

Determining the incidence of breast cancer in Mbekweni, Paarl, South Africa, and the lived experiences of the women involved: A mixed-methods study

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Background. Breast cancer was the most common cancer diagnosed in South African (SA) females in the year 2022, accounting for 24.1% of all cancers diagnosed. There are cultural factors that are thought to affect the early diagnosis of breast cancer in black SA women. No information on the incidence of breast cancer or its determinants specific to the study setting could be found.

Objectives. To determine the incidence of breast cancer in women aged 35 - 69 years living in the Mbekweni community in Paarl, SA, and to evaluate the lived experiences of the women involved.

Methods. This was a prospective observational study, with a convergent parallel mixed-methods design. The quantitative data were collected by means of a self-completed questionnaire, and findings on clinical breast examination, imaging reports and referrals to higher levels of care. The qualitative data were collected through small focus group discussions which were recorded, transcribed, and analysed through inductive thematic analysis.

Results. Of the sample population of 381 participants, a total of 55 (14.4%) were found to have suspicious clinical findings and required an imaging study. Upon receipt of the imaging reports, 4 (1.0%) required referral for biopsies or further management. At the time of writing, only 1 participant (0.3%) had been confirmed as having cancer, which was used to calculate an incidence of breast cancer of 6 cases per 1 000 person-years. Although only a single case was identified during the study period, there was some awareness of and insight into breast cancer in this community. There was also a perceived increase in the prevalence of breast cancer. However, it is a disease still stigmatised by a plethora of myths and cultural beliefs, which negatively influences women's choice to seek help early.

Conclusion. The incidence of breast cancer in women aged 35 - 69 years in Mbekweni was low in absolute terms, with only one confirmed case during the study period. Despite this, some insight and awareness surrounding breast cancer in the community was evident. There is a significant desire for more information in this community, which can provide healthcare workers with a valuable opportunity to educate and empower the members and positively influence the overall health of the community.

Keywords. Breast cancer, incidence, early diagnosis, lived experiences, community education, South Africa, Western Cape Province

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Breast cancer was the most common cancer diagnosed in South African (SA) females in the year 2022, accounting for 24.1% of all cancers diagnosed.^[1] In the same year, it contributed to 23.3% of all cancers diagnosed in black females, with the lifetime risk noted to be 1 in 43 women.^[1]

It is evident from the National Cancer Registry (NCR) that the rate of breast cancer in black women is relatively low compared with other ethnic groups,^[1] suggesting that there are various factors to be considered in the epidemiology of the disease. Possible factors include later age of menarche, early age at birth of the first child, high parity, and high breastfeeding rates.^[2] There are also various

cultural determinants that are thought to affect the early diagnosis of breast cancer in black SA women, especially in rural settings, such as the role of witchcraft, suspicion of modern medicine, the role of traditional healers, and the need for collaboration between family members when decisions are made regarding health.^[2]

The objectives of this study were to determine the incidence of breast cancer in women aged 35 - 69 years in the Mbekweni community, and to evaluate the lived experiences of a sample of women involved in small focus group discussions. No information on the incidence of breast cancer or its determinants specific to the study setting could be found.

Methods

Study setting

This study was conducted at Be Part Yoluntu Centre NPC, in the predominantly Xhosa-speaking community of Mbekweni, Paarl, Western Cape Province.

Study design

This was a prospective observational study, with a convergent parallel mixed-methods design. The quantitative data were collected through self-completed questionnaires, clinical breast examinations, imaging reports and referrals to higher levels of care. The qualitative data were collected through small focus group discussions and subsequent inductive thematic analysis. All participants were educated on breast self-examination and when to seek medical care.

Sample characteristics

The study population comprised female volunteers between 35 and 69 years of age who lived in the Mbekweni community at the time of screening, and who were willing to adhere to assessments, the visit schedule and referrals if needed. Participants were excluded if they had a known current breast cancer diagnosis. This age group was selected in line with the findings of the NCR that the highest numbers of black females diagnosed with breast cancer fell within this age group.^[1]

Sample size

The quantitative component had a target sample size of 385 participants, while for the qualitative component a target sample size of 30 - 40 participants was chosen.

Ethical considerations

The research protocol and study documents were approved by Pharma-Ethics on 27 October 2023 (ethics ref. no. 230825837).

Results

Demographic characteristics

A total of 385 women between the ages of 35 and 69 years were screened, but four women did not meet the study entry criteria as they were already receiving cancer treatment at the time and were therefore excluded from the study. Thirty-two participants were randomly selected and agreed to participate in the focus group discussions. The mean (standard deviation (SD)) age of the enrolled participants was 50.57 (9.84) years.

Participants reported their race via the questionnaire, with 378 (99.2%) identifying as black and 3 (0.8%) as coloured.

Of the participants, 169 (44.4%) were born in the Western Cape and 190 (49.9%) of the participants reported growing up in the Western Cape. The rest of the participants were born in other provinces and relocated to the Western Cape.

The majority ($n=226$; 59.3%) of the participants' highest level of education was high school (excluding Grade 12). The rest of the participants had primary school ($n=60$; 15.7%), Grade 12 ($n=75$; 19.7%), college ($n=16$; 4.2%) or university education ($n=4$; 1.0%).

The estimated household monthly income reported was ZAR1 000 - 5 000 for the majority of the participants ($n=247$; 64.8%), and most of these participants had three or more people in their household ($n=227$; 91.9%). The majority of the participants therefore came from households living under or close to the lower-bound poverty line of ZAR1 058 per person per month, as published in the Statistical Release on National Poverty Lines 2023.^[3]

The majority of the participants ($n=341$; 89.5%) only accessed state medical facilities for medical care, 21 (5.5%) only accessed medical care through private facilities or doctors, none accessed medical care from a traditional healer only, and 19 (5%) accessed medical care through a combination of these medical facilities, including 10 participants (2.6%) who accessed medical care from a traditional healer in addition to other facilities.

Pregnancy and contraception

The mean (SD) age of menarche in the study population was 14.96 (1.99) years.

One or more previous pregnancies were reported by 376 participants (98.7%), with a mean (SD) age at first pregnancy of 21.2 (4.18) years (Fig. 1). The mean number of pregnancies per participant was 3.3 (1.47), and the mean number of live births was 2.98 (1.31).

Of the participants, 344 (90.3%) reported having breastfed a baby, with a mean (SD) duration of breastfeeding of 52.1 (53.13) months. On average, participants had breastfed 2.59 babies.

Use of hormonal contraception (current or previous) was reported by 359 participants (94.2%), with a mean (SD) duration of use of 8.82 (6.85) years. The types of hormonal contraception used throughout their childbearing years are summarised in Table 1.

Family history

A family history of a first-degree relative with cancer was reported by 78 (20.5%) of the participants. Of those with a first-degree relative with cancer, 21 (26.9%) had a relative with breast cancer, 4 (5.1%) a relative with prostate cancer, and 8 (10.3%) a relative with lung cancer. None reported having a first-degree relative with colon cancer. The remaining 45 participants (57.7%) with a first-degree relative who had cancer reported other types of cancers such as head and neck malignancies, cervical cancer, endometrial cancer and skin cancer.

Social habits

Previous tobacco use was reported by 49 participants (12.9%), while 42 (11.0%) were current users at the time of screening.

No consumption of alcoholic beverages was reported by 238 participants (62.5%), while 106 (27.8%) reported drinking 1 - 2 units per week, 26 (6.8%) 2 - 3 units per week, 8 (2.1%) 3 - 5 units per week, and 3 (0.8%) >5 units per week.

Only 4 participants (1.0%) reported using any form of recreational drugs.

Clinical findings and investigations

On clinical breast examination, 55 participants (14.4%) were found to have suspicious clinical findings and required an imaging study.

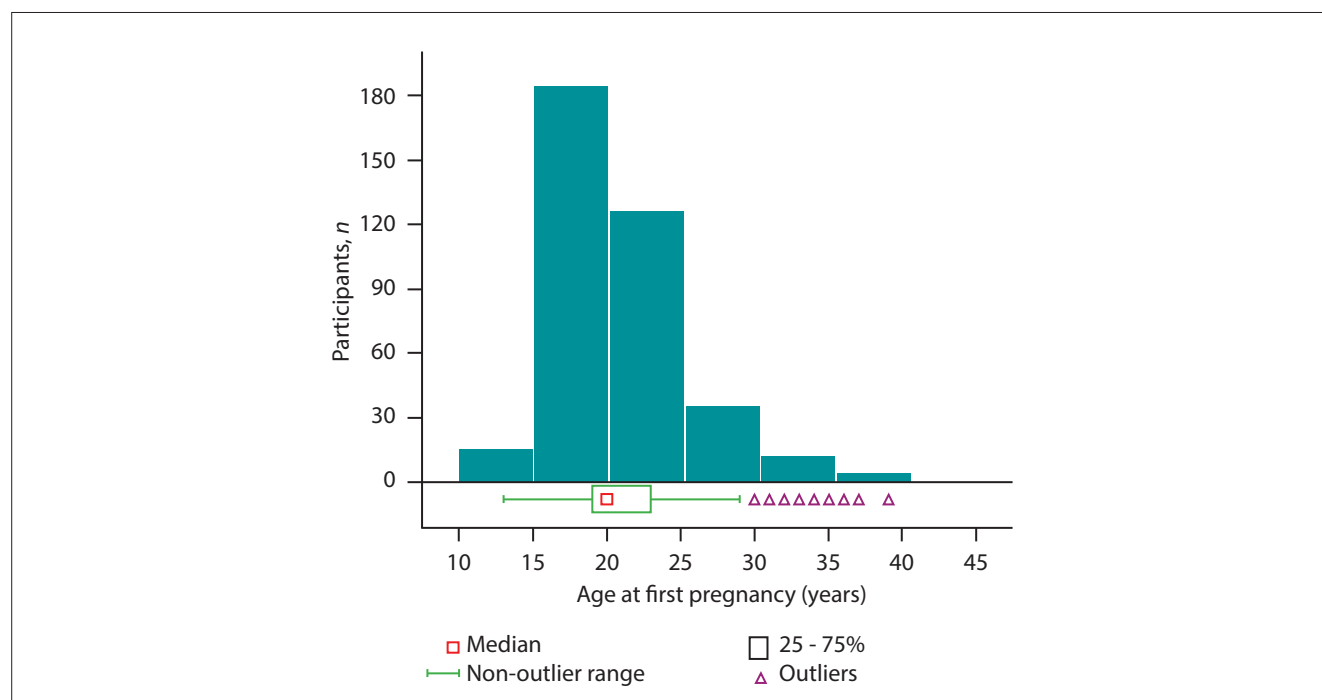


Fig. 1. Age at first pregnancy (years) (N=376; median 20.0, mean 21.2074, standard deviation 4.1844, minimum 13.0, maximum 39.0, 25th percentile 19.0, 75th percentile 23.0).

Upon receipt of the imaging study reports, 4 participants (1.0%) required referral for biopsies or further investigation. At the time of writing, only 1 participant (0.3%) had been confirmed as having cancer, two had confirmed negative biopsies, and one had benign findings on repeat imaging.

Incidence of breast cancer in the study population

The incidence of breast cancer in women aged between 35 and 69 years in the Mbekweni community was calculated as 6 cases per 1 000 person-years, with the following parameters and calculation:

- Population size: $N=381$
- Number of new cases: $n=1$
- Time frame: 5 months.

Calculation:

$$\begin{aligned}
 \text{Incidence} &= \frac{(\text{New cases})}{(\text{Population} \times \text{Time frame})} \\
 &= \frac{1 \text{ new case}}{(381 \text{ persons} \times 5 \text{ months})} \\
 &= \frac{1}{1\,905 \text{ person-months}} \\
 &= 0.0005249 \text{ cases per person-month}^{(4)}
 \end{aligned}$$

Convert to cases per person-years:

$$\begin{aligned}
 &= (0.0005249 \text{ cases per person-month}) \times (12 \text{ months/year}) \\
 &= 0.006299 \text{ cases per person-year} \\
 &= 6.3 \text{ cases per 1 000 person-years} \\
 &\approx 6 \text{ cases per 1 000 person-years}^{(4)}
 \end{aligned}$$

Table 1. Hormonal contraceptive methods used by participants (N=381)

Hormonal contraceptive method	Participants, n (%)*
Long-acting injectable contraceptives	331 (86.9)
Oral contraceptive pills	41 (10.8)
Subdermal implants	32 (8.4)

*Some participants used more than one method during their childbearing years.

Thematic analysis of interviews

Small focus group discussions were held to evaluate the lived experiences, fears and misconceptions of the women involved in the study. Two sessions were held, one before the clinical examination and one after. Questions pertaining to perceptions, awareness, knowledge and cultural beliefs surrounding breast cancer were asked. Suggestions about improving community awareness and participant expectations and experiences of the consultations were explored.

The discussions were led in isiXhosa and were recorded. The recordings were translated and transcribed. Inductive thematic analysis of the transcriptions was performed, which identified seven overarching themes with additional sub-themes.

Theme 1: Breast cancer is a growing community problem

Participants recognised that breast cancer is a significant problem in this community and that its prevalence in the community is increasing. They especially noted concerns regarding the consequences of delayed diagnosis and subsequent reduced survival rates.

'Sometimes you notice breast cancer when it has destroyed you.'

Theme 2: Religious and cultural beliefs

Participants discussed various cultural and religious beliefs surrounding breast cancer, including perceptions of bewitchment, punishment from higher powers, or viewing it as a temporary ailment that will pass. These beliefs influence how seriously a patient regards the disease and how early they seek medical help.

'Because it can wipe out the entire family ... I would think we are being punished.'

Theme 3: Fear and avoidance

There was undeniable fear among the participants regarding a cancer diagnosis.

'Knowing about cancer, we only know a little, that it kills.'

Many mentioned reluctance to get tested because of fear of the results and potential stigma associated with the disease. This fear is extended to and supported by the ever-present stigma surrounding other illnesses such as HIV.

'People are afraid to get tested ... people are afraid people will find out what you are living with.'

Theme 4: Awareness or knowledge

Despite perceived awareness of breast cancer in this community, the participants highlighted significant gaps in understanding the symptoms, the risk factors, and the importance of early detection. Some awareness exists regarding self-examination and seeking medical help when symptoms are detected, although this knowledge was limited.

'But what I know is that you always have to examine yourself, examine your breast like this, and immediately when you feel something you have to go to the clinic and have the lump checked out ...'

There was also a sense that while discussions about breast cancer take place, the information and awareness do not sufficiently reach the broader community. The participants expressed a desire for more education on self-examination and early detection methods.

Theme 5: Barriers and facilitators to accessing healthcare

Sub-theme 5.1: Healthcare access

Access to specific healthcare services, particularly diagnostic tests such as mammograms, was mentioned as a barrier, especially for those without medical aid. Participants expressed frustration with local clinic services, referring to long waiting times and perceived dismissiveness towards preventive health measures.

'... even if a person is seriously ill, they do not want to go to the clinic because they sit there for very long.'

The preference for traditional medicine among many community members was also mentioned as a strong barrier to early diagnosis and treatment of certain diseases, including cancer.

Sub-theme 5.2: Socioeconomic factors

Participants reported financial barriers that discourage people from seeking medical attention for preventive care. Socioeconomic factors, including diet and lifestyle choices, were discussed as possible contributors to the increased cancer prevalence, revealing good insight into disease processes.

'... the foods we eat have a contributing factor in the diseases we get.'

Sub-theme 5.3: Support

The importance of personal support networks and open communication about breast cancer emerged as an important sub-theme. Participants emphasised the need for sharing experiences and supporting each other through diagnosis and treatment. Family plays a critical role in decision-making regarding healthcare, often serving as the first point of support and advice for individuals facing potential diagnoses.

'The first thing, if you still have parents, you are supposed to speak to your mother, your father ...'

Sub-theme 5.4: Role of healthcare providers

Participants expressed expectations of thorough medical examinations and trust in healthcare providers for diagnosis and treatment. Many expressed the expectation of clear communication of results, and some also expressed expectations of emotional support from healthcare providers.

'I expect her [the doctor] to give me my results and not be afraid, because I want to know where I stand.'

Sub-theme 5.5: Personal responsibility and advocacy

Participants expressed newfound awareness about breast self-examination and the importance of early detection practices. They felt more empowered to take proactive steps in monitoring their own health and reducing reliance on harmful myths.

'Go and get treated, and you have to fight, go and get help, and don't look at what people are going to say.'

Sub-theme 5.6: Psychological impact

Fear of diagnosis, death and social stigma was evident in all the discussion groups, with many discussions centred on the emotional toll of a cancer diagnosis and the importance of accepting one's health condition. Participants highlighted examples of people living positively with cancer as a source of inspiration.

Theme 6: Community engagement and health promotion

There was a strong sentiment that more needs to be done to educate the community about breast cancer. The participants emphasised the importance of sharing information learned from programmes, such as this study, with other members of the community, in order to encourage early detection and reduce fear and misinformation. They suggested establishing support groups within the community for individuals dealing with breast cancer or other health challenges.

'I think there should be meetings where people are being educated so that they can take this thing [breast cancer] seriously ...'

Theme 7: Healthcare experiences

The study was acknowledged positively for its role in raising awareness and providing accessible healthcare services in this community. Participants expressed appreciation for the initiatives that bring health education directly to the community. There was a positive response regarding referrals and follow-up procedures.

'... there is [a benefit] because of the way you spoke to us, it's things we didn't think about ...'

Sub-theme 7.1: Suggestions for improvement

Suggestions include conducting awareness campaigns in places where people gather, such as churches, taxi ranks and markets, to reach a wider audience. There were suggestions of adding more clinics to the region and having disease campaigns to improve awareness.

Sub-theme 7.2: Emotional impact and gratitude

Participants felt empowered to take proactive steps in monitoring their own health. Those who had personal health concerns expressed gratitude for the study's assistance, and there was a sense of relief and reassurance after the clinical consultations. Participants also valued the opportunity to return to give feedback on their experiences, as they felt that their input could benefit future programme planning and community engagement strategies.

Discussion

The incidence of breast cancer in females aged 35 - 69 years in the Mbekweni community was calculated at 6 cases per 1 000 person-years. Focus group discussions revealed a notable awareness of breast cancer within the community. Additionally, there was a perceived increase in the occurrence of the disease. However, breast cancer remains stigmatised owing to persistent myths and cultural beliefs that influence individuals' willingness to seek timely medical assistance. The strong demand for accurate information and preventive care provides healthcare workers with an opportunity to educate and empower residents, thereby positively impacting on overall community health.

Several confounding factors were identified in this study. As participation was entirely voluntary, the observed incidence may be falsely elevated, as individuals with pre-existing concerns about their breast health may have been more likely to seek screening.

Although all the investigators employed a standardised method for clinical breast examinations, inter-examiner variability could have resulted in either inflated or underestimated referral rates for imaging studies.

Moreover, this population is characterised by above-average body mass indices, which may result in larger, pendulous breasts. This anatomical factor can complicate clinical examinations, potentially leading to the oversight of suspicious findings.

The authors acknowledge that recall bias could be a potential confounder, as participants self-reported some data, which can be

prone to inaccuracies or omissions. Additionally, the collection of data from only one site may not fully capture the experiences of patients who sought care at other facilities, potentially resulting in incomplete or biased representation of the study population.

Our findings should be interpreted with caution given the small number of participants and the fact that only one new case of breast cancer was identified during the study period. The limited sample size makes it difficult to draw firm conclusions or to generalise the observed incidence to the broader community.

Finally, it is important to note that the incidence of breast cancer among the entire female population of this community could not be calculated, as the study was limited to women aged 35 - 69 years. Including all adult females could risk identifying a higher number of benign findings, leading to unnecessary imaging and psychological distress for those individuals.

Recommendations

- A focus on preventive care should be emphasised within communities, including improved screening programmes, as a clear need for this was identified.
- Improved access to non-invasive screening methods should be advocated to reduce the number of unnecessary biopsies. Access to non-invasive screening could positively affect the willingness of patients to present for screening, as they know that the risk of having to undergo an invasive procedure is lower.
- A cost-effectiveness analysis comparing diagnostic pathways (imaging first v. routine biopsy) would help determine the optimal use of limited resources. The current practice is to perform fine-needle aspirations and/or biopsies on most breast masses prior to imaging, as access to specialised radiology is limited in state healthcare facilities.
- A reliable, reproducible, standardised method of clinical examination should also be researched and implemented, which could include the use of artificial intelligence and associated devices, to eliminate the inter-examiner differences in clinical examination.

Conclusion

The study investigated the incidence of breast cancer among females aged 35 - 69 years in the Mbekweni community, finding a rate of 6 cases per 1 000 person-years. There was some awareness and a perceived increase in the prevalence of the disease, which is often stigmatised by cultural myths that hinder timely health-seeking behaviour.

Importantly, the study revealed a strong desire for more information and preventive health practices among community members, suggesting openness to awareness campaigns that empower individuals to take control of their health. Such initiatives would be further supported by the availability of clear, accessible and convenient points of care where individuals, whatever their health concerns, can seek health screening.

The research highlights a demand for educational initiatives to improve community health outcomes while acknowledging several limitations, including potential biases in participant selection, variability in clinical examinations, and the challenge of accurately

representing the entire female population's incidence. Overall, the findings underscore the importance of enhancing awareness, education, and accessible healthcare to effectively address breast cancer in this community.

Declaration. None.

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Data availability statement. The data generated and analysed during the present study are available from the corresponding author upon reasonable request.

Conflicts of interest. None.

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