# Sharing the power through promoting heart health literacy: A participatory action research in Iran

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# Special Report

#### **Abstract**

**BACKGROUND:** Low health literacy can act as a barrier to effective disease self-management. The study aimed to promote heart health literacy in Iranian society.

METHODS: This study was conducted as a participatory action research (PAR) based on Zuber-Skerritt Model to design and implement a program for promoting heart health literacy in Iranian society. Participants were selected among adults with heart diseases and their family members, as well as their health care providers in Chamran Hospital, Isfahan Heart Friends association and researchers, and Isfahan Cardiovascular Research Institute, Isfahan, Iran. Data collection was conducted using interviews. Content analysis was used to analyze the data to promote heart health literacy. Promoting of heart health literacy was implemented in different levels in Isfahan from March 2017 to October 2017. The effect of the program was evaluated based on interviews, feedback, and focus groups at the individual level.

**RESULTS:** Finally, at the World Heart Week, a healthy heart campaign was formed with the slogan "Share the power". At the end of this program, participants experienced significant empowerment during the project to promote heart health literacy. The three main themes indicating this feeling of empowerment were "Being worried about the hearts of others", "Sensitization to the care of the heart", and "General understanding of heart health".

**CONCLUSION:** PAR can be an effective way to promote heart health literacy in Iranian society. It integrates the voices of the marginalized group promoting heart health literacy in Iranian society.

Keywords: Heart, Health Literacy, Action Research, Iran

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#### Introduction

Currently, chronic diseases, especially atherosclerosis, high blood pressure, and its consequences are considered to be the most important health problems in underdeveloped countries, as well as developed countries. <sup>1,2</sup> It is anticipated that by 2030, 23 million deaths will occur annually due to cardiovascular disease (CVD) worldwide. <sup>3</sup> In Iran, official statistics from the

Ministry of Health and Medical Education show that 33.0%-39.3% of deaths in the country are due to CVD.

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CVDs are the first cause of death with 39.3% of all deaths, of which 19.5% are related to heart attacks, 9.3% are due to stroke, 3.1% are due to hypertension (HTN), and the rest are related to other CVDs. According to a study conducted by Akbari Sari et al., to estimate 50 invasive procedures in Iran, there are 75 coronary artery bypass grafting (CABG) and 61 angioplasty per 100000 of population in Iran.4 Also, in a study in Kerman Province, Iran, the annual mortality rate due to these diseases in the population over 40 years of age was estimated 14 per 1000 people and the number of patients requiring outpatient care was estimated approximately as 1935000 people.<sup>5</sup>

In this regard, hospitals as the second and third level prevention centers should be able to serve proportional to the growth of these diseases. One of the important issues in prevention is improving the health literacy of individuals and their ability in the first to third levels of prevention.6 Health literacy means cognitive-social skills that determine the motivation and ability of individuals to achieve, understand, and use information in a way that maintains and improves their health.7 People with good health literacy will surely have better health. Today, the key role of individuals as the main factor in managing their health has been emphasized.8

The need for education and information provision to improve the ability of maintaining health and improving the health literacy of patients is essential. In a study in Australia conducted by mixed method through interviewing, a focused group of policymakers showed that in the first level of prevention of CVD, information provision, and integration of caring for patients with complex needs and experiencing many illnesses had better results for patients.9 However, another study has emphasized on barriers of education for cardiac patients.<sup>10</sup> Some other evidence has supported such a view. For example, a study about surveillance of cardiovascular health literacy level showed that about 60% of respondents were unaware of the symptoms of a heart attack, and 20% knew only two or four signs. Mean knowledge, attitude, and practice were 79.3, 74.3, and 48.0 percent, respectively. About 44% of the respondents had insufficient knowledge and less than 20% had adequate knowledge. The attitude and practice also, were 15.9% and 13.9%, respectively. This study showed that the level of health literacy in a lowincome country was low even among patients with CVD.<sup>11</sup> Awad and Al-Nafisi also reported that 60% of people did not know about their heart disease,

and symptoms such as shortness of breath or chest pain were signs that approximately 48% to 50% of people knew about. Most people considered the important role of the drug in controlling the disease and did not know the importance of observing other cases. This study showed that individuals' knowledge about CVD and preventive behaviors was inadequate and wider educational programs and interventions were needed.<sup>12</sup> Some studies in Iran also examined the level of health literacy at the community level and obtained results indicating that the level of health literacy in the community was moderate or borderline. 13-15

According studies and researchers' experiences, it seems that current programs in country hospitals often focus on care and treatment in the hospital environment, and follow-up and community-based dimensions are less covered. Based on these studies, collaborative qualitative research that helps people's ability can be useful in improving the level of health literacy in different fields. Therefore, the present study aimed to empower people through improving the level of health literacy in the field of CVDs in collaboration with Shahid Chamran Hospital and Isfahan Cardiovascular Research Institute, Isfahan, Iran.

#### Materials and Methods

The present study was a participatory action research (PAR) by Zuber-Skerritt method aimed to improve the heart health literacy in 4 consecutive phases including planning phase, action phase, observation phase, and reflection phase. PAR is one of the interdisciplinary research methods researchers carry out interdisciplinary research through exploratory and interventional interventions, with precise observation and continuous reflection of outcomes. Action research is a systematic exploration that collects and generates information about a specific problem and, while making changes in the system, leads to system reform.

The collaborative nature of the research project required individuals to be willing to participate in the study and consider themselves as part of the research team. Therefore, after forming the research team, the necessary planning for improving the heart health literacy was carried out in the community. First, the planning session with the relevant specialists for translation and provision of educational content and a joint educational conference on the contents of the necessary materials and providing education to community with the method of playing the roles and speeches between providers and recipients of services were held and the healthy heart friends campaign was organized with the participation of enthusiasts and specialists through the organization of the healthy heart association and virtual social networks. During the implementation of the campaign and providing sociologist education, observation and evaluation of the problems of the program was done from the viewpoint of the participants in the program. In the next stage, the reflection of the effects of the campaign was examined in the framework of a qualitative health literacy interview with the covered society. Participants in different phases were different in composition, diversity, and of characteristics of entering the study. So that, some people willing to participate in the study, who were able to express their experiences and opinions, were invited to interview. In order to enrich the information and gain a wider perspective, based on purposive sampling, participants from different age, gender, and education level were recruited. Regarding the diverse spectrum of participant samples in this research, the research environment included the Cardiology Research Institute of Isfahan University of Medical Sciences, Isfahan, and public places (parks and main squares in Isfahan) were used for the access to the individuals without CVD. In the sampling of reflection stage, 20 individuals without CVD who participated in the healthy heart campaign during the study were selected purposefully. The number of samples during the study was obtained according to the amount of information and continued until the data saturation was completed.16

All participants received written information and provided written informed consent. Data were collected anonymously. The study was approved by the Isfahan Cardiovascular Research Center.

In order to collect data in the reflection phase, a deep semi-structured interview method was used through questionnaires. <sup>16</sup> The interviews began with the question "What is your understanding and experience of heart health?", "Can you tell me what risks threatens your heart?", and "What are the strategies to prevent heart health?". The interviews were conducted in a dedicated room that only interviewer and interviewee were present. The duration of each interview was 30-90 minutes. Recorded interviews were immediately followed by each word after the completion of each interview and were transcribed verbatim. After the interview, the analysis was performed and then the next

interview was carried out, and so the work continued until data saturation.<sup>17</sup> Two additional interviews were conducted to ensure data saturation, but no new data were obtained. At the end of each interview, participants received a gift worth \$15.

The analysis team read all the transcripts and analyzed the data. For the analysis of the qualitative data, qualitative content analysis (Graneheim and Lundman<sup>18</sup>) was used. The study used inductive method to find the different dimensions and variables affecting the promoting of heart health literacy in Iranian society. In general, the content analysis process in this study was described in the sequential steps: determining the content of the analysis, defining the unit of analysis and initial coding, classifying the codes under the classes, forming sub-categories from these classes, and forming the main categories of the sub-categories. Data encoding was done independently, which was discussed for coordination. Managing and analyzing the data was done using MAXQDA 10 software (VERBI Software, Berlin, Germany).

Conducting interviews continued until reaching saturation, and selecting the sample was purposive, paying attention to the maximum diversity in the participants regarding age, sex, and education level. Different ratios of participants were considered to provide validity. In addition, peer and member check were used to determine the validity and appropriateness. To confirm the transferability of the findings, the position of the participants was fully and extensively described and details on the methodology and background information were provided to judge and evaluate others about the findings. Moreover, conducting open interviews and expressing the story of the experiences of participants, reflexivity and long-term presence, maintaining the documentation and accurate transmission, and maintaining the impartiality in delivering the results were considered as indicators of trustworthiness in a qualitative study.<sup>19</sup>

We used peer debriefing by three expert colleagues in qualitative research to assure the credibility of data; also we applied member checking of the findings by participants. To assure dependability of results, 4 participants read the transcription and categories.

### Results

As indicated in the Methods Section, this study was carried out in four phases of planning, action,

observation, and reflection, the results of four stages being presented as follows:

The result of the analysis of the documents/notes and experiences of the research team and other participants/providers during the planning process was indicated coherently after determining the main problem. At this stage, all of the participants considered improving the level of health literacy as one of the main problems of the Iranian community and planning began accordingly. In 7 three-hour focus groups, the research team looked at strategies for improving the heart health in the community. In the first focus group, the research team consisted of representatives of the Heart Friends Association, the supervisor of the Isfahan Heart Hospital, three cardiologists, the head of the Heart and Cardiology Center of Isfahan, and three heart researchers. The outcome of this meeting was to plan how to proceed through a storm of thought.

For example, one of the first programs to increase heart health literacy was to train specialist staff to train self-care of healthy heart in the community. For this reason, the nurse preparation workshop was held for six hours. In this workshop, which its scientific secretary was a faculty member with experience of expanding the role of nurses in the education in chronic non-communicable diseases (NCDs) and its lecturers were professors, nurses, doctors, nutritionists, and experienced psychologists, important topics and educational content for general education and improving health literacy in the form of the role of educator were presented and topics such as "education of the importance of HTN", "education of healthy nutrition", "education of the importance of exercise and physical activity", and "education of the importance of drug consuming" were presented to the community and the role of educator in the education of reducing stress and quitting smoking with practical examples was educated to the nurses who were members of the healthy heart campaign as well as a number of audiences of the community (Heart Friends Association).

After education of the trainers, at the same time as the World Heart Week, healthy heart campaign was held with the presence of trainers from nursing and pediatric groups in the main squares of Isfahan. In this campaign, cardiologists, heart nurses, heart friends, recovered heart patients, and a number of medical students who were involved in the workshop mentioned above and were skilled in this field, sensitized people to the prevention of heart disease and heart health education. In addition to the education and screening of the healthy heart campaign, five hike meetings with the motto of the World Heart Federation, i.e., "Share the power", were held in different places of Isfahan City. In this screening, high blood pressure along with providing the necessary training to the community was assessed. Many questions were asked from people to sensitize them. Some of these questions were: "Do you know what the heart is doing?", "Do you know what the fuel is for your heart?", "Do you know how long your heart works?", and "Do you know what to do to improve your heart's power?". After sensitizing, individual training was done. Speeches were held in the squares of the city. The question and answer in this campaign intensified. After organizing the workshop and setting up the campaign, the number of healthy heart friends and the participation of the healthcare team, especially nurses, increased, and the increased skills of service providers and educators on how to train the heart health literacy was the result of the campaign.

The three main themes indicating this feeling of empowerment are "Being worried about the hearts of others", "Sensitization to the care of the heart", and "General understanding of heart health".

"I have not been so worried about my heart so far, I just realized that I had to change my lifestyle, I had to tell family members how important it is to do something and not to have heart problems" (Participant 5).

Most of the participants in the campaign, after knowing the condition of the heart and being aware of heart disease and its solutions, became sensitive to their and others' hearts and began to train and sensitize the others as cascades.

One participant (a businessman) stated: "I really did not know that heart is so important, I thought heart disease is related to the old age, but now I found that the narrowing of the arteries begins from the very beginning" (Participant 14).

Another participant also stated: experiencing a lot of stress, now I realize that I have to get stress away from myself. I quit smoking today, promising to remember the things I learned" (Participant 19).

#### Discussion

The three main themes indicating the feeling of empowerment are "Being worried about the hearts of others", "Sensitization to the care of the heart", and "General understanding of heart health".

In the context of "Sensitization to the care of the heart", the present study showed that the sensitivity of individuals to CVD was improved during and after exercise. Several studies consistent with the present study showed that the sensitivity and health literacy of the heart patients was low.<sup>20,21</sup> Ghisi et al. reported that low health literacy led to the majority of these patients being re-admitted.<sup>21</sup> Training to improve the level of health literacy of patients with coronary artery disease (CAD) is essential and increases the knowledge, commitment, and the tendency to adhere to healthy lifestyle.<sup>22</sup>

The experiences of Ehrenthal et al. in a study suggest the usefulness of education for increasing health literacy, so that the learners' grades after the lecture were significantly higher and increased more for people with lower base scores.<sup>23</sup> Therefore, in line with the above study, it could be said that qualitative statements and narratives from an interview with the audience of educational programs in this study confirmed the results of quantitative studies related to health literacy.

Despite efforts to raise awareness among American women about the risk of heart disease, only about half of all women (56%) were aware of heart disease as the number one killer in the United States (US); among dark-skinned women, it was even less than one. This increasing of awareness should not only occur at the patient level, but also at the level of policymakers and care-providers. In order to achieve the goals of reducing heart disease among all people, brave and creative approaches are needed. By sharing experiences and what is learnt, people can add new healthy heart behaviors to their routine lifestyle. These relationships create a stable and professional career.<sup>24</sup>

Other topics in this study were concerns about the health of others. Although based on the slogan of World Health Organization (WHO), providing the health for all is responsibility of the community, the responsibility of the people of the community for their own health and for others should not be forgotten. In this regard, consistent with the current study, the study by Thompson et al. showed that individual counseling as well as community engagement was one of the most effective preventive learning styles among people in a rural area in Australia.<sup>9</sup>

General understanding of heart health was another theme obtained in this study. Communication at community level enhances interpersonal interaction and acts as a strong strategy for facilitating the use of subjective

knowledge by learners. Several studies have shown that observance of the principles of health literacy improves the comprehension of the subject and changes the behavior in the community.<sup>25-27</sup>

Therefore, according to interviews, the study results showed that the main aim, i.e., to raise the level of health literacy in the community, was achieved. Hence, the researchers continued this campaign on a weekly basis with the participation of other hospitals in Isfahan.

The limitations of the present study were: samples were selected from a small section of the population, and this qualitative study provided a limited perspective on the results of interventions.

#### Conclusion

The advent of health literacy is useful for providing theoretical guidance and practical strategies. Health literacy, in coordination with other determinants of health, has an increasing perception of the factors affecting health promotion in the individual, organizational, and environments. Since the combination collaborative approaches and social science theories can be effective in promoting interventions and health literacy levels in the community, researchers suggest that a study be conducted with this aim in the future. Also, designed health communications are often overly public, so it is suggested that a study in coordination with the abilities, preferences, and living conditions of learners should be designed and implemented.

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#### **Conflict of Interests**

Authors have no conflict of interests.

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