Contents lists available at ScienceDirect

# Heliyon



journal homepage: www.cell.com/heliyon

Research article

5<sup>2</sup>CelPress

# Less known but greatly feared: Cervical cancer in Ethiopia community awareness

Nega Jibat<sup>a</sup>, Rahma Ali<sup>b,\*</sup>, Wondimagegn Adissu<sup>c</sup>, Gerezgiher Buruh<sup>d</sup>, Alemseged Abdissa<sup>e</sup>, Gelila K. Goba<sup>f</sup>, Suzanne M. Garland<sup>g</sup>, Nigisti Mulholland<sup>h</sup>, Kim Mulholland<sup>i,j</sup>, Demisew Amenu<sup>k</sup>

<sup>a</sup> Department of Sociology, College of Social Science and Humanities Jimma University, Jimma Ethiopia

<sup>b</sup> Department of Population and Family Health, Faculty of Public Health, Jimma University, Jimma, Ethiopia

<sup>c</sup> School of Medical Laboratory, Faculty of Health Science, Jimma University, Jimma, Ethiopia

<sup>d</sup> College of Health Science, Mekelle University, Mekelle, Ethiopia

<sup>e</sup> Armauer Hansen Research Institute, Addis Ababa, Ethiopia

<sup>f</sup> Department of Obstetrics and Gynecology, University of Illinois, Chicago, USA

<sup>g</sup> Department of Obstetrics and Gynecology, University of Melbourne, Australia

<sup>h</sup> Family & Reproductive Rights Education Program, Royal Women's Hospital, Melbourne, Australia

<sup>i</sup> Department of Pediatrics, University of Melbourne, Murdoch Children's Research Institute, Australia

<sup>j</sup> London School of Tropical Medicine, UK

<sup>k</sup> Department of Gynecology and Obstetrics, Faculty of Medical Science, Jimma University, Jimma, Ethiopia

# ARTICLE INFO

Keywords: Cervical cancer HPV infections Vaccination Cervical screening Community awareness Qualitative Ethiopia

# ABSTRACT

To improve a community's awareness and attitude towards cervical cancer, strong evidence is needed to inform contextually appropriate policies. This study aims to explore community awareness about cervical cancer from the perspective of women, men and health extension workers (HEWs). The research was conducted from May to July 2021 in Jimma, Ethiopia. A total of 23 in-depth interviews were conducted. The study included married and unmarried women (15-19 and 25-29 years old), men of similar ages (married and unmarried), and HEWs. Furthermore, eight separate focus group discussions (FGDs) were conducted with both men and women. Thematic analysis was used to draw findings from the interviews and FGDs. Community awareness about cervical cancer was very limited. However, people who knew of it believed that cancer is fatal. A few participants were aware of cervical cancer through its symptoms, but most people did not know it by name and had never heard about HPV as the cause of cervical cancer. There was little understanding of HPV risk, transmission factors, prevention, vaccination, screening, or treatment. Participants considered their participation in this study as their first chance to learn about the disease. HEWs had limited knowledge about HPV and cervical cancer. Study participants demonstrated favorable attitudes towards HPV vaccination, cervical screening, and treatment after they received basic information about cervical cancer from the data collectors. Participants and HEWs strongly suggested awareness creation programs for the wider community members, including active involvement of men and HEWs in cervical cancer interventions. There is a critical information gap regarding cervical cancer, its cause and risk

\* Corresponding author. Jimma university and University of Copenhagen, Jimma, Ethiopia.

*E-mail addresses*: negajibat@gmail.com (N. Jibat), rahmiii.ali@gmail.com (R. Ali), wondeade@gmail.com (W. Adissu), gbamsc2002@gmail.com (G. Buruh), alemseged.abdissa@ahri.gov.et (A. Abdissa), ggoba@uic.edu (G.K. Goba), Suzanne.Garland@thewomens.org.au (S.M. Garland), Nigisti. Mulholland@thewomens.org.au (N. Mulholland), kim.mulholland@lshtm.ac.uk (K. Mulholland), demisame5@gmail.com (D. Amenu).

https://doi.org/10.1016/j.heliyon.2024.e28328

Received 13 May 2023; Received in revised form 26 February 2024; Accepted 15 March 2024

Available online 22 March 2024

<sup>2405-8440/© 2024</sup> Published by Elsevier Ltd. This is an open access article under the CC BY-NC-ND license (http://creativecommons.org/licenses/by-nc-nd/4.0/).

factors, HPV transmission, cervical screening, and treatment programs. Limited community awareness leads to poor uptake of cervical screening in the few settings where it is available. Therefore, community awareness programs about HPV, cervical cancer, and available services should improve the community's awareness of cervical cancer and HPV.

# 1. Background

Worldwide, cervical cancer accounts for the fourth-highest diagnosed cancer and fourth-highest cancer death rate among women [1]. The estimated global burden of cervical cancer in 2020 was 604,000 new cases and 342,000 deaths [2]. The disease burden is disproportionately borne by developing countries, which account for 86% of cervical cancer cases and 88% of deaths [1]. The highest incidence and mortality from cervical cancer occur in sub-Saharan Africa with 19 out of the top 20 cervical cancer burden countries in this region [3], with the highest rates in Eastern Africa [2]. In Ethiopia, approximately an estimated 33.7 million women aged 15 and above were at risk of developing cervical cancer. The estimate indicate that in 2020, there were approximately 7445 cases of cervical cancer and 5338 deaths from the disease [4].

Nearly 99% of cervical cancer is caused by the human papillomavirus (HPV) and it is largely preventable [5]. The World Health Organization (WHO) Director-General announced a global cervical cancer elimination program [6] and launched a global strategy to accelerate elimination in 2020 [6]. According to the strategy, countries should adopt the 3 pillars strategy, meeting 90%, 70%, and 90% targets for vaccination, screening, and treatment, respectively, by 2030 [6]. Despite this, barely 13% of eligible women in sub-Sahara Africa receive cervical screening [7]. This is mainly related to low levels of awareness [8–12] and limited access to services [11,13,14]. As part of a comprehensive cervical cancer prevention program, Ethiopia rolled out 4-valent HPV vaccination in 2018 targeting girls aged 14, and HPV is now part of routine EPI [15]. In addition, the country has designed a comprehensive cervical cancer screening program, but screening uptake remains far below WHO's target [15]. Ethiopia's Federal Ministry of Health (EFMOH) guidelines on cervical cancer prevention and control also include an awareness creation package as a prevention strategy [16].

Studies have shown that there is a significant gap in awareness and knowledge related to cervical cancer [8–10,17–20]. However, most were quantitative studies [8,9,17,18] or studies done from the perspective of women or girls [21–24] or focused only on high-risk groups such as HIV-positive women [19,20] or those visiting health facilities [10]. The majority of studies fail to address men's awareness and knowledge regarding cervical cancer prevention, early detection, and treatment. Male involvement in maternal health is a critical factor for increasing utilization of services as demonstrated by a variety of researchers [25,26] and recommended by several organizations including the WHO. Additionally, there has been little evidence regarding the knowledge and awareness of HEWs, who are the community level health care workers and health education providers for the community in Ethiopia.

Therefore, this study aims to fill this knowledge gap by investigating women's, men's, and HEWs awareness and perceptions about cervical cancer. Further, the findings of this study will inform policy makers to promote effective cervical cancer prevention strategies.

#### 2. Materials and methods

# 2.1. Study setting

We conducted this study in Jimma City and its suburbs as part of a broader study on epidemiological, economic, and sociological evidence to inform HPV vaccine policy in Ethiopia. Jimma City is located within Jimma Zone of Oromia, Ethiopia: it is one of the most populous zones in Oromia and it is well-known for its organic coffee production. The fieldwork was conducted from May to July 2021.

#### 2.2. Study design

We employed in-depth interviews, focus group discussions, and thematic analysis. The study participants were purposively recruited through HEWs. Married and unmarried men and women community members as well as HEWs participated in interviews and focus group discussions. Men and women study participants were selected based on their age, experience, knowledge, and marital status, whereas HEWs were recruited based on their roles related to the study. A total of 20 in-depth interviews were conducted with women between the ages of 15–19 and 25–29, and three with HEWs. Eight FGDs were conducted with men and women separately. Their willingness to participate in the study was considered for all participants and written consent was secured. Data collection was carried out at health posts and the required number of participants was determined by data saturation point when similar ideas recurrently emerged from different study participants.

We conducted interviews in the Amharic language or Afaan Oromo based on the language competency of the study participants using a pre-tested semi-structured interview guide. Interviews and FGD were audio-recorded and field notes were taken. The average durations of the interviews and focus group discussions were 45 and 70 min respectively. "What do you know about cervical cancer, HPV, HPV vaccination, cervical screening, and treatment?" is among the typical questions the study participants were asked. Audio materials were transcribed in the native languages, translated to English, and thematically analyzed. The analysis passed through open, axial, and selective coding based on the research questions and emerging patterns. The data analysis was started during the fieldwork but mostly undertaken after the fieldwork was complete. The data were stored in electronic devices protected with passwords. Materials in hard copy are safely stored in rooms separated for this purpose.

#### 2.3. Ethical clearance

Ethical approval for the study was granted by the Jimma University Ethical Review Board, of the College of Public Health and Medical Sciences (reference IHRPHD/379/19). Detailed information about the study was given and informed written consent was obtained from the study participants.

# 3. Results

# 3.1. Socio-demographic characteristics of the study participants

We conducted 23 interviews with women and HEWs, and 8 FGDs with men and women. Women and men FGD participants are separately categorized as married and single, while women interviewees were also categorized based on their marital status and age. Table 1 presents a summary of the study participants by methods, age, and sex categories.

The following five themes were developed (Fig. 1).

#### 3.2. Limited knowledge or guess about cervical cancer

This study revealed the community's limited knowledge about cervical cancer. Expressions such as "I have not heard about this disease" and "I do not know about it" were the most common responses when participants were asked about their knowledge of the disease. Phrases like "maybe" and "I think" were commonly used to associate cervical cancer with other diseases they know. Many study participants expressed that they had never heard about cervical cancer and HPV before they participated in this study. They considered their participation in this study as their first chance to be informed about the disease. While the study participants often referred to cancer as the most severe and incurable disease, most of them did not know the specifics of cervical cancer. Interviewees and FGD participants were aware of sexually transmitted infections and/or diseases. They mentioned HIV and syphilis as examples of such diseases and

know that avoiding having multiple sexual partners and practicing safe sex can prevent these infections. They more frequently mentioned blood, ovarian and breast cancer, than cervical cancer, the latter being understood as a 'new' manifestation of cancer.

I have heard mostly of breast and uterine cancer. I haven't heard about cervical cancer, but I recently heard while people were talking about someone who died of cervical cancer (29 years old married woman)

I think this cervical cancer is not known and recognized in the community as breast cancer and other cancers and maybe it's a new type. I don't know the specifics of cervical cancer, only what I know is that women die of cervical cancer (27 years old unmarried male).

These quotes illustrate that participants were aware of cervical cancer only after someone they knew died of it. The limited awareness regarding the existence and prevalence of the disease was partly attributed to rigid sexual norms restraining discussion about disease involving the genital organs. Mass media announcements and discussions, friends and relatives were indicated as sources of information about the fatality of cervical cancer though most of the participants did not have further information about the disease. This limited awareness of the disease among the participants can also be seen from their response to the question "*Do you know someone who has or has had cancer*? Regardless of indicating its seriousness and expressing fear, only a few had known women who had contracted cervical cancer. These participants mentioned some manifestations to define what they perceived as cervical cancer only after the interviewer briefed the participants about the nature of cervical cancer.

I had a friend whose wife was identified with cervical cancer and she was complaining of a burning sensation during urination and she has serious abdominal pain (28 years old married male)

I know a woman with cervical cancer but not sure whether she is alive or dead because it has been a long time since we met, she was even unable to urinate without a urine catheter (24 years unmarried woman)

Only a few participants indicated vaginal discharge with bad odor, vaginal bleeding, and pain internally as potential symptoms of cervical cancer. Perception about cancer in general and the

Summary of the composition of FGD groups by methods, sex, and age.			
Interviewees	Number	FGD participants	Number
Married women [15–19]	5	Married men [15–19]	2
Married women [25-29]	5	Unmarried men [25–29]	2
Single women [15–19]	5	Married women [15–19]	2
Single women [25–29]	5	Unmarried women [25-29]	2
Health Extension Workers <sup>a</sup>	3		
Total	23	Total	8

<sup>a</sup> HEWs in Ethiopia are exclusively females.

Table 1



Fig. 1. Themes identified in this study.

Consequences appeared to shape participants' understanding of cervical cancer. Referring to common assumptions and hyperboles about cancer in the public discourse, many participants guess cervical cancer is incurable like other cancers such as blood and breast cancers. In other words, the symbolic representation of cancer in general was transposed to cervical cancer. Many participants justified this perception by mentioning reported deaths of women even after seeking medical services at hospitals. HEWs themselves do not have adequate knowledge about HPV vaccination, cervical screening, and treatment because of their marginal involvement in the intervention programs and services. After they were exposed to the basic information through briefings during data collection, study participants including HEWs suggested awareness creation programs for the wider community members. They also suggested the active involvement of men and HEWs in cervical cancer interventions in encouraging women to seek the services.

#### 3.3. HPV is not known in the community

Most study participants - married and unmarried, males and females, had not heard about HPV. FGD participants' lack of familiarity with the term "HPV" was an issue during data collection. During the study, they became familiar with it through their shared gesture of seeking support from one another for an explanation about it. When asked about the cause of cervical cancer, almost none of the participants mentioned HPV. "It is my first time to hear this name" was a common expression when they responded to a question about HPV. A 22-year-old married man responded "I never heard about this virus" and another 28 years old married man added "It is my first time to hear about it." While a few participants reported hearing the name HPV, they did not know that it causes cervical cancer. More importantly, most of them did not know that cervical cancer is caused by a virus.

I do not know as cervical cancer was caused by a virus. I have no information about it. I was not informed about the virus when I was given the HPV vaccine. I did not hear about the virus at all (18 years old unmarried women).

Even those who were aware of cervical cancer, HPV vaccination, and cervical screening did not precisely know the exact causative agent, human papillomavirus, they had even not heard the name.

I heard about this cancer and its vaccination, and I have taken it once. I also heard that there is screening for the pre-cancer stage every 6 months. However, I don't know about the cause and the symptoms of cervical cancer (29 years old married woman).

Her response in the quote that she has taken the vaccination once, is evident that she doesn't know about the HPV vaccine as no woman at this age had the chance to take the HPV vaccine in Ethiopia. Even those vaccinated during the pilot introduction were up to 15 years old, and they were vaccinated 7/8 years ago. This implies that some women don't know the types of vaccines they have received.

Likewise, most study participants had no clear idea that HPV is transmitted through sexual intercourse. Commonly, the study participants do not identify the causes of transmission and risk factors. For a question, "Is cervical cancer transmitted through sexual intercourse?" a 27-year-old married male responded, "I don't think that it is caused by sexual intercourse, however, forceful sexual intercourse can cause laceration and this can cause cervical cancer". A 29-year-old married woman also said "I think female genital mutilation can cause cervical cancer." Most men participating in this study were not aware that HPV is a cause of cervical cancer. In addition, they did not know that HPV is transmitted through sexual intercourse.

# 3.4. Imprecise knowledge about the risk factors of cervical cancer

Awareness about the risk factors of cervical cancer is another gray area for the study participants which emanates from their limited knowledge of cervical cancer in the first place. Most of them loudly responded that they did not know the risk factors of cervical cancer. Among the study participants, there is a tendency to draw responses from their previous memories about sexual and reproductive health that may or may not fit to cervical cancer. They also associated their response with their general understanding about cancer, whereby they do not know about cervical cancer which is commonly observed across the discussions. The influence of health extension programs for HEWs seems to focus primarily on maternal reproductive health and this appears to have shaped their perceptions. Moreover, explanations about cervical cancer, HPV and related services provided to the study participants as part of the data collection opened ways for them to recall their previous knowledge and experiences about related issues.

I do not know about the risk factors of cancer. I don't think that risk factors for cancer are known. I don't know about cervical cancer too (26-year-old married woman),

Yet, most of the issues they raised during the discussions as causes, transmission and risk factors are valid for cervical cancer not to emphasize the misconceptions. They frequently cited female genital mutilation, early sexual initiation or early marriage, having multiple sexual partners, sexual abuse/forceful sex in marital lives and lack of genital hygiene to be related to cervical cancer. Harmful traditional practices which are often discussed in health extension packages were among the factors frequently stated as factors for cervical cancer. Many participants said that female genital mutilation and early marriage contribute to the development of cervical cancer in women. Female genital mutilation, the use of unsafe materials for this and associated excessive bleeding were incorrectly perceived to affect the uterus and gradually develop into cervical cancer.

I know that initiating sexual intercourse at a very young age can be a risk factor for developing cervical cancer. Early marriage can be also another risk factor. If a woman is not willing to have marriage and she is forced to have sexual intercourse, this can be a factor because laceration occurs during forceful sexual intercourse (29 years old married man).

The participants further argued that cervical cancer is caused by early sexual initiation and what they referred to as "excessive" and "abnormal" sexual intercourse. These terminologies were used to define having sexual intercourse with multiple partners as the main risk factor for cervical cancer. Women working in hotels and commercial sex workers were considered to be more vulnerable groups than other women due to their higher chance of having sex with multiple partners. However, the following quote from a 25-year-old married woman reveals a misconception.

Cancer is caused by female genital mutilation. Sharp materials were used during genital cutting. It was believed that the blood flows back during female genital cutting causes cancer.

In this sense, cervical cancer is understood as a critical manifestation of practices affecting the female genital organs. This was more articulated when the participants discussed how cervical cancer is associated with early marriage and sexual intercourse. Many participants emphasized the effects of sexual intercourse between a young woman and adult man, particularly when it involves force. This perception is shaped by their understanding of the impacts of child marriage on the physical health of the young women as well. Yet, the notion that the blood from female genital cutting flows back and causes cancer is a misconception. Another frequently mentioned risk factor was lack of personal hygiene, particularly about the genital organs. Some participants perceived lack of regular genital cleaning following menstrual bleeding and urination as the main factors contributing to the development of cervical cancer. Materials used to maintain what participants call "genital care" were considered important risk factors.

I am saying genital care; frequently washing the genital area after using toilet and during menstruation. Whether clothes and sanitary pads are used during menstruation for absorbing blood, a woman should change it frequently. If there is a lack of such activities, I think this will lead to cervical cancer (19 years old married women)

If a woman stays with blood-stained underwear for two to three days, it exposes her to cervical cancer. So, protecting one's hygiene during menstruation is an important protective measure against the disease (19 years old married women)

Overall, the study participants have identified a long list of risk factors for cervical cancer but most of them are not linked to HPV transmission and how they can be factors is not precisely defined.

#### 3.5. Misconception of cervical cancer as unpreventable and untreatable

Many study participants know that different vaccines have been provided for children, adolescents and women by healthcare workers at schools and health facilities, and the service has been promoted since the introduction of the Health Extension Program (HEP) in 2004.

The Vaccine is given prior to development of disease and this can be given periodically and there are various types, for example, it can be given to prevent cancer and tetanus. They are provided at schools and during pregnancy. There are also vaccines given for children that I don't know their exact names (29 years old married women).

Most of the participants did not know HPV vaccination or whether cervical cancer is a preventable disease. "Does cancer have a vaccine?" was a common response among interview and FGD participants when asked about HPV vaccination. The participants also

had no awareness about which age groups HPV vaccination is recommended for, although they assumed females would be targeted. Surprisingly, young women who had received the vaccine (confirmed by healthcare providers) also did not know the name or the benefits of the vaccine. Because of the perceived severity, incurability and fear of cervical cancer, the study participants see cervical screening as the single most important way to prevent the infection. They also believe that early screening could lessen the adverse physical and psychological consequences of cervical cancer. Consistent and participatory community awareness about the infection and its consequences would address misconceptions about the screening thereby encouraging a larger number of women to be screened for the infection in rural and urban areas.

Many study participants did not know about treatment methods for cervical cancer, but they tended to infer from other types of cancers.

Treatment for cervical cancer is unknown in our community. I don't think that there is treatment for this disease (29 years old married woman).

I don't know the treatment but there may be chance of getting cured if a patient seeks treatment earlier (26 years old married woman).

Some were able to describe other types of cancer but they stated that they do not know about cervical cancer. A typical response representing this view is as follows:

The treatment is based on the affected area. If it is breast, it may be removed and they may also take drug which limit dissemination to other parts of the body. If it is leg, it may be cut by doctors and the patient may be cured if it is not disseminated to other body parts. However, I don't know what is done for cervical cancer (26 years old married women).

Cancer treatment is with drug or injection which can be given for longer period of time. The same is true for cervical cancer. I don't think that the treatment can cure the patient. I know someone in my neighborhood who died after taking the drug for a long period. (27 years old married man).

Even if they do not have direct, first-hand information, the study participants guess the potential treatment for cervical cancer is manifested in their expressions like "*Doctors may treat them with laboratory tests and surgically*." They mainly rely on healthcare providers' authoritative expertise for the treatment even though they do not certainly know what is really done to diagnose and treat the disease. Another participant commented that "*If a woman visits a health facility and got examined, medical professionals can identify it with a tool such as an ultrasound*." A participant further said:

Doctors can identify this condition by using symptoms told by the patient like burning sensation during urination and pain during sexual intercourse. Furthermore, they can conduct laboratory investigation which can be urine examination (28 years old married man).

Informants identified various possible means of diagnosis, and treatment of cervical cancer including urine test, ultrasound, surgical and x-ray examinations. Nevertheless, most did not know about the treatment of cervical cancer as one said "I don't know how the doctors diagnose it, but there may be tests that can be done after taking fluid sample from the spot."

#### 3.6. Death is a nearly unavoidable consequence of cervical cancer

A few study participants had direct experience of observing or hearing effects of cervical cancer in their village. One responded by saying:

I know cervical cancer is a very dangerous and fatal disease even more than breast cancer. When diagnosed with cervical cancer people would not be interested to visit medical treatment because there is no drug to treat cancer. They want to stay at home and try with traditional drugs (17 years old unmarried man).

Others associate the symptoms of cervical cancer with women they know who may be suffering from similar illnesses even if they are not certain what it is. Most study participants were very fast to imagine effects of the disease as they were introduced to features of cervical cancer in the course of interviews or discussions. Above all, the participants fetch information from their general awareness about effects of cancer and apply to cervical cancer. Their responses to cancer in general and cervical cancer in particular largely overlap. Accordingly, multifaceted perceived negative effects of cervical cancer on patients and their families were identified. A study participant mentioned the effects as:

The first thing a woman with cervical cancer has to face is psychological problems. She may think that she will not recover from the problem and fear social impact of the illness. Physically, she may experience discomfort and prolonged pain in the reproductive organs during sexual intercourse. Besides, the woman may not get pregnant and bear children (25 years old married women).

The intractable condition and severe symptoms of the disease have adverse psychological, physical and social consequences for the patient. A 22 years old unmarried man described its effect on women as, "*Overall, the disease affects the entire life of a woman*." Receiving medical treatments exposing their genitalia to healthcare providers is considered as psychologically painful. Long-term feelings of loneliness and lack of interest in joining others can lead to depression. Participants of the study perceive that, patients experience self-blaming, loss of hope and sense of rejection. As informants have said, such illnesses are very disturbing for patients because there is no promise of a cure and the treatments are mainly aimed at prolonging the patient's life.

Cervical cancer can adversely affect the patient's relationship with the family as well, because it leads to dependency on the family. The study participants explain that cervical cancer patients experience difficulties in fulfilling their roles as wives, mothers, workers,

#### N. Jibat et al.

#### and neighbors.

The study participants explain that cervical cancer patients experience difficulties in fulfilling their roles as wives, mothers, workers, and neighbors. Its treatment is also economically demanding hence it negatively affects the economic profile of the family. Patients' productivity in the work place, sexual lives and childbirth are constrained. They all believe that patients experience long-time suffering and frequent hospital visiting. Above all, the study participants believe that cervical cancer finally leads to death and loss of loved ones. Nearly all of them tend to present death as unavoidable consequence of cervical cancer impliedly like other cancers.

Last week, a woman died in our vicinity from cervical cancer after treated at Black Lion Hospital through referral order (19 years old unmarried man).

I don't know what cervical cancer is but I hear as it is a fatal disease (17 years old unmarried women).

Even those who have reservations are pessimists about the possible effects of cervical cancer. Below are opinions of three unmarried girls, all reflecting uncertainties of cervical patients' survival as presented next:

I don't think that they all die; some may survive by chance (17 years old unmarried women). Some may survive still the majority will die (19 years old unmarried women)

I have never seen someone who recovered (survived) from cancer. For example, I know a woman who was diagnosed with breast cancer and doctors told her that she would survive if her breast was removed. Even though her breast was removed, she didn't survive (18 years old unmarried women).

# 4. Discussion

In this study we identified 5 themes, limited knowledge about cervical cancer, HPV is not known in the community, imprecise knowledge about the risk factors of cervical cancer, misconception of cervical cancer as not preventable or treatable, and death is viewed nearly as unavoidable consequence of cervical cancer. Specifically, there was a low level of awareness on the causes, transmission, prevention, and treatment of cervical cancer among participants. Nevertheless, they were aware that cancer exists and is a serious disease. The main symptom described was a burning sensation in the vagina. A few also mentioned symptoms such as vaginal discharge with a foul odor, bleeding, and pain. According to many participants, female genital mutilation, early marriage, early sexual initiation, genital organ hygiene, and multiple sexual partners contribute to cervical cancer development. Men also have very little knowledge of cervical cancer. Although they did not specify names, dosages, vaccination statuses, and the benefits of vaccination, the community is aware that health extension programs provide different vaccinations for children and adolescents. In addition, many women wait until symptoms appear before undergoing early cervical cancer screening. Generally, people have little awareness of cervical cancer treatment compared to other cancers. Many believe that cervical cancer doesn't have a cure and the treatment is only meant to prolong life.

It is crucial to understand the causes, transmission, and risk factors of a disease in order to prevent the disease. This also applies to cervical cancer. Nearly all participants from the community were unaware of the etiological agent of cervical cancer and had no idea that it is caused by a virus. This is similar to the findings of a previous study in Ethiopia ten years ago [21], which reported that participants did not know the causative agent and did not have general knowledge about cervical cancer. The finding is also consistent with other studies in Ethiopia [17,18,27] and Sub-Saharan Africa [8,10,11]. Although neither males nor females are aware of the etiologic agent or the way the disease is transmitted, they mentioned some risk factors, such as female genital mutilation, early marriage, and early sexual activity. The risk factors listed above are among the reproductive health issues addressed by HEWs in the family health segment of health extension package [28]. Though some of them were misconceptions, mentioning cervical cancer risk factors but not knowing the cause, transmission, and prevention indicates that awareness of cervical cancer risk factors is primarily drawn from general reproductive health education not from knowledge of the mechanism by which the risk factors is related with the disease.

It is well known in the community that vaccines are part of the health extension program's package specifically provided for children and adolescents. There is limited knowledge, however, regarding vaccine types, doses or benefits. Furthermore, study participants in this study were not aware of the presence of vaccines that can prevent cervical cancer. In spite of the fact that it is a quantitative study, similar findings were found in other parts of Ethiopia [29,30] and sub-Saharan Africa [31,32]. In contrast to this, knowledge about HPV vaccines among school children [33] and those living in Addis Ababa [34] is relatively good. The reason might be that school children are the target group for HPV vaccine and people in the capital city have better access to information. As for cervical cancer screening, women in our study had limited knowledge about it. Many of them believed that women would not pursue early cervical cancer screening until they experienced symptoms of the disease. The above result is in line with other studies [7,11,23,24]. Despite the fact that it is a common cause of cancer-morbidity [4], the health extension package, which provides essential information to the community at grass roots level, fails to give adequate attention to this issue [28]. It was evident from this study that some HEWs were unfamiliar with the causes, transmission and treatment of cervical cancer. In addition to the reasons explained above, poor physical accessibility of the screening service can also affect information accessibility in a community.

This study's participants mention that cervical cancer has no cure and the treatment focuses on extending life rather than curing it. Further, it was found that death as a nearly unavoidable consequence of cervical cancer. While cervical cancer can be a serious and potentially fatal disease, stating that death as a "nearly unavoidable consequence" is inaccurate and misleading. In East Africa, the oneyear and five-year survival rates for cervical cancer are 84% and 36%, respectively [35]. The rate drastically improves when identified at an early stage. This also shows the gap in awareness and knowledge about this disease. In addition, women tend to prefer indigenous medicine and religious healing options. The affordability and accessibility of indigenous medicine, as well as the fear of exposing private parts in health institutions, are some of the reasons given for choosing indigenous treatment or religious healing. Many will seek medical treatment in health facilities at the end, late in the disease stage. In another study [21], a similar pattern was observed a decade earlier. Furthermore, other studies in Ethiopia also indicate that most cervical cancer patients present to health care facilities at an advanced stage [36,37]. This will result in poor prognosis and increased mortality [38]. In addition, participants have rather little knowledge about cervical cancer's short and long term consequences, which is consistent with previous study [21].

Male involvement is essential for increasing reproductive and sexual health service uptake [39–41]. In spite of the fact that male participants in this study have low knowledge concerning cervical cancer, many of them are willing to support cervical cancer-related health services utilization after receiving information during the discussion. These days, different success stories regarding male involvement reveal that spousal coordination, shared responsibility and active involvement increases reproductive and sexual health service utilization [39–41].

# 4.1. Strength and limitation

The age and sex combination of the study participants allows us to understand whether there are sex or age-based differences in perspective. Also, we assess the awareness of HEWs, who are the closest health structure for the community. Our project study team is a multidisciplinary team which can be considered as strength for this study. The study also has some limitations, such as the findings might not be representative of rural settings, since the study participants were selected from urban and suburban areas. This study may have also been affected by social desirability bias, especially during the focus group discussions in which reality might be presented in alignment with what is considered socially acceptable. Triangulation of data obtained from different sources through various methods was useful to minimize effects of the social desirability bias.

# 5. Conclusion and implications

This study has shown limited community awareness about the occurrence, causes, means of transmission, means of prevention, prevalence and other characteristics of cervical cancer. Fear of cancer generally, inflicted unnecessary and excessive fear of cervical cancer. The study revealed the lack of awareness about HPV and limited knowledge of cervical cancer risk factors within the community. Most of the mentioned risk factors were inaccurate, indicating widespread misconceptions. This lack of knowledge extended to prevention and treatment, with a predominant perception that cervical cancer is neither preventable nor treatable. This study makes the following contributions to the study of cervical cancer. Firstly, despite its high fatality rate at the national level, the community regarding HPV infection partly emanates from lack of reliable and consistent information. While the health extension package is often said to improve the sexual and reproductive health of the community by focusing on prevention, this has not extended to increasing the awareness of cervical cancer in the community. This study demonstrates the importance of further evaluation of the country's progress towards achieving the WHO targets and identifying implementation gaps.

# 6. Future perspective

Research has identified low awareness as one of the biggest challenges in cervical cancer prevention. The study explores awareness of cervical cancer prevention, early diagnosis, and treatment. This can provide insights for researchers, policy makers, and other stakeholders on community awareness regarding cervical cancer screening, prevention and treatment. Furthermore, this will help identify where efforts should be focused to increase cervical cancer awareness in particular and prevention in general. In our study, we found that cervical cancer-related awareness is low. To improve communities' perceptions of cervical cancer, it is essential to plan for comprehensive education and information interventions that focus on risk factors, symptoms, treatment, complications, and prevention methods. The intervention should also extend to HEW, who are the bedrock of the health system structure.

## Data availability statement

The data that has been used is confidential.

# CRediT authorship contribution statement

**Nega Jibat:** Writing – review & editing, Writing – original draft, Methodology, Investigation, Formal analysis, Data curation. **Rahma Ali:** Writing – original draft, Methodology, Data curation. **Wondimagegn Adissu:** Writing – review & editing, Methodology, Data curation. **Gerezgiher Buruh:** Writing – review & editing, Methodology. **Alemseged Abdissa:** Writing – review & editing, Methodology, Funding acquisition, Conceptualization. **Gelila K. Goba:** Writing – review & editing, Methodology, Funding acquisition, Conceptualization. **Suzanne M. Garland:** Writing – review & editing, Methodology, Funding acquisition. **Nigisti Mulholland:** Writing – review & editing, Methodology, Funding acquisition, Conceptualization. **Kim Mulholland:** Writing – review & editing, Methodology, Funding acquisition, Conceptualization. **Demisew Amenu:** Writing – review & editing, Methodology, Funding acquisition, Data curation.

#### Funding statement

The study was supported by the London School of Hygiene and Tropical Medicine (Project ref: REF 102685ED). The funders had no role in the study design, data collection, analysis, and decision to publish, or preparation of the manuscript.

## Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

#### Acknowledgments

We would like to acknowledge data collectors and supervisors for their unreserved commitment. The authors also acknowledge study participants for their time and participation.

#### References

- L. Bruni, G. Albero, B. Serrano, et al., Human Papillomavirus and Related Diseases in the World. Summary Report 10 March 2023ICO/IARC Information Centre on HPV and Cancer (HPV Information Centre), 2023;(March.
- [2] H. Sung, J. Ferlay, R.L. Siegel, et al., Global cancer statistics 2020: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries, CA Cancer J Clin 71 (3) (2021 May 4) 209–249.
- [3] Cervical cancer | WHO | regional office for Africa [internet] [cited 2022 Oct 11]. Available from: https://www.afro.who.int/health-topics/cervical-cancer.
- [4] L. Bruni, G. Albero, B. Serrano, M. Mena, J.J. Collado, D. Gómez, J. Muñoz, S.S. Bosch FX de, Human Papillomavirus and Related Diseases in Ethiopia, 2021.
- [5] WHO. Cervical cancer [Internet]. [cited 2022 Oct 11]. Available from: https://www.who.int/health-topics/cervical-cancer#tab=tab\_1.
- [6] WHO, Cervical cancer elimination initiative [internet] [cited 2022 Oct 12]. Available from: https://www.who.int/initiatives/cervical-cancer-eliminationinitiative.
- [7] N.B. Yimer, M.A. Mohammed, K. Solomon, et al., Cervical Cancer Screening Uptake in Sub-saharan Africa: a Systematic Review and Meta-Analysis, in: Public Health, vol. 195, Elsevier B.V., 2021, pp. 105–111.
- [8] C. McCarey, D. Pirek, P.M. Tebeu, et al., Awareness of HPV and cervical cancer prevention among Cameroonian healthcare workers, BMC Wom. Health 11 (1) (2011 Oct 18) 45.
- [9] C. Kahesa, S. Kjaer, J. Mwaiselage, et al., Determinants of acceptance of cervical cancer screening in Dar es Salaam, Tanzania, BMC Publ. Health 12 (1) (2012 Dec 19) 1093.
- [10] M.M. Mabelele, J. Materu, F.D. Ng'ida, et al., Knowledge towards cervical cancer prevention and screening practices among women who attended reproductive and child health clinic at Magu district hospital, Lake Zone Tanzania: a cross-sectional study, BMC Cancer 18 (1) (2018 May 16) 565.
- [11] J.N.W. Lim, A.A. Ojo, Barriers to utilisation of cervical cancer screening in Sub Sahara Africa: a systematic review, Eur. J. Cancer Care 26 (1) (2017 Jan 1).
- [12] I.O. Morhason-Bello, F. Odedina, T.R. Rebbeck, et al., Challenges and Opportunities in Cancer Control in Africa: A Perspective from the African Organisation for Research and Training in Cancer, in: The Lancet Oncology, vol. 14, Elsevier, 2013, pp. e142–e151.
- [13] S. Anyangwe, C. Mtonga, Inequities in the global health workforce: the greatest impediment to health in sub-saharan Africa, Int J Environ Res Public Health 4 (2) (2007 Jun 30) 93–100.
- [14] P. Basu, HPV Vaccination and Screening for Cervical Cancer. Reducing Social Inequalities in Cancer: Evidence and Priorities for Research, International Agency for Research on Cancer, 2019.
- [15] FmoH FM of H-. Cervical Cancer National Program | MINISTRY OF HEALTH Ethiopia.
- [16] F.D. Republic, Guideline for Cervical Cancer Prevention and Control in Ethiopia Federal Democratic Republic of Ethiopia, vol. 23, Ministry of Health, 2015.
- [17] A. Saleem, A. Bekele, M.B. Fitzpatrick, et al., Knowledge and awareness of cervical cancer in Southwestern Ethiopia is lacking: a descriptive analysis, in: N. Erbil (Ed.), PLoS One 14 (11) (2019 Nov 12) e0215117.
- [18] T. Misgun, D.B. Demissie, Knowledge, practice of cervical cancer screening and associated factors among women police members of Addis Ababa police commission Ethiopia, BMC Cancer 23 (1) (2023 Dec 1) 961.
- [19] N. Belete, Y. Tsige, H. Mellie, Willingness and acceptability of cervical cancer screening among women living with HIV/AIDS in Addis Ababa, Ethiopia: a cross sectional study, Gynecol Oncol Res Pract 2 (1) (2015 May 18) 1–6.
- [20] S. Shiferaw, A. Addissie, M. Gizaw, et al., Knowledge about cervical cancer and barriers toward cervical cancer screening among HIV-positive women attending public health centers in Addis Ababa city, Ethiopia, Cancer Med. 7 (3) (2018 Mar 1) 903–912.
- [21] Z. Birhanu, A. Abdissa, T. Belachew, et al., Health seeking behavior for cervical cancer in Ethiopia: a qualitative study, Int. J. Equity Health 11 (1) (2012 Dec 29) 83.
- [22] C.M. Ndikom, B.A. Ofi, Awareness, perception and factors affecting utilization of cervical cancer screening services among women in Ibadan, Nigeria: a qualitative study, Reprod. Health 9 (1) (2012).
- [23] C.W. Ngugi, H. Boga, A.W.T. Muigai, et al., Factors affecting uptake of cervical cancer early detection measures among women in thika, Kenya, Health Care Women Int. 33 (7) (2012 Jul) 595–613.
- [24] V.K. Fort, M.S. Makin, A.J. Siegler, et al., Barriers to cervical cancer screening in Mulanje, Malawi: a qualitative study, Patient Prefer. Adherence 5 (2011) 125–131.
- [25] E. McEwan, An innovative approach to involving men in maternal and newborn health care: program experiences in the department of Matagalpa, Nicaragua 1–4 (2014).
- [26] J. Bond, The Commission on Paternal Involvement in Pregnancy Outcomes Presents : COMMISSION OUTLOOK : BEST and PROMISING PRACTICES for IMPROVING the Commission on Paternal Involvement in Pregnancy Outcomes Presents : C OMMISSION O UTLOOK, 2014 (June).
- [27] A. E., H. A., M. A., et al., Improving cervical cancer continuum of care towards elimination in Ethiopia: a scoping review, Res. Sq. (2023). https://doi.org/10. 21203/rs.3.rs-2791526/v1.
- [28] FMOH, Health Extension Program in Ethiopia, Heal Ext Educ Cent., 2007;(June, pp. 33–53.
- [29] M.T. Sinshaw, S. Berhe, S.G. Ayele, Knowledge and attitude towards human papillomavirus vaccine and associated factors among mothers who have eligible daughters in debre markos town, Northwest Ethiopia, Infect. Drug Resist. 15 (2022) 781.
- [30] G.N. Mihretie, T.M. Liyeh, A.D. Ayele, et al., Knowledge and willingness of parents towards child girl HPV vaccination in Debre Tabor Town, Ethiopia: a community-based cross-sectional study, Reprod. Health 19 (1) (2022 Dec 1).
- [31] D.U. Ramathuba, D. Ngambi, Knowledge and attitudes of women towards human papilloma virus and HPV vaccine in thulamela municipality of vhembe district in Limpopo province, South Africa, Afr. J. Reprod. Health 22 (3) (2018) 111–119.
- [32] S. Perlman, R.G. Wamai, P.A. Bain, et al., Knowledge and awareness of HPV vaccine and acceptability to vaccinate in sub-Saharan Africa: a systematic review, PLoS One 9 (3) (2014).

- [33] E.Y. Ukumo, F.G. Woldehawariat, S.A. Dessalegn, et al., Assessment of knowledge about human papillomavirus vaccination among primary school girls in Arba Minch Town, South Ethiopia, 2020 an Institution-based cross-sectional study, Cancer Manag. Res. 14 (2022 Jul 18) 2205–2214.
- [34] N. Dereje, A. Ashenafi, A. Abera, et al., Knowledge and acceptance of HPV vaccination and its associated factors among parents of daughters in Addis Ababa, Ethiopia: a community-based cross-sectional study, Infect Agent Cancer 16 (1) (2021 Dec 1) 58.
- [35] R. Kassa, Y. Irene, E. Woldetsadik, et al., Survival of women with cervical cancer in East Africa: a systematic review and meta-analysis, J. Obstet. Gynaecol. 43 (2023). Taylor and Francis Ltd.
- [36] M. Wassie, B. Fentie, Prevalence of late-stage presentation and associated factors of cervical cancer patients in Tikur Anbesa Specialized Hospital, Ethiopia: institutional based cross-sectional study, Infect Agent Cancer 16 (1) (2021 Dec 1) 30.
- [37] N. Dereje, A. Addissie, A. Worku, et al., Extent and predictors of delays in diagnosis of cervical cancer in Addis Ababa, Ethiopia: a population-based prospective study, J Glob Oncol 6 (2020 Feb 28) 277–284.
- [38] A. Dueñ as-GonzáLez, S. Campbell, Global Strategies for the Treatment of Early-Stage and Advanced Cervical Cancer, in: Current Opinion in Obstetrics and Gynecology, vol. 28, Lippincott Williams and Wilkins, 2016, pp. 11–17.
- [39] J.C. Fotso, A. Higgins-Steele, S. Mohanty, Male engagement as a strategy to improve utilization and community-based delivery of maternal, newborn and child health services: evidence from an intervention in Odisha, India, BMC Health Serv. Res. 15 (S1) (2015 Jun 8) S5.
- [40] M. Tokhi, L. Comrie-Thomson, J. Davis, et al., in: J.P. van Wouwe (Ed.), Involving Men to Improve Maternal and Newborn Health: A Systematic Review of the Effectiveness of Interventions., vol. 13, PLoS One, 2018 Jan 25 e0191620, 1.
- [41] T. Mutyaba, E. Faxelid, F. Mirembe, et al., Influences on uptake of reproductive health services in Nsangi community of Uganda and their implications for cervical cancer screening, Reprod. Health 4 (2007).