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ORIGINAL RESEARCH

Cancer Screening Practices Among Women Living with HIV in Istanbul, Turkey: A Qualitative Study

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Purpose: Women living with HIV (WLWH) are at a higher risk of developing cancers. Despite the presence of national cancer screening programs in Turkey, the participation and awareness of WLWH regarding these programs remain unclear. This study aims to explore the knowledge, beliefs, and behaviors of WLWH in Turkey regarding cancer screenings.

Patients and Methods: This is a qualitative study. In-depth interviews were conducted with women aged 20 and older who were being followed up at the HIV outpatient clinics of a training and research hospital in Istanbul, Turkey. Data was collected through phone interviews to ensure confidentiality and continued until data saturation was achieved. The collected data were analyzed using thematic content analysis with the help of Atlas.ti software.

Results: A total of 14 WLWH participated in the study, with a median age of 46.5 years (IQR:21 years). Three themes emerged: Cancer Awareness, Behaviors Towards Cancer Screening, and Barriers and Motivators in Cancer Screening Participation. Participants' knowledge about cancer and screening programs varied widely, with particularly low awareness of colorectal and breast cancer screenings. While some women practiced breast self-examination, regular participation in national screening programs was found to be low. The main barriers included lack of information, HIV-related stigma, and systemic challenges in accessing healthcare services. Many participants reported negative reactions from healthcare professionals upon disclosing their HIV status, leading to avoidance of screening services. Despite these challenges, the importance of early diagnosis was widely acknowledged, and participants said they would be more likely to participate in screenings if provided with proper information and support.

Conclusion: Low levels of cancer screening participation were observed among women living with HIV. To improve engagement in screening, these women need greater support, access to accurate information, and respectful care. Integrating screening into routine HIV services, providing training for health professionals, and reducing stigma are essential strategies to enhance participation and promote early detection in this vulnerable population.

Plain summary: Women living with HIV may face a higher risk of certain types of cancer, such as cervical, breast, and colorectal cancer. In Turkey, free national cancer screening programs are available, but it is not well known how women living with HIV use these services or what challenges they face.

In this study, we spoke with 14 women living with HIV in Istanbul, Turkey; all of whom were followed at the same infectious diseases clinic. Through one-on-one phone interviews, we asked about their knowledge, experiences, and feelings about cancer screenings. We focused on three types of screenings: breast, cervical, and colorectal cancer.

We found that while many women were aware that cancer screening is important, they often lacked clear information about what the tests are, how often they should be done, or where to go. Some women had done breast self-exams or had Pap smears in the past, but very few followed national screening schedules regularly. None of them had ever been screened for colorectal cancer.

Several women said they avoided screenings due to fear, embarrassment, or stigma related to their HIV status. Others felt more motivated to get screened because they wanted to stay healthy or because their infectious diseases doctor encouraged them.

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Our findings show that women living with HIV need more support, information, and respectful care to feel comfortable using cancer screening services. Training health professionals, reducing stigma, and making screenings part of regular HIV check-ups may help more women benefit from early detection.

Keywords: health knowledge, attitudes, practice, women's health, preventive health services, early detection of cancer, social stigma

Introduction

Various types of cancer, particularly those associated with viral infections have been reported to occur more frequently in people living with HIV (PLWH) due to immunosuppression compared to the general population.[1] Among the virus-related cancers with higher prevalence in PLWH are Kaposi's sarcoma caused by Human Herpesvirus 8 (HHV-8), non-Hodgkin lymphoma associated with Epstein-Barr virus (EBV), anogenital and cervical cancers linked to Human Papillomavirus (HPV), and liver cancers related to Hepatitis B virus (HBV) and Hepatitis C virus (HCV).[1] Moreover, cancer-related mortality is known to be higher in PLWH than in those without the infection.[2]

According to the Turkish National Cancer Screening Program, screenings are carried out in two formats: opportunistic screenings and population-based screenings.[3] Opportunistic screenings are generally implemented in secondary and tertiary healthcare institutions, whereas population-based screenings are conducted through Cancer Early Diagnosis, Screening and Training Centers (KETEM). These centers implement screening programs for breast, colorectal, and cervical cancers, aiming to improve both life expectancy and quality of life through early diagnosis.[3]

Among women living with HIV (WLWH), cervical cancer has a prominent place in the literature due to its high prevalence, more aggressive course, and inclusion in national screening programs.[4–7] Globally, cervical cancer ranks as the fourth most common cancer among women.[8] In WLWH, HPV infection poses a major concern, requiring a comprehensive and meticulous approach for its prevention, screening, and treatment.[7] Despite the fact that early diagnosis and treatment can significantly reduce the incidence and mortality of cervical cancer, multiple barriers to screening remain, particularly in low- and middle-income countries.[9]

While previous studies have explored the barriers and facilitators of cervical cancer screening in WLWH, awareness and attitudes toward other cancer screenings—such as breast and colorectal cancer, which are also included in national programs—have not been sufficiently studied in the Turkish context. Therefore, this study aims to examine the knowledge, beliefs, and behaviors of WLWH regarding national cancer screening programs in Turkey. Additionally, it aims to qualitatively explore the factors influencing their access to these services, including barriers and facilitators, based on the experiences of WLWH receiving follow-up care for at the infectious diseases clinic of a tertiary university hospital in Pendik, Istanbul, Turkey.

The study seeks to answer the following research questions:

- What is the knowledge, attitudes, and experiences of WLWH regarding national cancer screening programs (cervical, breast, and colorectal)?
- What are the barriers and facilitators influencing their access to cancer screening services?

Materials and Methods

Study Design

This is a qualitative study designed using a phenomenological approach. The primary aim of qualitative research is to uncover and explore lived experiences.[10] Phenomenology is a qualitative research method used to describe individuals' experiences, perceptions, feelings, and perspectives regarding a specific phenomenon or concept.[11] Therefore, phenomenological design, which is considered the most appropriate method for understanding human experiences, was deemed suitable for exploring the barriers and motivators affecting cancer screening participation among WLWH.

Study Setting

The study population consisted of WLWH, aged between 20 and 69, who were being followed up in the infectious diseases clinic of a public tertiary training and research hospital located in Pendik, a district of Istanbul, Turkey. Pendik is situated on the Anatolian side of Istanbul and is characterized by a medium socioeconomic and educational level.[12]

Recruitment

In Turkey, under the National Cancer Screening Program led by the Ministry of Health, free screening services for breast, cervical, and colorectal cancers are provided.[3] The main aim of the program is to detect cancer at an early stage to increase treatment success, prolong life expectancy, and improve quality of life. For breast cancer, Breast Self-Examination (BSE) and Clinical Breast Examination (CBE) are recommended for women aged 20 and above, while mammography every two years is advised for women aged 40–69. These screenings are conducted at Cancer Early Diagnosis, Screening and Training Centers (KETEM), Family Health Centers (FHC), Healthy Life Centers (HLC), and mobile screening units. Cervical cancer screening involves HPV-DNA testing every five years for women aged 30–65 and is also conducted in the aforementioned centers. For colorectal cancer, women and men aged 50–70 are screened using a fecal occult blood test (FOBT) every two years, and colonoscopy is recommended every ten years. Individuals with positive or suspicious results are referred to secondary or tertiary healthcare institutions for further investigation and treatment.[3] Accordingly, women aged 20–69 were included in the study. Participants were selected using the purposive sampling method of maximum variation sampling, based on voluntary participation.

Data Collection

Following the development of the research questions, pilot face-to-face interviews were conducted with two WLWH. During these pilot interviews, it was observed that the participants were not entirely comfortable answering questions face-to-face. Therefore, in order to facilitate a more comfortable environment, telephone interviews were selected as the data collection method. Telephone interviews were conducted between January 15 and January 30, 2025, and continued until targeted data intensity was reached. For participants who were not available at the time of the initial call, appointments were scheduled for a more convenient time. In total, 14 women were interviewed. During the interviews, participants were asked questions from a semi-structured interview guide developed by the researchers based on relevant literature. The questions were prepared under expert supervision and inspired by prior studies on similar topics. The semi-structured interview questions were organized from general to specific, but their order was flexibly adapted depending on the flow of the conversation. Each interview lasted approximately 20–45 minutes. Before the interviews, participants were informed about the purpose of the study, and details about the process (eg, audio recording, confidentiality, and duration) were provided. With the participants' consent, interviews were audio-recorded. If a participant declined audio recording, the researcher took detailed notes. All audio files were securely stored on an online storage system accessible only by the researchers.

Data Analysis

The recorded interviews were transcribed verbatim in digital format. Personal information and audio files were not shared with any third parties or institutions, and all data were presented anonymously. After transcription, the data were subjected to thematic content analysis. Codes, sub-themes, and overarching themes were generated based on the transcripts. Each transcript was analyzed by more than one researcher, who first developed preliminary codes. Later, all researchers met to create a joint coding framework. They independently coded the data using this guide, and final codes were determined through consensus and expert consultation. A confirmation meeting was held to ensure thematic saturation was reached, after which the themes were finalized. Braun and Clarke's six-phase thematic analysis method was used: (i) familiarization with the data, (ii) coding, (iii) generating initial themes, (iv) reviewing themes, (v) refining themes, and (vi) producing the report.[13] Triangulation was ensured through expert opinions, analysis by multiple researchers, and purposive sampling. Participant quotes were presented as direct excerpts in the findings section.

Atlas.ti software was used for data analysis. Throughout the research process, the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines were followed.[14]

Ethics

This study was conducted in accordance with the ethical principles outlined in the Declaration of Helsinki. Ethical approval was obtained from the Ethics Committee for Non-Drug and Non-Medical Device Research, Marmara University Faculty of Medicine (Approval No: 24.12.2024/09.2024.1579). Additionally, informed consent was obtained from all participants. All participants provided informed consent not only to participate in the study but also to allow the use of anonymized direct quotations in publications arising from the research.

Results

Fourteen female volunteers living with HIV with a median age of 46.5 years (IQR: 21 years) participated in our study. The participant characteristics are given in Table 1.

When looking at cancer screening behaviors, 9 of the participants stated that they had BSE. However, only 2 of them stated that they do it regularly every month. Eight of the women had previously had a CBE, but none of them stated that they had not had a regular CBE. Nine of women over the age of 40 had a mammogram, and most of them stated that they did not have a regular mammogram every 2 years. Ten women between the ages of 35 and 65 have previously had

Table 1 Participant Characteristics

Participant ID	Age	Marital Status	Occupation	Self-Reported Income Level	Year of HIV Diagnosis	Educational Level	Family History of Cancer
Participant 1	26	Married	Unpaid household worker	Medium	2021	Primary education	Yes (stomach)
Participant 2	25	Married	Teacher	Medium	2022	Bachelor's degree	None
Participant 3	32	Married	Domestic cleaner	Low	2024	Primary education	Yes (liver, lung)
Participant 4	65	Married	Unpaid household worker	Medium	2018	Primary education	Yes (cervix, breast)
Participant 5	48	Married	Unemployed	Medium	2019	Upper secondary education	Yes (hematologic cancer)
Participant 6	41	Married	Kitchen helper	Low	2024	Primary education	None
Participant 7	37	Married	Child care worker	Medium	2012	Upper secondary education	None
Participant 8	47	Widowed	Unemployed	Low	2019	Primary education	Yes (lung, malignant melanoma)
Participant 9	55	Married	Unpaid household worker	Medium	2014	Primary education	None
Participant 10	60	Married	Retired	Low	2011	Primary education	None
Participant 11	46	Single	Shopkeeper	Medium	2007	Primary education	Yes (bladder, colon, breast)
Participant 12	56	Single	Unemployed	Low	2012	Upper secondary education	Yes (malignant melanoma)
Participant 13	54	Single	Retired	Medium	2003	Bachelor's degree	None
Participant 14	35	Married	Driving instructor	Medium	2019	Bachelor's degree	None

Table 2 Themes and Sub-Themes

Themes	Sub-Themes
1. Cancer Awareness	1.1. Information about cancers 1.2. Information about cancer screenings 1.3. Information about early diagnosis of cancer 1.4. HIV and cancer screenings
2. Behaviors Towards Cancer Screenings	2.1. Breast cancer screening 2.2. Cervical cancer screening 2.3. Colorectal cancer screening
3. Barriers and Motivators in Cancer Screenings	3.1. Barriers to cancer screenings 3.2. Motivators for cancer screenings 3.3. Strategies for information and awareness

a smear taken, but they are not sure if HPV-DNA has been checked. None of the women between the ages of 50 and 70 have undergone FOBT and colonoscopy for colorectal cancer screening.

When the transcripts obtained from the participants were evaluated in our study, a total of 78 codes were reached. These codes were collected under 3 themes (Table 2). These main themes are "Cancer Awareness, Behaviors Towards Cancer Screenings and Barriers and Motivators in Cancer Screenings". Table S1 provides a comprehensive breakdown of the codes according to themes and sub-themes. In addition, as a result of the responses given by the participants, Figure 1 was created regarding the barriers and motivators for WLWH to participate in cancer screening programs.

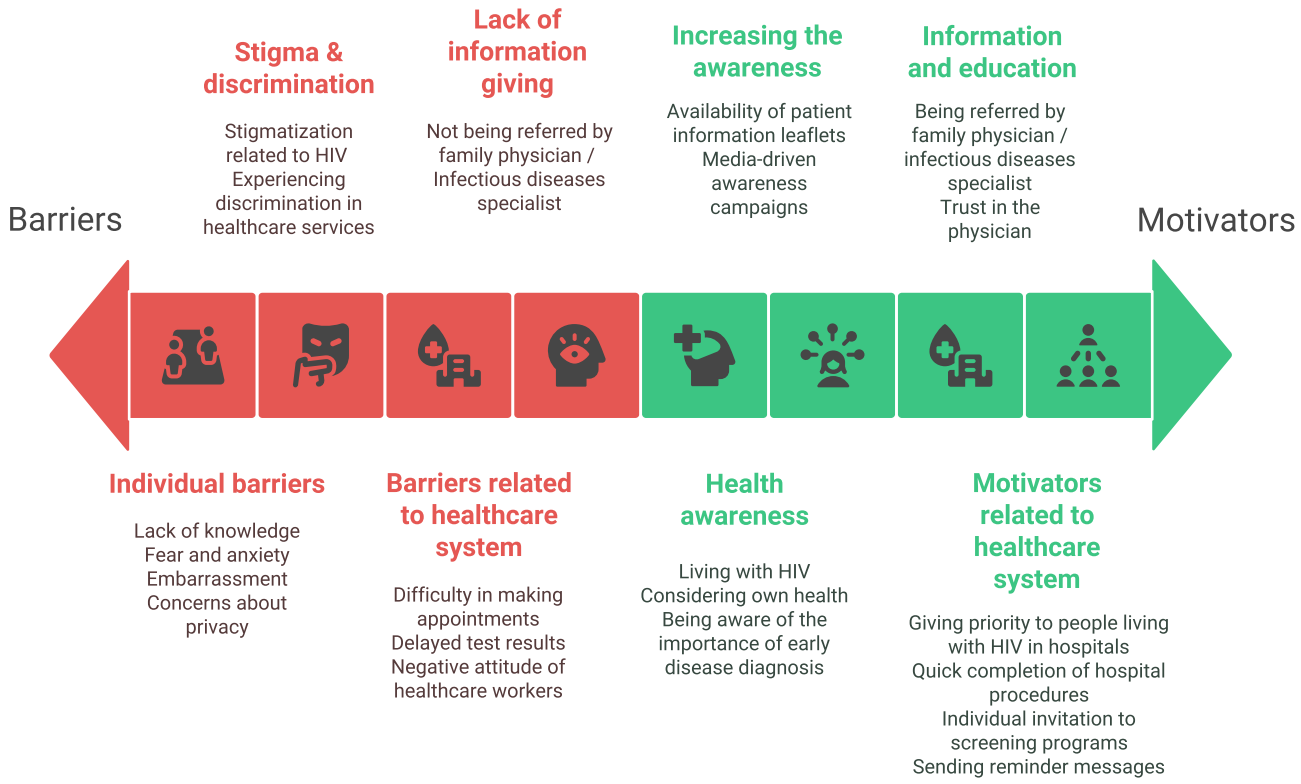

Figure 1 The barriers and motivators for WLHIV to participate in cancer screening programs.

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Cancer Awareness

Information About Cancers

It was found that the participants' knowledge about breast, cervical and colorectal cancer was generally limited. It has been observed that the participants had general information about breast cancer, but while some participants had basic information about cervical cancer, most of them confuse this type of cancer with other gynecological diseases or express that they do not have any information at all. On the other hand, there are a small number of participants who know the relationship between HPV and cervical cancer and can provide detailed information about it. The majority of participants know that HPV is sexually transmitted, but the depth and accuracy of this information vary. Most of the participants stated that they did not have any information about colorectal cancer.

> I don't know that much about cancers. (Participant 4, 65 years old)

> This is a little less known because it is something that is not usually brought up a lot. (Participant 13, 54 years old)

> I have no idea. I know that cancer is not contagious. (Participant 9, 55 years old)

> In fact, HPV definitely needs to be explained very well. It happens not only to women, but also to men. Or how it was transmitted is unknown. They think they can be protected with condoms. No. HPV cannot be protected even with a condom. (Participant 13, 54 years old)

The participants' sources of information about cancers are mainly health professionals, the internet, television and their social circles. Some participants stated that they were doing research personally because of their personal fear of cancer.

> I have nurse nephews, for example, I learn from them. I'm learning from TVs. I learn from friends when I go to the hospital. I'm asking everyone a question. (Participant 4, 65 years old)

> I go to the primary health care center. Because I usually go to the primary health care center, my doctor told me that. (Participant 8, 47 years old)

> The thing I've been most afraid of since long ago is cancer. That's why I always research, I'm looking at the internet, I used to ask my doctors. (Participant 6, 40 years old)

Information About Cancer Screenings

The participants' lack of knowledge about screening methods, especially related to cervical and colorectal cancer, drew attention. While some of the participants are aware of applications such as smear tests and mammograms, there are many people who are not aware of the purpose, frequency and age group of these applications.

BSE is relatively more well-known among the participants. However, this awareness does not indicate that the application is carried out in the way recommended by health professionals, it is understood that it is mostly based on personal and incomplete methods. However, the lack of information about cervical cancer screening is more pronounced; although some participants have had a smear test, they do not know about the content and purpose of the test.

> For example, a smear test is performed as a woman. After that, a mammogram related to breast cancer is performed or an ultrasound is performed. These can also be annual. I know these things are done. (Participant 13, 54 years old)

> When I go into the shower, I usually look at both sides of me with my hand like this. I'm looking all over it. To see if there's anything. That's what I usually do. (Participant 8, 47 years old)

Participants usually get information about cancer screenings from the internet, television, healthcare professionals around them, and relationship experiences. Although there are participants who receive information from doctors and nurses working in family health centers, the number of participants who indicate that they are not sufficiently informed by family doctors is also at an underestimated level.

> There is a midwife in the primary health care center, that lady taught me self-breast examination. (Participant 11, 46 years old)

Doctors also recommend it, and I'm a little curious about these issues. I am someone who prefers to research. That's why I'm researching on the Internet about diseases. But I also consulting with my doctors, of course. (Participant 14, 35 years old)

Information About Early Diagnosis of Cancer

The vast majority of participants agree that early diagnosis has a life-saving role in the fight against cancer. The expression "early diagnosis saves lives" is repeated by many participants and this discourse indicates the existence of an awareness at the level of social consciousness. However, this awareness remains mostly at a superficial level; awareness of technical and practical information, such as how early diagnosis is provided, which tests should be performed and how often, is quite limited. Participants state that early diagnosis ensures that the disease is diagnosed before progression and treatment is started on time, but information about this process is usually based on an application based on complaints.

If diagnosed early, it will save lives. So, it can be saved as much as possible. (Participant 1, 26 years old)

They say early detection saves lives. In other words, when it reaches the first stage or when it appears in a small cell in the blood, the cancer is diagnosed at least initially before it reaches the second and third stage, treatment begins. (Participant 6, 40 years old)

I think if you go regularly for check-ups, they'll all have an early diagnosis. The important thing is to go for regular check-ups. (Participant 1, 26 years old)

HIV and Cancer Screenings

Living with HIV has become an element of motivation for some participants to monitor their health more closely and participate in cancer screenings, while for others it has become a blocking factor due to fear, anxiety and stigma. In particular, the possibility of being diagnosed with a new disease creates psychological pressure and negatively affects screening behavior. However, some participants who felt well and trusted their doctor stated that HIV did not affect their screening decisions and that they had the necessary checks at the direction of the physician.

You're saying that I already have HIV. You are praying that there will not be another disease. You're afraid because the process after that might be that you need to have surgery etc. (Participant 11, 46 years old)

As long as I am not too uncomfortable, provided that it is not too difficult, I would like to participate in my follow-ups in a way that will not tire me out, because I am very obsessed a little psychologically, I guess. (Participant 9, 55 years old)

I'm already taking very good care of myself, thank God. I eat very healthily. As for cancer, of course, thank God I have a very good doctor like D… (infectious diseases doctor that follows her). She's already telling me what to do anyway. (Participant 12, 56 years old)

Behaviors Towards Cancer Screenings

Breast Cancer Screening

While some of the participants performed BSE regularly, some avoided this practice due to lack of knowledge or fear. Most of those who have experienced breast-related complaints have consulted to a doctor and had the necessary checks done. All of the participants received the breast cancer screening recommended by the doctors positively. In particular, they emphasized that the recommendations of infectious diseases doctors who do their own follow-up on cancer screening are very important. Experiences with mammography show variability; while some participants had it done, some had never had it done, the age factor was decisive. However, no participant stated that she had a regular mammogram every 2 years.

I look at it sometimes, after I've had a bath or something. I look sometimes when I think about it. I'm trying to touch it all over, see if there is any swelling. I'm looking to see if there's any painful area or something. (Participant 1, 26 years old)

I'm checking myself for breast cancer, I'll get checked out. I also do it every month. My doctor told me, she always said check it out, she said. (Participant 4, 65 years old)

I'm afraid of it too. If anything comes to my hands, I'll be scared to death. When I do it myself, I say there it is, so maybe there's nothing, but it came to my hand. It feels like there is, or something. I can't be sure. (Participant 12, 56 years old)

I had a swelling in my breast, I went to the hospital immediately. I had a mammogram and the results was clean. I go to the hospital immediately when I have a complaint. (Participant 8, 47 years old)

D… (infectious diseases doctor that follows her) told me that I should have these done every year. When she first said it, I thought, okay, let's do it then. I think it's even more important when my own doctor who follows me regularly tells it to me. (Participant 13, 54 years old)

Cervical Cancer Screening

The participants' experiences of cervical cancer screening vary. Some participants stated that they had regular smear testing, while others had it done only once or did not apply at all. However, it was found that they were not sure whether HPV-DNA was being looked at in the smear. The genital examination and sample giving process was found challenging for some participants due to the privacy and discomfort. The process of getting an HPV diagnosis has mostly taken place by chance or on a complaint. Some participants stated that they had a chance to intervene early by detecting serious precursor lesions in this process.

I already have HPV now. I'm trying to keep my immune system very high for it. For example, I quit smoking. (Participant 2, 25 years old)

I was HPV positive many years ago. There was a little bit of a problem. The last smear was also clean, HPV was negative. So I'm checking it too. (Participant 5, 48 years old)

I have a smear done, and D… (infectious diseases doctor that follows her) sends it every year or so. Nothing bad has happened so far, so it's been quite a year, I've had it done, more than a year even. (Participant 10, 60 years old)

Actually, I'm a little shy, so as a lady, it's very unpleasant to lie on that table (gynecological table) or do that thing, so it's not pleasant. But we have to endure. (Participant 9, 55 years old)

It makes me feverish when I think about it. So I didn't have it done. I don't know, there's no such thing, I thought. I felt scared." (Participant 12, 56 years old)

When I gave a smear, carcinogenic substances appeared in me, for example, they were cleaned by surgery. If I hadn't had it done, maybe it would have been in further processes. Maybe there would be no cure. A worse process could have been waiting for me. (Participant 14, 35 years old)

Colorectal Cancer Screening

The participants' experience of having a fecal occult blood test is quite limited, and none of the participants had this test for colon cancer screening purposes. Although most participants had not had a test before, they indicated that they were willing to take the test if it was recommended by a doctor. However, some participants have reservations about giving the test due to practical difficulties, such as toilet conditions, or privacy concerns. A small number of participants who had a stool test had this test because of a different health problem.

If the doctor says it will be done. I would do it if necessary, especially if I have a complaint. (Participant 10, 60 years old)

Of course, of course, I mean, whatever D… (infectious diseases doctor that follows her) says is okay for me, I mean, whatever my doctor says, yes. (Participant 12, 56 years old)

I wish I could, but I can't. Because it is very difficult for me to go to the toilet anywhere other than my home. Toilets are so bad in hospitals. You can't give stool anyway, you can't do it there. (Participant 13, 54 years old)

Barriers and Motivators in Cancer Screenings

Barriers to Cancer Screenings

Participants indicated encountering several obstacles in obtaining cancer screening tests at both systemic and individual levels. The most commonly cited systemic concerns included challenges in appointment scheduling, prolonged waiting periods, delays in test findings, and insufficient attention from healthcare providers. Participants underlined the need for a more efficient and well-organized screening testing procedure.

In addition to this, stigma, discrimination, and privacy problems are experienced by individuals living with HIV. Some interviewees said that the unfavorable attitudes of healthcare professionals made them feel isolated or humiliated. They reported feeling anxious and ashamed about disclosing their HIV status, which occasionally caused them to avoid seeking medical attention. Nevertheless, several participants indicated that they did not encounter discrimination and noted the supportive behavior of some healthcare workers.

> We can't get appointments at all. Let's say I came for cancer screening—they give me an ultrasound appointment three months later. Our doctor says, 'Come today, come tomorrow, come the next day.' I get an appointment for 10 o'clock, but they don't see me until 11:30. It's always delayed. Then when I do go, they get angry and say, 'Didn't I tell you not to come today but tomorrow? (Participant 6, 40 years old)

> For example, test results take a long time to come back, and there's always the fear of bad news. When the doctor is indifferent, it makes me anxious. The more indifferent they are, the more it affects my trust. (Participant 7, 37 years old)

> I'm talking about Turkey in general, things should be faster. If I've given a smear test, I shouldn't have to wait a month. It should be easier to get appointments. (Participant 14, 35 years old)

> When I told the doctor about my condition, they didn't want to treat me—they brushed it off. That really hurts, what can I say. And then they put only patients like us in one area, and everyone knows that space is for 'those' patients, so others know you're sick. It feels like discrimination. We're in treatment, so we're technically considered negative now anyway. (Participant 7, 37 years old)

> I feel ashamed, embarrassed. Even though it's not my fault, I still feel ashamed when I go to the doctor. I have to tell every doctor I see, even if I switch doctors. (Participant 8, 47 years old)

> Once, a doctor referred me to gynecology. They yelled at me there—in front of so many people. They said, 'You'll have to wait, we'll see you last,' and they shouted it publicly. I waited, and when it was finally my turn, they had laid out black garbage bags everywhere. I was examined like I had the plague. One of them shouted at me, 'You have AIDS.' (Participant 11, 46 years old)

Motivators for Cancer Screenings

In general, participants generally expressed a positive attitude toward engaging in cancer screening practices. Their trust in their doctors and their understanding of the value of early diagnosis played a significant role in this disposition. Key motivators for participation included proactive recommendations from their infectious disease specialists, a strong personal commitment to maintaining health, a desire to detect potential illnesses at an early stage, and heightened awareness due to weakened immunity.

While a few participants acknowledged experiencing anxiety or fear related to hospitals, this concern was generally outweighed by their desire to protect their health.

Moreover, many highlighted that being given priority during appointments and the efficiency of procedures encouraged them to participate in screenings. Furthermore, they recommended that as an efficient educational tool, cancer screening leaflets be distributed to all women who attend the hospital.

> If the doctor who follows my condition recommends a screening test, I definitely try to go. After all, fear doesn't change fate. (Participant 1, 26 years old)

> I would want to find things out early. Taking care of myself is important—especially since my immune system is weak. (Participant 2, 25 years old)

They could give us priority. I don't know. maybe the hospital where we're followed should make it somewhat mandatory. (Participant 13, 54 years old)

I mean, there shouldn't be repeated trips back and forth to the hospital. It should be made easier. (Participant 6, 40 years old)

Leaflets could be given to women coming to the hospital—no matter which department. I really think women should be informed about cancers. (Participant 11, 46 years old)

Strategies for Information and Awareness

Participants underlined that in order to promote enrolment in cancer screening programs, educational and referral initiatives must be strengthened. It was stated that general practitioners (GPs) ought to be actively involved in this process and that it would be beneficial to educate people about screenings when they visit primary care facilities. Furthermore, it was highlighted that other doctors who interact directly with patients throughout their treatment should consistently remind them about the importance of undergoing screenings. One participant suggested making screenings mandatory, implementing an individual tracking system similar to a "vaccination card", and utilizing the national e-Government platform to deliver reminder notifications.

It was proposed that media-driven awareness campaigns, particularly through television and digital platforms, be conducted to engage a wider audience, alongside enhancing the circulation of information via municipal authorities and home healthcare services.

Just like we have a vaccination card to track whether you have had a particular vaccine or not, I think there should be a similar cancer screening test card. It could be accessible on the e-Government system as well. For example, when a year is up, they should be contacted. The person would be notified that their year has passed, and they need to take the test again. There should be a warning asking whether the test has been taken. (Participant 14, 35 years old)

Actually, everyone who visits the family physician needs to undergo these screenings. The family physician should inform them, or when you go to internal medicine. For example, an internal medicine doctor could perform this kind of check-up once for everyone. (Participant 5, 48 years old)

Especially the information provided by the infectious disease specialist who follows the patient is very important. Because HIV-positive patients already take care of themselves, and their best guides are their own doctors. (Participant 12, 56 years old)

I think television is still a very effective channel. Information can be disseminated through it, which is more effective because it reaches everyone. (Participant 12, 56 years old)

Discussion

In this study, it was observed that WLWH who were being followed up at a tertiary healthcare institution in the Pendik district of Istanbul had limited awareness about cancer screenings.

Pendik, a district of Istanbul, holds a moderate level of socio-economic development compared to other districts across Turkey.[12] Similarly, when compared to other districts in Istanbul, Pendik ranks at a moderate in terms of education.[15] Considering that all women attending the hospital reside in the Pendik district, it is expected that their knowledge regarding cancer screening would be limited. Cancers are among the leading causes of morbidity and mortality among people living with HIV (PLWH). Although awareness of certain cancer risks, such as those associated with HPV, is relatively high among PLWH, the level of detailed knowledge concerning cancer risk factors and preventive strategies remains comparatively low.[16]

Although the majority of participants in the study possessed basic knowledge about cervical, breast, and colorectal cancers, this knowledge was often found to be incomplete or inaccurate. While participants were aware that HPV is a sexually transmitted virus, their understanding of transmission routes and preventive measures was limited. This lack of knowledge constitutes a significant barrier to participation in screening programs. Indeed, a meta-analysis focusing on sub-Saharan Africa demonstrated that among WLWH, having knowledge about cervical cancer increased screening

participation by nearly fivefold.[17] This finding highlights the need to enhance public awareness of HPV and underscores the importance of educational programs specifically targeting WLWH.

The low level of awareness regarding colorectal cancer among participants, and the fact that none had undergone colorectal cancer screening, is a noteworthy finding. Most participants were unaware of simple and widely used screening methods such as the fecal occult blood test. Although some assumed that the test involves collecting a stool sample, they generally lacked precise information. A study conducted within integrated healthcare systems showed that individuals living with HIV had higher participation rates in colorectal cancer screening compared to those without HIV.[18] This finding suggests that screening rates are influenced not only by individual awareness but also by the structure and organization of the healthcare system. In healthcare systems like that of Turkey, the lack of such integration may contribute to low levels of knowledge, awareness, and participation in colorectal cancer screening.

In the study, awareness of breast cancer screening was found to be higher than cervical and colorectal cancers. While some participants reported undergoing regular mammography, others avoided screening due to misinformation about age criteria, fear, or difficulties accessing the healthcare system. As this study was a qualitative analysis involving only WLWH, participation rates in mammography screening were not compared with those of women without HIV. However, a study conducted in Canada demonstrated that WLWH were less likely to undergo breast cancer screening compared to other women.[19] Moreover, the same study found that mammography participation was higher among WLWH who received regular care from both a primary care physician and an HIV specialist.[19] Notably, among our participants, knowledge and practice of BSE varied. Some reported performing it regularly, while others were uncertain about how to do it properly. These findings indicate that although breast cancer screening is more widely recognized in the community, individuals often face challenges in translating this awareness into action. In this context, it can be suggested that WLWH should be further educated on BSE, and that this practice should be integrated into healthcare services to ensure wider adoption.

Participation in cancer screening is largely influenced by individual motivation, fears, and difficulties in accessing the healthcare system. While some individuals regularly attend screenings such as the Pap smear, others avoid them due to reasons such as embarrassment, fear, or lack of time. A common concern expressed by many patients, the fear of receiving a poor test result, has also been noted in a meta-analysis. According to this study, one of the major barriers to cervical cancer screening among PLWH is the fear of being diagnosed with an additional illness.[20]

One of the most significant barriers to healthcare access among PLWH is the stigmatizing and discriminatory attitudes of healthcare professionals. Participants reported that some healthcare workers became distant or indifferent after learning of their HIV status, and in some cases, overt discrimination was experienced. These findings indicate that PLWH still face substantial barriers in accessing healthcare services, which may negatively impact their participation in cancer screening programs. In a study by Gordon et al, it was reported that many WLWH refrained from participating in cervical cancer screenings due to stigma.[21] Therefore, minimizing stigmatization toward people living with HIV within healthcare systems is essential to improving participation rates in cancer screening programs.

Participants made several suggestions to enhance awareness of cancer screenings. These included encouraging family physicians and infectious diseases specialists to provide more proactive referrals, increasing the amount of information healthcare professionals offer regarding HIV and cancer screenings, and prioritizing HIV-positive patients during follow-up appointments. A study conducted in Puerto Rico evaluated the knowledge levels of healthcare providers responsible for the care of PLWH regarding cancer screenings. The findings indicated that as healthcare providers' experience increased, so did their knowledge of cancer screening protocols and their likelihood of referring patients to screening programs.[22] In this regard, improving the knowledge of newly graduated healthcare professionals working in HIV clinics about cancer screening programs is of critical importance.

Our study has certain limitations. Despite the use of maximum variation sampling, the limited number of participants may have led to insufficient representation of some subgroups. As this is a qualitative study, the findings cannot be generalized to the broader population. This study focused only on the perspectives of women living with HIV regarding national cancer screening programs in Turkey. It did not include the views of healthcare providers or other stakeholders, and it addressed breast, cervical, and colorectal screenings together without detailed cancer-specific analysis. As barriers and facilitators are unlikely to be identical across all cancer types, future studies may benefit from focusing on a single cancer type (eg, cervical cancer) and exploring it from the perspectives of healthcare providers or other stakeholders.

Conclusion

This study demonstrated that WLHIV in Istanbul have limited knowledge of cancer types and screening practices, particularly for cervical and colorectal cancers, and often face misconceptions about early diagnosis. While HIV motivated some women to engage more actively in health monitoring, others reported fear, stigma, and anxiety as significant barriers. Systemic challenges such as delays in appointments and test results, together with negative healthcare experiences, further reduced participation in national screening programs. Trust in infectious disease specialists and physician recommendations emerged as key motivators for screening uptake.

To improve participation, cancer screenings should be integrated into routine HIV care, and healthcare professionals should be trained to provide non-stigmatizing, patient-centered services. Implementing policies that facilitate access to healthcare for WLHIV, introducing educational programs aimed at reducing stigma, and raising awareness among healthcare providers about HIV and cancer screenings may prove effective in increasing screening rates. Tailored educational programs, efficient reminder systems, and integrating cancer screening into routine HIV clinical follow-ups could serve as sustainable strategies to encourage regular attendance. Addressing psychosocial concerns and strengthening health system efficiency are essential to ensure equitable access to early cancer detection for WLHIV.

Artificial Intelligence (AI) Use Statement

Artificial intelligence (AI) technology (ChatGPT by OpenAI) was used for language editing and for assistance in the preparation of the plain language summary of this manuscript. The AI tool was not involved in content generation, data analysis, or scientific interpretation. All scientific content, including the plain language summary, was critically reviewed and approved by the authors. The authors take full responsibility for the accuracy and integrity of the entire manuscript.

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Disclosure

The authors declare that they have no financial interests or conflicts of interest related to this study.

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