

**PERCEPTIONS, AWARENESS AND HEALTH-SEEKING BEHAVIOUR OF WOMEN
REGARDING CERVICAL CANCER IN ADDIS ABABA, ETHIOPIA**

by

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submitted in accordance with the requirements for
the degree of

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SUPERVISOR: DR A MOSALO

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DEDICATION

I dedicate this dissertation to my partner, Anna, and our children, Mila and Leo, who have always been my support and comfort.

DECLARATION

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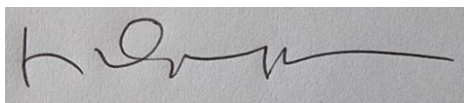
PERCEPTIONS, AWARENESS AND HEALTH-SEEKING BEHAVIOUR OF WOMEN REGARDING CERVICAL CANCER IN ADDIS ABABA, ETHIOPIA

I declare the above dissertation is my own work, and all sources used or quoted are indicated and acknowledged by complete references.

I further declare that I submitted the dissertation to originality checking software and that it falls within the accepted requirements for originality.

I further declare that I have not previously submitted this work, or part of it, for examination at Unisa for any other qualification or to any other higher education institution.

(The dissertation undergo examination unless this statement has been submitted)



SIGNATURE

Ekin Cagatay Ogutogullari

9 March 2022

DATE

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ABSTRACT

BACKGROUND

Cervical cancer is a worldwide public health concern and most common cause of cancer-related deaths in women. Whilst women in developed countries have shown an improved uptake of screening with reduced mortality from the disease, the same cannot be reported from less developed countries, as women are affected by the disease resulting in increased mortality and even death; this may be attributed to lack of resources and poor knowledge regarding the disease.

PURPOSE

The purpose of the study was to explore the perceptions, awareness and health-seeking behaviour of women regarding cervical cancer in Nefas Silk Lafto Sub-city, Addis Ababa, Ethiopia.

METHODS

This study used a qualitative exploratory research design. Data collection occurred by interviewing 17 women at Woreda 11 Health Centre in Nefas Silk Lafto Sub-City, Addis Ababa, Ethiopia, and analysed using qualitative content analysis.

RESULTS

Two main themes emerged, knowledge and perspective on cervical cancer and health seeking and concerns about cervical cancer screening, with four categories each. The categories under knowledge and perspectives on cervical cancer were (1) awareness of cervical cancer, (2) symptoms pertaining to cervical cancer, (3) sources of information pertaining to cervical cancer and (4) women's perspectives regarding cervical cancer.

The categories under health seeking and concerns about cervical cancer screening were (1) lack of awareness regarding cervical cancer, (2) perceptions regarding cervical cancer, (3) timing and frequency and (4) promotion of cervical cancer screening.

CONCLUSION

This study found the majority of the participants lacked knowledge about cervical cancer and screening, and that none of them had screened before. Most of the participants reported media as their primary source of health information, with none mentioning healthcare professionals as a source. These findings revealed there is a profound awareness and knowledge gap regarding cervical cancer and screening among women who participated in the study.

KEY TERMS

Awareness; Cervical Cancer; Cervical Cancer Screening; Ethiopia; Health Seeking Behaviour; Human Papilloma Virus; Perception; Uptake of cervical cancer screening.

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LIST OF ABBREVIATIONS

ANC	Ante-natal Clinic
ART	Anti-retroviral Treatment
BOFED	Bureau of Finance and Economic Development
CCP	Cervical Cancer Programme
CIN	Cervical Intraepithelial Neoplasia
DNA	Deoxyribonucleic Acid
FMOH	Federal Ministry of Health (Ethiopia)
GLOBOCAN	Global Cancer Observatory
HIV	Human Immunodeficiency Virus
HPV	Human Papilloma Virus
IRB	Institutional Review Board
LBC	Liquid Based Cytology
LMIC	Low- and Middle-Income Countries
OCP	Oral Contraceptive Pills
PAP	Papanicolau (Test)
PNC	Post-natal Clinic
SBCC	Social and Behaviour Change Communication
SVA	Single Visit Approach
UNISA	University of South Africa
VIA	Visual Inspection with Acetic Acid
VILI	Visual Inspection with Lugol's Iodine
WHA	World Health Assembly
WHO	World Health Organization
WLHIV	Women Living with HIV

CHAPTER 1

INTRODUCTION TO THE STUDY

1.1 INTRODUCTION AND BACKGROUND TO THE RESEARCH PROBLEM

Cervical cancer is one of the major global public health problems, with an estimated 570,000 new cases in 2018 (Ferlay, Ervik, Lam, Colombet, Mery, Piñeros, Znaor, Soerjomataram & Bray, 2018:22). Reportedly, it is the fourth most common cancer in women worldwide (Ferlay et al., 2018:23), and the second most common cancer among women living in low- and middle-income countries (LMIC); each year, more than 310,000 women die from it worldwide, with almost 90% of deaths occurring in LMICs due to lack of screening (Cohen, Jhingran, Oaknin & Denny, 2019:170).

The cause of cervical cancer is the persistent infection with high-risk oncogenic Human Papilloma Virus (HPV) (World Health Organization [WHO] 2020:1). Human Papilloma Virus (HPV) is implicated in the development of cervical cancer as globally, 70% of cervical cancers are caused by HPV 16 and 18, whilst other types, such as HPVs 31, 33, 35, 45, 52 and 58, are responsible for another 20% (Kessler 2017:1). According to the WHO (2020:1), there are non-cancer-causing HPV types, such as 6 and 11, which cause genital warts and respiratory papillomatosis. While most HPV infections heal naturally, some can lead to pre-cancerous lesions and if untreated, may lead to cancer of the cervix (Cohen et al., 2019:169).

Globally, HPV infection in women is around 11-12%, and the highest prevalence is noted in sub-Saharan Africa (Chidanyika, De Vuyst, Blumenthal, Santos, Jeronimo, Hedman, Nordin, Adnew, Zaw, Boxshall, Kumakech & Baravilala 2012:1). Human Papilloma Virus causes a gradual histological change on the cervix presenting as cervical intraepithelial lesions (CIN), which go through various clinical stages before becoming an apparent cervical carcinoma (Santesso, Mustafa, Schünemann, Arbyn, Blumenthal, Cain, Chirenje, Denny, De Vuyst & Eckert, 2016:252). Ongoing disease progression provides a great opportunity for early detection and treatment via screening (Landy, Pesola, Castañón & Sasieni, 2016:1140). Despite the slow progression of the disease, it is still a concern that detection in women in developing countries is only at advanced stages. Even though

several affordable methods are available to treat cervical cancer, the experiences of the situation are different in developing countries.

The prevalence of cervical cancer varies in different sub-Saharan African countries. According to the study done in LMIC (Ferlay, Soerjomataram, Dikshit, Eser, Mathers, Rebelo, Parkin, Forman & Bray, 2015:7), high-risk areas included Eastern Africa, Melanesia, Southern and Central Africa, with Eastern Africa, where Ethiopia is located, accounting for the majority of cervical cancer related deaths. According to the WHO (2020:1), 19 of the top 20 countries with the highest burden of cervical cancer globally are in Africa. Despite high mortality resulting from cervical cancer, the disease is highly preventable and treatable if detected at early stages. The Ethiopian Guideline for Cervical Cancer states that with effective screening more than 80% of cervical cancer morbidity and mortality could be prevented (FMOH, 2015a:44). Despite the fact that cervical cancer incidence has decreased in resource-rich countries, due to the effective screening and treatment interventions, the uptake of screening continues to be low in developing countries such as Ethiopia (Gebru, Gerbaba & Dirar, 2016:401).

1.2 STATEMENT OF THE RESEARCH PROBLEM

Cervical cancer screening is one of the most effective preventative programmes when implemented comprehensively and successfully, as incidence and deaths from the disease can reduce significantly. While screening has the potential to improve morbidity and death from cervical cancer, women in developing countries receive the diagnosis late when the cancer has already advanced (Compaore, Ouedraogo, Koanda, Haynatzki, Chamberlain & Soliman, 2016:760).

Visual inspection with Acetic Acid (VIA) as a screening method for cervical cancer is one of the different screening methods currently recommended by the WHO (2020:1), along with HPV testing for high-risk HPV types, and conventional (PAP) and liquid-based cytology (LBC) tests, which can be used in low resource settings that are closely monitored.

While resource-rich countries saw a decrease in cervical cancer incidence due to implementation of effective screening and treatment interventions, this has not been the case in low- and middle-income countries such as Ethiopia (Gebru et al., 2016:401).

Despite the implementation of cheaper alternative screening methods to control the disease, such as visual screening and HPV testing in low- and middle-resource countries, the utilisation remains poor even though available, such as in the setting where this study was conducted.

The Federal Ministry of Health of Ethiopia (FMOH) adopted VIA as a screening method for premenopausal women above 30 years of age, as per secondary prevention recommendations from the WHO (2020:1). VIA screening service, which has proved to have a significant positive impact in the reduction of the incidences of cervical cancer, is available at health centre level in all regions of Ethiopia (FMOH, 2015a:44). However, Nigussie, Admassu and Nigussie (2019:127) found the utilisation is still poor according to studies conducted in different parts of the country, as only around one in five women had a history of cervical cancer screening in their entire life.

In comparison to Visual Inspection with Acetic Acid and Lugol's iodine (VIA/VILI), a Pap smear is less feasible in resource poor settings due to the lack of infrastructure in both physical and staffing and related higher financial costs, and relevant intervention can only take place after the test results (WHO:2020:1). Although the Pap smear is not widely available in Ethiopia, the recommendation is for its use for women not eligible for VIA and when there is no alternative screening method in the clinical setting. Cervical cancer remains a public health concern in Ethiopia, accounting for 3,235 deaths among women annually (FMOH, 2015a:44).

The researcher, a humanitarian and development worker with an organisation that has public health sector in Ethiopia as one of its focuses, noted that despite the efforts to encourage cervical cancer screening, women in Addis Ababa barely utilise the services. Consequently, the researcher intended to explore the perceptions, awareness, and health-seeking behaviour of female residents of Nefas Silk Lafto Sub-City, in Addis Ababa, regarding cervical cancer and cervical cancer screening.

1.3 RESEARCH PURPOSE

The purpose of the study was to explore the perceptions, awareness and health-seeking behaviours of women regarding cervical cancer in Nefas Silk Lafto Sub-city, Addis Ababa, Ethiopia.

1.4 RESEARCH OBJECTIVES

The objectives of this study were to:

- Explore the perceptions of women residents of Nefas Silk Lafto Sub-City, Addis Ababa, regarding cervical cancer screening.
- Explore awareness of women residents of Nefas Silk Lafto Sub-City, concerning cervical cancer screening in Addis Ababa.
- Explore health-seeking behaviours of women in Nefas Silk Lafto Sub-City with regard to cervical cancer screening in Addis Ababa.

1.5 RESEARCH QUESTIONS

- What are the perceptions and awareness of women in Nefas Silk Lafto Sub-City, Addis Ababa, regarding cervical cancer screening?
- What are the factors influencing the health behaviours of women towards cervical cancer screening in Nefas Silk Lafto Sub-City?
- What interventions are available regarding promotion of screening for cervical cancer screening in Nefas Silk Lafto Sub-City, Addis Ababa?

1.6 SIGNIFICANCE OF THE STUDY

This study will contribute to the knowledge and practice of public health and research, especially to the promotion and prevention of cervical cancer through interventions to improve and increase cervical cancer screening, and to promote screening uptake.

1.7 DEFINITIONS OF KEY CONCEPTS

This section attempts to define and explain the key concepts. For the purpose of this study, the following terminologies and their definitions, as listed below, are used:

1.7.1 Awareness

Awareness: having or showing realisation, perception, view, or knowledge; being conscious of something. Knowledge that something exists, or the understanding of a

situation or subject at the time based on information or experience (*Cambridge Online Dictionary*, 2021, “awareness”). In this study, awareness relates to when women understand/know of cervical cancer and cervical cancer screening.

1.7.2 Cervical cancer

Cervical cancer is a cancer that develops on the cervix, which is the lower opening of the uterus. The existence of human papilloma virus (HPV) infection causes cervical cancer. HPV affects the normal functioning of cells, leading to distinct changes in the epithelial cells in the transformation zone of the cervix (Geremew, Gelagay & Azale, 2018:29).

1.7.3 Cervical cancer screening

Cervical cancer screening is testing for pre-cancer and cancer among women who are asymptomatic and may feel perfectly healthy (Kessler, 2017:3). Cervical cancer screening in this study refers to when women are screened and examined for cervical cancer.

1.7.4 Health-seeking behaviour

Health-seeking behaviour is any action taken by a person who perceives a need for health services with the objective of attending to a given health problem; this includes seeking assistance from allopathic and alternative health services (Small, Bacon, Bajaj, Chuang, Fisher, Harkenrider, Jhingran, Kitchener, Mileshekin, Viswanathan & Gaffney, 2017:2404). In this study, health-seeking behaviour is women acting when they perceive a need for health services concerning cervical cancer.

1.7.5 Perception

Perception is a judgment resulting from awareness or understanding of a subject, concept, etc. A belief or opinion often held by many people and based on how things seem (*Cambridge Online Dictionary* 2021, “perception”). In this study, perception means women’s judgement of cervical cancer due to their awareness or understanding of the disease.

1.8 RESEARCH METHODS AND DESIGN

Research methods are the strategies, processes or techniques utilised to collect data or evidence for analysis to unearth new information or to understand a subject matter better. Research design is the framework of research methods and techniques selected by a researcher. The design aids researchers to focus on research methods appropriate for the subject matter (Ishtiaq, 2019:23). An exploratory qualitative design guided the study, as qualitative methods allow the researcher to explore and understand the study phenomenon (De Vos, Strydom, Fouché & Delport, 2017:308).

Silverman (2016:12) reported that one of the aims of qualitative health research is to provide a multidimensional understanding of a health condition that goes in detail of an everyday or rational awareness, which leads to a more informed, nuanced and empathic practice. The strength of qualitative research is the ability to offer detailed complex descriptions about how people experience a given issue. Qualitative research offers an understanding about the human face of topics that relate to the often-opposing behaviours, beliefs, views, emotions, and relationships of individuals, hence, endeavours for an understanding of the whole. In addition, qualitative methods are effective in identifying intangible factors, such as social norms, socioeconomic status, gender roles, ethnicity, and religion, whose role in the research issue may not be readily apparent (Ormston, Spencer, Barnard & Snape, 2014:52).

An exploratory design was relevant for the study as there was limited research done on the research problem in Ethiopia. Exploratory research is research used to investigate a problem that has no clear definition (Ishtiaq, 2019:23). The conducting of this type of research is to have a better understanding of the existing problem. For such research, including this study, the researcher starts with a general idea and uses the research to identify issues that can be the focus for future research. It specifically explores a certain problem, which requires an in-depth study. Therefore, this study aimed to explore the perceptions, awareness and health-seeking behaviour of women regarding cervical cancer in Nefas Silk Lafto Sub-city, Addis Ababa, Ethiopia.

1.9 SETTING

The research took place in Nefas Silk Lafto Sub-City of Addis Ababa, Ethiopia, which is one of the city's 10 Sub-Cities. Each Sub-City has administrative sub-divisions, referred to as Woredas (Districts), with further division into Kebeles (Wards). Nefas Silk Lafto Sub-City is divided into 12 woredas and has a population of 335,740 people (BoFED, 2013:3). Nefas Silk Lafto Sub-City is an urban setting with residential areas, business centres, offices of government and non-government organisations, schools and universities, and therefore hosts people from diverse socio-economic backgrounds. The choice of Nefas Silk Lafto Sub-City for the research was because access to the research area was easier and the area hosts many women from very different backgrounds.

Woreda 11 Health Centre in Nefas Silk Lafto Sub-City, Addis Ababa, Ethiopia, was chosen for the research, as large numbers of women from different backgrounds use the health centre, which has different departments including outpatient, ART clinic, ante-natal clinic (ANC), post-natal clinic (PNC), etc., as well as ease of access for participants.

1.10 POPULATION

Population refers to a subset of the target population from whom the sample was chosen (Polgar & Thomas, 2011:6); it is a complete set of persons or objects that possess some common characteristics of interest to the researcher. Ethiopia adopted the WHO's (2013:7) recommendations that cervical cancer screening for HIV negative women between the ages 30-49 occur once every five years. It is further recommended that for the population whose sero-status is not known, screening should start from 18 years, which is the legal age for individual consent in Ethiopia, with re-screening every five years (FMOH, 2015a:44). Therefore, the population in the study consisted of all women between the age 18 to 69 years, residing in Nefas Silk Lafto Sub-City, Addis Ababa, and attending outpatient clinics in Woreda 11 Health Centre, whether or not they had undergone screening.

1.10.1 Inclusion criteria

- Women aged between 18 to 69 years old attending outpatient clinics at the Woreda 11 Health Centre in Nefas Silk Lafto Sub-City, Addis Ababa, Ethiopia

- Not diagnosed with cervical cancer at the time of the interview
- Conversant in Amharic, which is the official federal language spoken by many
- Able to consent (informed and in written) to participate in the study
- Having resided in Addis Ababa for the past year or more

1.10.2 Exclusion criteria

- Women under 18 years or over 69 years old
- Not having resided in Addis Ababa for at least the last year
- Not able to communicate or understand Amharic language
- Women unable to give consent due to disability or diagnosed with the disease

1.10.3 Sample and sampling method

Sampling relates to the selection of individuals, units or setting to be studied (Polgar & Thomas, 2011:56). The study sample comprised of all women who attended outpatient clinics at the Woreda 11 Health Centre in Nefas Silk Lafto Sub-City, Addis Ababa, Ethiopia. Convenience sampling selected participants who met the criteria for the study. The sampling of participants is because they are "conveniently" members of the target population, such as having easy accessibility, geographical proximity, being available at a given time, and the willingness to participate. Convenience sampling participants are selected as they just happen to be situated, spatially or administratively, near to where the researcher is conducting the data collection (Etikan, Musa & Alkassim, 2016:4).

The use of convenience sampling was because it is in line with qualitative research paradigm with no goal of generalisation of the results, rather for having an in-depth understanding of participants' meanings and perceptions, awareness, and health-seeking behaviours regarding cervical cancer (Ritchie, Lewis, Nicholls & Ormston, 2014:111).

The choice of convenience sampling for this study was because the participants were readily available at the Woreda 11 Health Centre. The centre has the most patient flow, with women from different backgrounds using the different departments, including outpatient, ART clinic, ante-natal clinic (ANC), post-natal clinic (PNC), etc., at this health centre and therefore, the ease of access to participants. In addition, the sample size for

this study was not pre-determined but saturation was the criteria for deciding the number of participants, with the intention of interviewing around 30 participants.

1.10.4 Data collection

Data collection commenced after receiving ethics approval from the Department of Health Studies Ethics Research Committee of University of South Africa (UNISA), (Annexure A). Permission to conduct the study was requested (Annexure B) and approved by the City Government of Addis Ababa Health Bureau (Annexure C), who communicated with the Nefas Silk Lafto Sub City Health Office. In addition, the Nefas Silk Lafto Sub City Health Office shared a support and permission letter (Annexure D) with Woreda Health Offices, including the Woreda 11 Health Centre, to inform them about the study. Permission from During a meeting, the Head of the Health Centre and the case team leaders of each clinic at the health centre granted permission.

Data collection occurred through semi-structured interviews conducted among eligible women in Woreda 11 Health Centre, Nefas Silk Lafto Sub-City, Addis Ababa, Ethiopia. In-depth interviews are optimal for collecting data on individuals' personal histories, perspectives, and experiences, particularly when exploring sensitive topics. A self-developed interview guide (Annexures I and J), informed by questionnaires from similar studies related to the perceptions, awareness and health seeking behaviours of women regarding cervical cancer, in the form of open-ended questions was used to explore the research questions in the study and to ensure all interviews covered the set points. It is important that experts validate an interview guide, to ensure it covers the scope of questions needed. The study supervisor, who is a qualified oncology specialist nurse, as well as other health experts in the field and colleagues involved in cervical cancer screening clinics, validated the interview guide. Two eligible participants meeting the criteria specified pilot tested the interview guide and the study supervisor reviewed it.

The researcher prepared the interview guide (Annexure I) in English, which was translated to Amharic (Annexure J) by a professional translator, conversant with both languages, and then translated back to English language by a different professional translator to keep the consistency of the questions and to prevent any loss of meaning.

The researcher initially sought to be solely involved in data collection, however, due to cultural issues and not being fully conversant with the language spoken (Amharic), he engaged a female research assistant conversant in Amharic language and knowledgeable on public health issues including cervical cancer, also residing in the same Woreda. The researcher and the research assistant recruited the study participants based on the eligibility criteria (1.10.1) and their willingness to participate in the study.

The nursing staff helped to identify suitable women who were at the health centre, meeting the eligibility criteria, who likely had an opinion on the topic and willing to participate in the study. The research assistant invited all women and informed them about the study as well as issues of consent. The conducting of the study was from 15 to 29 October 2019. Appointments were according to the times suitable for participants and the interviews proceeded accordingly. The interviews took 45 minutes to an hour, and conducted in a private room arranged with the managers of the centre to ensure privacy and confidentiality, a more neutral environment and to make the interviewees more comfortable. The research assistant interviewed the participants in Amharic language and recorded the interviews with the participants' permission (Annexures F & G).

To avoid interrupting the flow of the conversation, the writing of the field notes occurred immediately after the interviews in order not to miss any information, such as facial cues and emotions of the interviewees. Field notes, written in a small notebook, allowed the researcher to keep and comment on impressions, behaviours, and non-verbal cues that may not be satisfactorily captured with the audio recordings. These notes can offer significant context to the interpretation of audio-recorded data and help remind the researcher and research assistant of situational factors that may be of importance during data analysis. The research assistant conducted 15 interviews until reaching data saturation; the conducting of two additional interviews was to confirm the saturation. Saturation of information refers to the point where the data collection no longer reveals new information. In qualitative studies, it is suggested that saturation can often be reached after interviewing two to 15 and is often optimal to meet the standard, depending on the context (Silverman, 2016:13), so that the participants' number was limited by the saturation and sufficiency level of the information provided, which was 17 for the data collected in this study. The researcher considered revisiting the participants for missed information, clarity and additional concerns, but in this instance, this was not necessary.

1.10.5 Data management and analysis

This section will discuss the issue of trustworthiness to ensure the quality, data management, data analysis and ethical considerations. Prior to analysing the data, it was stored in an audio recorder, transcribed verbatim by the research assistant and translated by a language editor conversant in Amharic and English to make sure the meaning was retained. The use of field notes was for additional information that the audio recorder could not capture. Numbering the lines of text occurred as the analysis proceeded. After completing the transcription, the researcher and the research assistant read it together to make sure that it captured true reflection of what the participants shared. To ensure confidentiality, there were numbers used to identify participants instead of personal details.

Qualitative content analysis (Hsieh & Shannon, 2005:1277; Mayring, 2004:159) analysed the data in order to explore and understand the perceptions, awareness and health seeking behaviours of women regarding cervical cancer to unearth the meanings. Furthermore, qualitative content analysis provides a systematic and objective means of making valid inferences from data in order to describe and illuminate a specific phenomenon (Silverman, 2016:13; Elo, Kääriäinen, Kanste, Pölkki, Utriainen & Kyngäs, 2014:10).

Content analysis is a family of systematic, rule-guided techniques used to analyse the informational contents of textual data. There are several types of content analysis, including quantitative and qualitative methods, all sharing the central feature of systematically categorising textual data to make sense of it. The use of qualitative content analysis can be in either an inductive or a deductive way, and both processes involve three main phases: preparation, organisation, and reporting of results. The preparation phase consists of collecting suitable data for content analysis, making sense of the data, and selecting the unit of analysis. In the inductive approach, the organisation phase includes open coding, creating categories, and abstraction. In deductive content analysis, the organisation phase involves categorisation matrix development, whereby all the data are reviewed for content and coded for correspondence to or exemplification of the identified categories (Elo et al., 2014:10).

The research assistant began the analysis process after the first two interviews by listening to the audio recordings, transcribing the data verbatim, and reading the extracted transcripts to understand the hidden meanings in the text. The researchers re-examined the text to gain deeper comprehension of the emerging themes, looking at the whole text, or parts of, back and forth. There was careful reading of the of the study participant's recordings, seeking what was common among them for the construction of the codes, categories and themes, making it possible to comprehensively analyse the responses of the study participants, which the study supervisor also reviewed.

1.10.6 Trustworthiness (rigour)

Trustworthiness refers to the degree of confidence in data, interpretation and methods used to ensure the quality of the study. The quality of a research necessitates truth value, applicability, consistency, and neutrality. These issues are identified as the indicator of trustworthiness of a research, and in a qualitative research, these are known as credibility, transferability, dependability, and conformability (Smith & McGannon, 2018:101), which Chapter 3 explains in detail.

1.10.6.1 Credibility

Credibility refers to the confidence in the truth of data and its interpretations. To establish the credibility, the researcher considered techniques of prolonged engagement and revisiting, and study participants approached in a friendly manner with no pressure and interviewed in a comfortable environment (Smith & McGannon, 2018:101). Credibility is about evaluating integrity and quality in qualitative studies to ensure confidence in the truth of the data (Polit & Beck, 2012:724). An experienced qualitative research assistant worked with the researcher and appropriate discussions ensured credibility of the study. The collection of the data from different participants at different times also helped in this regard.

1.10.6.2 Transferability

Transferability relates to how the study's findings are applicable to other contexts and description of the phenomena under study, and as much of the context as possible in which the study took place is the most powerful technique for facilitating transferability

decisions (Smith & McGannon, 2018:101). A detailed description of the study proposal and report is available in order for peers in similar settings should they wish to replicate the study.

1.10.6.3 Conformability

Conformability is the degree of neutrality in the research study's findings (Smith & McGannon, 2018:101). In this study, based on the data analysed and the comparison of the results with literature, interpretation of the results was as close as possible to the participants' points of view. The study supervisor also analysed a number of the interviews to see if there were similar meanings attained, and there was a meeting held to discuss if any discrepancies to reach a consensus, as the researchers should not change or correct any statements of the participants (Polit & Beck, 2012:175).

1.10.6.4 Dependability

Dependability refers to evidence that the findings are consistent and stable over time and under different conditions, and is concerned with whether there would be the same results observed if applied in an almost similar context (Polit & Beck, 2012:585).

Different measures were in place to establish the rigour of the research and the findings of this study. Having notes, a quality recorder, a comfortable environment, and good communication maintained the data quality. Ensuring prolonged engagement, which refers to investment of sufficient time during the data collection phase to have an in-depth understanding of the views of the participants, was with interviews that lasted, on average, at least 45 minutes to an hour, depending on the length of the narratives. This allowed for building rapport with the participants, which in turn helped in obtaining useful, accurate and rich data.

1.10.7 Ethical considerations

Data collection commenced after obtaining ethical approval from the Research Ethics Committee of UNISA to conduct this study (Annexure A). A letter of permission was obtained from Addis Ababa Health Bureau (Annexure C), to conduct the study in the specified study area. Based on the Addis Ababa Health Office approval, Nefas Silk Lafto

Sub-City Health Office gave permission and further communicated with the Woreda Health Offices, including the Woreda 11 Health Office, to inform them about the study (Annexure D). After presenting this support and permission letter to the Woreda 11 Health Centre, there was permission obtained from the Head of the Health Centre and from the case team leaders of each clinic in the health centre before data collection.

The researcher and the trained research assistant from Addis Ababa University explained the objective of the study and the necessary information to the study participants. The participants received information regarding confidentiality of the information shared, and only the researcher, the study supervisor and research assistant had access to it. Each study participant gave written informed consent (Annexures F & G).

Data remained confidential; contact lists, recruitment records or other documents containing personal identifiers were to be destroyed when no longer required for the research after being retained for 5 years. In order to ensure the confidentiality, the research data was stored securely in locked cabinets, files containing electronic data were closed when computers were left unattended and electronic data was stored in password-protected computers. Participants' signed consent forms were stored securely in locked cabinets separately from the research data. Data collected will only have use for this research purpose. The research assistant was trained on the IRB (Institutional Review Board) approved methods for managing and storing research data.

1.11 ORGANISATION OF CHAPTERS

Chapter 1: Introduction to the study

Chapter 2: Literature review

Chapter 3: Research methodology

Chapter 4: Findings of the study and discussion

Chapter 5: Recommendations and conclusion

1.12 SUMMARY

This chapter outlined the introduction to this study, the statement of the research problem, the purpose and objectives, in addition to a concise description of the research methods and design. Chapter 2 will discuss the literature review regarding cervical cancer.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

Chapter 1 presented an overview of cervical cancer, the global burden of disease, the epidemiological distribution, and the development of cervical cancer, the associated risk factors, that done to date, what is still missing, and the purpose and significance of this study in relation to cervical cancer. The purpose of this review is to identify the research gaps and add evidence in relation to cervical cancer and the health-seeking behaviour of women depending on their geographical as well as socio-economic environment.

The literature review occurred systematically through search engines such as PubMed, Google Scholar, Medline, LexisNexis, Scopus and Web of Science. There was a further search of related articles using insights as well as keywords, such as cervical cancer, cervical cancer screening, awareness on cervical cancer, knowledge on cervical cancer, health-seeking behaviour on cervical cancer. The reviewing of significant peer-reviewed articles, reports, guidelines, and textbooks related to the topic aided in the synthesis and collation.

2.2 GLOBAL BURDEN OF CERVICAL CANCER

While cervical cancer is the fourth most common cancer among women globally, it is reported as the second most common cancer among women in low- and middle-income countries (LMIC) (Ferlay et al., 2018:5). According to Cohen et al. (2019:170), each year, more than 310,000 women die of the disease worldwide and almost 90% of these deaths occur in LMICs, with the highest prevalence and increased mortality rates in Sub-Saharan Africa. The risk of developing cervical cancer differs between countries and regions. The incidence and mortality of cervical cancer in resource-rich countries is under control compared to developing countries (Bray, Ferlay, Soerjomataram, Siegel, Torre & Jemal, 2018:394).

The prevalence also varies in different sub-Saharan African countries; in Ghana the prevalence is 42.5% (Obiri-Yeboah, Akakpo, Mutocheluh, Adjei-Danso, Allornuvor, Amoako-Sakyi, Adu-Sarkodie & Mayaud, 2017:688), Burkina Faso 34.4% (Rogomenoma, Sindimalgdé, Traore, Ouattara, Ouedraogob, Wendkuuni Djigma, Obiri-Yeboah, Ouedraogo & Simpoire 2018:22), and Nigeria 18.6% (Nejo, Olaleye & Odaibo 2018:105). According to the WHO (2020:1), the top 20 countries globally with the highest burden of cervical cancer were in Africa. According to studies conducted in Burkina Faso and South Africa, HPV infection has been reported to be significantly associated with HIV infection, and the prevalence of this is highest among women living with HIV (WLHIV) (Chikandiwa, Kelly, Sawadogo, Ngou, Pisa, Gibson, Didelot, Meda, Weiss & Segondy, 2018:78; Obiri-Yeboah et al., 2017:688).

2.3 DEVELOPMENT OF CERVICAL CANCER

Cervical cancer occurs in the cells of the cervix, which is the lower part of the uterus that connects to the vagina. The cause is persistent infection with Human Papilloma Virus (HPV) that affects the cells resulting in change in the epithelial cells. Cervical cancer occurs due to the abnormal growth of cells that can invade or spread to other parts of the body. It starts in the cervix, which is the narrow opening into the uterus from the vagina. The normal ectocervix, which is the part of the uterus extending into the vagina, has a covering of flat, thin cells called squamous cells. The make-up of the endocervix or cervical canal is columnar cells, and the area where columnar and squamous cells meet is the transformation zone (T-zone) and is the most likely location for abnormal or precancerous cells (Ginsburg, Bray, Coleman, Vanderpuye, Eniu, Kotha, Sarker, Huong, Allemani & Dvaladze, 2017:847). The squamous metaplasia in the cervix results from the physiological replacement of the everted columnar epithelium on the ectocervix by a newly formed squamous epithelium from the sub-columnar reserve cells.

The main types of cervical cancers are squamous cell carcinoma (up to 80%) and adenocarcinoma (up to 20%) (Obiri-Yeboah et al., 2017:688). Squamous cell carcinoma begins within the thin, flat cells (squamous cells) lining the outer part of the cervix, which projects into the vagina, whilst adenocarcinoma begins in the columnar-shaped glandular cells that line the cervical canal. Although both types of cells are involved in cervical cancer, the most common type is squamous cell carcinomas (Lin, Wang, Liu, Chen, Yuan, Wu & Gong, 2019:1054).

There are more than 120 HPV types identified and at least 14 of them are cancer causing, while others can cause genital warts (WHO, 2020:1). According to Colon (2018:337), approximately 40 HPV types can infect mucosal epithelial cells, such as those on genitals, mouth, and throat. The HPV subtypes 16 and 18 mostly have a link to cervical intraepithelial neoplasia (CIN) and account for about 70% of cervical cancers. Sexual behaviour and activity, such as early debut, having multiple partners, condom use - rather the lack of – and promiscuous male partners are the main reasons of HPV infection, which is also transmittable through direct skin-to-skin contact of the genital areas (Chikandiwa et al., 2018:78).

2.3.1 Etiology of cervical cancer

Human papilloma virus (HPV), which is a DNA virus, replicates with the host DNA to produce cancerous oncogenic proteins, which is the etiologic agent of cervical cancer (Colon, 2018:337). Oncogene proteins are proteins encoded by oncogenes (dysregulated or activated genes) and have the potential to cause cancer. Oncogenes control cell proliferation, apoptosis (natural cell death to eliminate old, unnecessary or unhealthy cells) or both. Oncogenes are activated through various triggers, which include structural mutations (caused by infections that lead to genetic changes), gene fusion (genetic recombination of two or more genes resulting in a new one) or amplification (an increase in the number of copies of a specific gene) (Aco-Tlachi, Carreño-López, Martínez-Morales, Maycotte, Aguilar-Lemarroy, Jave-Suárez, Santos-López, Reyes-Leyva & Vallejo-Ruiz, 2018:25).

Persistent infection with the human papilloma virus will result in cervical intraepithelial neoplasia, which is pre-cancerous condition where new abnormal cells grow on the surface of the cervix. However, only a small proportion of women acquiring HPV infection will develop into CIN (Mitra, MacIntyre, Lee, Smith, Marchesi, Lehne, Bhatia, Lyons, Paraskevidis, Li, Holmes, Nicholson, Bennett & Kyrgiou, 2015:1) as many HPV infections clear spontaneously within a few months (WHO, 2020:1) and about 90% of the infections clear within two years; only a small proportion of infections with certain types of HPV can persist and progress to cervical cancer over the years.

Most cases of HPV infection and most pre-cancerous lesions disappear spontaneously; however, there are about four major steps in cervical cancer development after HPV infection. The first step is oncogenic where HPV infection of the metaplastic epithelium occurs at the transformation zone.

The extended natural progression of cervical cancer increases the potential for successful prevention and early curative intervention. According to the WHO (2020:1), the duration for cervical cancer to develop takes 15 to 20 years in women with normal immune systems, and 5 to 10 years in women with weakened immune systems.

2.3.2 Cervical intraepithelial neoplasia (CIN)

Cervical intraepithelial neoplasia is a precancerous condition in which abnormal cells grow on the surface of the cervix. Intraepithelial means that the abnormal cells are present on the surface (epithelial tissue) of the cervix. The word neoplasia refers to the growth of new cells. Another name for CIN is cervical dysplasia. Cervical intraepithelial neoplasia types (CIN I, II and III) are premalignant lesions that have the potential to progress to full-blown cervical cancer unless treated. The classification of CIN is according to the extent of epithelium involved; CIN I (lower third of the epithelium), CIN II (middle third of the epithelium) and CIN III (entire epithelium) (Mitra et al., 2015:1).

Most lesions occur in the transformation zone of the cervix and if left untreated, CIN II or CIN III (collectively referred to as CIN II+) can progress to cervical cancer. Each year, 1-2% of all cases of cervical cancer reportedly have CIN II+, which tends to increase in HIV-positive patients, as HPV prevalence is higher among people living with HIV because of their weakened immune systems. CIN finally transforms to carcinoma in-situ that marks the formation of cancer, necessitating treatment (Chikandiwa et al., 2018:78).

2.4 RISK FACTORS FOR DEVELOPMENT OF CERVICAL CANCER

There have been various factors linked to the development of cervical cancer along with Human Papilloma Virus. HPV infection is associated with sexual activity; an explanation of the association could be the relationship between having multiple sexual partners, which increases the possibility of exposure to HPV, and having early debut (to sexual activity), which may result in possible early exposure to HPV, and risk of developing

sexually transmitted diseases (STIs), which can weaken the immune system. Reportedly, co-infection with other STIs (Chlamydia Trachomatis, HIV, and Herpes Simplex Virginalis) also contributes to the progression of cervical cancer. There is a high link between cervical cancer and HIV infection, usually called an HIV related malignancy (Chikandiwa et al., 2018:78). HPV infections are more likely to persist, and progress to pre-cancer and/or cancer when people are immunocompromised.

Other recognised main factors of risk of development of cervical cancer include low-economic status, smoking, prolonged use of oral contraceptive pills (OCP), and high parity, which are prone to increase the risk of squamous-cell carcinoma of the cervix among HPV-positive women, being under 17 years-old at first full term pregnancy (as the cervix is immature during adolescence hence become prone to persistent HPV infections, and consequently exposed to a higher risk of developing cervical cancer), a diet that is low in vegetables and fruits, being overweight, prolonged use of hormonal drugs, and a family history of cervical cancer. Having more than one of these risk factors also increases the risk of cervical cancer. According to the WHO (2020:1), most sexually active adults will have HPV infection in their lifetime. It is crucial at any opportunity to utilise effective screening, whether intentional or opportunistic. Cervical cancer, due to its longer pre-invasive nature, provides such an opportunity.

2.5 CERVICAL CANCER SCREENING AND PREVENTION

Cervical cancer screening is the systematic application of a test to identify cervical abnormalities in an asymptomatic population (Basu, Nessa, Majid, Rahman & Ahmed, 2010:131). Screening services may be provided either in an organised manner, such as a part of a programme with policy, guidelines, recruitment measures, adequate facilities, monitoring, evaluation and quality control, or in an opportunistic manner, such as in health facilities, particularly for high-risk women, in private facilities for low-risk women when they are utilising other services, or a combination of both of these (Huchko, Maloba, Nakalembe & Cohen, 2015:14). The purpose of prevention and control methods is to decrease the incidence of cervical cancer and associated morbidity and mortality, as well as improve the quality of life of the patients and their families (Mirghani, Jung & Fakhry, 2017:105). Additionally, the World Cancer Report (WHO, 2013) highlights the importance of early detection and treatment, which calls on all countries to establish comprehensive national cervical cancer control programmes. A focus on cervical cancer screening will

result in better survival rates and a better quality of life for patients and families. Early detection, aimed at the reduction in incidence and mortality linked with invasive cancer, can significantly increase the probability of successful treatment (Delgado, Menacho, Segura, Roman & Cabello, 2017:290). There are three major levels of prevention (primary, secondary and tertiary), which are helpful in detection, treatment and rehabilitation of the cases and the patients.

2.5.1 Prevention levels

2.5.1.1 Primary level prevention

Primary prevention aims to reduce the incidence of a disease or an injury or a disability within a population and advocate for optimal health by intervening before the health effects occur. Primary prevention involves prophylactic interventions even before there is any evidence of disease found. According to the WHO (2020:1), the target population for HPV vaccinations should be 9 to 14-year-old girls, as prophylactic vaccinations against HPV have proven effective (Mirghani et al., 2017:105). Currently, there are three vaccines available, Bivalent (Cervarix), which is effective against HPV 16, 18, Quadrivalent (Gardasil), which is effective against HPV 16, 18, 11 and 6, and Gardasil 9 (Nonavalent), found to be effective against nine genotypes (6, 11, 16, 18, 31, 33, 45, 52 and 58). These vaccines can prevent most of the invasive cervical cancers; however, they are not treatment for the disease and need administering prior to first sexual activity (WHO, 2020:1).

In 2020, the World Health Assembly (WHA) recommended a comprehensive approach to cervical cancer prevention and control, such as health information and warnings about tobacco use, and in addition to sex education, the recommendation of condom promotion and male circumcision as a part of primary level prevention. Appropriate health education towards limiting the number of sexual partners, effective condom use, early STI treatment, having a healthy diet and stopping tobacco use can play a significant role in the prevention of the disease (WHO 2020:1).

In Ethiopia, there was a launch of HPV vaccinations as a pilot project in December 2015, targeting adolescent girls (9 to 13-year-olds) in Tigray and Oromia regions. There was implementation of the quadrivalent vaccine in Gomma Woreda (District) of Jimma Zone

in Oromia Region and Ahiferom Woreda (District) of Tigray Region, and based on the findings, Ethiopia launched quadrivalent vaccine for 14-year-old girls (FMOH, 2015a:44).

2.5.1.2 Secondary level prevention

Secondary prevention aims to detect the disease in its earliest stage, before symptoms emerge, and halt the progression of the disease with treatment such as cryotherapy or thermal ablation, resulting in a better probability of recovery (Mirghani et al., 2017:105). Given its natural slow progression, with the development of precancerous lesions a long time prior to the occurrence of cancer, cervical cancer is especially well suited to secondary prevention (Mirghani et al., 2017:105). The WHO (2020:1) recommends screening all women 30 years or older with a high-performance test, such as HPV tests (DNA or mRNA), followed by immediate or as quickly as possible treatment of the pre-cancer lesions.

In those patients who have already developed symptoms and diagnosed, prevention of progression and recurrence becomes critical.

2.5.1.3 Tertiary level prevention

Tertiary prevention aims at diagnosing, managing and controlling the morbidity post diagnosis, which also includes the prevention of recurrence (Mirghani et al., 2017:107) through measures such as surgery, radiotherapy, or chemotherapy at any age. For the prevention of cervical cancer (in both HIV infected and HIV uninfected women) successful screening and therefore, the early detection and treatment of precancerous cervical lesions are key. According to studies conducted in Japan and USA, early cervical cancer screening has reduced incidence and mortality related with cervical cancer among HIV positive women (Lillo & Uberti-Foppa, 2006:810; Lambert, Chandler, McMillan, Kromrey, Johnson-Mallard & Kurtyka, 2015:271).

2.5.2 Screening methods

There are various screening methods currently available, such as the conventional Papanicolaou (Pap), liquid-based cytology (LBC), HPV DNA testing, and visual inspection with Acetic Acid/Lugol's Iodine (VIA/VILI). Different methods of screening can be utilised

to decrease morbidity from cervical cancer. Unfortunately, access to Pap smear, LBC and HPV DNA tests in LMICs is still limited, hence the WHO (2012:1) recommended utilisation of VIA/VILI tests for low-income countries that are resource limited provided they are done in closely monitored settings.

2.5.2.1 Papanicolaou (pap) test

The Pap test is a technique used to collect cells from the cervix for observation under the microscope to exclude cancer and pre-cancer. A Pap smear, or Pap test, is a cervical cancer screening procedure that tests for the presence of precancerous or cancerous cells in the cervix. In this procedure, after visualisation of the cervix with a speculum, a sampling device (spatula, brush) gently scrapes the cells from the cervix and the specimen immediately placed onto a glass slide for examination at the laboratory using the Papanicolaou staining method for abnormal growth. While this procedure may be mildly uncomfortable, it usually does not cause any long-term pain (Assoumou, Mabika, Mbiguino, Mouallif, Khattabi & Ennaji, 2015:37). The Pap test is used for triage testing after a positive HPV test result, as well as for follow up after treatment of cervical cancer. This test type requires well-trained staff, facilities and necessary supplies and equipment, referral and follow up systems, therefore, not suitable for low-resource settings where Liquid Based Cytology tests are a better method.

2.5.2.2 Liquid based cytology (LBC)

The liquid-based tests involve washing scraped cells into a vial of liquid and filtered, and a random sample presented in a thin layer on a glass slide and sent to the laboratory where the fluid is centrifuged to separate the cells from the preservative and other materials, such as mucus. This process allows for clearer, more even samples that are easier to analyse. The samples are placed on a glass slide to be stained and examined with a microscope. Skilled staff can screen these slides or subject them to partially automated imaging for results. Consequently, liquid-based cytology tests reduce repeat tests since they are more conclusive. These tests are also more sensitive, which means correct identification of a higher percentage of people with the disease. In addition, LBC tests help in specificity, as these tests help to exclude people without the disease at a higher percentage, therefore, are more effective in detecting cervical cancer.

2.5.2.3 HPV DNA test and self-collected HPV DNA test

HPV DNA testing detects viral DNA by inspecting pieces of the DNAs for high-risk or carcinogenic types of HPV in cervical cells. For HPV DNA testing, a sampling device (spatula, brush) gently scrapes cells from the cervix for examination at the laboratory. This test can occur at the same time as the Pap test with the same or a second swab (American Cancer Society 2021:1). HPV DNA testing offers improved protection against the disease and its precursors in comparison to cytology (Hesselink, Berkhof, Van der Salm, Van Splunter, Geelen, Van Kemenade, Bleeker & Heideman, 2014:890).

HPV DNA can also take place after women self-collect the samples. Offering self-collected HPV DNA testing, which successfully detects CIN2+, attracts a considerable number of women into the screening programme, who otherwise would not utilise screening programmes (Hesselink et al., 2014:890). Self-collected HPV DNA test may be a more comfortable way for women to screen, instead of going to a facility for cervical cancer screening, as they can self-collect the samples at their convenience with privacy and be beneficial for women with limited access. It can also help in the acceptability of screening for the disease, thereby increasing the coverage, prevention, and detection (Lazcano-Ponce, Lorincz, Cruz-Valdez, Salmeron, Uribe, Velasco-Mondragon, Nevarez, Acosta & Hernandez-Avila, 2011:1868).

2.5.2.4 Visual inspection with Acetic Acid and Lugol's iodine (VIA/VILI)

Visual inspection with Acetic Acid (VIA) test is by visualisation of the cervix with a speculum and then applying 3-5% acetic acid wash to the cervix to exclude precancerous changes on the cervix. VILI uses iodine instead of acetic acid. In this procedure, after visualisation of the cervix with a speculum, if there is a need for excision of the abnormal cells or lesions, the WHO (2020:1) recommends cryotherapy to remove abnormal cells by destroying abnormal tissues on the cervix by freezing.

VIA is a relatively cheaper option, and as the method does not require highly trained professionals can take place at lower-level health facilities. The results are immediate, and those found positive can receive treatment at the same time and place. For that reason, the WHO recommends VIA for use in resource limited but closely monitored settings.

Cervical cancer screening programmes have shown effectiveness in reducing the incidence and mortality of cervical cancer. These programmes also have increased public awareness of cervical cancer and its prevention, hence, a focus in screening will result in better survival rates and quality of life.

In developed countries, cervical cancer prevention and screening has received significant attention and in return, resulted in a reduction of the disease and related deaths. In developing nations this has not been the case due to competing needs for communicable diseases, fragile health systems, lack of laboratories and/or supplies and equipment for cytology and pathology, not having the resources for upscaling of programmes, and not having cervical cancer screening included in all medical training (Landy et al., 2016:1146).

2.6 CERVICAL CANCER SCREENING IN ETHIOPIA

Non-communicable diseases, including cancer, have only received attention as major public health issues in Ethiopia in the last decade (FMOH, 2015b:50). The most prevalent cancers among the adult population in Ethiopia are breast cancer, cervical cancer, and colorectal cancer (FMOH, 2015a:44). According to a study by Ferlay et al. (2015:13) on cancer incidence and mortality globally, around two-thirds of annual cancer deaths are occurring among women. In Ethiopia, cervical cancer is the most frequent cancer and among the leading causes of cancer mortality among women (FMOH, 2015a:44).

In Ethiopia, access to cervical cancer screening for the majority of women had been limited until Pathfinder International introduced the Single Visit Approach (SVA) as a cervical cancer programme (CCP) in 2009 and implemented in 14 health facilities. The project, named as Addis Tesfa (meaning New Hope), used the SVA for women infected with HIV. The SVA employed Visual Inspection of the cervix with Acetic acid (VIA) and offered immediate treatment of precancerous cervical lesions with cryotherapy. The SVA helped women as they only needed to visit the facility once to be screened and if necessary, receive immediate treatment during the same visit, which seizes on the opportunity of having women present for testing and immediately treated, given the barriers women face to access services mentioned (Pathfinder International, 2010:1).

Factors associated with low uptake of cervical cancer screening were poor awareness of the symptoms and benefits of cervical cancer screening, lack of knowledge of the disease

and its risk factors, fear of pain, being embarrassed during pelvic examinations where women may not be comfortable to reveal their bodies, as well as anxiety of finding a positive result (Tesfaye, Bhagavathula, Gebreyohannes & Tegegn, 2019:10; Duff, Ogilvie, Shoveller, Amram, Chettiar, Nguyen, Dobrer, Montaner & Shannon, 2016:366; Shiferaw, Addisie & Gizaw, 2016:93).

According to Ramjan, Cotton, Algosso and Peters (2016:141), when they reviewed literature of 25 articles published between 2001 and 2013 on barriers to breast and cervical cancer screening for women with physical disabilities, lack of female staff in health facilities (where women do not feel comfortable to be examined by male screeners), and inconvenient clinic operation times due to work or childcare were barriers for women. Other barriers that had a negative impact on the uptake of cervical cancer screening included the angst caused by the possibility of a cancer diagnosis, limited understanding of the screening procedures and need for additional information. To address the challenges mentioned above and to improve the uptake of services, relevant measures to address them need implementing, such as the SVA or self-sampling technique (Saleem, Bekele, Fitzpatrick, Mahmoud, Lin, Velasco & Rashed, 2019:1; Delgado et al., 2017:293; Bayu, Berhe, Mulat & Alemu, 2016:1).

Accordingly, the WHO recommended screening tests, such as visual inspections using acetic acid (VIA), cytology (Pap smear/LBC) and HPV test (WHO, 2020:1; Vu, Yu, Awolude & Chuang, 2018:457). These screening methods have the potential to decrease cervical cancer incidence and mortality significantly if implemented correctly. Whilst, the onset of screening age and frequency varies in different countries, the American Cancer Association recommends screening every five years, with HPV test or a co-test (Pap plus HPV) or a Pap test alone every three years between the ages of 25 and 65. However, the WHO (2020:1) recommends that women are screened with a validated HPV test every five to 10 years from ages 30 and regularly afterwards. Nevertheless, cervical cancer screening programmes remain limited in low resource settings, compared to resource-rich countries (Santesso et al., 2016:252).

Ethiopia adopted the WHO's recommendations and national initiatives, which laid a conducive ground to alleviate the burden of cervical cancer (FMOH, 2015b:48). Furthermore, individual, geographical, cultural, structural, infrastructural, and procedural barriers contributed towards limiting the health-seeking behaviour of women and could

be associated with decreasing participation or uptake of screening programmes (Haileamlak, 2018:110; Shiferaw et al., 2016:13; Wondimu, 2015:65).

Most studies have shown low participation and health-seeking behaviour in less developed countries (Page, Ibrahim, Park & Huchko, 2019:1; Habtu, Yohannes & Laelago, 2018:298; Binka, Nyarko & Doku, 2016:326). In contrast to the challenges experienced by women in low- and middle-income countries, women in developed countries have been cited to have high percentage of participation and follow up rates in cervical cancer screening programmes (Fitzmaurice, Allen, Barber, Barregard, Bhutta, Brenner, Dicker, Chimed-Orchir, Dandona & Dandona, 2017:524; Nwobodo & Ba-Break, 2015:484).

Although a few studies explored women's perceptions and awareness of cervical cancer screening, they do not explain how these overlap with their health-seeking behaviour. To address this gap, this study aimed to explore the perceptions, awareness, and health-seeking behaviours of women regarding cervical cancer in Nefas Silk Lafto Sub-city, Addis Ababa, Ethiopia.

2.7 FACTORS AFFECTING CERVICAL CANCER SCREENING UPTAKE

There have been various factors found that affect the uptake of cervical cancer screening among women (Haileamlak, 2018:110; Bejiga, 2017:2; Bayu et al., 2016:1). However, women's awareness, based on information received or experienced, plays an important role in their health-seeking behaviour.

2.7.1 Awareness about cervical cancer

Worldwide, the level of awareness with regard to cervical cancer varies from place to place. Studies conducted on awareness regarding cervical cancer, particularly in LMICs, reported that awareness about cervical cancer was significantly minimal compared to people living in developed countries, such as the studies of Alafifi, Kindratt, Pagels, Saleh and Gimpel (2019:332) and Esan, Fasoro, Olaiya and Bello (2019:2).

The differences may be due to educational, socio-economic, and cultural variations between these countries as access to education, information, women's participation in public sphere play an important role with awareness.

There are also differences within the countries, as factors such as place of residence, education and socioeconomic levels have an impact on women's awareness and knowledge, as reported by other studies that found that women who attended higher education and resided in the urban areas had better awareness about cervical cancer (Kadian, Gulshan, Sharma, Kumari, Yadav, Nanda & Yadav, 2020:2; Williams, Kenu, Adanu, Yalley, Lawoe, Dotse, Adu & Fontaine, 2019:897; Åkerman, Essén, Westerling & Larsson, 2017:194).

Poor awareness and knowledge of cervical cancer was reportedly the reason for the non-uptake of cervical cancer screening among women in Dallas, Texas, USA, and Shenzhen, China (Alafifi et al., 2019:332; Lin et al., 2019:1054). However, other studies suggest that lack of awareness and knowledge about screening of cervical cancer may also contribute to the low uptake of screening. A study conducted on awareness and knowledge of cervical cancer in Gabon (Assoumou et al., 2015:37), reported that despite the majority of participants having heard about cervical cancer, fewer participants reported to have heard about HPV infection and Pap smear test, suggesting a need for comprehensive information tailored to the audience for improved awareness and knowledge, and consequently, an improved uptake in screening. Studies conducted in Ethiopia showed that knowing someone diagnosed with cervical cancer and having a history of sexually transmitted diseases were significantly associated with knowledge towards cervical cancer (Haileamlak, 2018:110; Bayu et al., 2016:1).

Similarly, the majority of participants in Uganda and Burkina Faso had heard about cervical cancer and most of them mentioned having multiple sexual partners, human papillomavirus infection, and early onset of sexual activity as risk factors for cervical cancer (Mwaka, Orach, Were, Lyratzopoulos, Wabinga & Roland, 2016:854; Compaore et al., 2016:760). A cross-sectional study conducted in Northwest Ethiopia found only one third of the study participants had knowledge about cervical cancer and half of them had a favourable attitude towards cervical cancer screening (Geremew et al., 2018:29).

2.7.2 Perceptions towards cervical cancer

Women's perceptions of cervical cancer and screening have a direct impact on their health-seeking behaviour. A study conducted in Uganda, exploring women's perceptions about cervical cancer, found that the majority of women reported cervical cancer was preventable and was curable if diagnosed at the early stage (Mwaka et al., 2016:854). According to Bayu et al. (2016:1), some people believed that having sexual intercourse with a man who does not believe in God, or having traumatic/rough sexual intercourse, causes cervical cancer. Additionally, the study revealed that hygiene-related perceptions, such as not washing the genitals well, especially after sexual intercourse, and sexual intercourse during the menstrual period, were main causes for cervical cancer. In addition, some people believed that a woman who annoys spirits of dead elders and/or who had sexual intercourse before marriage would get cervical cancer (Bayu et al., 2016:1). In relation to mode of transmission, in a study in Uganda, some participants believed that cervical cancer, as a contagious disease, can be transmitted through contact and being near a person who is infected. They also believed that cervical cancer is an inheritable disease from mother, aunts, and grandmothers (Mwaka et al., 2016:854).

According to a study done in Ethiopia (Geremew et al., 2018:29), nearly three-quarters of participants believed that cervical cancer could not be treated even if diagnosed at an early stage. This indicates the importance of perceptions regarding cervical cancer and screening in women's health-seeking behaviour. In terms of screening, half of the participants in the study agreed that any sexually active woman was at risk of acquiring cervical cancer, whilst two-thirds agreed that pre-cervical cancer screening helped to prevent cervical cancer.

A study conducted among HIV-positive women in Ethiopia (Deribe, Tamire & Kaba, 2019:11) reported that the higher the perceived vulnerability to cervical cancer, the higher the chances for women to act on preventive measures. Women who perceived cervical cancer as a disease with serious, adverse medical, social, and economic effects, such as the negative impact it would have on their overall wellbeing, health, economic and social participation, were more likely to go for screening. Women who believe in the benefits of screening are likely to participate in screening uptake.

According to a study conducted in Iran by Mehraban, Namdar and Naghizadeh (2018:2155), women's perceptions of the severity of the disease also had an impact on their health-seeking behaviour. Women who believed that cervical cancer was not a treatable disease, but preventable through screening, were more likely to undergo cervical cancer screening. This indicates that if women perceive screening as beneficial, they may readily change their health-seeking behaviours.

2.7.3 Health-seeking behaviour

Any action taken by a person, who perceives a need for health services, with the aim to address a given health problem, including seeking allopathic and alternative health services, is health-seeking behaviour (Small et al., 2017:2404).

Studies conducted in Ethiopia reported that most women with cervical cancer seen in the healthcare system have late detection, at an advanced stage of cancer (Getinet, Gelaw, Sisay, Mahmoud & Assefa, 2015:2; Wondimu, 2015:74). A community-based study conducted in Southern Ethiopia (Habtu et al., 2018:298) reported limited health-seeking behaviour for cervical cancer among the study participants. Furthermore, respondents' poor knowledge, not receiving any information from healthcare providers and not actively searching information about cervical cancer were significantly associated with not seeking health prevention and control of cervical cancer. The concern, however, was that the majority of women in the study had no intention to undergo cervical cancer screening as they had never had the illness before. Conversely, a cross-sectional study in Northwest Ethiopia, on knowledge of cervical cancer and attitudes about screening (Geremew et al., 2018:29) revealed that significant proportions of women in Finote-Selam town agreed to screen in the future if screening was available free of charge.

2.8 SUMMARY

This chapter discussed literature pertaining to cervical cancer, and the global burden of disease, aetiology and development of the disease, including risk factors, sign and symptoms, screening and prevention, as well as treatment options. In addition, the chapter also dealt with awareness, perceptions, and health-seeking behaviours towards cervical cancer. Chapter 3 will focus on the conducting of the study by presenting the research method and design.

CHAPTER 3

RESEARCH METHODOLOGY

3.1 INTRODUCTION

This chapter presents the methodology used to execute the study. The chapter covers the study setting, approach, population, and the sample, as well as the sampling procedure. In addition, the chapter discusses the data collection and analysis.

3.2 RESEARCH METHODS AND DESIGN

Research methods are the strategies, processes or techniques utilised in the collection of data or evidence for analysis to uncover new information or create better understanding of a topic. Research design is the framework of research methods and techniques chosen by a researcher. The design allows researchers to focus on and use research methods that are suitable for the subject matter (Ishtiaq, 2019:23). Therefore, to explore the perceptions, awareness, and health-seeking behaviour of women regarding cervical cancer and cervical cancer screening, in Nefas Silk Lafto Sub-City in Addis Ababa, the researcher sought to obtain in-depth understanding of the participants' experiences, through face-to-face interviews and participant observations for collecting data instead of gathering statistics and numbers through a research assistant due to the language barrier. To accomplish the research, the researcher used a qualitative research approach, as this type of research is concerned with understanding an issue rather than explaining it. As participants of the study may have different perceptions of cervical cancer and cervical cancer screening, to use such an approach was critical to understand the reality constructed by the participants.

As scholars suggested, one of the aims of qualitative health research is to provide a multidimensional understanding of a health condition that goes into detail of an everyday or common-sense awareness, and which leads to a more informed, nuanced and empathic practice (Graneheim, Lindgren & Lundman, 2017:29; Silverman, 2016:13). The strength of qualitative research is its ability to provide complex textual descriptions of how people experience a given research issue. Qualitative research provides an

understanding of issues that relate to the often-contradictory behaviours, beliefs, opinions, emotions, and relationships of individuals, hence endeavours for an understanding of the whole. Qualitative methods are effective in recognising intangible factors, such as social norms, socioeconomic status, gender roles, ethnicity, and religion, whose role in the research issue may not be readily apparent (Ormston et al., 2014:54).

When there is no or scarce past data, with only a few studies for reference in a specific research problem, researchers use exploratory research design; therefore, there is an exploratory design conducted about a research problem when there are few or no earlier studies to refer to (Polit & Beck, 2012:53). Exploratory research tends to deal with new problems, on which there has been little or no previous research done (Graneheim et al., 2017:34). At times, the research is informal and unstructured and serves as a tool for initial research that provides a hypothetical or theoretical idea of the research problem. Exploratory research is conducted to determine the nature of the problem, not to provide conclusive evidence rather helping to have a better understanding of it. An exploratory qualitative design guided the study, as qualitative methods allowed the researchers to explore and understand the study phenomenon as opposed to explaining it (De Vos et al., 2017:308).

Exploratory research explores an issue that does not have a clear definition. Undertaking this type of research is to have a better understanding of the existing issue, but it will not provide decisive results, hence, the researchers start with a general idea and use this research type to identify issues that can be the focus for any future research. Based on new data or understanding, the researcher should be willing to adjust the course of the study as this is initial research forms the basis of more conclusive research. Such research will enable researchers to set a strong foundation for exploring their ideas, choosing the right research design and finding variables that actually are important for the analysis (Sreejesh, Mohapatra & Anusree, 2014:103).

An explorative design was the most relevant as the researcher wanted to explore in detail the perceptions, awareness, and health-seeking behaviour of women regarding cervical cancer and cervical cancer screening, in Nefas Silk Lafto Sub-City in Addis Ababa, Ethiopia.

3.2.1 Setting

The research took place in Nefas Silk Lafto Sub-City of Addis Ababa, Ethiopia, which is one of the 10 Sub-Cities of Addis Ababa. Each Sub-City has administrative sub-divisions referred as Woredas (districts), and a further division into Kebeles (Wards). Nefas Silk Lafto Sub-City has 12 woredas and a population of 335,740 people (BoFED, 2013:3). Nefas Silk Lafto is an urban setting and hosts residential areas, business centres, offices of government and non-government organisations, schools and universities, and therefore hosts people from diverse socio-economic backgrounds. The choice of Nefas Silk Lafto Sub-City for the research was because the area hosts many women from different backgrounds in terms of ethnicity, age, marital status, level of education, employment status, etc., and access to the research area was easier.

Woreda 11 Health Centre in Nefas Silk Lafto Sub-City was chosen for the research, as it is ranked first in terms of patient flow; it has the highest number of patients using the facility thus hosting women from different backgrounds using the health centre, which has different departments including an outpatient clinic that offers a wide range of diagnosis and treatment for conditions that do not require overnight stay, such as ART clinic, ANC, post-natal clinic. The diversity of patients and the ease of access to participants played a role in the selection of this setting.

3.3 POPULATION

Population refers to a subset of the target population from which the sample is chosen (Polgar & Thomas, 2011:8). It is a complete set of persons or objects possessing some common characteristic(s) of interest to the researcher. The population for this study consisted of all women aged between 18-69 years, residing in Nefas Silk Lafto Sub City, Addis Ababa, Ethiopia, and attending outpatient clinics in Woreda 11 Health Centre, Nefas Silk Lafto Sub-City, Addis Ababa, Ethiopia, whether or not they had undergone screening.

Ethiopia adopted the WHO's recommendations on cervical cancer screening that HIV negative women begin screening between 30-49 years of age once every five years, but for the population whose sero-status was unknown, it recommended screening starting from 18 years (the legal age for individual consent in Ethiopia), and rescreen every five

years (FMOH, 2015a:45); therefore, the criteria for inclusion and exclusion were decided based on these.

3.3.1 Inclusion criteria

- Women aged between 18 to 69 years old attending outpatient clinics at the Woreda 11 Health Centre in Nefas Silk Lafto Sub-City, Addis Ababa, Ethiopia
- Not diagnosed with cervical cancer at the time of the interview
- Being conversant in Amharic, which is the official federal language spoken by many
- Able to consent (informed and in written) to participate in the study
- Have resided in Addis Ababa at least for the past one year

3.3.2 Exclusion criteria

- All women under 18 years or over 69 years old
- Women who had not resided in Addis Ababa for at least the last year
- Women who did not understand and speak Amharic language
- Participants unable to give written informed consent
- Women diagnosed with cervical cancer

3.4 SAMPLE AND SAMPLING METHOD

Sampling relates to the selection of individuals, units or setting to be studied (Polgar & Thomas, 2011:111). The sample comprised of women attending the outpatient clinics at the Woreda 11 Health Centre in Nefas Silk Lafto Sub-City, Addis Ababa, Ethiopia.

Convenience sampling, a type of nonprobability sampling, selected participants for this study, as it is in line with qualitative research paradigm with no aim of generalisation of results, rather at having in-depth understanding of participants' meanings and perceptions, awareness, and health-seeking behaviours regarding cervical cancer (Ritchie et al., 2014:111). In convenience sampling, the participants are sampled just because they are "convenient;" the target population members who meet certain practical criteria, such as being available at a given time, or the willingness to participate, easy accessibility, geographical proximity, as such they just happen to be found, spatially or

administratively, close to where the researcher is collecting the data (Etikan et al., 2016:4).

In this study, the prospective participants were readily available at the Woreda 11 Health Centre, which has the most patient flow, with women from different backgrounds using the different departments including outpatient, ART clinic, ante-natal clinic (ANC), post-natal clinic (PNC) at this health centre and therefore, the ease of access to participants. The sample size for this study was not pre-determined, but saturation was the criteria for deciding the number of participants. The plan was to interview around 30 participants, but saturation occurred after conducting 15 interviews.

3.5 DATA COLLECTION

Data collection commenced after obtaining ethical approval from the Department of Health Studies Ethics Research Committee of University of South Africa (UNISA) (Annexure A), and permission to conduct the study from the City Government of Addis Ababa Health Bureau (Annexure C) who, after granting permission, further communicated with the Nefas Silk Lafto Sub-City Health Office (Annexure C). Before the collection of data, there was a support and permission letter (Annexure D) obtained from the Nefas Silk Lafto Sub-City Health Office and presented to the Woreda 11 Health Centre from where the Head of the Health Centre and the case team leaders of each clinic at the health centre also granted permission.

Semi-structured interviews took place with selected eligible women in Woreda 11 Health Centre, Nefas Silk Lafto Sub-City, Addis Ababa, Ethiopia, using an interview guide (Annexures I & J). In-depth interviews are optimal for collecting data on individuals' personal histories, perspectives, and experiences, particularly when exploring sensitive topics. There was data saturation attained after 15 interviews; two additional interviews were conducted to confirm saturation. Saturation refers to the point where the data collection no longer reveals new information. In a qualitative study, the suggestion is that saturation can occur after interviewing two to 15 participants, and it is often optimal to meet the standard, depending on the context (Silverman, 2016:13); the participants' limited number was due to the saturation and sufficiency level of the information provided, which was 17 for this study.

A self-developed interview guide (Annexures I & J), informed by a questionnaire from similar studies such as Deribe et al. (2019:89) and Zengwe (2016:74), included questions related to the perceptions, awareness and health-seeking behaviours of women regarding cervical cancer and was in the form of open-ended questions to explore the research questions and to ensure that all interviews covered these points. Professionals working in a clinic in the districts and the study supervisor, who is an oncology qualified professional, validated the interview guide. Two eligible participants pilot tested the interview guide, and the study supervisor and experts in the field and colleagues involved in cervical cancer screening clinic reviewed it.

Before data collection, the interview guide, which was prepared in English, was translated by a professional translator to Amharic language (Annexures I & J), and then back into English language by a different professional translator to keep the consistency of the questions and to prevent any loss of meaning.

The researcher initially sought to be solely responsible for data collection, however, due to not being fully conversant with the language spoken and cultural issues, such as women not being comfortable discussing reproductive and sexual issues with a male, he engaged a female research assistant from the same woreda where the women resided. The research assistant was conversant in Amharic language, and knowledgeable in public health issues, including cervical cancer. The researcher and the research assistant recruited the participants based on the eligibility criteria (1.10.1) and their willingness to participate in the study. The nursing staff helped to identify suitable participants who were at the health centre, who met the eligibility criteria, likely to have an opinion on the topic and willing to share.

The research assistant approached the women at the facility to participate while in the waiting area, and informed and discussed the details of the objectives of the study, the procedure, the time required for the interview, and the issue pertaining to informed consent form with the participants separately. The arranging of the appointments was as per the need of participants, and the interviews proceeded accordingly.

The interviews took, on average, 45 minutes to an hour. The interviews took place in a private room, as arranged with the managers of the centre to ensure privacy and confidentiality of the interviews, to ensure a more neutral environment, and to make the

interviewees more comfortable. The research assistant interviewed the participants in Amharic language whilst digitally recording the interviews with the participants' permission (Annexure K).

In addition, the writing of field notes was immediately after the interviews, to avoid interrupting the flow of the conversation, in order not to miss any information, facial cues and emotions during the interviews. Field notes allowed the researcher to maintain and comment upon impressions, environmental contexts, behaviours, and non-verbal cues that may not be adequately captured through the audio recording; they are typically handwritten in a small notebook. The notes provided important context to the interpretation of audio data and helped to remind the researcher of situational factors that could be of importance during data analysis. The documents remain separate from interview data to avoid linking to the interviews in order to maintain confidentiality of participants. There was consideration given to revisiting the participants for missed information, clarity and additional concerns, but this was not necessary.

3.6 DATA MANAGEMENT AND ANALYSIS

Before the data was analysed, the interviews stored on an audio recorder were transcribed verbatim by the research assistant and confirmed by a language editor conversant in Amharic and English to make sure the meaning was retained (Al-Amer, Ramjan, Glew, Darwish & Salamonson, 2015:157); there was also a review of the field notes. Lines of text were numbered. Once the transcriptions were complete, the researcher and the research assistant read them and corrected any spelling or other errors, such as interpretation of the spoken language, and the use of unique numbers instead of participants' identifiers ensured confidentiality.

Qualitative content analysis was utilised to analyse data. Qualitative content analysis represents a systematic and objective means of describing and quantifying phenomena (Elo et al., 2014:10). A prerequisite for successful content analysis is the reduction of data to concepts that describe the research phenomenon by creating categories, concepts, a model, conceptual system, or conceptual map. In qualitative content analysis, the abstraction process is the stage in which there are concepts created. The use of qualitative content analysis can be in an inductive or a deductive way. Both inductive and

deductive content analysis processes involve three main phases: preparation, organisation, and reporting of results.

The preparation phase consists of collecting suitable data for content analysis, making sense of the data, and selecting the unit of analysis. In the inductive approach, the organisation phase includes open coding, creating categories, and abstraction. The deductive content analysis includes the organisation phase, which involves the categorisation matrix development, whereby there is a review of all the data for content and coding for correspondence or exemplification of the identified categories. In the reporting phase, the content of the categories describing the phenomenon describes the results using a selected approach (either deductive or inductive) (Graneheim et al., 2017:29).

Qualitative content analysis is a research method that provides a systematic and objective means of making valid inferences from data in order to describe and illuminate specific phenomenon (Silverman, 2016:13) and this is in line with the purpose of the study.

The research assistant commenced the data analysis process after the first two interviews by listening to the audio recordings, performing verbatim transcription, and reading the extracted transcripts to understand the hidden meanings in the text. Once completed, the researchers re-examined the text to gain deeper comprehension of the emerging themes, repeatedly looking at parts of, or the whole text. There was careful reading of the study participant's recordings, seeking what was common among them for the construction of the codes, categories and themes, which made it possible to analyse the response of the study participants comprehensively; the study supervisor also reviewed it.

3.7 TRUSTWORTHINESS (RIGOUR)

Trustworthiness refers to the degree of confidence in data, interpretation and methods used to ensure the quality of the study. It is a key concept since it permits researchers to describe the virtues of qualitative terms outside of the parameters. The quality of a research necessitates truth-value, applicability, consistency, and neutrality. To ensure trustworthiness of the study the researcher strives to main the following credibility, transferability, dependability, and conformability and prolonged engagement (Smith & McGannon, 2018:121).

Notes, a quality recorder, comfortable environment, and effective communication maintained data quality. Prolonged engagement, which refers to investment of sufficient time during the data collection to have an in-depth understanding of the views of the participants, was with interviews that on average lasted at least 45 minutes to an hour, depending on the length of the narratives. This allowed for the building of rapport with the participants, which in turn helped in obtaining useful, accurate and rich data. The numerous conversations between the researcher and the research assistant to verify issues concerning data transcription and coding, also helped to ensure the quality.

3.7.1 Credibility

Credibility refers to the confidence in the truth of data and their interpretations. To establish the credibility, the researcher considered techniques of prolonged engagement and revisits, with study participants approached in a friendly, no pressure manner and interviewed in a comfortable environment (Smith & McGannon, 2018:121). An experienced qualitative research assistant was working together with the researcher and appropriate discussions were undertaken. The collection of data from different participants at different times also helped, as they provided data from a diverse pool. The idea of re-visiting participants was for any missed information, clarity and additional concerns, but was not necessary. In qualitative studies, credibility is about evaluating integrity and quality to ensure confidence in the truth of the data (Polit & Beck, 2012:724).

3.7.2 Conformability

Conformability is the degree of neutrality in the research study's findings (Smith & McGannon, 2018:121). In this study, the researcher interpreted the results as close as possible to reflect the participants' point of view based on the data analysed and comparing results with literature. In addition, after the study, the researcher let colleagues do reviews of the research processes and protocols, and held discussions to reach an agreement on the interpretations. The study supervisor analysed some of the interviews to compare similar meanings, and held a meeting to discuss if there were any discrepancies and to reach a consensus, as the researchers should not change or correct any statements of the participants (Polit & Beck, 2012:175, 585).

3.7.3 Transferability

Transferability relates to how the study's findings are applicable to other contexts and descriptions of the phenomena under study, and as much of the context in which the study took place as possible is the most powerful technique for facilitating transferability decisions (Smith & McGannon, 2018:121). A detailed description of the study report is available for researchers in almost similar settings to replicate in their settings.

3.7.4 Dependability

Dependability refers to evidence that the findings are consistent and stable over time and/or under different conditions, and is concerned with whether there would be the same results observed if applied in an almost similar context (Polit & Beck, 2012:175, 585). Dependability is the extent to which other researchers could repeat the study and that the findings would almost be similar. The extent to which results are consistent over time and an accurate representation of the participant under study refers to dependability; if the results of a study are reproduced under a similar methodology, then the research instrument is reliable (Smith & McGannon, 2018:121).

For this study, the researcher undertook all study procedures in line with the qualitative design principles and let colleagues check the research processes colleagues without compromising ethical principles and the study supervisor. The researcher coded two of the transcripts and reached reliability after the research assistant recoded them to attain an agreement after discussions on the inter-coder reliability.

3.8 ETHICAL CONSIDERATIONS

Data collection commenced once the Research Ethics Committee of UNISA (Annexure A) gave ethical approval to conduct this study. The City Government of Addis Ababa Health Office (Annexure C) issued a letter of permission to conduct the study in the Nefas Silk Lafto Sub-City and further communicated with the Nefas Silk Lafto Sub-City Health Office, which also granted support and a permission letter (Annexure D) and presented it to the Woreda 11 Health Centre. The Head of the Health Centre and the case team leaders of each clinic in the health centre granted their permission during a meeting before data collection commenced.

The researcher briefed the research assistant on the purpose, objectives, methodology, tools of the research and obtaining consent, interviewing the study participants and keeping the confidentiality. This enabled the research assistant to pursue the research process without compromising the quality at any point of the study and maintaining confidentiality of all the data gathered. The research assistant signed a confidentiality binding form (Annexure H).

The objective of the study and the information pertaining to the study was shared with the study participants, and that the researcher, the study supervisor and the research assistant would be the only people to have access to the information. Each study participant gave written informed consent (Annexures F & G), where the participant was unable to read and write the researcher read and explained the consent form and obtained consent accordingly. Data remained confidential; keeping contact lists, recruitment records and other documents that contained personal identifiers separate from the interview data was to ensure there was no link to the interviews. Destroying the documents will occur when no longer required for the research. The research data was stored securely in locked cabinets, files containing electronic data remained locked when computers were unattended, and electronic data was stored in password-protected computers, filled consent forms were in locked cabinets separate from the research data, and data was only for this research purpose. The research assistant was trained on the IRB (Institutional Review Board) approved methods for managing and storing research data.

As informed, the study participants received no incentives or direct benefits for taking part in the study; however, the information will help to improve interventions regarding cervical cancer screening and to inform policy makers on gaps identified. They were also informed there was no direct harm expected from participation in the study, except the study participant's time for the interview (average of 45 minutes to an hour), however, some questions could be sensitive and possibly arouse sad emotions. The researcher and the research assistant in order not to cause any problems or difficulties during interviews gave utmost care. In the event any of the respondents experienced any difficulties, any emotional reactions and needed counselling, they would receive a referral to the counsellor in the health centre without incurring any cost. Participants did not have to answer questions they were uncomfortable with, however there were probes engaged to

elicit responses. In addition, participants had the right to withdraw from the study at any time if they did not want to participate or continue, as these were their independent decisions.

3.9 SUMMARY

This chapter presented an overview of the research design and methods that guided the study. Also highlighted were the methods of data analysis, trustworthiness and ethical considerations. Chapter 4 presents the findings of the study.

CHAPTER 4

FINDINGS OF THE STUDY AND DISCUSSION

4.1 INTRODUCTION

Chapter 3 focused on the overview of the research methodology and design that guided this study, and discussed the setting, population, sample and sampling method, data management and analysis, measures taken to ensure the trustworthiness of the collected data and the ethical considerations.

This chapter presents the findings that emerged from the data, starting with the demographic data of the 17 participants, and continuing with the results based on the themes and categories that emerged from the data and discussion of the findings of the study.

4.2 SOCIO-DEMOGRAPHIC CHARACTERISTICS OF STUDY PARTICIPANTS

This section presents information about the participants, as displayed in Table 4.1. There were no identifiers used for the participants, rather numbers from P1, P2, up to P17. The information regarding age, gender, education, occupation, marital status, children, and screening status was included so that readers would understand the sources for the data.

Table 4.1 Socio-demographic characteristics of study participants (N=17)

Participant code	Age	Sex	Educational status	Occupation	Marital status	No of children	Screening status
P1	25	F	Grade 10	Private employee	Married	0	Not-screened
P2	50	F	No formal education	Unemployed	Divorced	1	Not-screened
P3	30	F	No formal education	Housewife	Married	3	Not-screened
P4	29	F	Grade 6	Janitor	Married	1	Not-screened
P5	33	F	No formal education	Daily labourer	Divorced	1	Not-screened
P6	28	F	Grade 6	Housewife	Widowed	3	Not-screened
P7	26	F	Grade 10	Private employee	Married	0	Not-screened
P8	25	F	Grade 5	Private employee	Married	0	Not-screened
P9	21	F	Grade 8	Waiter	Married	0	Not-screened
P10	28	F	No formal education	Housewife	Married	2	Not-screened
P11	21	F	Grade 10	Textile factory worker	Married	0	Not-screened
P12	26	F	Diploma	Housewife	Married	2	Not-screened
P13	20	F	No formal education	Government employee	Cohabiting	0	Not-screened
P14	45	F	Grade 6	Unemployed	Divorced	2	Not-screened
P15	25	F	Grade 4	Private employee	Married	3	Not-screened
P16	32	F	Grade 6	Private employee	Married	2	Not-screened
P17	33	F	Grade 4	Housewife	Divorced	1	Not-screened

The age range of the 17 women who participated in the study was between 20 to 50 years. Seven of the participants belonged to the 25-29 age group, and all were from urban areas. Eleven were married, four divorced, one cohabiting and another widowed. While only one of the participants had completed diploma education, eight had attended elementary school, three attended high school and five were illiterate, never having attended school and could not read and write. Seven participants (n=17) had two or more children, four had only one child, two were pregnant, and four had no children.

4.3 FINDINGS OF THE STUDY

This study focused on exploring the knowledge, perception and health-seeking behaviour of women, in Nefas Silk Lafto Sub-City, Addis Ababa, Ethiopia, regarding cervical cancer and screening for such. Accordingly, participants were asked to explain what they knew or understood regarding cervical cancer, who does it affect and how is it acquired, about the symptoms of cervical cancer, their sources of information on cervical cancer, their perceptions or experiences of screening for cervical cancer, who should be screened and

why and how screening and related issues could be promoted. Two main themes emerged from the data, 1) Knowledge and perspective on cervical cancer and 2) Health-seeking and concerns about cervical cancer screening, and eight categories developed (four from each theme), as presented in Table 4.2.

Table 4.2 List of themes, categories and quotes

Themes	Categories	Quotes emanating from the data
<p>Theme 1</p> <p>Knowledge and perspective on cervical cancer</p>	<p>Awareness of cervical cancer</p>	<p>“I do not have enough knowledge about cervical cancer since the disease is new for us Ethiopians.”</p> <p>“It might be because of lack of personal hygiene but I heard that it is a cancer that will affect the tip of uterus.”</p> <p>“If it is not treated early it will result a total damage of the uterus.”</p> <p>“If she has repeated pregnancies and labour, and heavy work.”</p> <p>“I heard that cervical cancer comes from genetics too.”</p> <p>“I heard people talk about cervical cancer, other than that I don’t know the cause of the illness.”</p>
	<p>Symptoms of cervical cancer</p>	<p>“My aunt told me that she had pain during sexual contact, she had lower pain.”</p> <p>“[one] might have an itching sensation.”</p> <p>“There is a discharge, which is all I know, there will be ulceration too.”</p>
	<p>Sources of information regarding screening or cervical cancer</p>	<p>“I heard it from TV promotion that cervical cancer can happen to anyone.”</p> <p>“I just heard some people talking about it around workplace.”</p> <p>“It is good that they talk about cervical cancer on TV (television), you will also get understanding for yourself.”</p> <p>“As I told you, I had two female friends when I used to work a year ago and we had the habit of discussing different health issues ... During that time one of the issues we had discussed was cervical cancer.”</p> <p>“I am wondering that if the disease is this much serious, why media like TV/radio and also health professionals take time to educate us.”</p>

Themes	Categories	Quotes emanating from the data
	Perspectives on cervical cancer	<p>“I believe that in order to have change in behaviour, creating awareness should start early as much as possible.”</p> <p>“It is not a secret that they will be involved in sex when they grow up so it is better to inform them now.”</p> <p>“I had two female friends when I used to work a year ago and we had the habit of discussing different health issues.”</p> <p>“Cervical cancer should be talked on radio and television because the information is very important; It increases our knowledge the issue is new for us so it will help us to know about it.”</p> <p>“By the way I suggest that the media (TV/radio) promotion will be through drama in order to get more attention by the audience.”</p>
Theme 2 Health-seeking and concerns regarding cervical cancer screening	Lack of awareness regarding cervical cancer screening	<p>“In my opinion, it is hard and does not make sense just to go to health facility when you do not have any symptoms.”</p> <p>“I heard that cervical cancer can happen to anyone. Even there might not be any symptom so everyone should be screened.”</p> <p>“I do not know about cervical cancer; I have given birth to my kids with all normal delivery so I have not faced any problem.”</p> <p>“I do not know about the risk factors, symptoms or treatment.”</p>
	Perceptions regarding cervical cancer screening	<p>“We do not go to the hospital unless there is something wrong with us. I did not go because I was not sick.”</p> <p>“What I think is blood test and the sample will be taken from the tip of the cervix that is just my assumption.”</p> <p>“I am sure lots and lots of women will be screened, most people are afraid that the cost.”</p> <p>“Since my friend told me they inserted an instrument in her private part, I was even scared for her.”</p> <p>“We women usually get ashamed, even the time I was sick if it was not for my husband, I did not have the guts to go. Because I was worried; how I could open my legs in front of other people?”</p> <p>“It is just that we women always feel ashamed and we are shy and we are not open.”</p>

Themes	Categories	Quotes emanating from the data
		<p>"If this screening is for free in the health facilities, I am sure lots and lots of women will be screened, most people are afraid that the cost for the screening is expensive. So, if it is free many women tend to use the service. ... That is one of my reasons why I didn't go."</p>
	Timing and frequency for cervical cancer screening	<p>"Women should be screened for cervical cancer every 3 months."</p> <p>"I do not have any knowledge about when we should screen."</p> <p>"It will be good not to be too frequent like every day or month."</p> <p>"I think they [women] should go whenever they have pain."</p> <p>"Every 15 days or a month."</p>
	Promoting cervical cancer screening	<p>"It will be good if education about cervical cancer is given at health facility daily through health professionals, posters and leaflets in addition to TV and radio promotion."</p> <p>"It would be good if education is given for us at the health centre and on media."</p> <p>"It would be good to educate community at different meeting ... giving home to home education through health extension workers, provide information through media ..."</p> <p>"If you include husbands during education, it is good, they will be willing to allow their wives for screening if they have the right and enough information so the education programme should include husbands."</p> <p>"If there is someone who can give counselling, or if it is told on TV or radio women will definitely be encouraged to go for screening ..."</p>

4.3.1 Theme 1: Knowledge and perspective on cervical cancer

Discussed and summarised in detail are the knowledge and perspective of study participants based on the four (4) emerged categories: awareness of cervical cancer looking at participants' knowledge on the causes and risks regarding cervical cancer, symptoms of cervical cancer, sources of information about cervical cancer, perspectives on cervical cancer.

4.3.1.1 Category 1.1: Awareness of cervical cancer

In spite of the participants claiming to know about cervical cancer, almost none of them were able to describe what cervical cancer is, with the exception of two participants who had an idea. Even after repeated probing, only a few of the participants tried to describe what they thought it meant. Based on the participants' narratives, the majority (n=15) of participants were not clear about what cervical cancer is and needed help to define it, as it was their first time to hear the word 'cervical cancer' from the researchers.

The following quotes are responses from study participants:

"I heard [the term] cervical cancer for the first time today from you (from the data collector)." (Participant 11).

"I do not have enough knowledge about cervical cancer since the disease is new for us Ethiopians, but I heard that it is a cancer that will affect the tip of uterus and if it is not treated early it will result a total damage of the uterus and makes a woman infertile." (Participant 12)

"I do not know about cervical cancer; I have given birth to my kids with all normal delivery, so I have not faced any problem." (Participant 3)

"It might be because of lack of personal hygiene, not changing underwear every day, having intercourse frequently." (Participant 8)

To further probe the participants regarding the knowledge of cervical cancer, they were asked how the disease occurred (causes), and different opinions were shared. Some reported that a woman could get cervical cancer if she did not pay attention to her hygiene, if she has repeated pregnancies and labour, and heavy work. A few others have reported that women who engage in unprotected sex could get the disease, such as HIV/AIDS.

One of the study participants described it as follows:

"... [Cervical cancer] may happen because of sexual contact, like for example, many people would not be infected with HIV unless you do something reckless just

like that, if women are not careful during sex she will be affected by cervical cancer.” (Participant 2).

Other participants explained as follows:

“I think cervical cancer is because of repeated pregnancy like giving birth every year.” (Participant 12)

“I heard that cervical cancer comes from genetics too, so since I don’t have any family history of cancer, it never bothers [me].” (Participant 8)

“I heard people talk about cervical cancer other than that I don’t know the cause of the illness.” (Participant 1).

4.3.1.2 Category 1.2: Symptoms of cervical cancer

Participants were asked to explain about the symptoms of cervical cancer and more than half (n=10) were able to list some of the possible symptoms of the disease. Accordingly, the majority reported that a woman who has cervical cancer could present with foul smelling vaginal discharge, bleeding, experiencing severe pain, painful sexual intercourse and ulcer of genitalia. The following narratives support this:

“My aunt told me that she had pain during sexual contact, she had lower pain, and she had bleeding with bad smell”. The participant further narrated: She had been bed ridden for more than a year and finally she passed away. Her experience was very bad, she suffered a lot from the disease. She got divorced, bed ridden, lost her work and finally died.” (Participant 12).

“There is a discharge, which is all I know, there will be ulceration too.” (Participant 16).

“... [one] might have an itching sensation, but I never heard anyone who had a complaint of cervical cancer so it’s hard for me to understand how the illness manifests.” (Participant 7).

However, some reported not knowing the symptoms at all, evidenced by the following:

“I don’t know about it [cervical cancer].” (Participant 5)

“I do not know about cervical cancer.” (Participant 10)

“I do not know anything about cervical cancer.” (Participant 16)

“I don’t know about that [cervical cancer].” (Participant 15)

“I do not know about cervical cancer.” (Participant 17)

“I do not know about the risk factors, symptoms or treatment.” (Participant 14)

4.3.1.3 Category 1.3: Sources of information regarding screening or cervical cancer

When asked where they get information regarding cervical cancer and screening, the majority (n=14), of participants reported television as their primary source of information, few heard about it from radio and their friends, as supported by the following narratives:

“I heard it from TV promotion that cervical cancer can happen to anyone. Even there might not be any symptom, so everyone should be screened.” (Participant 15)

“... I heard on media when they talk about it.” (Participant 4)

“I heard that a mother with 14 years old girl should bring her child to health facility for vaccination. Only this information.” (Participant 14)

Of concern was that participants relied on rumours, which similarly do not have much knowledge and some of the information might not be credible.

The following evidence supports this:

“I just heard some people talking about it around workplace.” (Participant 13).

“I heard people talking but I never saw that person with my own eyes I just heard the gossip saying a lady died because of cervical cancer.” (Participant 15).

4.3.1.4 Category 1.4: Perspectives on cervical cancer

Regarding participant's perspective on cervical cancer, there were different points raised on the issue. Some supported discussing cervical cancer openly with friends, and sharing their perspectives on how and what they usually discuss at their home and workplace. Most participants advocated for young girls/women to receive information about cervical cancer early in their lives, implying that the discussion about this issue should be with pubescent girls before they become sexually active. Additionally, the participants stated that discussions regarding cervical cancer through different media would help women gain knowledge about the illness.

“Cervical cancer should be talked about in the radio and television because it is good to gain knowledge. Just because a person walks [around] dressed up, it does not mean that person is healthy, so to get treatment and everything, it is good that they talk about cervical cancer on TV (television), you will also get understanding for yourself, for your child.” (Participant 3)

“I believe that in order to have change in behaviour, creating awareness should start early as much as possible not even late till high school but it should start early at elementary so that they [students] will know how to protect themselves from such disease in time and they can easily protect themselves.” (Participant 7)

“Girls should be informed about cervical cancer because these girls are going to grow, and we will never know what will happen. So, it is good if they are informed. It is not a secret that they will be involved in sex when they grow up so it is better to inform them now.” (Participant 1)

“The most important thing is to communicate the information on TV, since most women watch a drama on TV. If this screening is discussed in the middle of the drama as advertisement, then it will be really watched by women (as it is shown in the middle of the programme) ... other is if it is told at the health facilities using a speaker or something.” (Participant 6)

Similarly, another participant further stated the following:

“Cervical cancer should be talked about on the radio and television because the information is very important. It increases our knowledge. The issue is new for us

so it will help us to know about it and increase our need to go to health facility and treated”.

The participant further said: “By the way, I suggest that the media (TV/radio) promotion will be through drama in order to get more attention by the audience.” (Participant 12)

Other participants stated they do not discuss openly about cervical cancer and related issues, and very few pay attention because of not understanding the disease itself. The following statement is a narrative from one of the participants:

“We don’t talk openly about cervical cancer because no one is sick from my friends, so the issue never bothered us and also we do not have awareness on cervical cancer”. In addition, “I am wondering that if the disease is this much serious, why media like TV/radio and also health professionals do not take time to educate us? No one gives a concern to it till to date.” (Participant 1)

Another participant alluded to discussing the issue when there is a reason:

“As I told you, I had two female friends when I used to work a year ago and we had the habit of discussing different health issues during our break time. During that time one of the issues we had discussed was cervical cancer, about the cause, signs, symptoms, and the consequences. The reason we had discussed about cervical cancer was because of what we have seen from my aunt.” (Participant 7).

Only a few participants said something pertaining to vaccination:

“I heard that a mother with 14 years old girl should bring her child to health facility for vaccination. Only this information. I do not know about the risk factors, symptoms or treatment.” (Participant 14)

“I heard on TV last night that there is a vaccination given to young girls. I do not know anything than this.” (Participant 2)

When asked whether young girls/women should receive information about cervical cancer, the vast majority of participants advocated for such information:

“Yes, they should be informed ... because it’s always good to know your health status and to have self-awareness.” (Participant 14)

“Yes, they should be informed ... because a person who has knowledge and information will never fail. Because knowledge is power, it’s good even if they have a check-up. The time now is a modern time, for example my first born is a boy, 15 years old, he talks lots of things in front of me which I sometimes get embarrassed but I don’t want to make him ashamed so I just listen, I am telling you this, to let you know that even girls we think are young are not so young they know a lot so they should be told about what you were saying too.” (Participant 6)

“Yes...because knowing about cervical cancer as early as possible will help them to protect themselves from the illness.” (Participant 9)

One participant advocated for health education as early as primary school:

“I believe that in order to have change in behaviour, creating awareness should start early as much as possible not even late till high school but it should start early at elementary so that they [students] will know how to protect themselves from such disease in time and they can easily protect themselves.” (Participant 7)

Another participant said:

“Because knowing about cervical cancer help them to protect themselves. You can take me as example. I do not have any information about cervical cancer. No one told me about it until now so, I am not sure whether I have the disease or not, I do not know how to protect myself. If girls know about the disease early, it will help them to protect themselves.” (Participant 11).

However, a few did not think it was important/necessary. Their narratives were as follows:

“I don’t think so ... because they will not give it enough attention, since it’s not their concern now.” (Participant 8)

“... I have a 15-year-old girl, she is not married or did not have sex yet ... she is just a child, why would she be exposed to that [kind of] talk even?” (Participant 3)

4.3.2 Theme 2: Health-seeking and concerns regarding cervical cancer screening

Another emergent theme was women's health-seeking behaviour and concerns regarding cervical cancer screening. The categories that emerged were limited or lack of awareness regarding cervical cancer screening, perceptions regarding screening for cervical cancer, knowledge of the actual period when to screen for cervical cancer, and uptake of cervical cancer screening.

4.3.2.1 Category 2.1: Lack of awareness regarding cervical cancer screening

There were enquiries regarding women's awareness of cervical cancer screening; this included history of screening, frequency of screening, types of screening procedures. It was evident that the participants lacked information about cervical cancer screening. Although a few participants reported having heard about screening from the media, they did not pay much attention, as evidenced by the following narratives:

"I never got screened but I heard on television and radio when they talk about it and say "Go and get screened" that is all." (Participant 4).

"In my opinion, it is hard and does not make sense just to go to health facility when you do not have any symptoms. If you have pain or some kind of symptom then it is good to go sooner, otherwise I will not visit a health centre, without any pain or something." (Participant 3)

"I have not screened for cervical cancer, once my friend and I went to a hospital to get screened for cervical cancer but the doctor asked me if I ever had any sexual contact but I told him I did not have any (it was before I got married), so he said I will not be screened since I will not have the disease for sure." (Participant 7)

Alluding to the lack of information regarding uptake of screening:

"I heard that cervical cancer can happen to anyone. Even there might not be any symptom so everyone should be screened." (Participant 1)

"I do not know. I rarely come to health centre, so I do not have any information." (Participant 11)

Most participants (n=11) reported that screening benefits them by knowing their health status and to take care of themselves while lacking knowledge on cervical cancer and screening for cervical cancer:

“... it is good to know before the illness gets worse, if days and time pass, the disease will get worse.” (Participant 6)

“... it is good to know your health status and get treatment if there is a problem.” (Participant 8)

“One will know if she is health or not and then decide on her treatment.” (Participant 17)

None of the participants in the study had any knowledge regarding cervical cancer screening, as supported by the following narratives:

“What I think is blood test and the sample will be taken from the tip of the cervix that is just my assumption.” (Participant 15)

“What I think is urine test would be done and also a blood sample.” (Participant 1)

“Blood sample ... ultrasound.” (Participant 16)

“I do not know they have their own medical equipment's they are the one with the knowledge.” (Participant 7)

“I don't know but am sure that the doctors have their method of testing everything, you should always be open with your doctor, after God they are the one who we have.” (Participant 2)

4.3.2.2 *Category 2.2: Women's perceptions regarding screening for cervical cancer*

The findings from the study showed that none of the participants had ever been screened for cervical cancer, whilst only few of them knew someone who had underwent screening for cervical cancer. The participants' perceptions regarding screening raised issues such as fear of procedure, feeling ashamed or embarrassed of revealing their bodies in front

of health workers and cost of screening procedure (even though the screening is free of charge). Accordingly, the participants reported that they have no experience of visiting health care facilities unless they have some health disorders and medical check-up is not common.

According to some of the participants, when a person does not have any symptoms or any pain complaints, they should not be visiting health facilities or undergo screening.

“You do not have to wait until you became bedridden but still, when you have pain then it is right to go to hospital, but when there is nothing, it is not right to start thinking I may or may not have the disease.” (Participant 3)

“We do not go to the hospital unless there is something wrong with us. I did not go because I was not sick.” (Participant 4)

However, another participant had this to say when asked if she ever screened:

“I have not been screened for cervical cancer because I have no pain and I am not feeling anything different from the usual; I heard that cervical cancer comes from genetics too. So, since I don't have any family history of cancer, I never bothered to get screened. I was careless about it, but now I think I will be screened.” (Participant 15).

Other participants reported being fearful of the procedure, or ashamed and embarrassed. Participants had this to say:

“Since my friend told me they inserted an instrument in her private part, I was even scared for her.” (Participant 7)

“We women usually get ashamed, even the time I was sick if it was not for my husband, I did not have the guts to go. Because I was worried; how I could open my legs in front of other people?” (Participant 1)

“It is just that we women always feel ashamed and we are shy and we are not open.” (Participant 17)

“Women are afraid to go out of their home to go to the doctor...women who are just sitting in their home [those that do not work outside their homes] just fear to go to hospital, should go out and get a check-up. Women should not fear or feel ashamed. That is all.” (Participant 5)

Misinformation or misconceptions they had or heard from others including healthcare providers prevented a few of the study participants from undergoing screening for cervical cancer. Whilst few others reported being busy with domestic chores, childcare and lack of support to be able to go to the clinic. The following statements demonstrate such experiences:

“I have not screened for cervical cancer, once my friend and I went to a hospital to get screened for cervical cancer but the doctor asked me if I ever had any sexual contact but I told him I did not have any (it was before I got married), so he said I will not be screened since I will not have the disease for sure, but my friend got screened using an instrument I think they saw her and she was told she is negative.” (Participant 7)

“Women have a lot of challenges, starting from home [work] ...” (Participant 5)

“... after work, I usually run to my kids ... [to look after them].” (Participant 16)

Some of the participants reported access and the cost of screening as a barrier for women despite being free of charge at public health facilities.

“If this screening is for free in the health facilities, I am sure lots and lots of women will be screened, most [women] are afraid that the cost for the screening is expensive. So, if it is free many women tend to use the service. ... That is one of my reasons why I didn't go.” (Participant 4)

“... screening frequency should consider time and cost. I mean it will be good [for screening] not to ... be costly”. (Participant 7).

4.3.2.3 Category 2.3: Timing and frequency for cervical cancer screening

When asked about the timing and the frequency for cervical cancer screening, the majority of participants supported screening for women for cervical cancer and suggested they screen with 3 to 6 months' frequency, some said every 15 days, while others said every month, and/or every year is good. None of the participants knew or mentioned the ages for screening.

"Women should be screened for cervical cancer every 3 months, because it is good to know about our health frequently. If I get the chance I will screen every 3 months." (Participant 9)

"I do not have any knowledge about when we should screen but for me it will be good that the screening frequency should consider time and cost. I mean it will be good not to be too frequent like every day or month and costly because we will get bored." (Participant 7)

"I think they [women] should go whenever they have pain, when I come to hospital, I had a pain, discharge and burning sensation; so, a woman should go to hospital when she has this pain ... I think they should come when they have the symptoms that I told you, it should not be with a specified time". On further probing participant said: "Every 15 days or a month." (Participant 1).

4.3.2.4 Category 2.4: Promoting cervical cancer screening

When asked questions about how to increase utilisation of cervical cancer screening service and how women can be encouraged to go for screening, promoting screening plays a major role in prevention of cervical cancer and regular visits to health facilities, health worker promotion, community advocacy such as involving spouses or other members of the families to encourage women to go for screening, and utilisation of media were raised as contributing towards the uptake of cervical cancer screening.

"Health education about cervical cancer, especially during waiting time of doctors, it's good to give health education in the waiting area [of the health facilities], then women will be afraid anymore." (Participant 1)

“It will be good if education about cervical cancer is given at health facility daily through health professionals, posters and leaflets in addition to TV and radio promotion.” (Participant 12)

“As I told you, we do not have the behaviour of getting health services unless we are sick so to increase [screening] it would be good if education is given for us at the health centre and on media.” (Participant 10).

“By the way I suggest that the media (TV/radio) promotion will be through drama in order to get more attention by the audience.” (Participant 4)

“If the health facility gives a health education regarding this issue, if there is sensitisation in every community, it would be very good.” (Participant 14)

“It would be good to educate community at different meeting in the village like ‘idir’ [a common social support arrangement in Ethiopia], giving home to home education through health extension workers, provide information through media in detail like where to go, the cost.” (Participant 9)

“It is good if health facilities do sensitisation about cancer and its impact on life for example when it is time for vaccination they do sensitise the community by visiting house to house and they also promote on TV, so if the same is done for cervical cancer it will encourage women”. (Participant 12)

Regarding community, spouse/partner support, one participant stated:

“If these things are done, I do not think the community resist the screening because we all need being healthy. May be if the cost for the screening is high this is another issue but if it is free or cheap, and if you educate us we will be happy to get screened. Participant narrated further:

“Again, if you include husbands during education, it is good, they will be willing to allow their wives for screening if they have the right [correct] and enough information so the education program should include husbands.” (Participant 9)

Another participant said:

“... even the time I was sick if it was not for my husband, I did not have the guts to go ... But he encouraged me to go. So, I think support from a partner is important.”
(Participant 1)

In addition, other participants had strong ideas regarding promotion of screening:

“Because we are poor, so we give more value to money than our health. In addition to this, it will be good to give the education about cervical cancer by health extension workers doing home to home visits since the issue is new, everyone should get the right information so that they will get the motivation to get screened, if you include husbands, why not?” (Participant 12)

“... because the end result is death, it is good to be careful before the worst has come ... as I told you before it was not like this, everything was a secret, but now we even can communicate with our children openly, when I had my first menstruation I was shocked because there is no one who will talk to us, but in my kids' generation everything is talked freely, so my kids will not be shocked because we are talking inside the house openly ...” (Participant 6)

“... If there is someone who can give counselling, or if it is told on TV or radio women will definitely be encouraged to go for screening ... If it is constantly reminded through radio/TV people will think about it more, and also if another person also teaches about screening it is really good.” (Participant 8)

Underlining the importance of community engagement, one participant referred to ‘other people’ and when asked what she meant by ‘other people’ said:

“A person that was screened before.” (Participant 8)

4.4 DISCUSSION OF THE FINDINGS

The study explored the perceptions, awareness, and health-seeking behaviour of female residents of Nefas Silk Lafto Sub-City, in Addis Ababa, regarding cervical cancer and screening. Two main themes emerged, knowledge and perspective on cervical cancer

and health-seeking behaviour, and concerns about cervical cancer screening, with four categories each.

The categories under knowledge and perspectives on cervical cancer were, 1) awareness of cervical cancer, 2) symptoms pertaining to cervical cancer, 3) sources of information pertaining to cervical cancer, and (4) women's perspectives regarding cervical cancer, followed by the categories under health-seeking and concerns about cervical cancer screening which were, 1) lack of awareness regarding cervical cancer, 2) perceptions regarding cervical cancer, 3) timing and frequency and 4) promotion of cervical cancer screening.

The findings from the study showed that the majority of study participants lacked knowledge about cervical cancer and screening, that none had ever undergone screening for cervical cancer, and only a few knew women who had experience of screening for cervical cancer, as reported by other studies (Habtu et al., 2018:298; Azam, 2016:24; Bathija, Mallesh & Gajula, 2016:3; Ebu, Mupepi, Siakwa & Sampelle, 2014:34).

Most of the study participants reported media as their primary source of health information, with none mentioning healthcare professionals as a source. Mengesha, Messele and Beletew (2020:209) also reported mass media as the main source of information of the participants in their study on knowledge and attitude towards cervical cancer. These findings show there is a profound awareness and knowledge gap regarding cervical cancer and cervical cancer screening among the women who were participants of the study.

Most participants also reported that women do not need to visit healthcare facilities for any medical check-up unless they feel ill. A detailed discussion of these findings follows, with comparison with different studies.

Being aware of and knowledgeable about cervical cancer requires having information about what it is, the prevention methods, the causes, symptoms, screening methods and treatment options. However, as clearly indicated by the narratives, this study's participants lacked knowledge regarding cervical cancer as well as its causes. This finding concurs with other studies, in which knowledge and awareness regarding cervical cancer was reportedly low (Thapa, Maharjan, Petrini, Shah, Shah, Maharjan, Shrestha &

Cai, 2018:5; Mahajan, Jadhav, Magare, Adchitre & Salve, 2017:3593; Muasa, 2016:53). The finding from this study contrasts with that of Kadian et al. (2020:2) who, in their study on knowledge and awareness of cervical cancer in rural and urban Haryana, India, found the participants had good knowledge of cervical cancer due to women having a higher education level and living in urban settings. However, in this study, participants residing in an urban area did not have good knowledge of cervical cancer either. This finding contrasts with other studies in which living in an urban setting, access to health information and having better education were also mentioned as the reasons behind women having better knowledge of cervical cancer (Daniyan, 2019:8; Mahajan et al., 2017:3590; Owoeye & Ibrahim, 2013:51). Nevertheless, the researchers of these studies are of the opinion that there should be more attention given to raising awareness and knowledge of women on this important health issue.

Knowing the possible symptoms of cervical cancer would help women easily identify the symptoms, and an early visit to the healthcare facility would assist in early diagnosis and if necessary, institute treatment. Although the participants of this study mentioned some of the symptoms, most were not certain. There were similar findings reported in a study conducted with undergraduate students from Debre Berhan University, in which lack of knowledge of symptoms of cervical cancer was evident among the participants (Mruts & Gebremariam, 2018:1773).

Findings of this study indicated that women lacked detailed information, and even those women who had access to information, were mainly dependent on television for information about cervical cancer, which is consistent with a study in Gondar, Ethiopia (Mengesha et al., 2020:209). Irrespective of their educational status, none of the study participants mentioned healthcare professionals, written materials and/or the Internet as their source of information for cervical cancer and cervical cancer screening, which is extremely concerning in terms of women's access to information.

A number of other studies revealed similar findings, stressing limited access to information on cervical cancer hinders utilisation of screening services (Shrestha, Sapkota & Sapkota, 2019:68; Habtu et al., 2018:298; Mruts & Gebremariam, 2018:1774; Gebru et al., 2016:401), therefore, it is imperative to provide women with access to various mediums of information so they can enrich their awareness, knowledge and improve their health-seeking behaviour.

Ensuring women regard cervical cancer as one of the health issues that may affect them, and that they discuss with others, especially healthcare providers, is an important part of prevention and management of cervical cancer and its screening. Due to lack of awareness and knowledge and related factors, this study found that women rarely discuss cervical cancer and screening or do not openly discuss this issue at all; hence, it is crucial to create opportunities for discussion and encourage women to openly talk about their health, especially on cervical cancer and screening with each other and healthcare workers. As cited in a study undertaken in Ethiopia by Geremew et al. (2018:29), provision of health information, education and counselling by health workers will address lack of knowledge and improve women's perceptions and health-seeking behaviour regarding cervical cancer.

Unless women have awareness and knowledge about cervical cancer screening, it is unlikely that such screening services will be utilised, as reflected in this study. Similar studies have also reported that lack of awareness regarding cervical cancer screening is preventing women from utilising the services available (Geremew et al., 2018:29; Habtu et al., 2018:298; Mruts & Gebremariam, 2018:1773; Babatunde, Olusola, Olusegun & Sunday, 2017:755; Bathijja et al., 2016:5). Therefore, the emphasis should be on creating awareness about the benefits, access and process of screening.

Whilst having medical check-ups is an indication of valuing own health, the present study found that the experience of screening for cervical cancer was nil, as none of the participants had ever been screened for cervical cancer. There were similar findings from Finoteselam, Arbaminch and Debre Berhan areas of Ethiopia, where women did not screen for cervical cancer (Kasa, Tesfaye & Temesgen, 2018:630; Mruts & Gebremariam, 2018:1774; Gebru et al., 2016:401). A study in Nepal, on knowledge, attitude, practice and barriers of cervical cancer screening, indicated that vast majority of women have never had screening for cervical cancer (Thapa et al., 2018:6). As mentioned, different reasons contribute to such low level of cervical cancer screening experience, but this could change if relevant institutions give the necessary attention.

Timing and frequency of screening for cervical cancer is a big concern, similar to the utilisation of cervical cancer screening services. As indicated in the findings, women lacked adequate knowledge of timing and frequency of cervical cancer screening, which affects the utilisation of cervical cancer screening services and thus, affects the

management of cervical cancer as it may lead to late diagnosis or no diagnosis of cervical cancer. Accordingly, there should be efforts put in place to ensure that women utilise the cervical cancer screening services on time and return as per the recommended schedule.

As the findings of this study clearly show, the level of cervical cancer screening service utilisation is low. There were similar findings reported from different areas of Ethiopia and other countries in Africa (Habtu et al., 2018:299; Mruts & Gebremariam, 2018:1774; Gebru et al., 2016:401; Muasa, 2016:53). This issue demands multiple approaches in promoting service utilisation that targets the main factors that hinder women from visiting healthcare facilities and utilising the cervical cancer screening services available.

This chapter presented the study findings of knowledge and perspectives, health-seeking behaviour and concerns of participants regarding cervical cancer and cervical cancer screening based on the themes and subthemes resulting from the data analysis, and backed up by quotations from the participants of the study.

4.5 SUMMARY

This chapter presented the findings, the discussion of the findings and the analysis. Chapter 5 will discuss the justification of the study regarding its contribution, its limitations and finally the recommendations.

CHAPTER 5

JUSTIFICATION, LIMITATION, RECOMMENDATIONS OF THE STUDY AND CONCLUSION

5.1 INTRODUCTION

Chapter 4 presented the analysis, findings, and discussion of the findings of the study. This chapter focuses on the justification of the study regarding its contribution, as well as its limitations and recommendations.

5.2 JUSTIFICATION OF THE STUDY

The researcher, as a humanitarian and development worker with an organisation that has the public health sector in Ethiopia as one of its focuses, noted that despite the efforts to encourage cervical cancer screening, women in Addis Ababa barely utilise the services.

The researcher also noted there was limited research done on the research problem in Ethiopia, specifically in the capital city, and hence the decision to undertake this study.

Consequently, the researcher intended to explore the perceptions, the awareness and health-seeking behaviours of female residents of Nefas Silk Lafto Sub-City with regard to cervical cancer and cervical cancer screening, in Addis Ababa, Ethiopia.

An exploratory qualitative design guided the study and convenience sampling selected the participants. The sample size for this study was not pre-determined and saturation was the determinant for the number of participants; as a result, there were 15 interviews conducted.

Two main themes emerged from the data, Knowledge and perspectives on cervical cancer and Health-seeking behaviour and concerns about cervical cancer screening, and eight categories were developed. The categories under knowledge and perspectives on cervical cancer were, (1) awareness of cervical cancer, (2) symptoms pertaining to cervical cancer (3) sources of information pertaining to cervical cancer, and (4) women's

perspectives regarding cervical cancer. Under health-seeking behaviour and concerns about cervical cancer screening, the categories were (1) lack of awareness regarding cervical cancer, (2) perceptions regarding cervical cancer, (3) timing and frequency and (4) promotion of cervical cancer screening.

5.3 LIMITATIONS OF THE STUDY

The limitation was that there was only a small sample of participants used, thus the generalisability of the study was limited. However, despite the small sample, data saturation was with 17 participants.

Although the researcher initially sought to be solely involved in conducting the interviews, due to cultural issues and not being acquainted with the language(s) spoken by the participants, the researcher had to engage a female research assistant to conduct the interviews.

The participants were utilising the same facility, hence there was the potential that the participants could share information regarding the interviews and questions asked with others prior to the interviews.

5.4 RECOMMENDATIONS OF THE STUDY

The low awareness, inaccurate perceptions and poor health-seeking behaviours identified in this study suggest that significant effort is necessary from a number of actors, such as health facilities, healthcare providers, governments and non-governmental organisations, and researchers working on cervical cancer. As a result, the following recommendations are of note for utilisation for respective institutions and individuals.

5.4.1 Health facilities/healthcare providers

- Improvement in health education and counselling programmes to include sessions on cervical cancer and screening utilisation.
- Opportunistic approaches, such as using the time women spend in waiting areas for information sessions on cervical cancer and screening.

- Female health workers should be available at health facilities to attend to women who are not comfortable with male health workers.
- Provision of services at times that are suitable for women who are working at home or outside the home to improve access.

5.4.2 Governments and non-governmental organisations

- It is important to consider the development of tailored social and behavioural change communication (SBCC) materials, approaches and mediums aimed at increasing women's awareness and changing/improving their perceptions and health-seeking behaviours to promote cervical cancer screening.
- Involving youth, both boys and girls, in sexual and reproductive health education will increase awareness and health seeking, including HPV vaccinations.
- Further studies to ensure the SBCC happens via impactful means with the right messaging by assessing the experiences of women who have utilised the screening services to improve SBCC.
- Inclusion of men in awareness raising is important, as mentioned by some of the participants. The support or lack of support of partners can have a significant impact in women's health seeking.

5.4.3 Recommendations for research

- Mixed types of research for a better and more complete understanding of the research issue to tackle the limitations of this study.
- There should be further research conducted on utilisation of men/spouses as motivators of women towards screening.
- Further research looking at theoretical frameworks, such as the Health Belief Model (HBM) and the Social Ecological Model (SEM), both of which indicate the environment and sociodemographic characteristics influence individual health behaviours, knowledge and health-seeking perceptions.

5.5 CONCLUSION

This study found that the majority of the participants lacked knowledge about cervical cancer, its symptoms, mode of transmission, risk factors related to the disease, screening methods and the advantages of screening. These findings show there is a profound awareness and knowledge gap regarding cervical cancer and screening among the women who were participants in the study.

Most of the participants relied on media, such as television and radio, as their primary source of information, but none mentioned healthcare professionals as such. It is crucial that healthcare practitioners ensure that at every opportunity contact with women be utilised to share information regarding cervical screening services and treatment.

Of concern was that none of study participants had ever undergone screening for cervical cancer, and only few of them knew women who had experience of such screening.

These findings have revealed that the women in this study have limited access to information and services despite living in an urban setting, which is a concern. The findings also revealed widespread low awareness about the causes, signs, symptoms, risk factors and screening methods for cervical cancer. Regardless of the government's measures and the focus of its strategic plan, prevention interventions in the study area are yet to be visible, as women are not undergoing screening.

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ANNEXURES

**ANNEXURE A: Ethical clearance certificate from the Research Ethics Committee,
Department of Health Studies**



**RESEARCH ETHICS COMMITTEE: DEPARTMENT OF HEALTH STUDIES
REC-012714-039 (NHERC)**

06 September 2019

Dear Ekin Cagatay Ogutogullari

HS HDC/828/2018 Amended 2019

Student: Ekin Cagatay Ogutogullari

Student No: 50848658

Supervisor: Mrs A Mosalo

Qualification: MA

Joint Supervisor:

Decision: Approval

Name: Ekin Cagatay Ogutogullari

Proposal: Perceptions, awareness and health seeking behaviour of women regarding cervical cancer in Addis Ababa, Ethiopia

Qualification: MPH

Risk Level: High risk

Thank you for the application for research ethics approval from the Research Ethics Committee: Department of Health Studies, for the above mentioned research. Final approval is granted from 06 September 2019 to 06 September 2022.

The application was reviewed in compliance with the Unisa Policy on Research Ethics by the Research Ethics Committee: Department of Health Studies on 03/09/2019.

The proposed research may now commence with the proviso that:

- 1) The researcher/s will ensure that the research project adheres to the values and principles expressed in the UNISA Policy on Research Ethics.*
- 2) Any adverse circumstance arising in the undertaking of the research project that is relevant to the ethicality of the study, as well as changes in the methodology, should be communicated in writing to the Research Ethics Review Committee, Department of Health Studies. An amended application could be requested if there are*



University of South Africa
Pretoria Street, Muckleneuk Ridge, City of Tshwane
PO Box 392 UNISA 0003 South Africa
Telephone: +27 12 429 3111 | Facsimile: +27 12 429 4130
www.unisa.ac.za

substantial changes from the existing proposal, especially if those changes affect any of the study-related risks for the research participants.

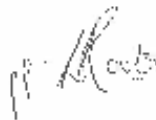
3) The researcher will ensure that the research project adheres to any applicable national legislation, professional codes of conduct, institutional guidelines and scientific standards relevant to the specific field of study.

4) You are required to submit an annual report by 30 January of each year that indicates that the study is active. Reports should be submitted to the administrator HSREC@unisa.ac.za. Should the reports not be forthcoming the ethical permission might be revoked until such time as the reports are presented.

Note:

The reference numbers [top middle and right corner of this communiqué] should be clearly indicated on all forms of communication [e.g. Webmail, E-mail messages, letters] with the intended research participants, as well as with the Research Ethics Committee: Department of Health Studies.

Kind regards,



Prof L Roets
CHAIRPERSON
roetsl@unisa.ac.za



Prof A Phillips
DEAN OF COLLEGE OF HUMAN SCIENCES



ANNEXURE B: Permission requested from City Government of Addis Ababa Health Bureau

18 October 2018

City Government of Addis Ababa
Health Bureau
Addis Ababa

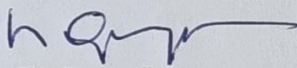
Dear Madam/Sir,

My name is Ekin Cagatay Ogutogullari and I am pursuing a Masters Degree in Public Health at the University of South Africa (UNISA). As a requirement of my studies, I am expected to conduct a research and submit a dissertation as a part of fulfilling of the qualification.

The title of the study is "Perceptions awareness and health seeking behaviour of women regarding cervical cancer in Addis Ababa, Ethiopia". I am planning to undertake the research in Nefas Silk Lafto Sub-city. I am attaching the relevant documentation and the Ethical Clearance Certificate from UNISA.

This is to request your support my study with an ethical clearance and a support letter to the relevant health office.

Thanks and regards,



Ekin Ogutogullari

Contact details:

Researcher: Ekin Ogutogullari – 50848658@mylife.unisa.ac.za – 0911.251.792

Supervisor: Anna Mosalo – mosala@unisa.ac.za - +27.12.429-6447

ANNEXURE C: Permission to conduct the study approved by the City Government of Addis Ababa Health Bureau

አዲስ አበባ ከተማ አስተዳደር ጤና ቢሮ
City Government of Addis Ababa Health Bureau

Ref.No. AA/AM/32006/227
Date... 13/3/2011

Nifasilk Lafto sub city health office
Addis Ababa

Subject: Informing about Conduct approved research on maternal health

This letter is written to support Ekin Cagatay to conduct a research, which is entitled as "Perceptions, awareness and health seeking behaviour of women regarding cervical cancer in Addis Ababa, Ethiopia." The study was reviewed and approved by Addis Ababa Health Bureau ethical Clearance Committee, and the investigator is informed with a copy of this letter to report any changes in the study procedures and to submit progressive report once in six months, apply for renewal 30 days prior to the expiry date, and submit technical report within three months of study completion.

Therefore we request the mentioned Facilities and staffs to provide support to the investigator



With Regards

[Handwritten signature]
ካሳሃይ አማራ
ሀገራዊ ጤና ምርምር
ዕድሜ ስነ-ምግባር ስራ ህዝብ
Kassaye Amaro
Addis Health Research Sub-Process Unit

- Cc
- EkinCagatay
 - Ethical Clearance Committee
Addis Ababa

ANNEXURE D: Support and permission letter from the Nefas Silk Lafto Sub-City Health Office

በንፋስ ስልክ ሰፍቶ ክፍለ ከተማ
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አዲስ አበባ



Nefas Silk Lafto Sub City
Health Office
Health promotion Disease prevention and control main processes
Addis Ababa

ቁጥር:- 7/1/4/ጤ.ጽ/---141---/ 01 /2011
Ref.No

ቀን:- 30 / 04 /2011
Date

በንፋስ ስልክ ላፍቶ ክ/ከተማ

- ሰወረዳ 1 ጤና ጽ/ቤት
- ሰወረዳ 2 ጤና ጽ/ቤት
- ሰወረዳ 3 ጤና ጽ/ቤት
- ሰወረዳ 4 ጤና ጽ/ቤት
- ሰወረዳ 5 ጤና ጽ/ቤት
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- ሰወረዳ 8 ጤና ጽ/ቤት
- ሰወረዳ 9 ጤና ጽ/ቤት
- ሰወረዳ 10 ጤና ጽ/ቤት
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- ሰወረዳ 12 ጤና ጽ/ቤት
- ሰወረዳ 13 ጤና ጽ/ቤት

አዲስ አበባ

ጉዳዩ :- ለሪሰርች ስራ ትብብርን ይመለከታል

ከላይ በርእሱ ለመግለጽ እንደተሞከረው አዲስ አበባ ከተማ አስተዳደር ጤና ቢሮ በቁጥር አ/አ/ጤ.ጽ/32006/227 በቀን 13/03/11 በተሳፈ. ደብዳቤ መሰረት "perceptions, awarness and health seeking behavior of women regarding cervical cancer in our sub city, Addis Ababa City Ethiopia." በሚል ርዕስ ጥናታቸውን ለማድረግ ዝግጅት ላይ ይገኛሉ ። ስለሆነም ለአቶ ኢክን ካጋታይ በእናንተ በኩል አስፈላጊውን መረጃ እንዲያገኙ ትብብር ታደርጎላቸው ዘንድ እንጠይቃለን



ከሰላምታ ጋር
[Signature]

ሰንታየሁ ድንቁ
የጤ/ማ/ቦ/መ/ዋና የሥራ ሂደት
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/ ለአቶ ኢክን ካጋታይ
አዲስ አበባ

ANNEXURE E: Research information sheet

Dear Madam,

My name is Ekin Ogutogullari. I am pursuing a Master's in Public Health at the University of South Africa. As a requirement of my studies, I am expected to conduct a research and submit a dissertation as part of fulfilling of the qualification. You are being asked to participate in a research study to explore the perception, awareness and health seeking behaviour among women aged residing in Nefas Silk Lafto Sub-City regarding cervical cancer screening.

The title of the study is "Perceptions, awareness and health seeking behaviour of women regarding cervical cancer in Addis Ababa, Ethiopia". The study will help identify women's knowledge gaps on cervical cancer and the factors that promote or hinder women's optimal health seeking behaviour on cervical cancer by asking questions on demographic information and on the perception, awareness and health seeking behaviours.

Although I am the primary researcher, due to privacy and language issues, a female research assistant Ms. Kalkidan Solomon will be conducting the interviews on my behalf. I am requesting that she is also allowed to use an audio voice recorder as she will not be in position to capture all needed information with taking notes only. These recordings will be listened to, the information will be transcribed for analysis as a part of the writing of the dissertation. The interviews are expected to last 45 minutes to an hour.

Please go through the information and contact me with questions (if any) or an expression of interest to participate in the research either directly at the facility, or by email, SMS or a phone call by 15 September 2019. You may also contact my supervisor Ms. Mosalo at University of South Africa, Department of Health Studies. Our contract details are at the end of this sheet.

Participating in the research is strictly voluntary and the participant will be free to withdraw anytime without giving any reason and without their rights affected.

Information obtained from the study is confidential. No names or any other forms of identification will appear on the research report or any other document produced.

There may be potential risks involved in participating due to the sensitive and stigmatised nature of the disease. However the research assistant will be trained to identify any potential risks, should it be necessary a counsellor is arranged at the facility to support you free of charge. You will not incur any financial cost, as this will be done freely from the clinic services.

You may not receive any incentives as this is done voluntarily. Although you may not receive a direct benefit from the study, it is anticipated that the findings and recommendations of the study will contribute to inform policy and implementation of interventions that promote awareness and optimal health seeking behaviour of women on cervical cancer in Nefas Silk Lafto Sub-City and similar settings.

Thank you for your consideration of this request to participate in the study.

Ekin Ogutogullari: Researcher

Contact details:

Researcher: Ekin Ogutogullari - 50848658@mylife.unisa.ac.za - 0911.251.792

Supervisor: Ms. Mosalo - mosala@unisa.ac.za - +27 12 429 -6447

Chair of Department of Health Studies Research Ethics Committee: Prof Maritz – hsrec@unisa.ac.za

ANNEXURE F: Informed consent form

Title of Research: Perceptions, awareness and health seeking behaviour of women regarding cervical cancer in Addis Ababa, Ethiopia.

PLEASE READ THE BELOW CAREFULLY AND RESPOND AS APPROPRIATE*

#	Statement	Response (Tick as appropriate)	
		YES	NO
1.	I confirm that I have read (or it was read to me) and have understood the information sheet for the above research.	<input type="checkbox"/>	<input type="checkbox"/>
2.	I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	<input type="checkbox"/>	<input type="checkbox"/>
3.	I understand that I will not be identified or identifiable in any document produced by the researcher.	<input type="checkbox"/>	<input type="checkbox"/>
4.	I understand that participation in this research is voluntary.	<input type="checkbox"/>	<input type="checkbox"/>
5.	I understand that I am free to withdraw at any time without giving any reason and without my rights being affected.	<input type="checkbox"/>	<input type="checkbox"/>
6.	I confirm that any risks associated with this research have been explained to me.	<input type="checkbox"/>	<input type="checkbox"/>
7.	I agree taking part in this research and being interviewed.	<input type="checkbox"/>	<input type="checkbox"/>
8.	I agree to have the interview recorded digitally.	<input type="checkbox"/>	<input type="checkbox"/>
9.	I agree to have the interview interpreted by the research assistant.	<input type="checkbox"/>	<input type="checkbox"/>
10.	I understand that the researcher will use the data he obtains for the purposes of his Master's Thesis and the data will be shared as appropriate.	<input type="checkbox"/>	<input type="checkbox"/>

	Full Name	Date	Signature (or thump print)
Participant			
Research Assistant	Kalkidan Solomon		
Researcher	Ekin Ogotogullari		

Contact details:

Researcher : Ekin Ogotogullari - 50848658@mylife.unisa.ac.za - 0911.251.792

Supervisor: Ms. Mosalo - mosala@unisa.ac.za - +27 12 429 -6447

Chair of Department of Health Studies Research Ethics Committee: Prof Maritz – hsrec@unisa.ac.za

***If the participant is unable to read and write, researcher will read each question below and record the responses as appropriate.**

One copy will be given to the participant and one copy will be kept by the researcher.

ANNEXURE G: Informed consent form (Amharic)

መግለጫ :- ሐ

50848658 አገልግሎት :- ለምርምር መረጃን ያካተተ የይዘት ቅፅ

የጥናት ርዕስ :- የማህፀን በር ካንሰርን በተመለከተ የሴቶች ግንዛቤ እና የጤና ፈላጊ ባህሪ በአዲስ አበባ ፣ ኢትዮጵያ ውስጥ

እባክዎን ከዚህ በታች ያለውን በጥንቃቄ ያንብቡ እና ተገቢውን ይመልሱ::

#	መግለጫ	ምላሽ (እንደአስፈላጊነቱ ምልክት ያድርጉ)	
		አዎ	አይደለም
1	ከላይ ለተጠቀሰው ምርምር የመረጃ ወረቀቱን ማንበቤን (ወይም ለእኔ መነበብን) አረጋግጣለሁ እና ስለ ምርምር ወረቀቱ ገብቶኛል::	<input type="checkbox"/>	<input type="checkbox"/>
2	መረጃውን የማገናኘት ሁኔታ አግኝቻለሁ ፣ ጠይቄም ጥያቄዎቼ በአጥጋቢ ሁኔታ መልስ አግኝተዋል ::	<input type="checkbox"/>	<input type="checkbox"/>
3	በተመራማሪው የተዘጋጀ ሰነድ በምንም መልኩ ማንነቴ እንደማይሰጠኝ ወይም ተለይቶ እንደማይታወቅ ይገባኛል::	<input type="checkbox"/>	<input type="checkbox"/>
4	በዚህ ምርምር ውስጥ መሳተፍ በፈቃደኝነት እንደሆነ ተረድቻለሁ ::	<input type="checkbox"/>	<input type="checkbox"/>
5	በማንኛውም ጊዜ ምንም ምክንያት ሳልሰጥ መብቶቼ ሳይነኩ ለመልቀቅ ነፃ መሆኔን ተረድቻለሁ::	<input type="checkbox"/>	<input type="checkbox"/>
6	ከዚህ ምርምር ጋር የተያያዙ ማናቸውም አደጋዎች እንደሚገለጹልኝ ተረድቻለሁ::	<input type="checkbox"/>	<input type="checkbox"/>
7	በዚህ ምርምር ውስጥ ለመሳተፍ እና ቃለ መጠይቅ ለማድረግ ይስማሙ ::	<input type="checkbox"/>	<input type="checkbox"/>
8	ቃለመጠይቁ በተመራማሪው በዲጂታል እንዲመዘገብ ተስማምተዋል ::	<input type="checkbox"/>	<input type="checkbox"/>
9	ቃለመጠይቁ በአስተርጓሚው እንዲተረጎም እስማማለሁ ::	<input type="checkbox"/>	<input type="checkbox"/>
10	ተመራማሪው ያገኘውን መረጃ ለማስተርስ ጽሑፍ ዓላማዎች እና መረጃዎቹ ካስፈለጉ በተገቢው መንገድ ማሰራጨት ይችላል ::	<input type="checkbox"/>	<input type="checkbox"/>

	ሙሉ ስም	ቀን	ፊርማ (ወይም አሻራ)
ተሳታፊ			
አስተርጓሚ			
ተመራማሪ			

የአውቲያ ገጠዘርዎች

ተጠራጣሪ : Ekin Ogutogullari - 50848658@my.ife.unisa.ac.za - 0911.251.792

ተቆጣጣሪ > Ms. Mosalo mosalo@unisa.ac.za +27 12 429 6447

የዚህን ጥናት መሣሪያ ሊሳጡበት የሚችሉ ሥነ ምግባር ኮሚቴ : Prof Meritz - hsrec@unisa.ac.za

* ተሳታፊው ማንበብ እና መላክ ካልቻለ ተጠራጣሪው እያንዳንዱን ቀደም ቢሆን ያሳል እና ኃላፊዎችን እንደ ተገቢው ይመዘግባል።
/ አንድ ወይን ስተላታሬው ያሳጣል አንድ ወይን ደግሞ ለተጠራጣሪው ይተላለፋል ።

ANNEXURE H: Research assistant confidentiality binding form

50848658 Ogutogullari: RESEARCH ASSISTANT CONFIDENTIALITY BINDING FORM

Title of Research: Perception, awareness and health seeking behaviour regarding cervical cancer screening among women in Addis Ababa, Ethiopia
Research Assistant: Kalkidan Solomon


I, Kalkidan Solomon, the Research Assistant for the study understand that I may have access to confidential information about the study participants and the sites.

By signing this agreement, I am indicating my understanding of my responsibilities to maintain confidentiality and agree to the following:

1. I understand that names and any other identifying information about study sites and participants are completely confidential.
2. I agree not to divulge, or otherwise make known to unauthorized persons or to the public any information obtained in the course of this research project that could identify the persons who participated in the study.
3. I understand that I am not to read information about study sites or participants, or any other confidential documents, nor ask questions of study participants for my own personal information but only to the extent and for the purpose of performing my assigned duties on this research project.
4. I agree to notify the researcher or his supervisor immediately should I become aware of an actual breach of confidentiality or a situation which could potentially result in a breach, whether this is on my part or on the part of another person.

Name of Research Assistant: Kalkidan Solomon

Date: 14 May 2019

Signature: 

ANNEXURE I: Self-developed interview guide

SECTION A: DEMOGRAPHIC DATA

INTERVIEW GUIDE					
SECTION A: DEMOGRAPHIC DETAILS					
				Q1	
A.1.	CULTURAL GROUP		1		
			2		
			3		
			4		
			5		
				Q2	
A.2.	PROVINCE (Not sure if this is needed, you can delete) if not appropriate		1		
			2		
			3		
				Q3	
A.3.	AGE	25-30	1		
		36-45	2		
		46 -55	3		
		56-60	4		
		>61	5		
				Q4	
A.4	MARITAL STATUS	Married	1		
		Co-habiting	2		
		Single	3		
		Widowed	4		
		Divorced	5		
A.5.	NUMBER OF CHILDREN			Q5	
		None	1		
		1- 3	2		
		4 -6	3		
		> 6	4		
				Q6	
A.6.	EDUCATIONAL LEVEL OF PARTICIPANT	Never went to school	1		
		Primary School	2		
		Secondary School	3		
		Tertiary	4		

50848658 Ogutogullari: INTERVIEW GUIDE

A.8.	EMPLOYMENT STATUS OF PARTICIPANT	Housewife	1	Q7
		Pensioner	2	
		State grant	3	
		Self-Employment	4	
		Employment	5	
		Unemployed	6	
A.9	EMPLOYMENT STATUS OF PARTNER			Q8
		Unemployed	1	
		Self-Employment	2	
		Employed	3	
		Pensioner	4	
		State Grant	5	

SECTION B:

B1. AWARENESS ON CERVICAL CANCER

Can you please tell me what you know about cervical cancer?

Probes: Can you explain more about the causes?

B1a. How common is this illness among women.

B1b. Can you tell me what the signs that can make someone to be suspicious of suffering from cervical cancer are?

Probes: What makes you think that can be that can be the cause, explain more

B.1c. Can you tell me what tests are used to check for cervical cancer?

B1d. Do you know someone who has been affected by the illness?

What was your experience with this person with the illness?

B2: PERCEPTIONS ABOUT CERVICAL CANCER

B2b. How often do you think women should be screened for cervical cancer?

Probes: **Can you clarify why you say that?**

B2a. Do you think that it is a good idea that women be screened for cervical cancer?

B2b. Do you think young girls should be informed about cervical cancer?

Probes: **Can you explain why you say so**

B2c: Do you and your friends talk openly about cervical cancer?

Probes: **Can you clarify please?**

B2d. Do you think it is a good thing that cervical cancer should be talked about in the radio and television?

Probes: **Why do you think so?**

50848658 Ogotogullari: INTERVIEW GUIDE

B3: HEALTH SEEKING BEHAVIOUR

B3a: Have you been screened for cervical in the past?

B3b: What was your experience with the process?

B3c: Can you explain how you felt during the time you waited you receive the results of the test?

B3d. Can you encourage other women to go for screening?

B3e. What do you think can be done to encourage women to go for screening for cervical cancer?

Thank you.

ANNEXURE J: Self-developed interview guide (Amharic)

የታላ መጠይቅ መመሪያ				
ክፍል አንድ፡ ዲሞክራሲ መረጃ				
				ጥያቄ-1
U.1	የባህል ቡድን		1	
			2	
			3	
			4	
			5	
				ጥያቄ-2
U.2	ግዛት (ይህ አንደኛው የሰነድ አርግጠኛ አይደለም ፣ እርስዎ መሰረዝ ይችላል) ተገቢ ካልሆነ		1	
			2	
			3	
				ጥያቄ-3
U.3	ዕድሜ	25-30	1	
		36-45	2	
		46-55	3	
		56-60	4	
		>61	5	
				ጥያቄ-4
U.4	የጋብቻ ሁኔታ	ያገባ	1	
		አብሮ መኖር	2	
		ነጠላ	3	
			4	
		የተፋታ/ች	5	
				ጥያቄ-5
U.5	የልጆች ብዛት	የለም	1	
		1-3	2	
		4-6	3	
		>6	4	
				ጥያቄ-6
U.6	የትምህርት ደረጃ ተሳታፊ	በጭራሽ አልሄደም	1	
		ትምህርት ቤት	2	
		የመጀመሪያ ደረጃ ትምህርት ቤት	3	
		ሁለተኛ ደረጃ ትምህርት ቤት	4	
		ሦስተኛ		

ሀ.፩	የሥራ ሁኔታ ተሳታፊ	የርታ አመሪያ	1	ጥያቄ-7
		የጠረቃ አበል	2	
		የሰብአዊ ጊዜ	3	
		የራስ ቅጥር	4	
		ተሳታፊ	5	
		ሥራ አጥጋቢ	6	
				ጥያቄ-8
ሀ.፭	የባለሥራት የሥራ ሁኔታ	ሥራ አጥጋቢ	1	
		የራስ ቅጥር	2	
		ተሳታፊ	3	
		የጠረቃ አበል	4	
		የሰብአዊ ጊዜ	5	

ክፍል ለ

ለ.1. በማህጸን ሜዳ ካንሰር ላይ የሚደረግ ግንዛቤ

ስለ የማህጸን ሜዳ ካንሰር ምን እንደሚለወጥ አባክኛን ይነገሩኝ?

ምርመራዎች :- ስለ መንከኢዎቹ የበለጠ ማብራሪያ ይችላሉ?

ለ.1.1 ያህ በሰቃ በሌሎች ላይ ምን ያህል የተለመደ ነው?

ለ.1.2 እንደ ሰው በማህጸን ሰር ካንሰር እንዲጠራጠር የሚያደርጉት ምልክቶች ምን እንደሆኑ ለተገኛ ይታላሉ?

መመሪያዎቻችሁ:- ያ ሊሆን ይችላል ብለው ያስቡዎታል መንከኢ ሊሆን ይችላል ፣ የበለጠ ያብራሩ?

ሲ.1.3 የግንባታ በር ካንሰርን ለማግኘት ምን ዓይነት ምርመራዎች ተቅም ላይ አንደዉሁሉ ሲተገናኝ ያቅላል?

ሲ.1.4 በሀመም የተጠቀሱ ስሙ ይጠቃሉ?

ከዚህ ወመም ጋር ከዚህ ስሙ ጋር ያጋጠሙዎት ተግባሮች ምን ነበር?

ሊ.2 ስለ ሰርቪካል ካንሰር ያሉ ግንዛቤዎች

ሊ.2.1 ሴቶች ከግንባታ በር ካንሰር ምን ያህል ሂደት ምርመራ ማድረግ አለባቸው ብለው ያስባሉ?

መመርመሪያዎች-ባምን አንደዎቹል ግልፅ ማድረግ ጎቸላለህ?

ሊ.2.2 ሴቶች ከግንባታ በር ካንሰር ምርመራ ቢደረግላቸው ጥሩ ዕሳቤ ነው ብለው ያስባሉ?

ሊ.2.3 ወጣት ልጆቻቸው ስለ የግንባታ ግዴታ ካንሰር ማስወጃ አላቸው ብለው ያስባሉ?

ምርመራዎች-ለምን አንደዎቹል ማስረዳት ጎቸላለህ?

ሊ.2.4 እርስዎ እር ዳርኛቸዎ ስለ የግንባታ ግዴታ ካንሰር በግልፅ ይናገራሉ?

ምርመራዎች አባባሎን ማበራረቅ ይችላሉ

ሲ.2.3 የምስራቅ ዘር ካንሰር ዘፈዳዮች እና ፍላጎትን ውስጥ መሪዎች ገጽ ለር ለሌሎች ያስባሉ፤

ምርመራዎች ለምን አንዲህ ብለው ያስባሉ?

መግለጫው :- ሐ

50848658 አገባብ ለገጽ :- ቃላት መጠይቅ መመሪያ

ይጻፍ፣ ጠናቅ የሚፈልግ ባህሪ

ሲ.3.1 ከዚህ ርዕስ የሚነሱት ጥያቄዎች ምርመራ ተፈጻሚ፤

ሲ.3.2 ከሂደቱ ጋር ያለውን ተጨማሪ ምን ያበር?

ሲ.3.3 ወሃውን ለመውሰድ በሚጠቀሙት ገቢ ምን አንድ ተጠያቂዎች ማስረጃዎች ይችላሉ?

ሲ.3.4 ሌሎች ሌሎች ለምርመራ አንዲህ ማበራረቅ ይችላሉ?

ሲ.3.5 ሌሎች ለምርመራ ጥያቄ ካንሰር ምርመራ አንዲህ ለምርመራ ተጠያቂዎች ማስረጃ ለሌሎች ብለው ያስባሉ፤

ANNEXURE K: Example of an in-depth interview

Perceptions, awareness and health seeking behaviour of women regarding cervical cancer in Addis Ababa, Ethiopia

Interview category: In-depth interview

Interviewer name: Kalkidan

Interview place: Nefas Silk Lafto Sub City, Woreda 11 Health Centre (OPD)

Interview duration: “09:34”

Transcriber/Translator name: Kalkidan

Key: I: interviewer, R: interviewee

SECTION A: DEMOGRAPHIC DATA

Demographic details	
Questions	Responses
Cultural group/ethnicity	Oromia
Age	25
Marital Status	Married
Number of children	None
Educational level of participant	10 th grade
Educational level of partner	Diploma
Employment status of participant	Private employee
Employment status of partner	Teacher/governmental employee

SECTION B

B1. AWARENESS ON CERVICAL CANCER

I: Can you please tell me what you know about cervical cancer?

R: Before months ago I used to have a burning sensation in my private part, I come here and they told me that it is a uterine infection. Then I got treatment and I got ok. So up until now am ok, that is all I know about cervical cancer.

Probes: Can you explain about the causes?

R: I heard people talk about cervical cancer other than that I don't know the cause of the illness.

Probe: What kind of people?

R: Rarely, my friends

I: How common is this illness among women?

R: I think most women have it, because I heard a lot of rumours talking that this lady got sick that lady got sick.

I: Can you tell me what the signs that can make someone to be suspicious of sufferings from cervical cancer are?

R: It will have ulceration and burning sensation.

Probes: What makes you think that can be that can be the cause, explain more.

R: I don't know

I: Can you tell me what tests are used to check for cervical cancer?

R: What I think is urine test would be done and also a blood sample

I: Do you know someone who has been affected by the illness?

R: No, I do not know.

What was your experience with this person with the illness?

(Skip question as the respondent answered no for the above question)

B2: PERCEPTIONS ABOUT CERVICAL CANCER

I: How often do you think women should be screened for cervical cancer?

R: I think they should go whenever they have pain. When I come to hospital I had a pain, fluid discharge and burning sensation so a woman should go to hospital when she has this pain.

Probe: So, you don't think she should test regularly within a specific time

R: I think they should come when they have the above symptoms that I told you, it should not be with a specified time.

Probe: What about before any of the symptoms began, just for screening? How frequent should women come?

R: Every 15 days or a month

Probe: Why?

R: Everybody needs a check-up that is most frequent

I: Do you think that it is a good idea that women be screened for cervical cancer?

R: Yes.

Probe: Why?

R: Women are the once who are usually affected by illness like cancer because there is breast cancer, cervical cancer. I have seen many women losing their breast because of cancer so it's good to have screening.

I: Do you think young girls should be informed about cervical cancer?

R: Yes, they should be informed.

Probes: Can you explain why you say so

R: Because these girls are going to grow, and you will never know what will happen so, it's good if they are informed. It's not a secret that they will be involved in sex when they grow up so it's better to inform them now.

I: Do you and your friends talk openly about cervical cancer?

R: I have one neighbour, that once told me that she had some mass that grew from inside her uterus, then I told her to go to hospital but she said let me first pray, when I asked her how it felt, she said it has an itching behaviour, but she never went to hospital. But I didn't ask her again.

Probes: Can you clarify please why didn't you ask her again and discuss

R: Because is much older than me, but I suspected it might be cancer because she said there is some forging thing that grow from that area

I: Do you think it is a good thing that cervical cancer should be talked about in the radio and television?

R: Yes, really it's good

Probes: Why do you think so?

R: Many people gain knowledge by just watching a TV so it's good

B3: HEALTH-SEEKING BEHAVIOUR

I: Have you been screened for cervical in the past?

R: No, I have not been screened for cervical cancer.

Probe: Why have you not been screened?

R: Because when I was sick last time they treated me for uterine infection and I got better so since then am healthy so I didn't come and am very busy with work so I don't have time.

I: What was your experience with the process? (Skipped this question as answered no for screening).

I: Can you explain how you felt during the time you waited you receive the results of the test? (Skip this question as answered no for screening).

I: Can you encourage other women to go for screening?

R: Yes, I can.

Probe: How can you encourage other women about that?

R: For example, the lady that I told you, if I go and ask her to go to health centre am sure she will go...if I ask again and again.

I: What do you think can be done to encourage women to go for screening for cervical cancer?

R: We women usually get ashamed, even the time I was sick if it was not for my husband I don't have the guts to go. Because I was worried how I will open my legs in front of other people. But he encouraged me to go. So, I think a support from a partner is important.

Probe: What else do you have in mind that can encourage women to go for screening?

R: Health education about cervical cancer, especially during waiting time of doctors, it's good to give health education in the waiting area, then women will be afraid any more.

I: If you have any additional views, questions or concerns?

R: I do not have any.

I: Thank you very much I have finished.

R: It is ok.

ANNEXURE L: Proof-reading and language editing

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Proofreading & Language Editing Services

59, Lewis Drive, Amanzimtoti, 4126, KwaZulu Natal
Cell: 071 352 5410 E-mail: moramist@vodamail.co.za

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Address	Dept. of Health Studies, College of Human Sciences, UNISA
Date	04/05/2022
Subject	Dissertation: PERCEPTIONS, AWARENESS AND HEALTH-SEEKING BEHAVIOUR OF WOMEN REGARDING CERVICAL CANCER IN ADDIS ABABA, ETHIOPIA
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I certify that I have edited the following for language, grammar and style, Dissertation: Perceptions, awareness and health-seeking behaviour of women regarding cervical cancer in Addis Ababa, Ethiopia, by E.C. Ogotogullari, to the standard as required by UNISA.

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ANNEXURE M: Originality Turnitin report

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