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EDITED BY

Robert Kerrison,
University of Surrey, United Kingdom

REVIEWED BY

Anurima Baidya,
Johns Hopkins University, United States
Vinit Nalawade,
Duke University Health System, United States

*CORRESPONDENCE

Charles Waihenya
✉ charleswaihenya@uonbi.ac.ke

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Barriers and facilitators to prostate cancer screening, early presentation and diagnosis-experiences of men diagnosed with prostate cancer in Kenya

Charles Waihenya^{1,2*}, S. M. Thumbi³, Daniel Kinyuru Ojuka^{1,2}, Camille Ragin^{2,4} and Charnita Zeigler-Johnson^{2,4}

¹Department of Surgery, University of Nairobi, Nairobi, Kenya, ²African Caribbean Cancer Consortium, Prostate Cancer Working Group, Philadelphia, PA, United States, ³Center of Epidemiological Modelling and Analysis, Institute of Tropical and Infectious Diseases, University of Nairobi, Nairobi, Kenya, ⁴Cancer Prevention and Control Program, Fox Chase Cancer Centre-Temple Health, Philadelphia, PA, United States

Purpose: To identify the barriers and facilitators to help seeking, and screening for early presentation and diagnosis of prostate cancer in Kenya.

Methods: Seven focus group discussions (FGDs) were held with a total of 46 patients diagnosed and living with prostate cancer, 65% ($n = 30$) from a public Hospital and 35% ($n = 16$) from a private hospital. An FGD guide was used to collect data on patients' barriers and facilitators of prostate cancer screening, help seeking, and diagnosis.

Results: The patients were distributed across different age groups: 4.3% ($n = 2$) were aged 50–59, 41% ($n = 19$) were aged 60–69, and 54% ($n = 25$) were aged 70 and above. The majority of the patients were in the 7th and the 8th decade 41% ($n = 19$) and 54% ($n = 25$), respectively. A larger population had at least secondary and tertiary education 39% ($n = 18$) and 35% ($n = 16$) respectively. Retired patients constituted 33% ($n = 15$), employed at 28% ($n = 13$), and 28% ($n = 13$) were unable to work. The main themes emerging from this study were barriers to help seeking: Lack of awareness of symptoms, symptoms misattribution and management associated stigma, impact on libido and perceptions, beliefs about prostate cancer and economic factors and financial constraints. Others were misdiagnosis, inadequate health infrastructure and failure to disclose diagnosis. Interventions emerging from the interviews were cultural sensitization and education programs, public education and awareness campaigns, positive masculinity messages and an option for gender-matched health providers.

Conclusion: The delay in early presentation and diagnosis of prostate cancer is a result of the complex interplay of multiple factors. This underscores the need for a multifaceted approach to improving early presentation and diagnosis of prostate cancer. Recognizing this complexity is crucial for the development of effective holistic strategies to improve timely presentation and diagnosis and ultimately health outcomes for men at risk of prostate cancer.

KEYWORDS

prostate cancer, Kenya, focus groups, barriers, facilitators

1 Introduction

Prostate cancer is the second most frequently diagnosed cancer and the fifth leading cause of cancer-related deaths among men worldwide with an estimated 1.4 million new cases and 375,000 deaths in 2020 (1). In Africa, there is a high case-fatality rate associated with prostate cancer, mainly due to late diagnosis (2). Despite advances in screening techniques, significant barriers impede early diagnosis particularly in low and middle-income countries (3, 4). Prostate cancer typically does not show symptoms in the early stages and due to lack of screening services most cases in developing countries are diagnosed after progression to an advanced stage (5) leading to poor prognosis. A significant challenge experienced in developing countries is the delayed presentation of prostate cancer patients at healthcare facilities (3, 6, 7). Routine surveillance and routine checkups are potentially helpful and should be emphasized in awareness campaigns.

In Kenya, prostate cancer is the most prevalent cancer among males with an Age-Standardized Incidence Rate (ASR) of 40.6 per 100,000 (8). In Kenya, there was a 22% (3,412) increase in the number of new cases of prostate cancer in 2020 compared to 2019 (9). It is projected that the number of cases will continue to rise by 2040 due to factors such as population growth, increased life expectancy, urbanization and risk factors for cancer (9). Early detection of prostate cancer is a key pillar to the achievement of the goal of cancer control strategy 2023–2027 in Kenya (9). Despite educational campaigns, the uptake of prostate cancer screening is low. Although approximately half of Afro-American men in the United States undergo screening for prostate cancer, the percentage of Africans and Kenyans screened for the disease ranges significantly lower, from 0% to 11% for Africans and from 4.1% to 11% for Kenyans (10).

This is exacerbated by the limited availability of screening and early detection services. Furthermore, patients living with various stages of prostate cancer experience various challenges ranging from lack of knowledge and awareness, negative perceptions, limited access to treatment, cultural barriers, lack of social and family support networks, stigma, and mental health issues (11). There is a paucity of studies on barriers to early presentation and diagnosis of prostate cancer especially among patients with prostate cancer. This study sought to explore the perceptions of patients living with different stages of prostate cancer in Kenya, to identify gaps in disease knowledge and unmet needs that could be addressed and barriers to early presentation and diagnosis for prostate cancer.

2 Materials and methods

2.1 Study design

This was a qualitative exploratory design that employed focus group discussions (FGD) to gain deeper insights into factors that influence men's decisions about screening, help seeking and diagnosis for prostate cancer. FGDs allowed for rich discussions and diverse experiences.

2.2 Study population and setting

The target population included men undergoing treatment and follow-up for prostate cancer at the Kenyatta National Hospital (KNH), a public national referral hospital, and the MP Shah Hospital, a private hospital located in Nairobi. Eligible men were aged 40 years or older who were histologically diagnosed with prostate cancer. This age was selected because prostate cancer is the most prevalent in this age group. All patients were purposely selected from the data sets of the African Cancer Genomic Registry (ACGR) and International Registry for Men with Advanced Prostate Cancer (IRONMAN) studies recruited over the last 2 years. Potential participants from the registries were contacted via phone and introduced to the study's purpose, after which a convenient date and time were scheduled for them to participate in the FGDs. The FGDs were conducted at Kenyatta Hospital (a Public Hospital) or at MP Shah Hospital (a Private Hospital) within the clinics where participants received follow-up care after the interviews. The FGDs were conducted in July 2024. Patients too sick to participate in a 90-min discussion were ineligible to participate.

2.3 Ethical considerations

Ethical approval for this study was obtained from the Kenyatta National Hospital/University of Nairobi Ethical and Research Committee (P189/03/2024). A research permit was also obtained from the National Commission for Science Technology and Innovation (NACOSTI P/24/37212). Written informed consent was sought from participants, where participants were informed of the study objectives, potential risks and benefits as well as the voluntary nature of participation. Men were provided informed consent in English or Kiswahili.

2.4 Data collection

The study utilized FGDs to explore the barriers to early presentation and diagnosis of prostate cancer among men. FGDs facilitated the exploration of diverse perspectives and experiences while providing context and depth to the data collected. A total of 7 FGDs (4 in a Public Hospital and 3 in a Private Hospital) were conducted to address the study objective. The number of FGDs was based on the rule of thumb where 3–4 FGDs are required per category of participants to ensure data saturation (12). FGDs comprised 6–8 individuals, totaling 46 individuals for the 7 FGDs. An FGD guide that included open-ended questions and follow-up probes was designed to gain deeper insights into factors that influence men's decisions about screening and help seeking and diagnosis of prostate cancer.

The interviews were audio-recorded with written consent from the study participants. Additionally, notes were also taken during the discussions. The FGDs lasted between 60–90 min, allowing for detailed discussions.

The first author conducted the FGDs with the assistance of the research team which included a male master's student and a female PhD researcher. Both assistants were trained in conducting

qualitative research. To minimize potential bias, the research team was interdisciplinary, allowing for a holistic understanding of barriers to early prostate cancer screening during data collection and analysis.

2.5 Data analysis

The recorded audio was transcribed and translated into English by research assistants fluent in Swahili and English. The transcripts were reviewed by cross-referencing them with notes to ensure accuracy and consistency. The data was imported into QSRNVIVO version 12.5.0 for the development of codes. Thematic analysis was conducted using both deductive and inductive coding approaches. Deductive coding was guided by the Health Belief Model (HBM), with the initial coding framework derived from its core constructs. On the other hand, inductive coding allowed for the identification of new themes that emerged from the FGDs. Two researchers coded the data independently to enhance reliability. Inconsistencies in coding were resolved through discussions and consensus between the coders. Themes were refined through multiple stages of coding and review to ensure participants' experiences were accurately represented. The FGDs revealed several key barriers to early diagnosis of prostate cancer. These barriers were categorized as lack of awareness and screening uptake, masculinity, cultural factors, healthy system barriers and financial constraints.

3 Results

3.1 Study participants' socio-demographic background

A total of 46 participants were recruited in this study. The patients were distributed across different age groups: 4.3% ($n = 2$) were aged 50–59, 41% ($n = 19$) were aged 60–69, and 54% ($n = 25$) were aged 70 and above. The majority of the patients were in the 7th and the 8th decade 41% ($n = 19$) and 54% ($n = 25$) respectively.

A larger population had at least secondary and tertiary education 39% ($n = 18$) and 35% ($n = 16$) respectively. Retired patients constituted 33% ($n = 15$), self-employed 28% ($n = 13$), and 28% ($n = 13$) were unable to work (Table 1).

3.2 Barriers and facilitators to prostate cancer screening

These barriers were grouped into lack of awareness, fear, stigma, psychological and social perceptions, misattribution of symptoms and self-management, delayed health-seeking behavior and neglect of symptoms, privacy concerns about reproductive health issues, cultural beliefs and alternative explanations, misdiagnosis by health providers, infrastructure and accessibility challenges, and financial constraints. These barriers are discussed below:

TABLE 1 The basic socio-demographic characteristics of FGD participants.

Participants	Frequency	Percentage (%)
Age distribution		
50–59	2	4.3
60–69	19	41.3
70+	25	54.3
Education level		
Primary	10	21.7
Secondary	18	39.1
Tertiary	16	34.8
Never attended school	2	4.3
Employment status		
Employed/self-employment	13	28.2
Retired	15	32.6
Out of work for 1 year+	4	8.7
Unable to work	13	28.3
Disability/Worker's compensation	1	2.2

3.2.1 Awareness of prostate cancer screening

Some participants reported awareness of prostate cancer screening through local sensitization campaigns or seminars conducted in churches or village outreach programs. Participants who were exposed to prostate cancer screening reported undergoing the screening process, which enabled early detection.

“In our church, there was a group that came from a mission hospital, and they told us that if we had any pain and had a problem urinating, we could go for a check-up by the doctors that had come.” (R1 Public Hospital)

“There was a church conference, and they had taught their congregants, one of my friends came and told me, and I told him that I had been checked, but he told me to go for cancer screening. I then decided to go to a doctor, and he told me that my PSA was high.” (R35 Private Hospital)

Additionally, some men became aware of prostate cancer screening after being referred by their doctors, as illustrated by the quote,

“For the longest time, almost 20 years, I have never gone for prostate cancer screening. It was only when my doctor saw that there was a problem that he took me to Kisumu, and it was then that he referred me to Nairobi.” (R 31 Private Hospital)

Another participant reported being aware of prostate cancer screening because there was a family history, which therefore heightened the awareness and concern about the risk.

“This made me to be very careful, but my father had ended up having prostate cancer. Therefore, I took care of him, and that was why I was careful that the disease can be very dangerous

if you don't go to the doctor and seek advice. So, I can say that I know about prostate cancer, and I knew I should go for screening when I got to 50 years old, so I was careful.” (R43 Private Hospital)

believed that they were not supposed to be touched by younger women who were almost age-mates with their grandchildren.” (R37 Private Hospital)

3.2.2 Fear of being diagnosed with prostate cancer

Fear of knowing one's status also discouraged some men from undergoing screening. This fear was driven by the emotional stress of a cancer diagnosis. Others avoided screening as they believed that being diagnosed with cancer was equal to a death sentence.

“In the past, during an HIV outbreak, I worked for an Indian employer who urged everyone to get tested. Older people, however, refused, saying they didn't want the stress of knowing their status and would rather live without that worry. Today, the same mindset applies, with many elderly avoiding cancer testing, fearing it would lead to stress and shorten their lives.” (R4 Private Hospital)

“I feared the diagnosis when I started experiencing symptoms. The thought of hearing bad results was discouraging, and I wanted to avoid it. But the earlier we know, the better. Delaying doesn't help, and I'm grateful the doctor did the PSA test and referred me early, which led to an earlier diagnosis.” (R39 Private Hospital)

One participant attributed the fear of screening to the treatment procedures people who have been screened for cancer undergo, as demonstrated by this quote:

“Some delay because they've heard about the treatment regimen, and they fear.” (R18 Public Hospital).

3.2.3 Stigma of being diagnosed with prostate cancer

Concerns about social perceptions of cancer also played a significant role. Men feared the stigma that would result with cancer diagnosis.

“When you are diagnosed with cancer, some people see that it is a very bad disease, and there is one person who came and told me that it would have been better if I had gotten AIDS because I would have lived longer.” (R7 Public Hospital).

“We fear because when we tell one person, and they tell others, they will leave you and say that you are about to die.” (R 30 Public Hospital)

In some cases, discomfort with healthcare providers discouraged men from undergoing screening. The presence of young women healthcare workers in the screening rooms created hesitation among men.

“Doctors from the local dispensaries, the doctors would call the older men to go and get tested for prostate cancer. So, those who went and saw women left because traditionally, they

3.3 Barriers and facilitators to help seeking for prostate cancer

3.3.1 Lack of awareness of symptoms

There was a consistent pattern in the health-seeking behavior of men across all the FGDs. Most men initially ignored their symptoms, perceiving them as minor or not severe enough to warrant medical attention, relying on self-treatment or waiting until symptoms were severe.

“I had trouble passing urine and constipation, but when the pain subsided, I decided not to get checked. On December 25th, the pain returned, and I struggled with both urine and stool. I tried to endure it, but by the next afternoon, my wife insisted I go to the hospital. I told her I would, though I didn't plan to. That night, my condition worsened, and she had to find a motorbike operator to take me to the hospital.” (R38 Private Hospital)

“I remember the time that I was urinating blood. We were supposed to go to the farm, and I told my wife that after going to the farm, I would go to the chemist and buy painkillers. After some time, I decided to go to the hospital.” (R5 Public Hospital)

3.3.2 Symptoms misattribution and management

Men across all FGDs reported misattributing their symptoms to other causes, which led to delays in seeking the appropriate medical evaluation. This misattribution was due to the nature of work or activities undertaken (strenuous work), existing medical conditions, past sexual experiences, and other lifestyle issues, as illustrated in [Table 2](#).

Some participants believed that changing behavior, such as reducing fluid or sugar intake, would resolve the issues further delaying necessary medical evaluation:

“I thought that I had diabetes, and I stopped taking sugar to see whether it would resolve. After 3 months, I still had the issue, and then I started retaking sugar.” (R5 Public Hospital)

“I had the urge to pass urine, but I wouldn't pass any urine, and it was also frequent. This also made me have a fear of taking any liquid because I would have the urge to pass urine, yet I wouldn't pass any urine, and I would feel pain.” (R44 Private Hospital)

“There was a time that I would feel a continuous widespread burning pain when I would pass urine, and it would last for almost 30 min. I would feel uncomfortable even when I was sleeping, and when I would go to pass urine, it would come out in little amounts. But when the pain would stop, everything would come back to normal, and I forgot about it. I started feeling this a long time ago, and sometimes, I saw it triggered when I drank water on an empty stomach. This made me not take water for some time.” (R 39 Private Hospital).

TABLE 2 Sources of symptom misattribution leading to seeking delayed medical evaluation.

Source of misattribution	Description	Quotes
Work-related	Attributing symptoms to physical demands of occupation	<i>I started with pain in the hip bones, and I thought it was my nature of work that caused the pain in the hip (R1 Public Hospital). I was a mechanic for a long time and associated the back pain with an injury that he had when he was pushing a gas cylinder (R1 Public Hospital).</i>
Past Sexual Experiences	Associating symptoms with previous sexual encounters with STIs	<i>The symptoms involve issues with difficulty while urinating. Most of us men in our youth might have contracted illnesses like gonorrhoea and the like, so when you have difficulty urinating, you tend to think that the illness has recurred and look for the drugs that were used to treat the illness from the counter (R14 Public Hospital).</i>
Existing Medical Conditions	Assuming symptoms are linked to known health issues	<i>I had frequent and sometimes painful urination, but I thought it was because of diabetes that I had been having since 2003 (R31 Private Hospital).</i>
Alcohol Consumption	Linking symptoms to intake of alcohol	<i>I had frequent urination, and I thought that it was because I used to take alcohol before. So, I continued experiencing pain (R1 Public Hospital).</i>
Aging	Linking symptoms to the aging process	<i>I had the urge to pass urine, but I wouldn't pass any urine. For 1 year and a few months. I just took it as a general aging problem that affects many old men (R44 Private Hospital).</i>

3.3.3 Impact on libido

Further, the reluctance of individuals to discuss symptoms related to reproductive health due to perceived privacy concerns delayed early detection of prostate cancer. Participants reported that issues surrounding reproductive health were considered private matters. As a result, most individuals delay seeking timely medical attention until symptoms worsen.

"People believe that getting infected on the prostate is embarrassing, and there is denial. Because if it were a headache, it would have been said, but because it is the prostate, they decided to be secretive." (R6 Public Hospital).

"Some conditions are embarrassing in the minds of some people." (R40 Private Hospitals).

Notably, a subset of men sought immediate medical attention due to low libido, highlighting that specific health concerns prompted a quicker response than others.

"My sex drive had reduced, and this is what made me decide to go and get tested. I decided to act fast because this was not normal for me." (R23 Public Hospital).

3.3.4 Perceptions and beliefs about prostate cancer

Some men reported having experienced the condition indirectly through observing others who had it or hearing about it from their social circles. The explanations for these conditions were often rooted in cultural narratives involving failure to observe rituals, curses within the family, or bewitching, commonly accepted within their communities.

"I have a brother who died in 1980, and I just recently discovered that it was cancer. Otherwise, people around were saying that his wife had murdered him. Though the wife was a bit hostile, they were relating his death to her hostility, saying that she must have given my brother something, and because of the same, he wasn't treated well and was cursed. It features in the community and did in my brother's case." (R11 Public Hospital).

"Culturally, people may perceive that certain rituals were not observed. Such as dowry, but not just dowry alone since other aspects are involved. I have witnessed that since my dad passed on for not paying a dowry. It came to finish him." (R14 Public Hospital)

One participant who attributed the condition to the failure to observe rituals in their community reported experiencing reduced severity after observing the specific ritual:

"In the village, they say men get sick because dowry wasn't fully settled. For me, it was a specific goat (Mburi ya Mururu) that hadn't been delivered. When my condition worsened, I was told I had to deliver the goat or die. I found my uncle's son in Nanyuki, as my uncle had passed, and gave him the goat my father owed for my mother's dowry. After that, my illness wasn't as severe, though it didn't fully go away." (R9 Public Hospital)

In addition, the condition was also perceived to be linked to social behaviors such as promiscuity and denial of conjugal rights from spouses, as elaborated in these quotes:

"I first heard about prostate cancer at 14, though it was known as Muthiori in the Agikuyu community. I learned about a man in the village who was sick, and the elders said it was because his wife denied him conjugal rights. It wasn't until 2019, when I was diagnosed, that I realized it was prostate cancer. I had believed I wouldn't get it because I was sexually active." (R21 Public Hospital)

"Whenever people hear that you are sick within the pelvis, they think it is a disease that you have contracted from women. So, they fear telling their family because they will think that the father is unfaithful. They also think my partner is refusing to sleep with me." (R44 Private Hospital)

3.3.5 Economic factors/financial constraints

Most participants were retired, making getting money for the required tests sometimes difficult. The financial burden of

undergoing tests often led to delays in seeking treatment, as was commonly reported among patients in public hospitals.

“Sometimes, you lack money and must look for it first, then seek medical care. If you don’t have anyone to help you, this disease is terrible.” (R8 Public Hospital)

Some participants felt they would be imposing a financial burden on their families and, therefore, were reluctant to have the tests done.

“Sometimes, at this age, our sons and daughters are beginning to have their own homes, so they don’t look after the old. It becomes tough for one to maintain himself. Because financially we aren’t able. Even having the tests done becomes a challenge.” (R15 Public Hospital)

“In the villages, when people are sick, they just look at the state of the family, and they just decide to die without getting the necessary tests and treatment.” (R43 Private Hospital)

Financial challenges persisted even for those with medical coverage, such as the National Health Insurance Fund (NHIF). While NHIF could cover medical expenses, the associated costs for transportation to testing facilities posed a burden, contributing to delays in obtaining the tests.

“At times, even if NHIF is paying, there’s the issue of travel. I have come from far; I won’t say where, but I’m not employed. I’m a retired teacher in the old system, and the pension is almost nil.” (R11 Public Hospital)

Moreover, in some cases, participants noted that NHIF coverage in some specific hospitals was limited or did not exist for diagnostic tests, only covering costs once a cancer diagnosis was confirmed:

“We have a monetary issue because some referral hospitals do not accept NHIF coverage, which is not comprehensive. Here, you use your own money until you become a cancer patient, at which point NHIF covers your treatment.” (R20 Public Hospital)

3.4 Barriers to diagnosis and treatment, following symptom presentation

3.4.1 Misdiagnosis

Most of the participants reported experiencing a series of misdiagnoses before prostate cancer was correctly identified. Participants reported receiving treatment for extended periods - months or sometimes years. Participants believed that the delay in accurate diagnosis resulted in the progression of the cancer to advanced stages.

“Last year, I began experiencing the same conditions as I did in the past. However, this frequent urination persisted this time, so I went to a private hospital, and was treated for a UTI. But after being given the medicines, they were not effective. I then went to another Hospital, and there was a doctor who

recommended PSA, which was not done. They did a back X-ray and diagnosed me with muscle spasm, and this is what they treated. After taking the drugs, my condition became worse.” (R6 Public Hospital)

A significant sentiment reported by men in most of the FGDs was that some doctors prioritized financial gain over patient care especially in private facilities. Participants frequently expressed concerns that some healthcare providers continue to treat patients without a definitive diagnosis. This often results in prolonged treatment periods without improvement. Further, despite the ineffective treatments, some healthcare providers rarely referred patients to experts who may have offered a more accurate diagnosis.

“At first, I went to the hospital, and I stayed for almost 2 years going to the same hospital, and they never sent me to the laboratory. In Kenya, many doctors love money more than helping people.” (R43 Private Hospital)

“The other problem that we have in the hospitals, is that you go there, and they treat you with painkillers without investigating the disease that you are suffering from. Some hospitals only look for money, like the hospital I first visited. I spent all my money there, and they used to give me painkillers.” (R5 Public Hospital)

Participants reported that the misdiagnosis was also due to a lack of specialization. Most expressed concern that many private and government healthcare providers were not adequately trained to handle some cases. Participants noted that many could diagnose and treat less complex illnesses like malaria, stomach ulcers and other general conditions. This lack of specialization contributed to misdiagnosis and subsequent delays in early detection of prostate cancer.

“What leads to the advanced cases is that unspecialized doctors treat the diseases. Like me, who has been diagnosed with diabetes for almost 22 years, the doctors were supposed to ask themselves, with the duration that this person has been treated for diabetes, could it only be diabetes that is affecting this man, could it be that his condition is worsening because of another issue? But they did not do that. I was just given Glucophage and sent home.” (R35 Private Hospital)

3.4.2 Inadequate health infrastructure

In addition to misdiagnosis by health providers, inadequate healthcare infrastructure was a significant barrier to the early diagnosis of prostate cancer. Most participants recounted experiences of visiting hospitals where essential diagnostic equipment such as MRI, CT, and PET scans were either unavailable or not functional. This often resulted in multiple referrals and significant delays in obtaining accurate diagnoses. These repeated referrals and additional financial strain further complicated their healthcare journey, often discouraging timely intervention.

“There are few machines used to test for cancer in rural areas. I asked my doctor what the way forward would be, and he told me that since they did not have the machine to test, he asked me to go to specific hospitals in Nairobi. I decided to go to

a public referral hospital in Nairobi because it was cheaper, and when I went there, they told me that they had seen the reports but also wanted to confirm. They sent me to a private facility in Nairobi with another referral letter. The test showed that it had spread to the bones and was in stage 4.” (R4 Public Hospital)

“So, when we went to a specific hospital, they had written PSA (Prostate Specific Antigen) and I did not know it. I paid for it, and they told me they had done it. When I went to another doctor, the urologist I saw told me that it had been written with no reagent and that they did not do the test, yet we paid for it. It would have been better if the test was explained more easily to me since I am not very educated.” (R6 Public Hospital)

3.4.3 Failure to disclose diagnosis

Participants reported that most health providers did not disclose their conditions. This left patients unaware of the seriousness of the issue, further delaying crucial treatment decisions.

“Even when they knew that I had cancer, they discharged me without telling me that I had cancer and when I went home, my situation started getting worse. My daughter wrote to the hospital, and the administrator gave us the histology; in the investigations, the cells that had been removed through the procedure had reached stage 4 cancer.” (R 3 Public Hospital)

“My symptoms started a long time ago with back pain and reduced sex drive. I went to the hospital repeatedly and was given medicine each time. At another hospital, a doctor had me do an X-ray, and after a prostate exam, he left without explaining the results. Confused, I continued with my earlier treatments. Eventually, my condition worsened, and a referral hospital confirmed it was prostate cancer. I then realized the previous doctor likely knew my diagnosis but hadn’t told me, costing me critical months.” (R 20, Public Hospital)

Sometimes, participants reported being often referred to other hospitals without explaining their health conditions. This led to confusion as patients were left to navigate the system without adequate information.

“A Level 5 hospital gave me an appointment, and a biopsy was done. After 2 weeks, I got the results, but the doctor did not explain what I had. Before the procedure, he had told me that the biopsy would determine if I had prostate cancer or if it was just an enlargement. When the results came, he just wrote a referral letter, gave it to my son, and told me that I should go to a specific national hospital, but he did not specify the doctor I was going to see or my condition.” (R29 Public Hospital)

Participants perceived that some doctors were hesitant to disclose the seriousness of the diagnosis directly. This was attributed to concerns about how the patient might react to the information.

“These doctors think that when they tell you, you will go home and commit suicide. But that is not always the case; if we had been informed earlier, then we would have taken the necessary steps to ensure that the diseases do not progress to an advanced state.” (R35 Private Hospital)

In addition to withholding information, a participant noted that sometimes doctors frequently use technical words, which is further confusing.

4 Addressing barriers to early prostate cancer diagnosis-patient perspective

Participants expressed that the recommendations would aim to address the challenges faced by men and improve early detection. These recommendations focused on raising awareness, increasing access to specialized care, reducing financial barriers, specialty transparency, and culturally appropriate care, as detailed by these quotes.

“The cost of diagnosis and treatment should be affordable so that many can go to the hospital for cancer screening. Because you will have to pay for each test, and many people cannot pay for it. Some people who suspect that they have the disease or have the disease may just die with the disease because they don’t have the money. It is a disease that affects everyone, and many people suffer silently at home, but they don’t know what to do because they can’t go to the hospital because of the expense.” (R34 Private Hospital)

“I recommend that seminars be introduced in rural areas so that men know their status since a lack of knowledge leads to late diagnosis. I wouldn’t have known if it had not been for the seminar I attended. If not for taking my brother to hospital, I wouldn’t have known that I had cancer and if not for the diagnostic process I underwent at Kenyatta, I wouldn’t have known. Right now, my cancer has regressed. So, I would recommend that seminars be introduced.” (R8 Public Hospital)

“It would be better if we could have a mobile clinic with a specialist doctor coming once a month to various sub-counties, carrying out tests.” (R12 Public Hospital)

“The church and the mosque should hold seminars to create awareness. The doctors should also visit such places to carry out tests as well. The barazas (community meetings) should make it friendly and encourage people to attend; it will seem normal to go for check-ups. Since there is still that fear amongst men about going for check-ups.” (R20 Public Hospital)

“The government should increase the number of machines, and NHIF should pay for the patients.” (R22 Public Hospital)

“The government should ensure that the doctors write their specialty on the door so you can’t waste time visiting the wrong doctor.” (R31 Private Hospital)

“Even when men go to the hospital, they will ask if there is an alternative for a prostate examination, mainly if very young women are conducting it. So, to ensure early diagnosis, we should be told if there is an alternative for prostate examination. This will ensure that many men will get diagnosed and treated earlier.” (R37 Private Hospital)

5 Discussion

Findings from the study revealed that despite men being aware of screening services through targeted campaigns, the awareness did not translate to higher screening rates. This was because cancer carried a significant stigma and is often associated with death. These cultural meanings attached to cancer, created barriers to seeking screening and diagnosis, as individuals may not fear the disease itself but also the social consequences of a diagnosis. These study findings align with a study in a rural community in Kenya where men were not willing to undergo screening due to the association of cancer with death, stigma and discrimination associated with prostate cancer (3). Further findings from this study revealed that although men were aware of the importance of prostate screening, men did not go for the screening. From this study, older men considered it inappropriate for young women to conduct prostate examinations on older men, a belief that is deep-rooted in cultural norms regarding respect and privacy. A study conducted among men suffering from lower urinary tract symptoms found that most men experienced discomfort with the idea of undressing in front of female healthcare providers, regardless of their professional capacity (13). These findings demonstrate that having information does not automatically translate to the uptake of screening services. Instead, health behaviors are influenced by a complex interplay of cultural beliefs, social norms and individual experiences. These findings contradict a study conducted among men in rural Kenya, where awareness of screening services was associated with increased prostate screening uptake (3, 14). This contrast in findings underscores the need for a comprehensive approach to promoting prostate cancer screening that goes beyond raising awareness and addresses underlying beliefs and social factors that may influence men's decisions to undergo screening.

Findings from this study revealed significant insights into how men perceive and experience symptoms that could indicate prostate cancer. There was a wide range of symptom experiences, with some similarities and differences across individuals. Men in the study often attributed these symptoms to lifestyle factors (use of alcohol, physical activity, multiple sexual partners) and pre-existing medical conditions such as diabetes and the natural process of aging rather than recognizing them as potential indicators of a severe health issue. Specifically, obstructive lower urinary tract symptoms (LUTS) such as the inability to pass urine and urinary dribbling were commonly misattributed to aging. This study's findings are similar to other findings that reported that men described urinary symptoms such as weak urine stream, urinary hesitancy, and urinary dribbling as not serious, attributing them to "an old man's disease" (15, 25). Furthermore, this study highlighted that some men highlighted the constant urge to pass urine as a pre-existing condition such as diabetes. In addition, the presence of blood in their urine with infections like urinary tract infections (UTIs) or sexually transmitted infections (STIs). As a result, some individuals often resorted to self-medication to address what was perceived as a recurring infection rather than seeking professional advice. This aligns with findings from a study among Nigerian men, where long-term complications of STIs were often attributed to both benign and malignant prostatic diseases (16, 17). This misattribution of symptoms often resulted in delayed medical assessment, as men tended to ignore the signs or attempt lifestyle changes, hoping

the symptoms would go away on their own. For example, in this study, men who experienced back pains often linked these pains to activities such as working too much on the farm. In contrast, other men linked the pains to their previous occupations, such as working as mechanics. Men in the study who associated the constant urge to pass urine with alcohol consumption ignored symptoms and stopped consuming alcohol. Individuals who linked their symptoms to lifestyle factors rationalized them as natural consequences of past behaviors. There is a need for programs that address common misconceptions and emphasize the importance of seeking medical advice for symptoms that persist.

The study revealed a consistent pattern in the health-seeking behavior of men regarding prostate cancer symptoms. Men frequently dismissed symptoms experienced as minor, often resorting to self-medication with painkillers, only seeking medical evaluation when the condition was severe and were unable to carry out daily activities. This tendency to delay until the condition becomes severe could be attributed to cultural expectations surrounding health and vulnerability, where strength is often valued, and seeking help may be perceived as a sign of weakness. In addition, embarrassment also emerged as a significant health-seeking issue. Diseases associated with the reproductive organs could have caused discomfort or shame for men, adding another layer of complexity to men's health-seeking behavior, and further delaying medical assessments. This was consistent with findings in studies on barriers to health-seeking practices among men where negative attitudes toward health-seeking behaviors were related to the traditional male gender role, the view of sexual-related symptoms being taboo and embarrassment played a significant role in help-seeking among men (13, 18). However, from the study, few men diverged from this pattern and sought medical evaluation from nearby facilities. The perception drove this motivation for opting for local dispensaries over more significant facilities, stating that more extensive facilities would require more time and involve complex processes. These finding sheds light on the role of convenience and accessibility in shaping health-seeking behaviors among men. The preference for local dispensaries as the first line of action among some participants underscores the importance of community-based healthcare options in promoting early detection of prostate cancer. Making prostate health services more accessible at the community level and providing male-friendly environments for consultations could likely influence timely medical evaluation. Notably, for some men, sexual health concerns such as low libido among men elicited quicker responses in seeking medical evaluation as compared to other symptoms. This could be attributed to the perceptions of sexuality and masculinity, where sexual prowess and behavior are associated with male identity among different cultures (19, 20). In most cultures, sexual dysfunction often carries stigma (20, 21). As a result, men are more inclined to avoid delays in seeking medical evaluation to prevent any social consequences. Cultural narratives and beliefs played a significant role in community interpretation and sometimes response to issues related to prostate cancer. These often involved believing in supernatural causes like curses due to failure to observe certain rituals or bewitching, especially for diseases not understood in the community. In some cases, depending on the beliefs, men would observe these specific rituals to lessen the severity of the symptoms. Further, within a particular ethnic group, the disease

was known as *muthiori*, a name associated with the affected reproductive organ. People in this specific community believed that it was linked to the denial of conjugal rights, where respected members of the community sanctioned women, and issues were discussed. The denial of conjugal rights as perceived to be linked to prostate cancer has been highlighted in several studies across the region (3, 4, 16, 22).

Findings from the study show a pattern of misdiagnosis among men during treatment for prostate cancer-related symptoms. This was attributed to financial motivations by healthcare providers over patient health and a shortage of specialized medical personnel. This led to misinterpretation of symptoms, incorrect diagnosis and subsequently delayed or inappropriate treatment. There are often significant challenges in diagnosing prostate conditions as sometimes the disease may be confused with non-cancerous conditions further delaying diagnosis and treatment (23). Shortage of medical equipment for testing further delayed diagnosis as men were forced to navigate several healthcare facilities in search of diagnostic tools. This not only prolonged diagnosis time but also increased the financial burden on the individuals and their families. This was particularly pronounced in rural areas where long-distance travel was necessary to access proper diagnostic equipment, which many found difficult due to financial constraints. Findings from the study revealed communication challenges between healthcare providers and men who sought treatment, significantly contributing to delayed diagnosis. The lack of transparency left the men uninformed about their condition resulting in misunderstanding about the severity of their conditions or the necessity for further treatment. Further, while referrals to specialists were crucial, findings from the study indicate that the referrals were often made without sufficient support. Individuals had to navigate the complex healthcare systems, without understanding the urgency of the referral. The lack of clear communication led to situations where individuals did not follow up on these referrals either due to confusion, perceived lack of importance or sometimes logistical challenges. These findings underscore the importance of healthcare providers supporting patients through referral processes and providing resources to help navigate the healthcare system effectively.

Financial constraints emerged as a significant factor in the delayed diagnosis of prostate cancer. The series of hospital visits before an accurate diagnosis placed significant financial burden over time. Further, the cost associated with the tests also presented a financial challenge, findings that align with other studies (3).

This study was subject to several limitations. The use of focus group discussions (FGDs), while effective as a qualitative method to explore in-depth perspectives, attitudes, and experiences, inherently limits the generalizability of the findings. FGDs were conducted with patients diagnosed with and living with prostate cancer to understand the reasons for late presentation and diagnosis. Although the approach yielded rich and nuanced insights, the findings are not generalizable to the broader population due to the small sample size and the purposeful, non-random selection of participants, which may have introduced selection bias. Additionally, contextual factors such as the chronic nature of prostate cancer, the presence of comorbidities, and the effects of treatment may have influenced participants'

recall. Despite these limitations, the findings provide valuable contextual understanding and can inform the development of hypotheses. However, future research employing larger, statistically representative methods, such as surveys or cohort studies, is necessary for broader generalization (12, 24).

6 Conclusion

The delay in early presentation and diagnosis of prostate cancer is a result of the complex interplay of multiple factors. This underscores the need for a multifaceted approach to improving early presentation and diagnosis of prostate cancer. Recognizing this complexity is crucial for the development of effective holistic strategies to improve timely presentation and diagnosis and ultimately health outcomes for men at risk of prostate cancer. This can be achieved by identifying barriers and facilitators to screening, help seeking, diagnosis, and treatment after symptom presentation.

7 Recommendations

Based on the findings from the study, several policy recommendations can be proposed to improve prostate cancer screening, diagnosis, and overall health outcomes for men: these recommendations aim to address the multifaceted challenges identified in the study and promote early presentation and diagnosis of prostate cancer.

7.1 Cultural sensitivity and awareness campaigns

Develop and implement awareness campaigns that address cultural beliefs and stigma associated with prostate cancer. These campaigns should involve community leaders and culturally respected figures to facilitate acceptance and reduce stigma. Customize messages to resonate with different communities and address misconceptions about prostate cancer, highlighting its seriousness and the benefits of early screening.

7.2 Enhance accessibility and availability of screening services

Increase the availability of prostate cancer screening services in local dispensaries and community health centers. Ensure that these facilities are equipped with necessary diagnostic tools and staffed with trained personnel. There is also need to deploy mobile health units to reach remote and underserved areas, providing on-site screening and diagnostic services.

7.3 Improve training and support for healthcare providers

Implement training programs for healthcare providers focused on cultural sensitivity, effective communication,

and the importance of early detection and referral processes. Developing clear protocols for managing referrals and ensure that healthcare providers support patients through the referral process, including providing information on what to expect and how to navigate the healthcare system.

7.4 Addressing financial barriers

Introduction of subsidies or financial assistance programs to help cover the costs of screening and diagnostic tests, especially for low-income individuals would be recommended. Advocating for policies that expand insurance coverage to include comprehensive prostate cancer screening and treatment. This should be done by implementing the universal health coverage for all and enhancing the NHIF/SHIF to cover the cost of diagnosis and treatment

7.5 Promote male-friendly health environments

Create healthcare environments that are sensitive to men's concerns and preferences, including privacy and comfort during examinations. We should borrow heavily from the breast and cervical screening programs. Employment of male health advocates or peer educators to promote prostate cancer awareness and encourage screening among their peers.

7.6 Public health education and community engagement

Develop and promote educational programs in schools, workplaces, and community centers to raise awareness about prostate cancer symptoms, screening, and the importance of early detection. Working with community leaders to promote help-seeking behaviors and dispel myths associated with prostate cancer would improve early presentation and diagnosis.

7.7 Strengthen healthcare infrastructure

Invest in healthcare infrastructure to ensure that diagnostic equipment is available at local healthcare facilities and that facilities are adequately staffed. Implement strategies to address shortages of specialized medical personnel through training programs and incentives for working in underserved areas.

7.8 Implement continuous evaluation and improvement

Regularly assess the effectiveness of prostate cancer awareness and screening programs and make data-driven adjustments

based on community feedback and health outcomes. Establish mechanisms for patients to provide feedback on their experiences with the healthcare system to identify areas for improvement.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving humans were approved by the University of Nairobi-Kenyatta National Hospital Ethics and Research Committee. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

CW: Conceptualization, Funding acquisition, Investigation, Methodology, Project administration, Writing – original draft, Writing – review & editing. ST: Conceptualization, Supervision, Writing – review & editing. DO: Supervision, Writing – review & editing. CR: Funding acquisition, Supervision, Writing – review & editing. Z-JC: Supervision, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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The author(s) declare that no Gen AI was used in the creation of this manuscript.

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Supplementary material

The Supplementary Material for this article can be found online at: <https://www.frontiersin.org/articles/10.3389/fcacs.2025.1521454/full#supplementary-material>