The Effect of Telephone Counseling and Education on Breast Cancer Screening in Family Caregivers of Breast Cancer Patients

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ABSTRACT

Background: Breast cancer is the most common form of malignancy among females. Family history is a key risk factor for breast cancer. Breast cancer screening practices are vital in patients with family history of breast cancer. Telephone counseling and education may be appropriate for improved breast cancer screening. This study was done to determine family caregiver patients’ knowledge of risk factors for breast cancer and practice of breast cancer screening and also to assess the effect of telephone counseling and education on mammography screening.

Methods: This study was a community-based trial. The participants of the study were 90 caregivers who were randomly divided into an experimental group, telephone counseling and education, and a control group. The intervention group received counseling and education phone calls. A three-section questionnaire was responded and filled out through telephone interviews with the participants. The collected data were analyzed with SPSS18, using descriptive and inferential statistics.

Results: The results showed that 88.9% of the participants did not know when to do breast self-exam (BSE). Mammography was performed by the participants before and after the telephone counseling in intervention group (P<0.00), which were 13.3% and 77.8% respectively. Moreover, the major cause of failure to participate in mammography was lack of enough knowledge in 73.3% of the participants.

Conclusion: This study concluded that knowledge and practice on breast cancer screening in family caregiver of breast cancer patients was low. Telephone counseling and educating may provide a suitable technique for earlier detection of breast cancer in family caregivers of breast cancer patients and it can influence the decision making regarding mammography screening among 40-year-old or older women.

Trial Registration Number: 2017052316870N3

KEYWORDS: Breast cancer, Telephone counseling, Caregivers, Early detection of cancer

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INTRODUCTION

Breast cancer is the most common form of malignancy among females. It is further considered the second leading cause of cancer death in women. One of the main public health problems in Iran is cancer and one of the most common malignancies is breast cancer among Iranian women. Rates of breast cancer incidence in women were 22 per 100,000. Even though the breast cancer incidence is still considered low in Iran, the number of patients recently diagnosed with breast cancer is increasing. Likewise, the trend for breast cancer mortality, the fifth most leading cause of cancer-related death among women, is on the rise.

Breast cancer is a multi-factorial disease, which may involve an interaction between age, anthropometric factors, lifestyle, hormonal and genetic factors. However, family history is the most important factor in the first degree family members. Studies indicate that first-degree female relatives of breast cancer (mother, sister, or daughter) are three to four times more prone to the risk of increasing breast cancer than the general population. Even Family history of breast cancer is a key risk factor for breast cancer; in other words, it is indicative of hereditary breast cancer. On the whole, the familial breast cancer guidelines, by National Institute for Health and Clinical Excellence (NICE), discuss the value of recording family history as a predictor of breast cancer risk. Breast cancer preventive behaviors such as early diagnosis through screening tests are critical for both the community and women’s health.

There are many ways to prevent diseases, among which screening is seen as an effective and safe way. Screening is likely to decrease the breast cancer risk and mortality. The goal of screening is to detect cancer at an early stage, mainly because cancers diagnosed at an early stage are treated easier than the one at its final stages, thus the survival chance is higher. The recommended screening methods for early detection and reduced mortality of the breast cancer include breast self-examination (BSE), clinical breast examination, and mammography. A screening mammogram is routinely used to evaluate a woman’s breast health and to screen women in order to reduce their risk of dying from the breast cancer. Some researches about mammography screening have revealed that the risk of dying of breast cancer in women who have regular mammograms is 10% to 25% lower than women who do not have mammograms.

Previous studies show that breast cancer screening practices are widespread for all women in the world. However, the proportions that engage in this practice and the frequency varies from country to country. Despite the benefit of screening to reduce the risk of breast cancer, limited information is available on screening behavior among women with a family history. What is more, the same is true for Iranian women. In a study carried out by Bird’s and colleagues not even a significant statistical correlation was found between having a family history of breast cancer and received breast cancer screening.

Comprehensive knowledge about breast cancer screening and appropriate beliefs and attitudes can play a very important role in women’s screening implementation. However, there is often lack of awareness in women about early detection measures of breast cancer. Lack of knowledge and inappropriate beliefs regarding prevention of breast cancer in females are responsible for the negative perception of the curability of cancer detected early and the effectiveness of cancer screening. Therefore, understanding of women’s perceptions on breast cancer is of particular importance in the development of preventive health programs. On the other hand, health education on screening practices for breast cancer is rare, and community-based intervention is recommended to fill this knowledge gap. The success of screening programs also depends on the commitment of health care professionals. Nurses can play an important role in the medical education; they should choose the best strategy to change health
behaviors and follow it exactly. Telephone calls require fewer resources than face to face interventions and can be used for health education at the community level, particularly if learners are unable to attend a session. It could be argued that in addition to educating women about breast cancer screening, reminding them of the breast screening time such as diagnostic mammogram is vital. Therefore, a simple reminder to the women’s mammography time is associated with the motivation approach and encourages them to get their routine mammogram. Telephone counseling has the potential to extend increasing access and ability to self-examine and screen breast cancer and can decrease the costs. Furthermore, a nurse-led telephone session induces decreased morbidity. Overall, despite increasing usage of telephone counseling and education in several studies, few studies have evaluated the effectiveness of mammography screening, especially in caregivers of women with the family history of breast cancer. This study firstly aimed at determining caregiver patients’ knowledge of the risk factors for breast cancer and practice of breast cancer screening among women with a positive family history of breast cancer. The second goal was to assess the effect of telephone counseling and education on mammography screening.

**Materials and Methods**

This study had an experimental design and a community-based trial with family history of breast cancer. Participants of the study were first-degree relative caregivers (mother, sister or daughter or any other) of breast cancer patients admitted into the surgical wards of Shahid Sadoughi Hospital in Yazd, Iran. This hospital was purposefully selected because it is the major state hospital of breast surgery in the city of Yazd.

Data were collected through telephone interviews during a 6-month period between May and October 2011 by making an average of two phone calls a day with each of the participants, at least three phone calls in total. Each telephone interview lasted approximately 45 minutes. Prepaid mobile phones prepared by the investigators were used.

In this study, to find out samples, the researcher assistant managed to get the telephone numbers of the patients who had a surgery for breast cancer. The researcher assistant made a list of phone numbers of the hospitalized patients in the last two years from whom 124 phone numbers were simple randomly selected. Then, the patients or their family members were contacted who provided the researcher with the first caregivers’ phone numbers. Thus the samples were contacted by phone. An attrition rate of 40% was anticipated (10% change phone numbers, 10% no response to phone calls, 10% lack of qualified caregivers, 10% others (not meeting inclusion criteria, refused to participate, etc).

The Sample size is calculated using the following formula, and the results of a previous study (25), with $\alpha=0.05$, $\beta=0.2$, $p_1$, $p_2$ were respectively equal to 0.36 , 0.5.

$$n = \frac{(z_{1-\alpha/2} + z_{1-\beta})^2 \times [p_1(1-p_1) + p_2(1-p_2)]}{(p_1 - p_2)^2} = 92$$

Therefore, the sample size for this study consisted 184 caregivers. After reviewing of list the eligible accessible population and the initial phone calls, 90 women were included in this study. They were randomly divided into two groups using the computer program, Random Allocation Software, version 1.0: Participants will be randomized 1:1 ratio to both 45 caregivers with telephone counseling and education (intervention group) and 45 caregivers without this (control group) using a random allocation sequence and block randomization with block size=4 (Figure 1). Inclusion criteria were: being a woman, having a family history of breast cancer (such as mother, sister, daughter or other caregiver), being aged 40 years or above, having access to the phone, not being deaf or having hard of hearing and speaking, having the ability to
speak Farsi, and having no history of breast cancer. Women who failed to respond to the call more than 3 times and were unwilling to continue cooperation were excluded. Women older than 40 years of age were eligible for the study because mammography was not recommended for screening in women less than 40 years of age.

Research assistant called the patients, explained the purpose of the study, and asked them to give family caregivers’ phone numbers. Then, at the beginning of the telephone calls to caregivers for clarity and verbal agreement, she explained the purpose of the study for caregivers, and invited eligible caregivers to participate if willing to do so. The following information was obtained: socio-demographic characteristics, breast cancer screening history, and breast cancer risk perception. Then, the intervention group were provided with counselling and education according to the protocol about breast cancer screening.

The counselor was a nursing M.Sc. who had prior counseling experience. The protocol on education and training involved information about the basics of breast cancer screening (such as breast self exam, clinical breast examination and mammography, time period, intervals, and screening location). Training was supervised for quality control by the nursing faculties (faculty members). The consultation and education were given through three phone calls of minimally 60 minutes and maximally 120 minutes. It is notable that the control group received telephone counseling and education after the study.

The participants responded and filled out a structured questionnaire by telephone. The questionnaire consisted of three sections: the first section concerned the socio-demographic characteristics of the women (age, education,
material status, occupation, family relation, and place of residence). The second section included questions about breast cancer screening knowledge levels, the use of preventive screening methods such as breast cancer screening: breast self exam, clinical breast examination, and mammography. The third section contained four questions about breast cancer risk perception. The content validity was confirmed by experts and the internal reliability was approved by calculating Cronbach’s alpha coefficients ($\alpha=0.84$). Mammography conduction was asked at the beginning of the study and then after a three-month interval for control group and after the end of counseling and education for each participant in the intervention group.

All of the data in this study were self-report. Data were analyzed using SPSS18, and descriptive statistics (frequency, mean, standard deviation) as well as inferential statistics were calculated. Chi square test and Fisher exact test were used for the comparison with different groups for univariate analysis in categorical variables. The McNemar test was used to analyze pretest-posttest study data. Independent t test was used to compare the means of the two groups. The level of significance was determined as $P<0.05$.

Ethical approval was obtained from the Ethics Committee of Research of Shahid Sadoughi University of Medical Sciences and Health Services (ir.ssu.rec.95). Permission was also obtained from Shahid Sadoughi Hospital to gain access to the telephone numbers of the patients. The eligible women were assured orally about the confidentiality of the information they provided by the researcher assistant, and the counselor, i.e., They received information about the study, their voluntary participation, and their freeness to withdraw from the study at any stage; all the data were kept confidential and anonymous.

**Results**

In this study, of 184 selected phone numbers, 94 of the numbers were excluded from the study since they failed to answer the first call or did not respond to any phone calls or refused to participate. Five people changed phone numbers, 20 people did not respond, 50 women who were younger than the age of 40 were excluded from the study, and 24 other women were also omitted from the study for other reasons. Consequently, 45 women in each group were included in the analysis. The intervention and control groups were similar in demographic characteristics, age, marital status, family relationships; educational status, occupation, and place of living. There were no significant differences between the two groups regarding participants’ demographic characteristics (Table 1).

The results showed that the participants in the intervention group in the first phone call had practiced breast self-examination by 6.7%, clinical-breast examination by 8.9% and mammography by 13.3%. The main reason of failure to perform BSE was lack of enough knowledge by 71.1%; only 8.9% knew the best time for BSE in non-pregnant or before-menopausal women and 17.8% knew the best time for BSE in pregnant or menopausal women. In addition, the major causes of failure to participate in mammography were regarded as 73.3% lack of enough knowledge and 71.1% lack of any physician prescription (Table 2).

Participants’ perceived risk toward breast cancer showed that the majority of 42.2% had a moderate risk for developing breast cancer and having cancer, and 44.4% had a moderate perception regarding the impact on their mood, relationship, and everyday life (Table 3).

The results showed that mammography was performed by participants before the telephone counseling by 13.3% and after the telephone counseling by 77.8% in the intervention group. The McNemar test showed a significant difference ($P<0.001$) of 20.0% before the study, and 24.4% after the study in the control group (Table 4). The McNemar test showed no significant difference ($P=0.791$). The exact Fisher test showed no significant
Table 1: Comparison of the socio-demographic data in the telephone consulting & control groups

| Variable         | Intervention group | Control group | Statistical Test * |
|------------------|--------------------|---------------|--------------------|
|                  | Mean±SD            | Mean±SD       |                    |
| Age              | 45.80±7.51         | 46.77±8.00    | T=0.59 P=0.55      |
|                  |                    |               |                    |
| Marital status   |                    |               |                    |
| Single           | 3 (6.7)            | 4 (8.9)       | X²=0.92 P=0.62     |
| Married          | 40 (88.9)          | 37 (82.2)     |                    |
| Divorced         | 2 (4.4)            | 4 (8.9)       |                    |
| Family relation  |                    |               |                    |
| Mother           | 10 (22.2)          | 9 (20.0)      | X²=0.94 P=0.37     |
| Sister           | 20 (44.4)          | 19 (42.2)     |                    |
| Daughter         | 10 (22.2)          | 11 (24.4)     |                    |
| Others           | 5 (11.1)           | 6 (13.3)      |                    |
| Educational status |                  |               |                    |
| Illiterate       | 11 (24.4)          | 11 (24.4)     | X²=1.1 P=0.77      |
| Primary/secondary| 23 (51.1)          | 19 (42.2)     |                    |
| Undergraduate    | 8 (17.8)           | 10 (22.2)     |                    |
| Postgraduate     | 3 (6.7)            | 5 (11.1)      |                    |
| Occupation       |                    |               |                    |
| Unemployed       | 39 (86.7)          | 32 (71.1)     | X²=5.2 P=0.07      |
| part-time        | 1 (2.2)            | 7 (15.6)      |                    |
| full-time        | 5 (11.1)           | 6 (13.3)      |                    |
| Place of residence |                  |               |                    |
| City             | 40 (88.9)          | 42 (93.3)     | X²=4.1 P=0.71      |
| Village          | 5 (11.1)           | 3 (6.7)       |                    |

*Independent Samples Test; **Chi-Square Tests

Table 2: Responses on breast cancer screening questions in the intervention group

| Questions                                             | Answer          | N (%) |
|-------------------------------------------------------|-----------------|-------|
| Have you ever done breast self-examination?           | Yes             | 3 (6.7) |
|                                                      | No              | 42 (93.3) |
| When should you do a breast self-exam?                | Every month.    | 3 (6.7) |
|                                                      | At irregular intervals. | 7 (15.6) |
|                                                      | Do not know.    | 40 (88.9) |
| Why did not you do self-examination? (if you did not) | I am not knowledgeable enough. | 32 (71.1) |
|                                                      | I don’t believe in its importance. | 7 (15.6) |
|                                                      | I do not have time. | 5 (11.1) |
|                                                      | I was afraid of finding lumps. | 7 (15.6) |
|                                                      | I forgot about it. | 6 (13.3) |
| What is the best time to do a self-breast exam for non-pregnant or before menopause women? | The few days before period starts | 3 (6.7) |
|                                                      | 1 to 3 days after the onset of menstruation. | 4 (8.9) |
|                                                      | Every day of the month. | 38 (84.4) |
| What is the best time to do a self-breast exam during pregnancy and after menopause? | Every day of the month. | 8 (17.8) |
|                                                      | It is not necessary for pregnant and menopausal women. | 4 (8.9) |
|                                                      | Do not know.    | 33 (73.3) |
| Have you ever had a clinical-breast exam by health professionals? | Yes. | 4 (8.9) |
|                                                      | No.             | 41 (91.1) |
| Have you ever done mammography?                       | Yes.            | 6 (13.3) |
|                                                      | No.             | 39 (86.7) |
| If you did any mammography, what were the reasons?    | I am not knowledgeable enough. | 33 (73.3) |
|                                                      | The doctor did not prescribe for me. | 32 (71.1) |
|                                                      | I was afraid of having cancer. | 5 (11.1) |
|                                                      | I do not have time. | 3 (6.7) |
|                                                      | I don’t believe in its importance. | 2 (4.4) |
|                                                      | High costs.     | 5 (11.1) |
differences between two groups in number of mammograms before the study (0.573) and significant differences were found after the study (P<0.001) (Table 4).

**DISCUSSION**

Based on the findings of this study, the majority of participants in the intervention group did not do BSE, clinical breast examination, and mammography at the beginning of the study. Among all these three methods of breast screening, mammography was done more frequently. It seems that in the developing countries like Iran, advanced methods of diagnosis are mostly used; however, the utilization of these methods are in urgent need of reflection which is beyond the scope of the present study. The participants’ knowledge about the best time of BSE regarding pregnant, menopause, and non-pregnant women, periods or intervals, and monthly performance of BSE was at a low level. The major reason for poor performance in BSE and mammography was lack of awareness. In the study of Subramanian and co-workers, the majority of the participants had a low level of knowledge for breast cancer risk factors that showed insufficient awareness. Other similar studies revealed that only less than ten percent of women had sufficient knowledge. Likewise, in another study, although one-third of the respondents had BSE knowledge, however just few women had done it which was inadequate. Educational interventions are required to persuade women to involve in regular BSE. Moreover, the results of another study asserted that health education programs are highly needed to promote women's awareness about breast cancer signs and effectual screening. The results reflect the need for extra educational programs to assist higher rates of breast cancer screening. In addition, there is a very vital need for regular learning courses for personnel concerning knowledge about the practice of breast cancer screening.

The results of this study showed that the perceived risk of breast cancer, breast cancer probability, impacts on mood and relationship and everyday life was moderate in the majority of cases. Cabrera and colleagues declared individuals with low perception of their cancer risk also had low concern levels. Likewise, in a different study, women in the group with the first-degree relative breast cancer had more agitation about breast cancer. The main objective of this research focused on the participants’ mammography conduction which was low before the study in both groups and no differences were seen.

| Questions | High | Moderate | Low |
|-----------|------|----------|-----|
|           | N (%) | N (%) | N (%) |
| What is the risk of developing breast cancer related to my family history? | 12 (26.7) | 19 (42.2) | 14 (31.1) |
| To what extent are you concerned about breast cancer? | 12 (26.7) | 19 (42.2) | 14 (31.1) |
| Considering a family history of cancer, to what extent this fact does influence your mood & relationship? | 11 (24.4) | 20 (44.4) | 14 (31.1) |
| Considering a family history of cancer, to what extent this fact does influence your everyday life? | 11 (24.4) | 20 (44.4) | 14 (31.1) |

**Table 3: Perception towards breast cancer risk the in intervention group**

| Group | Intervention group | Control group | Fisher’s Exact Test |
|-------|-------------------|---------------|--------------------|
| Before | 6 (13.3) | 9 (20.0) | 0.573 |
| After  | 35 (77.8) | 11 (24.4) | 0.000 |

**Table 4: Comparison of the mammography screening in the intervention and control groups**
Telephone counseling on breast cancer screening in caregivers

between the two groups. In this regard, the comparison of the experimental group’s performance before and after of the counselling showed a statistically significant difference considering mamography performance. In the case of the control group before and after the comparison, there was not any statistically significant difference considering mamography performance. After-test comparison of the the experimental and control groups indicated that there was a statistically significant difference considering mamography performance. In the study of Zhou and colleagues, a quarter of the participants had screening mammography, which was higher than controls and the effect of a telephone call reminder was appropriate.11

A similar study demonstrated that counseling intervention significantly improved the knowledge level of the persons who received genetic education and significantly lowered the cancer worry levels.31 What is more, other studies show that telephone backup intervention led to a significant increase in breast screening uptake.25 Likewise, half of the participants were planning colorectal cancer screening at the beginning of the telephone counseling phase, whereas, after consultation, it was almost the majority of the participants.33 According to another study,34 the uptake of telephone calls was more than letters, the difference not being significant though. In a study conducted by Hegenscheid and co-workers, a significantly higher attendance rate in the individual telephone counseling group was shown compared to controls.35 Baysal and Gozum reported that before being reminded by phone, only few women had mammograms but after counseling and coming to the Cancer Screening and Education Center nearly half of the women received mammograms.19

Moreover, telephone counseling was a feasible device for improving health practice and deceasing risk overestimates in breast cancer sisters’ women.20,21 In addition, telephone intervention, if proven successful, could supply an exportable strategy for achieving large numbers of high-risk people to support cancer screening.36 Moreover, participants who received telephone support reported an upgrade in their attitudes toward their breast cancer.37 Likewise, another researcher stated that telephone interventions with motivational and knowledge assistance can cause considerable quality of life development for breast cancer and their supportive partners.38 Telephone calls have improved mammography compliance by helping women to alter their perception of knowledge, risk, barriers, benefit, etc.19 Contrary to the mentioned facts, there was no statistically significant effect of the telephone session on the participants’ quality of life and their function and symptom scores evaluated after the final radiotherapy treatment.27

The strength of this study was the community-based nature of the sample, education, and counseling over the telephone during telephone conversations. One of the limitations of this study was that the follow-up period for outcome assessment was limited to three months post-intervention. In addition to the lack of access to adequate sample size, due to various reasons such as participants’ failure to answer the first phone call, their being younger than 40 and so forth, sampling took place at only one site which limits the generalizability of the results.

**Conclusion**

Based on the low level of knowledge and practice about breast cancer screening among family caregivers of patients, it is clear that education in female family caregivers needs to be intensified. Telephone counseling and education are appropriate strategies that may influence a woman’s decision regarding mammography screening in women aged 40 or above. Therefore, it is recommended that professional health care workers use this intervention to improve participation in health screening programs. Nevertheless, more studies in the future need to be done with longer follow-up periods, larger sample size and multicenter studies to obtain more evidence on
effects of telephone counseling and education on the breast cancer screening especially in high-risk women who are above the age of 40.

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