

Breast Cancer Awareness among Egyptian Women and the Impact of Caring for Patients with Breast Cancer on Family Caregivers' Knowledge and Behaviour

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Abstract

Background: Breast cancer is the most common cancer in Egyptian females. Most patients present at a late stage with subsequent poor outcomes.

Aim: To study the awareness of breast cancer, its risk factors and screening. To investigate the impact of caring for a family member with breast cancer on the awareness and future attitudes of caregivers.

Methods: The study included 704 females divided into two groups. A non-caregivers group including 248 participants representing the general population and a caregivers group including 456 family caregivers of breast cancer patients. We used a questionnaire comprised of 45 questions assessing four domains: individual risk factors, awareness of risk factors, awareness of screening, and the practice of and barriers to screening. Those who answered more than 50% of the questions correctly were considered to have good knowledge.

Results: Sixty-nine percent of participants showed poor knowledge of risk factors. In the screening awareness domain, only 44% of participants scored >50% indicating defective knowledge. Caregivers attained significantly higher scores in all domains ($p<0.001$). Yet, the overall assessment showed poor knowledge in both groups. Only 3% of non-caregivers and 19% of caregivers performed mammography ($p<0.001$); while 11% and 38%, respectively, underwent breast self-examination ($p<0.001$). Higher education level was associated with significantly better knowledge ($p<0.001$).

Conclusions: Breast cancer knowledge among Egyptian females is deficient. The level of education and caring for a breast cancer patient significantly affect the level of knowledge and attitude towards screening. There is a need to implement a comprehensive national awareness and screening programme.

Keywords: Awareness, Breast cancer, Family caregivers, Egypt, Screening

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Introduction

Breast cancer is the most common type of cancer in women and the first cause of cancer death among them ¹. In Egypt, it constitutes 33% of female cancer cases and more than 22,000 new cases diagnosed each year ². This is expected to rise exponentially over the next years given the enlarging population, changes in the population

pyramid and adopting the westernized lifestyle. Despite significant improvements in survival figures in many developed countries yet the 5-year survival in Egypt as reported in several studies remained lower ranging from 28% to 68 % ^{3, 4}. Multiple factors contribute to the lower survival outcomes and it is believed most patients are being diagnosed at late stages ⁵.

A study by the Egyptian Ministry of Health and the Demographic and Health Survey project

showed that only 2 % of the surveyed Egyptian women had some form of clinical screening (mammogram, ultrasound or clinical breast examination [CBE]) and only 6% performed breast self-examination (BSE) in the year prior to the survey ⁶. This could be due to a medley of factors, some of which can be put down to the service provider (i.e. health care systems) while other factors are related to patients including social, cultural, financial and fear of the disease but it is believed that one of the main factors keeping Egyptian women from undergoing breast screening is lack of awareness of breast cancer and the importance of screening in early diagnosis.

In a previous study we demonstrated that Egyptian women take on average 4.4 months (131 days) from the time they develop a breast symptom until presentation. There is another lag from the time they see a health professional until they commence the appropriate treatment whether systemic, surgery or radiotherapy ⁷. This lag time is variable according to the type of health care provider (private sector vs. public) and health care professional (gynaecologist vs. surgeon vs. oncologist). In most cases the time taken from developing symptoms until commencing treatment is more than 6 months, which is enough time for breast cancer to progress and upstage.

As patients contribute to the bigger part of the delay, we wanted to understand the rationale and causes behind this attitude by studying breast cancer perception and awareness of the disease and its risk factors. The authors also wanted to see if having a family member diagnosed with breast cancer would change breast cancer awareness among caregivers and if this would influence their future attitude and willingness to undergo screening.

Methods

Study design and population

The study was carried between August and November 2017. It included 704 women aged 17 or older. We studied two groups, non-caregivers and caregivers.

The “non-caregivers” group included 248 women representing the general population. This group was picked in a random manner from attendants at Ain Shams University hospital out-patient ophthalmology and physical medicine clinics. Non-caregivers were women coming to receive a service or family member attending with a patient.

The “caregivers” group comprised 456 female caregivers of breast cancer patients attending to a dedicated breast cancer centre in Cairo (Baheya Breast Cancer Centre) for investigations or treatment for breast cancer. Caregivers were either first- or second-degree relatives.

Data Collection

The study was conducted as a face-to-face interview with candidates via three final year medical students who were trained on the questionnaire, consenting and explaining to candidates the purpose of the study and giving them the liberty to refuse participation or withdraw at any time.

We used version 2 of the Breast Cancer Awareness Measure (Breast CAM) ⁸. This was modified and some questions were added to fit the local culture and the purpose of the study. The questionnaire was translated into Arabic language by a bilingual expert and the translated version was then reversed back to English and approved by a validated translator to ensure accuracy (Forward-Backward method). We asked 18 women to complete our questionnaire as a pilot study and some modifications were carried accordingly. Cronbach’s Alpha test was used to test reliability and this was 0.8. Time needed to complete the interview was 25 to 30 minutes in average. The questionnaire comprised 6 socio-demographic questions, a question on current breast symptoms if any, and 39 questions divided into four domains as follows:

1st domain (individual risk factors): 9 questions asking about menarche, menopause, pregnancy and family history of cancer.

2nd domain (awareness of breast cancer risk factors): 12 questions, starting with a general question asking about whether the candidate is aware of factors that might increase women’s potential risk of breast cancer going through specific risk factors - internal and external- like age, overweight, breast density, positive family history and hormone therapy.

3rd domain (awareness of breast cancer screening): 11 questions to examine candidates’ knowledge on breast screening methods, time, frequency and if they believe screening improves outcomes.

4th domain (current behaviour, barriers to screening and future intention): Candidates were asked whether they had previous breast

imaging, BRCA testing or done BSE and what might be possible obstacles against breast screening. The survey closed with 3 questions asking if the candidate is willing to practice BSE and/or screening.

A paper form was used to collect responses which were then pooled into a master datasheet. Responses were coded for statistical analysis. Data was analysed for each group separately then was compared to the other group.

For the purpose of this study, giving correct answers for more than half of the questionnaire questions was considered good knowledge of breast cancer. So, we used 50% score of right answers as a cutoff to categorize the study candidates into good vs. poor knowledge.

Statistical analysis

Numerical data were summarized as mean + standard deviation (SD) or median + range as appropriate while categorical data were summarized as frequency and percentage. Analysis comparing numerical data between the two groups were done using Student's *t*-test for independent samples while comparisons of categorical data were done using Chi-square test. Regarding demographic and clinical characteristics, missing data were not included in the analysis while regarding awareness missing data were considered lack of awareness. The correct answers were summed to get the participants' score and those who answered more than 50% of the questions correctly were considered to have good knowledge. Multivariate regression model was done to adjust for the significance between groups in demographic data. Pearson's correlation was used for correlation between the percent overall score and numerical and dichotomous data while Eta² was calculated for categorical data with more than 2 levels. All statistical tests were two-sided and *p* value <0.05 was considered significant. The analysis was done using IBM SPSS Statistics for Windows, Version 27.0. (Armonk, NY: IBM Corp).

Ethical considerations

This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Clinical Research Ethics Committee of Baheya Foundation for Breast Cancer on 28-June-2017 (Approval No. 0317/2017). The study aims were explained, written information

was handed and informed consent was obtained from all participants.

Results

Demographic and clinical data

The mean age of all participant was 39.92 years ranging from 17 to 86 years old. Around 73 % of the them were premenopausal and 78% of them were married. There were significant differences between the two groups regarding, age, menopausal status, marital status, and educational level. These data are summarized in Table 1.

The most common reported warning sign of breast cancer was pain in both groups but caregivers reported significantly higher rates of breast mass, axillary mass, and pain compared to non-caregivers as summarized in Table 2.

Awareness of risk factors for breast cancer

When asked about risk factors for breast cancer, the percentage of participant that correctly answered risk factors questions among non-caregivers vs. caregivers were as follows; older age (23.5% vs. 35.8%), family history (36% vs. 56%), benign breast disease (30% vs. 43.8%), radiation exposure (10% vs. 23%), increased breast density (6% vs. 20.6%), obesity (27% vs. 37%), early menarche (5% vs. 11.1%), oral contraceptive pills (20% vs. 50%) and late menopause (6.5% vs. 13.7%). Among participants, 56.2% knew that lactation is protective while 59.1% knew that breast cancer can be asymptomatic. Overall, 18.1% of non-caregivers were reported to have good knowledge about risk factors of breast cancer compared to 38.3% of caregivers (Table 3).

Awareness of breast cancer screening method and early detection

Caregivers demonstrated better knowledge of breast cancer screening than non-caregivers. More than 80% of non-caregivers were considered to have poor knowledge of the methods for breast cancer screening as represented in Table 3.

Seventy-two percent of caregivers vs. 44% of non-caregivers were aware that breast cancer can be early detected and 91.7% vs. 68.5% reported that screening can improve outcomes and disease morbidity. Breast self-examination, CBE and mammogram were recognized as methods of early detection by 97%, 27% and 47.8% of caregivers compared to 23.4%, 1.6% and less than 1% of non-caregivers, respectively.

Table 1: Socio-demographic data of participants

| Parameter | | Non-caregivers | Caregivers | <i>p</i> value * |
|--|-----------------|----------------|--------------|------------------|
| | | Mean (SD) | Mean (SD) | |
| Age ^a | | 43.2 (15.7) | 38.09 (13) | <0.001 |
| Age at 1 st menstruation ^b | | 13.2 (1.6) | 13.35(1.5) | 0.365 |
| Age at 1 st pregnancy ^c | | 21.1 (3.6) | 22.58(3.9) | <0.001 |
| | | <i>n</i> (%) | <i>n</i> (%) | <i>p</i> value** |
| Menopausal status | Premenopausal | 164 (66.4) | 352 (77.5) | 0.002 |
| | Postmenopausal | 83 (33.6) | 102 (22.5) | |
| Marital status | Yes | 210 (85.5) | 336 (74) | 0.001 |
| | No | 36 (14.6) | 118 (26) | |
| Current pregnancy | Yes | 14 (5.7) | 23 (5.1) | 0.715 |
| | No | 231 (94.3) | 431 (94.9) | |
| Current lactation | Yes | 12 (4.9) | 16 (3.5) | 0.38 |
| | No | 233 (95.1) | 437 (96.5) | |
| Family history of ovarian cancer | Yes | 15 (6) | 26 (5.7) | 0.851 |
| | No | 233 (94) | 430 (94.3) | |
| Educational level | No education | 99 (40.1) | 54 (11.9) | <0.001 |
| | Primary | 27 (10.9) | 21 (4.6) | |
| | Preparatory | 28 (11.3) | 32 (7) | |
| | High school | 55 (22.3) | 124 (27.3) | |
| | Junior college | 20 (8.1) | 71 (15.6) | |
| | Regular college | 18 (7.3) | 152 (33.5) | |

^a *n* = 246 non-caregivers and 444 caregivers, ^b *n* = 161 non-caregivers and 418 caregivers, ^c *n* = 247 non-caregivers and 454 caregivers;
* Student *t*-test, ** Chi-square test

Table 2: Frequency of warning signs of breast cancer reported by non-caregivers and caregivers

| Parameter | | Non-caregivers | Caregivers | <i>p</i> value* |
|---------------|-----|----------------|--------------|-----------------|
| | | <i>n</i> (%) | <i>n</i> (%) | |
| Breast mass | Yes | 3 (1.2) | 31 (6.8) | 0.001 |
| | No | 244 (98.8) | 425 (93.2) | |
| Discharge | Yes | 12 (4.9) | 24 (5.3) | 0.816 |
| | No | 235 (95.1) | 432 (94.7) | |
| Pain | Yes | 22 (8.9) | 98 (21.5) | <0.001 |
| | No | 225 (91.1) | 358 (78.5) | |
| Axillary mass | Yes | 7 (2.8) | 33 (7.2) | 0.016 |
| | No | 240 (97.2) | 423 (92.8) | |
| Skin change | Yes | 1 (0.4) | 11 (2.4) | 0.05 |
| | No | 246 (99.6) | 445 (97.6) | |

*Chi-square test

Table 3: Comparison of knowledge between non-caregivers and caregivers

| Parameter | | Non-caregivers | Caregivers | <i>p</i> value* |
|---|----------------|----------------|--------------|-----------------|
| | | <i>n</i> (%) | <i>n</i> (%) | |
| Awareness of breast cancer risk factors | Good knowledge | 45 (18.1) | 173 (38.3) | <0.001 |
| | Poor knowledge | 203 (81.9) | 279 (61.7) | |
| Awareness of breast cancer screening | Good knowledge | 44 (14.7) | 298 (65.4) | <0.001 |
| | Poor knowledge | 204 (82.3) | 158 (34.6) | |
| Overall knowledge | Good knowledge | 32 (12.9) | 201 (44.1) | <0.001 |
| | Poor knowledge | 216 (87.1) | 255 (55.9) | |

*Chi-square test

When asked about BSE, 41% of the whole study group knew that it should be done with fingers and only 27.6% of caregivers and 11% of non-caregivers knew that it should be done monthly.

Television, radio and social media were the main sources of information on breast cancer screening for study participants in both groups (51%) followed by friends (16%) and family members (5%).

Regarding previous screening, 18.6 % of caregivers had previous imaging and 38.1% performed BSE compared to 2.8% and 11.3 % of non-caregivers, respectively.

Overall assessment of knowledge

The median (range) overall percent score for non-caregivers was 23.8% (0-85.7) while for caregivers it was 47.6% (0 - 100) ($p < 0.001$).

When running a multivariate regression model with age, menopausal status, marital status, and educational level only educational level had a significant impact on the overall percent score by 56% ($p < 0.001$). After applying the regression model on each group, also the educational level was found to be affecting the overall percent score by 45% ($p < 0.001$) in non-caregivers and 46% ($p < 0.001$) in caregivers. It was found that the educational level affected the overall percent score nearly the same in both groups. Hence, the initial baseline difference might be due to chance or different sample size in each group. These data are summarized in Table 4.

We noticed that there was a significantly higher rate of college and high school education among caregivers than non-caregivers (76% vs. 38%, respectively), so we wanted to investigate whether the notable difference in breast cancer knowledge is attributed only to the difference in the level of education between the two groups hence we performed a comparison between the two groups based on educational level stratifying each group into higher education vs. lower education where the higher education group included those who received high school or college education and lower education are those who did not.

There were still remarkable differences between the two groups as shown in Table 5. In the High education group, 24% of non-caregivers demonstrated good knowledge vs. 53% of caregivers ($p < 0.001$). In the low education group, the percentages were 6.5% and 14.8% respectively. The differences were statistically significant.

Current behaviour, future intention, and obstacles to screening

Overall, 12.9% of the participants reported previous breast imaging while 28.6% reported previous BSE. Caregivers of breast cancer patients showed significant higher reporting of previous BSE and imaging compared to non-caregivers.

More than 65 % of the participants reported they have the intention to perform BSE, CBE and mammography. This data is summarized in Table 6. Several obstacles to breast cancer screening were described by the participants including unawareness of its benefit (46.1%), fear to discover cancer (35.5%), financial obstacles (14.3%), and others (12.3%).

Discussion

Breast cancer is the most common type of cancer in Egyptian women and although incidence rates are not as high as in the west, yet breast cancer mortality is considerably worse⁹.

A major cause in low- and middle-income countries is late stage presentation and Egypt is not an exception¹⁰. There is limited access to sophisticated technologies and targeted therapies in the public sector and prioritizing investing into early detection and diagnosis at an early stage is indeed more practical and cost-effective measure to improve disease survival and reduce mortality. The result of the United Kingdom national breast screening programme is a good example of how down staging breast cancer presentation via early detection and screening can improve cure rates¹¹.

Lack of awareness of different aspects of breast cancer was demonstrated in our study. In terms of risk factors, more than two thirds (68.9%) of study participants showed poor knowledge. Least recognized risk factors were early menarche and late menopause. While most recognized risk factors were positive family history and oral contraceptive pills. Most did not know that overweight can increase the risk of breast cancer (only 33% did). This is of particular concern as Egypt is among top countries in the world in terms of overweight and obesity with prevalence ranging from 74-86% among females according to the WHO¹² hence more effort is needed to increase awareness on obesity related morbidities including cancer in general and breast cancer in particular.

As regards screening awareness, caregivers of breast cancer patients demonstrated better awareness with 65% having a good level of

Table 4: Regression model with percent overall score as the outcome

| Variable | All participants | | Non-caregivers | | Caregivers | |
|--------------------|------------------|---------|----------------|---------|------------|---------|
| | Beta | p value | Beta | p value | Beta | p value |
| Age | -0.034 | 0.512 | -0.053 | 0.583 | -0.041 | 0.545 |
| Menopausal status | -0.027 | 0.563 | -0.07 | 0.415 | -0.015 | 0.797 |
| Marital status | -0.038 | 0.294 | -0.078 | 0.211 | -0.026 | 0.613 |
| Educational levels | 0.562 | <0.001 | 0.451 | <0.001 | 0.461 | <0.001 |

Table 5: Comparing overall knowledge between non-caregivers and caregivers according to education level

| Parameter | | Non-caregivers | Caregivers | p value * |
|--|----------------|----------------|------------|-----------|
| | | n (%) | n (%) | |
| Higher educational level (≥ high school) | Good knowledge | 22(23.7) | 184(53.2) | <0.001 |
| | Poor knowledge | 71(76.3) | 162(46.8) | |
| Lower educational level (< high school) | Good knowledge | 10(6.5) | 16(14.8) | 0.027 |
| | Poor knowledge | 144(93.5) | 92(85.2) | |

*Chi-square test

Table 6: Comparison of current behaviour and future intent to perform breast cancer screening between non-caregivers and caregivers

| Parameter | | Non-caregivers | Caregivers | p value * |
|--|--------------|----------------|------------|-----------|
| | | n (%) | n (%) | |
| Previous imaging | Yes | 7 (2.8) | 83 (18.6) | <0.001 |
| | No | 241 (97.2) | 36 (81.4) | |
| Previous breast-self examination | Yes | 28 (11.4) | 169 (38.2) | <0.001 |
| | No | 218 (88.6) | 273 (61.8) | |
| Intention to breast-self examination | Yes | 204 (82.3) | 377 (82.7) | 0.62 |
| | No | 40 (16.1) | 67 (14.7) | |
| | I don't know | 4 (1.6) | 12 (2.6) | |
| Intention to clinical breast examination | Yes | 172 (69.4) | 323 (70.8) | 0.579 |
| | No | 71 (28.6) | 119 (26.1) | |
| | I don't know | 5 (2) | 14 (3.1) | |
| Intention to mammogram | Yes | 168 (67.7) | 311 (68.2) | 0.698 |
| | No | 70 (28.2) | 132 (28.9) | |
| | I don't know | 10 (4) | 13 (2.9) | |

*Chi-square test

knowledge. Most of this group knew benefits of early detection and that screening can improve outcomes including morbidity and mortality. Yet they showed deficient knowledge in methods of screening, frequency, age and how to perform BSE. On the other hand, the vast majority of non-caregivers (82.3%) showed poor screening knowledge. Only 44% of study participants scored more than 50% indicating defective knowledge in the screening domain.

The cumulative overall percent score reflects total knowledge in all aspects of the survey. On the whole, the overall assessment showed poor knowledge in both groups. Caregivers despite attaining significantly higher scores in all domains particularly in screening section yet their overall

score was still less than 50%. Non-caregivers showed marked lack of overall knowledge with almost 9 out of 10 candidates failing to score beyond 50%. The overall better knowledge of breast cancer amongst caregivers could have impacted their awareness of their breasts and therefore explain the notably higher reported symptoms of breast mass, axillary mass, and mastalgia compared to non-caregivers.

Higher education was associated with better knowledge in our study and the effect was confirmed by correlation and regression analyses which were highly statistically significant. This was also observed and reported in other studies^{13, 14}. The level of education had the same effect in both groups and because the level of education was

remarkably higher in caregivers this indeed could have been a key factor for the higher scores in the level of knowledge and awareness in favour of caregivers. Nevertheless, this was not the only factor as a cross-comparison of responses among participants at the same level of education in both groups showed again higher scores and better knowledge among caregivers which indicates an effect of being a caregiver to a breast cancer patient. The effect of having a family member diagnosed with breast cancer on disease awareness was also a notable finding reported in several other studies¹⁴⁻¹⁷.

In terms of behaviour, the rates of screening in our study were higher than those seen in the 2015 DHS report. Rates of imaging were 18.6% in caregivers and 2.8 % in non-caregivers while rates of BSE were 38.1% in caregivers and 11.3% in non-caregivers. In the Demographic and Health Survey report, only 1.5% were screened radiologically and 6.2% conducted BSE. These are almost half of the figures noticed in non-caregivers of our study. The substantial better practice observed in caregivers could be the effect of higher rates of education and having a family member diagnosed with the disease.

It is worth noting that the age of women in the Demographic and Health Survey report (range 15 - 59 years) and in our study (mean = 39 years) was relatively young and large numbers of these women would not have been eligible for screening by age criteria.

Fear to discover cancer and unawareness of the importance of early detection were the main barriers to seek screening. There is a great need to raise public understanding of the disease highlighting the fact that early diagnosis is associated with higher cure rates and shortening treatment journey. Our study showed that television and media in general were the most influential source of information therefore these should be utilized as key tools in awareness campaigns.

The limitations in this study include involving women residing in Cairo only so does not necessarily reflect level of knowledge among all Egyptians. The two groups were not balanced and level of education was significantly higher in caregivers as aforementioned which contributed to the better scores observed in this group.

Conclusion

Breast cancer knowledge among Egyptian women is deficient. Better education and family history of breast cancer significantly affect the level of knowledge and attitude towards screening. There is a need to defy the fear of the disease and breast cancer stigma via the implementation of a national awareness program where television and social media can be valuable tools.

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Authors' contribution

Conception or design: AHA, MKJ; Acquisition, analysis or interpretation of data: All authors; Drafting the manuscript or revising it: All authors; Approval of the manuscript version to be published: All authors; Agreement to be accountable for all aspects of the work: All authors.

Conflict of interest

The authors declare that they have no conflict of interest to disclose.

Data availability

Deidentified individual participant data used to produce the results of this study are available from the corresponding author (AHA) upon request.

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Study registration

None.

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