COMMUNITY PARTICIPATION IN BREAST CANCER PREVENTION PROGRAMS TOWARDS BUILDING SUSTAINABLE PROGRAMS: INVOLVEMENT OR PARTICIPATION?

Asnarulkhadi Abu Samah [a] , Maryam Ahmadian [b], Ma'rof Redzuan [c], Zahid Emby [d]
[a,b,c,d] Department of Social and Development Sciences, Faculty of Human Ecology,
Universiti Putra Malaysia UPM Serdang, Selangor, Malaysia
[a] Corresponding author: asnarul_n9@yahoo.com

 ISSN 1923-6654 (print)
ISSN 1923-6662 (online). Available at http://www.ssrn.com/link/OIDA-Intl-Journal-Sustainable-Dev.html

Abstract: For future sustainable breast cancer prevention programs implementation, broad participation in prevention programs is necessary. In the context of developing strategies for health promotion, community participation is most relevant. Literatures also suggested that community involvement is essential for the successful promotion of health. This paper examines the levels of women's participation in breast cancer prevention programs. Community participation and community involvement are occasionally presumed to go hand in hand, but these two prominent concepts has potential difference. At times, the problem is that involvement does not mean participation. The study was conducted among 35-69 years old women who had mammogram in the last two years at 4 obstetric and gynecologic clinics in Tehran. A multistage cluster random sampling procedure and face-to-face interviewing method was used in the data collection process. Results from this study showed that the higher levels of participation (implementation monitoring, evaluation and planning), as mostly through health care professionals. Women's participation in breast cancer prevention programs is limited and it was just carried out at level1 (health benefits) and level 2 (activities). Although women were only involved at some health programs, they have no participation in decision making level. Nevertheless, the continuation of their involvement with commitment to the programs represents sustainability in community-based health programs.

Keywords: Breast cancer prevention, Community participation, Community involvement, Sustainable programs.

INTRODUCTION

There are many interventions and policies towards community development practice which initiated by public health through community participation in planning and implementing health programs. Community participation in breast cancer prevention has its own challenges. For a successful intervention program, the community members should be fully knowledgeable and willing to participate.

According to the national cancer registry, cancer is the third cause of death in Iran after coronary heart disease, accidents and other phenomena. Iranian women with breast cancer are younger (10 years) than their western counterparts and many of them are already in advanced stages of the disease resulting in high mortality (Mousavi, 2007). Iran does not have national program for breast cancer prevention but some attempts like breast cancer prevention advocacy is carried out in health centres, health houses, hospitals, clinics, work places, or by NGOs. Participation is one of the precondition elements for development (Stone, et al., 1992).

Table1: Levels of Women Participation in Community-Based Programs (n=86)

Levels	N	(%)	χ^2	df	P
Level 2 (Activities)	67	77.9	26.79	1	0.01*
Level 1 (benefits)	19	22.1			

Note * P≤0.01

The logic of public participation in health underpinned two major purposes. The first presumption is that health is a total well-being not only for individuals, but also communities, and the second stresses that health care is a responsibility of the people themselves, not only the trained professionals (Raeburn and Rootman, 1998). However, participation is influenced by the political, social, economic and cultural environment, in addition to the degree to which individuals and communities are empowered.

In the public health, community participation can be perceived as a means, or a process, which leads to health status improvement (Cohen & Syme, 1985). Other researcher believed that participation is a valued end or health outcome in itself (Oakley, 1989).The national and international literature notify another function of community participation in which it linked to these means/ends goals (Cohen & Uphoff, 1980; Zakus, 1998).

Previous literature showed that traditionally community participation has been assessed in quantitative forms, for example, by asking how many people have come to a meeting or how many people have joined in a community activity. Literatures also showed that people have involved with largely passive collaboration in health matters. Many dominant discourses about community involvement in health tend to presume that community involvement and community participation are positively related (Campbell, 2003). The problem is that the number of people attending the event does not mean participation. People are present, but they may not commit of what is going on (Rifkin, 2001).

Depending on the context, participation can be defined in various ways. Shaeffer (1994) pointed out different degrees or levels of participation, and showed seven possible definitions of the term as follows: (a) Involvement by the service users (e.g. children enrolment at school or primary health care facility usage); (b) Individual involvement through their contribution such as money, materials, and labour; (c) Individual involvement through attendance(e.g. attending meetings at school); (d) Individual involvement through consultation on a particular issue; (e) Participation in a service delivery; (f) Participation as implementers of delegated powers; and (g) Participation in real decision making and planning, implementation, and evaluation.

On the same note, Rifkin (1991) explained the five levels of participation in health programs as follows: (a) Health benefits whereby communities are only health or education services users; (b) Program activities where local communities contribute labour, land or money; (c) Implementation that focuses on local people's managerial responsibilities to carry out the program; (d) Monitor and evaluation of program activities; and (e) Planning where local communities decide on selecting of proper programs to be carried out.

Based on the above mentioned, Shaeffer (1992) emphasizes that the first four definitions means involvement with largely passive collaboration, whereas the last three definitions were active participation. However, Morgan (2001) indicated that community participation in health is also called popular participation, social participation and community involvement. Citizen participation means the social process of taking part (voluntarily) in formal or informal activities, programs and/or discussions to bring about a planned change or improvement in community life (Bracht ,1990). Active involvement in the social change process is important, because participants become empowered by their ownership of the program (Myezwa, et al., 2003). With regard to this, therefore, there is a need to shift the perception of participation from community involvement via consultation processes to meaningful participation in decision-making processes. Thus, revising the women participation in formal or informal breast cancer prevention program or activity in Iran, it is possible to make a shift from merely looking at participation as community involvement to participation in decision making level.

Table 2: Demographic Characteristics of Respondents

		Only level1 n=19(22.1%)		level2 n=67(77.9)		X2	sig
		%	n	%	n		
Age	<40	21.1%	4	23.9%	16	14.65	.002*
	41-45	31.6%	6	43.3%	29		
	46-50	15.7%	3	29.9%	20		
	>51	31.6%	6	3.0%	2		
Education	Primary &secondary school	21.1%	4	-	-	30.82	.001*
	diploma	36.8%	7	6.0%	4		
	Graduate	42.1%	8	79.1%	53		
	postgraduate	-	-	14.9%	10		
Marital	Married	78.9%	15	65.7%	44	1.459	.482
	Widow/divorced	10.5%	2	11.9%	8		
	Single	10.6%	2	22.4%	15		
Occupation	Full time Employee	36.8%	7	76.1%	51	23.66	.001*
	Part Time Employee	10.5%	2	17.9%	12		
	Unemployed or Housewife	52.7%	10	6.0%	4		
Income	low	10.5%	2	1.5%	1	3.648	.161
	middle	73.7%	14	83.6%	56		
	high	15.8%	3	14.9%	10		
Insurance	public	100.0%	19	86.6%	58	2.851	.091
	private	-	-	13.4%	9		

Note: * p<0.01.

This paper aims to look at the levels of women's participation in breast cancer prevention programs among the subgroup of women who were adherent to mammography in last two years to get better understanding of community participation or involvement in those programs in Iran.

MATERIAL AND METHODS

The data for this study consisted of 86 women aged 35-69 years who have a mammogram in the last two years. They were selected for interview from the 400 women attending the four obstetric and gynecologic clinics affiliated to Tehran University of Medical Sciences in Tehran, Iran using multistage cluster random sampling. A survey questionnaire about participating in breast cancer prevention programs was designed based on Rifkin's perspective of community participation in health programs. The community participation levels were measured by dichotomous scale that examined women participation levels whether they participated in any program for breast cancer prevention or not (Yes=1, No=0). Based on some interviews with health care professionals about current women participation situation in health programs, most of the questions were specified as level 1 (benefits) and level 2 (activity), four items and eight items, respectively. For measuring participation in implementing, monitoring and planning (level3, 4, and 5 respectively), 8 items were developed(See Table 4).

Table 3: The Levels of Women's Participation and its Frequency According to Respondents in Iran

Items			Only Level 1		Level 1 and Level 2	
1	I have participated as an audience in some of the community-based awareness programs about breast cancer prevention held in one of the places such as health center, work place or NGOs.	Seldom	19	100%	25	37.3 %
		Often			42	62.7 %
		Regularly				
2	I have followed health care professional's information which was mentioned in community -based awareness programs towards breast cancer prevention.	Seldom	19	100%	34	50.7 %
		Often			33	49.3 %
		Regularly				
3	I have consulted with my doctor / health staff regarding breast cancer prevention.	Seldom	19	100%	33	49.3 %
		Often			34	50.7 %
		Regularly				
4	I have been informed about breast cancer screening methods by health care staff.	Seldom	19	100%	33	49.3 %
		Often			34	50.7 %
		Regularly				
5	I have participated as a member in a breast cancer prevention program.	Seldom			49	73.2 %
		Often			18	26.8 %
		Regularly				
6	I have participated as a speaker in some of the programs about breast cancer prevention which were held in one of the places such as health center, work place or NGOs.	Seldom			67	100%
		Often				
		Regularly				
7	I have participated as a volunteer in some breast cancer prevention programs.	Seldom			18	26.8 %
		Often			49	73.2 %
		Regularly				

8	I have given consultation, comment or information to others about breast cancer prevention.	Seldom			67	100%
		Often				
		Regularly				
9	I have met other members outside of program to cooperate with them about breast cancer issue.	Seldom			67	100%
		Often				
		Regularly				
10	I have contacted other members of my current group in community meetings about breast cancer prevention.	Seldom			33	49.3 %
		Often			34	50.7 %
		Regularly				
11	I have advocated community-based program in my neighborhood or my work place regarding breast cancer prevention program.	Seldom			67	100%
		Often				
		Regularly				
12	I have donated money or any resources to help breast cancer prevention program in anywhere such as health center, work place or NGOs.	Seldom			27	40.3 %
		Often			40	59.7 %
		Regularly				

The participation was measured based on a 3 point Likert scale from 1 to 3 (1=”seldom”, 2=”often”, 3=”regularly”) in which, ‘seldom’ means 1 to 3 times , ‘often’ 4 to5 times, and ‘regularly’ over 5 times attending the program in a year. Questions asked are pertaining to their frequent participating in a cancer prevention activity held in district level.

Reliability test was conducted on a convenience sample on 31 women aged 35 or above. Based on pilot study, the alpha values are range from 0.72 to 0.96, which indicated the instrument developed is sound. Trained data collectors executed the face to face interview with the respondents who were in the waiting room of gynecologic clinics. Approval to conduct the survey was provided by the Cancer Institute (CRCI) in Iran. Letters permitting data collections at the participating hospitals were procured prior to the survey. Data analysis was carried out using Statistical for Social Science (SPSS13). Descriptive statistics such as frequency distribution, and percentages, were calculated to explain data preliminarily. Bivariate analyses were performed using chi-square tests. Preliminary exploratory data analysis was conducted to appraise for missing values, detect outliers and check for normality.

RESULTS

From a total of the 86 women participating in mammography in the last two years, 19 women were in level 1(benefits) and 67 women were in level 2(activities) [χ^2 (1)26.79, $p \leq 0.01$] (see Table 1). The chi-square ($\chi 2$) test showed that there is a significant relationship between age, education, occupation and higher level (activities) of participation ($P < 0.01$) (see Table 2). The findings showed the levels of participation which were achieved by women in community-based breast cancer prevention program or activity, were divided into two levels (benefit, and activities) (Ahmadian et al., 2010).

Table 4: The Instrument about the Levels of Women's Participation in health programs

Items		Yes	No
Level 1			
1	I have participated as an audience in some of the community -based awareness programs about breast cancer prevention held in one of the places such as health center, work place or NGOs.	( )	( )
2	I have followed health care professional's information which was mentioned in community -based awareness programs towards breast cancer prevention.	( )	( )
3	I have consulted with my doctor / health staff regarding breast cancer prevention.	( )	( )
4	I have been informed about breast cancer screening methods by health care staff.	( )	( )
Level 2			
5	I have participated as a member in a breast cancer prevention program.	( )	( )
6	I have participated as a speaker in some of the programs about breast cancer prevention which were held in one of the places such as health center, work place or NGOs.	( )	( )
7	I have participated as a volunteer in some breast cancer prevention programs.	( )	( )
8	I have given consultation, comment or information to others about breast cancer prevention.	( )	( )
9	I have met other members outside of program to cooperate with them about breast cancer issue.	( )	( )
10	I have contacted other members of my current group in community meetings about breast cancer prevention.	( )	( )
11	I have advocated community-based program in my neighborhood or my work place regarding breast cancer prevention program.	( )	( )
12	I have donated money or any resources to help breast cancer prevention program in anywhere such as health center, work place or NGOs.	( )	( )
Level 3 (13&14), Level 4 (15,16,17&18) and Level 5(19&20)			
13	I have taken an active part in organized group activities to carrying out breast cancer prevention programs.	( )	( )
14	I have joined organized committees for voluntary work about how breast cancer prevention program should be run.	( )	( )
15	I have evaluated and organized the community activities about breast cancer prevention program voluntarily.	( )	( )
16	I have encouraged others to join in a breast cancer prevention program group.	( )	( )

17	I have asked health staff agencies or government organization to provide the resources or materials which can help breast cancer prevention program.	( )	( )
18	I have organized individuals or groups to take greater control over breast cancer prevention program.	( )	( )
19	I have participated in planning program to identify the solution about breast cancer prevention.	( )	( )
20	I have made decisions about strategies or addressing the problems that women are faced to in getting breast cancer prevention.	( )	( )

Women who were in level one (benefits) admitted that they seldom participated in every item related to level one (100%), while 62.7% of women in level 2 acknowledged that they often participated as an audience in selected programs (see Table 3). For items related to level two (Activities), more than half respondents admitted that they contributed as voluntary labor (73.2%), contributed money or resource (59.7%) and attended community meeting (50.7%). The study showed that they often participated in program activities, particularly those items mentioned. From the results of study, it can be concluded that decision making, monitoring, evaluation and implementation are yet governed by health care professionals in Iran. It is noteworthy to state that community participation in the context of breast cancer prevention programs assumed community involvement based on the studies mentioned above.

DISCUSSION

The study addressed the levels of women's participation in breast cancer prevention programs to develop a better understanding of community participation or involvement on the subject of breast cancer prevention. The setting in which this study took place is unique as literatures revealed that community participation in Iran have produced changes in health status in small-scale programs especially in public health (Ahmadian et al., 2010) and offer special breast cancer prevention programs for women community.

Results confirmed that respondents in both levels (benefits and activity) did not participate regularly. Based on our observation, women's participation in breast cancer prevention has the inner drive to engage with and were enthusiastic to help any breast cancer prevention program by participating voluntarily and contribute labor and money. It seems participation in mammography (as a breast cancer prevention program or activity) is a voluntary participation. However, the time of mammography utilization and women attendance in any health program could not be properly envisioned in the current research. There is, however, a further assumption that high level of information on breast cancer screening such as mammography and to ask questions regarding breast cancer will make women participate in the breast cancer prevention programs. As mentioned above, this study was carried out among women participating in mammography in the last two years.

Consistent with this result, Shams (2008) also noted that community participation in Iran is limited to the first level (benefits) and sometimes the second level of participation (activities). Since there was no specific program on cancer prevention in Iran, therefore higher levels of participation among women (including participation in implementing, monitoring and planning programs) is not a phenomenon yet. Bossert and Beauvais (2002) also reported the same people participate in health benefit and program activities in Uganda. The authors stressed the higher levels of participation is mainly practiced by the designated leaders. It is notable to state that community participation in health programs primarily existed at the health benefit and program activity levels (Rifkin, 1991).

People are most likely to practice healthy behaviors (e.g. exercise) if they discover that their peers are doing so (Campbell, 2003). Thus, knowledge of breast cancer screening techniques such as mammography might lead directly to women participation in local breast cancer prevention projects. They should feel that their other counterparts are doing appropriate action regarding breast cancer prevention. In other words, women's participation in breast cancer prevention program might be associated with social support on breast cancer issue in Iran. Thus, it can be concluded that women just have passive involvement in health programs related to breast cancer prevention. Women were involved or present at some programs, but have no participation in decision making level. Though, community involvement and community

participation are really correlated (Morgan, 2001& Campbell, 2003). It seems the higher levels of participation, as mostly through health care professionals.

Apparently, there are many literatures suggesting the right of communities to participate in the design, implementation, and evaluation of interventions to affect their own health and well being. Within health context, particularly in the case of breast cancer prevention, individuals (women) are the frontline in prevention, care, and support attempts. Thus, huge number of women's involvement in benefits and activities, in Iran can facilitate to achieve the status of women's participation in future intervention with regards to breast cancer prevention.
However, the next challenging issue is that women may receive intervention program to make them aware about mammography and breast cancer prevention, which could empower them to take better care of themselves, but this may not lead to participation. This health behavioural issue was mentioned by Swartz, et al., (2006) in his study regarding community participation in AIDS vaccine trials.

This study is limited by a framework of analyses for community participation in health which might lead to unrealistic assumptions about community involvement and participation in general. Limitation of this study includes the need to perform more qualitative research with focusing on in-depth interview and focus groups with respondents to understand in detail about their choice of participation and preferences. Further, the lack of participation of potential key informants is noticeable in this present research. This study carried out on a small sample of women (n=86) and this may impact the generalisability of the findings. Thus, the findings need to obtain a large sample of participant in order to attain required statistical power. The current research may be overestimated due to social desirability response bias.

CONCLUSION

The purpose of this paper is to review the levels of women's participation in breast cancer prevention programs in Iran to enable public health planners and health care providers to make more realistic assumption about community participation or involvement in health matter. This study demonstrates that the potential benefits of community participation are not limited to the developed countries. The study showed that community participation in breast cancer prevention just achieved at level 1 (health benefits) and level 2 (activities).

In response to the challenge on potential differences between community involvement and community participation, previous researchers have emphasized that they are correlated to each other. There are different approaches to participation and this depends on community ability to participate in health programs. Women's involvement with largely passive collaboration in breast cancer prevention programs can lead to an active participation if they are committed to the programs and willing to participate actively. Nevertheless, the continuation of women benefits from the program activities represents sustainability in community-based health programs.

The findings from the study are useful for this at risk population (women) with emphasis on their role in health development. Since the government policy in Iran is dominated at the national level, powerful advocacy effort at the individual and community levels concerning breast cancer prevention could benefit many thousands of women throughout the country.

ACKNOWLEDGEMENTS

We would like to express our gratitude to members of ACECR, Cancer Institute, Tehran University of Medical Sciences, and Iranian Centre for Breast Cancer (ICBC), Tehran, Iran, to guide the researcher on the subject of breast cancer issue during the data collection. Finally, we would like to thank all the participants for their cooperation.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

REFERENCES

[1] Ahmadian M, Redzuan M, Emby Z, & Samah, A, A (2010). Women's community participation levels in community-based health programs regarding breast cancer prevention in metropolitan Tehran, Iran. *Asian Social Science, 6*(9), P12.

[2] Bracht, N., & Tsouros, A. (1990). Principles and strategies of effective community participation. *Health Promotion International, 5*(3), 99-208.

[3] Bossert, T. J., & Beauvais, J. C. (2002). Decentralization of health systems in Ghana, Zambia, Uganda and the Philippines: A comparative analysis of decision space. *Health Policy and Planning, 17,* 14–31.

[4] Campbell, C., & McLean, C. (2003). Social capital, local community participation and the construction of Pakistani identities in England: Implications for health inequalities policies. *Journal of Health Psychology, 8*(2), 247.

[5] Cohen, J. M., & Uphoff, N. T. (1980). Participation's place in rural development: Seeking clarity through specificity. *World Development*, 8, 213–235.
[6] Cohen, S., & Syme, S. (1985). *Social support and health*. Toronto: Academic Press.
[7] Raeburn, J., & Rootman, I. (1998). *People centered health promotion.* Chichester: John Wiley & Sons.
[8] Rifkin, S. B., & Pridmore, P. (2001). *Partners in planning.* London: MacMillan Education Ltd.
[9] Rifkin S. (1991). *Community participation in maternal and child health/family planning programs.* Geneva: World Health Organization.
[10] Oakley, P. (1989). *Community involvement in health development: An examination of the critical issues*. Geneva: WHO.
[11] Shaeffer, S. (Ed.) (1994). *Partnerships and Participation in Basic Education: A Series of Training Modules and Case Study Abstracts for Educational Planners and Mangers.* Paris: UNESCO, International Institute for Educational Planning.
[12] Shams, B., Golshiri, P., Zamani, A., & Pourabdian, S. (2008). Mothers' participation in improving growth and nutrition of the children: A model for community participation. *Iranian Journal of Public Health, 37*(2), 24-31.
[13] Stone, L. (1992). Cultural influences in community participation in health. *Social Science and Medicine, 35,* 409–17.
[14] Swartz, L., & Kagee, A. (2006). Community participation in AIDS vaccine trials: Empowerment or science? *Social Science and Medicine, 63*(5), 1143-1146.
[15] Morgan, L. M. (2001). Community participation in health: Perpetual allure, persistent challenge. *Health Policy and Planning, 16*(3), 221.
[16] Mousavi, S. M., Montazeri, A., Mohagheghi, M. A., Jarrahi, A. M., Harirchi, I., & Najafi, M. (2007). Breast cancer in Iran: An epidemiological review. *The Breast Journal, 13*(4), 383-391.
[17] Myezwa, H. & M'kumbuzi, V. (2003). Participation in community based rehabilitation programs in Zimbabwe: Where are we? *Asia Pacific Disability Rehabilitation Journal, 14*(1), 18-29.
[18] Zakus, J. D. L., & Lysack, C. L. (1998) Revisiting community participation. *Health Policy and Planning, 13,* 1–12.