening (ACCP, 2004; Bradly *et al.*, 2004; Kaku *et al.*, 2008; Satija, 2009; WHO, 2010). In a qualitative study done in Uganda, Mutyaba *et al.*

(2007) assert that having money increases the probability of utilizing cervical cancer screening and access to information and utilisation of health care services, while Satija (2009) and Kaku *et al.* (2008) find that low socio economic status interferes with adherence and follow up of treatment leading to further morbidity and mortality from the disease. Kagumire (2010) found that large proportions of women in Uganda cannot afford transport costs to the regional referral hospitals which provide cervical cancer screening services. Similar results are found in the United States of America (USA), South Africa and the Netherlands. In the USA, Garner (2003) found that women in minority, socio-economically disadvantaged, and rural populations have not equally benefited from Papanicolaou test (Pap smear) screening. Other studies in South Africa reported that women without partners were less likely to participate in screening (Bradley *et al.*, 2004; WHO, 2010), while in the Netherlands, a big number of participants in a study did not view cervical cancer as a big problem (Earker, 2001). Thus, to improve uptake of cervical cancer screening, it is crucial that organised screening programs take services nearer to the communities, and this needs to be coupled with information on its importance, and increased efforts to understand (and positively change) women's perception of the disease (Earker, 2001).



2.4 Knowledge and perceptions about cervical cancer and screening

Several qualitative studies have also revealed that, women's perceptions and limited knowledge about the importance of cervical screening influence uptake of cervical cancer screening (Fylan, 1998; Neilson, 1998; Nicky *et al.*, 2005; Merchant, 2007; Nakalevu, 2009). Women do not have a clear understanding of the interpretation of the screening outcome results. Many believe that an abnormal screening result means that a woman already has cancer, so they have fear and distress in case they screen and end up with an abnormal result. These studies also showed that, cultural norms of secrecy that bar women from discussing issues of reproductive health has made women not gain knowledge about the importance of cervical cancer screening. Other reasons cited for non- attendance include reluctance to go for a test in the absence of symptoms, uncertainty as to whether the screening is appropriate for certain age-groups (post-menopausal women and young girls up to age of 20 years) (Nakalevu, 2009). However, the results of a qualitative study conducted in Ireland by Riain (2001), showed that 45% of high risk women actually had knowledge about the purpose of Pap smear screening but they were less likely to attend a cervical screening voluntarily because of socio-economic related problems like low income and lack of social support.

Apart from lack of knowledge, Mutyaba (2007) asserts that cultural and economic issues dictate the reluctance among men to participate in women's reproductive health issues in Uganda yet they remain the sole providers of resources that enable women to access health care. Mutyaba's study methodology had wide representation that could produce more convincing results, because the participants were a mixture of men, women and health workers.

2.5 Cultural beliefs about cervical cancer and screening

Several studies in UK and South Asia show that cultural beliefs and perceptions influence uptake of cervical cancer screening (Scanlink, cited in Nicky, 2005; Cox, 2010). These studies revealed that black minority ethnic groups in United Kingdom and South Asian women consider cervical cancer as being caused by promiscuity; therefore it is considered a taboo, or a just punishment from God. As a result of these beliefs, a big proportion of women shy away from screening because they do not want to be associated with such a disease that is considered a curse from God. Many other studies have also reported embarrassment when seen seeking care for cervical cancer, stigma, and lowered self-esteem when one receives a negative result (International Agency for Research on Cancer, 2005; Kitchener *et al.*, 2006; Cann, 2008).

Additionally, a UK based study reported that women had fear of receiving abnormal screening results because of anxiety associated with such results (Fylan, cited in Nakalevu, 2009). The women claimed that abnormal results would have severe effect on day to day functioning leading to depressed mood, decreased libido and feeling of less attractive, tarnished, defiled or contaminated and dirty feelings. Correspondingly, Nicky (2005) reported an interesting finding of a cultural/religious belief that Muslim women can only be seen naked by their husbands; which influenced their preference for female general practitioners especially for cervical smears. Also in this study, it was revealed that Pakistani Muslims were not comfortable attending to a doctor from the same cultural background they would only go along for a smear test if the doctor was not of the same cultural background for fear of being 'found out'.

Additional studies that explored culture show that cultural gender roles and behaviours of women, may also affect the uptake of cervical cancer screening (Engender Health, 2002; Katahoire *et al.*, 2008; Markovic *et al.*, 2005; Cox, 2010). For example, an exploratory study that was conducted in Uganda revealed that cervical cancer being a condition affecting women's sexual and reproductive health was likely to be shrouded in silence since these are issues that are socially and culturally perceived to be private and cannot be openly discussed in public (Katahoire *et al.*, 2008). Therefore, women found difficulty in accessing information even when they experienced cervical cancer like symptoms.

In South Africa, a formative research uncovered the Xhosa belief that the health of a woman's womb reflects the health of the woman as a whole and that healthy wombs are associated with virginity, pride, and motherhood (Engender Health, 2002). Research results of this study also indicated that gender norms among the Xhosa people inhibited women who had undergone treatment for precancerous lesions from negotiating the recommended four weeks of sexual abstinence after treatment. Unlike previous studies that acknowledged lack of knowledge and information as a strong determinant in the uptake of screening, the authors of this study among Xhosa community, stress that since cervical cancer is caused by a sexually transmitted disease and involves open discussion about the female reproductive organs, even when women are adequately informed about risks of cervical cancer, they may not participate in screening. Similarly, a study carried out in Kisoro district among 'Bafumbira' tribe in Uganda, revealed that Bafumbira lack a local word for cervix, and the word vagina is a shameful / embarrassing word (Cox, 2010). "Female private parts" is replaced during translation, so in this case women would rather not take part in screening to avoid being embarrassed mentioning that they have come to screen a condition related to their private parts.

Other cultural gender roles and behaviours that hindered cervical cancer screening include inability to leave house-hold chores, pre-occupation with family problems and lack of approval from husbands (Fylan, 1998). However, Nakalevu (2009) argues that, if women and communities were educated and understood the importance of having a cervical cancer screening, and the importance of further follow up, culture would not be a bigger hindrance since the results of her study showed that, women's general attitude was positive towards

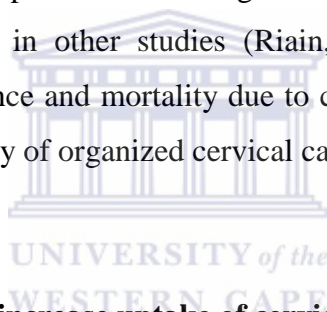
cervical cancer screening. It is important to note though that in this study, participant recruitment happened at health facilities among patients who could already be having a positive attitude towards seeking health. Therefore, the sample population may not be representative of the women population that could be targeted since this education awareness program would be targeting “the already converted ones”.

2.6 Practices and Behaviours about cervical cancer screening

Institutional factors have also been shown by different studies to be influencing uptake of cervical cancer screening. According to International Agency for Research on Cancer Organisation (2003), uptake of screening is increased when the governments ensure that there is an organized screening program in place. Hakama *et al.* (2008), Wabinga *et al.* (2000) and Mutyaba *et al.* (2007), showed that mortality due to cervical cancer reduced drastically in developed countries which had sustained organized screening program that were equipped with infrastructure, trained human resource, organized follow up and surveillance systems. A review of five qualitative studies that were conducted in Mexico, Peru and Ecuador showed that the main barriers to increasing uptake of cervical cancer included inaccessible and unavailability of high-quality health services, the lack of comfort and privacy in facilities, and unfriendly health workers (ACCP, 2004).

However, though various authors agree that a screening program is crucial in improving uptake, they strongly argue that other factors like knowledge, attitude of both women and health workers, socioeconomic, cultural beliefs and other supporting institutional factors like sufficient and trained staff supersedes just the availability of an organized screening program (PATH, 2000; Engender Health, 2002; Birmingham, 2003; Nakalevu; 2009). Analysis of data from a study conducted in Netherlands showed that women’s beliefs about cervical cancer screening and attendance are the best predictors of uptake of the service, even when organizational aspects are taken into account (Nastasi, cited in Nakalevu, 2009). In countries like Chile, Colombia, Costa Rica, Cuba and Mexico which have been having organized screening programs in place, mortality due to cervical cancer has remained the same or even increased. The reasons for this were reported to be other underlying factors such as inadequate infrastructure, insufficient human resource and lack of education among the masses. The countries have had to go back on the drawing board to address some of those challenges (Engender Health, 2002).

While the same factors have been considered in almost all of the cervical cancer screening uptake studies, the findings, as the literature indicates have been contradictory in some cases. For example, ACCP (2004) and Bradly *et al.* (2004) found that socio economic factors were important variables that positively and negatively influence a woman's decision to participate in screening in India and South Africa. Mutyaba *et al.* (2006; 2007) on the other hand, found that a combination of economic and male partner influences, knowledge, cultural beliefs and health service factors interacted with presence of an organized screening program in influencing a woman's decision to participate in cervical cancer screening in Uganda. Nakalevu (2009) found that culture does not matter as long as women have knowledge about the importance of screening, fears and perceptions addressed then they are likely to participate in cervical cancer screening in Fiji. International Agency for Research on cancer Organisation (2003), found that uptake of screening is ensured when there is an organized screening program in place yet in other studies (Riain, 2001; Engender Health, 2002), cervical cancer screening, incidence and mortality due to cervical cancer did not necessarily improve because of the availability of organized cervical cancer screening programs.



2.7 Recommended strategies to increase uptake of cervical cancer screening

Research has recommended some strategies which can increase uptake of cervical cancer screening in Uganda. For example, Nakalevu (2009) recommended that awareness and education programs need to be implemented to target women about cervical cancer screening, train more competent health providers, ensure that the women will receive their results face to face so their results could be discussed thoroughly with them and encourage them for further follow-up clinics. Mutyaba (2007) noted that men are potentially willing partners if appropriately informed about issues of women's reproductive health; so men should also be targeted during cervical cancer screening awareness campaigns. Fylan (1998) argued that increasing participation to up take of cervical cancer screening requires sustainable provision of information using proven quality communication mechanisms especially between health workers to patients and also to the communities. According to Fylan, there is also need to improve women's satisfaction by using female health workers in cervical screening and adapting the service to meet user's needs considering for example the timing of screening and

the screening place that is more convenient for women and all this is done while considering women's health beliefs.



CHAPTER 3: METHODOLOGY

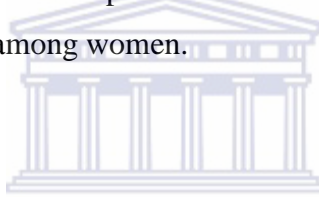
3.1 Aim of the study

The aim of the study was to explore the challenges to uptake of cervical cancer screening among women accessing maternal and child health care services in Nsambya Hospital, Kampala, Uganda.

3.1.1 Objectives

The specific objectives of this study were;

1. To explore the awareness about cervical cancer among women.
2. To explore perceptions about screening for cervical cancer among women
3. To explore the cultural and socio-economic factors that influence the uptake of cervical cancer screening among women.
4. To explore recommendations for practical interventions that can increase uptake of cervical cancer screening among women.



3.2 Study context/Area

The study was conducted in Nsambya hospital, a faith based private, not-for-profit (PNFP) hospital. It is one of the few hospitals that pioneered cervical cancer screening and treatment services in Uganda. The hospital is located in the outskirts of Kampala city about 2 km from the city centre. It was easily accessible by the neighbouring communities but it also serves a vast number of people from all over Uganda. The neighbourhood of the hospital comprises of mainly low income slum dwellers and a small number of middle income earners. Consequently, the hospital serves people from diverse socio-economic and cultural backgrounds. The running of the hospital depends mostly on donor funding but it also charges a relatively low fee to clients, which makes its services affordable for low income earners. In addition, due to the fairly good quality of care, the demand for health care at the hospital is always overwhelming. High numbers of women seek health care services from this hospital and this study targeted women who seek varied health care services from this particular health facility.

3.3 Study design

An exploratory and descriptive qualitative study was conducted to facilitate a broad understanding of knowledge and women's perception, social economic and cultural factors that hinder the uptake of cervical cancer screening among women. This type of design was chosen in order to obtain a comprehensive summary of an experience formed by the women's own social world and interaction with others (Grimes, 2002). Exploratory and descriptive designs also enables the researcher to guarantee that data collected from the respondents are not just descriptions of a neutral and stable reality but descriptions of a reality that is constructed by the respondents themselves (Green & Thorogood, 2004).

3.4 Study population and sampling

All women between the age of 18-64 years who access maternal child health care in Nsambya hospital's various clinics were eligible for inclusion in the study. Through purposive and homogeneous sampling techniques, 25 women were selected. The first step was purposive selection of five (5) clinics where women mostly visit in the hospital. These included antenatal clinic, postnatal clinic, paediatric ward, young child clinics and HIV/AIDS clinic. HIV AIDS clinic was included because there are women who have maternal and child health care needs. The second stage was homogeneous sampling from these various clinics where 5 women were selected from each clinic to make a total of 25. In every clinic selection of women for participation was done with the support of the various clinic staff who introduced the researcher to women. They were then approached to participate and those who expressed initial interest, were invited by the researcher to discuss this further after completing the clinic visit.

3.5 Data collection

3.5.1 Piloting of the interview schedules

The interview was piloted on two women, one at the antenatal clinic and another at paediatric ward. This provided the opportunity to get comfortable with the interview process and also gave insight that there was need to give room to women to tell their own story without emphasizing on specific aspects. This process helped to slightly make an adjustment to the interview schedule by relocating some of the probe question guide. The purpose of the pre-test was to improve the interview guide but the results from the pre- test were not reported in the final study findings.

3.5.2 Data collection tools and methods

Primary data was collected through individual semi-structured interviews, and these are data collection tools where there is a face-to-face interaction between interviewer and interviewee (Mays & Pope, 2000). Individual semi-structured interviewing was preferred, because such interviews are useful when one wants detailed information about a person's thoughts and behaviours or want to explore new issues in detail (Kuper *et al.*, 2008). A topic guide of pre-determined set of open-ended questions was developed based on the literature review and objectives of the study. It helped as a guide in focusing the interview and it contained the following main topics:

- Personal history
- Awareness on cervical cancer
- Individual perceptions on risk of cervical cancer
- Attitude and beliefs on cervical cancer and screening
- Barriers to cervical cancer screening
- Recommendations on the uptake of cervical cancer screening

The complete interview guide is found in appendix 3:

The interviews took place in private rooms at each clinic in the hospital to maintain privacy and to avoid disturbances from the clinic. The researcher first created rapport with the women and through interaction the researcher got more back ground information in detail. Thereafter the in-depth interview began with an opening sentence: "Could you explain to me what you know about cervical cancer?" The duration of the interviews varied between 28 and 40 minutes. The researcher also made notes on non-verbal communications and personal feelings.

3.6 Data management and analysis

The interviews were recorded on a digital audio recorder and a few text notes were also taken. The researcher transcribed the recordings and the exchanges that had been conducted in the local language were translated and also made ready for analysis. This stage in analysis helped in familiarization of the data where key ideas, impressions of respondents were identified and written down and it also helped in checking the data quality (Terre Blanche & Durrheim, 2002). This was done within 24 hours of completion of specific interviews.

The data were then subjected to a thematic content analysis, where the transcripts were coded to classify the data systematically. The first step involved structuring the interview data into

tables where each interview was put in a separate table. Secondly, a theme codebook was developed that comprised of the descriptions of the main themes and the various sub themes under each theme (Table 1). Numerical codes were attached to each theme and sub theme and these codes were added into a separate column of each table. Thereafter categorization of data tables was done to find patterns and the process also allowed the researcher to perform a code authentication (Gifford, undated; Masom, 2010). This provided an extra check on possible divergent cases and confirmed the emerging themes.

3.7 Rigour

To ensure rigour, first, I had to recognize my personal experiences as a woman who had experienced the advantages of cervical cancer screening and I was reflexive about in order to guarantee unbiased study. Additionally, I was aware that being of a middle socio-economic class could facilitate some power imbalance with the respondents. Therefore I ensured that good rapport with the respondents was established through social interaction before interviews began and I also encouraged them to be as free with me and reinforced that all they shared with me was confidential (Kuper *et al.*, 2008).

Rigour of data collection and analysis was ensured by following a systematic approach and documenting each step of the process in detail. For example comprehensive interview guides were used to collect data in order to reduce the researcher bias. The interview guide was structured in a way that more comfortable questions were asked first and this made the participants feel at ease before getting into detailed interviews.

The interviews were conducted in the local language, Luganda, which the researcher was fluent in and later they were translated to English, this made the participants express themselves freely during the interviews. The researcher also constantly counter checked the responses with participants by summarizing the discussion with them to ensure that the research is truly a reflection of the participants' realities and not those of the researcher.

In order to decrease threats to credibility of the data, the method of data collection in qualitative research is important (Barbour, 2001). Therefore semi-structured interviews were used as an appropriate method to answer the research question, since matters of reproductive health are sensitive and taken to be private, participants needed to reflect on their personal lives and experiences that influence their decision to screen for cervical cancer. Lastly credibility and trustworthiness were ensured by recording all data and making full transcripts, including cross-checking translations.

3.8 Ethical considerations

Ethical approval was obtained from the Ethics Committee of University of Western Cape and Uganda National Council of Science and Technology (UNCST). Participation in the research was voluntary and anonymous for all participants and they were requested to sign an informed consent before they took part in the research. An information sheet explaining the purpose of the study, benefits of participating in the exercise, assurance of maintaining confidentiality, and the right to withdraw in the study without giving an explanation was also provided to the respondents as part of the process of obtaining informed consent (Refer to Appendix 5).

All documents and interviews including the informed consent form were in the participants' local language. The participants were informed that the interviews would be recorded and the tape recorders would be kept securely and the information would be erased after transcription.

Indeed, the digital voice recorder and notes were kept in a locked cabinet and the data entered in the computer were password protected.

Data obtained was reviewed by the researcher, the supervisor and ethics committees as necessary. Participants who showed interest in cervical cancer screening were referred appropriately for further support.

CHAPTER 4: RESULTS

This chapter presents the study findings. In the first section a description of the socio-demographic characteristics of the study participants is provided. In the second section barriers and facilitating factors to cervical cancer screening are presented, according to the following themes and subthemes (Table 1):

THEMES	SUB-THEMES	CODES
1. Knowledge and awareness of cervical cancer screening	1.1 Awareness	1.1.1 Knowledge on signs and symptoms
		1.1.2 Perceived severity
		1.1.3 Risk perception and risk factors
	1.2 Knowledge about Health services	1.2.1 Health education
2. Health seeking behaviour of women	2.1 Individual factors	2.1.1 Fear of the outcome
		2.1.2 Appreciation of importance of screening
		2.1.3 Busy work schedules/Time
		2.1.4 Absence of pain
		2.1.5 Perceived susceptibility
		2.1.6 Willingness and determination to screen
	2.2 Social structures	2.2.1 Male partner support
		2.2.2 Family support
	2.3 Affordability	2.3.1 Transport and Distance
		2.3.2 Unofficial payment
	2.4 Health services barriers	2.4.1 Health education
		2.4.2 Unfriendly procedure of screening
		2.4.3 Long waiting times
		2.4.4 Staff attitude and motivation
		2.4.5 Adequate staffing levels
		2.4.6 Access to services
2.4.7 Inadequate personnel		
2.4.8 Availability of drugs		
3. Facilitating factors to screening for cervical cancer		3.1.1 Availability of screening services
		3.1.2 Availability and affordability of cervical cancer drugs
		3.1.3 Publicizing free screening services
		3.1.4 Linkages and referrals to screening services

4.1 Socio demographic characteristics of participants

The majority of the study participants (19/25) were Christians from different denominations while the rest of the study participants were Muslims. The study participants' age ranged from 18 to 55 years. Just less than half of the study participants (12/25) were business women working in the informal small-scale business sector, (3/25) were formally employed as nurses and teacher, (4/25) were housewives and 5/25) were students. Their education levels ranged from no education (3/25) to university education (4/25); the majority of study participants had primary education (13/25).

4.2 Awareness and knowledge of cervical cancer screening

The sub-themes here include ignorance on signs and symptoms, perceived severity, risk perception and risk factors.

4.2.1 Awareness about cervical cancer

Majority of these study participants (24/25) had heard about cancer as a disease in general. However, many (18 participants) could not distinguish cervical cancer from the other cancers such as breast cancer and uterine cancer.

R12: "I have heard about people talk about cancer of the breasts but that one I do not know it's not common in my ears" (21 year old single student)

R13: "I know that cervical cancer attacks the private parts of women and it is very dangerous and usually attacks women and it kills if you don't get treatment. It attacks the inside of the private parts down and the breasts of women" (38 year old business woman)

R5: "Cervical cancer is a disease of women and I hear that it catches women who have delivered and were not operated well. They are operated and some things remain inside, this can cause infection and then she gets cervical cancer" (43 year old unemployed widow)

4.2.1.1 Knowledge about signs and symptoms of cervical cancer

Despite the health education offered during antenatal and immunisation, many of the study participants were not able to identify clear cervical cancer signs and symptoms apart from those who had some form of medical training. A few (4/25) were able to identify bleeding during sexual intercourse and smelly vaginal discharge as major signs and symptoms for

cervical cancer. For some, having a sexually transmitted infection was equated to mean having cervical cancer as well.

The following quotes help to demonstrate variable knowledge about signs and symptoms about cervical cancer.

R11: “I know it affects the cervix, may be the signs, like when you have sex you bleed, it’s painful and I think....one of the things that causes it, is like when you have fibroids and you have fibroids, you don’t treat them, and let me say STDs you don’t treat them, they can develop into this” (24 year old university graduate and businesswoman)

R13: “Women can feel ‘small stone like things’ inside the private parts and also on the breasts and it is painful. Hard round things like boils in the woman’s inside private parts and later they become painful” (38 year old business woman)

4.2.1.2 Perceptions about severity of cervical cancer

Almost all (24/25) the study participants, acknowledged that cervical cancer is a deadly disease. The participants reasoned that cervical cancer is diagnosed late and because of this, little can be done to treat it adding that the eventual outcome of cervical cancer infection is death. The quotes below illustrate the participant perceived severity of cervical cancer disease.

R5: “I hear that all people who get cervical cancer die. Even me I know if they check me and find that I have I know I would be going to die. It is very severe because it kills” (43 year old unemployed widow)

R8: “I hear people say that it is a severe disease, they even say that HIV is better than cancer. I think it is a dangerous disease” (26 year old married tailor)

R15: “Uuuuh, If people come to know that you are suffering from cancer they start looking at you like you are going to die. They say that, so this one is suffering from cancer? You know the way people look at cancer they even say that I rather suffer from HIV because for it, it has medicine for making you live longer. But for cancer they say eeh how can this one be suffering from cancer (laughter). They just say even the HIV infected person is better than you” (35 year old self-employed tailor)

4.2.1.3 Knowledge of the risk factors of cervical cancer

The participants who were able to distinguish cervical cancer from the rest of the other cancer types exhibited knowledge about the risk factors for cervical cancer.

R2: “What I have heard about cervical cancer, I have heard about so many stories about cervical cancer like if a girl goes and sleeps with a man at a young age they normally get cervical cancer, if you sleep with a lot of men you get cervical cancer”
(25 year old beautician)

Others did not know the risk factors for cervical cancer with many of the respondents citing use of contraceptives as a risk factor.

R1: “I have heard about cervical cancer and I have heard that it affects women. Also the way it affects women like what causes it like unhygienic environment especially after women have delivered that is the time when they get it. This happens because of our things which you know like dirty things used to deliver. Then secondly there are germs which can cause it especially on women who don’t care about themselves so much in terms of visiting dirty toilets.” (45 year old widowed tailor)

R18:” Aaaaa.....They even say that family planning also causes it.... Especially that one which they insert in the private parts and also injections, they stop you from menstruating and you end up developing cervical cancer. Even these condoms can also cause it. That sort of thing like powder in the condoms can cause cervical cancer” (28 year old married businesswoman)

The study participants believed/knew that having multiple sexual partners and early sexual debut were major risk factors for developing cervical cancer in the future. In contrast the participants did not clearly understand who was at risk of developing cervical cancer. Majority of the study participants thought that women aged 25-45 years were at risk of developing cervical cancer. However, medically trained participants reported that cervical cancer risk increased as one aged into and out of child bearing ages.

4.2.2 Knowledge about cervical cancer screening services

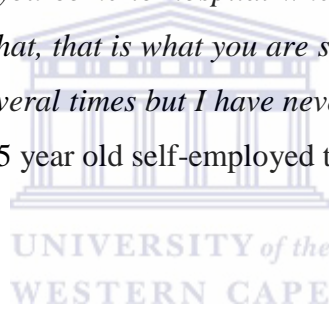
Knowledge about cervical cancer screening services was generally limited; with most respondents unable to identify places where they could access these services. The sub-theme was health education.

4.2.2.1 Health education

The participants who exhibited cervical cancer awareness reported that they had learnt about it during antenatal and immunisation visits or in the due course of their education. Learning about cervical cancer in the due course of one's education was only reported by the medically trained participants. There were two medically trained participants in this study. Only one participant whose mother was medical personnel reported the mother as the source of information about cervical cancer.

R5: "I don't know I have never heard doctors talk about it. Me I usually go to hospitals but they have never taught us about that. It seems they only tell you when you have the cervical cancer but for me I don't have" (43 year old unemployed widow)

R15: "I tell you this cervical cancer thing people don't know about it. There is no information at all unless you come to hospital when you already have that problem. They check you and find that, that is what you are suffering from. For me my children have got admitted here several times but I have never heard any one come to teach us about cervical cancer" (35 year old self-employed tailor)



4.3 Health seeking behaviour

Analysis of this study data revealed that women's health seeking behaviour related to cervical cancer was influenced by individual factors, social structures, affordability and health services barriers.

4.3.1 Individual factors

At the individual level, majority of (19/25) the women reported that they perceived themselves to be at risk of developing cervical cancer and the women generally felt that they had a high risk because of childbearing or multiple sex partners by their partners, something they stated that they had no control over. The individual factors were fear of the outcome, appreciation of importance of screening, busy work schedules/time, absence of pain, perceived susceptibility and willingness and determination to screen

4.3.1.1 Fear of the outcome

Overall, most women reported that they had not screened for cervical cancer because they feared a positive cervical cancer screening test and out of sheer laziness. This type of reporting was very common among housewives.

R2: *“Some women have fear they really fear they think cancer is a deadly disease when they tell her that you have cancer all she thinks about is death she thinks that she is going to die anytime. That they are going to live their kids and die”* (25 year old beautician, single mom)

R3: *“What makes it common among women is that women fear to test....sometimes I even fear because I am like what if they find that I have the disease, what would I do then? I hear the disease doesn't even have drugs which heal you. Those are things just to worry me”* (38 year old divorcee market vendor)

R6: *“The fear of what the results would be has been making me not test myself”* (28 year old married shop owner)

4.3.1.2 Busy work schedules/Time

A few number of women (4/25) in both formal and informal employment blamed their inability to screen for cervical cancer to busy schedule at work. The women in the formal employment reported that it was so hard for their employers to grant them leave in order to go and screen for cervical cancer when they looked healthy and did not present with any pain. In contrast the women in informal employment argued that they feared to lose customers as they went for cervical cancer screening.

R18: *“You find someone is an office person, for her to get the time and spend the whole day in Mulago hospital is difficult. You know the problem, doctors in Mulago are few even those few are not available, so when you have asked a permission to get time off work you don't want to spend all that time but the major issue here is that cancer does not pain immediately but if people had pain they would get the time to go and check”* (28 year old married businesswoman)

R22: *“Time is also a hindrance especially when you are working in the formal sector because they also don't understand that this routine screening is important. Especially for women, asking for permission from your boss that you are going for cancer screening, he may not allow you in any case you don't look like a sick person. He gives an option of going on the weekend and yet the hospitals don't screen on the weekend and there you are bound to miss your appointment”* (52 year old nurse)

4.3.1.3 Absence of pain

In addition, the women reported that the reluctance to screen was due to lack of pain caused by cervical cancer in its early stages. The women argued that it was easier to seek health care when one was in pain.

R3: "I have never checked myself because am just reluctant, and again you know when you are not sick it is hard just to go to hospital to check yourself" (38 year old divorcee market vendor)

R5: "If women are not sick, why should they then go to check? If a woman is pregnant then she can go but if you are not pregnant or you don't even have any pain then there is no reason why women should go" (43 year old unemployed widow)

R15: "You know the problem you can't go to the hospital when you don't have any pain, but when you start getting the pain that is when you think of going to hospitals" (35 year old self-employed tailor)

4.3.1.4 Perceived susceptibility to cervical cancer

Only two participants reported that they were not at risk of developing cervical cancer despite being in child bearing age and being married. The rest of the study participants reported that they were at risk of developing cervical cancer because they were either married or in the vulnerable age group for cervical cancer. The main reason why women perceived themselves to be at risk of developing cervical cancer was that they were sexually active and being in the age bracket of 25-45 years. The women argued that those women in the age bracket of 25-45 years were at an increased cervical cancer risk because they were still capable of giving birth. Many of the study participants, followed in this age bracket. The women maintained that being sexually active exposed them to cervical cancer risk and that this risk was increased by their partners by way of multiple partners. However, few of the women (6/25) perceived themselves to be at low risk of developing cervical cancer. This group of the women argued that there were a minority women argue their cervical cancer risk was low because they only had one sexual partner. Almost all women (23/25) reported agreed that having multiple sexual partners not only increased one's risk of sexually transmitted infection but also the risk of developing cervical cancer. Indeed, some of the women equated having sexually transmitted infections like syphilis and candida as early cervical cancer signs. The women's perceived risk of developing cervical cancer is illustrated by the following quotes:

R2: “..really I have a risk because I have never gone for check up. I have been sleeping around because already my four children have two fathers and I’m only 25 years so really I think I have a risk.” (25 year old beautician, single mom)

R5: “It gets women who have delivered, I haven’t seen it in those ones who have not delivered. My risk is not high, I know I can get also but the chance of getting is not high especially that for me I finished producing. The only risk which I have is that I am growing old” (43 year old unemployed widow)

R20: “For me I am not at risk because I have one sexual partner, I had my first sexual debut when I was 25 years. I don’t really think. And I am HIV negative” (34 year old married nurse)

4.3.1.6 Willingness and determination to screen

Related to the women’ perceived cervical cancer risk, was their willingness to screen for it. None of the women reported lack of willingness to cervical cancer screening. All the women reported that early and repetitive cervical cancer screening was helpful for early cervical cancer diagnosis. The women argued that the earlier, cervical cancer is detected the better the treatment outcome. Early treatment initiation was reported to be a benefit accruing from early screening.

The quotes below show the women’s willingness and determination to screen for cervical cancer screening.

R11: “I think it’s very important because it’s better to know it when it’s early because when it’s early it can be cured. But if you wait until it’s late it can’t be cured and you may end up having a long suffering” (24 year old single graduate and businesswoman)

However, a sizeable number of women (18/25), maintained that cervical cancer had no cure and that cervical cancer diagnosis meant death.

R6: “It is important because it helps you to get treatment because if you come to know early enough it can get better. But if you delay to screen and you later find that you have, you just die immediately the fact that it doesn’t have the medicine” (28 year old married shop owner)

In total contrast, although the women's reported willingness to screen for cervical cancer, only 3/25 women reported to have screened. Of these, two women reported to screen routinely for cervical cancer, one of whom was a nurse aged 52 years while the other was a nurse's daughter aged only 21 years.

4.3.2 Social structures

In relation to social structures, women's uptake of cervical screening was influenced by the either their spouse or family support. Male partner support was seen as very important in determining if a married woman could access cervical cancer screening services whilst for unmarried women family support to a lesser extent was reported to be important.

4.3.2.1 Male partner support

More than half of the study women reported that their partners would support them to go for cervical cancer screening. The partners' support would be financial to help them to meet the transport costs to and from the screening centre. The women explained that to get more support from the partners, it required their partners to be informed/ educated about the dangers of cervical cancer. The women explained that because cervical cancer early signs were painless, the partners had to be educated about the dangers of not screening for cervical cancer early enough. The women reasoned that their spouses had always supported them when the need arose. The women did caution that the spouse support depended on spouses' financial ability to offer support

R8: "The man doesn't have a problem if I tell him he can't refuse me to go. He is even the one who gave me transport today. But he doesn't also know about this cervical cancer, he would be encouraging me to go and check if he knew" (26 year old married tailor)

R17: "Aaaah he doesn't talk about it. I even don't know whether he knows about cervical cancer" (28 year old married hairdresser)

4.3.2.2 Family support

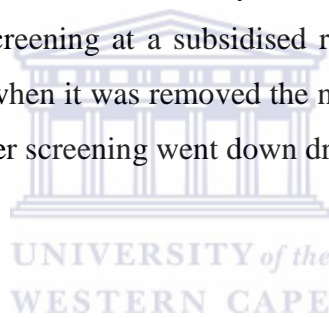
The other reported source of support for the women to undertake cervical cancer screening was their families. This was so mainly for the unmarried women. For the married women, their first point of contact for cervical cancer screening support would be the spouses. In case, such support was not forthcoming, then the family would be the second point of contact for support. However, the fair minority of the women reported that their families would not

support them. Some of these women argued that they were the main bread winners of their families while others had lost their partners.

R1: “For my case there is no way how the family can help because I have four children and all of them are still in school, no one is earning instead they all depend on me on school fees, food and other things, so that one is not even an option” (45 year old widowed tailor)

R3: “I don’t have any support, many of my relatives are in the village, I have only one relative in Kampala who also stays farther away from me and my children are young, it is instead me who gives them support” (38 year old divorcee market vendor)

There were no other reported formal sources of support outside the family and the spouse for cervical cancer screening. However, one woman who accessed HIV/AIDS health care from a certain HIV care centre reported that at one time they were referred by that HIV care centre at Nsambya hospital for cervical screening at a subsidised rate. This subsidy was reported to have been a short-lived one and when it was removed the number of HIV infected women on treatment taking up cervical cancer screening went down dramatically.



4.3.3 Affordability

Most of the women explained that cervical cancer screening was affordable to them. Reporting about the cost of doing the cervical cancer screening, there were only three women who reported that it was very expensive for them and therefore not affordable.

4.3.3.1 Transport and distance

The women justified their conclusion about cervical cancer screening affordability to living near Nsambya hospital where cervical cancer screening was carried out. Living near the hospital meant spending less on transport. The women estimated the transport cost to be about 0.20 US dollar on average. Indeed, more than half of the women agreed that the distance between their homes and the hospital was a walk able one. Most of them said;

R2: “Distance would not be a problem in any case I can’t fail to get transport” (25 year old beautician, single mum)

However, others mentioned transport and distance to be major barriers to accessing services;

R5: “Where I come from in Kisoro I stay very far from the hospital and even I stay alone. So when I fall sick I have to come to Kampala and my kids take me to the hospital. When I am alone it is difficult but even the money” (43 year old unemployed widow)

R25: “...people don’t have money even for their own health, some even fail to get transport. And in any case if you can’t afford transport will you then afford treatment, so people just decide to remain not knowing” (28 year old married businesswoman)

4.3.3.3 Unofficial payments

The three women who mentioned that cervical cancer screening was unaffordable argued that there were unofficial payments for the cervical cancer screening tests and the health workers were reported to charge variable fees from individual to individual. The rest of the women reported that cervical cancer screening became expensive the moment cancerous cells were suspected from the first screening. The following quotes illustrate that some of the women considered cervical cancer screening to be unaffordable.

R2: “...For Mulago case, they will tell you come back the other day when you go there they don’t even care and even start asking you money yet they say that the service is free” (25 year old beautician, single mom)

R9: “Services are free at Mulago hospital but again they are those hidden costs which you find yourself paying. For example you have to pay money for the card” (mother of one)

R18: “Some people don’t test themselves because they lack the money..... they usually tell us that government hospitals treatment is free but when you reach there they charge. Until you pay some money, you can never see a doctor and many of us can’t afford that money. Now imagine going to check for cervical cancer when you are not even in pain and you start paying money” (28 year old married businesswoman)

4.3.4 Health services barriers

Analysis of this data revealed that over 80% (22/25) of the women had never screened for cervical cancer. When the women were asked why they had not screened for cervical cancer, they reported a long list of barriers and these included: lack of awareness of the importance of screening, absence of health education, unfriendly screening procedure/posture, long waiting

queues, low motivated staff and unavailability of drugs/cure. From this list of barriers at least every woman reported two of them.

4.3.4.1 Health education

Most of the women revealed that they had not screened for cervical cancer because they were not aware of the need to do so. Some of the women explained that they were only given health education about cervical cancer screening when they turned up to immunise their children revealing the selective offering of cervical cancer screening services.

R1: “In the HIV AIDS clinic when they are health educating us some time they talk about it. They always keep on changing topics which they teach us and cervical cancer is one of them, so if you are lucky and on the day it is your appointment day when they educate about cervical cancer then you can learn. They usually tell us that the checking is done in the main hospital maternity side but the problem is that it seems they only check those maternity mothers only” (45 year old widowed tailor)

R2: “If you don’t visit a hospital you don’t get the information even some hospitals don’t give information to women at all even if you go to the hospital. Even in this very hospital really if you have not come to immunize a child really you can’t get information because for me one time my first child was admitted in the ward for kids for almost like four days and I really didn’t see anyone coming to really give women information about cervical cancer” (25 year old beautician, single mom)

4.3.4.2 Unfriendly procedure of screening

a. Young health workers

The women argued that some of the health workers attending to them were a lot younger than the women. The older women further reported that they were deterred from cervical cancer screening because the medical personnel doing the screening were young enough to be their children. These women argued that they could not imagine themselves undressing before their ‘children’. By ‘children’, the women meant young health workers.

R1: “realistically that is not comfortable at all.... It makes some people anxious including me and when the doctor is very young compared to me, it even makes it worse. Actually the way they test for cervical cancer could also be making women reluctant to go for screening especially when one finished producing long time like me” (45 year old widowed tailor)

R22: “And most times you find young health personnel doing the screening and you become anxious and you are like how can I raise my legs to this young person and yet you have to do it. Otherwise it is a procedure which I don’t like. I don’t like it at all”
(52 year old married nurse)

b. Posture during screening procedure

Even women who had ever screened for cervical cancer expressed discomfort about the cervical cancer screening procedure. The women explained that the cervical cancer screening procedure/posture made them uncomfortable. This was because they were made to lie on their back just as if they were giving birth and the health workers touched the women’s genitals. The women questioned the rationale of making them to lie in giving birth position when one was not giving birth. Indeed one woman reported that she missed her cervical cancer screening appointments because of the procedure. Some of the women explained that the cervical cancer screening procedure required her to undress before young health workers, making them lie-down on her back as if they were going to give birth and touching their private parts. The following help to point out women’s reasons for not undertaking cervical cancer screening.

R2: “...they make you lie-down on a table separate your legs and then they screen. ‘Ooooh’ it makes me anxious, ‘ehh’ just raising your legs there when you are not even in pain it’s not easy. You know us women we are used to spread our legs when you are going to produce but just showing your legs when you are not even in any pain it’s a bit difficult” (25 year old beautician, single mom)

R7: “Whenever I think about that procedure also ehhhh!! I think it is contributing to my not screening somehow” (45 year old small scale real estate owner)

R11: “I remember that time they were telling people to go for screening, but when I heard the way they screen, I refused to go. Actually I wanted to go but people were like, do you know how they screen?” (24 year old single graduate and businesswoman)

4.3.4.3 Inadequate staffing levels and long waiting times

The other bottleneck for cervical cancer screening was the low staffing levels. The women explained that when they sought health care, there were long queues because of the shortage of health workers. These long waiting queues were not only limited to the other health services but also included cervical cancer screening.

R1: “...I have a lot to do now I go to spend my whole time in these hospitals of ours where doctors are not even available, then I just say let me not go. You know our Uganda, how many times do you go to a hospital and the doctors work on you on time and then you go home? These doctors are never there even the available ones are overwhelmed. So instead of wasting my time there waiting for doctors I rather not bother and look after my customers” (45 year old widowed tailor)

R3: “..it is very difficult to get a doctor yet for us women we have many responsibilities at home, so it is hard for me to spend the whole day in a hospital waiting for a doctor. I hear that in Mulago hospital they check for free and from my place to Mulago it is not much money in transport but for me time of waiting for a doctor the whole day is my issue” (38 year old divorcee market vendor)

4.3.4.4 Staff attitudes and low motivation

The study participants reported that matters were further complicated by the low motivation of the health workers. The study women accused the health workers of barking at them and not attending to them with care, particularly female health workers.

R1: “Men are good, they are better than women, women are so rude. If a man checks you he tells you what you are supposed to do. I don't know what happened to women. Me I would want a man to check me and give my results. For a man I am always free to ask my question after they have given me my results and they patiently explain to you” (45 year old widowed tailor)

R2: “Aaah you know female health workers are not friendly” (25 year old beautician, single mom)

4.3.4.5 Unavailability of drugs

Finally, the women reported unavailability of drugs as a bottleneck for cervical cancer screening. The women questioned the rationale of going through the unfriendly cervical cancer screening when there were no drugs to treat them adding that they had heard over the radio that cancer treatment was very expensive adding that cervical cancer was no different.

R6: “But again, going to check and I find that I have the cervical cancer when I can't get the drugs worries me and it is discouraging. It makes me think that maybe I should stay without knowing anything instead of checking and I start getting worried” (28 year old married shop owner)

R24: “I think and I hear it is very expensive and women are poor to be able to afford..... It needs you to know your status when you can afford the treatment. If they found that I have I can even die quickly because knowing that I have cervical cancer when I don’t even have money to treat myself aaah I rather stay without knowing” (32 year old single businesswoman)

4.4 Facilitators to cervical cancer screening

Despite reporting the above cervical cancer screening bottlenecks, the study participants also reported that there were some facilitators to cervical cancer screening already in place, namely availability of screening services, availability and affordability of free drugs, publicizing the availability of free services and linkages and referrals to screening services.

4.4.1. Availability of screening services

The study participants reported that they knew about established cervical cancer screening centres in place including Nsambya hospital, which was the location of this study and Mulago national referral hospital.

R22: “..there should be services accessed to the communities taking services nearer to them for example it is only referral hospitals where they can screen for cancer but If services were taken down up to health centres, so that cancer screening is nearer to the people even the rural woman can be able to walk to the healthy facility and get that service” (52 year old married nurse)

4.4.2 Availability and affordability of cervical cancer drugs

Most of the study participants reported the need for cervical cancer drugs to be available and affordable to those tested positive for it.

R22: “the government should try to avail free drugs for cervical cancer. Other than that women will still not screen” (52 year old nurse)

R15: “They should also look for medicine, if the medicine is there women will then come and test as long as they are assured that after they are found with the disease there is hope of treatment. No one wants to die fast, I know women would come” (35 year old self-employed tailor)

4.4.3 Publicizing free screening services

One of the facilitating factors to cervical cancer screening the study participants reported was publicizing the availability of cervical cancer screening services. The study participants reported that they had heard, watched and read cervical cancer screening advertisements over the radio, television and in the newspapers. The women argued that by publicising cervical cancer screening services through the media, many people and women in particular became informed about the availability of cervical cancer screening.

R8: “The campaign to screen for cervical cancer should be taken to communities, you know it is not easy for someone to go to hospital and check when you are not even sick. Another thing, men should also be educated so that they can encourage their wives to come and check” (26 year old married tailor)

R16: “They should make public gatherings at village level, community and gather women and tell them about cervical cancer and the importance of cervical cancer screening” (31 year old married primary teacher)

4.4.4 Linkages and referrals to screening services

Another reported facilitator of cervical cancer screening services was the presence of a referral system in the national health care system which was linking suspected cervical cancer patients to higher health care providing services centres. The study participants explained that lower health care providing services should provide clear pathways to screen for cervical cancer and refer the suspected cases to higher health care providing centres.

R20: “...health care workers in the whole hospital must be sensitized and must be knowledgeable. Leave alone those working in ANC but it should be even those working in paediatric ward. When you see that this woman has heard a baby and she is here admitted talk to her... that have you heard cervical cancer screening? If not can we have it done since it is within the facility? Also the facility can extend these services to the community” (34 year old married nurse)

R1: “if every woman goes to hospital whether you have gone to test for malaria, whether it is ANC or any other disease the health workers should make sure that you are screened for cervical cancer” (45 year old widowed tailor)

4.5 Summary

This chapter has outlined the main findings of the study including barriers and facilitating factors to cervical cancer screening uptake. The barriers were related to knowledge and awareness of cervical cancer screening, individual and family and health system factors. Knowledge, availability and affordability of services were seen as major facilitating factors to cervical cancer screening.



CHAPTER 5: DISCUSSION

This chapter is a discussion of the key findings of the study mainly the knowledge and awareness about cervical cancer, barriers and facilitating factors to cervical cancer screening.

The aim of this study was to explore cervical cancer awareness, perceptions about cervical cancer screening and factors to increase uptake of cervical cancer screening among women accessing health services at Nsambya Hospital in Kampala, Uganda.

Studies done in the past have looked at barriers to cervical cancer screening among rural women (Hoque, Ibekwe & Ntuli-Ngcobo, 2009; Fort *et al.*, 2011) and among health workers (Mutuyaba *et al.*, 2006). The contribution of such research in providing evidence about cervical cancer knowledge and screening cannot be underestimated.

5.1 Knowledge and awareness about cervical cancer

In this study, many of the participants lacked knowledge about cervical cancer and thought it was the same as uterine cancer. Consequently, they had limited understanding of the signs and symptoms and risk factors of the disease. Lack of knowledge among women about cervical cancer has been cited in other studies (Gatune and Nyamongo, 2005; Mutuyaba *et al.*, 2007; Path, 2010; Fort *et al.*, 2011).

In terms of severity, most often the participants reported that any form of cancer was a death sentence and felt that it was worse than HIV. Similarly, findings from studies in Botswana and Ethiopia revealed that while knowledge was low, once the symptoms were explained many women perceived cervical cancer to be very severe (Hoque, Ibekwe & Ntuli-Ngcobo, 2009; Birhanu *et al.*, 2012).

5.2 Barriers to cervical cancer screening

Overall, this study revealed that many of the women had never screened for cervical cancer. This can be attributed to the low knowledge and uptake of cervical cancer screening. There were four sub-themes that emerged under this category and these were individual factors, social structures, affordability and health service barriers.

5.2.1 Individual factors

5.2.1.1 Fear of positive results

Overall, most women reported that they had not screened for cervical cancer because they feared a positive cervical cancer screening test. This was commonly reported by housewives confirming previous findings that unemployed women are less likely to participate in cervical

cancer screening (ACCP, 2004; Bradly *et al.*, 2004; Kaku *et al.*, 2008; Satija, 2009; WHO, 2010). Other authors have found similar results in other settings on women's fear of positive results (PATH, 2004; Gatune and Nyamongo, 2005; Wall *et al.*, 2010). Other studies have found that women had fear of receiving abnormal screening results because of anxiety associated with such results (Fylan, cited in Nakalevu, 2009; Drolet *et al.*, 2012). The women claimed that abnormal results would have severe effect on day to day functioning leading to depressed mood, decreased libido and feeling of less attractive, tarnished, defiled or contaminated and dirty feelings. Studies have shown the importance of allaying women's fears about cervical cancer while empowering them to act to prevent it (Amosuka, 2003; Ndikom and Ofi, 2011). So whilst the women's concerns are genuine, it appears the ability to succeed in increasing cervical cancer screening depends largely on communicating the right information in a respectful manner.

5.2.1.2 Busy work schedules/Time

Many of the respondents both in formal and informal employment stated that their busy schedules and work commitments were barriers to cervical cancer screening. They needed to secure their jobs and customers by being present at all times and this conflicted with the screening times. This concurs with other findings that suggest that women cannot forego work and income to seek health services (Fylan, 1998; Goldie *et al.*, 2005; Fort *et al.*, 2011). This implies that it would be better if women could find convenient times for them to be screened or services could be taken closer to the women to reduce the burden of women missing their income as a result of seeking cervical cancer screening services.

5.2.1.3 Absence of pain

Respondents felt that the absence of pain in the early stages of cervical cancer was a deterrent to screening since this did not give them motivation to seek health care early enough. Similarly a study in rural Malawi and Uganda revealed that women would only seek cervical cancer screening services if they developed signs and symptoms (Katahoire *et al.*, 2008; Fort *et al.*, 2011). This indicates the need for women to be educated so that they can improve their health seeking behaviour so that they can seek care regardless of whether symptoms are present or absent.

5.2.1.4 Perceived susceptibility

The findings show that many women consider themselves to be at high risk of developing cervical cancer as a result of being in the sexually active age bracket of 25-45 where they

were still capable of giving birth. Some of the women also regarded themselves to be at high risk due to their partners' unfaithfulness through having multiple sex partners something they felt was beyond their control. Interestingly, many of the respondents equated cervical cancer to sexually transmitted infections. This is in contrast to findings by Fort *et al.* (2011) that found that women in rural Malawi perceived themselves to be at low risk of getting cervical cancer possibly due to the reported low knowledge about cervical cancer.

5.2.1.5 Willingness and determination to screen

While only a few of the women had actually screened for cervical cancer, all the women expressed their willingness to screen noting that it helped to improve early diagnosis. Other studies in Nigeria, South Africa and Tanzania showed that the willingness to be screened for cervical cancer was high (van Schalkwyk, Maree & Wright, 2008; Kahesa *et al.*, 2012; Ezechi *et al.*, 2013). However, some of the women maintained that cervical cancer had no cure and that cervical cancer diagnosis meant death. In contrast, while the study in Malawi found that some women had a fatalistic view of cervical cancer, some of them had a lot of trust and faith in medicine with high hopes that they would be cured (Fort *et al.*, 2011).

5.2.2 Social structures

5.2.2.1 Male partner support

In this study, spousal support mainly financial and permission to seek screening services were considered to be very important to women's ability to access services. These findings affirm with other previous studies (Fylan, 1998; Denny *et al.*, 2006), the subservient role of women in the cultural context implies that women cannot make independent decisions about their own health. Other authors have also highlighted the importance of male partner support in cervical cancer screening counselling to increase the appreciation of the importance of cervical cancer screening (Mutuyaba, 2007; Ndikom and Ofi, 2011). In other studies done in South Africa report women who did not have partners were unlikely to take part in screening (Bradley *et al.*, 2004; WHO, 2010) and this highlights the importance of male partner support in encouraging cervical cancer screening uptake.

5.2.2.2 Family support

Family support was considered to be very important most especially by the unmarried women and was considered a second option by the married women. Similarly, a study by Barros and Lopez (2007) found that basic family support was important in helping women to face cervical cancer. However, some of the women reported that this support would not be available for them at all due to their sole breadwinner status. This shows that where women

find themselves as breadwinners, they tend to have competing priorities reducing their ability to rely on others for family support to make important health decisions.

5.2.3 Affordability

5.2.3.1 Transport and distance

Some of the women felt that transport and distance hindered them from accessing services as they lived very far from the hospital providing the service. According to Kagumire (2011) and Mutyaba (2007), a big number of women in Uganda are too poor to afford transport costs to the regional referral hospitals which provide cervical cancer screening services. However, many of the women in this study cited that they lived in the hospital area and therefore these were not barriers. However, the long waiting times and time taken off work increases the opportunity costs of seeking cervical cancer screening services making women weary of going for any follow-up appointments (Goldie *et al.*, 2005).

5.2.3.2 Unofficial payments

Some of the women cited informal payments charged by health workers as a barrier to the cervical cancer screening tests and the health workers. This reflects the lack of trust that women have towards the Ugandan health sector where informal payments are deeply-rooted in the minds of health workers. In a study carried out in Ugandan villages, it was found that although user fees were abolished, bribes are important if one would like medical attention from health workers in the public sector (Xu *et al.*, 2006; Hunt, 2007).

5.2.4 Health services barriers

5.2.4.1 Health education

Many of the women reported that they had not screened for cervical cancer because they were not aware of the importance. Some were only introduced to cervical cancer screening when they turned up to immunise their children revealing the selective offering of cervical cancer screening services. Health education can help to increase knowledge about cervical cancer as well as encourage the adoption of cervical cancer screening. Health education can be offered to women accessing different kinds of services in hospitals. A study conducted in Nigeria showed that 84% of those women who knew about cervical cancer had heard of it from a health worker (Mbamara *et al.*, 2011) suggesting that health workers have a crucial role to play in educating women about cervical cancer. In some cultures including Uganda it has been reported that reproductive health issues are normally shrouded in secrecy and women are not at liberty to discuss such issues freely (Katahoire *et al.*, 2008) thus impacting

negatively on their ability to gain knowledge and seek cervical cancer screening services even when symptoms are present. However, it is believed that culture is not a major barrier if women's knowledge and awareness is very high (Nakalevu, 2009).

5.2.4.2 Unfriendly procedure of screening

a. Young health workers

The women reported that they were deterred from cervical cancer screening because the medical personnel doing the screening were young enough to be their children. The women referred to these young health workers as 'children'. Similarly, Mutyaba (2009) reported that some women refused to be examined by young doctors even if they were female reflecting the unacceptability of a huge age and sex gap between the women and the health providers. In contrast, Steven *et al.* (2004) found that some women preferred female doctors as opposed to male doctors.

b. Posture during screening procedure

The study participants reported that they were not comfortable with the cervical cancer screening procedure and posture. They felt that they were being put in the awkward position similar to that of giving birth and the health workers touched their genitals. Ndikom and Ofi (2011) suggest that the health worker should communicate with the woman before, during and after the procedure so that any pain and discomfort is anticipated. Similarly, a study in Canada also revealed that fear of the procedure and discomfort were major barriers to cervical cancer screening (Steven *et al.*, 2004). This feeling of embarrassment has been also reported in other studies (Kitchener *et al.*, 2006; Cann, 2008). The implication is that women need to be educated constantly so that they are less embarrassed with the screening procedure.

5.2.4.3 Inadequate staffing levels and long waiting times

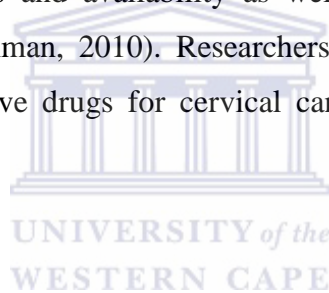
While many of the respondents reportedly identified the hospitals where they could possibly access care, they were deterred from seeking services due to long queues that required them to spend a long time waiting to be attended to and this was attributed to low staffing level. Similarly, a study in Kenya revealed that women were unlikely to access screening services if they felt the clinics were busy and the health workers were overburdened with other general duties already (ACCP, 2004).

5.2.4.4 Staff attitude and motivation

The study participants reported that female health workers were often very rude to them and this impacted on their ability to seek care. This has also been reported in Gatune and Nyamongo (2005) in rural Kenya that when health workers showed insensitivity to women's needs and did not communicate well, women preferred not to be screened. In addition, a review by Ndikom and Ofi (2011) highlighted the importance of good communication skills by health workers on issues surrounding cervical cancer counselling giving due respect and confidentiality to women's concerns and feelings.

5.2.4.5 Unavailability of drugs

The lack of drugs and cure was seen as a major barrier to cervical cancer screening citing that there would be no need of finding out a positive diagnosis and yet nothing could be done to alleviate pain and suffering. This was aggravated by reports that cancer treatment in general is very expensive and cervical cancer was no exception. Chemotherapy drugs are difficult to administer due to variable costs and availability as well as human resources for health challenges (Varughese and Richman, 2010). Researchers suggest that in resource limited settings, inexpensive and effective drugs for cervical cancer should be readily accessible (Basile *et al.*, 2006).



5.3 Facilitating factors to cervical cancer screening

The study also identified the enabling factors to increased uptake of cervical cancer screening services and these included availability of screening services, availability and affordability of cervical cancer drugs, publicizing free screening services and linkages and referrals to screening services.

5.3.1 Availability of screening services

The availability of cervical cancer screening services was seen as a motivating factor to screen for cervical cancer. The study participants reported that there were established cervical cancer screening centres in place at Nsambya hospital, which was the location of this study and Mulago national referral hospital. Organized screening programs have been found to be effective in reducing cervical cancer mortality (Hakama *et al.*, 2008; Wabinga *et al.*, 2000; Mutyaba *et al.*, 2007). Kagumire (2011) and Earker (2001) emphasize that it is crucial for organised screening programs to take services nearer in the communities if uptake of cervical cancer screening is to improve.

5.3.2 Availability and affordability of cervical cancer drugs

Most of the study participants reported the need for cervical cancer drugs citing that HIV testing coverage was now high due to the availability of anti-retroviral therapy. They did not see the point in screening if there are no medicines to prevent progression of cervical cancer disease as this would just increase their anxiety and worry. This is in line with Anorlu (2008) who suggests that cervical cancer must be given similar attention as has been accorded to HIV, TB and malaria.

5.3.3 Publicizing free screening services

The study participants reported that publicizing the availability of cervical cancer screening services would improve the knowledge and awareness of women and increase uptake of cervical cancer screening services. However, many limited resource settings cannot sustain expensive models of cervical cancer screening at regular intervals (Sankaranayanan *et al.*, 2001).

5.3.4 Linkages and referrals to screening services

The presence of clear referral systems from the lower level health units in the decentralized health system to the national level was cited as an important facilitator of cervical cancer screening. In addition, participants noted the importance of integration of cervical cancer screening with other services so that there would be no missed opportunity as opposed to the current situation where this service is reportedly offered only to women attending ANC. This was similar to findings in Malawi where women felt it was necessary for them to be offered cervical cancer screening services when they accessed other services in the hospital (Fort *et al.*, 2011). Other studies have shown that HIV infection is greatly associated with cervical cancer (Asimwe, 2006) pointing to the need for establishing linkages and integration of cervical cancer screening services in HIV care and treatment services.

5.4 Summary

This discussion chapter reveals that several factors impede access to cervical cancer screening among women including individual and health system level factors. The results of the study show that cervical cancer screening is not readily accessible to women. Furthermore, where services are available they are not publicized and are only selectively provided to women mostly attending ANC leaving out the vast majority of women. The lack of integration and prioritization of cervical cancer screening leads to low knowledge and uptake by women.

CHAPTER 6: CONCLUSION AND RECOMMENDATIONS

6.1 Conclusion

The aim of the study was to explore the knowledge on cervical cancer, the perceptions and attitudes towards screening for cervical cancer among women accessing Maternal Child Health Services in Nsambya hospital Kampala.

The conclusion of this study is based on three broad themes, namely; knowledge and awareness about cervical cancer, barriers and facilitating factors to cervical cancer screening. It is concluded that most women have limited awareness about cervical cancer and are unable to differentiate with other cancers such as breast cancer and uterine cancer. Although a few women perceive screening as important for cervical cancer prevention, some associate screening with pain, and an embarrassing procedure, while others are hindered from screening due to fear of the outcome (positive results). The main socio economic factors that influence uptake to cervical cancer screening are male partner support and busy work schedules while culture does not have any influence on uptake of cervical cancer screening. The main facilitating factors to cervical cancer screening are availability of screening services, availability and affordability of cervical cancer drugs and community health education about cervical cancer screening.

The results of this study will contribute to guidance of policy makers in designing and formulating health systems especially cervical cancer related health policies.

The study presents the following recommendations based on the findings of this study:

- Increase the health workers staffing levels so that the long queues are reduced and women are attended to promptly.
- The public should be sensitized about the existence and severity of cervical cancer and the importance of early and routine screening.
- Educate women about screening to reduce the negative attitude of embarrassment attached to the procedure.
- Information on the availability of cervical cancer treatment should be available to the public to reduce anxiety associated with the outcome of cervical cancer screening.

- Cervical cancer screening services should be integrated with other health services so that women accessing various health services can also be able to access cervical cancer information and screening services.
- It is important to promote spouse involvement in cervical cancer screening since men are decision makers in most homes and they provide financial support.
- Organized cervical cancer screening services should be taken closer to the communities in order to reduce the costs women have to bear associated with transportation and distance.
- Health workers should be trained in communication skills so that they can be courteous when relating to clients including women seeking cervical cancer screening services.



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APPENDICES

Appendix 1: Ethical Approval University of the Western Cape



UNIVERSITY of the
WESTERN CAPE

OFFICE OF THE DEAN DEPARTMENT OF RESEARCH DEVELOPMENT

01 November 2012

To Whom It May Concern

I hereby certify that the Senate Research Committee of the University of the Western Cape has approved the methodology and ethics of the following research project by:
Ms L Atuhaire (School of Public Health)

Research Project: Challenges and strategies to increase uptake of cervical cancer screening services among women seeking care for maternal child health services in Kampala, Uganda.

Registration no: 12/9/22

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.

The Committee must be informed of any serious adverse event and/or termination of the study.

*Ms Patricia Josias
Research Ethics Committee Officer
University of the Western Cape*

Private Bag X17, Bellville 7535, South Africa
T: +27 21 959 2988/2948 . F: +27 21 959 3170
E: pjosias@uwc.ac.za
www.uwc.ac.za

A place of quality,
a place to grow, from hope
to action through knowledge

Appendix 2: Ethical Approval Uganda National Council of Science and Technology



Uganda National Council for Science and Technology
(Established by Act of Parliament of the Republic of Uganda)

Our Ref: SS 3001

21st November 2012

Ms. Lydia Atuhaire
P.O Box 37514
Kampala

Dear Ms. Atuhaire,

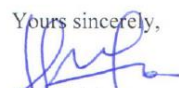
RE: RESEARCH PROJECT, "CHALLENGES AND STRATEGIES TO INCREASE UPTAKE OF CERVICAL CANCER SCREENING SERVICES AMONG WOMEN SEEKING MATERNAL AND CHILD HEALTH SERVICES IN KAMPALA, UGANDA"

This is to inform you that the Uganda National Council for Science and Technology (UNCST) approved the above research proposal on **13th November 2012**. The approval will expire on **13th November 2013**. If it is necessary to continue with the research beyond the expiry date, a request for continuation should be made in writing to the Executive Secretary, UNCST.

Any problems of a serious nature related to the execution of your research project should be brought to the attention of the UNCST, and any changes to the research protocol should not be implemented without UNCST's approval except when necessary to eliminate apparent immediate hazards to the research participant(s).

This letter also serves as proof of UNCST approval and as a reminder for you to submit to UNCST timely progress reports and a final report on completion of the research project.

Yours sincerely,


Jane Nabbuto
for: Executive Secretary

UGANDA NATIONAL COUNCIL FOR SCIENCE AND TECHNOLOGY

LOCATION/CORRESPONDENCE

*Plot 6 Kimera Road, Ntinda
P. O. Box 6884
KAMPALA, UGANDA*

COMMUNICATION

TEL: (256) 414 705500, (256) 312 314800
FAX: (256) 414-234579
EMAIL: inf@unest.go.ug
WEBSITE: <http://www.unest.go.ug>

Appendix 3: INTERVIEW SCHEDULE

UNIVERSITY OF THE WESTERN CAPE MPH Mini- Thesis Research

Interview Guide:

Participant No: _____

1- To start with I would just like to get some general demographic information from you, is that ok?

Can you tell me a bit about yourself?

Probe: Age, marital status, employment

2- Could you explain to me what you know about cervical cancer?

Probe: What do you know about cancer?

Probe: What is it that you have heard other people say about cervical cancer?

Probe: What are the risk factors for cervical cancer?

Probe: How common do you think cervical cancer is?

Probe: Can you tell me how cervical cancer screening is done for women?

Probe: What age are women most likely to develop cervical cancer

Probe: Do you regard cervical cancer to be a major health issue for women?

Probe: How do women discover that they have cervical cancer?

Probe: Can you please explain how cervical cancer can be prevented?

Probe: How accurate do you think the screening is, to detect abnormal cells

Probe: How often does a doctor recommend for women to screen themselves for cervical cancer?

Probe: The factors which increase the risk of developing cervical cancer

Probe: How can cervical cancer get cured

Probe: Could you explain to me how you got this information?

Probe: Do you feel that the information was easily accessible?

3-Could you tell me what you think your risk of cervical cancer is?

Probe: Is this something that worries you?

Probe: What have you based these perceptions on?

Probe: How do your perceptions influence or impact on you or your lifestyle?

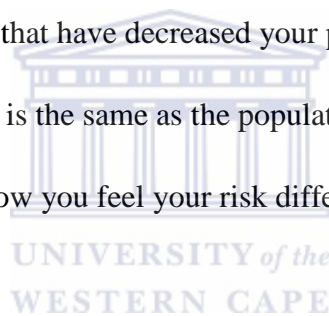
4-What factors or experiences do you feel influence your perception of risk?

Probe: Please explain the factors that you feel have increased your perception of risk

Probe: Please explain the factors that have decreased your perception of risk.

Probe: Do you feel that your risk is the same as the population risk for other cancers?

Probe: Please explain why and how you feel your risk differs from the population risk?



5-Do you feel that there is adequate health information for women in regards to cervical cancer?

Probe: If yes, why do you think this?

Probe: If no, what would you recommend or like to see implemented as a more effective approach?

6-Attitude and beliefs on cervical cancer and screening

i- Susceptibility and severity

Probe: How severe do you think the problem of cervical cancer is in Uganda?

Probe: How would you judge your risk of developing cervical cancer?

Probe: What do you think is the chance of cure of cervical cancer?

Probe: Please explain how difficult you think it is, to get the treatment of cervical cancer?

ii- Benefits

Probe: Do you think it is beneficial to have a cervical cancer screening? How beneficial is it?

Probe: Can you explain to me how cervical cancer screening can give you satisfaction?

Probe: How important is it to have regular cervical cancer screening?

Probe: How important is detecting precancerous cells before onset of symptoms?

8- Barriers-

Probe: What factors could facilitate or hinder women from accessing cervical cancer screening services at this hospital?

i-Emotional/pain

Probe: Can you explain to me how the procedure of cervical cancer screening is done?

Probe: Please explain to me how you feel about the procedure of cervical cancer screening?

Probe: Could you please comment of other gynecology health care procedures?

ii- Economic

Probe: Can you please explain to me how difficult it is for you to take time off and have a cervical cancer screening?

Probe: If distance is too long for them to get to the health centre where there is screening for cervical cancer?

Probe: If they feel it is necessary to visit the clinic for screening even when they are no signs and symptoms?

Probe: How important it is to visit a cervical cancer screening clinic even when they don't even have any other illness?

Probe: How expensive it is to have a cervical cancer screening?

iii- Feeling of Anxiety

Probe: Could you be having any fears on having a cervical cancer screening?

Probe: How they would feel if you they were found to have early signs of cervical cancer?

Probe: If you took a cervical cancer screening, how would you prefer to receive the result of your screening test?

Probe: Whom they would prefer to conduct their cervical cancer screening test?

Probe: What they would do if their results showed that they had some abnormal cells?

9- Recommendations

Probe: What do you think could be done in order to attract more women to screen for cervical cancer at this hospital?

Probe: How would you like the quality of services at Nsambya hospital to be like so that you would be interested in seeking cervical cancer screening services?

10-SUMMARY (Interviewer summarizes the discussion)

How well does this summary capture what you said today?

Is there anything else we should have covered but didn't?

Of all the cervical cancer issues we discussed, which is most important to you?

Can you explain to me what best describes how you feel about the topic we discussed today?

DESCRIPTION OF THE STUDY AND YOUR INVOLVEMENT

The study will include interviews with women between the age of 18-64 years who access maternal child health care in Nsambya hospital's various clinics specifically attending antenatal care, postnatal care, young child clinic, outpatient department and HIV clinic. You will be requested to have an open discussion with the interviewer about your general knowledge on cervical cancer and screening for cervical cancer.

CONFIDENTIALITY

Your name will be kept confidential at all times and I shall keep all records of your participation, including a signed consent form which I will need from you should you agree to participate in the study, locked away at all times and will be destroyed after the study is completed.

VOLUNTARY PARTICIPATION AND WITHDRAWAL

Your participation in this study is entirely up to you as you may not participate if you so decide. However, if you choose to participate, you may withdraw at anytime or may choose not to answer particular questions that may be asked. Please feel free to inform me if there is anything that you would prefer not to discuss. If you decide not to participate or withdraw from the research at any point, please be assured that you will not be adversely affected in any way.

BENEFITS AND COSTS

You may not get any immediate benefit from this study. However, it is hoped that the information and the suggestions gathered from this study will act as a guide to inform policy-making by the relevant authorities and the overall benefit of all concerned. The only costs that accrue to you for participating in this study is the time you spend in the interviews.

INFORMED CONSENT

Your signed consent to participate in this study is required before I proceed to interview you. I have included the consent form with this information sheet so that you will be able to review the consent form and then decide whether you would like to participate in this study or not.

QUESTIONS

Should you have further questions or wish to know more, I can be contacted as follows:

Lydia Atuhaire

P.O Box 2446, Kampala

Telephone: 0782 141265

I am accountable to my supervisor:

Should you have any questions regarding this study or wish to report any problems you have experienced related to the study, please contact the study coordinator:

Study Coordinator's Name: Dr. Brian Van Wyk

University of the Western Cape

Private Bag X17, Belville 7535

Telephone: +27 21 959 2173/ 082 804 9055

Email: bvanwyk@uwc.ac.za



If you have any problems with this research, you can contact:

Dean: Faculty of Community and Health Sciences

Professor Hester Klopper

University of the Western Cape

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Email: hklopper@uwc.ac.za