Perceptions of and perspectives on cervical cancer screening: a qualitative study among Somali women in Oslo

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Thesis submitted as a part of the Master of Philosophy Degree in International Community Health

September 2017
Abstract

Cervical cancer is rated as the fourth type of cancer worldwide and the second most common cancer in women living in developing countries. Early detection and treatment are important for the prevention of morbidity and mortality related to cervical cancer. Studies conducted in the US suggest that cervical cancer related morbidity and mortality are highest among immigrant populations and that immigrant women may be less likely to participate in cervical cancer screening compared to women in host communities. Similar studies indicate that Somali women, in particular, constitute one immigrant group that is less likely to participate in cervical cancer screening. However, statistics about the burden of cervical cancer among Somali women in Norway are lacking. In achieving the study objectives, a qualitative study design was employed where in-depth interviews and focus group discussions were used to explore the perceptions of and perspectives on cervical cancer screening as well as the barriers and the suggestions for reducing the barriers among Somali women. The data material was analyzed via a systematic process of thematic content analysis. The study revealed a lack of familiarity with cervical cancer and perceived irrelevance of screening among the participants. The study also found that they experienced the Pap smear test as unpleasant, painful and upsetting. In addition, the study revealed fear of the outcome of the test and embarrassment as emotional barriers to screening. Moreover, practical issues related to child care and lack of time, language difficulties, cultural and religious concerns, as well as mistrust of the health care system were identified as barriers to cervical cancer screening. The participants suggested that awareness creation, use of translated materials, and having their preference for female health providers accommodated could reduce the barriers to and facilitate participation in cervical cancer screening. The findings of this study suggest that, accounting for these barriers, implementing these recommendations and tailoring the cervical cancer screening program in ways attuned to the present-day multicultural population of Norway can potentially increase participation in cervical cancer screening among Somali and possibly other immigrant women as well.

Keywords: cervical cancer screening, Somali women, immigrant women, qualitative research.
Dedication

This thesis is dedicated to my family and more so my wife Sulekha who has exhibited resilience and, at the same time, given me courage and support during the years in which I have been a student in Norway. Equally, this study is dedicated to the Somali women who have taken part in this study as participants, for their sacrifice, their patience and the devotion they demonstrated during the data collection process. I humbly tell them “waad mahadsantihin dhamaan.”
Acknowledgements

First, I would like to appreciate all the research participants who voluntarily took part in this study. I sincerely acknowledge you for having shared your experiences and perspectives regarding the topic of cervical cancer and screening. Without your participation, this study would not have been a success. Further, I would like to recognise the role played by the research assistant Arifi Mohamoud Ali during participant recruitment and data collection. Arifi has been a diligent and resourceful person who earned the respect and trust of the community. She deserves more than a mere recognition.

Secondly, I wish to recognize my supervisors Christina Brux Mburu and Dr Ahmed Ali Madar for their tireless support and guidance throughout the study process. Similarly, I appreciate the courage and motivation they gave me to pursue a unique and exclusive way of presenting my thesis by submitting it with an article. Likewise, I acknowledge the knowledge and advisability I gained from them during the entire process of the thesis writing.

Thirdly, I would like to appreciate the unwavering support of the lecturers and staff at the Institute of Health and Society for their valuable lectures and administrative work. They have shaped me into a public health researcher, and hence a resourceful person for my community.

Finally, I would like to acknowledge my friends and colleagues for having given me courage and strength during the study period and thesis writing.
List of abbreviations

AIDS - Acquired Immune Deficiency Syndrome
BAME - Black, Asian and Minority Ethnic
CCS - Cervical cancer screening
CRN - Cancer Registry of Norway
FGD - Focus Group Discussion
FGM - Female genital mutilation
GD - Group discussion
GDI - Gender Development Index
GP - General Practitioner
HCP - Health Care Provider
HIV - Human Immuno-Deficiency Virus
HPV - Human Papilloma Virus
NSD - Norwegian Center for Research Data
REK - Norwegian Regional Committees for Medical and Health Research
UNDP - United Nation Development Program
WHO - World Health Organization
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Structure of the thesis

The thesis consists of five chapters (1) introduction (2) literature review (3) methodology (4) findings and (5) discussion, conclusion and recommendations.

Chapter one introduces the background of the study, followed by relevant contextual information about the research setting (Norway), the rationale for the study and the research objectives.

Chapter two consists of the literature review, in which concepts used in the literature are defined. It also reviews cervical cancer and risk factors for cervical cancer, as well as the prevention of cervical cancer. In addition, the epidemiology of cervical cancer in Norway, the perception of cervical cancer and screening, experiences of cervical cancer screening, barriers to cervical cancer screening, as well as the suggestions for reducing the barriers to uptake of cervical cancer screening are all topics addressed in the literature review.

Chapter three provides a detailed description of the research methodology, including the research design, study setting, methodological rationale, study sample and participant recruitment, data collection methods, data analysis, reflexivity and ethical considerations.

Chapter four covers the study findings, which are presented under four main thematic areas. (1) perceptions of cervical cancer and screening (2) experiences of cervical cancer screening (3) barriers to cervical cancer screening (4) suggestions for reducing the barriers to cervical cancer screening.

Chapter five contains a discussion of the main study findings, followed by a reflection on the strengths and limitations of the study as well as the conclusion and recommendations. Relevant studies is related to in the discussion, in the interest of situating this study within the current research field and contributing to a broader understanding of the study phenomena and findings.
CHAPTER ONE

1 Introduction

1.1. Background

Globally, cervical cancer is the fourth most common cancer affecting women, with an estimated 528,000 new cases in 2012 [1]. In developing countries, cervical cancer is ranked as the second most common type of cancer affecting women[2]. In 2012, 266,000 deaths occurred as a result of cervical cancer, and more than 85% of these deaths occurred in low- and middle-income countries [1]. Similarly, in Sub-Saharan Africa, cervical cancer is the leading cause of cancer-related mortality, In 2012, there were 75,000 women diagnosed with cervical cancer, and more than 50,000 died from the disease [3]. The highest incidence of cervical cancer has been reported in eastern, western and southern Africa [2].

Previous studies indicate that cervical cancer screening has reduced cervical cancer morbidity and mortality in Europe[4]. Studies conducted in the United States suggest that cervical cancer-related morbidity and mortality are highest among immigrant populations compared to the host population and that immigrant women may be less likely than non-immigrant women to participate in cervical cancer screening [5]. Similarly, studies conducted in the US indicate that Somali women are less likely to participate in cervical cancer screening [6-8]. Likewise, a retrospective register-based study of 1.3 million women in Norway showed that 50% of the immigrant women were non-adherent1, compared to 31% of native Norwegians [9]. Nonetheless, little is known about the statistics and burden of cervical cancer among Somali women in Norway. Furthermore, a recent study about the barriers and facilitators to cervical cancer screening among Pakistani and Somali women in Norway revealed barriers to screening on three levels, the individual level consisting of lack of understanding of the benefits to screening, the sociocultural level that included stigma related to cervical cancer and the belief that unmarried women are sexually inactive, and the system level that entailed a lack of trust in the health care system[10]. Likewise, the present study explores Somali women's perceptions of and perspectives on cervical cancer screening, their experienced and perceived barriers to screening, and their suggestions for reducing these. The present study

1 Non-adherent – In this study, non-adherent refers to women who have not attended screening test between 2008 and 2012.
thus contributes further to our understanding of not only the barriers to cervical cancer screening, but also potential ways of reducing these and better facilitating screening participation among Somali immigrant women in Oslo.

1.2 Norway’s profile

Norway is located in Northern Europe, bordering the North Sea and North Atlantic Ocean. It shares borders with Sweden, Finland and Russia. There are 5,258,317 people registered as residents in Norway in 2017, including foreign citizens [11]. The total land mass is 386,958 km², characterised by high plateaus and rugged mountains, broken by fertile valleys, small scattered plains, a coastline that is deeply indented by fjords, and arctic tundra in the north [12]. Norway is divided into 19 administrative regions that are further sub-divided into 426 counties.

Politically, Norway has been a constitutional state since 1814, after the acceptance of the first democratic constitution and the formation of the parliament. In 1905, Norway dissolved its union with Sweden to become a sovereign state. Furthermore, Norway is governed by three distinct levels of a parliamentary system, i.e. the national government, the county council and the municipal council, which are popularly elected bodies. The parliament has 169 members, who are elected on a four-year basis.

In addition to the political context, the economy of Norway can be described as a mixed economy, i.e. a capitalist market economy with a clear component of state influence [12]. The expansion of most industries is also managed by private property rights and in the private sector. Nonetheless, some industrial activities are governed or owned by the state. Norway also has a diverse wealth of resources, including petroleum, natural gas, fish, and timber. The economy is described as that of a welfare state in which the state and the local authorities ensure that all the residents have access to the most basic and fundamental services, like health care and education. These services are funded through export income from the resources and taxes paid by the residents.
1.2.1 Gender
Norway consistently ranks at or near the top of all nations with respect to gender equality [12]. According to the gender development index (GDI) published by United Nations Development Programme (UNDP) Human Development Report 2015, Norway has been ranked as the most gender equal nation [13]. The GDI measures gender in human achievements in terms of disparities between men and women in three basic aspects of human development: health, knowledge and living standard [13].

1.2.2 Health care system and organisation
The health care system of Norway is part of the welfare state based on the values of equal access to health care for all residents of Norway. This implies that all the inhabitants of Norway should enjoy equal access to quality health care despite social, economic and geographical differences [12]. Furthermore, to achieve this goal, the organisational structure of the health care system of Norway operates on three levels, i.e. the national level, five health regions and the municipalities. The national level is mandated with the task of monitoring legislation and allocating funds. The main task of providing health services lies with the five health regions for specialist health care and the 426 municipalities for primary health care, including nursing and dental care [12].
1.2.3 Cervical cancer screening in Norway

In the 1950s, the pap smear was introduced as a diagnostic and opportunistic screening tool in Norway [14]. The first organised cervical cancer prevention effort by means of screening for precancerous lesions was conducted in Østfold [15]. The Østfold study ran from 1959 to 1977 and exhibited a reduction in incidence and mortality in screened compared to non-screened populations [15]. However, these results did not lead to the establishment of nation-wide screening services, as were adopted by neighbouring Nordic countries. During the 1970s, cytology-based screening became popular in Norway, but this frequent and unorganised screening had little effect on incidence and mortality rates [14]. In 1990, the Norwegian Department of Health and Social Affairs opted to begin a national screening programme for cervical cancer grounded on the recommendation specified in the NOU 1987:8 (Norway’s public report) [14]. From 1990 to 1993, all voluntary cervical cancer screening performed was recorded in a central registry. Also, a pilot project was carried out in two counties of Vestfold and Sør-Trøndelag to assess the organisational features of the cervical cancer screening programme. Following the two pilot projects, the first nationally organised population-based screening programme was initiated in 1995 in Norway. The organised programme had centralised monitoring and management functions, and individual reminders were sent to those overdue for their screening test [15]. These efforts have led to a further reduction in cervical cancer incidence and mortality.

Cervical cancer screening in Norway is run by the Norwegian cervical cancer screening programme (NCCSP). The NCCSP is managed by the Cancer Registry of Norway (CRN) in conjunction with the National Institute of Public Health and the Norwegian Directorate of Health. The goal of the NCCSP is to reduce the morbidity and mortality associated with cervical cancer by 50% [14]. Furthermore, the NCCSP also provides advice and information to the general public about cervical cancer preventive measures.

The NCCSP targets women between the ages of 25 and 69, with recommended screenings every three years. Cervical cancer screening, diagnosis and registration are the functions of the CRN. The registry sends an information letter to all women living in Norway when they fill the age of 25 years. The letter describes the work of the cancer registry and highlights the importance of having a screening test. The cancer registry also sends a reminder letter to women every three years, and, if a test is not registered the next year, a new reminder is sent.
Women make appointments with their general practitioners for the Pap smear, either encouraged by the reminding letters or at their initiative. The diagram below illustrates the organization of the Norwegian cervical cancer screening programme.

**Figure 2: showing flow chart of the Norwegian cervical cancer screening programme**
1.3 Rationale for the study

Cervical cancer remains a public health problem that affects women worldwide. Cervical cancer is ranked as the fourth type of cancer affecting women worldwide [1]. It is estimated that 85% of the global burden of cervical cancer occurs in developing countries, where it accounts for 12% of all female cancers [1]. In 2012, cervical cancer accounted for 7.5% of all female cancer deaths worldwide [1]. In 2012, an estimated age standardized cervical cancer incidence rate of 11.4/100,000 and estimated age mortality rate of 3.8/100,000 were reported in Europe [16]. Furthermore, cervical cancer remains one of the three most frequent cancers in women between 25 and 49 years of age in Norway, with incidence and mortality rates of 9.5 and 1.7 per 100,000 women respectively [17].


The Cancer Registry of Norway (CRN) targets all women between 25 and 69 years of age for screening. While the general attendance for cervical screening after reminders has been 74%, more than 50% of the women diagnosed with cervical cancer had rarely taken a Pap smear test [18]. Early detection and treatment of cervical cancer through the use of pap smear testing is important for preventing the morbidity and mortality associated with cervical cancer.

Evidence-based studies show that immigrant women participate less in preventive screening than non-immigrant women. For example, Somali women empaneled to a large primary care practice in Minnesota were less likely than non-Somali patients to adhere to the recommended cervical cancer screening and other preventive health measures [6] Likewise, a cross-sectional study that merged data from four national registries confirmed lower rates of participation in the preventive cervical cancer screening program in Norway among immigrants compared to non-immigrants [18]. However, we lack statistics about the cervical cancer burden and rates of screening uptake among Somali immigrant women in Norway. Furthermore, a recent study about the barriers and facilitators to cervical cancer screening among Pakistani and Somali women revealed barriers to screening on three levels; the individual level that consisted of a lack of understanding of screening benefits, the sociocultural level that included stigma related to cervical cancer and the belief that unmarried women are sexually inactive, and the
system level that entailed a lack of trust in the health care system [10]. The present study explores Somali women's perceptions of and perspectives on cervical cancer screening, their experienced and perceived barriers to screening, and their suggestions for reducing these, thus contributing further to our understanding of not only the barriers to cervical cancer screening among Somali immigrant women in Oslo, but also the ways in which these barriers might be reduced and cervical cancer screening participation better facilitated. In this way, the study findings can potentially contribute to the development of a culturally-tailored intervention to increase participation in cervical cancer screening among Somali and other immigrant women in Norway.

1.4 Research objectives

1.4.1 Main objectives

- The aim of the study was to explore Somali women's perceptions of and perspectives on cervical cancer screening, with a particular focus on their perceived and experienced screening barriers and suggestions for reducing these.

1.4.2 Research questions

- What are the perceptions of and perspectives on cervical cancer and screening among Somali women in Oslo?

- What are their experiences, if they have participated in the screening program or supported a female family member in doing so?

- What do they identify or experience as potential barriers to the uptake of cervical cancer screening?

- What are their suggestions for reducing barriers to cervical cancer screening uptake?
CHAPTER TWO

2 Literature Review

2.1 Definition of concepts

Cervical cancer: is an abnormal growth of cervical cells, most often caused by a persistent infection with human papillomavirus (HPV) cancer causing types. Approximately 90% of the cervical cancers are squamous cells cancer and initiate in the transformation zone (T-zone) of the ectocervix, while the other 10% are adenocarcinomas that arise in the glandular columnar layer of the endocervix [19].

Human papillomavirus: HPV is a sexually transmitted virus that can be passed through genital or skin-to-skin contact. There are more than 100 types of HPV, of which seven out of ten (70%) of all cervical cancer and pre-cancerous lesions reported throughout the world are caused by only two types of HPV, i.e. HPV type 16 and 18. [19].

Papanicolaou smear: also referred as a Pap smear, is a screening test done to detect pre-cancerous and cancerous cells on the uterine cervix, performed for preventing cancer of the cervix [20].

Screening: is a public health intervention provided to an asymptomatic target population that is not undertaken to diagnose a disease, but to identify individuals with increased probability of having either the disease itself or a precursor of the disease [19].

2.2 Cervical Cancer

Cervical cancer often results from a persistent infection with the sexually transmitted, cancer-causing HPV. Approximately, 90% of cervical cancers are squamous cell carcinoma and initiate in the transformation zone of the ectocervix, while the remaining 10% are adenocarcinomas that arise in the glandular columnar layer of the endocervix [19]. There are more than 100 types of HPV, but HPV 16 and HPV 18 account for 70% of all cervical cancer cases and precancerous lesions [21]. Typically, HPV resolves itself without any treatment a few months after contact. In rare cases, HPV persists and, if left untreated, can progress to cancer. In the diagram below, the transformation zone clearly illustrated, as the T-zone is the location where the cells meet and where the precancerous cells are likely to develop.
Figure 3: showing the uterus and cervix of a woman of reproductive age

Source: http://www.nccc-online.org/hpv-cervical-cancer/cervical-cancer-overvie

2.3 Risk factors
Exposure to certain types of HPV causes cervical cancer, e.g. HPV types 16, 18, 31 and 33. However, additional factors are also known to predispose women to the risk of developing cervical cancer. These include early onset of sexual intercourse, multiple sexual partners, parity (number of babies born) and young age at first birth, use of oral contraceptives for over five years, smoking and other tobacco use, and suppressed immunity, e.g. due to HIV/AIDS [19].

2.4 Prevention of cervical cancer
Early detection and treatment are important strategies for the prevention of disease. Studies have shown that early detection and subsequent treatment of cervical cancer has reduced morbidity and mortality in developed countries. A scarcity of resources and poor prospects for early detection of precancerous lesions and treatment results in a much higher mortality rate in developing countries [22]. These elevated mortality rates are attributed to a lack of awareness and inability to implement national screening programs [22]. Furthermore, there are different methods used in the detection and prevention of cervical cancer. These include primary prevention, early detection through increased awareness and screening programmes, diagnosis and treatment, and palliative care for the advanced diseases [19]. The first level, which is the primary prevention, is achieved through community sensitization and awareness about the risk factors, as well as the establishment of efficient and affordable HPV
vaccinations for young girls. The second level of prevention entails organised screening programmes to detect the pre-invasive lesions and provide subsequent treatment, capacity building for health providers and informing women in the target group about the benefits of screening and the signs and symptoms of the disease. At this stage, the types of testing methods used include cytology tests like the Pap smear that is widely employed in developed countries and visual inspection with acetic acid, which is used in low-resource settings. The third level includes the diagnosis and treatment of disease, follow-up of positive cases and treatment of pre-invasive lesions and invasive cancer. Finally, the last level entails palliative care, during which treatment is given to reduce pain and suffering.

2.5 Epidemiology of cervical cancer in Norway

Although the incidence of cancer, in general, has been increasing in recent decades, there has been a decreasing trend in both incidence of and mortality from cervical cancer in Norway [14]. Initially, in the 1960’s, cervical cancer incidence and mortality rates were higher in Norway than in other Nordic countries [14]. This difference was attributed to the organised, nation-wide screening programmes implemented in other Nordic countries like Sweden and Finland, and the lack of this in Norway, where a screening programme had been implemented in the Østfold County only [14]. However, the establishment of screening programmes in 1995 and the more efficient use of resources led to a reduction in incidence and mortality in the following years in Norway [15]. In 2015, 370 new cases of cervical cancer were reported. This corresponds to an incidence rate of 14.3 per 100,000 in the same reporting year [23]. As discussed earlier, cervical cancer remains one of the three most frequent cancers in women between 25 and 49 years of age in Norway, with incidence and mortality rates of 9.5 and 1.7 per 100,000 women respectively [17].

2.6 Perceptions of cervical cancer and screening

Several qualitative studies have indicated misperceptions of cervical cancer and screening among immigrant women. The studies reveal that women from ethnic minority backgrounds have limited knowledge about cervical cancer and screening and are unfamiliar with the test. For example, qualitative study findings on barriers and facilitators for cervical cancer screening among Hispanic women indicated that Hispanic women had a misconception about the causes of cervical cancer, and none of the participants specifically mentioned HPV or a virus as the cause of cervical cancer [24]. Similarly, a qualitative study comparing self-
perceived barriers to cervical cancer screening among ethnic minority women to white British women revealed that ethnic minority women discussed a general lack of knowledge about cervical cancer in their community, particularly among the older generation. Several ethnic minority women involved in the study did not recognize the term cervical screening or smear, suggesting that the terminology used is not always familiar, even among English speakers [25].

Additionally, a qualitative study investigating knowledge and perceived barriers to cervical cancer screening among women in Serbia revealed poor knowledge about cervical screening, which could impact the uptake of cervical screening services [26]. Likewise, a study on perceptions and barriers among Somali women in Camden showed that the majority of the participants had heard about cervical cancer screening and believed it was important, however their familiarity was limited [27].

2.7 Experiences of cervical cancer and screening
Cervical cancer screening, as a procedure, is described in the literature as being experienced by women as both physically and emotionally uncomfortable, though to varying degrees. For some women, the Pap smear test was regarded as unpleasant, but nonetheless a routine and necessary health check, comparable to going to a dentist [28]. Other women, however, described their experiences with cervical cancer screening as unpleasant, awful and painful [29], as well as intrusive[27].

Similarly, qualitative studies conducted among immigrant women indicated strong emotional reactions to the Pap smear test, including embarrassment and shame. A study conducted on West African immigrant women in Australia highlighted that most of the women reported embarrassment related to a situation in which social norms surrounding nudity were broken [30]. Similarly, a study among Black, Asian and ethnic minority (BAME) women revealed that there was a particular concern among some about exposing their body, due to the belief that their naked body should only be seen by their husbands [25]. Furthermore, a study conducted among Somali women in Camden revealed concern about the practitioner’s response to the fact that they experienced female genital mutilation (FGM) and suggested that this might cause additional embarrassment [27].
2.8 Perceived barriers to cervical cancer screening

Cervical cancer remains a public health problem affecting women worldwide. As previously described, cervical cancer morbidity and mortality have been increasing in developing countries in recent years and, due to screening and early detection, decreasing in developed countries. At the same time, the uptake of screening services in developed countries has been very low for some groups, and particularly immigrants. Studies carried out in various parts of the world indicate that individual, sociocultural and structural factors serve as barriers to cervical cancer screening. For example, an explorative study examining barriers and facilitators of cervical cancer screening among women of Hmong origin in the United States found that both sociocultural and structural barriers were impediments to the uptake of cervical cancer screening. The sociocultural barriers included lack of knowledge about cervical cancer, language barriers, stigma, lack of time due to family responsibilities and embarrassment. The structural barriers included the attitudes and practices of health providers, lack of insurance and negative perceptions of services for the uninsured [31]. Similarly, Hispanic women are another immigrant group in the United States with a high incidence of and mortality rate associated with cervical cancer. Nationally, the incidence rate is 15.8 per 100,000 among Hispanic women and 8.7 per 100,000 among non-Hispanic women, and the corresponding mortality rates are 3.5 per 100,000 and 2.5 per 100,000 respectively [24]. Qualitative studies determined the following to be barriers to cervical cancer screening among Hispanic women in the United States: embarrassment, fear, hopelessness following diagnosis of cervical cancer, lack of knowledge and lack of health insurance [24].

A study conducted among Haitian women in the United States shows that they experience a high risk of cervical cancer mortality due to lack of access to and underutilization of routine Pap smear screening [32]. This study identified structural barriers, such as monetary-related obstacles, immigration status, language barriers, and limited access to health information about cervical cancer, as well as psychological barriers, such as fear and modesty-related concerns with respect to gynaecological exams [32].

Likewise, studies conducted in Africa demonstrate that individual, communal and structural barriers play a role in the low uptake of cervical cancer screening. A study undertaken in Malawi found that cervical cancer is widespread, with a mortality rate of 80% [33]. Moreover, the findings from the study identified lack of knowledge about cervical cancer, low perceived
threat of the disease, stigma, lack of transportation and time constraints as the obstacles to cervical cancer screening[33].

Studies in Europe and North America have explored if and how sociocultural matters potentially impede cervical cancer screening. A study that explored the barriers to cervical cancer screening among ethnic minority women in England showed that language was not a barrier to screening, though it is identified as such in other studies that have taken place among minorities [25]. Other obstacles to cervical cancer screening included lack of knowledge about cervical cancer, emotional responses like fear and embarrassment, pain, lack of awareness about cervical cancer screening and practical barriers like lack of time. Low perceived risk and lack of symptoms of the disease was identified as a barrier, as was the association of cervical cancer with pre-marital sex [25]. Similarly, a study carried out in the northeast part of Gothenburg, Sweden indicated that a lack of knowledge about the importance of preventive health care, fear of being diagnosed with cancer, unavailable childcare, and language problems as obstacles to cervical cancer screening [34].

Additionally, perceptions and commonly held beliefs about a cervical cancer, cervical cancer risk, and cervical cancer screening are potential barriers to the uptake of cervical cancer screening. A quantitative study in Minnesota, which compared cervical cancer screening completion rates for home-based HPV test kits and clinical Pap smears among Somali women showed that more than 80% of the informants believed that they were not at risk of getting cervical cancer [35]. Similarly, other studies conducted on the same population gave the same results. A study carried out to examine the barriers and facilitators for cervical cancer screening among immigrant women in Minnesota showed fear, pain associated with and embarrassment about the test, stigma related to the disease, lack of trust in the health care system, lack of knowledge and language to be barriers to screening [36].

2.9 Strategies for reducing the barriers to uptake of cervical cancer screening

Various international studies conducted in different contexts have suggested various strategies and interventions for increasing cervical cancer uptake. The majority have recommended education about the purpose of cervical cancer screening, support from the GP (general practitioner), affordability and cultural competency among health providers. A qualitative study on barriers and facilitators of cervical cancer screening among Hispanics suggested that
education about the requirement for the screening test and how it is performed would be a significant facilitator [24]. Moreover, a study on barriers and facilitators of cervical cancer screening among women of Hmong origin revealed the need for change in how health care services were provided [31]. The study participants stated the need for more cultural awareness, improved interpreter ability and effective mechanisms for establishing trust between patients and healthcare providers (HCPs) [31].

Additionally, a qualitative study on perceptions and barriers to uptake among Somali women in Camden suggested education about the purpose of the screening. Also, the study recommended the use of local health community workers to enable the women to understand better the importance of the test. Furthermore, the study revealed that many women attended screening services after they received advice from their GP, hence the researchers’ recommendation regarding the GPs’ role in encouraging Somali women to take up the screening test [27]. Moreover, written information was mentioned as unsuitable by the participants due to low literacy levels. Thus, verbal communication or health talks through workshops in community social settings was recommended [27]. Furthermore, the significance of cultural competence as a strategy for intervention has also been emphasized by the study participants. The study participants suggested that sample takers should be educated about female circumcision and other cultural issues to reduce embarrassment for both patients and providers [27]. In addition, a study exploring the barriers to screening among Somali women in Minnesota suggested ways to tackle barriers at different levels. At the individual level, the study participants suggested provision of language-appropriate messages that address cervical cancer screening services. At the community level, the participants suggested a focus on the stigma surrounding the sexual health of older and divorced women regarding cervical cancer screening participation. At the system level, the involvement of the healthcare providers and ways to appropriately tackle cancer screening for communities that are not competent in speaking English were also suggested by the study participants [36].
CHAPTER THREE

3. Methodology

This chapter provides an overview of the research methodology, describing the study setting and the methods used in conducting the study. In addition, it describes the process involved in data analysis, reflexivity, trustworthiness, research permission and dissemination of results.

3.1 Study setting

The study was conducted in Oslo, the capital city of Norway. Administratively, the city is divided into 19 districts, administered by locally elected district councils. The study was conducted between September and December 2016, in the following Oslo neighbourhoods: Grønland, Tøyen, Tråsterud, and Holmlia. Oslo is a natural place to conduct this study given its immigrant-dense population. These specific areas are among the ones in which many Somalis inhabit, representing also a certain amount of geographical and socioeconomic diversity.

3.2 Research design and methodological rationale

The study employed a qualitative, exploratory design to explore Somali women’s perceptions of and perspectives on cervical cancer screening, their experienced and perceived screening barriers, and their suggestions for reducing these. Qualitative research methodology, as conceived of in this study, involved the systematic collection, organization, and interpretation of textual material derived from talk or observation, utilized in the exploration of meanings of social phenomena as experienced by individuals themselves, in their natural context [37]. Specifically, this study employed the data collection methods of in-depth interviews, focus group discussions and group discussions. This approach was selected because it best suited the study aim of exploring the participants’ perceptions and perspectives. The qualitative design also provided the flexibility necessary for pursuing emerging themes as the study progressed. Moreover, this methodological design enabled the exploration of the subjective meanings and interpretations of the phenomena under study, from the perspectives of research participants [38].

3.3 Study sample and participant recruitment

Inclusion criteria for the study sample included the following: Somali women, between 25 and 69 years of age, living in Oslo, and consenting to participate in the study. The study used
purposive sampling to identify and select information-rich cases related to our research objective. Purposive sampling is a common sampling strategy for recruiting participants according to preselected criteria relevant to a particular research question [38]. This is done by identifying and selecting individuals or groups of individuals’ particularly knowledgeable about or experienced with the phenomena of interest [39]. Within the sample parameters, we strived for maximum variation with respect to age, marital status, education and duration of residency in Norway, to ensure that we achieved a heterogeneous sample. The recruitment was carried out by the researcher and a research assistant in different geographic regions of Oslo and in various social settings, which included community gatherings, business premises, and mosques. During the recruitment process the purpose of the study was explained to the participants and it was made clear to them that participation was voluntary.

3.4 Data collection methods

3.4.1 In-depth interview

In-depth interview is a technique designed to elicit a vivid picture of the participant’s perspective on the research topic [38]. During the interviews, the participant was regarded as the expert and the interviewer as the student. The personal nature of these interactions and the fluid and flexible structure of the interviews enabled in-depth exploration and discussion of both pre-identified and unexpected themes. This study utilised a semi-structured, thematic interview guide, which contained sample open-ended questions. This method of interviewing allowed the participants to share their experiences, meanings, and perspectives freely. A total of 15 in-depth interviews were conducted between September and December 2016, in the participants’ homes and at community centers, in quiet spaces free of interruptions and in which the privacy and confidentiality of the participants was achieved. Each of the interviews lasted about an hour. Five interviews were conducted in English and the remaining ten in Somali, using a translated version of the thematic guide for in-depth interviews.

3.4.2 Focus group discussion

The study also employed focus group discussions (FGDs) as a method of data collection. FGDs are organized discussions among selected groups of individuals to gain a collective view about a research topic and establish the range of perspectives that might be found [40]. The focus group discussion is typically comprised of people of similar sociocultural
backgrounds, with similar experiences and concerns. This is based, in part, on the assumption that a group of people with common characteristics or experiences have a shared platform from which they can discuss understandings, experiences and perspectives related to a particular topic, as opposed to a collection of unique and individual views or experiences [41]. The study used this method because it provides an opportunity to gain insight into the range of perspectives potentially present in the group and the similarities and differences therein. It also enables an exploration of the group dynamic and interactions that take place among participants in a format in which they converse with each other more so than directly with the researcher. Ideally, FGDs empower the participants by providing them the opportunity to describe and discuss their experiences and understandings of, as well as meanings attributed to, the topic [42]. In this study, a total of four FGDs were conducted, each comprising of 8-9 members. The total number of the FGDs was not uniform since some had eight participants while others had nine. In addition, two group discussions (GDs) were conducted in October and November 2016. The GDs were initially intended to be FGDs but failed to meet the numbers adequate for FGDs as planned previously. The FGDs were conducted between September and December 2016, at the various locations in Oslo described previously. The FGDs were conducted during the weekends, after five o clock in the evening. This time was selected because it was convenient for most of the participants and it helped as to minimize delays and absence. Each of the FGDs and GDs were conducted in Somali, using the translated version of the thematic guide for FGDs. The FGDs and GDs lasted about one and a half hours.

With the permission of the research participants, the in-depth interviews and FGDs were audio recorded and transcribed. As the project’s primary researcher was male, we made the assumption that female participants might prefer to be interviewed by a female due to the sensitive aspect of the interviews. In this case, a female research assistant was utilised. Prior to the interview and FGD sessions, we introduced ourselves and reminded the participants about the significance of privacy and confidentiality and of how the data collected would be utilised. The research assistant, who was also the FGD moderator, explained the rules related to this, prior to facilitating the FGDs while the main researcher took notes.

In-depth interviews and focus group discussions were carried out in pursuit of a meaningful degree of saturation. Saturation refers to the point at which the significance of new findings
and additional data collection diminishes and a meaningful coherence among the data emerges [43]. In qualitative research, there are no published guidelines or tests for estimating sample size to reach saturation. Rather this process is determined by the researcher's evaluation, depending on the adequacy and the comprehensiveness of the results [44].

3.5 Data analysis

The majority of the data analysis occurred after the interviews had been transcribed. However, the researcher engaged in preliminary and ongoing analytic reflections throughout the fieldwork period, for the sake of identifying emerging themes and adapting the data collection accordingly. Upon the completion of the data collection, a systematic and comprehensive process of thematic content analysis was carried out. Thematic content analysis is a method for identifying, analysing and reporting patterns or themes within the data [45]. Through a process of manual coding, patterns, categories and themes were identified, grouped and compared. Initially, all of the transcripts were read and re-read. This helped the researcher to familiarise himself with the data and the context within which the data was collected [41]. Initial codes were developed and closely examined to check whether they reflected the contents of the data material. At this stage, a semantic approach was employed, in which the surface meaning of the data was identified at a relatively descriptive level of what the participants had said [45]. The themes were reviewed and checked to see if they worked well with the data set and the themes that did not fit well with the data set were identified and changed. The developed codes were shared with project supervisors and peers for the sake of eliciting alternative perspectives and clarification. Some of the salient themes developed earlier were merged with other themes, thus reducing the number of themes. For example, ‘absence of symptoms’ was changed to ‘perceived irrelevance of screening’ and merged with ‘lack of familiarity with cervical cancer’. Similarly, ‘trust’ evolved into ‘mistrust in the health system’ and ‘socio-cultural factors’ were renamed as ‘cultural and religious concerns’. Thematic analysis at the latent level was also undertaken to determine the underlying ideas, assumptions and conceptualizations and ideologies that are theorized as shaping or informing the semantic content of the data [45]. Finally, the main themes from the data material were presented in a separate section with the discussion.
3.6 Trustworthiness

Several measures have been introduced by both qualitative and quantitative researchers to judge the trustworthiness of their studies. These methods of evaluating research trustworthiness capture similar issues within the quantitative and qualitative research paradigms, but have been referred to in different terms to indicate differences in application and interpretation. Naturalistic, interpretivist researchers often prefer to use different terminologies to distance themselves from the positivist paradigm. One such scholar is Guba, who proposed four criteria for qualitative researchers in the pursuit of trustworthiness [46, 47]. These criteria have been employed to ensure the trustworthiness of my study.

3.6.1 Credibility

Credibility, also referred to sometimes as truth value, refers to the ability of the study to capture the multiple realities of those we study [43]. The strategies for increasing credibility of the research study includes activities that bring the researcher closer to the study subjects and that help the researcher to negotiate with the study participants about the findings [43]. In achieving credibility for my study, I used considerable time during the data collection in the field. I started data collection in September and finished in December 2016. This helped me to understand more deeply the realities and experiences of the research participants and how they related to the topic under investigation. Prolonged engagement with the participants in the field also helped me to build trust with the study participants. It is generally believed that, the longer the time that the researcher spends in the field, the greater the likelihood the researcher grasps the reality of those studied [43].

In addition to the above, having the same cultural and ethnic background as the participants helped me to become familiar with the context with which the study was taking place. The researcher must acquire cultural competence and become familiar with overall context during the study [43]. During the interview sessions, I understood the meanings and perspectives shared by the participants in relation to the topic under investigation in ways that might have been difficult for a researcher who lacked a shared language and culture.

Also, triangulation of methods helped me to achieve credibility in this study. In triangulation, we evaluate an issue with the help of perspectives that come from several different angles [43]. Triangulation, in qualitative design, can involve combining different methods of data
collection. In achieving this, I used both in-depth interviews, focus group discussions and group discussions to cross check the responses from the participants and achieve a more comprehensive understanding of the study phenomena. This helped me to achieve credibility for my study.

Additionally, the use of peer debriefing as a tool helped me to achieve credibility in my study. Peer debriefing in this context refers to the presentation of preliminary findings to colleagues so as to evaluate one’s own role in the research process [43]. This allowed me to get input and critical remarks from those not involved in the research process. Also, the role played by my supervisors during the entire research process, from designing the study to data collection and constant supervision and feedback played a critical role in enhancing credibility for the study. During the analysis, I had discussions with my supervisors to evaluate the identified codes and further analyze the emerging themes. This process helped me to make some adjustment in the themes and categories. As discussed earlier, some of the salient themes developed earlier were merged with other themes, thus reducing the number of themes overall and enabling a more precise and deeper analysis of those identified as most salient in the material.

3.6.2 Dependability

Dependability is a concept used in qualitative methods that corresponds to reliability in quantitative methods. In quantitative methods, the concept is used to denote whether or not, if the work was repeated in the same context, with the same methods and with the same participants, similar results would be obtained [46]. However, in qualitative research, the notion of being able to repeat the same data collection activity with similar outcome is problematic [43]. In qualitative research, the concept of dependability is used to signify the ability of the researcher to account for the constantly changing conditions of the phenomenon studied, for the interaction with the study participants and for the entire research process carried out within an emergent design [43].

In this study, a qualitative research method was the most suitable, given the explorative nature of the inquiry and that it enabled me to gain an understanding of the meanings and interpretations the participant attributed to the phenomena under study. Furthermore, Lincoln and Guba suggest that dependability be evaluated through inquiry audits in which another researcher should be able to follow the decision trial used by the researcher [43]. During the
entire process of research, my supervisors monitored closely my study and provided guidance as necessary to ensure that the protocol of the study was followed appropriately.

3.6.3 Conformability
The concept conformability corresponds to objectivity in quantitative research. Conformability in qualitative research refers to the neutrality of the data rather than the neutrality of the researcher [43]. This implies that measures must be taken to ensure that the research findings are the meanings, interpretations and responses of the participants and not the preference of the researcher. Among the most important measures undertaken is this study was triangulation, as discussed earlier. Further, I have engaged reflexively with the entire research process from data collection to the analysis of the study.

3.6.4 Transferability
Transferability, also referred as external validity or generalizability in quantitative research, is the extent to which the findings from the research findings are applicable to other contexts [43]. To ensure transferability, it is the task of the researcher to make sure that adequate contextual information about the fieldwork sites is provided to enable the reader to make such a transfer. To achieve this, a thick description about the phenomenon under study has been provided to allow the readers to gain understanding and make an evaluation of the transferability of the findings.

3.7 Reflexivity
Reflexivity, referred to metaphorically as “the knowers mirror”, is an attitude of attending systematically to the context of knowledge construction, especially to the effect of the researcher, at every step of research process [37]. Similarly, Horsburgh (2003) referred to reflexivity as active acknowledgement by the researcher that his or her own actions and decisions will inevitably impact upon the meaning and context of the experience under investigation[48]. Therefore, it is significant to account for how my position as the researcher may have impacted the study.

During the fieldwork period, conducting research among participants from the same ethnic and cultural background was an added advantage to the study. Throughout the interview process, some of the responses regarding the cervical cancer screening, and particularly the barriers, seemed obvious. However, I consciously questioned my assumptions and used a
number of probing questions to elaborate more discussion and ensure that I had understood, rather than taken for granted, the participants’ responses.

In the course of the research preparation, I made an assumption that being a male researcher would impact the responses during data collection. I was concerned that the participants might not respond well to the interview questions or be uncomfortable with my presence. To counter this issue, I recruited a female research assistant to conduct the interviews. However, during the interview sessions, my presence did not appear to have an impact on the responses from the participants, and the participants indicated clearly that they were comfortable with my participation. The participants engaged well and discussed openly the topic under study.

Since I was conducting a study related to a medical condition, I consciously avoided medical terminology during the interview sessions and developed an interview guide with simple, accessible language and questions. I translated from English to Somali and shared this with one of my supervisors who also speaks the same language. Some clarifications were made and we used this as a semi-structured thematic interview guide during the interview sessions.

During the fieldwork, I was also conscious about the issue of power relations. It is important that the participants feel that they are on the same level with the researcher and can interact freely. I achieved this by introducing myself as a student researcher and not as a health worker during the interview session. This helped me to easily establish rapport with the participants during the entire fieldwork.

3.8 Ethical consideration
Ethical considerations are worth mentioning since the principal motive is to safeguard the participants from any harm in the process of the study. This has been articulated as three core principles in the Belmont report as it forms the basis for research ethics. First, respect for persons requires commitment to ensuring the autonomy of the research participants. Second, beneficence requires commitment to limiting the risk associated with research, including psychological and social risk. Third, justice requires a commitment ensuring distribution of risk and benefits resulting from the research [38]. This study was carried out in accordance with all three principles articulated in the Belmont report.
3.8.1 Research permission

This study safeguarded matters of ethical integrity by ensuring that informed consent, participant anonymity and confidentiality were prioritised and that research permission was obtained. A preliminary project assessment was requested from the Norwegian Regional Committees for Medical and Health Research Ethics (REK). REK confirmed that this project, given its focus on subjective perceptions and perspectives, fell beyond the mandate of the Health Research Act and could be conducted without their approval. The project was then reported to the Norwegian Centre for Research Data (NSD), which gave the approval to conduct the study. Participant recruitment and data collection began after this was obtained.

3.8.2 Informed consent

Informed consent is a mechanism for ensuring that people understand what it means to participate in a particular research study so that they can decide in a conscious, deliberate and voluntary way whether they want to participate [38]. During the recruitment stage, informed consent was obtained from the participants. This consent was again confirmed just prior to the beginning the interviews. The informed consent document, including the information about the study and the signature form, was written in English and Somali. The participants had the possibility to select the language they understood best. The informed consent document provided information about the background and purpose of the study, the potential risks and benefits of participation, and matters of privacy and confidentiality. Given literacy limitations among some members of the participant sample, the researcher ensured that verbal information was provided as well, and participants were given the choice between written and verbal consent. Most of the participants consented in writing and a few consented orally. Likewise, the researcher informed the participants about the use of tape recorder and none objected.

3.8.3 Confidentiality

Confidentiality, in a research context, applies to information that has been communicated in trust and confidence, with protection from disclosure [49]. Confidentiality was maintained in all stages of the research process. To safeguard privacy and confidentiality, participants were identified using anonymous codes instead of their names, which were used consistently in all the phases of data collection and analysis. Also, during the data collection process, the participants were reminded not to use their names because the interviews were recorded. This
helped me to gain the trust of the participants and ensure that privacy and confidentiality was maintained.

3.8.4 Data storage and handling
Data storage and handling is a critical stage in maintaining the privacy and ensuring the confidentiality of the participants. To secure this, the audio recorded interviews and the transcripts were stored in a password locked laptop by the primary investigator. Similarly, other critical documents, like field notes, were also secured in a safe place. Participants were assured of the handling and storage of the audio and data materials. Once the study was complete, the participants were informed about the deletion of the audio recordings and non-anonymous materials.

3.9 Dissemination of findings
The study findings are submitted in the form of this master's thesis to the Department of International Community Health, and a manuscript was submitted to the scholarly journal of immigrant and minority health. In addition, find attached copy of the manuscript in the appendices section for your further perusal.
CHAPTER FOUR

4. Study findings

The study findings are presented according to the research objectives and then followed by the themes that emerged from the data material. The findings from the study overlap and interact at thematic levels, thus providing a broader understanding of participants’ perceptions of and perspectives on cervical cancer screening and their perceived and experienced barriers, as well as their suggestions for reducing these barriers. The chapter is divided into the following four thematic sections:

I. Perceptions of cervical cancer and screening

This section focuses on the participants’ perceptions of cervical cancer and screening, risk factors and the benefits of cervical cancer screening

ii. Experiences of cervical cancer screening

This section describes the experiences of both participants who participated in cervical cancer screening and those who had not themselves participated in screening but nonetheless heard about similar experiences from other women they knew.

iii. Barriers to cervical cancer screening

This section explores the barriers for cervical cancer screening, as identified by the participants.

iv. Suggestion for reducing the barriers to uptake of cervical cancer screening

The suggestions for reducing barriers to the uptake of cervical cancer screening will be presented in this section.

4.1 Perceptions of cervical cancer and screening

The perceptions of cervical cancer and screening fell into three broad categories, i.e. cervical cancer and screening familiarity, risk factor awareness, and perceived benefits of screening.

4.1.1 Cervical cancer and screening familiarity

The majority of the women in the in-depth interviews and focus group discussions stated that they were not familiar with cervical cancer as a disease. The participants mentioned that they
first heard of cervical cancer when they received the invitation letter, while the few remaining participants stated that they heard through other women. Moreover, according to the Somali language, there is no specific name for cervical cancer. The general term “Kansar” is used, which means cancer, followed by the part of the body affected. In our study context “kansarka afka-ilmagaleenka” was used by the participants, meaning cancer of the mouth of the uterus.

“I have never heard about cervical cancer. This is my first time to hear about it, and back in our home country people used to refer to it as “kansar” meaning cancer. People then used to describe where it affects. Like so and so got the cancer of the foot. People used general term kansar to describe different types of cancer”. (FGD 4 Participant 5)

Moreover, nearly all the participants in the FGDs described cervical cancer as risky and dangerous, as shown in the quote below

“I don’t have knowledge about the disease, but I think it’s a dangerous disease that is risky and deadly that people fear. Any person diagnosed with this disease is seen to die”. (FGD1 Participant 1)

In addition, when the participants were asked about their perception of cervical cancer screening, most of them mentioned that they had limited knowledge about cervical cancer screening.

“I don’t think whether they are really aware of it. I think its lack of knowledge. For me, my mother didn’t tell me about cervical cancer screening and if she did not, it means that she did not know anything about the screening. Maybe if she doesn’t know, then her friends also doesn’t know about it”. (Interview 5)

A similar sentiment was expressed by another participant about her perception of cervical cancer screening.

“Personally, I don’t have a lot of knowledge about the purpose of the test but they use instruments to collect the sample and send it for testing”. (FGD 1 Participant 7)

Furthermore, the participants could not distinguish the screening test from other medical diagnostic tests. Most of the participants in the FGDs mentioned that the test was done to check whether one had cervical cancer or not.
“According to me cervical cancer screening is a test done to examine the individual’s health. (...) A specimen is collected to find out whether you have cervical cancer or not. If you have the disease, then you will get the results and if you don’t have the disease you will receive the results in the doctor's journal”. (FGD 4 Participant 5)

A similar opinion is shared by another participant in the FGDs as shown in the citation below.

“It’s a test carried to determine whether one has cervical cancer or not and this is done by collecting a specimen which is then sent to the laboratory for testing”. (FGD1 Participant5)

Conversely, one participant from the indepth interview mentioned “cell testing” to indicate the purpose of cervical cancer screening as shown in the excerpt.

“Yes I heard about it. (...)I think it is that you will go to a gynaecologist and do checkups. You will probably undergo some cell testing, but apart from that, I don’t know the procedure for such a test”. (Interview 4)

4.1.2 Risk factors awareness
The participants had various perceptions of the risk factors for cervical cancer. Most of the participants described the risk factors for cervical cancer as an infection and bad hygiene that, if not treated, can progress into cancer. Also, according to the Somali language there is an overlap when it comes to the use of the word causes and risk factors. Therefore, the majority of the participants used these terms interchangeably, as shown in the excerpt below.

“Yes I heard about it. (...)I think it is that you will go to a gynaecologist and do checkups. You will probably undergo some cell testing, but apart from that, I don’t know the procedure for such a test”. (FGD 4 Participant 3)

Similarly, another participant stated that if one did not seek treatment for infections this could further develop into cancer:

“I heard that when one grows older and experiences a lot of infection, these infections can develop into cancer. If one does not consider these infections and get treated, then they can develop to cancer”. (Interview 9)
However, one participant had a different opinion of the risk factors for cervical cancer. The participant mentioned that cervical cancer was caused by bacteria that affect the mouth of the uterus:

“I think it is caused by a bacteria that affects the mouth of the uterus and many women refer to this as an infection. They do not visit their GP, and this can develop into cervical cancer”. (GD 1 Participant 2)

Furthermore, some of the participants linked cervical cancer with the cultural practice of female genital mutilation (FGM) among Somali women. The women stated that, due to FGM and difficult child births, they were more exposed to infection than other women:

“We are more susceptible to infections as Somali women compared to other women because we have been exposed to female genital mutilation (FGM), we have experienced difficult childbirths and due to these reasons I think we are more exposed to cervical cancer than other women and if one is not tested, we are likely to get cervical cancer”. (Interview 9)

Similarly, this view was shared by another participant as shown in the quote below:

“Maybe for Somalis, it could be caused by female genital mutilation. The cervix is part of the reproductive system, and it’s an important organ that it’s predisposed to many things, that is why women get this disease (...) For example when the girls are circumcised, and they get their monthly periods. The menses might not flow as expected but some of the menses might still get trapped. This could cause an infection which could develop further into cervical cancer.”(Interview 14)

Nonetheless, one participant mentioned HPV as a risk factor as shown by the excerpt below:

“I have no idea, to be honest, but I think it is something to do with the HPV virus because boys and girls are receptive to that virus. If you have that virus and its dominant maybe you can get it”. (Interview 5)

Besides, another participant in the in-depth interviews stated the use of contraceptives as a risk factor for cervical cancer.
“According to me I think, the use of contraceptives can contribute to cervical cancer. Also if one doesn’t go for routine check-ups, then it can be risky because you will not be able to tell whether you have it or not”. (Interview 8)

In addition, the participants expressed fatalistic views about the risk of cervical cancer. The majority of the participants have stated that cervical cancer is natural, and that it comes as a result of God’s fate. Likewise, they described feelings of despair in the case that one does develop the disease.

“I don’t know the risk factors, but it’s something that is natural and comes as a destiny from God. (...) I firmly believe it’s destiny from God”. (Interview 12)

In addition, most participants stated that they did not believe in getting cervical cancer, as shown in the citation below.

“I met ladies who have disposed the invitation letter upon receiving it. They argue that they don’t believe in getting this disease and it’s not meant for them”. (Interview 11)

Similar sentiments were shared by another participant, as indicated in the quote below.

“I heard it is a deadly disease and as Muslims we don’t believe that we can get this disease”. (FGD 1 Participant 5)

4.1.3 Benefits of cervical cancer screening

Despite the fact that the majority of the participants were not familiar with cervical cancer and screening, and risk factors for cervical cancer, most participants perceived the benefits of cervical cancer screening as a protective measure. Furthermore, the participants’ stated that women could benefit from treatment, if the disease was detected at an earlier stage.

“The advantage of taking the test is that if the person is found to have the disease then she can be treated earlier. The test can serve also as a protective measure”. (Interview 2)

Similarly, the same opinion has been shared by the other participants about the importance of detecting the disease at an early stage.

“The advantage of the test is, you will be able to know whether you have cervical cancer or not. If the results show that you have cancer which is still in an early stage, then you have the
chance to live, but if it’s detected at a later stage then your chance of living is minimal. It’s always important to detect the disease earlier than a later time”. (Interview 11)

“If you are diagnosed with cervical cancer at an early stage, it can be treated before it spreads to the rest of the body and if not then one can die from it”. (FGD 4 Participant 1)

Additionally, most of the participants stated the benefits of cervical cancer screening as affirming their health. The participants mentioned that, after having received a negative test result, they felt assured of and were confident in their health.

“The individual will know whether she has the disease or not. In case she is diagnosed with cervical cancer, she will benefit from treatment and if she doesn’t have the disease it’s still beneficial for the person since she will get reassured. (GD1 Participant 4)

“The advantage of the cervical cancer screening is that if one is tested for the cervical cancer and found not to have the disease; she will get confidence that she is healthy”. (GD1 Participant 5)

“The advantages are that it gives you self-confidence when you are informed that you are healthy after the test. (...)This also makes you happy”. (FGD1 Participant 6)

One participant from the in-depth interviews stated the significance of the test for the reproductive health of women. The participant mentioned the relevance of the test for young females planning to start a family.

“It’s important for the health of women in general and particularly the reproductive organs, especially the young girls who are planning to get married and get children”. (Interview 14)

4.2 Experiences of cervical cancer screening

When the participants were asked about their experiences with cervical cancer screening, the majority of the women who had previously undergone screening described it as unpleasant, uncomfortable, painful and upsetting. The remaining participants, who had themselves not participated in the screening, had nonetheless heard about similar experiences from other women they knew.
“It’s unpleasant to take the test. (…). it’s also painful and if you ask other women they will tell you it’s not pleasant. I believe many women who could do the test are afraid of that pain”. (Interview 11)

Similarly, another participant described her experience with the Pap smear test as indicated in the excerpt below.

“I experienced slight pain during specimen collection (…) one does not like it during the procedure but for me I am not comfortable with this type of examinations”. (Interview 9)

A similar view was shared by another participant, as experienced during the Pap smear test sample collection as indicated in the quote below.

“The procedure causes pain and discomfort during the test e.g. if the doctor is inexperienced he or she can hurt you during specimen collection”. (FGD2 Participant 2)

Yet another participant mentioned that she endured a lot of pain, which prompted her to change her GP.

“One of the problems related with the tests is the instruments. During the specimen collection one can get hurt and start bleeding. Another problem can be the negligence of the doctor during specimen. “I experienced myself during the sample collection where my doctor was not careful enough during the examination and I felt a lot of pain which forced me to change my doctor”. (FGD2 Participant 5)

In addition, the participants mentioned their feelings related to the intimate nature of the test. The participants stated that the test was too intimate and they were not comfortable with it. Moreover, the women stated that they felt shy in undergoing the test, which required them to undress part of their bodies.

“Culturally, it might be difficult for women to undress in front of a male doctor because it's intimate and private”. (Interview 15)

“It’s an intimate procedure and this could make it difficult for women, you make sure that the gynecologist is someone you feel comfortable with in doing the procedure. There can be discomfort during the procedure. It's not something people are familiar with. It’s a very delicate matter”. (Interview 5)
Similar experiences were shared by other participants who took the screening test, as shown in the excerpts below.

“According to our Somali culture, we have learnt at a younger age that, you can only expose your private parts to your partner and no one else. It's unpleasant for us to lie on an examination bed and take the test. I took the test, and I felt uncomfortable with it and I felt also shy”. (Interview 8)

“At the beginning, when I received the invitation letter, I didn’t understand what the test was about, but when I went for the test I didn’t like the test because I felt shy”. (Interview 10)

“Maybe as non-married Somali women, for me, it was one of the first experiences with somebody in doing anything in that area. As a Somali woman, you are not always comfortable getting undressed in front of somebody unknown, and I thought more insecure about it. It was awkward but a bit uncomfortable”. (Interview 7)

One participant shared her sentiments about how she reacted upon receiving the invitation letter,

“I got shocked to hear that my cervix is going to be examined. I asked myself how did they come to know about my cervix and what are they going to test. (Interview 1)

4.3 Barriers to cervical cancer screening
The theme about barriers to cervical cancer screening was further categorised into five sub-themes. The sub-themes include lack of familiarity with cervical cancer and perceived irrelevance of screening, emotional barriers, practical barriers, cultural and religious concerns, and mistrust in the health system.

4.3.1 Lack of familiarity with cervical cancer and perceived irrelevance of screening
When the participants were asked about the barriers to cervical cancer screening, lack of familiarity with cervical cancer was mentioned. As previously discussed, the majority of the women reported that they were not familiar with the disease back home and nearly all of them stated that they heard about cervical cancer in Norway. Furthermore, the participants reported that they used to hear of people who died of cancer but not specifically cervical cancer. Nonetheless, the participants stated that they sought treatment when they were critically ill and they did not put much emphasis on their health issues.
“According to me, (...) back in our home country nobody used to talk about this disease, and there was no awareness about it. (...) but as for me I started hearing about cervical cancer in Norway. I used to hear this person died of “Kansar” (cancer) but this specific type of cancer I have not heard about it before. One had to seek treatment when one was critically ill and as Somalis we don’t put a lot of emphasis on our health issues”. (FGD4 Participant 2)

Similarly, the participants mentioned that they were not familiar with the disease in their home country. The participants also reported that they could not tell the signs but could contact the doctor thinking that it was an infection.

“In our home country, cervical cancer was not familiar. (...) women are not aware of themselves whether they have the disease. It has signs but we don’t know. what makes the women to immediately contact the doctor is that, she does not suspect to have the disease (...) she might think that she has an infection and continue living with this problem for so long. (FGD4 Participant 3)

Furthermore, the participants mentioned that they believed cervical cancer was something people just liked talking about but, due to their limited knowledge about cervical cancer and screening, they did not understand the relevance of having the test.

“We believe that this is something people like talking about it but in reality it is due to our lack of knowledge that we don’t understand the relevance of the test and the disease”.(Participant 9)

Additionally, most of the participants stated that they lacked information about the disease and they were not good at seeking information regarding the disease as shown in the quote below:

“The reason why women don’t go for the test is that they don’t have a lot of information about the disease. Also, we don’t seek for information to learn more about it. We tend to take everything lightly”. (Participant 10)

Besides lack of familiarity, the participants reported that they did not think cancer could affect the cervix, but rather, only other parts of the body like the stomach.
“Some of the things that hinder women include lack of knowledge about the disease. Because we don’t believe that cancer affects the cervix, when you ask the other women, they reply you how does cancer affect the cervix? They believe that cancer affects other parts of the body like the stomach”. (FGD3 Participant 2)

Nonetheless, one participant mentioned that a barrier to the cervical screening was the rarity of the screening test in Somalia and the subsequent lack of familiarity with it upon immigrating to Norway.

“What I can say as the main obstacle to the screening is the unfamiliarity of the screening test. We are new in Norway and we never used to have such tests in our home country”. (FGD2 Participant 6)

In addition, absence of symptoms of cervical cancer was stated as a barrier to cervical cancer screening. Most of the participants believed that they were healthy and did not require going for the screening test.

“Women don’t believe that they have the disease and this makes them not go for the screening services. Why I personally have not gone for the test is that I don’t believe I have the disease”. (Interview 2)

A similar opinion related to the asymptomatic nature of cervical cancer was shared by one participant as she expressed that she did not have cervical cancer and therefore she did not see the reason to go for the test.

“Another hindrance is if the person asks herself “I don’t have cancer why should I go for the test” when you challenge her to go for the test, she will answer you I don’t have cancer and may God protect me from getting it”. (FGD 3 Participant 9)

Likewise, one participant mentioned that this disease was not familiar and that none of her family members or friends has had the disease, thus prompting her not to go for the screening.

“I think because you have this idea that it’s a test you should take, (....) but it’s something that is far away in the illness itself. You don’t feel it’s so common. None of my family members or friends has had the disease. For that reason, it’s something that is over there and not close to me, (Interview 4)
4.3.2 Emotional barriers

Furthermore, when participants were asked about barriers to cervical cancer screening, fear of the outcome of the test was stated as an emotional barrier. Most of the participants described fear of being told that they have cervical cancer. These thoughts were aggravated by their fatalistic perceptions of a positive test result. The participants explained that, once the test was suggestive of cervical cancer; there was nothing that could be done.

“Most of the Somali women don’t go for the screening because they fear the outcome. (....). Most of the women fear to be told that they have cervical cancer after the screening”.
(Interview 1)

“Some of the women fear what the test might find and therefore decline to go for the test. Also many women believe that once you get cervical cancer, there is nothing which can be done”. (Interview 9)

“I also dont feel happy to go to the GP to do screening because I think, if the result turns positive what will happen”. (Interview 11)

Similar sentiments were expressed by another participant after having received the letter of invitation.

“When I got the invitation letter I haven’t gone for the test because I feared the outcome of the test”. (FGD2 Participant 7)

Additionally, embarrassment related to female genital mutilation was also cited as an emotional barrier to cervical cancer screening. One participant reported that the older generations were not interested in going for the test because they felt embarrassed exposing themselves during the screening test.

“For the most of the people, the procedure does not excite them. The older generation might feel embarrassed about taking this test because of the female genital mutilation. The fear is exposing themselves to the doctor, and I think a lot of women do”. (Interview 7)

4.3.3 Practical barriers

Practical issues were also mentioned by the participants as a barrier to the screening. Most women stated that they had a lot of activities to do at home, like taking care of children, going
to school, and attending job training workshops. Due to these competing demands, some of the participants stated that they had to prioritize between the appointments. In this case, the one found to be most relevant was prioritized, thus dissuading many women from attending the Pap smear test.

“Somali women have a lot of things to do. Most of them have a lot of children to take care of. They have a lot of appointments, for example, I have three children, on the coming Friday, I have an appointment 08:00am at the school for Christmas breakfast. I also work. The more you have children, the more workload you have. If you receive an invitation letter, mostly you will prioritise the appointments, which one to go and which one to leave. Mostly, one can drop having the test”. (Interview 8)

“According to me what hinders women from going for the test is simple. The mother always puts other issues before her own life until she becomes sick. I don’t think whether there are any other obstacles, but I think it’s because of these family activities”. (FGD 4 Participant 1)

“Some of the women have a lot of work to do at home. Others go to work, workshops and school. Therefore most of the women say that they don’t have time to go for the test”.

(GD2 Participant 3)

Similar reasons have been stated by other participants for not attending the test, as shown in the quotes below:

“I think also many women cannot turn up for their appointments. It's possible that when you get the invitation, you have a lot of children to take care of or maybe you may forget the appointment to take the test”. (Interview 9)

“For me what hindered me from accessing the test was that I didn’t t have enough time (...). I gave more priority to my children like going for the school appointments”. (Interview 10)

However, one of the participants stated that they gave priority to taking care of their children. This was done for fear of losing children to the child protection services.

“Women are busy going after their daily activities like going to schools; they also have the responsibility of looking after their children. They do this with the fear of losing their children to the child welfare services”. (Interview 12)
Additionally, language was frequently mentioned as a practical barrier. The majority of the participants and, particularly, the older generation, stated that they were not fluent in the Norwegian language. The participants reported that they were unable to understand the contents of the invitation letter and were thus unable to consider the relevance of the test.

“I know many Somali women especially the older generation; I think they would not take such a test because there is a language barrier. When they come across a written document, they do not have the skills to understand, the importance of it”. (Interview 4)

In a similar situation, one participant commented that, despite receiving the invitation letter several times, she had thrown it away. However, she suggested that, if it was written in a language that she understood, then she would have opted for the test.

“I have received the invitation letters many times but why I threw the letter away is because it was written in a language that I don’t understand, if it was written in a language that I understood, I would have gone for it”. (GD2 Participant 3)

Furthermore, most of the participants reported that they threw away the invitation letter because they did not understand its relevance.

“I received the invitation letter but I didn’t understood the importance of the letter therefore I threw it due to lack of knowledge”. (FGD3 Participant 3)

4.3.4 Cultural and religious concerns

Concerns about matters important within Somali culture and faith were described by the participants as rendering them reluctant to participate in screening. The participants from both groups, i.e. in-depth interviews and focus group discussions, and particularly the younger and unmarried participants, commented about how taking the Pap smear test was their first experience with exposing and providing access to this part of their body. Moreover, most of the participants stated that the Pap smear test was invasive and could damage their virginity, as indicated in the citations below.

“I think the whole experience for a lot of people at a young age who are not married; this is one of the first experiences when it comes to doing anything with their female anatomy (...). I think some people are afraid that it might take away their virginity”. (Interview 7)
A similar comment about virginity was expressed by another participant.

“Women are not comfortable with gynaecological examinations, especially for the younger and unmarried women. They feel that the procedure is invasive and it will damage their virginity”. (Interview 14)

Likewise, one participant narrated what she had heard from her friend about the Pap smear test.

“I met a lady who is a friend of mine. She told me that she received the letter but I cannot go for it. She told me she is young, virgin and not married. She told me this will destroy her future. (GD 2 Participant 1)

Furthermore, most of the participants mentioned that the test compromised their values of modesty and their understanding that women are not supposed to show their body to strangers. There was also the perception that this type of test was only recommended for older, married women and that young, unmarried women would be viewed with suspicion for taking this test.

“First, it has cultural perspective where women are not supposed to show their body to strangers. (...)If you go for this type of testing then you are signaling to people that it's something you do when you are fully a woman and you could do that. But why would a young girl go to a doctor to test private areas like what could she have done and so on.... people will start speculating”. (Interview 4)

In addition, gender played a role in the acceptance of cervical cancer screening. The male doctor or gynaecologist was mentioned as the barrier to cervical cancer screening by the participants. Most of the participants stated that they were not comfortable with the male doctor or gynaecologist.

Some of the women are not comfortable with a male doctor or male gynaecologist, and they prefer a female doctor to carry out the screening”. (Interview 14)

Similarly, one participant stated that she accepted to take the test when she was received by a female doctor,
“I accepted to be tested when I saw it was a female doctor who came to receive me. I would have dropped the test if I saw it was a male doctor”. (FGD2 Participant 4)

Likewise, one participant stated that she had a male doctor when she received the invitation letter; however she underwent the screening at the health clinic where she was attended to by a female doctor, as shown in the quote below:

“When I received the letter I had a male doctor but I felt shy. I did the test later at the health clinic with a female doctor. Women always prefer a female doctor to collect the specimen”. (GD2 Participant 1)

Furthermore, when the participants were asked about barriers to cervical cancer screening, the majority of the participants cited fatalistic beliefs. Most of the participants mentioned that they don’t want to be examined because they believed that it is through God’s destiny that one can get cancer and that no one else can do anything about it.

“Just like me most of the Somali women don’t like to be examined, and we believe that it's only through the destiny of God that one can get this type of disease”. (Interview 9)

“Women also believe that one can get cancer if it's destined by God and no one else can do something about it”. (Interview 10)

Similar fatalistic attitudes were expressed by other participants, as shown in the excerpts below:

“People follow the tradition and beliefs about this disease, that it’s a destiny from God and they don’t see the relevance of going for the test”. (Interview 12)

“Invitation letters are usually sent but some women are not interested in going for the test. They say it’s through God’s fate that one gets the disease and he is the one who cures it”. (FGD 3 Participant 5)

4.3.5 Mistrust in the health system

When the participants were asked about the barriers to cervical cancer screening, the issue of mistrust came up, especially in the focus group discussions. One participant mentioned that she could not trust the person examining her, which was particularly concerning given the importance of the organ being examined.
“There are many things that can cause doubt, for example, you can’t tell whether the person examining you is helping you or deceiving you. Since an important organ is being tested, it can happen that you might not trust the person examining you”. (FGD1 Participant 2)

Similarly, participants also described a poor relationship with their GPs as a barrier to screening. For example, few participants in the focus group discussion mentioned that the doctors were concerned about the number of children they had and explained that this made difficult for them to go for the screening.

“(…) each one of them asks you, do you come from Somalia, how many children do you have? Are you looking for another child? This becomes a challenge to go and do the test. This is what I believe are the obstacles to the cervical cancer screening. This makes us use private GPs when we have our own GPs; this is due to lack of good reception and welcome from our own GPs. (FGD 1 Participant 3)

A similar opinion was shared by another participant in the focus group discussion, as shown in the quote below:

“I think the reason why women don’t go for the screening is what they experience when they go for the routine visits like whether they are interested in having more children. Therefore we see that we are not going to get help even if we go for the test”. (FGD 1 Participant 6)

Likewise, the participants explained that they did not feel welcome during the routine visits and that they feared the gynecologists, as shown in the quotation below.

“One of the biggest obstacles is mistrust on the side of the doctors. When you go for a routine visit, and you are not welcomed, you notice this from the facial expression and as a community, we have a lot fear from the doctors especially the gynecologist”.

(FGD 1 Participant 3)

Equally, the participants mentioned that they were skeptical about the Norwegian doctors because they did not understand the language and lacked confidence in them as well.
“We are also skeptical about the Norwegian doctors. Therefore we prefer a Muslim gynecologists whom we trust and understand their language very well. Women don’t understand the language, and they don’t have confidence in Norwegian doctors.

(FGD 1 Participant 2)

Similarly, the lack of native Somali doctors was stated as one source of mistrust. Most of the participants mentioned that Somali doctors understand their language and would be able to explain the procedure and the results.

“The Lack of native Somali doctors has caused mistrust because of language problems. It’s easier for a Somali doctor to explain to you the procedure and the results”.

(FGD 2 Participant 8)

4.4 Suggestions for reducing the barriers to cervical cancer screening

During the interviews and focus group discussions, the participants were asked about their suggestions for reducing barriers to cervical cancer screening. The majority of the responses included measures like creating awareness about cervical cancer, language translated materials, and an assurance that one could choose a female practitioner.

4.4.1 Creating awareness

The majority of the participants stated that there was a need for awareness about cervical cancer and screening. The participants mentioned that increased awareness about the disease and relevance of the test would help them to understand the test as important and dispel the concerns associated with it.

“We need to create awareness so that the women can understand this test is not something that will create a problem for them, but beneficial for the health. We also need to create awareness about the disease and inform the women about the relevance of the test”.

(Interview 14)

Similarly one participant suggested the need to sensitize the women about the existence of cervical cancer and the relevance of the test, as shown in the citation below.
“We need to explain to women that cervical cancer exists and that they have to go for the test. (...) we need to carry out awareness and tell the women about the relevance of doing the test. (Interview 13)

In addition, the participants suggested that awareness can be raised by organizing seminars and workshops for the women in all the neighbourhoods of Oslo in order to sensitise the women about the disease. Equally, the participants suggested that women could be educated about how they can prevent themselves from developing the disease.

“We need information about the disease. Seminars and workshops should be conducted in all the neighbourhoods so that the women can be well informed. Women should be taught how they can prevent themselves from the diseases”. (Interview 12)

“We also need to carry out awareness, we can do this by holding meetings for women and sensitising them on how they can prevent themselves from this disease, and what the test entails”. (Interview 9)

Similarly, another participant stated that organizing seminars for women and teaching them about the advantages and disadvantages of having the test can motivate the women to go for the test.

“One of the things that can make easier for women to take the test is to create awareness by organizing seminars for women, teach them about the advantages and disadvantages of having the test. I think by doing this, the women can get encouraged to go for the test”.

(FGD 1 Participant 7)

Another participant suggested that the ministry of health should reach out to the public and teach the public about the disease, the signs and symptoms and where to find information, also using locals who speak the Somali language to teach about the disease:

“According to me, the ministry of health should reach out to the public. They should inform the public about the disease, signs and symptoms, and where to find contact. They should send people who speak native language to every community. (...)There are lots of Somalis who can give the information to the Somali community. They should contact this people so that they can inform the others about the disease”. (FGD 4 Participant 2)
In addition, the participants expressed that general practitioners should encourage their patients to be screened, given that many women have regular contact with their GPs.

“The GPs also need to encourage women to go for the screening since many women have contact with their GPs”. (GD1 Participant 6)

A similar opinion was suggested by another participant, as shown in the quote below:

“I think the doctors should encourage the women when they go for the appointments. Because this is the first contact women have with the health providers. The GPs should take part in encouraging women because we have always contact with them”. (FGD 4 Participant 1)

Likewise, the participants mentioned that their GPs should encourage the women as well as explain to them the relevance of the test, since this creates a better understanding of the disease and the screening test.

“The GPs should encourage the women and explain to them the importance of the test. This will create more understanding of the disease”. (Interview 11)

4.4.2 Translated materials

Additionally, the participants suggested the use of translated materials that would easily be understood by the women. Most of the participants have proposed that the invitation letters should be written in the Somali language, which would be understood by all the women.

“What we need to do is to inform them in a way that they can understand for example like the invitation letter. I don’t think it’s enough unless we have it in Somali”. (Interview 4)

“The people who sent me the letter, if they send it to my mother in Somali that will be easier for her. Language is a barrier especially in Norway. Like my mother, she is not good in Norwegian language and if she gets the letter in Somali, that will be better”. (Interview 5)

Similarly, one participant suggested that translated materials written in the Somali language should be made available in designated areas, like health clinics, so that they are accessible to the women during the visits.
“I think just having brochures and information packs in Somali language might help especially in designated areas like the health clinics especially when they go for the antenatal check-ups”. (Interview 7)

4.4.3 Gender preference

Additionally, the gender theme was discussed during the interviews and FGDs. The participants from both groups mentioned that they preferred a female doctor or gynaecologist to carry out the Pap smear test.

“Another way to increase attendance of the cervical cancer screening is we need a female doctor or gynaecologist”. (FGD 2 Participant 3)

“We also need female gynaecologist who can screen the women. most of the women have mentioned the male doctor as the problem, we need to give a trial to the female to see whether many women will come for the screening”. (GD1 Participant 5)

Similar comments were shared by another participant as indicated below

“We also require the doctors we are visiting to be female doctors or gynecologists who are willing to welcome and encourage women to have the test”. (FGD1 Participant 4)
CHAPTER FIVE

5 Discussion
This study explored Somali women’s perceptions of and perspectives on cervical cancer screening and, in particular, their perceived and experienced barriers to cervical cancer screening and suggestions for reducing these, thus contributing further to our understanding of the barriers and the facilitators to cervical cancer screening among Somali immigrant women in Oslo. The study revealed that the majority of the participants had limited familiarity with cervical cancer. The participants mentioned that they had not previously heard about cervical cancer in their home country and they became aware of it only upon receiving the invitation letters. This finding is consistent with a previous study that found that there was lack of understanding of cancer and cancer screening services among Somali women [50]. Furthermore, the participants’ understandings of cervical cancer seemed to be shaped by their general perception of cancer as dangerous, frightening and deadly. The study findings revealed that the majority participants conceived of cervical cancer as risky and dangerous, and as as a medical condition for which death was a fairly certain result. Similar findings were reported in a recent study in which women perceived cervical cancer as a death sentence [51]. In addition, the study findings indicated that the participants were not familiar with the purpose of cervical cancer screening. Most participants perceived the pap smear test as a diagnostic test and not a screening test. This finding is consistent with another study that has reported on the barriers to cervical screening services among Somali women in Minnesota [36].

Despite their limited familiarity with cervical cancer and screening, the participants’ understandings of the risk factors for cervical cancer were quite nuanced and seemed to be informed by diverse influences, like the medical understanding of cancer, religious orientations and notions of fate, the practice of FGM, matters of hygiene and, not the least, the moralities that surround sexuality and intimate areas of the body. In this study, most of the participants stated risk factors for cervical cancer as an infection that, if not treated, could develop into cervical cancer. This finding is in accordance with another study among Somali women about perceptions of and barriers to cervical cancer screening [27]. Nonetheless, two participants in the in-depth interviews mentioned HPV and the use of contraceptives risk factors for cervical cancer. It is possible that these two participants were familiar with the risk
factors due to their higher literacy levels. Moreover, the findings highlighted the impact of religious beliefs on perceptions of the risks of cervical cancer, with most participants believing that such a disease was an indication of God’s will, which also then coincided with fatalistic attitudes about not only the development of cervical cancer, but also the outcome. The participants stated that they did not believe in getting cervical cancer and therefore did not see the need to go for the screening. These findings are consistent with other studies conducted among Somali women [27, 52, 53]. These findings may be interpreted as indicating the influence of religious beliefs on health decisions and health seeking behaviour, particularly in this case in which the majority of the women did not believe in getting cervical cancer and therefore did not perceive screening as necessary.

Despite the fact that the majority of the participants were not familiar with cervical cancer and screening, and that some of them associated cervical cancer with certain death, the majority of the participants perceived the benefits of cervical cancer screening as a preventive measure that one could benefit from by, in the case of concerning results, seeking treatment earlier rather than later. This finding indicates that there are perhaps competing rationales that these women negotiate when trying to decide whether cervical cancer screening is relevant or irrelevant. Therefore, this study suggests an understanding of these nuances of simultaneously present and at times contradictory rationales that the women negotiate, which might in turn generate insight into culturally and religiously relevant ways that public health efforts might better engage these women, so as to avoid producing barriers and to actively facilitate participation instead. Furthermore, the findings highlighted the benefits of cervical cancer screening as health affirming and confidence-boosting, particularly after receiving a negative result. These findings are consistent with previous studies among immigrant women [54, 55]. In addition, the findings also demonstrated the relevance of screening for reproductive health. One participant stated the importance of the Pap smear test for young Somali women, particularly those planning to start a family. This view can be explained by the importance that the Somali community places on their sexual and reproductive health with regard to childbearing. As reported by a previous study, many Somali women think it important to stay healthy in order to fulfil their role of childbearing, which might also then be a reason for participating in screening [52]. Our study suggests that culturally and religiously informed concerns that are sometimes regarded from a public health perspective as barriers can instead,
if taken seriously as legitimate and rational, actually provide important channels for facilitating participation.

Additionally, the findings revealed that the participants experienced and perceived cervical cancer screening as unpleasant, uncomfortable, painful and upsetting. These findings relate both to the experiences of those participants who had been screened and the impressions of the women who had not themselves gone for the screening test but who had nevertheless heard about it from other women. One participant reported having experienced pain and bleeding during the procedure. These findings are consistent with findings from a recent study on the experience of cervical cancer screening, which some participants had described as uncomfortable or even painful, even reporting side effects such as constant pain and bleeding [56]. Similarly, a recent study among Somali women has attributed the pain associated with this to circumcision, given that the majority of immigrant Somali women have undergone female genital mutilation type three, which is the most severe form of cutting and which involves stitching the labias together, thus leaving a small opening that can cause pain during the procedure, particularly for unmarried women [10].

Furthermore, the study findings showed the participants’ concern about what they perceive as the intimate nature of the screening test. Most of the participants felt shy and were reluctant to expose their body during the screening test. This act was considered immodest and inconsistent with the cultural norms, beliefs and values of the community. These findings are consistent with other studies that have explored the role of religion and modesty with regard to cervical cancer screening [36, 51].

In addition to the perception of cervical cancer and screening, the study findings identified lack of familiarity with cervical cancer as a barrier among Somali women. As discussed earlier, the majority of the participants stated that they were not familiar with cervical cancer back home and that they heard about cervical cancer in Norway. These findings are consistent with other findings from relevant literature on barriers to cervical cancer screening among Somali women [25, 27, 57]. Moreover, the findings revealed the lack of familiarity with the cervical cancer screening as a barrier to cervical screening. One participant in the focus group discussions mentioned the rarity of the screening test in Somalia and the subsequent lack of familiarity with it in Norway. These findings fit well with those from a study on knowledge and beliefs about health promotion and preventive health care, in which the rationale for the recommended preventive health services such pap smear and
mammography was low among Somali women [50]. These findings might be explained with respect to the paucity of cervical cancer screening programmes in Somalia and the lack of shared concept of preventive health among Somali women.

The study findings also identified perceived irrelevance of screening as a barrier to cervical screening. Most participants stated that they felt healthy and therefore did not see the relevance of taking the Pap smear test. Similar findings were reported among Somali women in Minnesota [36]. Furthermore, a study conducted among ethnic minority women in the UK found that immigrant women were more likely to believe that they do not need a smear test if they do not have symptoms [58]. Moreover, (Pavlish, Noor, & Brandt, 2010) studied Somali women’s health experience and reported that the act of attending a clinic for screening and illness prevention was unfamiliar to Somali patients who were accustomed to only seeking healthcare when ill[59].

The study findings also demonstrated fear of the outcome of the test as an emotional barrier to screening. Most participants stated that they feared to get a positive result since they associated cancer with death. These findings are consistent with other relevant studies on immigrant women [25, 27]. Similarly, the study findings also identified embarrassment related to the practice of FGM as an emotional barrier. One participant mentioned that the older generation of women were not interested in going for the Pap smear test because of embarrassment related to FGM. Similar findings were reported by a previous study that showed that Somali women were not likely to attend cervical cancer screening due to the additional embarrassment associated with FGM and the potential anxiety of being faced by a male sample taker [27].

Our study findings also highlighted practical issues, like a lack of time and language, as significant concerns of the participants with regard to the barriers to cervical cancer screening. Both participants from interviews and focus group discussions stated that they had various demanding tasks to accomplish, like taking care of children and going for language courses, and that they thus lacked time to go for the pap smear test. Similar findings have been reported in other relevant studies in which women stated lack of time and competing demands on their time, particularly women with multiple children who had difficulty in securing child care as barriers[25, 27, 36].

Nonetheless, one unique finding in this study is the fear of the child protection services as a barrier to screening. Therefore we need to consider why this is the case and what significance
this has for the topic of cervical cancer screening. The Norwegian child protection services is the part of the welfare state system that is intended to support and safeguard the best interest of the child, just as the health care system offers screening services intended to serve public health interests. However, the Norwegian child protection services has a particularly poor reputation among many immigrants and is often associated with a fear of losing custody of one’s children on unfair grounds. In the present study, the participants stated that they prioritised looking after their children for fear of losing them to the child protection services. A qualitative study on parents’ perception of contact with the Norwegian child protection services indicated fear and insecurity. In particular, parents worried that their involvement with the child protection services might in some way risk that they would be overruled, not listened to, not believed and not understood. Several parents reported fear of losing custody of their children on unfair grounds [60]. This finding suggests that a negative relationship with one aspect of the welfare state, like the child welfare protection services, can have important consequences for their relation to another.

In addition, international studies conducted on immigrant groups indicate poor language proficiency as one of the most significant barriers to screening [27, 61, 62]. Language, communication and effective use of interpreters is a key area of focus in the approach to matters of immigrant health, as this is an issue of accommodating a multicultural population within public health initiatives. Nonetheless, this study identified language as a practical barrier to cervical cancer screening. The majority of the participants in the in-depth interviews and FGDs, particularly the older generation, stated that they are not fluent in the Norwegian language. Norwegian is a second language for all the Somalis who have immigrated to Norway and the majority of first generation Somalis might not be fluent in the Norwegian language. These findings are consistent with studies conducted among Somali women, in which participants identified language as a barrier to screening uptake [10, 27, 36]. Moreover, adequate communication possibilities promote accessibility to health care services, such as screening. Hence, it is important that the recipients can read and understand the contents of the screening invitation letter and communicate with health care professionals [63]. Furthermore, the study findings demonstrated that the participants lacked the language skills necessary to understand the contents of the letter, thus impacting their perception of the relevance of the Pap smear test. This finding suggests a failure on the part of the health care system to provide sufficiently translated materials to the women in order to facilitate a better
understanding of the relevance of the screening. Therefore, this study suggests both translating the invitation letter and the provision of translated information materials in designated areas, like health clinics where women seek services, in order to facilitate their understanding of the importance of taking the screening test.

Findings from the study also identified cultural and religious concerns as barriers to cervical cancer screening. During the interviews, the participants voiced concern about the Pap smear test as potentially compromising cultural and religious values about sexuality, especially for the young and unmarried. Most participants from both in-depth interviews and FGDs regarded the test as invasive and worried that it could damage their virginity. This finding is consistent with a previous study in which participants reported that the pap smear test for unmarried women of any age was not possible, and that the women felt uncomfortable undergoing the screening [36]. Moreover, the study findings revealed the problems associated with taking the pap smear test as a young, unmarried woman, as illustrated by the participant who explained that there was a shared view in the community that the test was suitable for older and married women, but that younger and unmarried women were viewed with suspicion if they opted for the screening. This finding pinpoints a potentially common view among Somali women, for whom sex outside marriage is stigmatised, that gynaecological examinations like the Pap smear test are only for married women. These findings are concordant with those of recent studies in which Somali women perceived the need for testing as a sign of poor health or sexual activity outside marriage, and hence as something that was stigmatised due to religious and cultural norms [10, 36]. In addition, a concern that they would be met by a male practitioner was identified as a barrier to screening by the study participants. Most of the participants in the in-depth interviews and FGDs stated that they were not comfortable with male doctors or gynaecologists and that they preferred a female physician. Similar findings have also been reported by studies among Somali women [10, 27].

Trust has conventionally been regarded as a cornerstone of an effective doctor-patient relationship [64]. However, the study findings have demonstrated mistrust in the health system as a barrier to cervical cancer screening. One participant from the FGDs stated that she could not trust the doctor examining her, and that this was particularly concerning given the vital organ being examined. This finding is consistent with that of a previous study in which mistrust of the health care system was based on reports by friends or relatives regrading problems they have encountered [52]. One possible explanation for this finding may be
interpreted as the perceptions Somali women share among themselves, based on their past negative experiences with health care services and the fear of misdiagnosis, which could further impact their health seeking behavior. Moreover, the study also revealed a poor doctor-patient relationship as a barrier to the cervical cancer screening. One participant in the FGDs stated that they felt they were not welcome during the visits, but that the doctors were instead concerned about the number of children they had. The GPs serve as the first contact point for their patients and play a significant role in shaping women’s perceptions of health services [25]. Therefore, it is important to ensure that the health providers at the primary health care level, like the GPs, are culturally competent and invested in improving the experience of health care in general and cervical cancer screening in particular among minority women [25].

In addition, the study revealed the lack of native health providers as a barrier to cervical cancer screening. The participants mentioned that they did not understand the language of the doctors and felt that the doctors did not understand matters important within their religion and culture, and this appears to have caused some scepticism between the provider and the patient. This finding is concordant with a result from a previous study in which barriers to screening, such as mistrust in the health care system, were linked to language problems and a preference for providers with the same religious background [52]. Similarly, a recent study on the barriers and facilitators to cervical cancer screening among Pakistani and Somali women attributed lack of trust in the health care system to language, cultural and gender related barriers [10].

Increasing awareness as a strategy for reducing barriers to screening uptake was highlighted by the study findings. Most of the participants stated that there was a need for increased awareness about cervical cancer and screening. The participants from both the interviews and FGDs suggested that this can be addressed by organising seminars and workshops for the women in various neighbourhood of Oslo. This topic has also been discussed by a researcher who conducted a recent study among Pakistani and Somali women in Oslo [10]

Furthermore, the findings revealed that encouragement from the GPs, who the women described as having regular contact with, as a strategy for reducing barriers to screening uptake. The majority the participants mentioned that the GPs should encourage their female
patients to be screened. This finding is consistent with that of a recent study in which many women had been screened as a result of advice from their GPs [27].

In addition, the study demonstrated, as already discussed, the importance of using translated materials as an approach to reducing barriers to screening uptake. Most of the participants from the interviews suggested that the letter of invitation be printed in the Somali language and that translated information materials be made available at designated areas where women receive services like the health clinic. These findings have been documented by a recent study among Pakistani and Somali women in Oslo [10].

Moreover, gender was a central theme in the participants’ suggestions for reducing the barriers to uptake of cervical cancer screening. Most participants from the FGDs stated that they were comfortable with and preferred a female doctor or gynaecologist to carry out the pap smear test. These findings are consistent with other studies among immigrant women in which there was a general preference among participants to have a female physician and specialist [10, 27, 51].

5.1 strengths and limitations of the study
The use of a relatively large sample is an asset for the study, since it contributed to range of diversity and captured differing views about and experiences with the topic of cervical cancer screening. Similarly, the triangulation of data collection methods enabled a comprehensive exploration, from different angles, of the study phenomenon and thereby enhanced the trustworthiness of our data material. Moreover, the fact that the researcher and the research assistant were native Somali speakers was an extra benefit for the study, since they were able to comprehend the responses and meanings the participants shared during the interviews. The findings of the study were consistent with other studies conducted in other contexts, which also validates to some extent the trustworthiness of the study. The use of purposive sampling as a sampling method ensured that we recruited cases that were relevant and provided the study with a rich data.

Despite the strengths of the study, the inclusion of only first generation women as study participants might limit the transferability of the study to other, potentially younger women of Somali background, who might have a different view of the topic under study. Similarly, even though we made efforts to mediate and assess the presence of male researcher during the interviews, we cannot be entirely sure of the effect this might have had on the responses of the participants.
5.2 conclusion and recommendation

This study explored Somali women's perceptions of and perspectives on cervical cancer screening and, in particular, their perceived and experienced barriers to cervical cancer screening and suggestions for reducing these, thus contributing to our understanding of not only the barriers, but also a number of potential facilitators for cervical cancer screening among Somali immigrant women in Oslo. The study findings revealed limited familiarity with cervical cancer and screening. Moreover, participant perceptions about the risk factors and therefore also the relevance of screening for cervical cancer were influenced by “fatalism” and the belief that everything is predestined by God. However, the majority of the participants in this study understood the benefits of cervical cancer screening as preventive and, in the case of cervical cancer, as enabling earlier treatment. Furthermore, pain associated with the smear collection and the intimate nature of the test were important themes in the participants’ discussions of their experiences and concerns.

In addition, the study revealed a lack of familiarity with cervical cancer and perceived irrelevance of screening as barriers. Emotional barriers like fear of the outcome and embarrassment were also identified by the study as barriers to screening. Moreover, practical issues related to child care, lack of time and language difficulties were highlighted by the study. Similarly, cultural and religious concerns regarding virginity and gender preference were identified as barriers to screening. The study findings also indicated mistrust in the health system as a barrier to screening. Likewise, the study demonstrated that awareness creation, the use translated materials, and the assurance of female practitioners could be strategies for reducing barriers and facilitating cervical cancer screening uptake.

Additionally, the findings contribute to the existing literature and may be used to develop a culturally adapted intervention that improves the uptake of cervical cancer screening among Somali and other immigrant women in Norway [10]. The study also generates insight into and contributes to the evolving body of scholarship about this topic. Furthermore, this study makes clear the importance of carrying out awareness campaigns, particularly in social settings like mosques, job training centres and in the local neighbourhoods where women meet. This can be an important strategy in improving the women’s knowledge about cervical cancer and demystifying the screening process, potentially countering the negative perceptions of it, as were described in this study. A previous study that accounted for the views of Somali women and men demonstrated that faith-based messages can potentially reinforce the views
of those already inclined to screening and encourage those with reservations [65]. Therefore, this study recommends the use of faith-based messages by engaging local imams who might dispel or at least mediate fatalistic understandings and address concerns about matters of modesty and sexuality as part of intervention. Another finding from an evidence-based study showed that prompting by GPs motivated women to attend cervical cancer screening [66]. In view of this finding, this study recommends the involvement of the health providers, particularly the GPs who serve as regular contacts for the women, in encouraging the women to take the Pap smear test, thus helping to facilitate cervical cancer screening. As revealed by the study findings, a closer examination on the impact of the child protection services on the uptake of cervical cancer screening and other important services among Somali and other immigrant women is recommended by the study. Finally, the study calls for more research to explore the perspectives of the health providers in the context of cervical cancer screening among Somali and other immigrant women.
References


Appendices
Appendix 1: A copy of the manuscript submitted for publication
Barriers to cervical cancer screening: A qualitative study among Somali women in Oslo, Norway

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Abstract

Background: Research suggests that immigrant women are less likely to participate in cervical cancer screening. Increased understanding of the barriers confronted and possibilities for facilitating screening participation is needed.

Methods: Interviews and focus group discussions were conducted among 57 Somali women in Oslo to explore experiences with and perceptions of cervical cancer screening.

Results: The study revealed a lack of familiarity with cervical cancer and perceived irrelevance of screening, emotional barriers such as fear and embarrassment, practical challenges related to child care, and language, cultural and religious concerns related to modesty and sexuality, and mistrust. Participant suggestions for reducing these barriers and facilitating screening participation included awareness creation, translated materials, and female practitioners.

Conclusion: Accounting for these barriers, implementing these recommendations, and better attuning the screening program to the present-day multicultural population of Norway can potentially increase participation in cervical cancer screening among Somali and potentially other immigrant women.

Keywords: cervical cancer screening, Somali women, immigrant women, qualitative research
Introduction

Globally, cervical cancer ranks as the fourth most common form of cancer affecting women, with an estimated 528,000 new cases in 2012[1]. In developing countries, cervical cancer ranks as the second most common type of cancer affecting women[2]. In 2012, 266,000 deaths occurred worldwide as a result of cervical cancer, and more than 85% of these deaths occurred in low- and middle-income countries[19]. In Sub-Saharan Africa, cervical cancer is the leading cause of cancer-related mortality, with more than 75,000 new cases and over 50,000 deaths reported each year[2]. Human papilloma virus is the leading cause of cervical cancer, with over 90% cases caused by HPV 17 and 18[19].

Previous studies indicate that cervical cancer screening has reduced cervical cancer morbidity and mortality in Europe[4]. Studies conducted in the United States suggest that cervical cancer-related morbidity and mortality are higher in immigrant than in host populations and that immigrant women may be less likely than non-immigrant women to participate in cervical cancer screening[5]. Somali women have been identified as one particular group less likely to participate in cervical cancer screening [5, 6, 8]. In Norway, the national cancer registry sends a screening invitation letter, written in Norwegian, to all women between the ages of 25 and 69. A retrospective register-based study of 1.3 million women in Norway showed that 50% of immigrant women were non-adherent compared to 31% of native Norwegians[9]. Nonetheless, statistics about the burden of cervical cancer among immigrant women in Norway are lacking. A recent study about barriers and facilitators to cervical cancer screening among Pakistani and Somali women in Norway revealed three levels of barriers: the individual level consisting of a lack of understanding of screening benefits, the sociocultural level that included stigma related to cervical cancer and the belief that unmarried women are sexually inactive, and the system level that entailed a lack of trust in the health care system[10]. The present study, in addition to exploring barriers to cervical cancer screening among Somali women in Oslo, lent particular attention to their suggestions for reducing them, thus contributing further to our understanding of not only barriers but also potential facilitators to cervical cancer screening among Somali immigrant women in Norway.
Methods

A qualitative study design was utilized, in which in-depth interviews and focus group discussions were conducted among Somali women to explore their experiences and perceptions of cervical cancer screening, with a particular focus on barriers to screening and their suggestions for reducing them. This study was reported to and approved by the Norwegian Centre for Research Data (NSD).

Participant sample and recruitment

The study sample consisted of 57 first generation Somali women aged 25 and above, and residing in Oslo. Purposive sampling was used to identify and select information-rich cases related to the research objective[38]. This was achieved by striving for maximum variation with respect to age, marital status, education and duration of residency in Norway in the interest of achieving a heterogeneous sample. Recruitment was carried out by the researcher and a research assistant in different geographic areas of Oslo and various social settings, which included community gatherings, business premises, and mosques.

Data collection

Data collection consisted of 15 in-depth interviews, four focus group discussions (FGDs) with approximately eight participants each, and two group discussions consisting of three and five participants respectively. The interviews and FGDs were conducted between September and December 2016. A semi-structured, thematic guide of open-ended questions was utilized during the interviews, which enabled the participants to share their experiences and perspectives freely and the researcher to adapt the interviews accordingly. The interviews were conducted in the women’s homes and at community centers, in quiet and private spaces, free of interruptions and in which confidentiality was achieved. The FGDs and group discussions were conducted at community centers located in the areas in which the women resided. Each of the in-depth interviews lasted about an hour, and the FGDs and group discussions lasted about one to one and a half hours. Five of the in-depth interviews were conducted in English. The rest of the data collection was conducted in Somali. With the permission of the research participants, all of the data collection was audio recorded and transcribed by the first author. Data collection was carried out in pursuit of a meaningful degree of saturation, with saturation referring to the point at which the significance of new
findings and additional data collection diminished and a meaningful coherence among the data emerged [43].

Data analysis

Initial forms of data analysis began during the data collection process, which enabled emerging themes to be identified and further explored as the data collection evolved accordingly. Upon the completion of the data collection, an iterative, systematic, and comprehensive process of thematic content analysis was performed. Initially, all the transcripts were read and re-read to establish familiarity with the data and the context in which it was collected[41]. Initial codes were developed by the first author, applied to the entire data set, adapted, and closely examined to ensure that they reflected the contents of the data material. As descriptive codes evolved into more analytic ones, a set of themes was established and analyzed by all three authors.

Results

Fifty seven first generation Somali women were recruited both for the in-depth-interviews and focus group discussions. The age of the participants ranged from 25 to 56 years. More than half of the women were married (N=30), while the remaining were unmarried (N=27). Similarly, the majority of the women had some level of formal education, while few had higher education (N=5). The duration of stay in Norway ranged from 2 to 25 years.
Table 1 characteristic of the study population

<table>
<thead>
<tr>
<th>Variables</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age, years</strong></td>
<td></td>
</tr>
<tr>
<td>25 – 35</td>
<td>22 (39%)</td>
</tr>
<tr>
<td>36 – 45</td>
<td>19 (33%)</td>
</tr>
<tr>
<td>46+</td>
<td>16 (28%)</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
</tr>
<tr>
<td>Unmarried</td>
<td>27 (47%)</td>
</tr>
<tr>
<td>Married</td>
<td>30 (53%)</td>
</tr>
<tr>
<td><strong>No of children</strong></td>
<td></td>
</tr>
<tr>
<td>0 – 3</td>
<td>25 (44%)</td>
</tr>
<tr>
<td>&gt;3</td>
<td>32 (56%)</td>
</tr>
<tr>
<td><strong>Level of education</strong></td>
<td></td>
</tr>
<tr>
<td>≤ Secondary school</td>
<td>52 (91%)</td>
</tr>
<tr>
<td>&gt; Secondary school</td>
<td>5 (9%)</td>
</tr>
<tr>
<td><strong>Duration of stay (years)</strong></td>
<td></td>
</tr>
<tr>
<td>2 – 13</td>
<td>22 (39%)</td>
</tr>
<tr>
<td>13+</td>
<td>35 (61%)</td>
</tr>
</tbody>
</table>

* Unmarried category includes single /divorced/separate and widowed

**Barriers to cervical cancer screening**

The study identified five types of barriers to cervical cancer screening: (1) lack of familiarity with cervical cancer and perceived irrelevance of cervical cancer screening, (2) emotional barriers, (3) practical barriers, (4) cultural and religious concerns, and (5) mistrust in the health system. Each of the barriers is described below. Quotations are provided in the tables.

**Lack of familiarity with cervical cancer and perceived irrelevance of screening**

The study participants were largely unfamiliar with cervical cancer and screening. The majority of the women reported that they had not been aware of the disease in Somalia, where screening is rare, and that it had come to their attention only after immigrating to Norway (Table 2, Quotes 1 and 2). In addition, the absence of cervical cancer symptoms was stated as a barrier to cervical cancer screening. Most of the participants believed that, because they lacked symptoms, they were healthy and did not require the screening test (Table 2, Quote 3).
Table 2: Lack of familiarity with cervical cancer and perceived irrelevance of screening

Quotes

1. “Back in our home country nobody used to talk about this disease, and there was no awareness about it. [...] but as for me, I started hearing about cervical cancer in Norway. I used to hear this person died of “Kansar” (cancer) but this specific type of cancer I have not heard about it before.” (FGD4 Participant 2)

2. “What I can say as the main obstacle to the screening is the unfamiliarity of the screening test. We are new in Norway and we never used to have such tests in our home country.” (FGD2 Participant 6)

3. “Women don’t believe that they have the disease and this makes them not go for the screening services. Why I personally have not gone for the test is that I don’t believe I have the disease.” (Interview 2)

Emotional barriers

Emotional barriers to cervical cancer screening included fear of the outcome of the test and, in particular, learning that one has cancer, as well as embarrassment, particularly related to exposing oneself during the procedure and due to circumcision (Table 3, Quotes 1, 2 and 3).
Table 3: Emotional barriers

Quotes

1. “Most of the Somali women don’t go for the screening because they fear the outcome. [...] Most of the women fear to be told that they have cervical cancer after the screening.” (Interview 1)

2. “When I got the invitation letter I haven’t gone for the test because I feared the outcome of the test.” (FGD2 Participant 7)

3. “For most of the people, the procedure does not excite them. The older generation might feel embarrassed about taking this test because of the female genital mutilation. The fear is exposing themselves to the doctor, and I think a lot of women do.” (Interview 7)

Practical barriers

Practical barriers included a lack of time and language difficulties. Most of the women described having many responsibilities at home and with respect to caring for children. Due to competing demands on their time, some of the participants described having to prioritize these other responsibilities and appointments (Table 4, Quote 1 and 2). One of the participants, when emphasizing the importance of prioritizing children, described fear of the child protection services (Table 4, Quote 3). Additionally, language was frequently described as a barrier. The majority of the participants, and the older generation especially, stated they were not fluent in Norwegian and were thus unable to understand the contents of the screening invitation letter (Table 4, Quote 4).
Table 4: Practical barriers

Quotes

1. "Some of the women have a lot of work to do at home. Others go to work, workshops and school. Therefore most of the women say that they don’t have time to go for the test.” (GD2 Participant 3)

2. “I think also many women cannot turn up for their appointments. It's possible that when you get the invitation, you have a lot of children to take care of or maybe you may forget the appointment to take the test.” (Interview 9)

3. “Women are busy going after their daily activities like going to schools; they also have the responsibility of looking after their children. They do this with the fear of losing their children to the child welfare services.” (Interview 12)

4. “I know many Somali women especially the older generation; I think they would not take such a test because there is a language barrier. When they come across a written document, they do not have the skills to understand the importance of it.”

(Interview 4)

Cultural and religious concerns

Concerns about matters important within Somali culture and faith were described by the participants as rendering them reluctant to participate in screening. Most the participants stated that the Pap smear test was invasive and could damage their virginity. (Table 5, Quote 1). Furthermore, most of the participants explained that the test compromised their values of modesty, given their belief that women are not supposed to show their body to strangers (Table 5, Quote 2). In addition, most of the participants stated that they were not comfortable with a male doctor or gynaecologist (Table 5, Quote 3). Furthermore, a fatalistic belief about cervical cancer was identified as a barrier to screening, and most of the participants believed that it is through God’s destiny that one gets cancer (Table 5, Quote 3 and 4).
Table 5: Cultural and religious concerns

<table>
<thead>
<tr>
<th>Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. “Women are not comfortable with gynaecological examinations, especially for the younger and unmarried women. They feel that the procedure is invasive and it will damage their virginity.” (Interview 14)</td>
</tr>
<tr>
<td>2. “Some of the women are not comfortable with a male doctor or male gynaecologist, and they prefer a female doctor to carry out the screening.” (Interview 14)</td>
</tr>
<tr>
<td>3. “Just like me most of the Somali women don’t like to be examined, and we believe that it's only through the destiny of God that one can get this type of disease.” (Interview 9)</td>
</tr>
<tr>
<td>4. “Invitation letters are usually sent but some women are not interested in going for the test. They say it’s through God’s fate that one gets the disease and he is the one who cures it.” (FGD 3 Participant 5)</td>
</tr>
</tbody>
</table>

Mistrust in the health system

When the participants were asked about the barriers to cervical cancer screening, the issue of trust came up, especially in the focus group discussions. One participant mentioned that she could not trust the person examining her, which was particularly concerning given the importance of the organ being examined (Table 6, Quote 1). Similarly, participants expressed that their doctors were predominantly concerned about the number of children they had (Table 6, Quote 2) and lamented Norway’s lack of Somali doctors, who they would have trusted to share and respect their language, culture, and faith.
Table 6: Mistrust in the health system

Quotes

1. “There are many things that can cause doubt, for example, you can’t tell whether the person examining you is helping you or deceiving you. Since an important organ is being tested, it can happen that you might not trust the person examining you.” (FGD1 Participant 2).

2. “[...] each one of them asks you, do you come from Somalia, how many children do you have? Are you looking for another child? This becomes a challenge to go and do the test. This is what I believe are the obstacles to the cervical cancer screening. [...]This makes us use private GPs when we have our own GPs; this is due to lack of good reception and welcome from our own GPs.” (FGD 1 Participant 3)

Suggestions for reducing barriers to cervical screening

As the participants identified clear barriers to screening, they were also asked to share their suggestions for reducing these barriers and encouraging more women to participate in screening. The participants proposed increasing awareness through seminars and workshops in local neighbourhoods to inform women about the relevance of the test (Table 7, Quote 1). Similarly, they suggested that GPs encourage their patients to be screened, given that many women have regular contact with their GPs (Table 7, Quote 2). Additionally, the participants suggested the use of translated materials that could be easily understood by the women, such as the invitation letter that is sent out to all women in Norway and information materials that could be made accessible in areas attended frequently by these women, such as the maternal and child health clinics (Table 7, Quote 3). Lastly, the research participants also emphasized the importance of accommodating their preference for having the screening carried out by female doctors or gynaecologists (Table 7, Quote 4).
Table 7: Suggestions for reducing barriers to cervical screening

Quotes

1. “We need information about the disease. Seminars and workshops should be conducted in all the neighbourhoods so that the women can be well informed. Women should be taught how they can prevent themselves from the diseases.” (Interview 12)

2. “The GPs also need to encourage women to go for the screening since many women have contact with their GPs.” (GDI Participant 6)

3. “I think just having brochures and information packs in Somali language might help especially in designated areas like the health clinics especially when they go for the antenatal check-ups.” (Interview 7)

4. “Another way to increase attendance of the cervical cancer screening is we need a female doctor or gynaecologist.” (FGD 2 Participant 3)

Discussion

This study explored barriers to cervical cancer screening among Somali women in Oslo and their suggestions for reducing these. The study findings reveal a lack of familiarity with cervical cancer and screening among the participants, who explained that they had not heard about cervical cancer until immigrating to Norway and receiving the screening invitation letter. This finding is consistent with results from previous studies [27, 50, 57]. The study findings also suggest that this, together with a general lack of familiarity with preventative health and tendency to seek health services only when ill, contributed to a perception of cervical cancer screening as unimportant and of little relevance for the research participants. Similar findings have been reported in a study conducted among ethnic minorities in the U.K., where immigrant women were more likely to believe that they do not need a smear test if they do not have symptoms [58].

As reported in previous studies, embarrassment, fear of the outcome of the test, lack of time, and language difficulties have been identified as barriers by this study [25, 27, 36, 57]. A finding unique to this study is the fear of child protection services. The Norwegian child protection services has a poor reputation among many immigrants. In particular, there is a
concern among parents that they will not be listened to, understood or believed and, ultimately, that they might lose custody of children on unfair grounds [60]. This findings suggest that a negative relationship with one aspect of the welfare state like the child welfare protection services can have important consequences for their relation to another.

Findings from the study also identified cultural and religious concerns as barriers to cervical cancer screening. The study findings that the Pap smear test was perceived as potentially conflicting with cultural and religious values about sexuality and modesty, considered invasive, and understood as potentially compromising the virginity of young and unmarried women are consistent with a previous study among Somali women [36], as well as with a recent study among Pakistani and Somali women in Oslo that found that unmarried women are not expected to undergo screening due to cultural and religious expectations that they remain sexually inactive until married [10]. The study findings that the research participants prefered female practitioners and avoided screening due to concern that they might be met by a male practitioner are also similar to the findings of previous studies conducted among Somali women [27, 50]. Also consistent with other studies was that the participants believed that the presence or absence of disease was a matter of God’s will, which also then coincided with fatalistic attitudes about not only the development of cervical cancer, but also its outcome [27, 52, 53]. That most of the participants stated that they did not believe in getting cervical cancer and therefore did not need to be screened suggests that religious beliefs have an important influence on health decisions and health seeking behaviour.

The study findings have identified mistrust of the health system as a barrier to cervical cancer screening. The finding that the research participants did not fully trust the doctors who might examine them is consistent with the findings of a previous study in which mistrust of the health system was based on reports from friends or relatives regarding problems that they had encountered [52]. Furthermore, the study findings also revealed a poor doctor-patient relationship, in which the participants perceived themselves as poorly received and their doctors as predominantly and problematically concerned about the number of children they chose to have, as a barrier to screening. A recent study about barriers and facilitators to cervical cancer screening among Pakistani and Somali women attributed lack of trust in the health care system to language, cultural, and gender-related barriers [10]. Trust has conventionally been regarded as the cornerstone of an effective doctor-patient relationship.
The GPs serve as a first contact point and play a significant role in perceptions of health services [25]. As suggested by these findings, the relationship that women have with their GPs and other health providers at the primary health care level is of potential importance to their decisions about whether or not they participate in screening services. Furthermore, the study findings suggest that, in addition to involving the GPs, raising awareness, making information materials written in Somali accessible in places frequented by Somali women, and ensuring that preferences for a female doctor are accommodated are promising strategies for potentially increasing participation in cervical cancer screening. This is consistent with findings from a recent study [10]. Finally, the study suggests use of interactive social media such as SMS and other social websites that have the potential for increasing participation as highlighted by a recent study [10].

The use of a relatively large sample is an asset for this study, since it contributed to a range of diversity and captured differing views and experiences. Similarly, the triangulation of data collection methods enabled a comprehensive exploration, from different angles, of the study phenomenon and thereby enhanced the trustworthiness of our data material. Nonetheless, the inclusion of only first generation women as study participants might limit the transferability of the study to younger women of Somali background, who might have a different view of the topic under study. Even though we made efforts to mediate and assess the presence of a male researcher during the interviews, we cannot be entirely sure of the effect this might have had on the responses of the participants.

Despite these limitations, the study has arrived at a number of conclusions and recommendations. This study supports the suggestion of a recent study that recommended developing a culturally-tailored intervention to potentially increase participation in cervical cancer screening among Somali and other immigrant women in Norway [10]. A previous study that accounted for the views of Somali women and men demonstrated that faith-based messages can potentially reinforce the views of those already inclined to screening and encourage those with reservations [65]. Therefore, this study recommends the use of faith-based messages by engaging local imams who might dispel or at least mediate fatalistic understandings and address concerns about matters of modesty and sexuality as part of an intervention alongside other practical suggestions raised by the participants. Another study showed that prompting from GPs motivated women to attend cervical cancer screening [66],
and this study hence also recommends the involvement of health providers, particularly the GPs who serve as regular contacts for the women, in encouraging the women to take the Pap smear test. A closer examination of the impact of the child protection services on cervical cancer screening uptake is also recommended by the study. Finally, the study calls for more research about this topic that explores the perspectives of health providers.

Acknowledgements
The authors would like to acknowledge the participants of this study for sharing their valuable experiences and time. Similarly, the authors wish to recognize the contributions of the research assistant Arifi Mohamoud for recruitment and data collection.

Funding:
This study was funded by the Institute of Health and Society, University of Oslo.

Conflict of interest:
None of the authors have conflict of interest to declare
References


Appendix 2: Ethical clearance exemption from REK in Norway

Vår ref.nr.: 2016/1018 A

Vi viser til skjema for framleggingsvurdering mottatt 19.05.2016, angående prosjektet «Perceptions of and perspectives on cervical cancer screening: a qualitative study among Somali women in Oslo». Fremleggingsvurderingen er vurdert av komiteens leder. Formålet med prosjektet, slik det fremkommer av fremleggingsvurderingen, er å undersøke oppfatninger av og synet på screening for livmorhalskreft blant Somaliske kvinner i Norge.

Livmorhalskreft er et alvorlig helseproblem som påvirker kvinner i hele verden. Det er regnet som den fjerde hyppigste krefttypen i verden, og en av de vanligste krefttypene for kvinner som lever i Somalia. Tidlig diagnostisering og behandling er viktig for å forbygge alvorlig sykdom og dødsfall forårsaket av livmorhalskreft. Studier fra USA indikerer at kvinner innvandret fra andre land, herunder Somaliske kvinner, er mindre tilbøyelig til å delta i screening for å oppdage livmorhalskreft. Prosjektleder skriver at vi vet lite om Somaliske kvinner i Norge sitt syn på screening for livmorhalskreft, noe som vil bli undersøkt i dette prosjektet.


Medvennlighilsen
Camilla Bø Standal
Seniorrådgiver Tlf 22845821
Appendix 3: Approval for storage of information through the Norwegian Social Science Data service (NSD)

Christina Brux Mburu
Institutt for helse og samfunn Universitetet i Oslo
Postboks 1130 Blindern
0318 OSLO

Vår dato: 09.08.2016
Vår ref: 49177 / 3 / HIT
Deses dato: Deses ref:

TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 04.07.2016. Meldingen gjelder prosjektet:

49177  Perceptions of and perspectives on cervical cancer screening: a qualitative study among Somali women in Oslo.
Behandlingsansvarlig Universitetet i Oslo, ved institusjonens øverste leder
Daglig ansvarlig Christina Brux Mburu
Student Mohammed-nur Addawe

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilråer at prosjektet gjennomføres.

Personvernombudets tilråding forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, ombudets kommentarer samt personopplysningsloven og helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.


Personvernombudet vil ved prosjektets avslutning, 01.06.2017, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen
Kjersti Haugstvedt
Appendix 4: Request for participation in a research project in English language

My name is Mohammed-nur Ahmed Addawe; I am a researcher and a student from the University of Oslo. This is a request to participate in a study where the objective of the study is to explore Somali women's perception of and perspectives on cervical cancer screening and, in particular, their views on potential barriers and their suggestions for reducing barriers to uptake of cervical cancer screening. The study is part of the academic fulfilment for master’s degree in International Community Health at the University of Oslo.

What does participation involve?

If you choose to participate in this project, you will be invited to take part in either an individual, in-depth interview or a focus group discussion where questions will be asked and your responses to the questions is anticipated. The interviews will take approximately about 45-90 minutes and the data will be collected using audio tapes with your permission.

What will happen to the information about you?

Following the interviews, all personal data will be treated confidentially and used only for the purposes of this study. Data will be securely stored on a password-protected computer and server. Access will be limited to the researcher. A coded list will link your name to your data, and this will be kept locked and stored separately from the data. Your anonymity will be fully ensured, and neither your name nor any other personal identifiers will appear in any reports or publications arising from this study. All non-anonymous data materials will be deleted upon project completion in November 2017.

Voluntary participation

Kindly be informed that it is voluntary to take part in the study, and you can at any time choose to withdraw your consent without stating any reason. If you decide to withdraw, all your personal data will be made anonymous. The study has been notified to the Data Protection Official for Research, NSD - Norwegian Centre for Research Data. If you would like to participate or if you have any questions concerning the project, please contact:

Mohammed-nur Ahmed Addawe
Consent for participation in the study

The objective of the study is to explore Somali women's perceptions of and perspectives on cervical cancer screening and, in particular, their views on potential barriers and their suggestions for reducing barriers to uptake of cervical cancer screening. Taking part in the study is not mandatory but voluntary as stated. In the event that a participant feels that it’s necessary to leave the study, he or she can leave at any stage.

I have received information about the project, and I am willing to participate

.................................................................

(Signed by research participant, date)

I confirm that I have given adequate information about the research to the participant.

.................................................................

(Signed by the researcher, date)
Appendix 5: Request for participation in a research project in Somali language

Codsi kaqaybqaadasha mashruuca cilmi bariis


Waa maxay ka qaybqaadashadu?

Haddii aad doorato inaad kaqaybqaadato cilmi baristan, waxaa lagu martiqaadi doonaa inaad kaqaybqaadato wareysi shaqsi ah ama wareysi ka kobaan koox dumar ah, halkaasoo su'aalaha lagu weydiin doono iyo jawaabahaaga su'aalaha laga filayo. Wareysiyaada waxay qaadan doonaan qiyaastii 45-60 mirir. Waxaa xogta lagu ururin doonaa iyadoo la isticmaalayo cajalado duubis ah oo leh ogolaanshahaaga.

Sidee loo keydin donaa macluumaadka kugu saabsan?


Ka qaybgalka iktiyaariga ah

Waxaa si diraan lagu ogaysinaya in ay tahay ikhtiyaari inaad kaqaybqaadato daraasadda, waxaadna wakhti kasta aad dooran karta inaad ka noqoto oggolaanshaha ka qabgalka cilmi baristaan adiga oo aan sheegin wax sabab ah. Haddii aad go'aansato inaad ka baxdo,
Dhammaan macluumaadkaaga shakhsiyeed waxaa lagu sameyn doonaa magac la’aan. Daraasadan ayaa la ogeysiyeey lanta Ilaalinta Macluumaadka ee NSD - Xarunta Noorwijiijiga ee Cilmi baarista. Haddii aad jeclaan lahayd inaad kaqaybqaadato ama aad qabto wax su'aalo ah oo ku saabsan mashruuca, fadlan la xiriir:

Mohammed-nur Axmed Addawe
M.n.a.addawe@studmed.uio.no
96910980

Oggolaanshaha ka-qaybgalka cilmi barista

Ujeedada daraasaddan ayaa ah mid lagu barayyo aragtida haweenna ee kusaabsan baritaanka kansarka afka ilmagaleenka, gaar ahaan aragtiidooda ku wajahan caqabadaha kahortaaqan baritaankan iyo ra’ yi gooda kusaabsan yarenta caqabadaha baaritaanka kansarka ilmagaleenka. Ka qayb qaadashada daraasaddan ma aha mid khasab ah, laakiin ikhtiyaari ah sida lagu sheegay. Haddii ay dhacdo in ka qaybgalaha uu dareemoo in ay lagama maarmaan ay tahay in uu jojiyoo ka qaybqaadashadu, isaga ama iyadu, waxuu /wexeey kaa tagi karta waqti kasta.

Waxaan helay macluumaad ku saabsan mashruuca, waxaana rabaa inaan ka qayb qaato

........................................................................................................................................
(Saxiixa ka qaybgalaha cilmi-baarista, taariikhda)

Waxaan halkan ku cadeeneyaa in aan siiyay ka qaybqaagalaha cilmi barista macluumaad ku filan oo ku saabsan cilmi baarista

........................................................................................................................................
(Saxiixa cilmi-baaristaha, taariikhda)
Appendix 6: Thematic guide for in-depth Interviews

Interview no

Location

Date

Starting time

Ending time

Demographics

Age

Marital status

No of children

Education level

Duration of stay in Norway

Cervical cancer

Can you tell me about your familiarity with cervical cancer?

What comes to your mind when I ask about cervical cancer?

Can you tell me anything about the disease itself e.g. what are the risk factors for cervical cancer?

What will you include as the signs and symptoms of the disease?

Cervical cancer screening

Have you heard of cervical cancer screening? (If yes ask…) Please tell me about where you have heard about it.

Can you tell me more about the purpose of cervical cancer screening?

What are your thoughts about the possible benefits and harm of cervical cancer screening?
Have you ever had the test? (If yes, ask). If you did yourself what was your experienced of this, can you tell me about what it was like for you?

**Barriers**

Can you tell me what hinders you or other women from accessing cervical cancer screening services?

**Suggestions**

What are your suggestions for reducing increasing the barriers to uptake to cervical cancer screening?
Appendix: 7 thematic guide for Focus group discussions

Interview no

Location

Date

Starting time

Ending time

Demographics

Age

Marital status

No of children

Education level

Duration of stay in Norway

Cervical cancer

Can you tell me about your familiarity or understanding of cervical cancer?

What comes to your mind when you hear of cervical cancer?

What will you include as the risk factors for cervical cancer?

Cervical cancer screening

Have you ever heard of cervical cancer screening/ pap smear? (if yes, ask) Please tell me about where you have heard about it?

Can you tell me more about the purpose of cervical cancer screening?

Have you ever had the test? (If yes, ask). If you have it done yourself or accompanied a family member what was your experienced of this, can you tell me about what it was like for you?
What are your thoughts about potential benefits and disadvantages or harm of cervical cancer screening?

**Barriers**

Can you tell me what hinders you or other women from accessing cervical cancer screening services?

**Suggestions**

What are your suggestions for reducing the barriers to the uptake of cervical cancer screening test?
Appendix 8: A copy of the invitation letter in Norwegian

Viktig informasjon fra Livmorhalsprogrammet til deg som fyller 25 år i 2016
Ta celleprøve og reduser risikoen for livmorhalskreft!

Hvert år får 3 000 kvinner påviset alvorlige celleforandringer som behandles for å forebygge utvikling av livmorhalskreft. En fjerdedel av disse er i alderen 25-29 år. Livmorhalskreft utvikler seg fra celleforandringer i livmorhalsen. Celleforandringer kan oppdages med celleprøve.

Hvorfor er det viktig at du tar celleprøve, selv om du er ung og frisk?
Livmorhalskreft rammer oftest kvinner som ikke har tatt celleprøve. De fleste celleforandringer i livmorhalsen gir ikke symptomer, men kan oppdages med celleprøve. Du kan forebygge livmorhalskreft dersom du får tatt en celleprøve fra livmorhalsen hvert tredje år.

Hva er celleforandringer?
Nesten alle celleforandringer skyldes en vedvarende infeksjon med høyrisko Human Papillomavirus (HPV); viruset overføres seksuelt. De fleste får minst én HPV-infeksjon i løpet av livet. Flertallet av infeksjonene er ufarlige og går over av seg selv; men i noen tilfeller fører infeksjonen til alvorlige celleforandringer. Celleforandringer er ikke det samme som kreft, men de kan utvikle seg til kreft.

Mer informasjon om hvordan proven tas, Livmorhalsprogrammet og dine rettigheter. Se neste side.

Livmorhalsprogrammet er et viktig forebyggende tiltak mot kreft.
Jeg håper at du velger å delta.

Vennlig hilsen

Amelie Tropé
Leder for Massasundhetsseksjonen mot livmorhalskreft
Hvordan tar jeg en celleprøve?
Celleproven tas ved en underlivundersøkelse hos fastlegen eller gynækologen din. Du må selv bestille time. Under-
søkelsen tar noen få minutter, og kan være forbundet med litt ubehag. Celleproven tas med en liten borste som
legen bruker for å samle overflateceller fra livsmørhatten. Om du går til gynækolog, kreves det i de fleste tilfeller
heving fra fastlege. Du må selv dekke utgiftene til undersøkelsen, men legenhonorar blir automatisk registrert på
egen ansattskort ditt.

Hvordan bør du forberede deg?
Du bør ikke ta celleproven mens du har menstruasjon. De to siste dagene før prøvetaking bør du ikke bruke tam-
ponger, fødselspreventivt skum, geller, vaginale kremer eller vaginale medisiner og du bør helst unngå samleie.

Hva skjer dersom prøven viser at du har celleforandringer?
Legen din tar kontakt og informerer om den videre oppfølgingen dersom celleproven din viser celleforandringer.
Noen kvinner kan føle engstelse og uro fram til svaret på prøven kommer. Dette er en normal reaksjon. Snakk med
legen din om fordel og ulemper ved screening.

Organisering av Livmorhalsprogrammet
Kreftregisteret drifter Livmorhalsprogrammet og sender brev med påminnelse til kvinner mellom 26 og 69 år når
det nærmer seg tid for ny prøve. Tar du prøve oftere enn hvert tredje år, får du ikke påminnelse.

Reservasjon og personvern
Du kan reserere deg mot permanent lagring av personidentifiserbare opplysninger knyttet til normale prøver
Du slett all personopplysinger knyttet til normale prøver, kvalitetstikker framtidige prøver, og sletter dem i
lepet av seks måneder. Vi vil ikke kunne sende deg påminnelse, siden informasjonen din i siste celleprøve er nedv-
endig for å kunne sende dette brevet.
Reservasjon kan gjøres elektronisk ved å logge inn på www.kreftregisteret.no/reservasjon, eller du kan skrive ut
reservasjonskjøring fra vår nettside og sende det i posten.
Dersom du ikke ønsker brev, men synes det er greit at vi lager personopplysninger, kan du benytte samme frem-
gangsmåte som over, eller sende oss en e-post.

Du kan lese mer om reservasjon og personvern her:
http://kreftregisteret.no/livmorhals/Reservasjon-og-personvern

Vennligst ikke oppgi helseopplysninger i e-post