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Prevention, early detection and treatment of breast cancer in Benghazi-Libya: Patients' points of view: A qualitative study

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A B S T R A C T

Programs focusing on prevention, early detection, and treatment of breast cancer (BC) are crucial for enhancing survival rates, improving quality of life, reducing morbidity and mortality. Patients' experiences play important role in detecting gaps in present programs help creating and executing initiatives that raise awareness about risk factors, promote screenings, and ensure early detection and effective management of BC.

Aim of the study:

- Explore patients' experiences and knowledge.
- Address use of Breast Self-Examination (BSE), screening programs.
- Describe financial burden of BC management.

Participants and method:

Qualitative study during January- March 2022, at Benghazi Medical Center. 31 patients participated. In-depth interviews conducted, recorded. Familiarizations of data, coding, identifying thematic framework, indexing, charting, mapping, interpretation and reporting findings.

Results:

Half the sample were below fifty, no family history of BC, one-third of patients discovered by (BSE). Two themes developed: 1) Prevention, Education and Early detection: patients lack scientific knowledge of BC risk factors and causes. Two-thirds of patients never applied BSE. Most cases diagnosed in advanced stages. Lack of communication between healthcare providers and patients led to late detection. 2) Diagnosis, treatment and support: public health financing programs inadequacy, medical system weakness led to delay in diagnosis and treatment. Lack of fundings caused out of pockets spending, (catastrophic spending). Need of patient groups to provide medical, psychological and social support.

Conclusion:

Urgent need to improve screening and diagnosis, treatment and palliative care of BC patients. Need to develop organized frameworks and management guidelines for prevention, early detection and management of BC in Libya.

1 Introduction

About 12% of all cancer cases are breast cancer, making it the most common type of cancer to be identified worldwide. It is the main cause of cancer-related fatalities among women. (Fox & Shaaban, 2022). Globally, 2.3 million women had a breast cancer diagnosis in 2020, and the disease's death rate was 30%. In the last five years, 7.8 million women had

been afflicted by the disease, making breast cancer the most prevalent type of cancer. In 158 out of 183 nations, breast cancer accounts for 86% of all cancers in women, making it the most common type. Breast cancer is the leading cause of cancer- related deaths among women in 173 out of 183 nations (95%), highlighting the need of addressing this disease prevention and management (WHO, 2023). The development of precise plans and the implementation of a long-term, well-organized program that targets the right population group, guaranteeing coordination, continuity, and quality of action at all levels of care, are crucial components of the successful management of breast cancer. Early detection strategies in the population, regardless of the method, are also important. Applying a methodical test to a group of people who are thought to be asymptomatic is known as screening.

Breast cancer is the most common cancer in Northern Africa, accounting for 36.9% of all malignancies and the primary cause of death for women. Breast cancer accounts for 19.3% of all cancers and is the most common malignancy in both sexes. Compared to much of sub-Saharan Africa, its prognosis is comparatively better in North Africa. (Ferlay, et al., 2024).

The absence of screening programs like routine mammograms, which are essential for early diagnosis, is one of several interconnected factors contributing to the high morbidity and mortality of breast cancer in lower and middle-income countries (LMICs). Because of this, breast cancer is frequently discovered at a later stage, when therapy is less successful. The general public's lack of knowledge about breast cancer symptoms and the significance of early diagnosis causes them to put off seeking medical attention. Access to healthcare is hampered by the underfunding of many LMICs' healthcare systems, which makes it difficult to find qualified medical personnel, specialist cancer treatment facilities, and diagnostic facilities. Due to financial limitations, many people in LMICs may find the expense of diagnosis and treatment to be exorbitant, which causes them to put off or avoid getting medical care. (Ginsburg, et al., 2017).

However, there is a lot of diversity throughout the Arab world, with lower- to middle-income nations experiencing worse outcomes. For instance, the 5-year survival rates for breast cancer were 85.3% in Qatar and 43.1% in Jordan. (Fearon, et al., 2020).

The breast cancer characteristics of Arab women differ from those of those in the developed world. In some Arab groups when the tumor is first diagnosed, the disease is more advanced, the tumor is larger, and the patients are at least ten years younger. Additionally, data indicates a higher tumor grade, a greater percentage of negative hormone receptors, and increased axillary lymph node invasion. (Chouchane & Boussen 2013). Most diagnoses came from women presenting with symptoms rather than screening, and many Arab women reported a delay between the beginning of symptoms and a diagnosis. This period was marked by uncertainty and many visits to both conventional and contemporary healthcare professionals. When Arab women found out they had breast cancer, they experienced extreme fear and worry. Typically, they don't talk to their doctors about their concerns. On the other hand, they either travel abroad to obtain second views and therapy, or they comply with the recommended tests and treatments. (Soliman et al., 2019).

The previous findings vary from study to study, but all pointed to a lack of knowledge and awareness of the disease and its prevention. Some found that knowledge of breast self-examination was weak, that there was a significant lack of awareness and knowledge of the disease, risk factors and protection against breast cancer, and that those with the disease were diagnosed in the late stages after the onset of symptoms, rather than by periodic screening (Hashim et, al., 2018; Fearon, et al., 2020; Ferlay, et al., 2024; Fox & Shaaban, 2022). However, all the studies agreed on the importance of this topic and stressed that awareness, education and early detection and development of framework and guidelines for breast cancer management are necessary. Women should be aware of the importance of screening for breast cancer as it completely changes the course of the disease, and the early detection; ensure the body's response to treatment and it mitigates the damage and increases five years survival rates. A multifaceted strategy is necessary due to the rising incidence of breast cancer in the Arab world and the intricacy of the risk factors linked to this disease. More palliative care, better access to cheap therapy, early detection and diagnosis, lifestyle changes, and increased public awareness are all critical concerns that require attention. Only a collaborative effort from the public, healthcare professionals, and policymakers can successfully execute these improvements. (Hashim et, al., 2018).

In Libya, it is challenging to estimate the incidence of cancer cases due to the lack of data collection and the ineffectiveness of the cancer registry and documentation system. According to one of the few sources that are currently available, lung cancers are

the most common cancers among men. From 2003 to 2005, there were 1367 cancer-related deaths; the most common causes of cancer-related deaths were lung cancer (29.3%), colorectum cancer (8.2%), and brain cancer (7.3%) in men and breast cancer (14.8%), colorectum (10.6%), and liver cancer (7%) in women. All cancers combined had a 5-year relative survival of 22.3%; men had a lower survival rate (19.8%) than women (28.2%). Among the rates of different cancers in women, breast cancer continues to have the highest occurrence. (El - Mistiri et al., 2015).

Aim of the study:

- To investigate the experiences and understanding of Libyan patients on screening and the utilization of breast self-examination, in the early disease detection, identify knowledge gaps, and list the problems associated with diagnosis and treatment.
- To discuss, and the financial burden of disease management on Libyan patients.

2 Materials and Methods

A qualitative study conducted during the period from 15 January- 24 March 2022, at Benghazi Medical Center. Aiming at gathering comprehensive, and deep understanding of factors affecting the planning, and implementation of programs for prevention, early detection and management of breast cancer in Benghazi, Libya. These factors include: the knowledge, socio-cultural and financial factors.

Ethical approval was obtained (IRB) from the ethical committee of the faculty of public health, University of Benghazi and Benghazi Medical Centre.

Semi-structured in-depth interviews were used. Thirty -one Libyan breast cancer patients who were either completed or still receiving the treatment were interviewed. The interviews were conducted at the hospital or through the phone, all interviews were recorded. A full explanation of the aim of the study, freedom to refuse to answer any question or withdraw from the participation with insurance of secrecy and confidentiality of reported information. Consents of participation were received from every participant verbally and in written forms. The sample was deliberately selected on the assumption that these participants would be able to express their experiences with the disease. All participants were indicated with numbers from 1 to 31, their sociodemographic factors (age, education, and marital status) were added.

Analysis of data obtained from in-depth interviews by using a five-stage methodological framework (familiarization, identification of a thematic framework, indexing, charting, mapping and interpretation) After transcription and writing audio recordings of interviews in the form of written texts, encoding and processing them using Microsoft office word 2010, and designing a thematic framework whose main and sub-dimensions and topics were derived from the analysis of interview texts and research objectives, and based on the themes included in the theoretical model of the research. List of the encoding index was done and applied to the entire dataset.

3 Results

Socio-demographic:

Nearly two-thirds of the sample (61.3%) were at young age group (Under 49 years old). One -third (38.7) of patients were fifty years and above. About half (51.6%) had a university level of education; and the majority were married (80.6%). Family history of breast cancer was found in less than half of the sample (41.9%). Regarding the stage at which they were diagnosed with breast cancer. Only half (51.6%) of the sample were diagnosed in the first stage.

The disease was discovered, through breast self-examination (BSE) in only three cases (9.7%), and the remaining 90.3% were discovered and diagnosed by specialist doctors and by radiology and diagnostic devices confirmed.

Table 1: Socio-demographic factors of patients with breast cancer:

	Number of patients (31 patients)	%
Age group:		
Under 40 years old	7	22.6%
40-49	12	38.7%
50 and above	12	38.7%
Education level:		
Primary	3	9.7%
Secondary	9	29.0%
High-school	3	9.7%
University	16	51.6%
Marital status:		
Married	25	80.6%
Unmarried	6	19.4%

Based on the analysis of interviews, the evaluation of prevention, early detection and treatment of breast cancer in Benghazi can be described and evaluated through the patient's perspective into two broad themes. The first theme included the prevention, education and early detection, and the second theme

included diagnosis, treatment and support. The following tables summarize these themes, and the dimensions contained in each theme.

Theme 1: Prevention, Education and Early detection

The first theme focused on prevention, education and early detection, and included several dimensions: knowledge of causes and risk factors of breast cancer in general among women, the extent of knowledge of Breast Self-Examination (BSE) in the right ways, in addition to barriers of early detection and management of the disease. In the following table (2) representative quotations related to the dimensions of this topic from patients' point of views, regarding the dimension of knowledge of breast cancer, the respondents with the disease mentioned several causes of the disease that reflect their lack of correct scientific knowledge of the screening programs and early detection of the disease, their insufficient and poor knowledge of its risk factors and causes. Most of the respondents believed that stress, tension and other psychological and social reasons are the reasons behind their disease, while only five of them stated that it was for genetic reasons.

In the present research we explored the dimension of knowledge of breast self-examination (BSE), and to identify the extent of knowledge of self-examination among the respondents. The interview included a question about the extent to which they knew or heard about this method, and another question in which the respondents were asked to explain the method practically to the researchers' assistants.

Only three of the respondents answered that they knew and used the BSE method, 13 answered that they had previously heard about it from various sources including television or the Internet, while another 15 reported that they've never heard of the method. When asked to explain the method of self- examination in practice to the researchers' assistants, it was found that only 8 of them (out of 31 respondents) were able to explain it correctly, while the rest of the respondents could not explain it correctly.

Table 2: Theme of prevention, education and early detection

Dimension	Representative Patients' Quotations
Knowledge about risk factors of the breast cancer	"I believe that getting pregnant after the age 30 years old is one of the causes of the disease, beside the war violations, distress, and the current situation of the country have led to an increase in the prevalence of the disease" (**Interviewee 19**: **Breast cancer patient, 40 years old**). "Stress, sadness and social problems have caused many diseases, including cancer of all kinds" **(Interviewee 21: Breast cancer patient, 46 years old**).
Knowledge of Breast Self-Examination (BSE)	"I used to hear about BSE, but I didn't apply it" (**Interviewee 14: Breast cancer patient, 44).** "I've heard of it, but I don't know the details" **(Interviewee 18: Breast cancer patient, 50 years old**). "Before the illness I used to hear about the examination, but honestly my breast is small, and I didn't expect to get the disease, I thought that only those with big breasts would get sick, I never applies the BSE" **(Interviewee 29: Breast cancer patient, 40 years old**).

Theme 2: Diagnosis, treatment and support:

The second theme that emerged from patients' interviews was the diagnosis, treatment and support, which covers issues of services provided in the public sector in public health facilities. Their opinion about survivor treatment and support with increased focus on long-term side effects of survivors, with breast cancer, and the need for efforts to strengthen and develop regulation in the field of breast cancer. Table 3 presents selected quotations for the dimensions of the subject of diagnosis, treatment and support.

Table 3: Theme of Diagnosis, Treatment and Support

Dimension	Representative patients' quotations
Services provided in the public sector	"The difficulties, discrepancies and inadequacy of health services in public sectors". (**Interviewee 5: Breast cancer patient, 40 years old**). "Disparities in access to services. The plight of low-income people and residents outside Benghazi who do not receive the necessary services, as well as unequal access to treatment abroad". (**Interviewee 9: Breast cancer patient, 55 years old**).
Lack of management and treatment in public facilities	"Public sectors do not offer the needed investigations and treatment which will led to delay in my treatment". (**Interviewee 16: Breast cancer patient, 58 years old**).
High cost of private services, and need to travel abroad for services	"Lack of funding at public facilities forced me to travel abroad and pay all the expenses of investigations, and treatment". **(Interviewee 6: Breast cancer patient, 44 years old**).
High cost and Catastrophic spending	"The first operation was to take the sample and cost about 2500 dinars, the surgery cost about 5000 dinars, the tests cost about 5000 dinars, the chemotherapy I took in a free public hospital, the treatment and medicines I did not take from abroad, because they were all available in the oncology clinic for free" (**Interviewee 4: Breast cancer patient, 55 years old**). "The cost of medical examinations and analysis is about $2,000, the cost of surgery is $3,000, the cost of the rest of the treatment and medications is about $7,000, in addition to the costs of travel for the patient, facilities, accommodation and living costs, and other additional costs of about $14,000". (**Interviewee 31: Breast cancer patient, 46 years old**).
Managing survivorship	"There is a group of **Talk Freely**, which is for new patients, starting from diagnosis and chemotherapy to the stage of recovery" (**Interview 11: Breast cancer patient, 48 years old**). **"Brave Heart Group** was formed from the recovered patients support group, help to overcome difficulties, complete the journey and discuss how they deal with side effects of chemotherapy" (**Interview 10: Breast cancer patient, 51 years old**).

4 Discussion

Our research confirmed the poor level of knowledge of breast cancer causes, risk factors and prevention among Libyan patients, it highlighted the critical gaps in patient knowledge, healthcare infrastructure, healthcare service provision and support systems. These challenges are faced by many low- and middle-income countries (LMICs) and have a profound impact on the ability to diagnose and treat breast cancer effectively. Addressing these issues requires a multi-faceted approach to improve outcomes and reduce breast cancer morbidity and mortality. The study identified two primary themes: (1) prevention, education, and early detection, and (2) diagnosis, treatment, and support. Each of these areas requires attention to improve outcomes for breast cancer patients.

The study findings indicated a significant lack of awareness and understanding among patients regarding breast cancer causes, risk factors, symptoms, and early detection methods. While breast self- examination (BSE) is a simple and cost-effective tool, only few of the participants practiced it, and many were unaware of its importance. Most cases were diagnosed in advanced stages, with only a few identified through BSE. These findings are consistent with the findings of most previous studies that conducted in Libya and other Arab countries (Al-sharbatti et al., 2014; El-Lassy & Madian, 2015; Al-Hussani's, 2017; Ziuo et al., 2018), which confirmed that there was a significant lack of knowledge about the disease and methods of early detection of breast cancer. Also, the findings of Al-Hussani's (2017) that conducted in western Libya, stated that more than half of the cases were diagnosed in the late stages (third and fourth stages of the disease). Similarly, Ellobiid et al. (2014) who noted that limited knowledge about early detection practices significantly hinders breast cancer management in LMICs and highlighted the importance of education programs in raising awareness about breast cancer and increasing participation in screening activities. And Rabbani et al. (2019), which emphasized the lack of awareness and education as major barriers to early detection programs.

Socio-cultural factors further exacerbate the issue, with misconceptions about breast cancer being prevalent. In our study many participants believed that

the psychological stress and social factors were the primary causes of their illness, which reflect the pervasive myths surrounding the disease. Such misconceptions are not unique to Libya; in Saudi Arabia, stigma and traditional beliefs, significantly impact breast cancer management. The reluctance to discuss breast health, as observed in this study, Al-salamh et al. (2024) who stated that cultural taboos discourage Saudi women from seeking routine screening. This silence around breast cancer often results in advanced-stage diagnoses and poorer outcomes. Same results also reported by Piana, (2014), who stated that in Arab world, approximately 73% of breast cancer cases are identified at an advanced stage of the disease, and 30% of affected women are under 40, according to an article about the disease. She discussed that, the primary challenge that Arab women face is the taboo surrounding the discussion of medical matters pertaining to a private female body part. Therefore, women are unable to receive routine early detection tests to discover breast cancer at an early, curable stage if they are unable to discuss the disease. The primary goal of healthcare professionals is to dispel the taboo around breast health in the traditional Arab culture. Saving the lives of women was the ultimate objective.

Educational interventions have been shown to improve awareness and early detection behaviors. For instance, El-Lassy & Madian (2015) reported that health education programs in Egypt significantly enhanced BSE practices among females' university employees, demonstrating the potential of targeted education initiatives. However, in Libya, as in many LMICs, such programs are sparse or non-existent, leaving patients ill-equipped to recognize early symptoms or seek timely medical care.

This study highlights a systemic challenge in the Libya's including misconceptions about the disease, lack of information about the disease added to poor healthcare infrastructure, particularly in public sector facilities, with insufficient diagnostic facilities, limited access to advanced treatments, and delays in service delivery. In Benghazi, these issues were compounded by geographical and financial barriers, as patients from rural or underserved areas face additional challenges accessing diagnostic and treatment facilities. The inadequacy of public health services, financial constraints force many patients to seek care abroad or rely on private healthcare with high costs, incurring catastrophic expenses.

These findings also align with Ginsburg et al. (2017), who reported that the underfunding of healthcare systems in LMICs limits access to essential diagnostic and treatment services. Inadequate healthcare infrastructure also exacerbates late- stage diagnoses. Limited availability of routine mammography and other diagnostic tools often results in delayed detection, reducing treatment efficacy and survival rates.

Penalba et al (2019), stated that communication gaps between patients and healthcare providers (HCPs) were highlighted as a barrier to effective care. Participants reported insufficient guidance and emotional support during their treatment journey. The perception of communication gaps between patients and HCPs about symptoms. Better understanding of these gaps is needed to ensure that patient-centered care is delivered and that patients' symptoms can be appropriately managed in oncology clinics.

Cazap et al. (2016), It was highlighted that in low- and middle-income countries (LMICs), the deficiency of support structures, such as patient advocacy groups and survivor networks, coupled with the dearth of palliative care services, has resulted in emotional and psychological voids.

The challenges identified in this study are reflective of broader issues faced by LMICs. Mahdi et al. (2022) noted significant disparities in breast cancer survival rates across the Arab world, with outcomes closely tied to the strength of healthcare systems and public health policies, which highlighting the impact of organized screening and treatment programs. To achieve similar improvements in Libya, systemic reforms and resource allocation are imperative.

5 Conclusions

Despite the increase in the incidence of breast cancer in developing countries and Arabic countries including Libya where breast cancer remains a significant public health challenge. This study underscored the lack of knowledge about breast cancer prevention and early detection programs. A well designed and implemented national framework and guidelines can help in the early detection and treatment of breast cancer which helps in reducing the morbidity and mortality of the disease. In Libya as a country with unequal distribution of resources as stated in this study and fragile health systems, there should be standardized, organized, preventive programs including raising awareness and dealing with misconceptions about the disease, knowledge about risk factors and emphasizing that screening should be performed even when asymptomatic with better direction of resources. As stated by patients in this study, the barriers and

miscommunication between health-care providers and breast cancer patients should be tackled and eliminated for building trust and eliminating the misconceptions and the taboo about the disease.

6 Recommendations

1- Advocate for Policy Changes: Advocate for government policies, development of framework and guidelines that prioritize breast cancer prevention, including funding for public health campaigns, research, and infrastructure improvements.

2- Promote Awareness and school education by developing educational materials tackling and integrate breast health education into school curricula, teaching young women about risk factors and the importance of early detection.

3- Launch widespread campaigns using social media, television, and radio in local languages to educate women about the importance of regular breast self-examinations and clinical screenings.

4- Development of national regular screening programs: According to international standards and should include breast screening guidelines that recommend mammograms for women aged 40 and above, or earlier for those with a family history of breast cancer. Mammography Access: Increase access to affordable mammography services, especially in rural and underserved areas,

5- Health Insurance Coverage: to ensure that breast cancer screenings are covered by health insurance plans to reduce financial barriers.

6- Holistic approach of the patient: Strengthening Primary Care services and training primary healthcare providers in breast cancer risk assessment, early detection, and patient counselling. Language and trust barriers between women and healthcare providers need to be minimized for practical and efficient implementation of successful breast cancer management programs to provide patients with proper psychological, social and medical care.

7- Geographic distribution of services and use of Telemedicine: Develop strategies to improve healthcare access in rural and remote areas, where women may have limited access to screening and treatment services and the use of telemedicine to provide consultations, follow-up care, and education to women in areas with limited access to healthcare facilities.

8- Support Research and Data Collection: Increase research on breast cancer prevention, particularly studies focusing on the Arab population to better understand regional risk factors and effective interventions.

9- Cancer Registries: Establish or strengthen national cancer registries to track incidence, prevalence, and outcomes of breast cancer, which can inform decision makers about the gap in the present programs.

10- Support Groups: Establish support groups for women diagnosed with breast cancer, as well as for survivors, to provide emotional support and share experiences.

7 Strengths and Limitations

This qualitative study is used which is a strong research method used usually to explore and evaluate the patients' point of views and attitudes via face to face or through the telephone by using semi- structured in-depth interviews with each patient and allowed them to fully express their experience with the disease. It helped to explore patients' knowledge about breast cancer and uncover the gap in the present programs to help decision-makers in developing national framework, screening modalities among Libyan women, guidelines of preventive measures and management options. Some limitations to this study should be considered, including the research was conducted only in Benghazi city, the findings may not be generalized to all women in Libya. The inability to gather data about the use Breast Self-Examination and the use of investigative tools in the management due to poor medical data recording and incompleteness of the cancer registry programs.

Author Contributions:

Conceived and designed, by MF. Analyzed the data and the writing of the manuscript: BG.

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