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### Shaping Service Delivery For Cervical Cancer Screening: Understanding Knowledge, Acceptability And Preferences Among Women In The Neno District Of Malawi

Melissa Marie Emilie Carvalho  
Yale University, [melissa.carvalho@yale.edu](mailto:melissa.carvalho@yale.edu)

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Shaping Service Delivery for Cervical Cancer Screening: Understanding  
Knowledge, Acceptability and Preferences among Women in the Neno  
District of Malawi

By

Melissa M. Carvalho

Thesis submitted in partial fulfillment of the  
Requirements for the degree of  
Master of Public Health  
In Chronic Disease Epidemiology  
At  
The Yale School of Public Health

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## Abstract

**Background:** Located in south-eastern Africa, Malawi is a low income country with a population of 16.4 million. It is currently estimated to have the highest age-standardized rate of cervical cancer in the world at 75.9 per 100,000 population. Cervical cancer accounts for 28% of all reported female cancers in the country, and 80% of women diagnosed with the disease die from it, making cervical cancer a public health priority for the country. Despite the fact that cervical cancer screening services (by visual inspection with acetic acid (VIA)) has been offered free of charge at public health facilities in the country since 2004, the services remain underutilized across the country. The purpose of this study was to explore potential factors associated with the acceptability and utilization of cervical cancer screening services among adult women in the Neno district of Malawi, and to identify their service delivery preferences in order to guide the design of effective cervical cancer education and screening programs.

**Methods:** This study employed an exploratory qualitative research study design. Data was collected between July and August 2015 in the district of Neno, Malawi by conducting in-depth semi-structured interviews within a sample of 50 women between the ages of 18-55 years. Participants were recruited among women attending health facilities and community screening events within the district using a purposive sampling technique. Constructs from the Health Belief Model and Socio-Ecological Model were used to construct a conceptual framework for this study.

**Results:** Several themes emerged from the data, namely: misconceptions about how cervical cancer develops, low perceptions of risk of the disease, effects of interpersonal interactions on preventative behaviors, barriers limiting access to cervical cancer screening services, and service preferences for the integration of cervical cancer screening. Despite limited understanding about the transmission and development of cervical cancer, knowledge about its risk factors and signs and symptoms was relatively high among the study sample. Perceived barriers to using cervical cancer prevention services included: distance from health facilities, challenges in accessing transportation, limited availability and awareness of services, logistical factors, and a low perception of risk. Facilitators to using the services were based on: high satisfaction with healthcare, strong desires to know about one's health status, interpersonal interactions with health professionals, husband's approval, and faith in the curative abilities of western medicine. Women in the sample reported high acceptability and intention to obtain screening if the services were available at a nearby location. The study sample was also highly receptive of integrated approaches to receiving cervical cancer screening both at health facilities and community screening events

**Conclusions:** Knowledge and awareness about cervical cancer and its risk factors among the study sample was relatively high, indicating that sporadic health education and awareness raising about the disease has been taking place throughout health facilities within the Neno district. Misconceptions about the disease however highlight the importance of having a systematic method and coordinated strategy for delivering cervical cancer health education. The expansion of cervical cancer screening services across all health centers in the district is needed in order to address barriers to accessing preventative services and to increase coverage and utilization rates for VIA screening services in Neno.

## **Acknowledgements**

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## **I. Introduction**

### **1.1 Global Burden of Cervical Cancer**

The global burden of cancer is growing, and women's cancers, notably breast, cervical, and ovarian cancer, are now responsible for hundreds of thousands of premature deaths every year. These cancers affect women at their peak years when they are the most productive, having major economic as well as public health implications. Cervical cancer in particular remains a significant contributor to global cancer-specific morbidity and mortality, despite it being one of the most preventable and treatable cancers (Ferlay et al., 2015). As of 2012, it was the fourth most commonly diagnosed cancer in women, accounting for 528,000 new cases and 266,000 deaths worldwide (GLOBOCAN, 2012). Whereas incidence and mortality for this disease have significantly declined over the past 60 years in high-income countries, largely as a result of improved early detection and treatment, cervical cancer continues to be one of the most common causes of cancer-specific deaths in women from low and middle income countries. Approximately 85% of the global burden and 87% of global deaths from this disease occur in developing countries. Furthermore, the average risk of dying from cervical cancer before the age of 75 is three times higher in low and middle income countries as compared to high-income countries (Ferlay et al., 2015).

### **1.2 Cervical Cancer in Sub-Saharan Africa**

In Sub Saharan Africa (SSA), the burden of cervical cancer is particularly high, as 16 of the 20 countries with the highest incidence of the disease are located on the continent (Maseko, Chirwa, Muula et al., 2015). Cervical cancer represents 22% of all cancers in African women (Anderson, Sangvhi, Kibwana et al., 2010). Moreover, every year an estimated 80,400 of these women are diagnosed with the disease, and 50,030 die because of it. Countries in Eastern and Central Africa, including: Zambia, Malawi, Mozambique, and Tanzania, have among the highest cervical cancer rates worldwide, with age standardized rates (ASRs) estimated to be over 50 cases per 100,000 people (Jemal, Forman, Ferlay et al., 2012). These high reported rates are a consequence of low coverage of cervical cancer screening and limited access to treatment services. Cervical cancer is therefore an important public health challenge for health systems in these high-risk developing countries (World Health Organization (WHO), 2013).

### **1.3 Natural History of Cervical Cancer**

Cervical cancer arises in cells lining the cervix, the lower part of a woman's uterus which connects the body of the uterus to the vagina. The cervix is composed of two types of cells: squamous and glandular cells. These cells are each located on opposite ends of the cervix, but they meet at a location known as the transformation zone. Most cervical cancers arise in epithelium at the transformation zone via a series of 4 steps: the transmission of an oncogenic

human papillomavirus (HPV), the persistence of an HPV infection, gradual pre-cancerous changes in infected cells, and finally the development of invasive cervical cancer (Schiffman, Castle, Jeronimo et al., 2007). Cervical cancer is unique in that it has a detectable preinvasive period during which an initial HPV infection progresses to invasive cancer. During this period, cytologically and histologically distinct precancerous phases develop, which include cervical dysplasia and cervical intraepithelial neoplasia phases (CIN 1, 2, or 3) (Anderson et al., 2010). Precancers are typically established within 5-10 years after an initial HPV infection, however this only occurs in less than 10% of new HPV infections (Schiffman et al., 2007). A minority of women with precancers subsequently develop invasive cancer after an additional 5-7 years (Anderson et al., 2010). This relatively slow progression of precancerous lesions to invasive cervical cancer provides a window of opportunity to detect and prevent the progression of cervical cancer.

#### **1.4 HPV Transmission**

Several large-scale epidemiologic studies have established the human papillomavirus (HPV) as the etiologic cause of cervical cancer, as over 99% of invasive cervical cancers and its precursors are related to an HPV infection. HPV is a necessary but not solely sufficient precursor to cervical cancer. More than 100 HPV subtypes exist, however only a small subset have been linked to the development of cancer (Anderson et al., 2010). HPV16 and HPV18 are the two most oncogenic HPV subtypes, and are responsible for 70% of cervical cancers.

HPV infections are sexually transmitted by skin-to-skin or mucosa-to-mucosa contact, and viral particles are able to reach cells in the basal layer through tears to the mucosa. (Schiffman et al., 2007). There is therefore a high probability of HPV infection per sexual act. Consequently the peak prevalence of infection with oncogenic HPV subtypes is close to the initiation of sexual activity in adolescence or young adulthood. Evidence suggests that at least 50% of sexually active adults will be infected with one or more genital HPV subtypes at some point in their lifetime (Anderson et al., 2010). Most of these HPV infections however are cleared or are suppressed by cell mediated immunity within 1-2 years, therefore failing to cause symptoms or invasive disease (Anderson et al., 2010).

#### **1.5 Risk Factors for HPV Infection and Cervical Cancer**

Risk factors for HPV include an early sexual debut, a history of sexually transmitted infections (STIs), and multiple lifetime sexual partners (of a woman or her partners) (ACCP, 2004). The Human Immunodeficiency Virus (HIV) also puts women at higher risk for HPV infections as it suppresses the immune system, allowing HPV infections to persist. Several studies have provided evidence suggesting that HIV-infected women have a higher prevalence of HPV oncogenic subtypes and that these infections are more persistent compared to HIV-negative women. Furthermore, HIV-infected women have a higher risk of developing invasive cervical cancer, with some studies indicating a 5-fold increased risk. Cervical cancer also appears to

progress more rapidly in HIV-infected women, as these women tend to develop the disease 10-15 years younger than HIV-negative women (Anderson et al., 2010).

Smoking, multi-parity, and long-term use of oral contraceptives are other risk factors that have been found to double or even triple the risk of precancer and invasive cancer among women infected with oncogenic HPV subtypes. Low socioeconomic status is another external factor that has been associated with increased risk of precancer, even when accounting for recent medical care (Schiffman et al., 2007).

## **1.6 Primary Prevention of HPV infection**

Primary prevention efforts for HPV infections have previously centered on health education programs promoting abstinence, encouraging the use of barrier contraceptives ( primarily condoms), and advocating for a reduction in the number of sexual partners (Schiffman et al., 2007). Available data however suggest that these programs would have a weak effect in reducing HPV infections, given the fact that even mutually exclusive monogamous couples are still able to transmit HPV infections (obtained from previous relationships) to one another (ACCP, 2004). Furthermore, a number of cross-sectional studies have failed to demonstrate the effectiveness of the use of condoms by men in reducing the risk of transmitting HPV infections in women. One longitudinal study carried out among young undergraduates at the University of Washington however, appeared to demonstrate that male condoms do reduce the risk of male-to-female genital HPV transmission. In this study, the incidence of genital HPV infection among women whose partners used condoms for all instances of intercourse during follow-up was 37.8 per 100 patient-years at risk, compared to an incidence rate of 89.3 per 100 patient-years at risk among women whose partners only used condoms less than 5% of the time. Yet results from this study also demonstrate that even strict adherence to condom use is not completely protective against HPV transmission, given that the male external genitalia is not completely covered (Winer, Feng, O'Reilly et al., 2006). Alternatively, there is evidence that male circumcision might be protective against HPV infection, reducing the risk of transmission (Schiffman et al., 2007).

The best option for long-term prevention of HPV infections still remains the immunization of adolescent girls and young women who have not yet become sexually active. Three vaccines against HPV have been developed and are now licensed in most countries. These vaccines prevent more than 95% of infections caused by HPV subtypes 16 and 18 and have shown to provide some cross protection against other less common HPV subtypes that also cause cervical cancer (WHO, 2013). Although vaccination can protect young adolescent girls against infection, secondary prevention measures are still necessary for adult women who have already been infected with HPV.

## **1.7 Prevention of Cervical Cancer**

Global efforts to prevent cervical cancer have primarily focused on screening asymptomatic women for abnormal cervical tissues, by detecting and treating precancerous lesions before they

progress to advanced stages. Screening reduces cervical cancer morbidity and mortality, as studies have shown that it decreases the risk of dying from cervical cancer by 80 - 90% (Maseko et al., 2014). A number of cervical cancer screening techniques are currently available worldwide, and have proven to be effective in the early detection of precancerous lesions (WHO, 2013).

Cervical cytology, also known as the Papanicolaou (Pap) smear test, was introduced in 1949, and has been associated with measurable reductions in cervical cancer incidence and mortality in high income countries. It is based on the cytological examination of a sample of cells collected from the cervix using a wooden or plastic spatula or brush during a speculum or pelvic examination. The cells are then smeared and fixed on a slide in a laboratory and evaluated by a trained cytology technician. This screening procedure therefore requires a multistage process before results can be available to the patient. Furthermore the sensitivity and specificity of cytology has not been consistently high in certain settings, specifically resource-limited ones. (ACCP, 2004). Cytology-based screening programs present a number of challenges for developing countries as a result of: weak health infrastructures, a lack of trained cytology technicians, a shortage of cytology laboratories, and high costs (Anderson et al., 2010).

Due to these limitations, alternative strategies to cytology have been developed to screen for cervical precancerous lesions which include HPV DNA testing and screening by visual inspection. Screening by visual inspection involves swabbing the cervix with 3-5% acetic acid (VIA) or Lugol's iodine (VILI) using a cotton applicator during a pelvic examination. When vinegar is applied to the cervix, precancerous lesions appear white, differentiating themselves from normal cells. Similarly, when abnormal cervical cells absorb iodine they appear yellow, whereas normal cells retain a mahogany-brown color. Screening by visual inspection (VIA or VILI) can be implemented in a wide range of settings as it requires a minimal amount of resources, and like cytology, it can be administered by trained nurses, midwives, clinical assistants, or physician's assistants. Additionally, because no laboratory processing is required for this screening technique, results can be obtained immediately. Studies have shown that the sensitivity of VIA has been equivalent or better than cytology, while its specificity has been lower. A key advantage of these techniques is that they offer the ability to provide immediate treatment on the same visit, known as the single-visit approach (ACCP, 2004).

Safe and effective outpatient treatment methods for precancerous lesions are available, notably cryotherapy and loop electrosurgical excision procedure (LEEP). Cryotherapy destroys precancerous cells by freezing them in the cervix, using compressed carbon dioxide or nitrous oxide gas. The second method, LEEP, uses a looped shaped electric wire to remove precancerous lesions. Unlike cryotherapy however, it requires local anesthesia and a continuous power supply. It still remains a less expensive and less invasive option than carrying out a more complex inpatient method, such as a hysterectomy (ACCP, 2004).

## 1.8 Cervical Cancer Screening Programs in Malawi

Malawi is a small landlocked country in southern Africa with a population of 16.4 million. It remains one of the poorest and least developed countries in the world, ranking in the bottom 17 countries on the Human Development Index (United Nations Development Program (UNDP), 2010). Health indicators for Malawi demonstrate that the country faces several health challenges, notably: a high HIV prevalence rate (10.6% for women and men aged 15-49 years), a high maternal mortality ratio (675 deaths per 100,000 live births), and high under-five mortality levels (112 deaths per 1000 live births) (National Statistical Office (NSO) and ICF Macro, 2011). Among conditions affecting Malawian women, cervical cancer is considered to be a public health priority in Malawi, as the country is currently estimated to have the highest age-standardized incidence rate of cervical cancer in the world at 75.9 per 100,000 population (Maseko et al., 2015). In comparison the United States had an age standardized rate of 7.5 per 100,000 population in 2013 (National Cancer Institute, 2016). Cervical cancer accounts for 28% of all reported female cancer cases in Malawi, and 80% of women diagnosed with this cancer present at late stages when the cancer has spread and is no longer operable (Hami et al. 2014). On average, 3,684 women are diagnosed with cervical cancer every year, and 85% of those women die as a result of the disease.

This high mortality rate exists even though cervical cancer prevention programs were established in the country since the late 1980s. These programs were initially carried out with financial support from various international non-governmental organizations (NGOs) in a limited number of districts. As of 2004, the Ministry of Health (MOH) took full control of the programs and implemented a national cervical cancer screening program, providing VIA services free of charge at central and district hospitals across the country. The program aims to screen 80% of all Malawian women aged 30-55 years, over a 5-year period (Hami et al. 2014). Cervical cancer screening and treatment activities have also been integrated into reproductive health services in all districts, with some districts even taking the initiative to expand the service to their health centers (Maseko et al., 2015).

Yet despite all these efforts, healthcare utilization data indicate that very few women have obtained screening. Based on the WHO 2010 Malawi summary report, between 2.5% and 3.7% of women aged 18-69 years utilized screening services between 2000 and 2001 (Maseko et al., 2014). Furthermore, a study assessing cervical cancer screening coverage in 57 countries, found that Malawi was one of three countries with the highest proportion of women reporting never having received a pelvic exam, and more than 90% of women reported never having been screened for cervical cancer (Gakidou et al., 2008). A number of studies have found that VIA programs are not well understood and remain underutilized in Malawi (Fort, Makin, Siegler, Ault, Rochat, 2011). Lack of utilization of cervical screening services accounts for the late diagnosis and high disease burden of cervical cancer in developing countries (Maseko et al., 2015).

## **1.9 Sociocultural Factors in Cervical Cancer Prevention**

Health interventions pertaining to sexual and reproductive health require a socially and culturally integrated approach, as the influence of traditional values, beliefs, and social norms can play an important role in determining women's access to sexual and reproductive health information and their utilization of services. Gender-influenced power relations also have a significant impact on a woman's ability to control her sexual and reproductive health (WHO, 2010). This issue is especially relevant in Malawi, where 40% of ever-married women have suffered from spousal or partner abuse (physical, emotional, sexual), and 25% of all women report being victims of sexual violence. Furthermore only 55% of women report participating in decisions about their own healthcare and 30% participate in decisions about major household purchases (NSO, 2011).

The role of social stigma has also been increasingly recognized as a potential barrier to cervical cancer screening acceptability, as the fear of rejection by their partners, families and communities can prevent women from seeking preventative services. In fact, as a result of the stigmatization of cervical cancer among Zambian women, the Cervical Cancer Prevention Program in Zambia (CCPPZ) rebranded itself as the "Cervical Health" program in order deemphasize the reference to cancer (Mwanahamuntu et al., 2011). Cancer-related stigma has not been explored in great depths, especially within the African context. More research is needed about the impact of stigma on the acceptability and utilization of cervical cancer prevention services.

## **1.10 Study Rationale**

In order to design and implement an effective cervical cancer screening program among any given population, it is essential to identify knowledge gaps, sociocultural beliefs, and behavioral patterns that may facilitate or hamper the success of a program. In 2014, only 350 cervical cancer screenings were conducted in the Neno district of Malawi, despite it being composed of 33,080 women of childbearing age (Malawi National Statistics Office, 2008). As of August 2015, VIA screening was only being offered at 3 health facilities operating in the district, with plans to expand services in all health facilities in Neno. As part of the planning process, this study was undertaken to explore patient and system-centered factors that impact cervical cancer screening utilization among at-risk women in the Neno district of Malawi.

Previous studies conducted in other districts of Malawi suggests that the most prominent barriers to cervical cancer screening are: low knowledge of cervical cancer, low perceived susceptibility, low perceived benefits from the service, and a lack of transportation (Hami et al., 2014; Fort et al., 2011; Kleine & Nkhoma, 2004). This study however will seek to go further than just investigating factors limiting access to care, but will also elicit women's preferences regarding reproductive health services delivery and the integration of these services in various models of care. Too often, women's views have not been taken into account in the process of developing and delivering health care programs for their benefit. It is important to empower

women to voice their opinions so that more effective health programs can be crafted in low-resource settings.

### **1.11 Study Objectives & Aims**

The purpose of this study was to investigate potential factors associated with accessibility and acceptability of cervical cancer screening services among women attending health facilities in the Neno district of Malawi, and to identify their service preferences relevant to receiving VIA screening services across health facilities and community screening events in the district. Results from this study will provide insights on culturally relevant strategies to design future health education and intervention campaigns with the goal of achieving high coverage and strengthening the delivery of cervical cancer prevention services in the Neno District of Malawi.

#### Specific Objectives

- To assess general knowledge and awareness of cervical cancer and its prevention methods in a sample of women attending health facilities or community screening events in the Neno district of Malawi
- To explore perceptions and attitudes regarding cervical cancer screening and to determine acceptability of the VIA screening procedure
- To identify major barriers and facilitators to accessing screening services and service delivery preferences for VIA screening among the study sample
- To understand the effects of gender-influenced power relations on acceptability and intention to obtain cervical cancer screening

This study was carried out in collaboration with Partners in Health, an international non-governmental organization based in Boston, with the aim of improving Neno District's cervical cancer screening program in a manner that is responsive to identified needs.

## **II. Methods**

### **2.1 Study Design**

This research study draws primarily on qualitative research methods, using semi-structured interviews, to gain a comprehensive overview of women's thoughts regarding cervical cancer prevention in the Neno district of Malawi. A qualitative research design provided for an in-depth exploration of participants' personal experiences, knowledge, and attitudes towards cervical cancer and VIA screening services. Qualitative research methods allow researchers to explain the way in which people in a particular situation think about, account for, and take action regarding a specific topic and can lead to the development of theory regarding health behaviors (Miles & Huberman, 1994).

### **2.2 Adapted Conceptual Framework**

A conceptual framework provides a context in which a phenomenon can be understood by examining a set of key variables and relationships (Ulin, Robinson, & Tolley, 2005). In this research study, constructs from the Health Belief Model (HBM) and the Socio-Ecological Model (SEM) were used to develop a framework that would conceptualize the dynamics of women's acceptability of cervical cancer screening and intention to be screened. The Health Belief Model's theoretical framework has been widely used to understand cancer-screening practices among underserved women. It describes elements of individuals' health beliefs that are likely to predict health behaviors, notably a person's: perceived risk of developing a disease or condition, perceived beliefs about the severity of a disease, beliefs about the benefits or negative consequences of adopting a health strategy, their own health motivation, and internal or external cues to action (Gillam, 1991). Alternatively, the premise of the Socio-Ecological Model is that individuals are part of a social, institutional, and physical environment and that interactions between the individual and other forces in their environment influence health and well-being (Ulin et al., 2005). The study's conceptual framework examines relationships at the individual, interpersonal, and organizational level.

### **2.3 Study Site**

We carried out a qualitative study in the Neno district of Malawi. Neno is rural district located in the southern region of Malawi, with a total population of 130,612 (Herce, Kalanga, Wroe et al., 2014). Over half of Neno's population lives below the World Bank poverty line of \$116 USD per person per year. Ninety percent of Neno's population rely on agriculture as their main livelihood (Malawi National Statistics Office, 2008). Most of the district's economic and health indicators reflect the country's national averages, however life expectancy in Neno is slightly higher for both men and women compared to the national average. The Malawi MOH provides essential health services free of charge throughout public health facilities in the district.



Furthermore since 2007, Partners in Health, has been supporting the MOH in providing comprehensive healthcare to district residents. Neno is served by a district hospital, one community hospital, and 11 government health centers (Herce et al., 2014).

## **2.4 Study Population**

Our study population consisted of adult women between the ages of 18-55 years, attending health facilities and community screening events across the Neno District in 2015. To participate in the study women had to be able to express themselves in Chichewa or English the two official national languages of Malawi. Women who had previously been or were currently diagnosed with any type of cancer were excluded from the study. Critically ill persons were not eligible to participate in the study.

## **2.5 Sampling and Recruitment**

A purposive sampling technique was used to recruit participants into the study. The number of participants was not set a priori, as the final sample size was dependent on when theoretical saturation was reached ( the point where no additional insight or when the complete range of constructs making up a framework is fully represented by the data). Study participants were recruited from outpatient departments and Integrated Chronic Care (ICC) clinics at the Neno district hospital, the Lisungwi Community hospital, and 10 other government health centers providing health services across Neno district. We also recruited participants at district-wide community screening events organized by Partners in Health.

## **2.6 Research Instrument**

In order to carry out in-depth interviews, we crafted a semi-structured interview guide that was adapted from sample questions developed by the Alliance for Cervical Cancer Prevention (ACCP, 2004) to assess community perspectives related to cervical cancer. Other validated instruments from which we adapted our questions includes a questionnaire from a study investigating potential barriers to mammography screening in Hispanic/Latino women living in the Northeast United States (Jones, Doyle & Torres et al. 2011). Furthermore we incorporated questions exploring various constructs from the Health Belief Model into our interview guide. We included demographic and health- related questions to provide a basic profile of the study population. The semi-structured interview guide was translated into Chichewa and local study investigators reviewed it prior to use in order to ensure that it was culturally sensitive, comprehensive, and that it provided a thorough framework for obtaining precise information from study participants. The interview guide was pilot tested with women attending health services at the Neno District Hospital to assure content validity and improve question comprehension.

Women's knowledge, attitudes and perceptions of risk were also quantitatively assessed within the semi-structure interview guide. Women who reported being aware of cervical cancer were evaluated on their knowledge of key risk factors for the disease. A knowledge score was generated by asking six True or False questions regarding the following risk factors: early sexual debut, multiple sexual partners, multiple deliveries, HIV, tobacco, and family history. A single point was awarded for every right answer. Attitudes regarding VIA screening were quantitatively evaluated using a Likert scale (1 = not at all concerned, 2 = a little concerned, 3 = somewhat concerned, 4 = very much concerned). Women were asked to rate how concerned they felt about the pain, danger, and embarrassment of the VIA screening procedure. They were also asked to rate their fear of getting diagnosed and their concern about transportation. Lastly, perception of risk for cervical cancer was measured by asking women to rate their probability of developing cervical cancer in their lifetime (from 1= very low, 2= low, 3= neither high nor low, 4= high, 5=very high).

## **2.7 Interviewers**

We selected six staff members from the Partners in Health (PIH) Monitoring and Evaluation team and Neno District Health Office to carry out one-on-one interviews with study participants. Interviewers consisted of both males and females. Prior to data collection, all members of the research team were required to complete the NIH Protecting Human Subjects Training online and to participate in a training workshop where they were given a comprehensive overview of cervical cancer and the VIA screening procedure and were further trained in qualitative research data collection methods by the Neno district medical officer and senior staff from the PIH Monitoring and Evaluation team.

## **2.8 Data Collection**

We recruited participants during a 4 week period between July and August 2015. Women waiting at outpatient departments, ICC clinics, and community screening events who were between the ages of 18-55 years, who had never been diagnosed with cervical cancer, and who met other inclusion criteria (listed above 2.4), were purposely approached by research team members and were asked to participate in the study. Women were recruited between 8am – noon at most health facilities and after 3 pm at community screening events. Women who were willing to participate in the study were given further description about the study objectives and procedures. Verbal consent was obtained from all participants prior to each interview. One-on-one interviews were carried out in a private setting at each health facility and community screening event. All interviews were audio-recorded and conducted in Chichewa, lasting on average 45 minutes to an hour. Throughout the data collection process, field notes were taken by the primary investigator in order to report descriptive information about actions, behaviors, or interview setting that might be of importance to interpreting the data. Women received a bag of

sugar and bar of soap equivalent to \$4 USD for their participation. Furthermore, participants received information about cervical cancer and VIA screening at the end of each interview.

## **2.9 Data Analysis**

All audio files were translated and transcribed verbatim into English, by two independent interpreters in order to verify the accuracy of the transcripts. Descriptive statistics describing the sample were generated using the R statistical software, while the QSR NVivo 10 software was used to analyze qualitative data generated from the study. A subset of the data was first analyzed for emerging themes through a process of open coding. This process consisted of examining the data for common patterns to create relevant categories. Two of the study's investigators independently conducted open coding, generating thematic codes. The investigators then compared their list of codes to assess inter-coder agreement and to clarify and resolve discrepancies. A formal codebook was produced and used to analyze the remaining interviews. Themes were organized and further developed when connections between categories were identified.

## **2.10 Ethical Considerations**

This research study was approved by Human Subjects Committee at Yale University and the National Health Sciences Research Committee of Malawi under existing umbrella IRB protocols at Partners in Health Malawi. Informed consent was obtained from each participant before inclusion in the study.

## III. Results

### 3.1 Study Population Characteristics

The study population consisted of 50 women attending from outpatient departments, Integrated Chronic Care clinics, and community screening events in the Neno district of Malawi. Participants ranged between 18-55 years of age with a mean age of 35.2 years (sd  $\pm$  9.9). Seventy-eight percent (n= 39) of women in the study were married or living with a partner, 8 % (n= 4) were single, and 14 % (n= 7) were either separated, divorced, or widowed. All but 4 married women in the sample were in monogamous marriages. Over three-fourths of the study sample had a primary school level education (n= 39), and only a small subset (n=7) of women had ever received an education beyond this level. Most women supported themselves through farming (57.1%) or through a small business (32. 7%) selling food products in the market or charcoal by the side of the road. Over a quarter of the women in sample (26.5%) were Seventh Day Adventist, 20.4 % were Catholic, and the rest of the sample was composed of members from a wide range of Christian protestant denominations operating in Malawi (53.1%). No participants of Muslim faith were sampled in this study (**Table 1**).

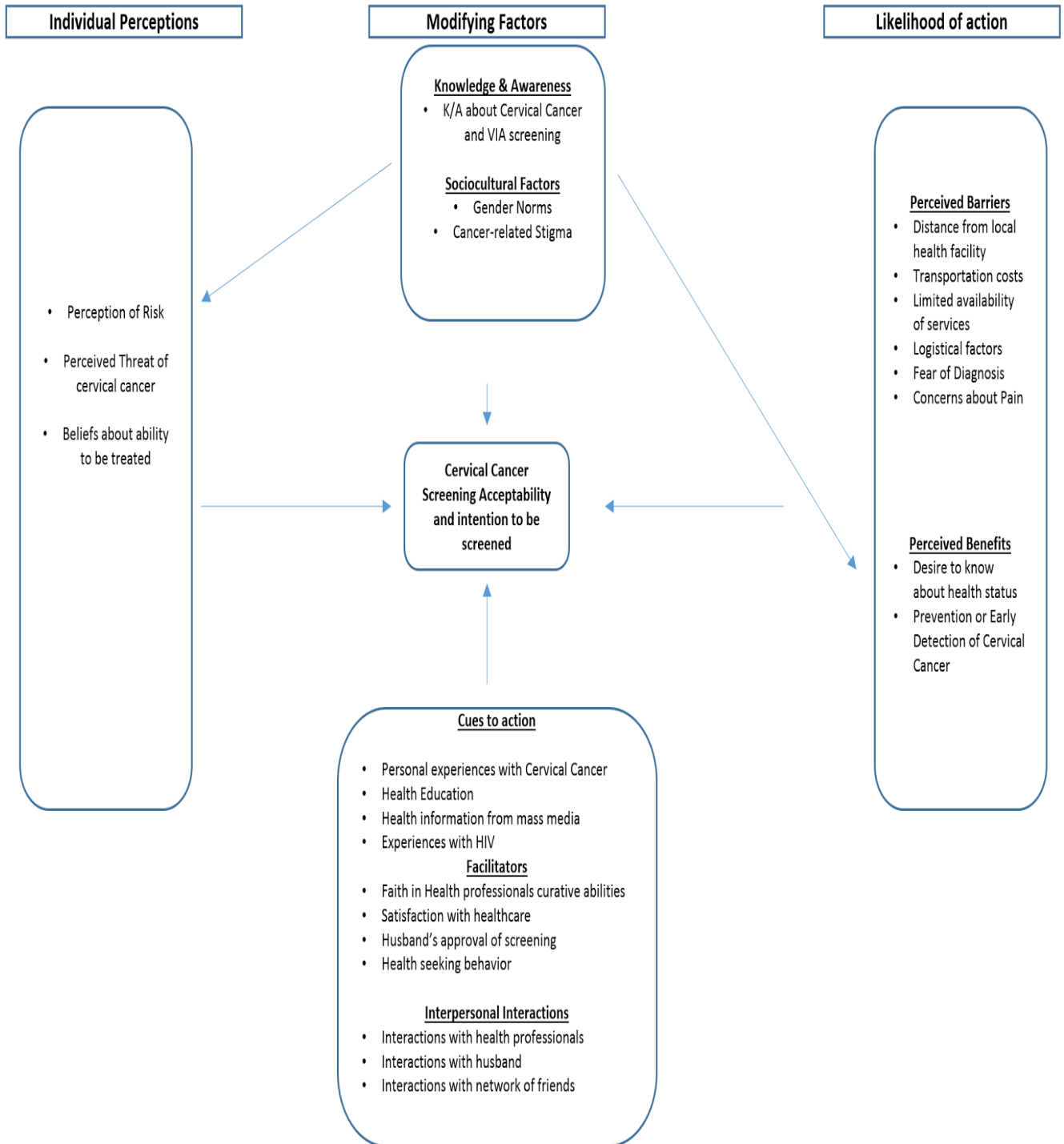
Thirty percent (n= 15) of women in the sample were HIV positive. Participants had on average 4.5 (sd  $\pm$  2.5) live births, though the vast majority (n= 39, 78.0 %) had previously utilized family planning methods. Less than a third of the sample had ever received a pelvic exam (n=14, 28%) and less than a quarter had previously obtained cervical cancer screening (n=12, 26%) (**Table 1**).

Within the prior six months, the average frequency at which women in the study population sought care at any given health facility was approximately 3 visits (**Table 1**). Almost half of the study participants (n= 22, 46.8%) indicated that their primary source of health information were health facilities, health care workers, or health surveillance agents. Other reported primary sources of health information for women in the sample included radio broadcasts programs (N= 16, 34 %), community health talks (n=4, 8.5%) and village health workers (n= 2, 4.3%) (**Table 1**).

### 3.2 Study's Conceptual Framework

Contributing factors influencing cervical cancer screening acceptability and intention to be screened were uncovered to build a conceptual framework which was adapted using constructs from the Health Belief and Socio-Ecological Models. This adapted conceptual framework (see **Fig. 1**) presents the interconnections between significant factors emerging from the data that influenced women's intentions and ability to participate in cervical cancer prevention behaviors within the context of Neno, Malawi. The various concepts in this framework are laid out under the following major themes: knowledge and awareness about cervical cancer, individual perceptions of the disease, perceived benefits and barriers of cervical cancer screening (VIA), the effect of sociocultural factors and interpersonal interactions, and finally facilitators and cues to action.

**Fig 1: Adapted Conceptual Framework using the HBM and SEM**



### 3. 3 Knowledge & Awareness about Cervical Cancer

Among the study population, cancer was generally perceived as a dangerous and fatal disease. Women often portrayed the disease as an eruption or a swelling of “*something*” inside the body, while others believed it developed from wounds. Most women also understood that there were multiple types of cancers and would describe the disease as attacking various organs or specific parts of the body. Many women specifically made references to “leg cancer”, as that was the body part most were aware that cancer affects. *“I heard that cancer can affect the leg, then the leg starts swelling. They say that when one has a wound on the leg today, it may progress to cancer if not properly treated. And eventually the leg may be amputated.”*

Since leg swelling is a common symptom of Kaposi sarcoma, which is observed at higher rates in countries plagued with a significant AIDS burden, like Malawi, it is possible to assume that these women were describing features of this particular type of cancer (Ferlay et al., 2015). Not all women in the study population were aware of cancer however. Approximately one fifth of the sample had no notion about what cancer involved. These women indicated that they had heard of the word “cancer” and most knew that it was a disease, but beyond those facts, they could not elaborate further about what it entailed.

*“I did not have much interest to ask what cancer is. I have just heard but I don’t know what it is. I should lie here, I have hardly asked how cancers comes, or what cancer means. Not at all.”*

*“mmmh about cancer, I do not know much. I just hear about the disease but I don’t know.”*

In contrast, awareness about cervical cancer more specifically was much higher among the study sample, as 92% (N= 46) of women reported that they had heard of the disease (**Table 2**). Cervical cancer was generally understood by most women to be a disease affecting the cervix, however when asked to provide more details regarding the characteristics of the disease, few women could offer specifics beyond the fact that they had heard it was dangerous and that women should obtain cervical cancer screening to prevent it.

*“What we heard was just to inform us that there is cervical cancer. But we were not told about some of the dangers. We were told that there is cervical cancer and there is need to get screened.”*

#### A. Knowledge about Cervical Risk Factors

Despite limited knowledge about the nature of cervical cancer, a substantial proportion of women were able to identify risk factors for the disease. The mean knowledge score for women in the study was 4.4 (sd ± 1.0) out of 6 possible points (**Table 2**). Women in the study sample generally understood that cervical cancer was linked to sexual and reproductive behavior. Most women correctly noted that having multiple sexual partners increases the risk of developing

cervical cancer. Furthermore, they clearly recognized the role men played in the development of cervical cancer, however many implicated them for “*spreading the disease*”. There was a pervasive notion among them that cervical cancer in and of itself could be contracted during sex. Many of these women believed that men could directly transmit this disease to women during sexual intercourse. So they assumed that men were asymptomatic carriers for cervical cancer, who could spread cervical cancer after having sexual intercourse with women who had developed the disease. As one woman noted “*maybe one of your partners slept (or had sex) with a woman with [cervical] cancer, the infection contracted from there is passed to you.*” Women perceived their risk of cervical cancer as depending less on their own sexual behavior than on that of their husband or other male partners.

There were also a number of similarities between the ways women described how cervical cancer developed with how HIV is transmitted. A subset of women believed that cervical cancer could be transmitted through blood, as one woman explained “*since you are mixing the blood of this person, of that person, and the other person; altogether to become yours. Eeeh! It is very dangerous as you can die any time. You can easily contract diseases without any doubt*”. Moreover, many women indicated that uncircumcised men were more likely to transmit cervical cancer, therefore increasing their susceptibility of contracting the disease. “*Mainly I believe that men who are not circumcised are on top of spreading this disease, so by having sex with them you can easily contract it if they have it.*”

Though cervical cancer itself is not a sexually transmitted disease it is the direct consequence of a sexually transmitted infection. And only five women in the study sample were cognizant of a link between acquiring a viral infection and developing cervical cancer. As one woman stated “*They said it comes from the males, when you have sex with them and they have the virus that is when they transmit it to you and you also feel vaginal pains.*” None of these women however specifically mentioned HPV by name. Other than through sexual intercourse, a few women expressed difficulty understanding how cancers could be contracted. One woman in particular expressed her confusion in the following way: “*This cancer can be passed. Or it can be passed or not. For example, a child can be suffering from cancer. Likewise, if I am not being involved in sexual intercourse but then have cancer. So I ask myself, I am not being involved in sexual intercourse but how come I have cancer? I really wonder.*” During the interviews, it was also uncovered that a small subset of participants believed cervical cancer was a contagious disease that could be transmitted from person to person simply by touching someone affected by the disease.

A woman's reproductive behavior and family planning use was also often associated with the development of cervical cancer. A number of study participants frequently remarked that cervical cancer was a consequence of frequent child-bearing, as expressed here by one participant “*Giving birth several times is what is causing this type of cancer. That's why I am saying failing to take care of oneself. Nowadays, childbearing is by choice; giving birth to few babies' means the uterus will not get any diseases since you have given birth to a small number of children.*” These women believed that having multiple deliveries with little child-spacing

would wear out the womb as *“the uterus is not being given enough time to rest”*. Others pointed out that the cervix could sustain wounds from tears during childbirth, and that cervical cancer could then develop from those wounds. *“Maybe when you have given birth at home and you have sustained a tear. And there is a wound inside. ... Slowly it continues to grow and then some small wounds develop there (on the initial wound). I think that’s where it (cervical cancer) develops from.”*

Contraceptives were also mentioned by a handful of participants as a source of cervical cancer. These women were interviewed at different health facilities, yet all of them alluded to having heard rumors from people in their communities regarding the use of contraceptive methods leading to cancer. *“I have just heard that contraceptive methods have started causing cancer. So we are much concerned that if contraceptive methods give cancer, what will we do then.”*

Additionally, some participants also pointed to hygienic practices as factors contributing to cervical cancer. Some mentioned the lack of cleanliness in the genitalia area as a reason why cervical cancer developed. While others believed the use of soaps to clean the vagina or the practice of douching contributed to the onset of the disease. Furthermore, some participants noted that inserting foreign things into the vagina was a major contributor to cervical cancer, as one woman stated *“when you are using a cotton in times of monthly period and that cotton goes near the womb then that can contribute to cervical cancer.”*

## B. Cervical Cancer Signs & Symptoms and Prevention

Well over half of the women in the sample were able to identify signs and symptoms of cervical cancer. Reported symptoms included abnormal vaginal bleeding or discharges, abdominal pain, and pain during sexual intercourse. Wetness or itching of the vagina were also often reported as signs of the disease, even though these symptoms are associated with gynecological conditions other than cervical cancer. When asked to explain how they could prevent cervical cancer and protect themselves from developing the disease, the vast majority of women mentioned avoiding multiple sexual partners as a key strategy. They believed that having one sexual partner was the best way of *“taking care of oneself”*. Women also noted that their partners had to be loyal to them as well in order to ensure their protection. As one participant explained *“When you have had sex with a man, one cannot protect oneself. But when he is your man from home whom you rely on, then you can be protected”*.

Most women additionally pointed to the practice of child-spacing and avoiding frequent births as a means of preventing cervical cancer. One woman recommended that *“By stopping to give births. When you have given birth to many children, you should stop there and then one will be able to care for oneself.”* The use of condoms was also mentioned by a subset of women as a method of protection from cervical cancer, though one woman noted that protection through this method was not guaranteed as men often tampered with condoms in order to get women pregnant *“Relying on condoms would not help either because men puncture at the tip in order to make you pregnant..”* Only a handful of study participants specifically identified screening as a



method of protection, while six other women indicated that rushing to the hospital early or receiving counseling from health professionals after the onset of symptoms was the best way to prevent cervical cancer.

Participant's interviews revealed that the major sources of knowledge and awareness about cervical cancer were coming from health workers and health surveillance assistants (HSA), and national radio broadcast programs. Women were also exchanging information about cervical cancer among themselves. When comparing participants' knowledge scores, they were only found to be significantly different based on women's reported primary source of health information ( $p=0.012$ ). Women who reported their primary source of health information to be community health talks had higher knowledge scores while women who reported their primary source to be village health workers had lower knowledge scores (**Table 3**).

### **3.4 Individual Perceptions of Risk, Severity, and Treatment**

A woman's perceived risk of developing cervical cancer was generally based on whether she engaged in the risk factors she had identified for the disease. Results from the study indicated a relatively low perception of risk among women in the sample (mean score:  $1.8 \pm 1.8$ , **Table 3**). Additionally, perception of risk was not found to be significantly different between women varying across the study's demographic factors.

Women who perceived their risk to be low would often mention that they only had one sexual partner or that they had no manifestations of signs or symptoms of the disease. One woman specifically indicated that her risk was low because she was regularly taking ART *"As of now, I don't have any risks [of getting cervical cancer] because I am currently taking drugs and I strictly follow instructions from here at the hospital. Therefore, I don't have any worries of getting cervical cancer."* "On the other hand women who perceived their risk to be higher generally: expressed doubt about their husband's fidelity, or thought they had higher risk because of their HIV status, their history of multiple births, or their lack of screening.

Though cervical cancer was overwhelmingly thought to be a severe disease by women aware of the disease, most women believed that it could be successfully treated if it was detected early. Women generally understood the concept of cancer progressing to various stages and therefore recognized the importance of early detection.

*"It can be treated if one has realized it earlier that you have cervical cancer. And then you go to the hospital to see doctors as soon as possible"*

*"It is dangerous and when it reaches its highest point it cannot be cured, but when they notice it at an early stage they do cure it but when it does affect the whole inner womb they only remove it."*

Many women expressed faith in western medicine's ability to cure cervical cancer, and they generally demonstrated an optimistic view about the prognosis of a patient with cervical cancer. They would point out that there is *"medication at the hospital"* and that a person simply had to take the appropriate drugs in order to be cured. Others would cite hysterectomies as an available

option for treatment in order to prevent the progression of cancer. Women in the sample tended to perceive cervical cancer as an acute condition, as opposed to a chronic illness requiring lifelong treatment. One HIV-infected women noted *“Yes it can be treated. I believe that its drugs can be found compared to the problem which we have because it (HIV) is lifelong. It (HIV) is different with that one (cancer); it (cancer) can be treated.”*

Women also demonstrated a deep trust in health workers’ abilities to treat cervical cancer. They seemed to put the fate of their health into these individuals’ hands, as one women points out *“Like with the expertise of adokotala (meaning health worker such as nurse or clinician), through their expertise, they [health workers] can do to end [treat] the disease of cervical cancer. Because you will be taking medications with the belief that adokotala is helping you. Therefore, you need to be taking drugs knowing that adokotala is helping you.”*

Alternatively, the subset of women in the sample who expressed skepticism or doubt that cervical cancer could be treated in their area, seemed to be influenced by their personal experiences with individuals who had succumbed to the disease:

*“Since we have lost many people due to cervical cancer. We hear that one has died from cervical cancer, therefore, I do not have evidence that it can be treated.”*

*“But here I have hardly heard that someone was diagnosed with cervical cancer and she got treated. I just hear that she has died. When she becomes sick, we surely know that she will die. We get drugs just to relieve pain but I have hardly heard that one has been cured.”*

Another women further elaborated that she believed cervical cancer could be treated, however there was an unavailability of drugs for cancer treatment in the Neno district. The only drugs she believed were accessible to cancer patients in the area were palliative drugs.

*“Because when it (cervical cancer) has been detected at an early stage, they (healthcare workers) say that they have drugs which can be used to treat the person and she can be treated. But due to scarcity of these drugs, people just die. The drugs which these people [with cervical cancer] get are only to relieve pain and not to treat the disease.”*

### **3.5 Attitudes and Perceived Benefits of Cervical Cancer Screening**

Sixty-two percent of women (N= 31) in the sample were aware of cervical cancer screening (VIA), and 12 women (24%) had previously been screened for cervical cancer (**Table 2**).

Women who were aware of VIA screening were asked to describe what they knew or had heard about the screening procedure. Several women frequently remarked that it was an examination to detect cervical cancer and to reveal the health status of their uterus. Many reported that a metal instrument was used during the screening. Others had heard about cervical cancer screening, but

were unfamiliar with the details regarding the screening process, as one woman pointed out “*I have hardly heard. But I just know that there is screening. Let’s put it this way; I hear about screening but I do not know how the screening procedure is conducted.*”

When women were asked to express how they might feel about undergoing a pelvic exam, over two-thirds of participants expressed little concern over the procedure. On average, women reported low concerns about VIA screening being painful (mean score:  $1.5 \pm 1.3$ ), dangerous (mean score:  $1.1 \pm 0.9$ ), or embarrassing (mean score:  $1.4 \pm 0.9$ ). On the other hand, women were somewhat more fearful about getting a cervical cancer diagnosis (mean score:  $2.7 \pm 1.3$ , **Table 4**).

In contrast to some of the quantitative results, the in-depth interviews uncovered a subset of women in the sample who indicated that they would feel apprehensive about the procedure, as they were worried about the pain that would result from the use of a metal instrument during the examination. “*I think I could have felt pain, can you imagine that tool duck looking thing inserted into you, mmh. I could have felt pain*”.

Even some women who had obtained VIA screening mentioned that the procedure was painful. “*Eeeh! I felt pain since the instrument was causing lots of pain. So, I felt painful. It started when inserting the instrument as well as when withdrawing I also felt the pain.*”

One woman in particular indicated that this fear of pain was preventing other women in her community from using screening services “*Yes here at Magaleta hospital, they would come here but they never find more people, most women around here they are afraid to go for screening, because lots of our friends do scare us, but for now, we are willing and we would like to go for screening, we are afraid of the metal tool inserted into me, ehh that’s dangerous, and we simply lack courage.*”

Despite this fear of pain, many of these women believed that having a pelvic exam to minimize the risk of developing cervical cancer would be helpful and beneficial. There was a general desire among all women in the sample to know the “truth” about their health status, as one woman noted “*I think that, while performing the exam, it will give a true picture of what is inside our vagina so that they may know the problem with the cervix.*”

Several women also felt that screening offered the opportunity to receive advice, obtain treatment if needed, and to plan accordingly about how to change lifestyle behaviors. “*if you have been examined and they have found you with it (cervical cancer), they will tell you advices to be following. Then maybe you can live longer. But when you haven’t been examined, you can hardly know what to do hence you can live as you have been because you have not been screened and you hardly know whether you have the disease or you don’t have.*”

### **3.6 Perceived Barriers to Cervical Cancer Screening Services**

A number of barriers to accessing and utilizing cervical screening services within health facilities in Neno district were revealed during participants’ interviews. Barriers to cervical cancer prevention were influenced by distance, transport challenges, a lack of knowledge and awareness about services, logistical factors, and limited availability of services.

Distance to health facilities is a known barrier to accessing health services and indeed, most women in this study reported having to travel long distances on foot to reach their local health centers (N=42, 85.7%). On average, the women traveled 1 hour and 45 mins to reach their nearest health facility, with travel times ranging from a few minutes to 7 hours (**Table 1**). Women were markedly open about the challenges they had to overcome to reach their local health facilities. One woman in particular specifically likened their struggles to a form of slavery:

*“We have been very worried very much; starting of very early in the morning –how will I wake up and what time will I get there? When walking, we really feel very tired but we keep going considering that we haven’t reached the hospital. We really complain a lot for this. On our way we converse that we are really in trouble –will this slavery come to an end? We were saying this while crossing Nkulumadzi River –in the water which was very cold. When you step in the water with this cold weather, we would wonder if slavery will end here in our area.”*

Many women revealed their deep fears of not being able to reach a health facility in time for child-delivery or in a situation where their children might suddenly fall ill. These women pointed out that a number of women would walk long distances while in labor, which often lead to fatal consequences.

*“A pregnant mother for instance, starting off for [Neno], she delivers on her way. Then she can bleed a lot. But when you have reached the hospital earlier, you are assisted. But when you have delivered on the way and lost a lot of blood, your life ends there.”*

Others recounted personal experiences having to seek emergency care for their sick children.

*“It a long distance. ... If we walk when a child is sick, we really walk. However, sometimes we face problems especially if children have Malaria, they start convulsions on our way. I have mostly experienced this for some time up to an extent that adokotala (a health worker) told me that the moment I realize that a child has developed fever, I shouldn’t hesitate but to start off regardless of the time.”*

Difficulty securing transport to health facilities was cited as a major obstacle to seeking services and care. Women who have few resources and are in poor health, as is often the case in many rural Malawian villages, also have the most challenges accessing treatment services, not to mention preventive services. Women in the present study expressed deep concerns about the inability to afford transportation to health facilities (mean score:  $3.2 \pm 1.2$ ) (**Table 4**), as one woman stated *“I develop worries because I don’t have money. Then I would borrow so that I go to [the hospital to] get help.”*

Additionally, the in-depth interviews revealed that a lack of knowledge and awareness about cervical cancer prevention services being offered in the district prevented women from utilizing existing VIA screening services. One woman noted *“If I could have heard that at such a place they are giving such services I could have gone to know whether I have it or not.”*

The lack of availability of the screening service in their area was also mentioned as a key reason for not utilizing the service. Indeed this was often the case at most health centers in the district, however some others [ e.g Matandani] had just recently begun offering the service but women were not aware. Others noted that they were waiting for providers to come to their area to offer the service.

*“The challenge here is that there is no such place to get screened. If those who conduct screening come here, people will be coming to get screened in order to know how they are.”*

*“Previously, we were just told that they were coming. We were waiting for the healthcare workers to come and provide screening.”*

Logistical issues were uncovered as a barrier to receiving VIA screening services, based on some women’s experiences attempting to receive VIA screening across health facilities in Neno. Two women who had sought to obtain screening at a health facility in the district had to travel 2-3 separate times to that facility because a health worker was not available to conduct the procedure.

*“There were three scheduled dates. The first time they came, I failed to turn up. I just heard from my friend that they have had the exam. Then they gave another date. We came here but we returned without getting examined. We came again later but we returned home without getting examined as well. And now I have not heard when they are coming again. But I want to get screened.”*

Two others revealed that they had attempted to get screened at an event, but because of timing issues, health workers were unable to provide them with the service.

*“Two months ago there were activities related to the disease you have mentioned. But they did not conduct the screening because they run short of time. What they helped was that they only explained and enlightened to us on cervical cancer disease. But they said that they were very willing to conduct the screening but due to limited time we have failed.”*

Still others mentioned that the service could not be provided at their local health facility as a result of a lack of equipment.

### **3.7 Cervical Cancer Screening Acceptability and Intention to be screened**

Despite a low perceived risk of cervical cancer, a majority of women reported high acceptability and intention to obtain screening if the service was provided at location near them (mean acceptability score: 3.6 out of 4) (**Table 4**). Proximity of the services and the desire to know their health status were the two key factors linked to acceptability. Women suggested that if screening services were available nearby it could motivate them to use the services more frequently so that they could regularly monitor their health. Many also stated that it would provide an incentive for them to obtain screening as it would address their transport, costs, and limited time barriers. *“I can welcome it with warm hands because it is near and we will be getting screened frequently. You cannot have difficulties walking long distances.”*

### 3.8 Sociocultural Factors and Interpersonal Interactions

Dialogues with women revealed a relatively low level of stigma among study participants in regards to cervical cancer. All the women interviewed indicated that they would be open to speaking and being around an individual with cervical cancer because in the Malawian culture, a person should not be discriminated due to their disease. As one woman noted “*it is a disease and we don't reject each other because of diseases.*” Women in the sample generally believed that they had to treat a person with cervical cancer equally, as that person was a human being just like them. The women also tended not to shed any responsibility for the disease on the individual with cervical cancer or suggest that she had immoral behavior. “*That person, she is a human being like myself; her problem just came. It wasn't by choice but it just come.*” In fact many women indicated that speaking with someone with cervical cancer would be an opportunity for them to learn about the disease and understand how to prevent it.

*“But for this friend, she can be open to explain to me how the disease started and therefore, I can also learn from her that when I notice such signs and symptoms, I will know that this is the problem. I can notice this earlier and quickly go to the hospital to get help which can make me protected without reaching the stage where my friend was.”*

The study participants generally believed that if they were ever diagnosed with cervical cancer, it was their family member's responsibility to take care of and support them, therefore they had to be open with their husbands or their relatives about their disease. However when asked to give their thoughts about whether individuals with cervical cancer could be rejected by their husbands, the women were divided, as participants had varying viewpoints in regards to the gender norms that define women and men's responsibilities to their partners in times of illness. Some believed that husbands could not discriminate against their partners and had an obligation to take care of them, while others noted that Malawian men would often abandon their sick wives. This latter half often pointed to the fact that men would reject their wives because they could no longer satisfy their sexual needs. “*Since she is now sick the fruits of marriage are no longer realized. Chikwati (Conjugal rights). They (husbands) feel that it is useless to be just staying. Yeah! Some husbands say that.*”

One women in particular noted that men, unlike women, were unwilling to stand by their partners during times of illness. “*I should tell the truth here; you men do run away and leave your wives while sick to look for another healthy woman. You know we (women) try hard to care for our husbands when they fall sick –you accept it.*”

Women's opinions were also divided about whether relatives or friends would discriminate against an individual with cervical cancer. Some women believed that having cervical cancer could be potentially stigmatizing because of its association with death, and could subsequently lead to rejection by friends or members of a community. Many women referred to their personal experiences with HIV to describe their views, as one HIV-positive women noted “*her friends can discriminate her we are all different people; some, even the way I am on [ART] drugs, the*

*cup I use they cannot use as well because you have diseases. It is the same with friends. There are some friends who love you when you are well. But when they see that you have a problem, they start discriminating you.”*

### **3.9 Facilitators and Cues to Action**

Women’s past experiences with HIV, given the high burden of the disease in Malawi, seemed to have a positive influence on their acceptability of other screening services. One women noted that HIV prevention in the country resulted in a greater trust of authorities in power and has become a cue to action for engaging in preventative services for other diseases.

*“If you can be told to get examined –it is like what happened in the first place. We were asked to test for HIV but we were refusing. “Should I get prick and then they get my blood?” That’s what we were saying. And now this law which has come asking us to get screened for cervical cancer, we can also get screened. Because they want to rescue your life –this is a disease.”*

Satisfaction with services from healthcare professionals also seemed to be a major facilitator to the acceptability of cervical cancer screening services. Interviews with women in the study clearly indicated that most participants were satisfied with the treatment they received at their health facilities. Most women reported that they had positive experiences with health workers and that they were treated accordingly. They tended to describe their relationships with health workers very warmly, as one woman stated *“We know that they love and are open to us and we are also open to them.”* Most women also mentioned that health workers treated them equally without any differentiation. *“They treat us good, because we do get the help us quick as possible and we all stand on the same line.”* Furthermore, a majority of women noted that health workers protected their confidentiality. As one woman put it *“They are like anankungwi (people who initiate young boys during initiation ceremonies, marking the beginning of adulthood). So, anankungwi do not disclose any information anywhere. They do keep secrets we know.”*

One facilitator related to gender norms, was the approval of a participant’s husband. Women in the sample frequently remarked that their husbands would approve of them obtaining cervical cancer screening, therefore in the present study, this approval reinforced their innate health seeking behaviors.

### **3.10 Service Delivery Preferences**

The vast majority of the woman in the study (96%) reported feeling comfortable with obtaining VIA screening at their local health facilities. Women (90%) also indicated that they would be comfortable with a male provider carrying out the screening procedure, as many pointed out *“male healthcare workers also assist us in childbirth.”* Though no consensus day for obtaining VIA screening at a local health facility was reported among the sample, a majority of women indicated Wednesday as their preferred day to obtain the service (**Table 5**).

Several women pointed out that this was the day they attended health facilities for family planning services. *“Wednesday is good because it is also the day when women come here for*

*family planning services. Therefore, most women will be available because it is Wednesday.”*

The majority of women (78%) also wanted the service to be provided early in the morning before 10 am , as one woman noted “ *In the morning so that one should not have problems with the sun since we walk by foot.*”

In the 6 months prior to this study, only 12 % of the women in the study had attended community health screening events within Neno district, as most women reported being unaware that these events were taking place. When women were asked to provide their opinions in regards to a location where they would feel comfortable obtaining VIA screening services, a substantial proportion of the study sample, indicated that they could get screened at any of the proposed locations (**Table 5**), provided a private room was available and a trained health professional was conducting the screening. Locations that garnered the most resistance from the study sample were churches, schools, and child health day events. Half of the sample believed that churches were a place of worship, and therefore were not appropriate places to conduct screenings. The presence of children at schools or child health events also deterred some women from feeling comfortable with obtaining screening services at those locations because they believed there would be a lack of privacy and that children would disrupt them.

A consensus day for obtaining VIA screening at community screening events was also not reported among the sample, but again more women tended to mention Wednesday as their preferred day. The majority of women (62%) also wanted the screening service to be provided at community screening events early in the morning before 10 am, however some women were now also comfortable with obtaining the service in the afternoon.

In terms of the season preferences for obtaining screening services among the sample, a majority of women indicated a preference for obtaining the service between the months of May and August, during the winter season in Malawi (**Table 5**). Most women in the Neno district are farmers, many participants mentioned that they would have completed their farm work during this period and could therefore have more available time to travel to a health facility.

The vast majority of women in the sample were also interested in having the opportunity to receive other services in addition to VIA screening, when attending health facilities or community screening events. Women seemed very receptive to the idea of having integrated services, as they could receive services for multiple issues all at once.

*“They should be offered on the same place. Then people would be relieved.”*

*“You have to know how you are in your body. The good thing is that those people have come for several services. So they should not miss these. They have to do all at once”*

Family planning, HIV Testing and Counseling (HTC), STI and Gynecological services were all popular options (**Table 5**). Child health immunizations less so, most likely as a result of the fact that some women were reluctant about including their children when seeking care for their own sexual and reproductive health.

Some women suggested that integrated services could improve HIV testing coverage rates since people would no longer be able to tell what services an individual was seeking. As one woman noted “*Only if it can be a full pack like the way you have said it, because being for HIV*



*test only people cannot like it. Since they do not want others to know what service they are looking for”* A subset of women also reported wanting screening services for non-communicable conditions, such as high blood pressure testing and diabetes screening, as some mentioned that they were conditions affecting them.

## IV. Discussion

The objective of this study was to explore the knowledge, attitudes, and perceptions regarding cervical cancer and cervical cancer screening by visual inspection with acetic acid (VIA) among women in the rural district of Neno, Malawi. This study also identified service delivery preferences that would facilitate women's engagement and acceptance of existing and future cervical cancer prevention programs in the Neno district. Effective strategies targeting VIA screening are critical in reducing cervical cancer incidence and mortality all across Malawi, as cervical cancer screening provides an opportunity to detect precancerous lesions and to treat them before invasive cancer develops.

The emerging theory from this study provided important insights into themes surrounding cervical cancer prevention in the Neno district. This theory (provided in Fig. 1) shared conceptual similarities with other validated health research models (e.g Health Belief Model, Socio-Ecological Model) focusing on psychosocial, knowledge, sociological, and cues to action constructs to provide explanations for individuals' health behaviors (Ulin, Robinson, & Tolley, 2005). The overwhelming majority of women who participated in this study reported high acceptability of VIA screening and expressed favorable intentions of obtaining screening if cervical cancer prevention programs were available at a nearby location. Though these results are encouraging for future cervical cancer prevention programs, literature on health behaviors suggests that a gap exists between intention and behavior, and that it is common for people not to behave in accordance with their intentions (Schwarzer, 2008). Therefore it is important to not disregard the potential effects of other factors explored in this study.

In-depth interviews with women in this study revealed several barriers to participation in existing VIA screening programs in the Neno district, notably: 1) challenges in accessing preventive services 2) limited availability and awareness of VIA screening services, 3) lack of understanding about cervical cancer development and 4) low perception of risk of cervical cancer.

### *Access to service challenges*

Distance to health facilities was the predominant factor that seemed to influence health-seeking behaviors within our study's emergent theory. Many women cited their reluctance to undertake the long journey to reach a health facility, given their poor health status or their lack of funds to use transport to these facilities. The importance of distance as a significant barrier in this study is also consistent with findings from previous studies investigating barriers to HIV testing or maternal health services in Malawi, which point to distance from health services as the principal obstacle that women face in accessing care (Namakhoma et al., 2010; Kambala, Morse, Masangwi, 2011). The difficulty of accessing health services is probably a major contributor to many women's decisions to only seek preventative care when receiving treatment for other essential services such as: antiretroviral therapy, family planning, or maternal and child health

services. Furthermore, distance from a health facility could also be a significant factor to women receiving information regarding cervical cancer prevention, given that a majority of women in the present study indicated that health care facilities and health workers were their primary source of health information.

#### *Limited Availability and Awareness of services*

Another major barrier to screening was the limited availability of VIA screening services throughout the district. Screening services could only be obtained at the Neno district hospital, Lisungwi Community hospital, and 2 out of 13 health centers in the district (Matandani and Zalewa). Moreover, the screening services in these health facilities were not consistently provided, as many logistical factors in the provision of this service at health facilities were uncovered during study participants' interviews. Several women noted that they could not obtain VIA screening services because they were unavailable at their local health facilities due to a lack of equipment. Others shared their experiences seeking to obtain the service, but having to travel 2 or 3 times to a health facility because a trained health worker was not on hand to perform the exam. Interviews with women at the few health centers where screening was provided, revealed that many women were simply unaware that VIA services were available at that particular local health center. These findings suggest that if VIA screening services only remain available at a limited number of health facilities, it is probable that the program will not be able to gain large-scale traction in the Neno district. Even if it is not possible to increase the number of facilities that provide this service in the short term, women should be made aware of the location and times of available services. Improving scheduling and reducing the rate of cancellation of VIA screening services would provide more incentives for women to travel to health facilities to obtain the service, as they would have greater faith about receiving the service once they arrive on scheduled days. The findings also highlight the need to train more health workers on proper VIA screening techniques in order to address the shortage of available trained health workers who can carry out the procedure at individual health facilities.

#### *Lack of Understanding of Cervical Cancer Development*

The lack of knowledge about prevention and symptoms of cervical cancer can be a significant barrier to participation in cervical cancer screening, and indeed, a small subset of women in the present study simply had no notion of cervical cancer or VIA screening. A majority of women in the sample were aware of the disease however, and their knowledge about cervical cancer risk factors was relatively high. Many women were also aware of the signs and symptoms of cervical cancer and even cited the importance of early detection. Yet despite the fact that most women were aware of cervical cancer and were able to describe general features of the disease, there was a noticeable lack of understanding about the cause and the complex transmission risks of the disease. The majority of women seemed to believe that cervical cancer in and of itself could be directly contracted through sexual intercourse, likening it to other sexually transmitted diseases.

In fact, only a handful of women were even able to make a link between cervical cancer and an initial infection with a virus, and none were able to specifically mention HPV. This draws attention to the importance of tailoring a health education curriculum for cervical cancer that includes information about HPV in order to improve women's understanding about how the disease develops. Furthermore a subset of women in the sample seemed that believe that cervical cancer was contagious, and that it could be transmitted simply by touching a person with the disease. This lack of understanding about how the disease develops could potentially have major implications in terms of influencing stigmatization or discrimination of persons affected by this disease.

#### *Low Perception of Risk*

As a result of their limited understanding about cervical cancer transmission and development, women's perception of their risk of cervical cancer was quite low. Women in the study tended to believe that if they abstained from engaging in any of the risk factors for the disease and if they had no manifestations of symptoms, then they were not at risk of developing cervical cancer. Most women incorrectly believed that by simply practicing safe sex measures and being in a monogamous relationships, they could ensure their protection from the disease. Women generally compared their risk of cervical cancer to that of HIV or other STDs, and applied what they knew about preventing those diseases to the prevention of cervical cancer. Women's misunderstanding about their risk underscores the need for educational programs that will teach them how to accurately gauge their risk and will emphasize the importance of screening as preventative measure.

#### *Belief in Curative Abilities of Health System*

Faith in the curative abilities of health professionals and of western medicine seemed to reduce many women's fears about being diagnosed with cervical cancer. Even though they perceived the disease to be serious, they also believed it was treatable if detected early. It is unclear however whether women perceived early detection of the disease to before or right after the manifestations of symptoms. The majority of women believed in the potency of drugs to cure cervical cancer. Others who were more skeptical and perhaps expressed more realistic levels of trust in the capacity to treat the disease tended to be influenced by their personal experiences with relatives or acquaintances who had succumbed to the disease. These findings present a challenge for health professionals who need to on one hand reduce fatalistic views about cervical cancer given that it is a highly treatable disease, but on the other hand manage expectations about the curative abilities of the health system and emphasize the importance of early detection.

#### *District Wide Cervical Cancer Sensitization*

The findings obtained from this study clearly demonstrated that a number of women in the sample had received some type of health education about cervical cancer prior to the study.

Based on participants' interviews, it seemed that at least since 2014, health professionals, health surveillance assistants, and village health workers across the district have been taking the initiative to inform women about the dangers of cervical cancer and to promote VIA screening. Yet this was somewhat surprising, given that the Neno District Health Office (DHO) operating through the Malawi Ministry of Health (MOH) had no knowledge of a district wide cervical cancer prevention sensitization campaign.

Health professionals play a crucial role in disseminating information about cervical cancer prevention and in promoting the utilization of VIA screening services. Results from this study demonstrate that this is the case, as 7 out of the 12 women in this study who had previously been screened reported having received information about cervical cancer screening from a health professional. Women in this study generally expressed deep trust in health professionals and faith in their recommendations, which could lend further support to VIA screening. However, the misconceptions of cervical cancer by the study's participants highlight the importance of having a coordinated strategy and systematic method of disseminating information about cervical cancer. Crafting a culturally-relevant cervical cancer prevention education program that could be carried out at all district health facilities, will ensure a uniformity of messaging across all communities in the district. This increased awareness however will need to be coupled with the expansion of services throughout all health centers in the area.

### *Stigma and Gender Related Issues*

Cervical cancer might also be perceived as a stigmatized condition due to its association with sexual behavior and death. Stigma associated with cervical cancer or cancer in general can be harmful to prevention programs as the fear of stigma might act as barrier to seeking care. Some women might wish to avoid cervical cancer stigma by not utilizing VIA screening, which is why this study attempted to explore whether there was any indication of cancer-related stigma among women attending health facilities in Neno. Interviews with women revealed low levels of stigma towards individuals with cervical cancer among the study population. However some women believed that having cervical cancer could be potentially stigmatizing, not because of its connection with sexual behavior, but because of its association with death. This stigmatization could subsequently lead to discrimination by friends or members of a community.

Many women also expressed the belief that husbands could abandon their wives if they were ever diagnosed with cervical cancer. This belief was not specifically tied to cervical cancer, but rather to this notion that women could be rejected if they failed to satisfy the demands of their husbands. Women believed that men rejected their sick wives because these women could no longer meet their sexual needs, reflecting a greater theme of gender norms and gender inequality. Indeed, studies have found that Malawian women tend to be submissive and subordinate to males, and that their lower social and cultural status increases their risk of contracting STIs (Lindgren, Rankin, & Rankin, 2008). Furthermore, more than half of Malawian women are married, pregnant, or have children by the time they reach 18 years of age (NSO, 2011). This gender related inequality is relevant to cervical cancer prevention, because studies

have associated risk factors such as early sexual debut or frequent childbirth with increased probability of developing invasive cervical cancer. Therefore it is critical for cervical cancer prevention efforts to address gender inequality, by empowering women to prioritize their health and well-being.

### *Service Delivery Preferences*

Improving public-sector healthcare provision is crucial for expanding access to care for women. Regardless of whether health-services are offered in poor-resource settings, if quality of services provided is not acceptable, then utilization of those services will remain inadequate (Honda, Niekerk, McIntyre, 2015). This study sought to elicit service delivery preferences for VIA screening among women in the district in order to guide the planning of future service provisions for women's sexual and reproductive health. Interviews with study participants revealed a high level of satisfaction with the services they received from their local health providers, and as a result a majority of women in this study reported a high level of comfort with obtaining VIA screening at their health facilities. Yet more importantly, women were very open to receiving VIA services at various community settings provided their privacy would be ensured and the service would be administered by a trained health professional. Obtaining VIA services at local community based organizations (CBOs) or at an organized National Cervical Cancer day event were especially popular options. Another notable service delivery preference was to receive VIA services during the winter months of May to August, as a number of women indicated that they would have completed their farm work during this period and therefore could reserve sufficient time to travel to a health facility. Women in the study generally had favorable views of the integration of cervical cancer screening services with other sexual and reproductive health services, such as HTC or family planning services. Women endorsed the benefits it would provide them in terms of saving time and transport costs, while promoting the utilization of multiple preventative services at a single visit.

### **4.1 Limitations**

The use of in-depth individual interviews generated rich qualitative data that may be applicable to study populations that are similar to the one investigated, however the findings from this study are not generalizable. Women in the sample were not selected using random sampling techniques, therefore the sample cannot be considered to be an accurate representation of all women in Neno district. Furthermore, women were only sampled from health facilities, which could have biased the findings as the study population may have been instinctively more prone to adopting preventative measures and espousing favorable opinions about health providers. Additionally because of their frequent access to health workers, they might have benefited from increased exposure to cervical cancer education as compared to most women in the district. Therefore the knowledge and acceptability assessed in this study sample may have been disproportionately higher than the larger population of at-risk women in the Neno district.

## 4.2 Implications

This study's focus was to empower women to express their views and their experiences in regards to their access and provision of care, in order to inform cervical cancer prevention strategies in Neno and all across Malawi. By taking these women's views into account and addressing the various psychosocial and logistical factors influencing access to care, key decision makers can have direct input from women who utilize health services, and will be better able to design effective cervical cancer prevention programs.

The findings in this study, indicate that there is a need to incorporate screening at every healthcare facility in the Neno district, and if logistically possible to extend this service to community screening events. The limited availability and inconsistent provision of screening services in the district underscore the need for more health care workers to receive the appropriate training and for supplies to be reliably procured, in order to reinforce the capacity to screen and treat cervical cancer. Routine screening at high volume sites (e.g. maternal and child health services, integrated chronic care clinics) has the potential to vastly increase VIA screening coverage rates and in the process save many lives. Additionally, the integration of cervical cancer screening with other sexual and reproductive health services could provide a unique opportunity to take a comprehensive-approach in addressing women's gynecological issues and sexual health, given their increased vulnerabilities to STIs as a result of gender inequality.

Findings from this study have also highlighted the need for a coordinated cervical cancer prevention education campaign within the district to ensure the dissemination of accurate information to the public regarding cervical cancer prevention, treatment, and care. The inclusion of cervical cancer education at schools, community based organizations, or integrated chronic care clinics is needed to increase awareness and knowledge about the disease. It is crucial for women to grasp the role HPV plays in causing cervical cancer so that women understand the importance of HPV vaccination for their children. The vaccine is currently not widely available in Malawi, however its future introduction is feasible given that the Global Alliance for Vaccines and Immunization (GAVI) has included the HPV vaccine in their supported vaccination programs to assist low-income countries. Furthermore, the success of cervical cancer prevention strategies will rely on the capacity of health care workers to spread correct information, therefore they too must receive up-to-date education and training about cervical cancer, VIA screening, as well as HPV vaccination.

Some women in the study also expressed the desire to learn more from women diagnosed with cervical cancer. This offers the opportunity to strategically use women who have been previously screened for cervical cancer or who have received health benefits from treatment for cervical cancer to share their knowledge and experiences about the disease and the screening process with their peers. This could be an additional method to relay cervical cancer education while simultaneously providing opportunities to empower women across communities in the district.

## **V. Conclusions**

The burden of disease caused by cervical cancer remains high in many developing countries, particularly in Sub-Saharan Africa, where it is the leading cause of cancer deaths in women (Jemal et al., 2012). Despite Malawi having initiated free VIA screening programs within their public-sector in order to address the high incidence of cervical cancer, utilization of this service by Malawian women has been inadequate. This study therefore attempted to explore various factors that influence women's acceptance and participation in cervical cancer screening programs and to identify their service delivery preferences. The study found that although women in the Neno district of Malawi valued efforts to prevent cervical cancer, their engagement in existing prevention programs was limited by challenges in accessing health facilities, lack of knowledge and awareness about the disease and VIA screening services, low perception of risk, deep faith in the curative abilities of the health system, and limited and inconsistent provision of the service at the district level. Improvements in service delivery are therefore essential to incentivize women to utilize the services. Moreover, cervical cancer education is needed to ensure women participate and understand the importance of preventive behaviors.



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## VII. Appendix A – Tables

<b>Table 1. Demographic Characteristic of Study Sample</b>	
<b>Characteristics</b>	<b>N (%) n=50</b>
Age (years, mean $\pm$ SD)	35.2 $\pm$ 9.9
Education	
None	4 (8.0%)
Primary school	39 (78.0%)
Secondary school or beyond	7 (14.0%)
Marital Status	
Single	4 (8.0%)
Married	39 (78.0%)
Separated/ Divorced/Widowed	7 (14.0%)
Religion	
Catholic	10 (20.4%)
Seventh Day Adventist	13 (26.5%)
Other Protestant denomination	26 (53.1 %)
Occupation	
Farmer/ Housewife	28 (57.1%)
Business (selling food, charcoal, etc.)	16 (32.7%)
Other (e.g piecework, VHW, teacher etc.)	5 (10.2%)
Transportation to health facility	
Walking	42(85.7%)
Bicycle	5 (10.2 %)
Motorbike or Minibus	2 (4.1%)
Travel time (hours, mean $\pm$ SD)	1.75 $\pm$ 1.4
Primary source of health information	
Health facility, healthcare worker, or health surveillance agents	22 (46.8%)
Radio	16 (34.0%)
Community health talks	4 (8.5%)
Village Health Workers	2 (4.3%)
Other (e.g. family & friends, village chiefs)	3 (6.4%)
Knows someone diagnosed with Cancer	16 (32.0%)
Parity (mean $\pm$ SD)	4.5 $\pm$ 2.5
Frequency of health visits within last 6 months	2.9 $\pm$ 1.5
Has previously used family planning	39 (78.0%)

Has previously had a pelvic exam	14 (28.0%)
HIV Status	
Positive	15 (30%)
Negative	34 (68.0%)
Unknown	1 (2.0%)

**Table 2. Knowledge and Awareness of Cervical Cancer and Cervical cancer Screening**  
N (%) n=50

<b>Awareness</b>	
Ever heard of Cervical Cancer	45 (90.0%)
Ever heard of Cervical Cancer screening (or VIA testing)	31 (62%)
Has previously been screened for Cervical Cancer	12 (24.0%)
<b>Knowledge of Risk factors</b> (% answered T/F question correctly)	
Early Sexual debut	41 (89.1%)
Multiple Pregnancies	33 (71.7%)
Multiple Sexual Partners	44 (95.7%)
HIV	31 (67.4%)
Tobacco	36 (78.3%)
Family History	19 (41.3%)
Knowledge Score (mean # correct out of 6 ± SD)	4.4 ± 1.0

<b>Table 3. Associations between Demographic factors and Knowledge and Perception of risk Score</b>				
<b>Demographic Factors</b>	<b>Knowledge (Mean Score)</b>	<b>p-value</b>	<b>Perception of Risk (Mean Score)</b>	<b>p-value</b>
Age Group		p=0.411		p= 0.652
18-24	4 ± 0.6		2.3 ± 2.1	
25-34	4.8 ± 1.2		1.6± 1.8	
35-44	4.6 ± 0.7		1.6± 1.8	
45- 55	4.2 ± 1.5		2.4 ± 2.0	
Primary Source of Health information		p= 0.012**		p= 0.124

Healthcare Worker or HealthCare facility	4.2 ± 0.9		1.6 ± 1.7	
Radio	4.8 ± 0.9		2.3 ± 1.8	
Community Health talks	5.7 ± 0.6		1.0 ± 2.0	
Village health workers	3.0 ± 1.4		4.5 ± 0.7	
Education		p=0.668		p=0.456
None	4.8 ± 1.0		1.0 ± 2.0	
Primary Level	4.4 ± 1.1		1.8 ± 1.8	
Secondary or more	4.7 ± 0.5		2.4 ± 1.5	
Relationship Status		p= 0.794		p= 0.602
Single	4.3 ± 1.0		1.0 ± 0.8	
Married	4.4 ± 1.1		1.9 ± 1.9	
Separated/ Divorced/ Widowed	4.6 ± 0.8		2.1 ± 1.9	
Religion		p= 0.374		p= 0.96
Catholic	4.8 ± 0.6		1.7 ± 1.4	
Seventh Day Adventist	4.2 ± 0.8		1.9 ± 2.1	
Other Protestant denominations	4.4 ± 1.2		1.8 ± 1.8	
HIV Status		p=0.675		p= 0.675
Positive	4.6 ± 1.0		1.5 ± 1.6	
Negative	4.4 ± 1.1		1.8 ± 1.9	
Occupation		p= 0.491		p= 0.791
Farmer	4.4 ± 1.2		1.9 ± 1.8	
Market Seller	4.8 ± 0.8		1.7 ± 1.8	
Other skilled professions	5.0 ± 0		1.2 ± 1.0	
Travel time to health facilities		p= 0.735		p= 0.121
Less than 1 hour	4.4 ± 0.8		3.4 ± 2.2	
1- 3 hours	4.3 ± 1.0		4.5 ± 1.7	
Greater than 3 hours	4.6 ± 1.2		3.3 ± 2.1	
Parity		p=0.589		p=0.412
0-2	4.6 ± 0.9		2.2 ± 1.7	
3-5	4.5 ± 1.0		1.4 ± 1.6	
6+	4.2 ± 1.1		2.1 ± 2.1	
Family Planning		p= 0.976		p= 0.58
Yes	4.4 ± 1.1		1.7 ± 1.8	
No	4.4 ± 0.9		2.1 ± 2.1	
Knows someone with Cervical Cancer		p=0.877		p=0.522
Yes	4.4 ± 0.7		2.1 ± 1.8	
No	4.5 ± 1.2		1.7 ± 1.8	
Previously been screened		p=0.082		p=0.285
Yes	4.9 ± 0.8		1.5 ± 1.6	
No	3.5 ± 2.1		3.0 ± 2.8	

**Table 4. Perception of Risk, Attitudes and Acceptability of VIA Screening,**

	<b>Mean Sample Score (n=50)</b>
<b>Perception of Risk</b> (1=very low to 5=very high)	
Probability of developing cervical cancer in one's lifetime	1.8 ± 1.8
<b>Attitudes regarding VIA Screening</b> (1= not at all to 4=very much)	
Concerned about pain	1.5 ± 1.3
Concerned about risk or danger	1.1 ± 0.9
Concerned that it may be embarrassing	1.4 ± 0.9
Fear of diagnosis	2.74 ± 1.3
Concerned about the cost of transport to a health facility	3.22 ± 1.2
<b>Acceptability of VIA Screening</b> (1=very unlikely to 4=very likely)	
Likelihood of obtaining screening if available at nearby location	3.6 ± 0.7

**Table 5. Service Delivery Preferences among Women attending Health Facilities in Neno district**

Preferences	<b>N* (% ) n=50</b>
Comfortable obtaining screening at local health facility	48 (96.0%)
Comfortable having male provider conduct screening	45 (90.0%)
Preferred day of the week to attend local health facility for VIA screening	
Monday	9(18.0%)
Tuesday	7 (14.0%)
Wednesday	13 (26.0%)
Thursday	7 (14.0%)
Friday	12 (24.0%)
Preferred time of the day to attend local health facility for VIA screening	
Before 10 am	39 (78.0%)
10-12 am	4 (8.0%)
After noon	0 (0%)
Attended community health screening event in the past 6 months	6 (12.0%)
Comfortable obtaining screening from trained provider at following location:	

Integrated Chronic Care Clinic	43 (86.0%)
School	35 (70.0%)
Community Based Organization	46 (92.0%)
Community Outreach Clinic	42 (84.0%)
Community Screening Event	44 (88.0%)
Local church or other religious organization	25 (50.0%)
Child Health Day Event	39 (78.0%)
National Cervical Cancer Day Event	45 (90.0%)
Preferred day of the week to attend community screening event for VIA screening service	
Monday	6 (12%)
Tuesday	9 (18%)
Wednesday	15 (30%)
Thursday	9 (18%)
Friday	6 (12%)
Saturday	2 (4%)
Sunday	1 (2%)
Preferred time of the day to attend community screening event for VIA service	
Before 10 am	31 (62.0%)
10-12 am	0 (0%)
After noon	11 (22.0%)
Preferred Season to obtain VIA screening	
Jan- April	11(22.0%)
May – Aug	29 (58.0%)
Sept - Dec	7 (14.0%)
Interested in obtaining the following services at the same time as VIA screening:	
Family Planning	48 (96.0%)
Gynecological Services	44 (88.0%)
Child Health Immunizations	39 (78.0%)
STI services	46 (92.0%)
you HTC services	46 (92.0%)

---





No ..... 2

10. RELIG

What is your religion?

- Catholic..... 1
- Seventh Day Adventist..... 2
- Muslim.....3
- Other ..... 4 **[Specify]**

11. OCCUP

What is your current occupation? \_\_\_\_\_

*I am now going to ask you about questions regarding your health and your access to health facilities.*

**Health Information**

12. TRANS\_TIME

How long does it take you to reach your nearest health facility?

\_\_\_\_\_

13. MODE\_TRANS

What is your mode of transportation to your nearest health facility?

\_\_\_\_\_

14. PRIM\_SOURCE

What are your main sources of health information?

\_\_\_\_\_

All Sources (tick all)		Coding
<input type="checkbox"/>	Health facility, healthcare worker, or health surveillance agents	1
<input type="checkbox"/>	Traditional healer	2
<input type="checkbox"/>	Radio	3
<input type="checkbox"/>	TV	3
<input type="checkbox"/>	Newspaper	3
<input type="checkbox"/>	Community health talks	4
<input type="checkbox"/>	Family, friends, or neighbors	5
<input type="checkbox"/>	Village headman/chief	6
<input type="checkbox"/>	Village Health Worker	7
<input type="checkbox"/>	Other	8

15. FAM\_PLAN                      Have you ever used family planning services before?
- Yes ..... 1
- No ..... 2
16. PAR                              What is the total number of times you have given birth? \_\_\_\_\_
17. HIV\_STAT                      Have you ever obtained HIV testing?
- Yes ..... 1
- No ..... 2
- Don't Know.....3
- 17a. If Yes: What is your HIV Status?
- Unknown ..... 1
- Negative ..... 2
- Positive..... 3
- 17b. HIV\_DUR      What year were you diagnosed with HIV? \_\_\_\_\_

**I. Knowledge and Awareness about Cervical Cancer**

*The next set of questions will focus on what you know about cancer and cancer that affects the mouth of the womb (cervical cancer).*

18. \_\_\_\_\_                      What do you know about cancer?

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19. \_\_\_\_\_ KNOW\_DIAG                      Have any of your friends or relatives ever been diagnosed with cancer?

Yes ..... 1

No ..... 2

Don't Know.....3

20. \_\_\_\_\_ AWARE\_CC                      Have you heard about cancer that affects the mouth womb (cervical cancer)?

Yes ..... 1

No ..... 2

- 20a. *If Yes:* Where have you heard about Cervical Cancer ?

---



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- *If No: establish knowledge about cervical cancer. A cancer that develops in a women's birth canal, after infection with the HPV virus, a common virus that is sexually transmitted. Skip to question 27*

21. \_\_\_\_\_ What have you heard about cervical cancer?

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22. \_\_\_\_\_ How do you think someone gets cervical cancer? (e.g by an HPV infection spread through sexual contact)

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23. \_\_\_\_\_ What symptoms might make a woman think that she has cervical cancer? (e.g. abnormal bleeding, discharge, or pain in the lower belly or pelvis)

---



---

*I am now going to read you several statements about cervical cancer risk factors. For each one, please tell me whether you think the statement is true or not. If you feel you cannot give me an answer, let me know.*

24. KNOW\_(1-6) Knowledge about Cervical Cancer risk Factors

	True	False	I don't know
1. An earlier sexual debut increases the risk of cervical cancer			
2. Multiple pregnancies decreases the risk of cervical cancer			
3. Multiple sexual partners increases the risk of cervical cancer			
4. HIV increases the risk of cervical cancer			
5. Smoking decreases the risk of cervical cancer			
6. Family history increases the risk of cervical cancer			

25. \_\_\_\_\_ Do you believe cervical cancer can be treated? Why or Why not?

---

---

26. \_\_\_\_\_ How do you think women can protect themselves from cervical cancer? (e.g by obtaining cervical cancer screening)

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**II. Awareness and Attitudes about Cervical cancer Screening**

27. \_\_\_\_\_ PELVIC Have you ever had a pelvic exam? [Explain: *A pelvic exam is when a doctor or a nurse checks your birth canal to make sure everything is normal by inserting a duck mouth shaped instrument into the vagina*]

- Yes ..... 1
- No ..... 2
- Don't Know.....3

**If Yes:** How did you feel about that experience?

---

---

**If No:** How do you think you would feel about such an exam?

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*Cervical cancer is a disease that develops in a women's birth canal, after infection with the HPV virus, a common virus that is sexually transmitted.*

28. \_\_\_\_\_ How would you feel about having a pelvic exam if it could help to prevent you from getting cervical cancer?

---

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29. AWARE\_ CCS Have you ever heard of cervical cancer screening (or VIA testing)?  
 Yes ..... 1

No ..... 2 (Skip to question 32)

30. \_\_\_\_\_ What have you heard about cervical cancer screening (or VIA testing)?

---

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31. ACCESS Do you know where to access cervical cancer screening services in your area?

- Yes ..... 1  
 No ..... 2

**If Yes:** [Specify] \_\_\_\_\_ (e.g. health centers, mobile clinics, DHO)

*Cervical cancer screening is a type of pelvic exam to detect abnormal cells on the mouth of the womb that could lead to cancer. When performing this test the doctor or nurse places an instrument in the women's vagina so that he/she can see the mouth of the womb after applying vinegar.*

32. SEEK\_CCS Have you ever sought to obtain cervical cancer screening in your area?

- Yes ..... 1  
 No ..... 2 (skip to 34)

33. HAD\_CCS **If Yes:** Have you ever obtained cervical cancer screening?

- Yes ..... 1  
 No ..... 2  
 Don't Know.....3

o **If No:** Describe why you were unable to get this service.

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### III. Barriers to Cervical Cancer and Screening

*I will now ask you questions about your thoughts regarding cervical cancer screening. There is no right or wrong way to answer these questions, and you can choose to skip any question that makes you uncomfortable.*

34. CCS\_ATT(1-5) Attitudes about Cervical Cancer Screening

	Not at all	A little	Somewhat	Very Much	I don't know	Decline to answer
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1. How concerned are you that cervical cancer screening may be uncomfortable or painful?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. How concerned are you that cervical cancer screening may be risky or dangerous?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. How concerned that cervical cancer screening may be embarrassing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. How afraid are you of possibly finding out you have cancer as a result of cervical cancer screening?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. How concerned are you about not being able to afford the costs of transport to a health facility?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

35. \_\_\_\_\_ How do you think your husband or partner would feel about you getting screened for cervical cancer? (Or ask “relatives” for unmarried women)

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**V. Perceptions of Risk and Stigma**

36. PERC\_RISK1 What do you think your chance is of getting cervical cancer in your lifetime?

- Very Low ..... 1
- Low .....2
- Neither High nor Low..... 3
- High ..... 4
- Very High .....5
- Don't Know .....6

37. \_\_\_\_\_ If you were diagnosed with cervical cancer would you tell anyone? Why or why not

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38. \_\_\_\_\_ Would you feel comfortable talking or being around someone with cervical cancer? Why or why not?

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39. \_\_\_\_\_ If a person developed cervical cancer do you think their spouse, their family or friends would reject them? Why or why not? Explain

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**VI. Screening Acceptability**

40. ACC\_CCS      How likely is it that you would accept to get cervical cancer screening once it is available at a location near you?

- Very unlikely ..... 1
- Unlikely .....2
- Likely..... 3
- Very Likely ..... 4
- Don't Know .....5

**VII. Service Delivery Preferences**

*We are looking to expand service delivery for cervical cancer screening. We would like to hear about your preferences for how we can improve this service.*

41. \_\_\_\_\_ GEN\_TREAT      Where do you usually get treatment when you are sick?

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42. \_\_\_\_\_ HEALTH\_SEEK      In the past 6 months, how often have you sought care at {insert answer from above}?

---

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43. \_\_\_\_\_ How do you feel about the way you are treated when you go there? [*Probes: Are you treated the same as other people at the health center? Do medical providers and staff respect your privacy?* ]

- 
- 
- *Cervical cancer screening is a type of pelvic exam where a health care provider places an instrument in the women's vagina to see the mouth of the womb. They apply vinegar solution and observe any changes.*

44. \_\_\_\_\_ HF\_CCS      Would you be comfortable getting cervical cancer screening at this health facility?

- Yes ..... 1  
 No ..... 2  
 Don't Know.....3

**If No:** Why not? What could help you change your opinion?

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45. \_\_\_\_\_ HF\_TIME      If you were to attend a health facility for cervical cancer screening, what would be the best day of the week to offer the service?

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45a. When would be the best time of the day to offer the service?

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46. \_\_\_\_\_ COMM\_EVENT      Have you attended a community event with health screening or services in the past 6 months?

- Yes ..... 1  
 No ..... 2 (skip to 47)  
 Don't Know.....3

47. \_\_\_\_\_ COMM\_EVENT\_TYP      **If Yes:** What event did you attend? What services were provided?

---



48. \_\_\_\_\_ PREF\_LOC We are trying to learn the best places to offer cervical cancer screening.  
 If a

private room were set up, would you feel comfortable obtaining cervical cancer screening from a trained healthcare provider at a community event organized at a(n) ....

	Yes	No	I don't know	If no, what concerns do you have?
• Health Facility				
• Integrated Chronic Care clinic				
• Event hosted at a local School				
• Community based organization				
• Community Outreach Clinic				
• Community Screening Event				
• Event hosted at a local Church or Religious organization				
• Child Health Day with extra services for women				
• Organized event like National Cervical Cancer Day				

49. \_\_\_\_\_ CS\_TIME What would be the best day of the week to attend community events to receive cervical cancer screening?

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48a. What would be the best time of the day?

---

50. \_\_\_\_\_ PREF\_GEND Would you be comfortable if a male health worker conducted the cervical

cancer screening?

- Yes ..... 1
- No ..... 2
- No preference.....3
- Don't Know.....4

51. \_\_\_\_\_ CCS\_SEAS What would be the best season of the year for you to get cervical cancer screening?

[Specify]

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52. \_\_\_\_\_ADD\_SERVS Are there other services you would be interested in obtaining during a cervical cancer screening?

\_\_\_\_\_ *If the woman does not have suggestions, read this list and ask her to choose preferences*

	Yes	No	I don't know	If no, what concerns do you have?
• Family Planning				
• Gynecological services				
• Child Health Immunizations				
• STI services				
• HTC services				

## VII. Appendix C

### Verbal Consent Text

Thank you for accepting to talk with me today, my name is [Interviewer ], and I work as a \_\_\_\_\_ at APZU/MOH. I am inviting you to participate in our research study designed to learn more about what women living in the Neno district know about cervical cancer and how they feel about cervical cancer screening.

#### **Procedures:**

If you agree to participate in this study, I will be asking you questions about your age, education, relationship status, HIV status, family planning use, and occupation. I will also be interested in understanding your views about cervical cancer screening. Therefore I will ask you to tell me about what you know about cervical cancer, how you would feel about cervical cancer screening, and how we can improve your access to this service.

This interview will require about 1.5 hour of your time. By participating, you will receive a compensation of a bag of sugar and a soap tablet for participating. This interview will be audio recorded, but only with your permission. If you do not agree to have the interview recorded, please let us know.

#### **Risks and Benefits:**

There are no physical risks to participating in this study, however we are asking you to share with us some personal information, therefore some questions may make you uncomfortable. Although this study will not benefit you personally, we hope that our results will improve cervical cancer screening services for women in the Neno district.

#### **Voluntary Participation:**

Your participation in this study is voluntary. You may refuse to participate or to answer any question that you do not want to answer, and you can end your participation at any time for any reason. Refusing to participate will involve no penalty or loss of benefits or compensation to which you are otherwise entitled or negatively impact you in any other way.

#### **Anonymity:**

All of your responses will be anonymous, and none of the information you give will be traced back to you. A study number rather than your name will be used.

#### **Questions:**

If you have any questions about this study, you may contact me or any other study investigator (will provide local phone number).

Before we begin, do you have any questions for me

# VII. Appendix D

