

The Role of Cancer Charities in Breast Cancer Prevention in Iran

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Background: Cancer is a significant public health problem, and its burden is increasing globally, especially in low- and middle-income countries. Cancer charities, alongside the government, could address health issues based on their goals. We studied the activities of cancer charities related to breast cancer (BC) prevention in Iran.

Methods: We designed a situational analysis study. We abstracted the cancer charities' objectives that were members of the "Iran Cancer National Network of NGOs and Charities (IRCNNC)." We also searched for their international activities. We reviewed the BC prevention programs conducted by Iranian cancer charities and collected their data and information regarding BC awareness and screening.

Results: Overall, 43 charities were an active member of the IRCNNC and were engaged in 6 areas, including 1) financial and non-financial supports, 2) providing medical services, 3) providing accommodation to companions of the patients traveling from other cities, 4) supplying infrastructure and medical equipment to cancer hospitals, 5) conducting scientific and research activities, and 6) running educational and awareness campaigns. Most actions were on financial and non-financial supports. Seven charities are a member of the Union for International Cancer Control (UICC). Five charities reported their movement on BC prevention.

Conclusion: Most charities did not document their prevention programs and did not follow an organized screening program. Training and capacity building is needed to support the cancer charities for the evidence-based cancer prevention program.

Keywords: Cancer Control Program, Prevention, Breast Cancer, Charity, Screening, Iran



INTRODUCTION:

Breast cancer (BC), with 2.26 million new cases (25% of all cancers) in 2020, is the most common cancer worldwide. According to Globocan 2020, BC is the fifth leading cause of cancer deaths in both sexes. Every year, 654,996 deaths occur in the world due to BC. The age-standardized mortality rate (ASMR) of BC was 13.6 in 100,000 women in 2020 (1-3) (**Figure 1**).

According to the latest report from the International Agency for Research on Cancer (IARC), 16,967 BC cases occurred in Iran, and 4,810 women died in 2020 (ASMR: 10.8 per 100,000 women). The prevalence of

BC in Iran in 2020 was 55,915 patients (1). With an ASR of 31.8 in 100,000 women, Iran is known as a low-incidence country for BC. However, the BC incidence rate is increasing in Iran, and the number of incident BC cases will be 23,000 within 20 years in 2040 (4).

Early detection is one of the crucial parts of any cancer control program in the world. The objective of early diagnosis is to detect the disease in the early stages. Management of the disease in the early stages is more straightforward, more effective, and cheaper. Compared to the advanced stage of the disease, treatment in the early stages improves survival and the quality of life and reduces mortality. Early detection includes screen-

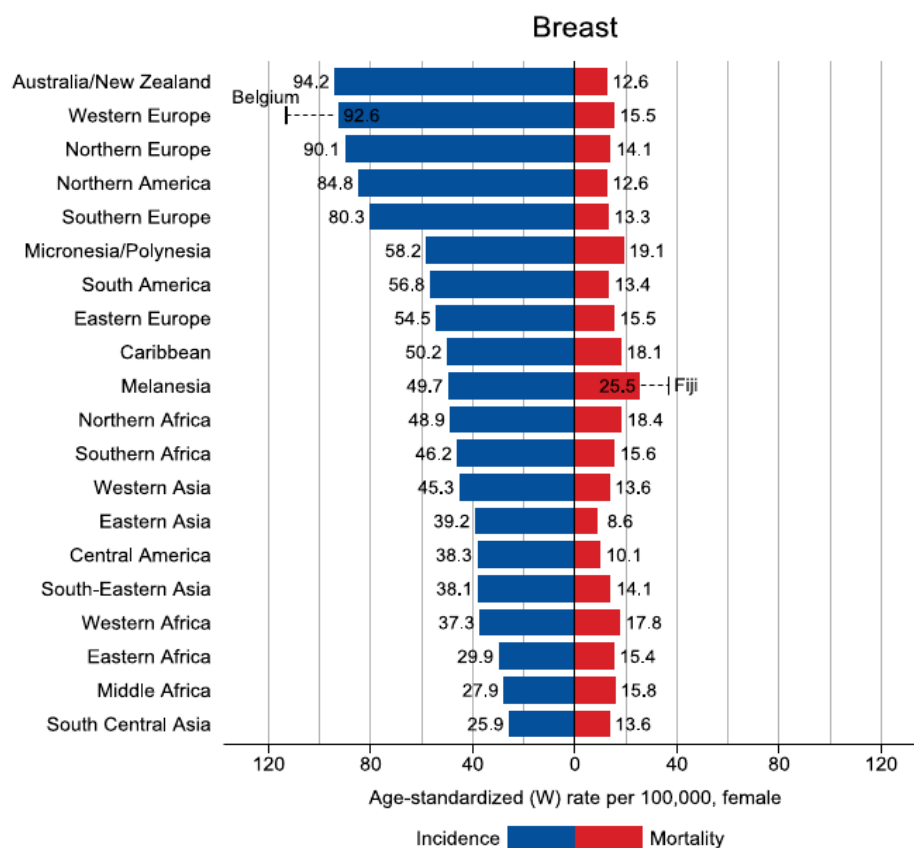


Figure 1. Breast cancer incidence and mortality in the world (3)

ing and early diagnosis. Compared to early diagnosis, which aims to detect the symptomatic patients in their initial phase, the screening program aims to detect the early stages of cancer among the asymptomatic general population (5).

Methods for early detection of BC include awareness, breast examination, sonography, mammography, and magnetic resonance imaging (MRI). Mammography is the best method for BC screening. This method is the only effective method to reduce mortality in high-income countries (6, 7).

According to the latest studies conducted by IARC, there is strong evidence on the effect of mammography in reducing mortality in BC for women aged 50-74 years, but in the age group of 40-49 years, the evidence is not sufficient (6). IARC studies have shown that mammography screening reduces breast cancer mortality by 40% in women aged 50-69 (7). A world-

wide review and meta-analysis of cohort studies on the effect of mammography screening programs showed a significant reduction in BC mortality (22%) with the invitation to screening and a 33% reduction with actual attendance at the screening program (8).

Figure 2 shows the countries with a cancer control program that prevented mortality from BC (9).

The ministry of health and medical education (MOHME) of Iran developed evidence-based BC strategies for early detection and screening. Non-governmental organizations and charities are among the most important capacities in such a program. Charities are one of the key players in cancer control programs in the world. Cancer charities could help policymakers with tobacco control, early detection and screening programs, and access to high-quality care such as supplying medicine and pain control (10).

In Iran, charities have been established at national and

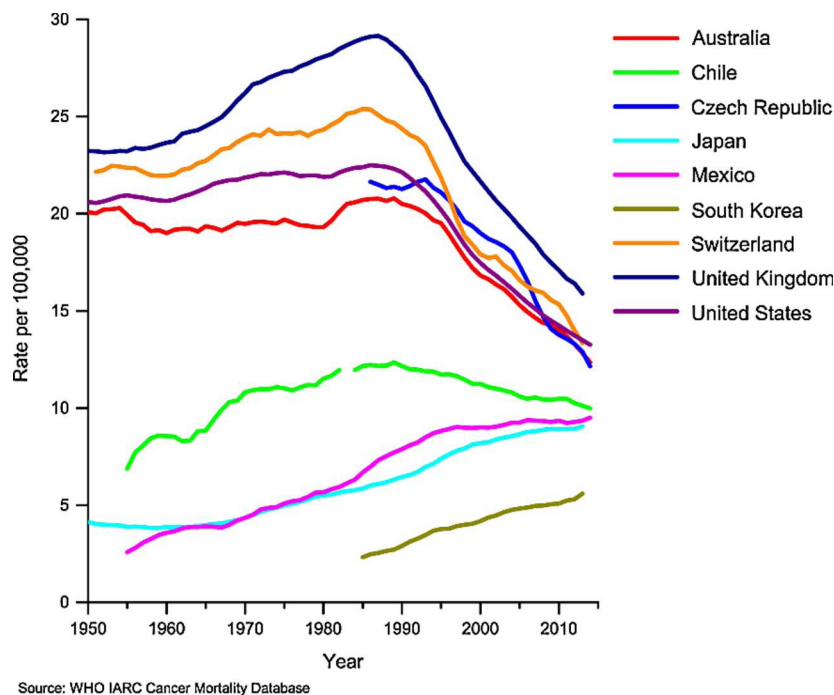


Figure 2. The trend of breast cancer mortality in some countries (9)

local levels. Even though most of these organizations' activities are related to supporting patients and their families, these organizations, especially in recent years, have paid more attention to the field of cancer prevention. Some cancer charities, such as the "Society for Helping Cancer Patients," located in Babol city, Mazandaran province, have had a great interest in breast cancer screening and established some clinics to foster early detection of cancer in this region. Besides, some other charities, including Shams, Daheshpour, Nastaran, and Pejvaktaher, performed primary prevention and screening campaigns for breast cancer in different parts of Iran (11). No study has so far evaluated these efforts and their impact on the prevention of breast cancer. We aimed to review these activities and introduce challenges and opportunities for breast cancer prevention

led by cancer charities in Iran.

METHODS:

This is a situational analysis study. We based our data gathering strategy on the information received from the IRCNNC. There are 43 cancer charities in 18 provinces that are members of the IRCNNC (**Figure 3**). The activities of eight cancer charities were about childhood cancers and 35 about adult cancers. The IRCNNC is a network of non-governmental organizations and charities in cancer and acts as the voice of cancer patients and the general public. Through advocacy, empowerment, and knowledge and information exchange, the network developed a coalition among its members to promote the national cancer control program goals and foster prevention, early diagnosis, treatment, and sup-

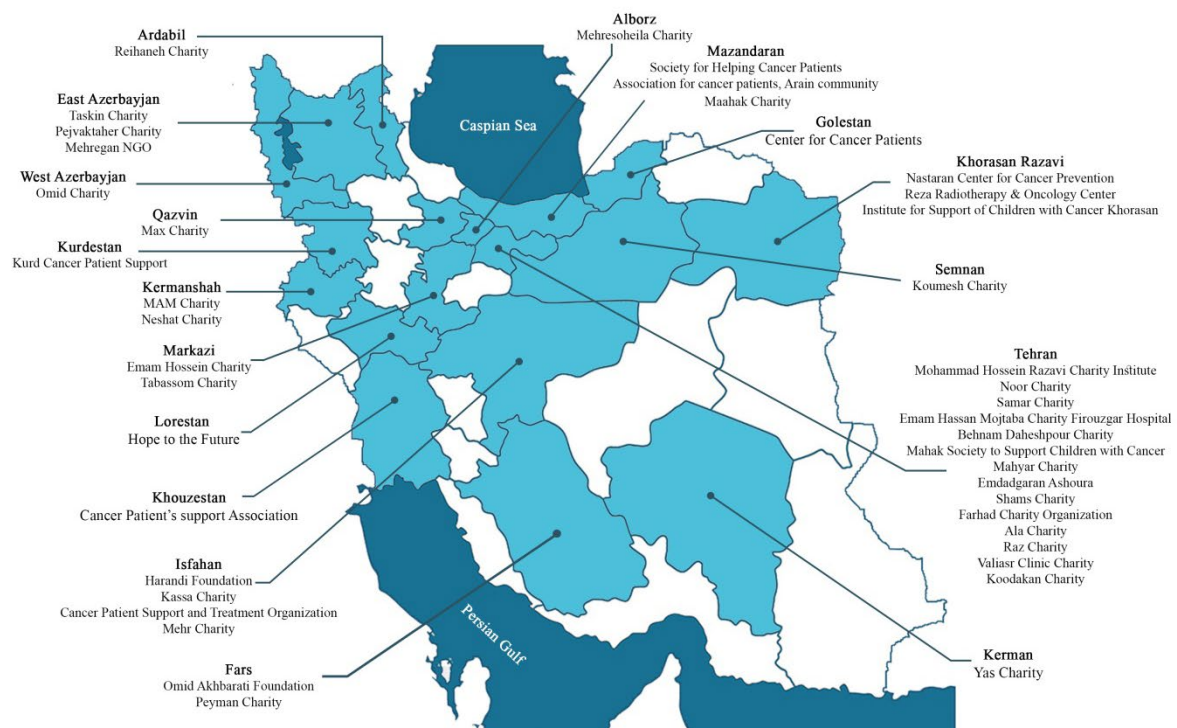


Figure 3. The cancer charities covered by the IRCNNC in different provinces of the country (Explanation: The total number of charities is more than 60 organizations, 43 of which are members of the network.)

portive and palliative care programs.

First, we received a list of cancer charities from the IRCNNC. We sent a questionnaire to 35 charities working on adulthood cancers. The questionnaire contained information about the objectives, areas of activity, and requested reports of cancer charities and the result of actions if they have had any BC prevention and screening program.

Most cancer charities did not document their activities regarding BC prevention. Therefore, we could not find any written report about their methodology and screening indicators, including target population, participation rate, recall rate, the proportion of suspicious women with a physical examination, proportion of mammography screening, the incidence rate of BC, stage at the diagnosis, etc. Therefore, we qualitatively evaluated the submitted documents and extracted related information and data from the submitted reports. We tried to find out about cancer charities' collaboration with international cancer organizations such as

UICC, the oldest international organization in cancer. UICC is an international organization with 1200 members in 172 countries. UICC supports cancer communities to control cancer around the world. UICC consists of cancer organizations and policymakers, cancer scientists, and researchers (12). We searched for the memberships of UICC in Iran.

We also searched for reports of BC prevention activities on the charities' website.

RESULTS:

We found that members of the IRCNNC were working in six areas, including 1) financial and non-financial supports for patients and their families, 2) providing medical services, 3) providing accommodation to companions of the patients when traveling to big cities for treatment, 4) supplying infrastructure and medical equipment to cancer hospitals, 5) performing scientific and research activities, and 6) public patient education and awareness. **Figure 4** shows the number of charities

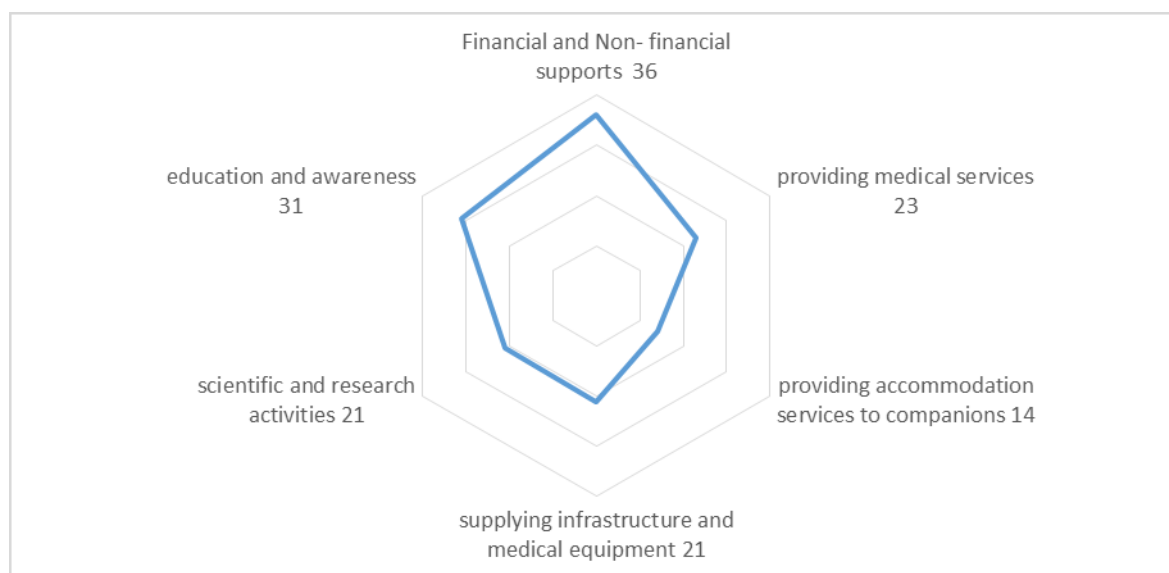


Figure 4. Areas of activity of cancer charities in the country (numbers indicate the number of charities operating in the field.) Explanation: The total number of charities is more than 60, of which 43 are members of the IRCNNC.

activating in each of these areas.

Seven charities reported being members of the UICC. Behnam Daheshpour, Mahak Charity, Noor Cancer charity, and Kassa charity were the full members of UICC. Reza Radiotherapy & Oncology Center was an associate member of UICC. Seyed Mohsen Razavi was a member of UICC, but its membership type was not defined. Shams charity was not directly a member of UICC. However, this charity is linked to the Cancer Institute of Iran, which is a full member of UICC.

Through websites, we found four charities (i.e., Omid, Koumesh, Ala, and Raz) were active in BC awareness campaigns, workshops, cycling, walking campaigns, and two charities (Mohammad Hossein Razavi and Ala) had screening programs.

The experiences of charities in BC prevention

Based on the survey, we received reports of BC prevention program from five charities, including the Society for Helping Cancer Patients, Shams Charity, Nastaran Center for Cancer Prevention, Behnam Daheshpour Charity, and Pejvaktaher association. That means the response rate was 14.2%. These programs are considered primary and secondary prevention programs, and they reported awareness campaign, and screening.

The experiences of the Society for Helping Cancer Patients

This association was founded in 1994 in Mazandaran province. The ASR for BC in this province was 39.88 in 100,000 women in 2016. The Society for Helping Cancer Patients aimed to expand education and cancer diagnosis in the region. The association started its educational purpose by preparing educational videos on cancer prevention and implementing cancer awareness programs from its earliest years.

In 2007, in collaboration with Imam Khomeini Relief Foundation, this organization started a screening program for 4,265 members of the committee and could diagnose four breast cancer patients.

A mammography screening program was performed for women living in Babol city in 2018-2019. This program was a pilot study for a comprehensive plan. In this program, all women over 40 years referred to the urban clinics of the association were admitted, and trained general practitioners performed clinical examinations. Women at moderate to high risk (positive family history, obesity, immobility, having benign breast masses, a history of ovarian cancer in themselves or their first-degree relatives, the presence of high-density breast tissue, or any clinical suspicion by doctors) were invited to mammography screening. The mammography reports were checked by a radiologist specialized in breast radiology, and the women were followed up. Mammography screening was repeated every two years.

A total of 5,994 women were screened in this program. Based on the above factors, 2278 women (38%) were selected for mammography, 1586 (26%) were referred for further evaluation by ultrasound, and 477 patients (7%) were referred for both methods. After reviewing the mammography imaging, 53 patients (2.3%) were introduced to the surgeon. Of these, 27 (50%) had breast cancer. In other words, the prevalence of cancer in this study was 450 patients per 100,000 referral population and 1,200 patients per 100,000 suspects who were candidates for mammography. **Table 1** shows the age distribution of the 5,994 patients referred to the Society for Helping Cancer Patients for this program.

The experiences of Shams organization

Shams organization is located in Tehran and held a BC awareness program annually for different groups, including healthy women and BC patients.

In 2018, Shams charity conducted awareness workshops and screening programs. That year, Shams screened 430 women, referred 208 women to mammography service, and 142 women to sonography. We could not find any follow-up information in this report,

Table 1. Age distribution of participated women in breast cancer screening program (2018- 2019)

Age group	Number of referred patients	Percentage of referred patients
20>	21	0.35
21-25	185	3.09
30-36	505	8.43
31-35	952	15.88
36-40	1052	17.55
41-45	897	14.96
46-50	869	14.5
51-55	639	10.66
56-60	545	9.09
61-65	214	3.57
66-70	88	1.47
71-75	20	0.33
76-80	7	0.12
Total	5994	100

and the report did not provide the number of cancer patients diagnosed during this program.

In October and November 2019, the campaign coincided with the world international BC month.

Training and awareness sessions were held in public places, parks, and hospitals. These education sessions were conducted along with clinical breast examinations for attendants by cancer specialists and subspecialists. From 500 participants, 300 women were referred for mammography and ultrasound, which led to early detection of BC in five women. This detection rate is equal to 1,000 patients per 100,000 populations, or 1,600 patients per 100,000 in suspected women. While the ASR for BC is 39.59 in 100,000

women in Tehran. Shams Charity provided financial support to the five patients diagnosed in this campaign.

The experiences of Nastaran Center for Cancer Prevention

Nastaran Center for Cancer Prevention is a charity located in Khorasan Razavi province, Mashhad city in the northeastern part of Iran. The ASR for BC in this province is 32.58 per 100,000 women. During 2018-2019, this organization held eight training and awareness workshops for BC in Khorasan Razavi. Afterwards, they screened 444 women. Forty of these women needed annual examinations, and 30 women were suspected of BC. They were referred to Imam

Reza Hospital in Mashhad for further investigation. Unfortunately, we found no data about the follow-up and outcomes in the report of this organization.

The experiences of Behnam Daheshpour Charity

Behnam Daheshpor Charity is located in Tehran. One of the objectives of this charity is cancer prevention. The charity has held several public cancer education programs for several years. Regarding BC prevention, it has specifically held training and awareness programs and workshops since 2016. Besides, they carried out a BC awareness and screening project among 500 women living in Tehran. The charity also conducted BC prevention awareness programs for Afghan women with relevant organizations and the Academic Center for Education, Culture, and Research in 2017-2018.

In 2019, the national campaign “All Together for Prevention of BC” was conducted at several places to enhance awareness and screening. This year, the charity donated an advanced ultrasound device to the Golestan Screening Center in Ahvaz city in the western part of Iran for BC early detection. Despite this charity’s extensive efforts about BC prevention, unfortunately, we found no data on the indicators and outcomes of these activities.

The experiences of Pejvaktaher association

Pejvaktaher association was founded in 2009 in Tabriz. The ASR for BC in East Azarbaijan was 25.17 per 100,000 women in 2016. The association covers over 2,500 cancer patients and aims to provide patient support, treatment and education services, prevention, consultation, and research. In 2019, the NGO, in collaboration with Behboud hospital, screened 558 cancer patients’ relatives for BC, gastrointestinal cancers, and cervical cancer.

For BC prevention, the NGO invited 500 women, and 387 accepted the invitation (the response rate was 75%). After a physical examination, they followed

up 210 women with sonography and 80 women with mammography. Four women were diagnosed with BC. This program continued in 2020 in collaboration with Behboud hospital and two imaging centers (Kimia and Dr. Adhami).

DISCUSSION:

We performed a study to review cancer charities and non-governmental organizations’ experiences and demonstrated their role in preventing and screening BC as a cancer control strategy. In this study, we introduced some cancer charities in Iran and reviewed the existing BC screening and prevention experiences as a member of the IRCNNC.

Unfortunately, in the review of the reports submitted by cancer charities, we found that they did not specifically work on cancer prevention and screening in terms of their services. In total, out of 43 members, research was the area of activity of 21 (49%) charities, and 31 (72%) of them reported educational activities as their mission. However, the details of these activities were not available. Published statistics from the charities’ experiences showed a practical case finding as they detected more than 1,000 patients per 100,000 women. It is significantly higher than the incidence and prevalence rate of BC in Iran. In 2018, BC incidence and prevalence in women over 30 were about 77.8 and 200 per 100,000, respectively (2).

Many studies have been conducted to show the role of cancer charities in cancer control programs. Most studies have shown that the cooperation of charities in cancer control programs has a considerable impact. In 2009, Durstine et al. in Latin America demonstrated that cancer charities were not in the leadership team of cancer control programs for several reasons, including lack of survivorship campaigns, lack of reliable patient information, and the inability of the government to work with charities in cancer control programs (13). The Union for International Cancer

Control (UICC) published a guideline for European countries and emphasized that cancer charities can work in four areas of cancer control: consultations to policymakers, implementing a screening program for breast, cervical, and colon cancers, quality assurance assessment, and evaluating and improving existing screening programs (14).

The role of BC charities in countries with limited resources was shown in a study conducted in 2011. The result suggested that these organizations increase BC awareness, disseminate information, and provide direct medical services and early detection campaigns. Spiritual care is another support that these institutions can provide. (15).

In Romania in 2016, Popa et al. found that policymakers should consider cancer charities as partners in a cancer control program (16).

The experiences of five cancer charities in BC prevention have shown that screening programs, when accompanied by BC awareness, make it more likely to find women with BC when they have no symptoms, improve costs, quality of life, and survival rate. These organizations will have a better opportunity to cooperate with cancer control programs if supported by the government, especially by the MOHME, and contribute to screening programs.

Being a part of an international organization like UICC could increase cancer charities' knowledge about cancer control. UICC supports its member in convening, capacity building, and advocacy. The mission of UICC is to support cancer organizations to reduce cancer, encourage equity, and warrant policymakers to work on cancer control as one of the most important priorities (12). We found that Iran had seven members in UICC. These organizations could exchange their experience and knowledge with UICC with other members of IRICNNC and thus promote the effective activities of cancer charities to reduce the cancer burden.

A study conducted in Iran has also shown that ed-

ucation played an important role in improving BC screening knowledge and practice. The authors recommended policies for training, developing screening centers, and sending regular reminders for BC screening. Many studies have been designed in Iran, confirmed the above study's results, and have shown that education has increased women's awareness of breast self-examination (16-20).

We appreciate the positive role of charities in cancer prevention in Iran, where the general population faces severe economic pressure due to the new international sanction posed by the Trump administration in the US since 2016 (11).

To the best of our knowledge, this is the first report from the East Mediterranean Regional Office (EMRO) about the role of cancer charities in cancer screening. However, this study had several limitations. Most screening projects were carried out within a campaign, and none of the organizations prepared a standard report for their campaign and its effectiveness. They did not define the target population, and different age groups participated in these campaigns without prioritization. Therefore, it was not possible to analyze the programs of charities in terms of effectiveness and cost-effectiveness. As we showed in Table 1, based on the Society for Helping Cancer Patients' statistics, the maximum age of the participants in the screening program in this association was 36-40 years, and even people under 20 years old had participated in the program. It suggests that some of the efforts may be due to the campaigns' emotional situations, do not fit the standard screening protocols and waste resources. It may also cause side effects such as performing mammography at a younger age, performing unnecessary sonography, and multiple surgical operations for benign masses.

The organizers cannot estimate the response rate of the population to the screenings during a campaign. It is not clear what percentage of the people received an invitation for screening during the campaigns and

what percentage referred to hospitals for the follow-up. Only three charities reported screening statistics and their outcomes.

These campaigns usually increase awareness of the population and policymakers about BC prevention. Symptomatic women may be more sensitive to the campaign message and attend the screening clinics. Although these activities are not classified as organized screening programs, BC's high prevalence was more than 1,000 per 100,000 people reported in these projects. This indicates that these activities could be useful when screening programs are not in place in low- and middle-income countries. It may also help to detect the prevalent cases in an earlier stage and improve the outcomes. This type of intervention is called an early diagnosis of BC, which leads to early diagnosis of the disease and reduces the patient's delay in diagnosis and treatment. It also leads to reduced treatment costs (21). However, complete information such as age or other patient outcomes, including benign masses, deaths, or patients' recovery, were not available to evaluate these programs' effectiveness in more detail.

Charities must evaluate their results and improve their programs. It is suggested that research teams work closely with these organizations. The results of screening programs performed by the Society for Helping Cancer Patients, Shams Charity, and Pejvaktaher association showed that these organizations could screen women for BC. Awareness actions are essential and can lead to early detection of BC. Given that a limited number of charities have cooperated in BC prevention and awareness, we suggest organizing more activities to support prevention programs and increasing cooperation between cancer charities and the MOHME. Designing and implementing prevention programs with details (including population coverage, the response rate to calls, patient profiles in terms of age and disease history, and processes such as education, screening, number of referred patients,

treatment, rehabilitation, statistics and information, research, and finally their outcomes) should be carefully evaluated and documented.

In general, Iranian women are hesitant to participate in the screening programs (22). Although the effectiveness of mammography screening has been confirmed based on well-conducted clinical trials, women may refuse to participate because of several reasons such as the lack of an appropriate and low-cost screening program, false-positive screening results, and culture and beliefs among women in the community (23). Conducting training courses and educating women about risk factors and screening methods could encourage women to improve their screening motivation. Holding these courses is one of the activities that charities can easily do. Available statistics showed that almost 80% of the organizations work in this field. Despite the importance of these programs and charities' activities, it is crucial to train the charities and support them for better preparation and documentation when they conduct a screening program.

CONCLUSION:

Compared to the current situation in Iran, where a national BC screening program does not yet exist, charities' role can be more prominent. It may pave the way for the implementation of a program in the country. The cross-sectional examinations, mammography screenings, and projects performed by cancer charities do not follow the standard recommendation for early detection programs, and the indicators are not usually available. However, they can conduct awareness campaigns and motivate the general public to participate in early detection programs. Therefore, it is wise to use these resources and improve cancer prevention programs at the regional or national level. Cancer charities should work closely with the universities and research centers to design their program properly, develop standard reports for their screening programs, and show their screening program indica-

tors.

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