

OSLOMET

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“They take the whole uterus out of you and put it on the table. They examine it from the table and after they put it back”

A qualitative study of women’s and health care workers’ knowledge, beliefs and attitudes towards cervical cancer and cervical cancer screening in Fort Portal, Uganda.

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Abstract

Cervical cancer is a disease that is emphasised as one of the gravest threats to women's life. In low and middle-income countries, it is the cancer type that kills most women and girls. The World Health Organisation situates cervical cancer as a public health problem and highlights that countries need to put focus on strategies towards eliminating cervical cancer as a global burden of disease. In alignment with this, the Ugandan MoH emphasise comprehensive screening services to control and prevent the disease throughout the country. However, a report shows that 80 % of women in Uganda only seek professional help when cervical cancer is in an advanced stage. This qualitative study is an exploration of women's and health workers' knowledge, attitudes and beliefs towards cervical cancer and screening in Fort Portal, Uganda. Through in-depth interviews and observations this study explores if these factors influence choices and motivations to present for cervical cancer screening. It suggests that health behaviours cannot be separated from national and global policies; hence this study facilitates a holistic perspective. Based on findings this study reveals that local understandings, beliefs and attitudes as well as societal, historical, economic and political dynamics are critical factors in order to succeed when implementing health services. By providing insights into women's and health workers' knowledge, beliefs and attitudes towards cervical cancer screening, and shedding light on access- and awareness in Uganda generally and Fort Portal particularly, this study can contribute to more knowledge on how to implement cervical cancer services that are sensitive to local needs and hence may encourage more women to come forward for screening.

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List of abbreviations

IMF	International Monetary Found
MoH	Ministry of Health
KfC	Knowledge for Change
RHU	Reproductive Health Uganda
SAP	Structural Adjustment Program
SRH	Sexual and Reproductive Health
UCI	Ugandan Cancer Institute
UN	United Nations
VHT	Village Health Team
WHO	World Health Organisation

Introduction

Cervical cancer and cervical cancer screening in Uganda

In April 2020, the World Health Organisation (WHO), situated cervical cancer as a global public health problem as it is one of the gravest threats to women's lives¹. It is the fourth most common cancer type worldwide, but in low and middle-income countries it is the leading cause of cancer deaths among women. In fact, 85 % of those affected are women living in the world's poorest countries, including Uganda (WHO, 2020, p. 5). Uganda is classified as a low income-country and has a population of 44 million people (World bank, 2019). It was my first meeting with the severity of cancer disease in a low-income setting that sparked my interest on women's health and medical anthropology. As a nursing student in Tanzania I was introduced to women with immense cancer tumours, that due to barriers and circumstances such as socioeconomic status, place of residence as well as beliefs and attitudes had delayed seeking professional help. Additionally, I was introduced to a public health sector that failed in providing sufficient cancer services. Since then, I have understood the importance of local understandings when it comes to health care. In fact, they may be decisive when it comes to utilization of health services (Helman, 2007).

In January 2020 I travelled to Fort Portal, Uganda, as I was given the opportunity to conduct a study with the organisation 'Knowledge for Change'(KfC), hosted by Salford University, England. KfC is an organisation based on charity that got established in 2012 and is working to improve health care services in Uganda. KfC has, among several projects, set up a cervical cancer screening service in Fort Portal based on the "see-and-treat"-approach further discussed in Chapter 2, where women can be screened for free. However, they have met challenges with women not showing up. An aim of this study was to gain knowledge that may serve to enhance the use of, and access to, screening services that in the long run is hoped to prevent Ugandan women dying from cervical cancer.

The aim of this study was to access the knowledge, beliefs and attitudes Ugandan women and health workers have about cervical cancer and screening, with focus on issues related to 'myth-debunking', awareness, production of knowledge and the existing policies

¹ In 2018, the prevalence of cervical cancer worldwide was 570 000 and the mortality 311 000. By 2030 it is estimated that the cervical cancer incidence may increase to 700 000 and deaths to 400 000 if measures emphasised by WHO (mentioned in Chapter 2) is not implemented by countries throughout the world, and especially in regions where the disease burden is highest (WHO, 2020).

aimed at encouraging women to come forward for screening. Moreover, I wanted to explore if knowledge, beliefs and attitudes influence choices and motivations to present for cervical cancer screening. Additionally, as people's health problems cannot be separated from their larger economic and political dynamics that can shape and sometimes constrain their choices (Helman, 2007, p. 14), this study endeavours to facilitate a holistic perspective.

The health system in Uganda is influenced by historical factors that influence the use and access to health services today. Briefly outlined, Uganda got independence from British rule in 1962 and the post-colonial years were filled with political and economic upheaval; Misrule of Idi Amin and the global economic recession in the 1970s as well as a brutal civil war in the early 1980s, resulted in a general system failure (Tashobya et al., 2019). The health sector was characterized by insufficient funding, low or no salaries to health workers and permanent shortage of medicines and supplies (ibid, p. 5). In 1986, president Museveni assumed power and several reforms got implemented. The international monetary institutions, such as the World Bank and the International Monetary Fund (IMF), prompted to help countries around the world that faced economic crisis, by providing loans. However, these loans came with conditions that governments had to implement immediately, known as Structural Adjustment Programmes (SAPs) (Swaroop, 2016). Uganda turned to the World Bank and IMF and started implementing SAPs in 1987 (Green, 2010).

SAPs were first and foremost based on neo-liberal market principles, leading to a sharp reduction of the role of government and decentralisation of services in Uganda. The role of the Ugandan government became restricted to policy formulations and technical guidance, and public funding's towards health promotion and prevention of diseases. International donor-programmes increased and private entities such as NGOs and faith-based organisations, became the prominent providers of health care (Kentikelenis, 2017; IMF, 1998). For instance, 75 % of spending on HIV-services in Uganda were in 2016 funded by international donors (Kakaire et al., 2016). Although a decentralisation of services led to decisions-making closer to local needs, health projects often failed due to lack of funding, coordination by the government and having a vertical approach² (Tashobya et al., 2006, p. 5). In light of this and a concern for the overall health status of the population, the Ugandan MoH introduced a health sector strategic plan and sector-wide approaches in 2000 that favoured, among other things, a public-private partnership.

² A vertical approach of health services “implies a selective targeting of specific interventions not fully integrated in health systems” (Msuya, 2005, p. 2).

At this point, a brief introduction to the study setting is pertinent. Fort Portal is a town located in western Uganda and has a population of roughly 50 000 (Ugandan Bureau of Statistics (UBOS), 2014). The economy of the region is mainly based on subsistence agriculture, animal husbandry and commercial fishing in the crater lakes and rivers (Lyons, 2020). There are several national parks close to Fort Portal and with the Rwenzori mountains surrounding the town, it becomes a central stop for tourists. The town homes one public regional hospital, one private and one faith-based hospital, as well multiple, both public and private, health clinics.



Figure 1: Map of The Republic of Uganda (Nasejje, 2013, p. 2).

In Chapter 1 I discuss the methodology I used to approach the topics, my own role as a researcher and the ethical aspects of this study. Chapter 2 provides an outline of cervical cancer and sexual- and reproductive health (SRH) in Uganda, strategies towards eliminating cervical cancer as a public health problem as well as how the health system is organised and functions today. In Chapter 3 and 4, I present my findings from fieldwork. Chapter 3 is concerned with women's and health workers' knowledge, beliefs and attitudes towards cervical cancer and screening. Inspired by Kleinman's concept of three interconnected health sectors, I discuss attitudes towards health care in Uganda and as they relate to cervical cancer and screening in Fort Portal. Chapter 4 builds on the previous chapters and is concerned with how Uganda's governance and health system influence women's access to- and awareness of cervical cancer and screening. The final Chapter is where I make my conclusive remarks and reflect on the significant role NGOs have in providing health care in Uganda today.

Chapter 1

Methodology

In 2019 Oslo Metropolitan University organised a research market where organisations and institutions presented master projects to students. A representative from KfC introduced projects on health care in Uganda. Afterwards I had a chat with them and got the opportunity to ask further questions, which inspired me to apply particularly on the cervical cancer screening project. We had ongoing contact prior to fieldwork, and they provided housing and local guidance in Fort Portal during fieldwork in the time period of January-March 2020. It is hoped that the findings from this study can contribute to KfC's work on cervical cancer and the ongoing screening service in Fort Portal.

1.1 Study design

Qualitative research seeks to understand people's experiences and perspectives (Moen & Middelthon, 2015). In health research, medical anthropologists emphasise the importance of local knowledge as it provides an empirical ground for what is likely to be of concern when it comes to medical interventions (Adams et al., 2014, p. 183). With the objective of studying women's and health workers' understanding of cervical cancer and screening, I found a qualitative research design most appropriate. Inspired by ethnographic approaches in qualitative health research, this project will endeavour to get a better understanding of shared cultural behaviour and attitudes as they relate to illness, disease and health practices. Additionally, it endeavours a holistic perspective, including economic and political factors that influence women's and health workers health behaviours. Hence, I apply theories from critical medical anthropology as the field has a tradition of studying how political and economic powers take part in shaping people's experiences of health and illness (Walker, 1998).

1.2 Data collection

Prior to leaving for fieldwork I planned to conduct semi-structured interviews, focus groups and observations. As Moen & Middelthon (2015, p. 328) point out, one must be flexible in qualitative research, as some methods may work better than others. I soon realised that women in Fort Portal were reluctant towards openly discussing a sensitive topic such as cervical cancer. The balance between providing a setting where people can share experiences

and the potential invasion of privacy, can be subtle. I was motivated by the fact that individual interviews can limit the discomfort when exploring sensitive topics (Elam & Fenton, 2003). Although focus groups have been praised for their practicality and open discussions (Bryman, 2012, p. 503), I decided after careful consideration against it. Focus groups are difficult to organise (Bryman, 2012, p. 517), which is particularly relevant in the context of Fort Portal. Due to the hectic work schedule of health workers and the difficulty in recruiting women, gathering people for focus groups would have been hard to achieve. Accordingly, inspired by the motto “do no harm” I regarded the use of semi-structured interviews and participant observation, to be an appropriate strategy that allowed me to explore women’s and health workers’ health knowledge and health behaviours sufficiently.

1.2.1 Individual interviews

During fieldwork in Fort Portal I conducted 11 interviews with women lasting for 30-45 minutes and 5 interviews with health care workers, lasting for 60-90 minutes. In-depth interviews served to provide insights into women’s and health workers’ own perceptions and beliefs about reproductive health issues and their knowledge about screening. As scholars recommend a semi-structured interview-guide due to its flexibility and openness to incorporate informants’ perspectives (Moen & Middelthon, 2015, p. 343), I developed one prior to interviews that I tried out on my Ugandan female colleagues at KfC. This provided insight into the interview situation and allowed me to adjust and refine the interview-guide as well as providing me with new and wider perspectives and understandings. As cervical cancer may be a sensitive topic, it was essential to make the participants feel safe and at ease (Elam & Fenton, 2003). Hence, I adapted the interview style to each respondent: some were comfortable with me leading the conversation while others preferred to talk more freely. The interviews with both women and health workers were held in what could be described as “a safe and neutral environment”, a place of their own choosing, such as a café or in their homes.

1.2.2 Observations

In contrast to non-participatory observation, participant observation is a method used to gain deeper understandings of shared emotions and behaviours through interacting with people in given situations. It provides insight into emotions that may not be exceedingly expressed through verbal interviews (Moen & Middelthon, 2015, p. 348). By working with KfC, I was given the opportunity to do participant observation by following the health personnel around during their routine activities at clinics/hospital. I did observations of cervical cancer

screening by holding a certain distance and did not participate during the procedure. I did not participate in any medical treatment or processing of personal data, and I did not approach patients' medical records.

Despite limited time and language difference, I managed during my time in Fort Portal to both observe and interact with women and health workers which I believe allowed me to get a deeper understanding of their knowledge, beliefs and attitudes toward cervical cancer and screening and the barriers they face as providers and users in the health care system of Uganda. Using a variety of methods such as observations, interviews and theoretical perspectives, provided me with triangulation and assured validity of this study (Bryman, 2012, p. 392).

1.3 Sampling and recruitment strategies

For this research I have chosen to focus solely on women and female health workers due to three practical reasons; to narrow down the study population, the fact that cervical cancer is relevant to women only as well as most of the health workers within the field of reproductive health are women. My focus on both women and health workers have contributed to a broader understanding of attitudes to- and knowledge and beliefs of cervical cancer. Additionally, this have facilitated a comparative perspective that can provide insights into issues concerning access to and rationales behind choices to attend/not attend cervical cancer services. During my fieldwork the process of recruitment was slow at first as it took time to immerse myself in the field and to get acquainted with new colleagues, the organisation and as best I could, the culture. This is what Pole & Hillyard (2017) call "field relations". Balancing the importance of collecting data in time and establish field relations is essential. In fact, taking time to establish a good relationship with colleagues at KfC, as to make sure they understood my purpose for being there, laid the foundation for getting included and to organise my fieldwork.

1.3.1 Women

Prior to fieldwork, a tentative sample size had been set to 6-8 in-depth interviews. However, due to varied quality and length of interviews, I ended up with 11 individual interviews of women aged 20-49 years. This age limit was set in accordance with the eligible age of screening services. KfC assisted in recruiting informants by purposive sampling of a heterogeneous group. This was motivated by the desire to get a broader understanding of topics embedded in my research questions (Creswell & Poth, 2018). During fieldwork I was engaged in work on a door-to-door survey to establish how many eligible women in Fort

Portal had attended screening. Through this work, I met women who fit my criteria and who were interested in being interviewed. The interviews with women provided valuable insights into their knowledge of- and beliefs and attitudes to cervical cancer screening. At times I remained at their house, other times I schedule to come back or to meet at a neutral place in town to do interviews. I also interviewed women after church and in-between breaks at the market. These were women recruited on basis of connections through KfC.

1.3.2 Health care workers

Through working with KfC I got to meet several health care workers. I used the snowball-technique (Bryman, 2012) to interview health personnel working at clinics, NGOs and at the regional referral hospital in Fort Portal: colleagues at KfC suggested as well as put me in contact with other health personnel. In total five in-depth interviews with health workers provided me with rich saturated data.

1.3.3 Transferability

Sampling is closely connected to transferability or validity, such as whether and to what degree the study can be generalized across social settings (Malterud, 2001, p. 484). Although this study includes a heterogeneous group of women living in Fort Portal, it needs to be emphasised that women residing in other areas of Uganda, may have different understandings of, as well as access to, cervical cancer services. This study has a holistic angle that looks at health issues in connection to underlying societal, cultural, political and economic factors (Bryman 2012, p. 392) and thus findings from this study may for instance be transferable to other settings where poor governance, inequalities and health reforms do influence the health care sector and use of health services.

1.4 The analysis

The analysis is a process that goes on from the very beginning to the end of a research, and act as an indicator if the social research concept has been followed properly (Moen & Middelthon, 2015, p. 356). I transcribed most of the empirical data during fieldwork, but the organisation, typing up fieldnotes and making sense of the data, happened after I returned from fieldwork, using thematic analysis. I reviewed the transcriptions and started the continuously process of coding, recoding and rearranging codes. During this process, themes and sub-themes started to emerge frequently. I had some of the themes, such as “Knowledge”, “Beliefs” and “Attitudes”, already in mind based on literature review prior to fieldwork and

they emerged as prominent in my empirical data as well. Additionally, sub-themes such as “Awareness”, “Access”, “Health information” and “Religion”, came up as relevant themes in the interviews, during fieldwork more generally and during the process of coding, and altogether ended up with creating the foundation for the thematic chapters.

1.5 Reflexivity

The researcher in a qualitative inquiry do determine what there is to be investigated, and which angle, methods and findings are relevant. Hence, it is essential that the researcher is aware of and can identify how preconceptions, background, motives and values influence the research process. This is known as “reflexivity” or as Malterud (2001) describes as “the knower’s mirror” (p. 484). Reflexivity is connected to credibility, that is, whether the researcher have acted in good faith and findings are trustworthy. It is important to address that my professional background as a nurse, provided me with motivations and pre-study knowledge about the significance of cervical cancer screening. I was aware that my low-expectations and beliefs towards the health system and cultural constrains regarding access and awareness needed to be addressed and thoroughly reflected upon to avoid any risk of bias. In light of this, I attempted to have an open mind during fieldwork and used fieldnotes for personal reflections.

However, my professional background and my connections to KfC, shaped how I was received by informants and health workers and positioned me in a role as “knows what is right”. In fact, health workers wanted me to practice nursing and did not acknowledge my role as a researcher to begin with. As cervical cancer screening is a rather private medical procedure, this misunderstanding lead to important ethical considerations. By making my intentions clear and by position my-self as a novice researcher eager to learn, I manage to facilitate successful interviews and observations. Scheduling interviews outside of health facilities and not fully dress as a health worker at clinics, also helped me to position myself in the right field.

1.6 Ethical considerations

In qualitative studies, the in-depth nature and investigations of people’s experiences make ethical considerations essential (Bryman, 2012). All choices made before, during and after the research for this study have been made in line with the principle “no harm”. Prior to the interviews the participants received an informed consent sheet about my study. The informed consent sheet included information regarding the purpose of the research, what kind of

questions would be asked, how and where the data collected would be stored and for how long data would be kept for. It was before interviews thoroughly reviewed orally to be sure the participants understood the purpose of the project, my own role as well as rights to decline or withdraw from the study. The participants signed the consent sheet after receiving the information about my study (see Appendix 3 and 4). Participants thus had the choice to participate or to decline; they were under no obligation to answer any question if they did not want to. An interview is a situation that is highly voluntary, and I strived towards creating a setting that was safe, friendly and comprehensible, such as carefully considering my use of language and vocabulary (Moen & Middelthon, 2015). Since English is a shared language spoken in Fort Portal, forms and interviews were provided in English.

All data resulting from in-depth interviews were audio-recorded with a recording device. Recordings were immediately uploaded at the end of the day and deleted from the portable device. Field notes was locked in a closet and data was stored on a password and username protected USB-memory stick. During transcription all the participants were given a pseudonym and personal information was fully de-identified. Any information that potentially could have been used to later identify an individual was removed, along with names of the specific communities visited.

Although observations as part of my research were meant solely to facilitate a broader understanding of health sectors and rationales behind the use of cervical cancer services, it did involve me being present at hospitals/clinics and intervene with patients. I applied for ethical clearance through the Norwegian Centre for Research Data which was granted. Additionally, through KfC, I received ethical clearance for doing health research in Fort Portal. It became apparent through my fieldwork that doing research in a hospital setting and in a country with unfamiliar systems, hierarchies and culture, is challenging and takes time. Previous experiences such as colonialism, foreigners prying or bad reputation in the media, may underline cautions towards you and your research, and even see you as a threat. These were issues that I was conscious of throughout my fieldwork. By continuously being aware of my role and doing interviews outside of hospital settings, I believe I was able to avoid any potential harm.

Chapter 2

Situating cervical cancer and cervical cancer screening in Uganda

WHO (2020, p. 5) emphasises that countries need to implement national screening- and vaccination services that are delivered through platforms that are sensitive and respectful to women's needs as well as cultural, societal and economic barriers to be able to successfully implement them and to eliminate cervical cancer as a public health problem. Likewise, a holistic perspective is highlighted by critical medical anthropologies when it comes to health programmes, that relates individual behaviour with macro influences such as economic and political inequalities. This chapter is inspired by this perspective: In addition to displaying cervical cancer disease, I will shed light on the context in which health services such as cervical cancer is carried out in Uganda - a context that amongst other things is characterised by poor governance and weak public health care.

2.1 Cervical cancer and cervical cancer screening services

Cervical cancer is one of the few cancer diseases that is preventable, and studies have illustrated that comprehensive approaches such as screening to control and eliminate the disease are feasible (Engelsen, 2020). In April 2020, WHO forwarded a global strategy towards eliminating cervical cancer as a public health problem, in alignment with the 2030 agenda for UNs Sustainable Development Goals (SDGs)³. The global strategy has three main pillars: To prevent, screen and treat. It is a comprehensive approach with specific targets to be reached by 2030: A 90 % coverage of HPV vaccination of girls by 15 years of age, 70 % of women are screened by the age of 35 and again at 45 years and that 90% of women identified with cervical disease receive treatment (WHO, 2020).

In Uganda, cervical cancer is the cancer type that cause most deaths in women aged 15 to 44 years. An estimate of around 6400 are diagnosed with cervical cancer yearly and almost three quarters of these die from the disease (HPV information centre, 2019). In 2010, The Ministry of Health (MoH) developed a strategic plan for cervical cancer prevention and control with the aim to reduce cervical cancer incidences by 50 % through screening of all eligible woman in Uganda and to introduce HPV-vaccination programs in the entire country.

³ SDG 3: Promote healthy lives and well-being for all at all ages, SDG 3.4: Ensure universal access to sexual- and reproductive health care services, including family planning, information and education and the integration of reproductive health into national strategies and programmes, SDG 5: Gender equality and empowerment of all women and girls and SDG 10: Reduce inequalities (UN, 2015).

However, these efforts by the MoH have been uncoordinated and with limited success: At least 80 % of all cervical cancer tumours are diagnosed in an advanced stage in Uganda (Nakisige et al., 2017, p. 39).

2.1.1 Cervical cancer: risk factors, symptoms and treatment

Cervical cancer is mainly transmitted through an infection of the human papillomavirus (HPV). HPV is a big group of viruses that are extremely common worldwide, but 70 % of all cervical cancer incidences are caused by only two types: 16 and 18. Risk factors for getting infected by HPV is first and foremost behavioural risks, such as unsafe sex, early sexual activity, multiple sexual partners, young age at first birth and multiple pregnancies (WHO, 2014, p. 40; Burd, 2013). Women living with Human Immunodeficiency Virus (HIV) are at high risk for HPV-infection. In fact, they are six times more likely to develop cervical cancer in young age than HIV-negative women (WHO, 2020, p. 9).

Cervical cancer disease can be described through gradings, from I to IV. Stage I is less severe as the carcinoma in situ is limited to the neck of the cervix. In stage IV the cancer has spread to surrounding organs or tissues (WHO, 2014, p. 177). Unfortunately, many women remain asymptomatic until the disease is advanced and in stage III or IV. This can take years as cervical cancer is a cancer type that progress slowly. Nevertheless, early symptoms may be abnormal vaginal discharge, irregular bleeding in women of reproductive age and postmenopausal bleeding (ibid, p. 171). In advanced stages, the most common symptoms are low abdominal pain, severe backpain, weight loss and urinary frequency. Early stage cervical cancer is treatable by surgery and radiotherapy which can result in long-term survival and cure.

2.1.2 “Screen-and-treat”-approach

As mentioned, cervical cancer is a disease that progress slowly and remains asymptomatic in early stages. Hence, regular screenings of women to control and prevent the disease is essential (WHO, 2020). The national guideline in Uganda is to screen women from age 25 and up every third year. HIV-positive women should be screened annually (MoH, 2010a, p. 33). However, there are financial and technical constrains of implementing cytology-based screening programmes, such as present in high-income countries. Therefore WHO (2014) recommends screening by visual inspection of the cervix using acetic acid (VIA) as an alternative in low-income settings, such as Uganda. By using VIA, trained health personnel can cost-effectively screen women since it requires very little equipment. Additionally, VIA

provides rapid results (30 seconds), giving health workers the opportunity to start treatment with cryotherapy immediately; this is known as the “See-and-Treat Approach”. With that, women who screen positive for pre-cancer cells, can ideally start treatment the same day and at the same location. This limits extra visits to health facilities and the time required for the diagnostic steps (Mezei et al., 2017; WHO, 2014). Cryotherapy is a treatment method that takes about 15 minutes and is generally associated with only mild discomfort. Thus, it is performed without anaesthesia. Treatment such as cryotherapy aims to destroy, and freeze areas of the cervix identified as pre-cancer. The equipment to carry out cryotherapy is simple and relatively inexpensive and can be performed by trained and competent health workers (WHO, 2014, p. 156). Hence, if a woman starts screening at late age, the chances are higher that pre-cancerous cells have developed into cancer and thus need more comprehensive treatment.

Studies have demonstrated that screening by VIA is a feasible approach as the sensitivity is similar to that of cytology, even though its specificity is consistently lower (WHO, 2002; Proma et al., 2013). Nevertheless, NGOs and health facilities can be part of providing quality VIA-screening in low-income settings. For instance, by sending pictures of tests through a technological device to physicians abroad to confirm a positive test, as done at the clinic supported by KfC in Fort Portal. As the implementation and utilization of screening services are affected by its context, the next section will illustrate how the health care system in Uganda is organised.

2.2 The health system in Uganda

In order to understand some of the challenges many women and health workers in Fort Portal expressed that they were facing, it is necessary to turn to how the health system is functioning and the way it is organised. In Uganda the health sector is divided into a two-tier-system: The government provide basic health care for free which take up about 55 % of total health care facilities. The remaining is provided by the private health care sector. The private entities include private-non-profit, often faith-based and non-governmental organisations (NGOs), and private-for-profit organisations as well as complementary health care providers such as in traditional medicine (MoH, 2014a, p. 33). Although separate, health sectors are interconnected as the public and private health providers collaborate to deliver health care in Uganda.

2.2.1 The organisational structure and functioning of the health system

As illustrated in the Introduction, political and economic factors such as SAPs have influenced the development of the health system in Uganda. Although SAPs contributed to weaken the role of the government, other factors such as corruption⁴ may also hamper the Ugandan State in delivering quality services (Moreau, 2017, p. 15). However, there are inadequacies in the public health sector today that influence service delivery: inadequate leadership and management, shortage of medicines and medical equipment, deficiency in health personnel and low salaries, and lack of investment in training and re-training of health personnel (Nampala, 2018; WHO, 2019a). In 2017, governmental spending on health was estimated to be 6 US\$ per person, compared to Norway with 6783 US\$ per person (World Bank, 2017). Wage cuts and hiring freeze may led to loss of health personnel and the desire to migrate in search of better employment opportunities, known as “brain drain” (Kentikelenis, 2017, p 4). In fact, today there is a density of 0.9 physicians and 6.3 midwives and nurses per 10 000 population, compared to, for example, Germany with 41.1 physicians and 132 midwives and nurses per 10 000 population (WHO, 2019a, p. 112).

The private health sector has a prominent role in Uganda. In 2017, the private health expenditure on health per capita was estimated to be 50 US\$ (The World bank). Private-non-profit organisations play an essential part in filling the gaps in provisions of health care services today. In fact, faith-based organisations provide approximately 30% of all health care facilities (Boulenger et al., 2012, p. 66). However, the 2000-2004 national health sector reform placed emphasised on improving sector performances and to facilitate cooperation between public and private health sectors. With that, efforts can be coordinated in order to provide quality services instead of wasting limited resources (Lochoro et al., 2006, p. 84). In fact, as seen in Fort Portal, NGOs such as Reproductive Health Uganda (RHU) are subsidised by the government to do outreaches, health training and skills development of health personnel. However, as further discussed throughout this thesis, it may be an unsuccessful partnership. In fact, one may argue that the two-tier health care system in Uganda increase, rather than lessen, health inequalities. Although fees to private services have been reduced due to subsidies from the state, the private sector is mainly available to those who can afford

⁴The Corruption Perception Index (2019), an index that ranks countries based on how corrupt the public sector is perceived to be, Uganda ranks a 28. Zero is perceived to be highly corrupt, whereas 100 is very “clean”. A rank of 28 indicates that corruption in the governance is severe, resulting in poor and less trustworthy governance as well as a governance that undermine fundamental human rights (Transparency International, 2019). In fact, a recent article in a Norwegian newspaper, E24, shows that corruption hamper Uganda in receiving aid. <https://e24.no/internasjonaoekonomi/i/IE1dq7/norge-krevde-tilbake-bistand-etter-svindler-trusler-og-utpressing>

them (ibid, p. 90). Health insurance in Uganda exist, but only 5 % are covered due to low income wages and lack of awareness that it exists (National Population Council, 2019, p. 85). In 2016, Uganda had a GINI coefficient ⁵ of 0.42 (The world Bank).

Furthermore, the health system in Uganda is shaped by processes of decentralization, as the country got an increased number of districts and local authorities in the years after independence (Green, 2006, p. 87). At the top of the healthcare chain in Uganda is the national hospital named Mulago located in the capital Kampala. Then, each region has regional referral hospitals. The national hospital and the regional hospitals provide services at a more comprehensive and advanced level. Below the regional hospitals are health care facilities, divided into health centre I, II, III and IV. Starting at the lowest level, are the Village Health Teams (VHT), providing preventive and promotive services at community level. Health centre II is placed in parishioners and provide treatment of common diseases such as malaria. Health centre III facilities are placed at every sub-county and have provisions for basic laboratory services, maternity care and in-patient care. Health centre IV or referred to as general hospitals, are the level below regional hospitals and provide services at county level, and have provisions for an operating theatre, in-patient and laboratory services (MoH, 2014a, p. 36). The system works such that if a health centre II cannot handle a case, it refers the patient upwards to the health centre III (see Figure 2).

⁵ A measure of equity where 0 is perfect equity and 1 is perfect inequality

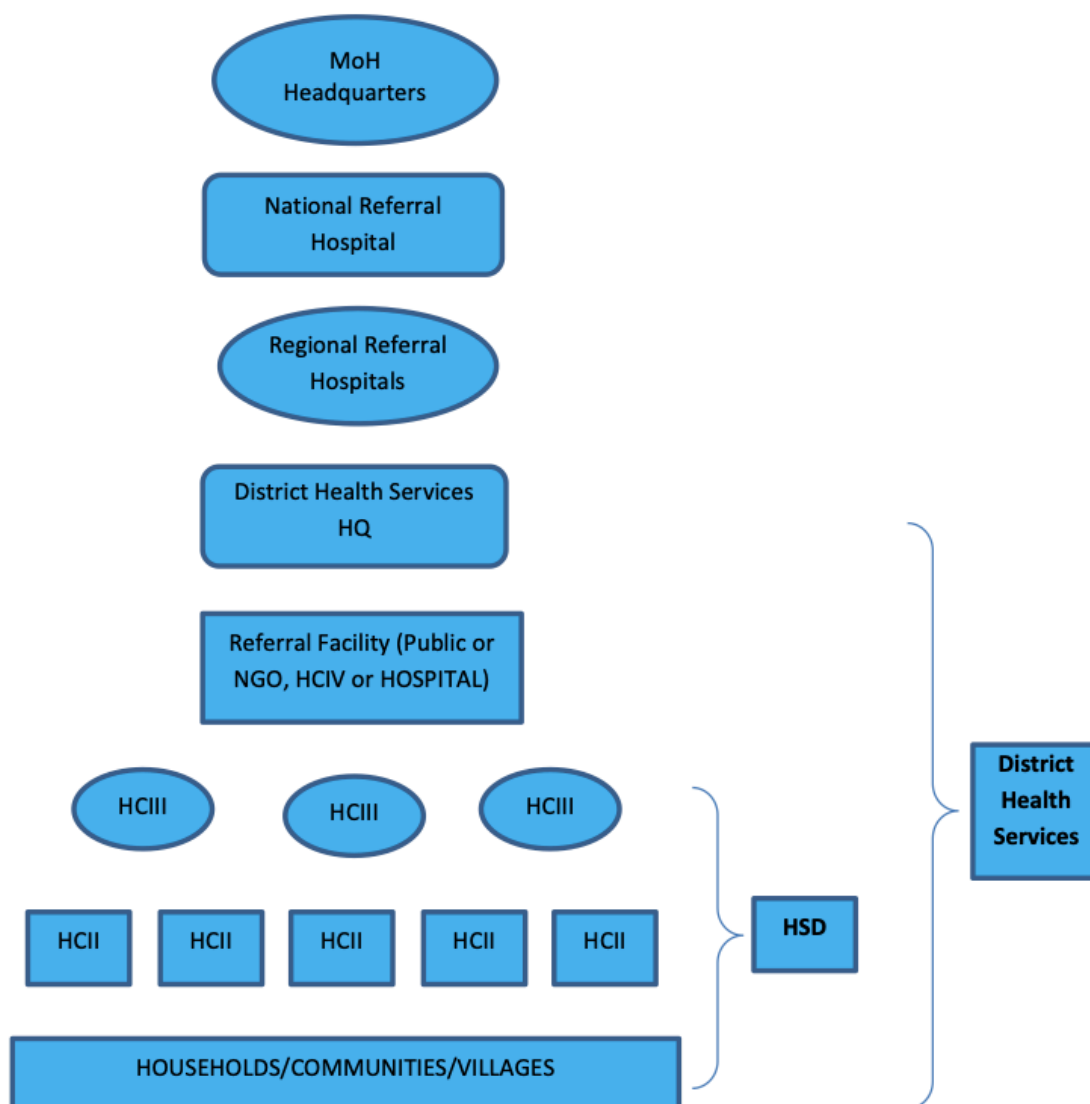


Figure 2: The health system levels in Uganda (MoH, 2014a, p. 34).

2.3 Reproductive and sexual health services in Uganda

For this thesis, I have focused on women’s health and utilization of sexual and reproductive health (SRH) services, with a particular focus on cervical cancer screening. In order to discuss utilization of screening services, it is essential to turn to women’s provision of services and women’s access to these services in Uganda. Uganda has a young population as more than half is under the age of 15 and the life expectancy at birth is 64 years (United Nations Population Fund (UNFPA), 2020). The Government of Uganda acknowledges SRH as an important field for achieving development and has included SRH in the 2015-2020 health sector plan. This plan, heavily inspired by the SDGs by UN, emphasises increased information and awareness as well as

universal access to SRH services such as family planning (MoH, 2015, p 22). The total fertility rate per woman in Uganda is 4.9 and it was estimated that 34 % of girls were married by the age of 18 (UNFPA, 2020). According to the Ugandan Demographic and Health Survey (2018, p. 73), in 2016 an estimate of 18 % of Ugandan women have their first sexual encounter by age 15. Being married and sexually active at young age increases the risk of teenage pregnancy, which can have a crucial effect on the health and lives of girls.

There are barriers to accessing SRH services in Uganda. First of all, as discussed, the public health sector is failing in allocating sufficient resources, equipment, medication and sufficient number of health personnel (WHO, 2019a). Additionally, individual beliefs and attitudes, sexual taboos and cultural moral practices can lead to barriers in accessing health information and use of health services (Moreau, 2017, p. 14). Although the Ministry of Health in Uganda highlights SRH such as family planning (MoH, 2014b), 34 % of women between age 15-49 do not use any family planning method (UNFPA,2020). The connection between poor governance, a weak health sector and social barriers have been widely discussed in the literature. That is, there are several factors that may influence the uptake and utilization of health care services. As I will illustrate with my findings from fieldwork in Fort Portal, use of cervical cancer screening was no exception. In addition, utilization of cervical cancer screening highlights the inequalities in accessing health care in Uganda and the role of NGOs and faith-based organisations. In the following chapter, the concept of “medical pluralism” is introduced as a tool to discuss the therapeutic worlds that often coexist in societies and health care.

Chapter 3

Women's and health workers' knowledge, attitudes and beliefs towards cervical cancer and screening

Local understandings, attitudes and beliefs are important factors that can influence use of health care services (Helman, 2007). In fact, they may be an important barrier in seeking timely care. This chapter shed light on women and health workers' knowledge, attitudes and beliefs towards cervical cancer and utilization of screening services. Adams, Burk & Whitmarsh (2014) argue that it is significant that policymakers and other instances, such as Ministries of Health and private international actors, include local ideologies and experiences, to understand how local people may respond to interventions. Implementing a cervical cancer screening-service that do not include local understandings of the disease might lead to failed interventions and potentially reproduce structural inequalities. This chapter will illustrate that illness and health are more than medical facts: they are also socially, culturally and institutionally produced and loaded with meaning from lived experiences.

3.1 Knowledge of cervical cancer and screening

Knowledge and understanding can provide an important barrier to seeking timely health care. A gynaecologic oncology report by Nakisige, Schwartz & Ndira (2017, p. 49) on cervical cancer screening and treatment in Uganda, indicate that even though women living with HIV are at high risk of HPV-infection, 96 % of women in Uganda receiving HIV-care had never heard of HPV. The fact that 18 % of Ugandan women have their first sexual encounter by the age 15 and 1 in 4 girls aged 15-19 have given birth or is pregnant with the first child (UBOS, 2018), shows the necessity of adolescents' girls to access quality SRH knowledge and services.

In this section, I will highlight the knowledge women and health workers in Fort Portal presented during interviews. Inadequate access to knowledge about health and services may lead to women and girls being more exposed to ill health, through experiencing unwanted pregnancies, unsafe abortions, infections, injuries and cancer. Based on women's and health workers' narratives on health care, cervical cancer and screening in Fort Portal, I will in the following discuss their understanding and knowledge about these issues. As will be shown at the end of this section, however, there is a gap in knowledge among health workers related to the availability of screening services in Fort Portal.

3.1.1 Knowledge of cervical cancer and screening among women in Fort Portal

«Because I have never been sick, I don't know the risks of that [cervical cancer] » - Mary⁶ (45), Fort Portal

During my fieldwork in Fort Portal it soon became clear to me that there was a divergence as to the level of knowledge on cervical cancer and screening amongst women. Julia (29), one of the first ladies I had an interview with was very straightforward as well as freely spoken throughout the interview. She told me she attended screening when she was getting family planning: “I was going to use IUD (intrauterine device) as family planning, and before inserting it, it is a must to test for cervical cancer”. She thought that the risk factors for getting infected by the HPV-virus were closely related to having many sexual partners, unprotected sex and being HIV-positive. She continued to describe her understanding of the symptoms; “bleeding during sexual intercourse, abnormal discharge from the private parts, itching”. My second interview was with Mary (45) who stated: “because I have never been sick, I don't know the risks of that. To assure you, I don't know how you feel when having cervical cancer”. Even though Mary was not able to identify the risk factors or severity of cervical cancer, she had heard about cervical cancer on the radio and saw the need to go for screening. She was fearing cancer because of the rapidly increase of people getting sick around her, and she had heard a neighbour explaining the disease as: “Continuing, continuing paining, not sitting, not sleeping, yeah, like that”.

Nevertheless, some women had never heard of the disease. As Anita (25) stated: “cervical cancer? I have never heard of that one. I have never heard”. Others had heard about the disease but did not know anything about it such as symptoms, risk factors or severity, and hence not gone for screening. As Elisabeth (25), whom I had an interview with at the market, expressed: “For me I heard, but I don't understand that cervical cancer”. Moreover, despite some women had supplementary knowledge about cervical cancer, the majority had not gone for screening themselves. As Harriet (26) straightforward noted: “I just feel scared for the check-up”. Rumours and cultural perceptions that appeared to flourish about the disease and screening made some women reluctant towards screening: “The instruments they use, I just heard a rumour they use metal ones. So that is what scared me. The rumour especially about it” (Harriet, 26). Another woman, Sarah (30), had also received some information about

⁶ All names are fictitious

cervical cancer and the screening procedure from another woman: “It is a dangerous disease. Either she dies or they remove the cervix, yeah. If not dead. That’s it. I hear from people that sometimes the person who screen you can hurt you and then you get the cancer”.

Consequently, Sarah had not gone for screening but did however believe that if a lady was suspecting something abnormal, she should go and get screened.

What became evident after meeting these women in Fort Portal, is that there was a variation on the level of knowledge on cervical cancer as well as motivations to attend screening. Knowledge and health information are essential to health literacy and self-care, but also for navigating health systems and the medical landscape more generally. Low levels of knowledge, limited access to health information as well as rumours and cultural perceptions may, I suggest, work as a barrier to accessing proper- and quality care, and hence contribute to health disparities in a population.

3.1.2 Knowledge of cervical cancer and screening among health workers in Fort Portal

Well-organised health programs and services are dependent on knowledge and skills among health professionals. All six health workers I met and interviewed in Fort Portal presented knowledge about cervical cancer such as risk factors, symptoms, eligibility for screening and screening intervals that are consistent with information from WHO. However, several of those working in the public sector underlined that shortage of equipment, medication and health workers was limiting services such as cervical cancer screening. They told me that they had been trained in doing screening at their previous workplaces, when working in the private sector and through NGOs. As midwife Ellen remarked: “I encountered [training] when I was working at the other clinic” and midwife Dorothy: “I was trained where I previous was working. I was working in a clinic that was an organisation, an NGO”. Another midwife, Anna, explained: “Even me, I was a midwife, but I didn’t know much about cervical cancer, until I was trained by an NGO and started screening”.

During nursing school as well as at the two-year specialization for becoming a midwife, cervical cancer and screening form part of the education but only theoretically. According to midwife Anna, who got trained in doing screening by an NGO, student nurses and midwives do not engage in practical training throughout their education:

We learn about cervical cancer but most time we do not go deep into it. Like I didn’t know about the regents to use, like the acetic acid how it is supposed to be mixed, we

were just talking about theory thing about cervical cancer. How it can cause infertility. But I didn't know how to carry out the procedure and what to use and such kind of stuff. But ever since I was trained particularly for cervical cancer, I am happy I am doing something very good.

The study by Nakisige, Schwartz & Ndira (2017) shows that training programs for health professionals have been ongoing, but mostly been project-or research-related. Also, the training projects are often not very well-coordinated and not committed to financially by the MoH, resulting in their inability to have any sustained measurable impact (ibid, p. 39). In an interview with Rose, a clinician working for an NGO, she expressed that health services need qualified health workers, and without continued financial commitment from the state, training in use of equipment and clinical procedures, medical staff will not be able to conduct proper screening.

NGOs, such as KfC and RHU, cooperate with the community and the state to provide safe and free cervical cancer screening services in Fort Portal. Midwife Anna saw the possibility to get trained and get engaged in women's health, and hence applied for a job at an NGO. Henceforward, Anna noted: "Ever since I was trained, since last year around May or June, we have screened like... more than 300 women. And I feel like I can still go on". A study by Mutyaba, Mmiro & Weiderplass (2006, p. 2) shows that medical and nursing students leave school without adequate skills to be able to effectively screen women for cervical cancer. The lack of continuing funding and further formal education and training, for example through courses or medical specialization, may lead to public hospitals not being able to provide quality health care services to, in this case, girls and women. Ellen, the midwife now working at the regional referral hospital in Fort Portal, also addressed this problem:

The challenge we have now, right now, is that mothers come in advanced stage. At gynaecological ward one can really see. One can hardly finish a week without getting a cervical cancer patient. There are very many patients actually. On average in a month it is like five or six cervical cancer patients, but most of these ones come in stage three.

Although health care personnel presented with good theoretically knowledge about cervical cancer and screening, not all had the skills and training to perform screening. A weak public health sector that do not provide re-trainings and adequate funding, become a barrier to health personnel to provide quality care and services such as cervical cancer screening. In addition,

lack of communication between health workers at different facilities limits quality services to function well, as illustrated in the next section.

3.1.3 Gap in knowledge between health personnel on cervical cancer services

Reproductive Health Uganda (RHU) is an NGO with great influence throughout Uganda. They have a clinic in Fort Portal where they carry out cervical cancer screening, both at the clinic and at outreaches. According to informants in Fort Portal, besides doing patient-oriented services, RHU have workshops and trainings of other health personnel on cervical cancer and screening. In addition, every week they go to the regional referral hospital (public hospital) to carry out screening services. However, when I talked to health professionals working at the regional referral hospital, all expressed uncertainty about the service carried out by RHU. Grace, a midwife at the regional referral hospital, stated: “Actually it used to be there [RHU]. There was a staff who told me that there is an organisation called Reproductive Health Uganda, they used to go there [hospital]. They go there and do cancer screening. I heard that they stopped coming, but I am not sure”. Grace’s co-worker Dorothy also expressed during an interview that: “Because they don’t have the services there yet [regional referral hospital], they don’t have screening”. She also saw the main problem being too few screening services:

Cervical cancer screening here in Fort Portal, well, the good thing is that we have agents and organisations that come in and do it at some costs. But like, public facilities - we have few public facilities that do the cervical cancer screening and as of now the regional referral hospital does not, it was initially doing it because it had support from one organisation. But right now, they are not doing cervical cancer screening.

Furthermore, a challenge for the health sector in Fort Portal may be the discrepancy between health services and health providers in terms of what is being said and what is being done. Inconsistency and unclear knowledge about cervical cancer screening services among health personnel can perhaps lead to less women being referred for screening. As midwife Ellen explained: “Ideally right now when you get clients, they need to go to those private facilities like RHU, Marie Stopes and KfC”. However, at some of these private facilities services cost money. Public services at the referral hospital are meant to be for free and accessible to people that cannot afford services at private facilities. Hence, if not being offered at public facilities many women will most likely not access screening services. Midwife Anna seemed to be concerned with the functioning of the public health sector:

The bad side is that referral hospitals are not supposed to refer to a health centre III, but they have been doing that. So, it's not good. These people have all the requirements they are supposed to have, they have doctors, health workers so they are supposed to carry out this service. But they are referring patients to health centre III, which it's not good. So, it means you are tuning a health centre III into a referral hospital.

Discrepancies between health workers communication and knowledge about health services such as cervical cancer screening can lead to patients receiving misinformation and hence reduced levels of quality care. According to health workers in Fort Portal, the flow of information and cooperation between public as well as private facilities are not well-coordinated by the government. Consequently, women can become reluctant towards services that are not well-established. In the following chapter attitudes towards cervical cancer and screening will be elaborated.

3.2 Attitudes to health care and cervical cancer services in Fort Portal

Illness, health and medicine do not exist in a vacuum in African countries. Colonialism and post-colonial processes such as introduction of biomedicine or SAPs, forced changes in the political economy, affecting the health system and the organisation of health institutions. As Langwick (2011, p. 232) states: “Healers and their medicine live in a world where national governments intervene in the lives of their citizenry through biomedicine, where scientific knowledge formulates the boundaries of care and where pharmaceutical drugs constitute paths of transnational power”. Anthropologists often use the tool “medical pluralism” to explain that there can be more than one medical system for health and illness in societies, such as both biomedicine and traditional medicine (Langwick, 2011, p. 234). In the following I will use Kleinman’s concept of three interconnected health sectors: 1) the professional sector, 2) the popular sector and 3) the folk sector, in order to discuss women’s and health workers’ attitudes and behaviours towards health care.

3.2.1 The professional sector of health care

During the last century the professional sector, also called “biomedicine” or “scientific medicine”, has spread to cover much of the globe. The professional sector is however dependent on health professionals, which in many places in the world is a scarce resource. The World Health Statistics Report (2019) illustrates the huge variation in the availability of nurses, midwives and doctors throughout the world. Uganda is one of the countries

experiencing a critical shortage of health workers. This lack of qualified health personnel was verified by Julia (29), one of the women I interviewed: “Getting a health professional is hard, sometimes they just give you those student nurses. To get a doctor you have to pay some money, it’s hard to get a professional doctor there at the hospital”. Nurse Tina, working at a public clinic stated that they need more “manpower” because often they find themselves alone at the hospital and being too overworked to attend to a woman that actually has come forward for screening. Yet one could assume that inadequacies in the public health sector affects women’s attitudes towards use of health services, this was not the case in Fort Portal. I asked women about their thoughts on the hospital and what they would do if someone in their family became ill. Mary (45), for example, explained: “Like, if you have fever, maybe at night... The first thing you can do is get a towel and put in the water, you try to squeeze the towel and put it there to be cold. Then tomorrow you take yourself to the hospital”.

Additionally, Sarah (30) who had heard that cervical cancer screening is dangerous as they may remove the cervix or you die, stated: “My beliefs are in the hospital!”. Nevertheless, when we talked more specific about diseases such as cervical cancer it became clear that for some women you are only to visit the doctor with clear symptoms and being truly ill. However, since cervical cancer is a disease that is asymptomatic in early stages, screening is necessary to control and detect the disease at an early and preventable stage. Yet, as midwife Ellen explained to me, the common attitude and discourse among women and people in Fort Portal is that you have to be very sick before seeing the doctor: “Most people feel that if I’m not sick, if I’m not really very sick, why should I go in routinely to the hospital and open my legs and they insert that instrument and what with the screening?”.

Women in and around Fort Portal seemed, however, to have different attitudes toward the hospital, clinicians and cervical cancer screening. Where some saw the necessity to go and check yourself in accordance with the guidelines, others had the attitude of not to see a doctor if not being truly ill or presenting with clear symptoms. Midwives working in the public sector and at gynaecological wards appeared to appreciate working with women’s health and saw the importance of educating them about cervical cancer so more women would come in for routinely screening. As midwife Anna noted:

Ever since I was trained in doing cervical cancer screening, I am happy, I am doing something very good. It is really not easy for these women to open up and tell you or

get ready for screening. So ideally it needs a staff with patience, good communication and that is open and can talk to these mothers because they really need their time.

Health workers attitudes, values and norms are all placed at the centre of health care, yet systemic and socioeconomic limitations and barriers can influence the service and care given to patients as well as health workers both mentally and physically (Jaffré, 2012, p. 8).

Midwife Ellen expressed the issues very well:

Of course it affects you because you are the one handling these patients and under that particular time you want to do something like maybe you want to give a pain killer to this patient but you don't have the pain killer that moment and when you tell the patient to go and buy and they tell you I don't have money at this moment sorry. You really feel bad seeing someone in pain and you cannot really help, you cannot do much. It is really pain.

Although health workers in Fort Portal expressed dissatisfaction with governmental facilities lacking the means and resources needed, it did not seem to negatively influence their values or attitudes. However, it may end up with health workers doing their best, with the motto, to paraphrase Jaffré (2012, p. 13): “One does what one can for a few. But one cannot do it for everybody”. Nevertheless, women I interviewed and encountered in Fort Portal were positive towards the professional sector. If being sick women expressed that they preferred going to the hospital and seek treatment from biomedicine. However, the threshold for seeking health care when being sick was rather diverse among the women.

3.2.2 The popular sector of health care

Globally the main mode towards “health for all” has been to emphasise primary health care (WHO, 1978). In Uganda the first education, a Master of Medicine in Community Practices, got established in 1989. It contributed to an increase of physicians working in rural areas and hence an effort to support primary care in the country (Ssenyonga & Seremba, 2007, p. 624). In addition, in 2000, the Ugandan MoH established Village Health Teams (VHTs) to empower communities and provide quality health care to people living in remote areas (Kozuki & Wuljji, 2018, p. 6). How people manage illness depends on, among other things, access to health care and personal values and attitudes. In the popular sector, the role of the family, self-care and community beliefs and activities are essential. It is the family who evaluate and decide what to do when someone is sick and self-treatment such as different types of food, diets, prayers or rituals is often the first therapeutic interventions (Kleinman, 1980, p. 51).

In the public health sector in Uganda, the family of the patient do become central as they often need to buy medicine, tests, X-rays and blood-infusions themselves. Shortage of health personnel, medication and instruments to measure temperature and blood pressure as well as good medical artefacts and data, put a strain on health personnel in their everyday work (Munabi-Babigumira et al., 2019). Once again, turning back to my interviews, midwife Ellen explained the situation in Fort Portal as:

You want to take them for operation, and it is urgent but things to use in the theatre are not there, and they are really suffering. They say: "Please can you tell my God in the village, so we get the money". It is challenging.

Furthermore, midwife Dorothy working at the regional referral hospital, explained the important role of family in health care as:

You find like there is 100 patients but there is only one nurse. So, tell me how will I be able to change the beds for each and every one of them? I cannot do that, it is impossible. So, the work of an attendant, the role of the family members, like we call them "attendants" is to keep changing the bed lining for the patient, help the patient with whatever the patient wants, buy food for the patient – those are the roles of the attendant.

A frail public health sector with low access to health professionals and services can in fact be critical. According to midwife Anna: "It is hard to get a doctor, even people put on clinical clothes pretending to be one and then rob you". Incidents such as this may contribute to further lack of trust towards health services and personnel. As Julia (29) stated: "Many women are scared about cervical cancer screening, so they don't want to hear about it". A mistrust between women and the health sector can be destructive as well as deadly, in the sense that women avoid coming for screening and check-ups. Nevertheless, according to informants in Fort Portal, when it comes to cancer, self-treatments such as diets or popular remedies were not the preferred health care methods. Mary (45) expressed the view on popular remedies as:

Herbals yeah, some use herbals like those trees. Sometimes there is a doctor, who put on their sign post that they are selling herbal medicine, yeah, maybe they treat fever they told you, they told you ulcers, stomach pain, they told you cough, they told you sinuses. But with cancer I don't think. Yeah, cancer I don't think.

Community health care and VHTs may, if implemented successfully, contribute to accessing health care and information in remote areas and hence may play an important role in people's attitudes and values towards health care and use of self-treatment methods. Although the public health sector in Uganda is frail and individuals can purchase any medicine at

pharmacies, informants in Fort Portal expressed that when it comes to cancer the first encounter would not be the popular sector and self-treatment methods.

3.2.3 *The folk sector of health care*

The folk sector is positioned somewhere in-between the popular and professional sector and consists mainly of traditional health practitioners that are not part of the official medical system. For example, shamans, healers and herbalists (Kleinman, 1980, p. 59). Once again turning to Julia (29), who knew much about traditional medicine but appeared sceptical: “We have herbalists, but most of those things are not effective. Most of them are just money-minded, they haven’t got enough training in those herbal things”. Moreover, Mary (45) did verify that there were herbal doctors in town and that it was possible to go and pick herbs yourself, but that it mostly is useless. Vivian (30) however did believe in some remedies such as oils: “I have a problem with my hand. I shake and I cannot carry things on a tray to give to someone like a visitor. I tried to take cod liver oil; you know it? it makes the body strong”. Among health workers the attitude was more reserved. As midwife Dorothy commented: “they [in the village] use the traditional medicine but of course it cannot help”.

Among women and health workers I talked to in Fort Portal there seemed to be a common narrative about rural versus urban dwellers, making a distinction between “they, the village people” and “us in the city”. This would be expressed through statements such as “those village women who are not informed and educated” and “in villages they don’t even understand what cervical cancer is”. One woman stated that people in the villages use traditional healers, but not in and around Fort Portal:

In villages they don’t even understand what cervical cancer is and you may find that they are affected but they don’t know. Even if you go to those people in the village and you ask what the cause of cervical cancer is, they will tell you it is family planning.

Traditional medicine used to be the dominant medical sector available to millions of people throughout Africa, both in rural and urban communities (Abdullahi, 2011, p. 115). In fact, it was in 2012 estimated that over 200 000 traditional healers practiced in Uganda (WHO, 2019b, p. 79). Hence, for many people the first point of call for health services is to see an herbalist. However, habitually if the condition has not improved people go to a health centre to get help (Langwick, 2007). Interconnected health care systems may enhance the need for an innovative partnership between traditional and medical practitioners, so that healers can

address biomedical diseases and refer patient to hospitals, but also that governments and NGOs refer to traditional medicine (Poudyal et al, 2003, p. 958).

Women's narratives of the distinction between urban and rural use of traditional medicine, indirectly shows that they are familiar with traditional medicine but that they present themselves as more modernized. Moreover, in Fort Portal women appeared negative towards use of traditional medicine and the folk sector. However, it needs to be addressed that my background and ethnicity may have influenced the view women expressed towards traditional medicine and healers, making them biased towards the professional sector even though they may consider it differently when talking to, for instance, their families. Scholars do argue that western medicine have created unequal power-relations that stigmatize the traditional health care system in Africa. Colonialism and the influence of biomedicine has in many societies side-lined or repressed traditional medicine (Abdullahi, 2011). According to Langwick (2011), however, cooperation's between health providers of both traditional and modern medicine can create good health outcomes.

3.3 Beliefs towards cervical cancer and cervical cancer screening in Fort Portal

According to Adams, Burk & Whitmarsh (2014, p. 181) local contexts are culturally, socially, regionally and nationally different, yet they often form a kind of "black box" in conventional approaches in global health that is not always considered critical to the intervention. Frictions can arise if global policies, ideologies or strategies are not aware of this when making local impact. As Helman (2007, p. 377) states: "Specific beliefs and behaviours, can be causal, contributory or protective in their relation to ill health". In the following sections I will illustrate beliefs women and health workers had towards cervical cancer and screening. Although cervical cancer screening is a rather biomedical procedure in itself, there may be different notions of biology and health services in local communities that can influence the uptake of screening services. Finally, I will discuss how cultural taboos and moral practices can lead to barriers in accessing health services.

3.3.1 Women and health care workers' beliefs towards cervical cancer and screening

During my interviews with health workers, several mentioned that the main challenge when it comes to uptake of screening was women's poor perceptions and cultural beliefs towards cervical cancer and the procedure itself. The midwives appeared well-acquainted with the beliefs that did flourish among women and believed that an important part of the job was to

inform women that “those beliefs are not true” (Anna, midwife). One of the beliefs women have is that speculums are dangerous: Either they cause cancer, or they harm you. Midwife Anna expressed that women believe that if the speculum is of metal it will be used on every woman without being sterilized. This belief was also confirmed by Harriet (26) who stated the following: “They use the instrument on each and every patient. If that one is positive and you are the next, then you also get it”. Some women seemed to not attend screening even though they knew it was offered for free. As Sarah (30) expressed it: “The main reason [for not being screened] is that I am afraid of the machine. They may remove the cervix and leave you with a wound on it”.

Furthermore, women had several perceptions about cervical cancer screening that seem to differ widely. As midwife Grace explained: “there are some mothers who used to come and say that they take the whole uterus out of you and put it on the table... they examine it from the table and after they put it back”. According to Grace, they would tell that to friends and family and the diffusion of wrong information starts: “If one patient starts to bleed after screening, maybe because she has an infection or wound, she goes telling everyone that whenever they screen you, you bleed”. Among the majority of health care workers, it seemed important to do screening well, as midwife Anna explained: “When they come I screen them. If it is painful tell me, I will leave and not continue. Or other times I tell them it is better to know the pain once than not knowing what is going on with your health”. Annas co-worker nurse Tina explained it as: “When you handle one very well, she can spread the gossip to others”. Nevertheless, the procedure itself may lead to women not wanting to be screened. Julia (29), one of the women from Fort Portal, explained the procedure as “being funny” and “done by the brave ones”:

The procedure is also funny [Laughing]. Just the showing of your private parts, it's funny. That's why most women don't go there, if it was like testing for blood very many women would be doing it. Many women are naturally shy, remaining negative in front of someone when you are not feeling any pain or are not giving birth. Its somehow difficult, it's done by the brave ones.

Fear seemed to make women refrain from screening for cervical cancer. Studies have shown that the word “cancer” itself is scary and connected to negative associations as death, pain and no cure (Donovan et al., 2003; Agustina et al., 2017). One woman did not want to learn about cervical cancer as she was scared of it: “If they test me and find me positive with cancer, it's my end. So, let me first wait until I'm getting ready to receive those news”. Nevertheless,

getting familiar with beliefs women have about cervical cancer can be decisive. One example is a clinic in Fort Portal that changed from metallic to disposable speculums after they learned through the village health team (VHT), that women feared the metallic ones. After this change, the clinic got an increase in women attending cervical cancer screening. It shows the importance of integrating local understandings of medical interventions when implementing health services as cervical cancer screening.

3.3.2 Contraceptives as the cause of cervical cancer

During fieldwork, I was engaged in work on a survey that aimed towards creating awareness around sexual- and reproductive health issues, mainly with focus on cervical cancer screening. Together with the VHT employed at the clinic supported by KfC I travelled around the district on boda-bodas⁷ to talk to women and girls. One day I met Vivian and Beth; two ladies being 30 years old. Originally, I had an interview with Vivian but that soon turned into a mini “focus group”, as Beth entered the room to visit her friend and unsolicited joined the conversation. They had heard about cervical cancer but had never been screened. They both believed that family planning such as condoms and injections (the contraceptive injection Depo) could cause cervical cancer. They told me they both had used injections, but due to side-effects had stopped using them. As Vivian stated: “I bled for three consecutive months”. Other rumours from friends, such as contraceptives causing cervical cancer or that it removes the appetite for sex and make you fat, were reasons given for not using it. As Vivian expressed it:

To my own belief, I don't want to go for those things [contraceptives]. Like even I don't use condoms. Like when I am going to meet my husband, I just count my days, I don't even use the injections.

Beth nodded and continued:

My boda-boda driver was even telling me that many women are complaining that cervical cancer is caused by family planning. It has side effects which can cause cervical cancer. In my own thinking I was also thinking that was the cause, because you will find our grandfathers having like five or seven wives, but then cervical cancer wasn't there. I am so surprised even me I was thinking it may be the cause. Sometimes I worry I used family planning, maybe one time I may go and check and find myself positive for cervical cancer.

⁷ Daily motorcycle transport

Vivian and Beth told me that they would rather count the days, known as the “calendar method”, instead of using family planning. The contraceptives were blamed for being the cause of cervical cancer and were therefore by some women in Fort Portal avoided. It seemed that the two ladies had experiences that did not favour the use of family planning methods, As Vivian clarified: “I was once working in the community... This is me to tell you the truth. There was a lady that inserted the ring. She got problems and they ended up removing the womb”, Beth continued: “You know, there is a man who came here he told me as he was doing it to the woman [laughing] the condom went in the woman, so he could not remove it. So, I fear those things”. Beliefs such as those mentioned by Vivian and Beth can lead to perceptions about contraceptives being the cause of cervical cancer, which further can lead to women stop using family planning methods, and consequently, making them more at risk in getting infected of the HPV-virus and other sexual- and reproductive diseases such as HIV. Misconceptions, lack of information as well as taboos and cultural and morals practices may influence health-seeking behaviours and may at times have a detrimental effect of health and well-being.

3.3.3 Sexual practices, taboos and moral values

Taboos and local dynamics of social and moral beliefs can lead to crucial barriers in improving young people’s SRH rights and access to services, but additionally, make open discussions about SRH topics difficult. Ugandan youths’ behaviours do mirror that of their counterparts all over the world who continue to engage in sexual activities, even though the state authorities, parents or elders do not find it acceptable. Admonitions and social and cultural values may discourage it, but youths in Uganda are still engaged in sexual activity. However, culturally grounded taboos are making it unacceptable to talk openly about sex in Uganda, as in most countries around the world (Råssjö & Kiwanuka, 2010, p. 160). A qualitative study by Bell & Aggelton (2012) on sexual behaviours and health programs (first and foremost on HIV) among Ugandan youths shows that sexual activity was consistently portrayed as an “adult” privilege and as something that take place within marriage in Uganda. Respecting the elderly within families is essential and it is considered disrespectful, for example, to argue or disobey adults and parents. Consequently, girls and women may find it difficult to use health services such as family planning or screening, as they are not supposed to be involved in sexual activity before marriage.

It did not seem as a problem, however, to discuss sensitive topics in an interview-situation, though women were not very direct in their way of speaking, approaching the topics with exposition such as “the private parts”, a point also noted by Bell and Aggelton (2012, p. 393). In addition, in Fort Portal health workers did frequently refer to women that come for screening as “mothers” and not “women”. This may be an indicator of those dynamics of not acknowledging that adolescents engage in sexual activity and the taboo of talking openly about sexual matters. Also, for some women it seemed to be a taboo to talk openly about SRH with their general practitioner. As Julia (29) explained it:

Just sometimes for us in this African culture we grow up knowing that the private parts are private. Even if you are sick (cervical cancer) some fear telling the doctor and instead say am feeling fever and what what. We call it “backwardness” - or something like that.

Julia used the expression “and what what” when explaining that many women are shy and do not want to elaborate on gynaecological symptoms with their doctor, hence rather mentioning all other symptoms so that the general practitioner would do a health check. Sexual taboos and moral values do have an impinge on girls- and women’s sexual- and reproductive health. Girls are often the ones to suffer if getting an unwanted pregnancy or if parents find out that they are being sexually active, the consequences potentially being forced to leave school, increased experience of poverty, facing unsafe abortion and social exclusion (Bell & Aggelton, 2012, p. 390). With this in mind, it is crucial to be aware of local beliefs and moral values when providing services as they are of great significance and important factors in the “black box”.

As discussed throughout this chapter, knowing what is going on at the local level, such as women’s and health workers’ knowledge on cervical cancer, attitudes towards health sectors and beliefs about cervical cancer and screening, provide an empirical basis for knowing what is likely to be of concern and priority for those who are going to provide and use screening service. A “bottom-up” approach may lead to successfully implemented health services such as through good health outcomes and respectful health care. In fact, screening-programs in one place or in one country might differ radically in method and success from those in another location. Having this in mind, in the following chapter I will discuss access to, and awareness of, cervical cancer screening in Uganda.

Chapter 4

Awareness and access to health services

International and national organisations and institutions in Uganda have, as noted in Chapter 2, during the last decade declared cervical cancer as a public health problem and have placed an emphasis on eliminating cervical cancer through screening and vaccination. However, Uganda's poor health governance can hinder access to quality health care services, such as cervical cancer screening. This chapter will seek to shed light on access to cervical cancer screening in Uganda and Fort Portal and discuss some of the effects such policies may have. It illustrates the inequalities people face towards accessing health care and health information. In fact, awareness, communication and sensitization are significant factors towards increased uptake of health services (WHO, 2020). This chapter will hence also discuss awareness of cervical cancer and screening and conclusively elucidate the role of religion in health care in Fort Portal.

4.1 Accessing health services in Uganda

The divergence in challenges and opportunities in health care between high, middle and low-resource countries is significant. As of 2020, nearly 30 % of low-income countries have reported having national cervical cancer screening programmes, available cancer diagnosis- and treatment services in public sector as well as introduced the HPV-vaccine into their national immunization schedules (WHO, 2020, p. 11). In high-income countries on the other hand, more than 80 % of countries have implemented all of the above-mentioned interventions (ibid). In countries where the disease burden is highest, such as Uganda, the strategies for reducing cervical cancer rates have not yet been successfully implemented. In this chapter I will discuss inequalities in accessing health care throughout Uganda more generally and discuss access to cervical cancer screening in Fort Portal more particularly.

4.1.1 Disparities in accessing health care services

The two-tier health care system in Uganda and the privatization of health care services, as noted in Chapter 2, can be understood as a commodity to be bought for those who can afford it (Zikusooka et al., 2014, p. 5). This exclude many of those poorer members of society who do not have the resources to pay for private health care or that live in remote areas with less availability or access to health care services (ibid). About 90 % of private-for-profit facilities

are located in Kampala district (MoH, 2014a, p. 33) and in rural areas, where over 70 % of the population live, nearly all health facilities are government or public owned (Omaswa et al., 2017, p. 4). The government is providing basic health care for free, but according to information that emerged through my own interviews and observations, there is a discrepancy in the quality of health care at public and private facilities, as well as between rural and urban areas. Julia (29) described the discrepancy by saying:

The regional hospital is for free, but you spend a lot of time to get a doctor and there are no drugs most of the time. You spend a whole day at the hospital and don't even get what you wanted. So, if you can afford you go to private and get what you want and pay. Also, most time the governmental hospital don't have enough services. So most time you will decide to pay to get the best services. We have many other clinics that have good health services, but they cost.

According to a hospital and health centre IV census survey (2014a, p. 19) by the Ugandan MoH, public hospitals and level IV primary care facilities¹⁰ are evenly distributed across the country, although central Uganda is supposed to have higher hospital density than the other geographical areas. Furthermore, the survey measured the quality and safety in public and private hospitals and health centres IV around Uganda, and found that when it comes to medicine, 41 % of urban, 13 % of rural, 44 % of private and 13 % of public facilities had at least half of the medicines required (ibid, p. 30). The decentralization that followed due to Structural Adjustment Programs (SAPs) has actually resulted in widened disparities between the districts of Uganda. Those richer districts with powerful local politicians who are able to persuade NGOs and other private entities to work in their district, have received more resources from the state (Okuonzi, 2004, p. 1173). For instance, the availability of emergency services varies between districts from 5 % to 62 % in availability (MoH, 2014a, p. 25).

There is an unequal distribution of health workers between rural and urban areas in Uganda, and between public and private providers. Nearly 70 % of doctors are in urban areas serving 13 % of the population (MoH, 2010b, p. 21). All health facilities do require skilled health workers to be able to provide quality care. As noted in Chapter 2, there is an overall shortage of health workers in Uganda. In fact, at the Ugandan Cancer Institute (UCI), there was in 2015, 183 approved vacancies but only 94 were filled (Ministry of Finance (MoF), 2015). Uganda, similar to the rest of Sub-Saharan Africa, is facing a challenge with brain

¹⁰ See Chapter 2 the organisational structure and functioning of the health system

drain. Due to the opportunity to migrate to a high-income country where wages are higher, countries are losing their own human capital and face with a shortage of skills both in the public and private sectors. Only 4 % of the population in Sub-Saharan Africa is possessing higher education, and about 20 % of these are travelling to high-income countries after completing the education (Goldin & Reinert, 2012, p. 176). A study by Kizito et al. (2015, p. 3) shows that out of 251 final year medical students in four of Uganda's universities, 44.6 % had the intention to leave the country after graduation. Reasons given were lack of equipment and supplies in hospitals, overwhelming patient numbers, risky working environment and low payments to doctors. Consequently, the health sector in Uganda face a lack of skilled health personnel and other resources to provide sufficient health services throughout the country, and the burden fall on the vulnerable who cannot afford services at private clinics.

4.1.2 Access to cervical cancer screening services in Fort Portal

A study by Bishwajit & Kpoghomou (2017, p. 46) of Kenyan women, shows that urban women had a higher change of utilizing cervical cancer screening compared to their rural counterparts. In Uganda, cervical cancer care has not been decentralized and the UCI at Mulago hospital in Kampala is the only facility in the country that offers services for cervical cancer in advanced stage (MoF, 2015, p. 2). According to Grace, one of the midwives working at the regional referral hospital in Fort Portal, it is a critical situation to be without a cancer unit in the district: "The most challenging thing or bad thing is that we don't have a unit for cancer of the cervix. Most women come when they are in a late stage and it cannot be treated here, the only thing they need is referral to Mulago Hospital. Most mothers do even die before referral". Clinician Rose also expressed this concern when we discussed cervical cancer screening in and around Fort Portal:

In Kabarole District [western Uganda], we don't have the extra services to treat severe cancer of the cervix. We have to refer to Ugandan cancer institute at Mulago Hospital in Kampala. We do not have any cancer services around. Even nowadays you find Health Centre II they do not carry out screening. Many rural communities can only access health centre II, meaning they cannot have the services. The government has to do something about it.

The strategic plan for cervical cancer prevention and control by The MoH (2010a) emphasises that all regional and referral hospitals throughout Uganda should offer cervical cancer screening using VIA or cytology (p. 10). However, very few women have access to biopsy as part of a colposcopy when invasive cervical cancer is suspected. This procedure is only

routinely offered at three high-level government facilities and there is only one government pathology laboratory that processes the specimens (Nakisige et al., 2017). Moreover, during the time period January-March 2020, cervical cancer screening was not offered at all at the regional referral hospital in Fort Portal. Despite the disparities between health personnel about available services, as noted in Chapter 3, nurse Ellen elaborated:

When it comes to cervical cancer screening here in Fort Portal, the good thing is that we have agents or organisations that do it at some costs and some also do it for free. But like, we have few public facilities that do cervical cancer screening, as of now the regional referral hospital does not. When you get a client, all you can do is sending them to private facilities like Reproductive Health Uganda or Marie Stopes. For the ones that come with cervical cancer, we can refer them to Mulago, talk to their relatives, comfort them and link them to the palliative care systems.

Contrariwise, screening and cryotherapy were offered at different health clinics supported by NGOs, such as KfC, RHU and Maries Stopes in Fort Portal, but not at the regional hospital as emphasised by the MoH. In addition, several of the health clinics in the region carried out outreaches to give free health services to people in rural communities who are not able to visit a health centre or due to lack of health centres II (Oryema et al., 2017). This illustrates the role of NGOs in Uganda in filling in the gap and providing services public facilities are unable to provide. The challenge is nevertheless to get adequate financial resources for equipment, training and manpower to perform sustainable and quality screenings. Likewise, the VHTs have not been successfully implemented by the government in all regions. According to Lloyd et al. (2019, p. 41) it is due to an inadequate supply of sufficient resources and funding from the government to meet public needs.

Furthermore, private services may be costly and hence not available to all. At an private-non-profit clinic, clinician Rose could tell that cervical cancer screening cost 10 000 shillings (25 NOK) and this at times was reason for low uptake on screening: “Someone may come and really need help, but when you offer the service someone just leaves due to costs”. Rose believed that if given the opportunity through more financial commitment, cervical cancer services could be given for free as well as reach every community in the region and hence increase the awareness and number of women getting screened. As part of cancer care, the MoH have implemented a palliative care program in Uganda (Nakisige et al., 2017). However, it is not universally available, and according to Amandua et al. (2019, p. 1), only 69 out of 112 districts are providing palliative care through both the government and NGOs. The

frequently stockouts of medicine such as morphine underlines the challenges in implementing palliative care services in the public health sector.

With this in mind, it is clear that cervical cancer screening and treatment is not easily accessible for every eligible woman in Fort Portal. There seem to be a discrepancy in access to health care based on socioeconomic status and place of residence. Efforts towards strengthening health care services through strategies exist but the ability to provide sufficient resources to produce good outcomes, seems to be difficult (Lloyd et al., 2019). Disparities in availability of cancer management services such as screening, biopsy, cryotherapy, cancer surgery or palliative care, may lead to women becoming reluctant to, or unsure, about services offered. As long as there are screening services and treatment available, information and sensitisation are vital measures to increase the uptake of services.

4.2 Awareness and sensitisation of cervical cancer and screening in Fort Portal

A challenge mentioned by mutual health workers I interviewed concerned the lack of knowledge and awareness about cervical cancer and screening. As clinician Rose elaborated:

Now we have very many myths and conceptions, cultural conceptions, several of them that are still hindering the case of cervical cancer screening. You know, the myths diffuse faster than the quality information. Once something is said that is very bad, it is like a drop of blood in a big bottle of many. Yeah, we need to sensitise people.

Population scale-up interventions such as mass campaigns and community mobilisation are means emphasised by WHO (2020, p. 6) and Ugandan MoH (2010a, p. 11) to create awareness and achieve targets towards eliminating cervical cancer as a global public health problem. However, the implementation of SAPs in Uganda did limit the role of the government in providing health care, and enhanced the role of other entities, such as faith-based organisations. Ugandans are on the whole fairly religious, and in 2014, 84 % of the population were Christians and 13.7 % were Muslims (Lyons et al., 2020). Through my fieldwork it became clear that the role of religion can be decisive when it comes to health care and sensitisation, points further discussed in the following sections.

4.2.1 Awareness of cervical cancer and screening among women and health workers

During fieldwork connections between socioeconomic factors, health and access to health care emerged as clear both through knowledge derived from interviews and from observations. Julia (29) had gain knowledge of risk factors and symptoms due to access to

free internet at work. I asked her how she got information on cervical cancer and she replied laughingly: “I have free internet at work and Google has everything”. Irene (49) had her own business in the informal market, selling food, goods and cement. Her highest level of education was primary 6. Irene had seven children and a husband who worked on their small farm. She had heard about cervical cancer from neighbours but had little information about it or about screening: “Only what I know is that in case I go into my period and it doesn’t stop, that means I have it [cervical cancer]”. While this cannot be generalized, the difference between Julia and Irene illuminates that literacy and education can be crucial in accessing health information and use of health care services. Julia’s education provided her with the opportunity to easily access health information. In fact, socioeconomic inequalities are some of the most important causes of ill health, since poverty may result in low levels of education, access to health care, lack of work, poor housing and nutrition (Helman, 2007, p. 5).

Although Julia (29) used internet to gain knowledge she revealed that she got information about cervical cancer screening due to campaigns: “I got to know about it like three years back, then when it was campaigns. Specially through NGOs such as Marie stopes, KfC and RHU”. Several of the health personnel that I interviewed explicated that an important part of their job was exactly to sensitise people through providing information about diseases and services. Either by talking to patients or through campaigns. As nurse Tina affirmed: “My role is to sensitise women to come for cervical cancer screening, and also to clear the myths”. She continued:

The only contribution I can make is to talk. When you get a client, you know these clients come from different places, so when you talk to one, she can spread the gossip to others. When you handle one very well, she can spread the gossip to others.

Her colleague Anna had similar views:

The best way to inform these people is radio and mass media because it spreads all over. Some people may spread information by walking door to door (VHT), but of course they cannot walk that far. The best way I think is radio talk shows or mass media.

The clinic supported by KfC was in 2019 sponsored to make a campaign about cervical cancer that was sent on the local radio. According to health personnel the process was easy and very successful: “We just went on the radio to put an advertisement about cervical cancer; how to get it and where you can have the service. It really helped a lot of people. It also

improved the service and we got a big number to come in for the service”. In fact, when I asked women in interviews where they had heard about cervical cancer screening, several of them answered on the radio. As Mary (45) affirmed: “They told us on the radio it is good to go for cancer screening”. Irene (49) was likeminded: “Nowadays it is common that people are going for screening because they heard announcement on the radios”. However, as midwife Anna accentuated, not every woman may be able to listen to radio: “We have been doing sensitisation on the radio, but maybe someone is at the office (work) and are not allowed to put on the radio. Have you ever had a radio around here? [KfC-office]. No, so this person will miss the information”. Later on, when interviewing women, this concern seemed to be accurate. In addition, several women told me that it is not common to talk openly about cervical cancer with friends or family. This may result in lack of health information and prevent women seeking health services, including screening. Harriet (26) explained her access to information well in our interview: “There is no information unless you visit the health centre. Some may do research on Google”. She continued: “We rarely talk about cervical cancer and screening openly. We don’t talk about cancer generally”.

After having completed the interviews I invited the women to ask questions and nearly all of them asked me to elaborate about the disease and the topics we had touched upon. Mostly they wanted to know the risk factors, symptoms and treatment, and whether what they had told me was correct. As Sarah (30) asked: “If you have cervical cancer what are the signs that can show that you have cervical cancer?”, or Mary (45): “I want to ask you [smiling] to tell me the symptoms of cervical cancer, it is good to know them”. This may suggest that many women are not well-informed about cervical cancer and that it is not talked about openly, yet the interest in getting educated about it is present. I provided simple information about cervical cancer but requested them to turn to their general practitioner or the nearest health centre for information about diseases and services.

4.2.2 The role of religion in health care: prayers or medication?

In rural areas in Uganda where public hospitals have scarce resources, the contributions from faith-based organisations is especially notable and by many considered both more desirable and trustworthy than public services (Olivier et al., 2015). All of the informants in Fort Portal stated that they were religious. However, although religious beliefs can have an impact on people’s health seeking behaviours, such as discouraging behaviours associated with nightlife, non-acceptances of blood transfusions or use of prayers instead of health care (Lloyd et al., 2017, p. 70), all women being interviewed stated that they did not use prayers instead of

hospital treatments. As Irene (49) stated: “True prayers can help you when you get sick, but I go first to the hospital”.

Furthermore, Julia (29) talked about the role of religion in health care in Fort Portal and told me: “I am religious, I am practicing catholic. For us at the hospital we go to, the management is of catholic religion. Before they had free services for children and free delivery, but that project, I think, ended”. I asked her if religion would be of any help if she or her son got sick. She responded: “If it is severe and you get referred outside of country like to India, then religion come in as the church can help you pay for medical bills”. Midwife Grace, working at the regional referral hospital in Fort Portal, explained how she saw the relationship between religion and the role of modern medicine:

In health care it is like I treat, and God heals. You come with headache I give you paracetamol, and God heals. Me I am a midwife and during deliveries, sometimes I look at the mother, there are no progress in labour, so I just tell her “you know what, start to pray”. We do it with hope, directions and guideless, of course.

Grace continued and told me another story how she uses religion when she practices health care:

There was a lady who came into hospital, she was in marriage for ten years without a kid. Then after ten years she got pregnant and she got an abortion on that very pregnancy. Remember someone has been longing for pregnancy for ten year, and that person did marry officially in church. She has been longing for pregnancy for ten years, and she gets pregnant and that baby dies in the womb. That scenario - How can you talk to that person? The only thing I did was to pray. There is nothing we can do, the only right thing to do is to pray. I think God has a reason why it happened like that, we have to be like... God has to feel you and comfort you. We encourage them to pray according to the condition they are in. I do encourage them to pray.

The women and health workers included in my study in Fort Portal confirmed that they were all religious which may have influenced their lifestyles and health behaviours. However, religion did not seem to affect the use of health services negatively. If a person is in a financial emergency, church communities or faith-based organisation can provide aid, so that the person can afford treatment or travels that are necessary. Likewise, health workers saw their role as first to treat with modern medicine then to use religion such as through prayers.

4.2.3 Role of religion in creating awareness

The women I interviewed stated that they sometimes got access to health information in church. As Vivian (30) related it: “They once communicated with us on that cervical cancer,

that's the first time I ever heard about it". Mary (45) also mentioned that she had heard about cervical cancer in church and answered on the question if she thought religion to be important if she became sick: "Like, in church they told us it is good to go to hospital to check you what is going on in your body, then they treat you. It's okay to go even after the hospital then to go to church they will pray for you. But you need to go first to the hospital". Church leaders are highly respected in Uganda in general and can play an important role in mobilizing people and influencing health behaviours. According to Lloyd et al. (2019, p. 67) the church leaders' words "weigh a lot". Health care workers appear to value this and cooperate with religious leaders to create awareness around health topics. Midwife Grace explained it as:

You know there are times there are some people in villages, actually we met that challenge during outreaches, we tell them to go for the screening, and they say "I know God will heal it. If I have it, I will pray, and God will heal. But when the leader tells people to go for cervical cancer screening, it is good. That person will say "oh my pastor told me, our priest told us, or the reverend told us to go".

Midwife Anna also saw the benefit and necessity of church leaders to get involved in creating awareness. She mentioned it as an important contribution to getting women to present for cervical cancer screening:

Like I don't think there is any time they [church leaders] can preach and don't talk about health. Because most times they know people don't consider their healthy status to be something important, so they always give them that information, because they know they get access to every type of person, because in church every type of person come so they give out health information. It is that good cooperation. Other times you find like others are reverends but also doctors.

Nurse Dorothy had similar thoughts and stated in my interview with her that the best way to inform women about cervical cancer screening was precisely to engage the church leaders:

People believe the church leaders are the holy ones, so when like a church leader makes such kind of communications no other church member will miss. People will try their best to attend to what this is about, because they believe it means so much. So, after like the service priests tell them we have this nurse we have these people who wants to tell you something about health issues that is very important to you. Then you decide after the prayers we want to meet all the mothers, because they always have those groups in the churches".

I went a couple of times to a local Anglican church. At my first visit I had to introduce myself and to pay my respect to the church leader. He was very eager about my research and wanted to learn about cervical cancer services and to pass the information onto women in his church community. In this matter churches provide a good venue for dissemination of medical

information and advices. It shows that religion can be a voice for health campaigns and thus create awareness about life-threatening diseases, such as cervical cancer.

The role of health workers, NGOs, faith-based organisation as well as respected community leaders, such as priest, on creating awareness through campaigns, radio or communication is essential in Uganda. In addition, to provide quality health services as Uganda's poor governance often limits successful services. In the following conclusive remarks, I will reflect shortly on the significant role of NGOs in providing health services in Uganda.

Conclusive remarks

Cervical cancer is the fourth most common cancer type among women worldwide and in low and middle-income countries the leading cause of cancer deaths among women. As it is a disease that progress slowly and remains asymptomatic in early stages, screening is critical to providing control and prevention of the disease. The aim of this thesis has been to explore what encourage or restrain women to come forward for screening in Uganda. Through in-depth interviews and observations in Fort Portal, I gained insight into women's and health workers' knowledge, attitudes and beliefs towards cervical cancer and screening. I wanted to explore if these factors influence choices and motivations to present for cervical cancer screening. During fieldwork it became clear to me that health behaviours must be understood within a wider framework that includes both national and global policies, initiatives and discourses. Hence, this thesis has sought to facilitate a holistic perspective.

Limitations, however, to this study may be that I was not able to recruit women living in remote areas and that women recruited through surveys, were provided with, specific information about cervical cancer and screening before the interviews were carried out. Additionally, due to restricted time during fieldwork I did not have the opportunity to explore factors such as socioeconomic status, education, urban and rural differences and politics, important factors that influence uptake of cervical cancer screening, and which may have facilitated a more holistic perspective.

In the third chapter I outlined and discussed women's and health workers' knowledge, attitudes and beliefs towards cervical cancer and screening. My findings show that there is a variation as to the level of knowledge about cervical cancer as well as in the motivations to attend screening among women in Fort Portal: Some women saw the importance of screening, others had never heard of it. Rumours, cultural conceptions and beliefs, such as screening being a dangerous procedure, led to fear and reluctance towards it. I applied Kleinman's concept of three interconnected health sectors in order to explore attitudes to health care in Uganda. This provided a way into analysing the ways access and quality of services may come to impact the various ways people manage illness. Yet as I have shown, when it comes to cancer care, the professional sector, that is, biomedicine, is the preferred medical treatment method among the women I interviewed in Fort portal. Although health workers in low-income settings may become restricted in their work due to structural factors, health workers in Fort Portal showed good knowledge of cervical cancer and how to treat and prevent it as well as compassion and dedication to their patients. However, poor governance and inadequacies in the public health sector limited their work.

In the Introduction and Chapter 2 I have provided a brief outline of the development of the health system in Uganda, and further explored the impacts of polarisation between public and private health sectors in Chapter 4. There is a discrepancy in access to health care based on socioeconomic status and place of residence that contribute to the present health disparities found in Uganda. Despite the increased focus towards women's health, sexual taboos and moral practices still limit women's rights to access health services. Increased health sensitisation is essential to encourage more women to show up to screening. Based on my findings, use of religious institutions and religious leaders may provide a good channel for dissemination of information in Uganda.

As illustrated throughout this thesis, limitations to services being successfully implemented by the Ugandan government have enhanced the role of NGOs and donor-organisations in Uganda. In fact, in Fort Portal, cervical cancer services were not provided at the regional referral hospital, but at health clinics supported by, for instance, Knowledge for Change and Reproductive Health Uganda. Through international donors they are able to supply health centres with equipment, training and supervision. Although they fill the gap and provide services the government is unable to, international engagements in states with poor governance poses a risk of aid-dependency. Paternalism may lead to failed interventions in the long run as they do not always provide sustainability and development (Sarden et al., 2015). Additionally, donor-organisations often take a vertical approach that do not seek to treat the underlying issues and structures related to health and diseases, and the need to strengthen the health system itself (Packard, 2016). Generous efforts by NGOs such as volunteers and short-stay health workers may contribute to a lack of long-term care and create large gaps in expectations of clients as well as undermining the credibility of local health workers (Adams et al., 2014, p. 188).

There are comprehensive international and national strategies towards eliminating cervical cancer as a public health problem and that emphasise the immediate need for screening services. The "see and treat"-approach is an appealing screening alternative to cytology and may enhance sustainable screening services in low-income settings. However, improved access to, and awareness of, cervical cancer and screening should be of high priority as it is a prerequisite for women's uptake of available services. Moreover, as Adams, Burk & Whitmarsh (2014) argue, local ideologies and experiences as well as cultural, societal and economic barriers, need to be included to understand how people respond to interventions. There are several factors in the "black box", such as local beliefs, attitudes and sexual taboos that need to be taken into consideration for interventions to succeed on both

community and national level. Adams et al. (2014) emphasise a slow-research approach, that entails a deep and realistic understanding of the intervention in question. Hopefully this study can contribute to a more nuanced understanding of the various factors that prevent women from seeking timely health care in Uganda and in the long run encourage more women to come forward for screening.

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Appendix 1: Letter from the Norwegian Social Science Data Service

06/11/2020

Meldeskjema for behandling av personopplysninger



NSD sin vurdering

Prosjekttittel

How can women in Uganda be encouraged to present for cervical cancer screening in order to reduce the number of deaths from cervical cancer

Referansenummer

750215

Registrert

07.10.2019 av Benedikte Victoria Lindskog - benedik@oslomet.no

Behandlingsansvarlig institusjon

OsloMet - storbyuniversitetet / Fakultet for samfunnsvitenskap / Institutt for sosialfag

Prosjektansvarlig (vitenskapelig ansatt/veileder eller stipendiat)

Benedikte V. Lindskog, benedik@oslomet.no, tlf: 98818637

Type prosjekt

Studentprosjekt, masterstudium

Kontaktinformasjon, student

Guro Kjøde Dragset, gurodragset@gmail.com, tlf: 92615835

Prosjektperiode

08.01.2020 - 01.11.2020

Status

03.11.2020 - Avsluttet

Vurdering (1)

18.11.2019 - Vurdert

Det er vår vurdering at behandlingen vil være i samsvar med personvernlovgivningen, så fremt den gjennomføres i tråd med det som er dokumentert i meldeskjemaet den 18.11.2019 med vedlegg, samt i meldingsdialogen mellom innmelder og NSD. Behandlingen kan starte.

MELD ENDRINGER

Dersom behandlingen av personopplysninger endrer seg, kan det være nødvendig å melde dette til NSD ved å oppdatere meldeskjemaet. På våre nettsider informerer vi om hvilke endringer som må meldes. Vent på svar før endringen gjennomføres.

TYPE OPPLYSNINGER OG VARIGHET

Prosjektet vil behandle særlige kategorier av personopplysninger om helse og alminnelige personopplysninger frem til 01.11.2020.

LOVLIG GRUNNLAG

Prosjektet vil innhente samtykke fra de registrerte til behandlingen av personopplysninger. Vår vurdering er at prosjektet legger opp til et samtykke i samsvar med kravene i art. 4 nr. 11 og art. 7, ved at det er en frivillig, spesifikk, informert og utvetydig bekreftelse, som kan dokumenteres, og som den registrerte kan trekke tilbake.

Lovlig grunnlag for behandlingen vil dermed være den registrertes uttrykkelige samtykke, jf. personvernforordningen art. 6 nr. 1 a), jf. art. 9 nr. 2 bokstav a, jf. personopplysningsloven § 10, jf. § 9 (2).

PERSONVERNPRINSIPPER

NSD vurderer at den planlagte behandlingen av personopplysninger vil følge prinsippene i personvernforordningen om:

- lovlighet, rettferdighet og åpenhet (art. 5.1 a), ved at de registrerte får tilfredsstillende informasjon om og samtykker til behandlingen
- formålsbegrensning (art. 5.1 b), ved at personopplysninger samles inn for spesifikke, uttrykkelig angitte og berettigede formål, og ikke viderebehandles til nye uforenlige formål
- dataminimering (art. 5.1 c), ved at det kun behandles opplysninger som er adekvate, relevante og nødvendige for formålet med prosjektet
- lagringsbegrensning (art. 5.1 e), ved at personopplysningene ikke lagres lengre enn nødvendig for å oppfylle formålet

DE REGISTRERTES RETTIGHETER

Så lenge de registrerte kan identifiseres i datamaterialet vil de ha følgende rettigheter: åpenhet (art. 12), informasjon (art. 13), innsyn (art. 15), retting (art. 16), sletting (art. 17), begrensning (art. 18), underretning (art. 19), dataportabilitet (art. 20).

NSD vurderer at informasjonen som de registrerte vil motta oppfyller lovens krav til form og innhold, jf. art. 12.1 og art. 13.

Vi minner om at hvis en registrert tar kontakt om sine rettigheter, har behandlingsansvarlig institusjon plikt til å svare innen en måned.

FØLG DIN INSTITUSJONS RETNINGSLINJER

NSD legger til grunn at behandlingen oppfyller kravene i personvernforordningen om riktighet (art. 5.1 d), integritet og konfidensialitet (art. 5.1. f) og sikkerhet (art. 32).

For å forsikre dere om at kravene oppfylles, må dere følge interne retningslinjer og eventuelt rådføre dere med behandlingsansvarlig institusjon.

OPPFØLGING AV PROSJEKTET

NSD vil følge opp ved planlagt avslutning for å avklare om behandlingen av personopplysningene er avsluttet.

Lykke til med prosjektet!

Kontaktperson hos NSD: Elizabeth Blomstervik
Tlf. Personverntjenester: 55 58 21 17 (tast 1)

Appendix 2: Letter of acceptance Knowledge for Change



University of
Salford
MANCHESTER



Knowledge for Change (Uganda)
Plot 39, Saaka Road
P.O Box 392
Fort Portal
Kabarole district

Date: 29th November 2019

Guro Dragset
Faculty of Social Sciences
Department of Social Work
Oslo Metropolitan University
Pilestredet 46, 0167 Oslo, Norway

Re: Research Placement with Knowledge for Change, in Partnership with Mountains of the Moon University (Uganda) and the University of Salford (UK).

Dear Ms Dragset,

Knowledge for Change 'K4C' is delighted to be able to offer you a 2.5-month student placement beginning in January 2020. K4C represents a long-term international collaboration between Mountains of the Moon University 'MMU' (Fort Portal, Uganda), the University of Salford 'UoS' (Manchester, UK) and Kabarole District Health Office (Uganda). This relationship was formalised in the signing of a Memorandum of Understanding in May 2014, and the organisations agree to be jointly responsible for the negotiation, organisation and management of the placement.

The placement being offered will be research focused and will involve close collaboration with staff and students from the above-mentioned partners and additional stakeholder organisations in the Kabarole region of Uganda. A preliminary research topic has already been identified and discussed with you, focusing on cervical screening in Uganda. It will involve conducting interviews and data collections to encourage more women in Uganda to present for cervical screening with the long-term goal of reducing the number of deaths from cervical cancer.

Aside from the research activity, you may integrate with local students in the faculty of health sciences at MMU and attend relevant lectures, seminars and other events. All K4C projects are active development projects so the primary research goal is to provide an evidence base which can inform current and future policy and interventions.

There is the possibility of utilising the final week of the placement to travel to the University of Salford in the UK, where you will integrate and share experiences with Social Work and

Social Policy students, attend various lectures and perform a formal presentation of your research project to staff and students in the Faculty of Health and Society.

Students are responsible for making their own flight, travel, accommodation and subsistence arrangements in both Uganda and the UK, ensuring they are covered by an appropriate insurance policy for the duration of their placement. K4C and its constituent partners will assist students wherever possible in making these arrangements. Pastoral support, research support and academic supervision will be provided jointly by MMU and UoS.

The total tuition fee chargeable for the above placement will be GBP1,225.

For any questions or queries please contact K4C using the details provided below.

Yours Sincerely,



Mr Ndawula Allan
Project Manager (Mountains of the Moon University)
Project Manager (K4C, Uganda)
Address: Faculty of Health Sciences
Kabundaire Campus
Mountains of the Moon University
Fort Portal, Kabarole District, Uganda
Email: garyallan46@yahoo.com
Phone: +256 (0) 774 671 007



Mr James Ackers-Johnson
Project Manager (University of Salford, UK)
Project Manager (K4C, UK)
Address: Room L530, Allerton Building,
Faculty of Nursing, Midwifery,
Social Work & Social Science
Salford, United Kingdom
Email: J.Ackers@salford.ac.uk
Phone: +44 (0) 161 295 2823



Appendix 3: Informed consent form to women in Fort Portal

*adapted from the WHO informed consent template for qualitative data collection

Request to participate in my research project

This informed consent form is for women in Fort Portal who are willing to participate in research on cervical cancer screening. The research title is “How can we encourage more women in Uganda to present for cervical cancer screening in order to reduce the number of deaths from cervical cancer?”.

Principle investigator: Guro Kjøde Dragset

Organization: Department of Social Work, Child Welfare and Social Policy at OsloMet

Project: How can women in Uganda be encouraged to present for cervical cancer screening in order to reduce the number of deaths from cervical cancer?

This Informed Consent Form has two parts:

- Information Sheet (to share information about the study with you)
- Certificate of Consent (for signatures if you choose to participate)

Part I: Information Sheet

Introduction

I am Guro Dragset, a master student from Oslo, Norway. I am doing a research on cervical cancer screening as part of the organization called Knowledge for Change. I am going to give you information and invite you to be part of this research project. You do not have to decide today whether or not you will participate in the research, and before you decide you can talk to anyone you feel comfortable with about this research project. This consent form may contain words that you do not understand. Please ask me to stop as we go through the information and I will take time to explain. If you have questions later, you can ask them of me or of another researcher.

Purpose of the research

Many women in the world today are getting very sick from cervical cancer. Cervical cancer is a disease that can be cured if diagnosed early. To find out if you have cervical cancer you need to get screened. We want more women to get screened and not become ill of cervical cancer. We believe that you can help us by telling us what you know about cervical cancer. We want to learn what women that live here in Fort Portal know about the disease, as well as women’s thoughts and attitudes towards it and towards being screened. This will give us a better understanding of women’s choices

and practices concerning women's health issues. Hopefully this will lead to a better understanding, openness and better health services for women in your community in the future.

Type of Research Intervention

This research will involve your participation in an individual interview that will take about one hour.

Participant Selection

You are being invited to take part in this research project because we feel that your experience and your knowledge as a woman between the ages 25-50 can contribute much to this research, as well as to Knowledge for Change, and help us to understand better how to best contribute to increased cervical cancer screening in Uganda.

Voluntary Participation

Your participation in this research is entirely voluntary. It is your choice whether to participate or not. If you choose not to participate, all the services you receive at the hospital or from Knowledge for Change will continue and nothing will change. You may change your mind later and stop participating even if you agreed earlier.

Procedures

We are asking you to take part in this research project to help us learn more about cultural practices concerning women's health in Fort Portal, and your beliefs and knowledge about cervical cancer. If you accept, you will be asked:

Personal interviews: to participate in an interview with me. During the interview I will sit down with you in a comfortable place. You can decide where you want the interview to take place – it can be at the Knowledge for Change office, in town or in your home or a friends' home. If you do not wish to answer any of the questions during the interview, you can say so and I will move on to the next question. No one else but me will be present unless you would like someone else to be there. The entire interview will be audio-recorded, but no one will be identified with name on the tape. The information recorded is confidential, and no one else except me will have access to it. I will keep the tape secured in a closed closet and on a password-safe computer. The tapes will be destroyed after 24 weeks.

Duration

The research project takes place over three months in total. During that time, I will visit you one time for the interview, and it will take about one hour.

Risks

We are asking you to share some very personal and confidential information, and you may feel uncomfortable talking about some of the topics. You do not have to answer any question or take part in the discussion/interview if you do not wish to do so, and that is also fine. You do not have to give us any reason for not responding to any question, or for refusing to take part in the interview.

Benefits

There will be no direct benefit to you, but your participation is likely to help us find out more about how to encourage women to present for cervical cancer screening in your community.

Reimbursements

You will not be provided any incentives to take part in the research. However, we will make sure that the interviews are in convenient location for you.

Confidentiality

We understand that Fort Portal is a rather small town and being part of this research project may draw some attention to you. We will not be sharing information about you to anyone outside of the research team. The information that we collect from this research project will be kept private. Your name will be a number, and only the researchers will know what your number is and we will lock that information up with a lock and key.

Sharing the Results

Nothing that you say today will be connected to your name. The knowledge that we get from doing this will be shared with you before it is made widely available for the public. You will also receive a summary of the results. Following this, we will publish the results so that other interested people may learn from the research project.

Right to Refuse or Withdraw

You do not have to take part in this research if you do not wish to do so and choosing to participate will not affect your life situation or job in any way. You can also stop participating at any time that

you wish without being afraid of your job or you getting affected. At the end of the interview/the discussion I will give you an opportunity to add, change or remove some remarks if you feel like it – maybe I did not understand you correctly, we can have a look at it at the end. You can also ask that your personal data is deleted, that incorrect personal data about you is corrected, to receive a copy of your personal data, and you also have the right to send a complaint to the Data Protection Officer or The Norwegian Data Protection Authority regarding the processing of your personal data.

What gives us the right to process your personal data?

We will process your personal data based on your consent. Based on an agreement with Oslo Metropolitan University (OsloMet) and NSD – The Norwegian Centre for Research Data AS – has assessed that the processing of personal data in this project is in accordance with data protection legislation.

What will happen to your personal data at the end of the research project?

The project is scheduled to end **01.11.2020**. All collected data about you will be de-identified, meaning no names, personal identification number or any directly recognisable information about you will be stored or shared. The information that will be collected in this research project will be kept private. Your name will be a number, and only the researcher and supervisor will know what your number is and we will lock that information up with a lock and key. The interview will be recorded and written down and then the recording will be saved on an encoded memory stick. After this the recordings will be deleted from the recording device.

Who to Contact

If you have any questions, you can ask them now or later. If you wish to ask questions later, you are more than welcome to contact me, Guro Dragset, gurodragset@gmail.com.

Where can I find out more?

If you have questions about the project, or want to exercise your rights, contact:

- Oslo Metropolitan University via Benedikte V. Lindskog by email: benedik@oslomet.no or by telephone: +4798818637.
- Our Data Protection Officer at Oslo metropolitan University: Ingrid S. Jacobsen by email: personvernombud@oslomet.no by telephone: +4767235534.
- NSD – The Norwegian Centre for Research Data AS, by email: personverntjenester@nsd.no or by telephone: +47 55582117.

Yours sincerely,

Project Leader (supervisor)

Student

Part II: Certificate of consent

I have been invited to participate in a research project about cervical cancer, and how to encourage more women to present for cervical cancer screening.

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions, and any questions have been answered to my satisfaction. I consent voluntarily to be a participant in this study. I give consent:

to participate in an individual interview

I give consent for my personal data to be processed until the end date of the project
01.11.2020.

(Signed by participant, date)

Statement by the researcher/person taking consent

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands that the following will be done:

- 1. I will ask questions about the participants knowledge, beliefs and attitudes towards cervical cancer and cervical cancer screening**
- 2. All information shared by the participants will be confidential**
- 3. The knowledge that I get from this research will be the basis for my master thesis, and thus most likely shared with the public**

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this ICF has been provided to the participant.

Print Name of Researcher/person taking the consent _____

Signature of Researcher /person taking the consent _____

Date _____

Appendix 4: Informed consent form to health care workers in Fort Portal

*adapted from the WHO informed consent template for qualitative data collection

Request to participate in my research project

This informed consent form is for women health care workers in Fort Portal who are willing to participate in research on cervical cancer screening. The research title is “How can we encourage more women in Uganda to present for cervical cancer screening in order to reduce the number of deaths from cervical cancer?”.

Principle investigator: Guro Kjøde Dragset

Organization: Department of Social Work, Child Welfare and Social Policy at OsloMet

Project: How can women in Uganda be encouraged to present for cervical cancer screening in order to reduce the number of deaths from cervical cancer?

This Informed Consent Form has two parts:

- Information Sheet (to share information about the study with you)
- Certificate of Consent (for signatures if you choose to participate)

You will be given a copy of the full Informed Consent Form

Part I: Information Sheet

Introduction

I am Guro Dragset, a master student from Oslo, Norway. I am doing a research on cervical cancer screening as part of the organization called Knowledge for Change. I am going to give you information and invite you to be part of this research project. You do not have to decide today whether or not you will participate in the research, and before you decide you can talk to anyone you feel comfortable with about this research project. If this consent form contains words that you do not understand, please ask me to stop as we go through the information and I will take time to explain. If you have questions later, you can ask them of me or of another researcher.

Purpose of the research

Many women in the world today are getting sick and die from cervical cancer. Cervical cancer is a disease that can be cured if diagnosed early, and one important part of that is to be screened for cervical cancer. We do not want women to become ill and therefore want more women to get screened of cervical cancer. We believe that you can help us by telling us what you as a health care worker know about cervical cancer, the health care facilities in Fort Portal and cancer prevention.

We want to learn what women that work here in Fort Portal know about the disease, as well as your thoughts and attitudes as a health worker towards it and towards being screened. This will give us a better understanding of women's choices and practices concerning women's health issues. Hopefully, this will lead to a better understanding, openness and better health services for women in your community in the future.

Type of Research Intervention

This research will involve your participation in an individual interview that will take about one and a half hour.

Participant Selection

You are being invited to take part in this research because we feel that your experience as a female health care worker can contribute much to this research and help us to understand better how to best contribute to increased cervical cancer screening in Uganda, and by so doing minimize the risk of cervical cancer.

Voluntary Participation

Your participation in this research is entirely voluntary. It is your choice whether to participate or not. The choice that you make will have no bearing on your job or on any work-related evaluations or reports. You may change your mind later and stop participating even if you agreed earlier.

Procedures

We are asking you to take part in this research project to help us learn more about cultural practices in Fort Portal concerning women's health, and your beliefs and knowledge about cervical cancer. If you accept, you will be asked:

To take part in a personal interview: During the interview I will sit down with you in a comfortable place. You can decide where you want the interview to take place – it can be at the Knowledge for Change office, in town or in your home or a friend's home. If you do not wish to answer any of the questions during the interview, you can say so and I will move on to the next question. No one else but me will be present unless you would like someone else to be there. The entire interview will be audio-recorded, but no one will be identified with name on the tape. The information recorded is confidential, and no one else except me will have access to it. I will keep the tape secured in a closed closet and on a password-safe computer. The tapes will be destroyed after 24 weeks.

Duration

The research project takes place over three months in total. During that time, I will visit you one time for the interview. The conversation will take about one and a half hour.

Risks

We are asking you to share some very personal and confidential information, and you may feel uncomfortable talking about some of the topics. You do not have to answer any question or take part in the interview if you do not wish to do so, and that is also fine. You do not have to give us any reason for not responding to any question, or for refusing to take part in the interview.

Benefits

There will be no direct benefit to you, but your participation is likely to help us find out more about how to encourage women to present for cervical cancer screening in your community.

Reimbursements

You will not be provided any incentives to take part in the research. However, we will make sure that the interviews are in convenient location for you.

Confidentiality

We understand that Fort Portal is a rather small town and being part of this research project may draw some attention to you. We will not be sharing information about you to anyone outside of the research team. The information that we collect from this research project will be kept private. Your name will be a number, and only the researchers will know what your number is and we will lock that information up with a lock and key.

Sharing the Results

Nothing that you say today will be connected to your name. The knowledge that we get from doing this will be shared with you before it is made widely available for the public. You will also receive a summary of the results. Following this, we will publish the results so that other interested people may learn from the research project.

Right to Refuse or Withdraw

You do not have to take part in this research if you do not wish to do so, and choosing to participate will not affect your life situation or job in any way. You can also stop participating at any time that

you wish without being afraid of your job or you getting affected. At the end of the interview I will give you an opportunity to add, change or remove some remarks if you feel like it – maybe I did not understand you correctly, we can have a look at it at the end. You can also request that your personal data is deleted, that incorrect personal data about you is corrected/rectified, receive a copy of your personal data, and you also have the right to send a complaint to the Data Protection Officer or The Norwegian Data Protection Authority regarding the processing of your personal data.

What gives us the right to process your personal data?

We will process your personal data based on your consent. Based on an agreement with Oslo Metropolitan University (OsloMet) and NSD – The Norwegian Centre for Research Data AS – has assessed that the processing of personal data in this project is in accordance with data protection legislation.

What will happen to your personal data at the end of the research project?

The project is scheduled to end **01.11.2020**. All collected data about you will be de-identified, meaning no names, personal identification number or any directly recognisable information about you will be stored or shared. The information that will be collected in this research project will be kept private. Your name will be a number, and only the researcher and supervisor will know what your number is and we will lock that information up with a lock and key. The interview will be recorded and written down and then the recording will be saved on an encoded memory stick. After this the recordings will be deleted from the recording device.

Who to Contact

If you have any questions, you can ask them now or later. If you wish to ask questions later, you are more than welcome to contact me, Guro Dragset, gurodragset@gmail.com.

Where can I find out more?

If you have questions about the project, or want to exercise your rights, contact:

- Oslo Metropolitan University via Benedikte V. Lindskog by email: benedik@oslomet.no or by telephone: +4798818637.
- Our Data Protection Officer at Oslo metropolitan University: Ingrid S. Jacobsen by email: personvernombud@oslomet.no by telephone: +4767235534.
- NSD – The Norwegian Centre for Research Data AS, by email: personvertjenester@nsd.no or by telephone: +47 55582117.

Yours sincerely,

Project Leader (supervisor)

Student

Part II: Certificate of Consent

I have been invited to participate in a research project about cervical cancer, and how to encourage more women to present for cervical cancer screening.

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions and any questions have been answered to my satisfaction. I consent voluntarily to be a participant in this study. I give consent:

to participate in an individual interview

I give consent for my personal data to be processed until the end date of the project
01.11.2020.

(Signed by participant, date)

Statement by the researcher/person taking consent

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands that the following will be done:

- 1. I will ask questions about the participants knowledge, beliefs and attitudes towards cervical cancer and cervical cancer screening**
- 2. All information shared by the participants will be confidential**
- 3. The knowledge that I get from this research will be the basis for my master thesis, and thus most likely shared with the public**

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this ICF has been provided to the participant.

Print Name of Researcher/person taking the consent _____

Signature of Researcher /person taking the consent _____

Date _____

Appendix 5: Interview guide in-depth interviews with women

Background information

- Can you please tell me a bit about yourself?
- Can you tell me what a general day look like for you, from you wake up until you go to bed?

Health care in Fort Portal

- If you or any in your family get ill. What do you do?
- Have you or any in your family ever been ill and submitted to the hospital, if yes: How was that was for you?
- What health care facility do you normally go to?
- Can you explain the role of religion if you become sick? (important if being sick?)
- What are your thoughts on natural medicine or traditional medicine?

Cervical Cancer

- What do you know about cervical cancer?
- If a woman has cervical cancer, what do you think happens with the body?
- Have you heard about cervical cancer screening?
If yes: what have you heard?
If yes: where did you hear about it?
- Have you ever been screened for cervical cancer,
if yes/no: why?
If yes: how would you describe the experience of screening?
If no: do you know of anyone who has been screened?
- What are your thoughts on what a woman should do if she suspects she has cervical cancer? (if anyone in your family got cervical cancer, what would you do?)

Attitudes at home and in society:

- What does your husband/partner think about cervical cancer screening?
- In your community what are the attitudes towards cervical cancer screening?
- How do you experience access to health information in your community?
(how do you get health information?)

Appendix 6: Interview guide in-depth interview with health care workers

Background information

- Can you please tell me a bit about yourself?
- Can you tell me what a general day at work look like for you?
- Can you tell me how it is for you to be a midwife/nurse/clinician at your hospital?

Cervical cancer

- What is your opinion about how cervical cancer screening in Uganda and Fort Portal is?
- Can you please tell me about the risk factors for getting cervical cancer?
- And what are the symptoms?
- What are the different screening types for cervical cancer?
- Have you ever been screened for cervical cancer?

Health care system and awareness

- Can you tell me about cervical cancer screening at your hospital? What are the challenges?
- Do you have any thoughts how to improve the services on cervical cancer screening?
- What are the most important factors as your role as health care worker when it comes to cervical cancer screening?
- What can you contribute to as a health care worker when it comes to getting women to present for cervical cancer screening?
- What are your current thoughts about getting women in Fort Portal to present for cervical cancer screening?
- What do you think is the best way to inform about cervical cancer screening?
- In your community what are the attitudes towards cervical cancer screening?