COMMENTARY

A Model for Community Participation in Breast Cancer Prevention in Iran

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Abstract

Context: Genuine community participation does not denote taking part in an action planned by health care professionals in a medical or top-down approach. Further, community participation and health education on breast cancer prevention are not similar to other activities incorporated in primary health care services in Iran. Objective: To propose a model that provides a methodological tool to increase women's participation in the decision making process towards breast cancer prevention. To address this, an evaluation framework was developed that includes a typology of community participation approaches (models) in health, as well as five levels of participation in health programs proposed by Rifkin (1985&1991). Method: This model explains the community participation approaches in breast cancer prevention in Iran. In a 'medical approach', participation occurs in the form of women's adherence to mammography recommendations. As a 'health services approach', women get the benefits of a health project or participate in the available program activities related to breast cancer prevention. The model provides the five levels of participation in health programs along with the 'health services approach' and explains how to implement those levels for women's participation in available breast cancer prevention programs at the local level. Conclusion: It is hoped that a focus on the 'medical approach' (top-down) and the 'health services approach' (top-down) will bring sustainable changes in breast cancer prevention and will consequently produce the 'community development approach' (bottom-up). This could be achieved using a comprehensive approach to breast cancer prevention by combining the individual and community strategies in designing an intervention program for breast cancer prevention.

Keywords: Breast cancer - community participation approaches - models - Iran

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Introduction

The emphasis on community participation in health from 1978 in the Alma-Ata conference as the heart of primary health care has increased the need for planners in health programs and in funding agencies to understand the way in which community participation develops (Rifkin, 1986). The involvement of community members in public health planning, implementation and even evaluation offers an alternative approach to get people involved in health–related issues and their solutions (Neuhauser et al., 1998). This is particularly true in community–based health programs. Community-based prevention program is an approach to health promotion and disease prevention in many countries.

A number of growing educational programs in Iran exist to provide information about adolescent health promotion, family planning, STIs, HIV/AIDS, and even sex issues understanding to various age spans of both genders. These programs are received by families and the authorities. In recent years, other issues have been assessed such as breast and uterine cancer screening, treatment of anemia, aging problems, and osteoporosis (Malekafzali, 2004). Breast cancer is the most common cancer among women in developed and developing countries. In line with that, breast cancer prevention programs demand the involvement of community members to control or prevent it.

But most women do not usually participate in preventive health programs such as breast cancer prevention programs because they suffer from lack of education and knowledge and thus are less likely to engage in health preventive behaviours. So, community participation in breast cancer prevention programs such as giving awareness to women on early detection can be very crucial in Iran. Iran health care delivery in the past has focused on health improvements by mobilizing communities to take preventive immunizations so that good health depends on involvement through empowering individuals and communities to change their attitudes and behaviors.

Community participation was also focused on prevention of communicable diseases, mother and child care, family planning and first aid. Therefore, it is necessary for health staff to give information about preventive health behaviors including breast cancer

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screening (e.g. breast self exam, clinical exam, and mammography) and to support efforts for the individuals and communities' health. Women also take decisions and action for solving their own breast problems instead of relying on health professionals to provide all the answers. If community participation is to emphasize the bottom-up approach in planning and implementation of prevention programs, women should clearly be seen as active participants compared to the usual top-down approach that health professionals are keen to design for them.

The issues of health education and community participation regarding breast cancer prevention are not similar to other activities including primary health care services, such as family planning in Iran. Thus, training or educating the communities on preventive health behaviors like breast cancer prevention by health workers, community leaders, health educators, health care professionals, teachers and women volunteers should be emphasized at the district, province and national levels. In addition, when women are involved in breast cancer preventive behaviors like mammography screening, they may be able to promote breast cancer prevention among their friends, family and colleagues. In other words, they will turn from health consumers into community health workers.

The previous literature on community participation in health neglected to focus on individual participation as a fundamental step and the role of individual decision making in health development. The strategy for achieving active community participation in health needs integration between individual and community. This is referred to the integration of the individual and community in the model for community participation in breast cancer prevention as proposed in this paper.

Here the emphasis would not be on the knowledge and awareness of an individual that might affect their participation in preventive health behaviour, but their involvement in a preventive health practice can persuade them to participate at the community level. Thus, health care professionals will have to consider community participation as an intervention among members of any community. The most vital contribution is the planners or health care professionals encouraging communities to participate in available health programs.

This paper intends to consider a model which explains the community participation approaches in breast cancer prevention in Iran. It is expected that a focus on the medical approach (top-down) and the *health services* approach (top-down) in less developed countries such as Iran will bring sustainable changes in breast cancer prevention and will consequently produce the community development approach (bottom-up).

Objective

The objective of this paper is to describe a model for community participation approach to breast cancer prevention programs to facilitate women's participation in the decision making process towards breast cancer preventive behaviors, particularly mammography screening in Iran.

Theoretical Base

We have drawn the model for community participation approach to breast cancer prevention based on Rifkin's perspective of community participation in health which highlights the community participation models in health and levels of public participation in health programs. On that same note, Taylor (2004) remarked three main approaches to community participation named contribution approach, the instrumental approach and the community empowerment approach. The author emphasized on the previous literature that have been already claimed by Oakley and Marsden (1984), Rifkin (1986 and 1996), Williams and Labonte (2003) which is important to draw the study model to discuss community participation models such as compliance, contribution and collaboration.

The model proposed in this study, uses the individual and community strategies in designing an intervention program for breast cancer prevention. In fact, this model focuses on activities and processes to increase communities' capacity to identify and solve their breast problems by their own. As a result, the study looks at women's breast cancer preventive behaviours in medical approach such as breast cancer screening (mammography), as well as the process of women's participation in health service approach such as participation levels in preventive health programs (health benefits and some program activities). A large-scale study in Sweden on social participation and coronary heart disease reflects a move toward focusing on personal and interpersonal correlates of social participation (Sundquist et al., 2004) which supports the current study.

Since the mid-1970s, community based-approaches of health promotion and disease prevention have been widely used to provide a proper strategy for addressing a cost-effective way of solving health problems. Community-based approach to health support the idea that individual participation in a preventive health behavior (e.g. mammography) and voluntary participation in community-based preventive health programs (e.g. breast cancer prevention programs) are inseparable in this model. This is because it is a cost-effective way of solving health problems among communities.

Women in Iran mostly rely on doctor's advice for individual participation in mammography. This practical model emphasizes on preventive behaviours (e.g. doing mammography) as a starting point which has a direct impact on the health and well being of women. Regarding the health services approach, this model focuses on women's participation levels in breast cancer prevention programs available at the district level. In other words, the model considers that community participation can occur both as an individual participation and community participation. We expected that Iran has merely accepted the medical approach to solve the health problems and also health planning approach.

Many researchers have discussed the characteristics and nature of participation. Rifkin (1996) proposed three characteristics of participation in health and believed that participation should be active, voluntarily chosen, and

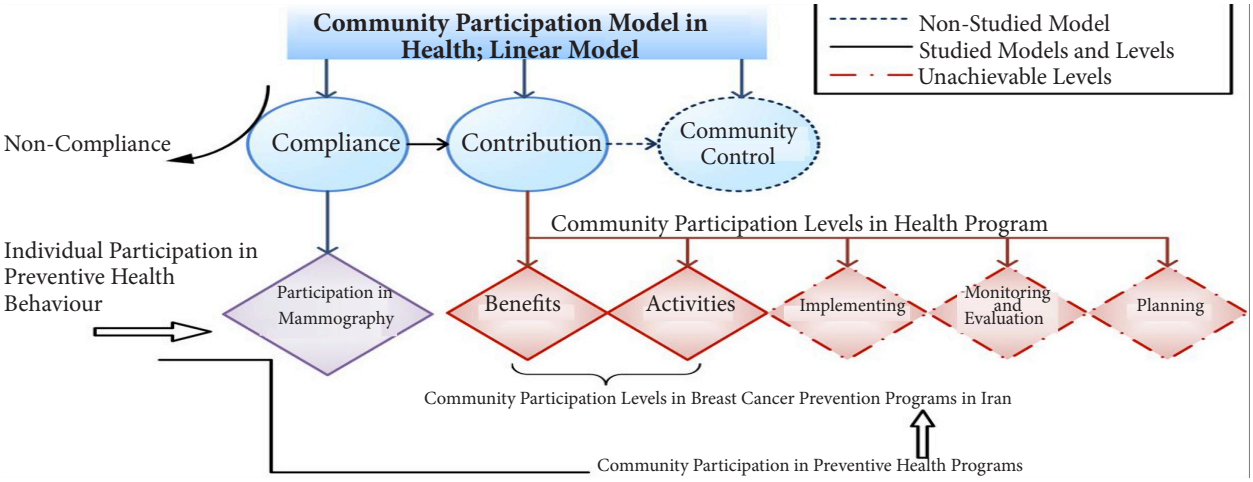

Figure 1. A Model for Community Participation in Breast Cancer Prevention Programs. A Schematic of Community Participation Model and Levels in Health: Individual Participation in Mammography and Community Participation Levels in Breast Cancer Prevention Program in Iran, […...] Refers to Non-Studied Model, [_____] Refers to Studied Models and Levels, [.__.__.] Refers to Unachievable Levels.

hold the possibility of being effective. Based on in-depth studies of community-based programs in Asia, Rifkin (1996) characterized three approaches that health planners use to explain community participation based on different assumptions about the effective ways of decision-makings to improve health.

The medical approach

It involves decisions made by health professionals who direct community members towards supporting health services. The participation outlines a linear process or involvement from a one-way process of receiving information or a preventive health practice to control and collaborate with other key players for all decisions with regard to preventive health programs. In this study, the model assumes compliance to health recommendations such as mammography use is necessary to take action to resolve health issues by individuals. Through the individual participation in a preventive health practice, which is the core component of community participation in breast cancer prevention in the model, individuals can recognize that the problem of breast cancer among women community. In fact, this model stresses the way in which women reach the decisions they can have an effect on their breast cancer preventive behaviour.

The health services approach

It involves communities contributing to health care by giving human resources, materials, or money. To explain women's role in the contribution model, the study argues Rifkin's views on participation levels in community-based program to assess the actual level of participation in the study population. Rifkin (1991) stated that there are five levels of public participation in health programs as follows:

(1) Health benefits
(2) Program activities
(3) Implementation
(4) Monitor and evaluation
(5) Planning.

In this model, women's participation levels in breast cancer prevention programs starts from a level of passive participation where women participate to get benefits to the higher level that underlines their participation in planning programs. In fact, this approach enables women to identify the problems regarding breast cancer issue and deal with the health care professionals to develop participatory planning and decision making to meet the breast cancer prevention needs of women's community.

The community development approach

It is the third one in which a community collectively identifies social, political, and economic aspects of health problems to find solutions (Rifkin 1985). In the third approach, active involvement in the social change process is reliable, because participants become empowered by taking ownership on the program (Myezwa, et al., 2003). These approaches remind us of three models of community participation in health named compliance, contribution, and community control posed by Rifkin (1986).

Conceptualizations of the models and levels of community participation are seldom examined in previous studies. A model of community participation in breast cancer prevention in the study places the emphasis on individual and community participation, and allows us to explore the implications of findings on individual health seeking behavior as a basic step in community participation in health. Norman and Bennett (1996) noted that those who suppose they have control over their health are more likely to engage in health promoting behaviors. Therefore, if we aim to explain the way in which individuals in particular places make decisions on their health preventive behavior, we could adopt a framework that highlights the way in which community participate in health issues. Women's decision making in regard to breast cancer preventive behaviors such as mammography is mostly influenced by health care professionals in Iran. Thus, the focus should be on the top down approach to affect women's capacity to obtain actual participation at the community level. A comprehensive approach can be reached by combining the individual and community strategies results in improvement of community participation in breast cancer prevention, and could reduce delay to diagnosis, improve

treatment, and also enhance health promotion strategies in breast cancer issue. As a consequence, it can be a dynamic, genuine, and feasible way to provide the mean/end goal in community participation in health.

Community Participation in Health: Means or End

In the public health segment, community participation is a means, or a process that leads to health status improvement (Cohen & Syme, 1985; House, Landis, & Umberson, 1988). Other researchers dispute that participation is a valued end, or health outcome, in itself (Vuori, 1986; Oakley, 1989). The national and international literature notify three lane purposes, or functions, of community participation which are linked to these means/ends goals (Cohen & Uphoff, 1980; Oakley, 1991; WHO, 1991; Stone, 1992; Mikkelsen, 1995; Zakus, 1998).

In the model, the most notable experience in community participation in breast cancer prevention is the mean/end goal. It emphasizes that community participation can happen with or without professionals if women just decide on health prioritization such as doing mammography. A recent study found that evidence of beneficial health outcomes and increased uptake of services as a result of community participation (Preston et al., 2010). Another latest study showed that there was little evidence of the effects of consumer participation in health care decisions at the population level (Nilsen et al., 2010). Given these evidences, the use of the mean /end goal and active participation of individuals in community participation in health are critical.

Limitations

It is not practical to illustrate a unique model for producing community participation in health programs. This framework cannot explain other inquiries for example all relevant factors (e.g. cultural or structural) into what works in community participation in breast cancer prevention programs. There may be a large gap between conceptualizations of the models and levels of community participation in health and the reality of community participation in breast cancer prevention. Another challenging issue is the border between participation and activity which is not measured in the quality of community participation in breast cancer prevention.

Conclusions

A model for community participation in breast cancer prevention is conceptualized using Rifkin's perspectives to increase women's participation prevention programs. It is the linear process of community participation from mammography compliance, to control and collaborate with health care professionals for all decisions related to breast cancer prevention programs. Nevertheless, community participation in the planning, implementation, and evaluation of health initiatives is under the authority of governmental organizations in Iran.

Since women's participation in prevention programs especially in developing and less developed countries is faced with cultural, social, and structural difficulties, the emphasis on individual decision making in breast cancer preventive behaviors (e.g. mammography screening) would be very critical in successful community participation in breast cancer prevention. Such participation can create equitable and sustainable improvements in health. If this power of decision making could be inclined slightly to a partnership between health care professionals and individuals, especially NGOs, it would build the community capacity to generate sustainable changes at all levels to achieve and maintain optimal health for those who bear the greatest burden of disease.

There will be hope in future women mobilization towards breast cancer prevention based on their responsibility and commitment provided that the government and private sector facilitates the health policies about training and its requisites for women. Conceptualizations of the models and levels of community participation in this study place emphasis on individual and community participation and tend to view the top down approaches (the medical approach and health services approach) as a mobilization strategy in community participation in breast cancer prevention programs.

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References

Cohen J M, Uphoff N T (1980). Participation's place in rural development: Seeking clarity through specificity. *World Development*, **8**, 213-35.

Cohen S, Syme S (1985). Social support and health. Toronto: Academic Press.

House J, Landis K, Umberson D (1988). Social relationships and health. *Science*, **241**, 540-5.

Malekafzali H (2004). Population control and reproductive health in the Islamic republic of Iran. *Archives of Iranian Medicine*, **7**, 247-50.

Mikkelsen B (1995). Methods for development work and research: A guide for practitioners. New Delhi: Sage.

Neuhauser L, Schwab M, Syme S, Bieber M, King Obarski S (1998). Community participation in health promotion: Evaluation of the California wellness guide. *Health Promotion International*, **13**, 211.

Nilsen ES, Myrhaug HT, Johansen M, Oliver S, Oxman AD (2010) Methods of consumer involvement in developinghealthcare policy and research, clinical practice guidelines and patient

Oakley P, Marsden D (1984). Approaches to participation in rural development International Labour Office.

Oakley P (1989). Community involvement in health development: An examination of the critical issues. Geneva: WHO.

Oakley P (1991). Projects with people: The practice of participation in rural development. Geneva: ILO.

Preston R, H Waugh, ONE AUTHOR, et al (2010). "Community participation in rural primary health care." *Australian J Primary Health,* **16**, 4-16.

Rifkin S (1991). Community participation in maternal and child health/family planning programs. Geneva: World Health Organization.

Rifkin S B (1985). Health Planning and Community Participation: Case Studies in Southeast Asia. New York: Routledge.
Rifkin S B (1986). Lessons from community participation in health programs. *Health Policy and Planning*, **1**, 240.
Rifkin S B (1996). Paradigms lost: Toward a new understanding of community participation in health program. *Acta Tropica*, **61**, 79-92.
Stone L (1992). Cultural influences in community participation in health. *Social Science and Medicine*, **35**, 409-17.
Sundquist K, L Lindstrom, et al (2004). Social participation and coronary heart disease: a follow-up study of 6900 women and men in Sweden. *Soc Sci Med*, **58**, 615-22.
Taylor J (2004). Community participation in the organization of rural general medical practice: Three case studies in South Australia (Unpublished doctoral thesis). University of SA, Adelaide.
Vuori H (1986) Community participation in primary health care: a means or an end. In H. Vuori & J. E. F. Hastings (Eds.), Patterns of community participation in primary health care . World Health Organization Regional Office for Europe, Copenhagen.
WHO (1991). Community Involvement in Health Development: Challenging Health Services. Report of the WHO Study Group, (WHO Technical Report Series No. 809) Geneva, World Health Organization, 1991.
Williams L, Labonte R (2003). Changing health determinants through community action: Power, participation and policy. *IUHPE – Promotion and Education*, **5**, 65-71.
Zakus J D L, Lysack C L (1998) Revisiting community participation. *Health Policy Planning*, **13**, 1-12.