

# Design, implementation and Evaluation of Self-Care Program in the Prevention of Breast Cancer Among Women in Isfahan: A Community-Based Participatory Action Research Protocol

**Maryam Kianpour**

Isfahan University of Medical Sciences

**Fariba Taleghani**

Isfahan University of Medical Sciences

**Mahnaz Noroozi**

Isfahan University of Medical Sciences

**Mitra Savabi-Esfahani**

Isfahan University of Medical Sciences

**Zahra Boroumandfar**

Isfahan University of Medical Sciences

**Maryam Hashemi** (✉ [maryamhashemi956@gmail.com](mailto:maryamhashemi956@gmail.com))

Isfahan University of Medical Sciences

**Tahereh Changiz**

Isfahan University of Medical Sciences

**Shaghayegh Haghjooy Javanmard**

Isfahan University of Medical Sciences

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## Study protocol

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# Abstract

**Background:** Breast cancer is one of the most prevalent cancers among women in Isfahan, Iran but unfortunately its prevention is not desirable in this city. This disease poses several health, social and economic burdens upon women. In order to promote women's self-care in breast cancer prevention, this study aims to design, implement and evaluate a self-care program in the prevention of breast cancer among women in Isfahan through using a community-based participatory action research method.

**Methods:** The present study will be conducted based on a community-based participatory action research in Isfahan, Iran. The participatory action research in this study will include four general phases of organizing, action planning, action and rethinking. The mentioned phases will be as follows: In the organizing phase, the needs of the participants and the action research settings are examined. This means that the current situation is identified and the views of the process owners are evaluated. In the action planning phase, using the results of the first phase, some strategies are designed in order to promote self-care behaviors in the prevention of breast cancer among women in Isfahan. In the implementation phase, the selected strategies are implemented with the help of the process owners. Finally, in the rethinking phase, the results of the implementation of the strategies are monitored and evaluated, and this cycle continues until the intended results are achieved.

**Discussion:** Changing the role of individuals from a passive state in the care process to an aware and active state requires motivation, responsibility and active participation of people in the disease control process. Moreover, there are many cultural and social factors which affect the active participation of Iranian women. As such, using a community-based participatory action research, people can be involved in promoting their health.

## Plain English Summary

According to the results of the studies conducted in Isfahan, breast cancer is one of the most prevalent cancers among women in Isfahan. Breast cancer can bring about much health, social and economic challenges for women living in Isfahan. However, through designing effective interventions for the promotion of self-care behaviors; we can prevent this disease to some extent. Since changing the role of individuals from a passive state to an aware and active state in the care process requires motivation, responsibility and active participation of community members in the disease control process, a community-based participatory action research can involve people in the promotion of their health. This participatory action research will be conducted in the four phases of organizing, action planning, action and rethinking. In the organizing phase, the needs of the participants and the action research settings are examined. In the action planning phase, using the results of the first phase, strategies for the promotion of self-care behaviors are designed in order to prevent breast cancer among women in Isfahan. In the action phase, the selected strategies are implemented with the help of the process owners. In the rethinking phase, the results of the implementation of the strategies are monitored and evaluated, and this cycle continues until the optimal results are achieved. Design and evaluation of prevention programs

based on these socio-cultural conditions and with the participation of citizens lead to improvement in self-care and breast cancer prevention.

## **Background**

Breast cancer is the most prevalent type of cancer among women and the second most prevalent one worldwide. The incidence of this disease is increasing rapidly, so that in 2018, more than two million new breast cancers were diagnosed [1]. Given the steady increase in the incidence of the disease, it is predicted that 2.7 million new cases will be diagnosed by 2030, 60% of which (1.72 million) will be in less developed countries [2]. In other words, the burden of the disease is expected to increase in developing countries in the future [1].

The epidemiological pattern of breast cancer in Iran is similar to that of the Eastern Mediterranean and other developing countries. The incidence of this cancer has changed in recent years, so that the number of patients with breast cancer is increasing [3]. According to the results of the studies conducted in Isfahan, breast cancer is one of the most prevalent cancers among women in Isfahan [4]. However, the prevention of breast cancer in this city is unfortunately undesirable and many women refer to the medical centers in the advanced stages of the disease [4, 5]. Cancer imposes a heavy economic burden on the patient and the health system, and the costs of cancer treatment are extremely higher than its prevention, and this is while that there are limited financial and human resources in the health system [6]. Indirect costs of breast cancer including medical visits, reduced incomes caused by absenteeism, and reduced work benefits are estimated to be \$ 11,527 per patient [7]. Most importantly, after cancer and its treatment, patients suffer from many physical and psychological complications and thus are no longer able to play their roles properly in the family and society. Breasts, additionally, are part of women's sexual identity and breast cancer can somehow challenge this identity of women [8,9].

Accordingly, breast cancer can bring about much health, social and economic challenges for women living in Isfahan. However, through designing effective interventions for the promotion of self-care behaviors, we can prevent this disease to some extent. In this regard, Isfahan University of Medical Sciences, as the custodian of health in Isfahan province, intends to reduce the incidence of breast cancer in Isfahan by promoting health and self-care behaviors of women. Since changing the role of individuals from a passive state to an aware and active state in the care process requires motivation, responsibility and active participation of community members in the disease control process, a community-based participatory action research can involve people in the promotion of their health. Thus, this study aims to design, implement and evaluate a self-care program in the prevention of breast cancer among women in Isfahan through using a community-based participatory action research method.

### **The research objectives**

1. Determining the risk factors for breast cancer in women using literature review
2. Explaining barriers and facilitators for self-care in breast cancer prevention among women in Isfahan

3. Designing a self-care program for the prevention of breast cancer among women in Isfahan
4. Explaining the effect of the implemented program on self-care behaviors for the prevention of breast cancer among women in Isfahan

## **The research type**

The present study will be conducted based on a community-based participatory action research. Participatory action research is the most appropriate research for the implementation of change. This kind of research is methodologically flexible and depends on the research setting; action or change is the core of the process and the members of the research team participate equally in the process and, finally, the decision for the implementation of operations depends on the participants. The researcher facilitates but does not control the process. Action research has a cyclical nature that begins with the identification of the problem and continues with action planning and, then, with action and evaluation of the actions and the obtained results [10].

This participatory action research will be conducted in the four phases of organizing, action planning, action and rethinking. These phases are summarized as follows:

In the organizing phase, the needs of the participants and the action research settings are examined. This means that the current situation is identified and the views of the process owners are evaluated.

In the action planning phase, using the results of the first phase, strategies for the promotion of self-care behaviors are designed in order to prevent breast cancer among women in Isfahan.

In the action phase, the selected strategies are implemented with the help of the process owners.

In the rethinking phase, the results of the implementation of the strategies are monitored and evaluated, and this cycle continues until the optimal results are achieved [11].

## **1. Phase 1: Organizing**

**The objectives of this phase are as follows:**

1. Determining the risk factors of breast cancer in women through using literature review
2. Explaining barriers and facilitators of self-care in breast cancer prevention among women in Isfahan

In this phase, the following actions are taken in order to achieve the mentioned objectives:

1. Review of the studies conducted in Iran and in the world to evaluate the risk factors for breast cancer in women as well as the self-care promotion strategies for preventing breast cancer
2. Specify the research settings and process owners
3. Identify committees and support units existing in the study settings
4. Negotiate with the process owners

5. Identify the barriers and facilitators of the research implementation with the help of the process owners and strategies to promote self-care behaviors in the prevention of breast cancer among women in Isfahan
6. Forming special committees to expedite action research processes

## **1.1. Review of the literature**

In this stage, in order to gain the existing knowledge in the field of breast cancer risk factors, barriers to self-care and strategies for the promotion of self-care to prevent breast cancer, studies conducted in Iran and in the world will be reviewed. In order to search the existing databases, keywords are determined based on Mesh and the title of the research and, then, combining the existing keywords, the existing texts will be reviewed. To this end, using the keywords such as breast cancer, breast neoplasms, self-care, risk factors and prevention, breast cancer risk factors and self-care promotion strategies in breast cancer will be searched in the databases for publishing care guidelines, GIN, NGC, NICE, SIGN, GAC, New Zealand, NHMRC, WHO, Breast Cancer Screening Guidelines, American Cancer Society, American Cancer Society Prevention, Early Detection Guidelines, PUBMED/MEDLINE, CINAL, COCHRANE, SCOPUS, ProQuest, IranMedex, Magiran, SID and IranDoc.

Self-care promotion strategies for the prevention of breast cancer in women, which are extracted from the texts, are included in the decision matrices and used in the program development process.

### **1.2.1. Identification of the Study Settings**

#### **Study Setting**

To interview with employed and non-employed women in Isfahan metropolis, the researchers will refer to health centers, offices, cultural centers, mosques, parks, recreation centers, clubs, homes, etc. To interview with experts, the researchers will refer to the offices of these experts in hospital or university, health policymakers at the level of the ministry and the university, Isfahan health center, comprehensive health service centers, offices of gynecologists and breast surgeons and sonography and mammography units.

#### **Study population**

In community-based action research studies, the views of those people should be evaluated who are at risk. Accordingly, employed and non-employed women living in Isfahan (15 districts) are part of the study population. Moreover, explaining the views of process owners is of great significance to design strategies for promoting self-care behaviors in the prevention of breast cancer among women in Isfahan. As such, service providers (gynecologists, radiologists, general surgeons specializing in breast surgery, PhD in reproductive health, PhD in nursing, general practitioners, nurses and midwives, health policymakers, officials and experts of the Cancer Department of the Ministry of Health, experts of the Non-Communicable Diseases Control Center and the middle-aged unit of the provincial health center) are also among the study population.

### **1.2.2. Identification of the Process Owners**

Given the fact that the purpose of this study is to promote self-care behaviors in the prevention of breast cancer among women, the process owners of this study are as follows:

- Both employed and unemployed women living in Isfahan
- Policymakers, officials and experts of the Cancer Department of the Ministry of Health
- Experts of the Cancer Department of Isfahan Health Department
- Middle-aged unit of Isfahan Health Center
- Faculty members of Oncology Departments, gynecologists, general surgeons specializing in cancer surgery, adult health nursing, community health nursing, midwifery and reproductive health in the School of Nursing and Midwifery of Isfahan University of Medical Sciences

### **1.3. Identification of the committees and support units in the study settings:**

The committees and support units in this study are as follows:

- Vice Chancellor for Research in Isfahan University of Medical Sciences
- Cancer Department in the Isfahan Health Department
- Middle-aged unit of Isfahan Health Center
- Isfahan Municipality Health Culture Committee
- Isfahan Health Donors Association
- Active NGOs in the field of health in Isfahan province

### **1.4. Negotiation with process owners**

In this study, self-care packages and educational media will be developed with the help of faculty members of Isfahan University of Medical Sciences. Additionally, the necessary negotiations will be held with the Health Culture Committee of Isfahan Municipality, active NGOs in the field of health in Isfahan province and the Secretariat of Cultural and Artistic Centers of Isfahan mosques to hold health campaigns in parks, recreation centers and mosques of Isfahan. In order to finance the project, it will be sent to the Vice Chancellor for Research of Isfahan University of Medical Sciences. Moreover, to attract financial support, necessary negotiations will be conducted with the representative of the World Health Organization in the Ministry of Health and Medical Education, Isfahan Municipality Health Culture Committee, Isfahan Health Donors Association and active NGOs in the field of health in Isfahan province. Also, in order to promote women's health literacy with regard to the prevention of breast cancer, the necessary consultations are carried out with Isfahan broadcasting organization.

### **1.5. Identification of the barriers and facilitators of the research implementation through conducting a qualitative research**

This qualitative research will be used a content analysis approach.

## **Participants**

In the present study, the participants will be selected using purposive sampling method. So that, after visiting the mentioned centers in-person, the experts in the field of breast cancer prevention who have inclusion criteria, will be selected and interviewed after obtaining informed and written consent. The researcher continues to select and interview with participants until data saturation is reached. The interviews continue until the interviews do not add any new data to the previous data. In qualitative research, the number of participants cannot be determined before the study but during it. In such research, the participants are selected using purposive method which may be based on the inclusion criteria and continue gradually until saturation is reached. The participants also become so involved in the study that they no longer have anything new to say. Therefore, there is no need in these studies to estimate the number of participants in advance and purposive sampling method is often used [12].

## **Inclusion criteria**

Employed and non-employed women in Isfahan who would like to participate in the study; moreover, gynecologists, radiologists, general surgeons specializing in breast surgery, PhD in reproductive health, PhD in nursing, PhD in health education, health policymakers, officials and experts of the Cancer Department of the Ministry of Health, experts of the Non-Communicable Diseases Control Center and the middle-aged unit of the provincial health center, general practitioners, and midwives and nurses who have experience in educating, treating or caring for breast cancer patients can participate in the study.

## **Exclusion criteria**

Each participant who is not willing to continue his/her cooperation can be excluded from the study.

## **Data collection**

Data collection method at this phase includes open and semi-structured interviews and focus group discussions (FGDs).

In the present study, employed and non-employed women of Isfahan metropolis and members of the health group who are eligible are selected using purposive sampling method and, after obtaining informed consent, are invited for in-depth, semi-structured and individual interviews. In semi-structured interviews, there are no fixed, pre-determined questions, and the questions are formed based on the interview process. The following are some samples of questions asked of the participants:

- What factors do you think may make you more susceptible to breast cancer?
- What lifestyle changes do you think can help prevent breast cancer?
- What are your barriers to breast cancer prevention?

- In your opinion, what measures should policymakers and officials of health systems do with regard to breast cancer prevention for women in Isfahan?

Samples of questions asked of health team members are as follows:

- Please tell us about your experiences of breast cancer prevention among women living in Isfahan?
- What are the barriers and facilitators for preventing breast cancer among women living in Isfahan?
- In your opinion, what measures should policymakers take to reduce the risk factors for breast cancer among women living in Isfahan?
- What strategies do you recommend to remove barriers to modulating breast cancer risk factors among women living in Isfahan?

Interview guiding questions are reviewed after several interviews and obtaining new ideas. The duration of each interview depends on factors such as the situation and environmental conditions, the agreement of the parties, the subject of the interview and the used method.

Interviews continue until data saturation is reached. Saturation refers to the completion of all categories and non-emerging of new conceptual information that requires new code or the expansion of new code.

At the group discussions sessions, the researcher, was acting as the facilitator and guider of the discussions, and another person was present to take notes.

### **Data analysis method in the qualitative phase**

Content analysis method will be used in the qualitative phase of study for data analysis [13].

### **Phase 2: Action planning**

The purpose of this phase is to design a self-care program for the prevention of breast cancer among women living in Isfahan. To achieve the mentioned purpose (action planning), the following activities will be performed in this phase:

1. Determining the criteria for the prioritization of strategies
2. Review of the strategies in group discussions with the presence of executive committee members and process owners
3. Final review and approval of strategies in the Joint Committee
4. Planning for the implementation of the strategies in the study setting (development of operational plan)

#### **2.1. Determining the criteria for the prioritization of strategies**

In this phase, the strategies obtained in the organizing phase, which is the result of reviewing the literature and qualitative content analysis (semi-structured interviews and FGDs with women and semi-

structured interviews with process owners), will be combined and used to develop the program. Since the implementation of all strategies obtained from the organizing phase is impossible, the proposed strategies should be prioritized.

Decision matrices will be developed to prioritize the extracted strategies. Self-care promotion strategies for breast cancer prevention are put in the rows of decision-making matrices, and the criteria for prioritization of strategies (ease of implementation, cost-effectiveness, time-consuming, effectiveness, efficiency, acceptability, and compliance with policies and values of community) are put in its columns. Then, the members of the expert panel are asked to give each strategy a score of 1 to 5. Then, the mean score of the available strategies is determined and the program is developed based on the obtained scores.

The matrices are distributed among process owners and experts in the field of breast cancer prevention. After collecting the matrices, the researcher enters the data into SPSS software version 16 and calculates the mean and standard deviation of each item using the basics of descriptive statistics. The matrix items are then sorted based on the mean scores, and the priority of the proposed strategies and the items agreed upon by the experts are specified. The mean scores of each strategy and the level of agreement are determined based on the variance of the answers and the quartile range. If more than 80% of the members agree on an area and the quartile range is zero, the agreement is estimated to be very high. If more than 60% of the members agree and the quartile range is more than 1, the agreement is considered moderate; and if less than 60% of the members agree and the quartile range is more than 2, the agreement is considered weak. Consensus is reached when the level of agreement is very high. Therefore, in decision matrices, when more than 80% of members agreed with each other, a consensus is reached and those strategies are introduced as suggested ones for self-care behaviors in preventing breast cancer [13].

## **2.2. Examining the strategies in group discussions with the presence of the executive committees members and the committee of the process owners**

For the prioritization of the strategies, an expert panel is formed. This panel is formed with the presence of representatives of the employed and unemployed women and the members of the executive committee. Another panel is formed with the presence of process owners and specialists (gynecologists, radiologists, general surgeons specializing in breast surgery, PhD in reproductive health, PhD in nursing, general practitioners, oncology nurses, Midwives, policymakers, officials and experts of the Cancer Department of the Ministry of Health, experts of the Non-Communicable Diseases Control Center and the middle-aged unit of the provincial health center, and faculty members of the Oncology Department). This expert panel is held in the presence of members of the research group and experts of this field as a group discussion. In order to confirm the prioritization of self-care promotion strategies for breast cancer prevention, first, expert panels are held. Then, based on the results of the panels, the initial version of the self-care promotion program for breast cancer prevention is prepared and designed. Holding these panels is such that after the formal and written invitation of the intended subjects and their presence, the goals

and agenda of the meetings are described at the beginning of the meetings and, then, the researcher presents the results of prioritizing strategies for the promotion of self-care behaviors in preventing breast cancer. Then, the participants express their views on the prioritization of the strategies and discussions and exchanges take place to reach a consensus. The researcher, as the secretary of the session, takes notes and records the contents of the meeting. These sessions are managed by the researcher who records all agreed and disagreed contents.

### **3. Phase 3: Action**

For better implementation of the program, activities, subjects, resources and implementation time of each activity in the program are determined and, then, a meeting is held to prepare the members of the executive committee.

### **4. Phase 4: Rethinking**

This phase aims to "explain the effect of the executive program on self-care behaviors in the prevention of breast cancer among women in Isfahan." Rethinking will be performed in this phase. Rethinking is a mental process in which events, experiences, problems, or situations are re-examined so that a better understanding of the situation can be achieved. This understanding will lead to the appearance of strategies, ideas, improvements and changes. Rethinking is, in fact, a dialogue of thought enabling the researcher to determine the patterns that emerge from the interactions between participants and the environment; that what strategies are effective, what changes are needed in the environment, what changes are vital, and what other information and planning actions are required. In this research, rethinking is done in two stages: 1) During the implementation stage, and 2) In the final stage, each of which will be discussed in detail.

#### **4.1. Rethinking during the implementation stage of the program**

In order to identify issues and problems during the implementation of the program, feedback is taken from the participants including the women participating in the study, members of the research team and the executive committee. In this study, for rethinking during the implementation, the Gibbs' framework is used. This framework has six stages which are useful for rethinking. In the first stage, the event which should be reconsidered (women's self-care behavior promotion program) is described in full detail (where it happened, the context of the event, the outcome, the people involved in the event, and how it will be implemented). The second stage examines the feelings and thoughts existing in the minds of the research team members, the executive team, and the participating women. To this end, the following questions will be used: How did you feel when the program started? What were you thinking about at the time? What feelings are created in you by the other members of the team? How do you feel about the outcome of the program? In the third stage, assessment is performed. At this phase, a judgment is made about what has been good and what has been bad about this experience. In the fourth stage, the program for promoting women's self-care behaviors about breast cancer prevention is broken down into its components and each component is examined separately. What has been wrong or does not change and

how it should be done is examined in this stage? What has been performed well? What has been wrong or has not changed and what has been conducted well? What have others done well? And what should be done for the better implementation of the program? The conclusion is made in the fifth stage. In this stage, the opportunity is provided for learning from previous experiences based on the analysis of the event in the previous stages. In the sixth stage, planning is done for the next cycle. In other words, it is examined whether it will be done differently in the future or probably be done similarly? [14].

Various methods of data collection such as self-report, field notes and review sessions are used in this research to get feedback during the implementation.

1. Self-report technique: Self-report techniques are the most prevalent methods of data collection in clinical studies which, because of their immediacy, are very powerful. Using these techniques, researchers usually gain information they cannot obtain through other methods.
2. Field notes: In different situations and times and during different stages of the study, researchers observe women's self-care behaviors and take the necessary notes.
3. Review sessions: Holding regular meetings by the research team from the beginning of the study to its final stages is one of the effective and efficient ways of knowing about the opinions, views, suggestions and criticisms of the participants. These meetings are held once every two weeks after each intervention.

#### **4.2. Final assessment of the program (final rethinking)**

Quantitative and qualitative methods are used for the final assessment of the program. In order to evaluate the quality of the study, the participants' experiences about the effectiveness of the program are considered after the program. In order to evaluate the program quantitatively, after the implementation of the program, the level of the knowledge, attitude and practice of women about self-care behaviors for preventing breast cancer are evaluated through a questionnaire to determine the effectiveness of the program. Moreover, quantitative indicators such as the number of patients referring to medical centers and doctors' offices for ultrasound or mammography or breast examination are used to determine the effectiveness of the program.

## **Discussion**

Numerous studies have referred to the role of socio-cultural factors in women's self-care behaviors. Lack of understanding and underestimating the risks and complications of breast cancer affects women's participation in self-care programs [15, 16]. In some cultures, women believe that what is not paid attention will not happen or will eventually disappear. Such beliefs are rooted in the cultural issues of a society and may affect the extent to which women participate in self-care programs and the prevention and control of breast cancer. According to the Health Belief Model, in order to perform a healthy behavior, individuals must first feel threatened by the problem (perceived sensitivity); then, the depth of the risk and the severity of its complications should be understood (perceived severity); and then, individuals should

believe in the usefulness and applicability of the healthy behavior based on the positive symptoms they receive from the environment (action guide). Therefore, in educating women, they should be sensitized about the risk of breast cancer and the norms of that society about self-care behaviors should be examined [17]. In Iranian society, fear of cancer diagnosis [18], lack of trust in health team members, lack of independence in decision-making among women, fatefulness, lack of women's empowerment [19], and personality traits (not paying attention to one's health and prioritizing family, as well as emotional responses such as the conflicting effects of fear and shame) are the most important obstacles to women's participation in self-care programs [20, 21]. In order to remove these obstacles, the design of prevention programs according to the economic, social and cultural conditions of the Iranian society seems to be necessary. The self-care program in the prevention of breast cancer among women living in Isfahan is a missing link in the provision of services related to women's health which can play an important role in the promotion of health and the prevention of the disease. This becomes more important knowing that the age of breast cancer in Iranian women is a decade lower than the average age of it in the world. Changing the role of individuals from a passive state in the care process to an aware and active state requires motivation, responsibility and active participation of people in the disease control process. Since various socio-cultural factors affect women's self-care behaviors, the design of prevention programs based on these socio-cultural conditions and with the participation of citizens has a special priority to provide more optimal services.

Therefore, it seems that using a community-based participatory action research, women can be involved in promoting their health.

## Abbreviations

FGDs: Focus group discussions

## Declarations

- **Ethics approval and consent to participate:**

Ethical approval for this study has been obtained by the ethics committee affiliated with Isfahan University of Medical Sciences, Isfahan, Iran (no. IR.MUI.RESEARCH.REC.1398.785)

- **Consent for publication:** Not applicable.
- **Availability of data and materials:** Not applicable.
- **Competing interests:** The authors declare that they have no competing interests.
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- **Authors' contributions:** FT, MSH, MK, TC and SHHJ were involved in study conception, design and drafting of the manuscript. MSH wrote the first draft of this study protocol. MK and MN reviewed the first draft of the protocol and manuscript. MS provided the qualitative design. FT was responsible for

coordinating the study. MS will be responsible for interview with participants, description and data analysis. FT and MS will review and will involve in data analysis and qualitative phase. FT, MK, ZB and MN will be responsible for delivering and intervention. FT will provide the quantitative design. All authors have read and approved the final version of the manuscript.

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