

Community Participation in Community-based Prevention Programs; A Short Review of the Literature on Challenges to Breast Cancer Prevention Programs or Activities

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Abstract: This article reviews the potential of widely used psycho-social factors affecting community participation in community-based prevention programs among diverse communities. Besides, we specifically appraised the previous literature to look into the psycho-social, structural, and demographic factors which create latent challenges to community participation in breast cancer prevention programs. We believe communities with lack of behavioral and psycho-social change components are likely to have low motivations to participate in health programs against diseases such as breast cancer. Additionally, certain demographic characteristics and potential structural factors control a distinct participation in health programs. Clarification of participation in public health programs and its psycho-social, structural, and demographic attributes are keys to explicate why and how socio-cultural, behavioural, and multifaceted interventions should be main concern in the evaluation of community participation in health promotion programs. The idea here is rather to emphasize on community participation in breast cancer prevention activities for community development undertakings.

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Introduction

Community development, as a strategy for a health promotion program, is an important attempt in the prevention of diseases. Furthermore, community-based prevention program is an approach to health promotion and disease prevention. Nowadays, the community-based health prevention program has brought about a new path to emphasize on investment in prevention and support care among any sub-population.

Community development strategies stress the principles of the Ottawa Charter for Health Promotion (1986) and emphasized on the community participation for seeking solutions for health problems. Health promotion encourages individuals and communities to take greater responsibility for their health (WHO, 1978). Nowadays, community-based health promotion programs have become an integral part of overall health promotion efforts (Shea and Basch, 1990). Community-based programs alter public health policies to change health behaviours and to reduce health risks of community members. Individual behaviour change is a basic priority for participatory activities which are planned by the government such as anti-smoking and nutrition campaigns, and displayed a lifestyle view of health promotion (Pinder, 1994).

With the rapid rise in health care costs all around the world, health services need to find effective ways to prevent diseases and promote health. At the same time, there is increasing evidence that community participation is a pivot for new public health programs and it can significantly improve communities' knowledge, attitudes and behaviours to contribute to health promotion. The problem is that the number of people attending the event does not denote participation. People are present, but they may not commit of what is going on (Rifkin, 2001). People have no participation in decision making level. However, Abu Samah et al., (2012) noted that community involvement in health tends to be assumed community participation.

The concept of health and health care, as defined by the World Health Organization (WHO) demands participation from communities. This concept impacts on the standard of housing, maternity and child care, nutrition and diet, potable water, and hygiene. At the WHO conference in Alma-Ata in 1978, health was interpreted beyond the absence of illness. Since that time, the concept of primary health care (PHC) has implied that a community takes responsibility for its own health. However, despite these endeavors, there are still many barricades and challenges which stand in the way of community participation in health programs.

The impact of challenges and barriers to community participation in community-based prevention programs are seldom studied among general population or sub-populations. The purpose is to understand even very simple experiences of general population to make program planners and managers consider community participation in health prevention programs and to facilitate the policy-making process, practically. Psycho-social, structural, and demographic attributes are crucial in the identifying challenges to public participation in health prevention programs.

One of the fastest growing public health concerns is breast cancer which needs community participation. The incidence of breast cancer increased over the past 20 years, and this fosters the worry about psycho-social and physical well-being of healthy women at risk of breast cancer. In line with that thought, very few studies have been done based on theoretical models regarding women's participation in breast cancer prevention groups such as support group (Gilbar & Neuman 2002; Cameron et al., 2005). In addition to this, at the structural level, social, economic and cultural barriers, and at the individual level, motivation can influence community participation in health care (Kapiriri et al., 2003).

This paper will outline the previous literature to look into the psycho-social, structural, and demographic factors to identify potential challenges to community participation in health programs, activities, and groups. A whole host of aspects came into play in this literature review, which we are only just beginning to appreciate community participation in public health prevention programs, particularly women's involvement in breast cancer programs or support groups based on voluntary work or getting health benefits.

Methodology

More than 80 articles published from the year of 1990 through 2012 were reviewed mostly by following electronic databases such as Science Direct, Pub Med, ISI Web of Sciences, and Google Scholar. The findings from applicable published studies were summarized to identify challenges and barriers to community participation in community-based health prevention programs. The inclusion decisive factor were "psychosocial factors", "structural factors", and "demographic factors" in combination with "community participation in health programs", "community participation in community-based prevention programs", and "women's participation in breast cancer prevention programs or groups". The factors influencing prevention programs were categorized in three main domains such as psychosocial issues, structural factors, and socio-demographic factors.

These studies confirmed that the decision to engage with a health prevention program is influenced by a variety of variables such as age, education, occupation, access to health services, attitude, and perceived barriers. In mapping out the factors, there are many factors which affect community participation in health prevention programs and many diseases which can be prevented by participation of lay people. But this study tends to fall under the divisions of psychosocial, structural, and demographic factors along with current health promotion programs (e.g. breast cancer, obesity, physical activity, family planning, etc.) which held by health care providers around the world. The underlying assumption is that these factors should be understood in terms of tangible challenges to women's participation in breast cancer prevention programs or activities.

Demographic Factors

Community participation in health programs is realized to be crucial in health and social development. Little is known about how often socio-demographic factors influence participation in community-based prevention programs. The relations between different age, gender, ethnicity, and socioeconomic characteristics controlled a mixed participation in health programs. However, the lack of serious commitment might be a barrier to the sustainability of community-based control strategies (Sindato et al., 2008).

These factors are too plentiful to be reviewed here deeply. For example, Nobles and Frankenberg (2009) discovered that socio-demographic characteristics of mothers are associated with the choice to participate in community activities regarding their children health in Indonesia. Similarly, Boyce (2001) has already noted that the numbers and types of community participation are influenced by geography (Cohen & Syme, 1985), socioeconomic status (Sills, 1968; Widmer, 1987), gender (Wells et al., 1990), and group heterogeneity (Litwin, 1986). Therefore, community-based strategies must be adaptable to the ecological local setting, cultural and social differences (Lloyd et al., 1992). In fact, a package of specific socio-demographic factors associated with preventive diseases will be essential for sustaining community participation in a public health setting.

Gender

With regard to age and gender, Boyce (2001) stated that attitudinal barriers to young women's participation demands women to be separated into different age groups to encourage participation. Boyce (2001) mentioned that gender also affects community participation and self help activities. For instance, men participated mostly in advocacy activities, while women participated in social support groups and self-help activities. Previous studies documented that

female, younger, white, better educated, and middle-class people tend to participate excessively in support groups related to health issues (Berglund et al., 1997; Deans et al., 1988; Krizek et al., 1999; Helgeson et al., 2000; Plass & Kock, 2001). In contrast, Sherman et al., (2008) did not find gender differences in public participation in cancer support groups.

Age

Age as a demographic factor has been a potential contributor to participation in health programs. As mentioned above, younger people are more likely to participate in health programs such as cancer support groups (Berglund et al., 1997; Deans et al., 1988; Krizek et al., 1999; Helgeson et al., 2000; Plass & Kock, 2001). There is little published information regarding the relationship between age and community participation in health programs, particularly in breast cancer prevention. In a recent study, there was a significant relationship between age and high level of volunteering in community-based breast cancer prevention programs in Iran (Ahmadian et al., 2011). However, in general, younger women tend to participate in family planning programs in Iran. This may relate to the higher education level or having a job among Iranian women who participated in family planning programs. In contrast to this, association between age and participation in cancer support group was not significant in a study in the United States (Sherman et al., 2008).

Education

In some way, there are various socio-demographic factors that hinder the community participation in health programs. According to Boyce (2001) community members with very low educational levels had minimal level of participation usually as clients and volunteers, and no interest in taking responsibility at project management positions. Despite the various benefits of local community participation in health prevention programs, it needs to be realized that their commitment to the possible gains from community participation is important.

Previous literature demonstrated that relationship between education and participation in cancer support group was significant and participants had slightly higher education than non-participants (Sherman et al., 2008). Stevens & Duttlinger (1998) also found that established participants in a breast cancer support group were mostly educated. Literature proved that there were trends for greater participation in breast cancer support group among those with higher education (Bauman et al., 1992; Meyer & Mark, 1995; Stevens & Duttlinger, 1998; Eakin & Strycker, 2001).

Similar to other western societies, a research in Iran showed that community participation levels in breast cancer prevention programs were influenced by women's education. Educated women were more

enthusiastic to participate in programs regarding their health and well-being such as family planning and breast cancer programs (Ahmadian et al., 2011). These findings were supported by previous studies carried out by Ahmed (2003) and Sarker (2005) in Bangladesh that education grants women a voice against social injustice.

Marital status

With regard to community participation and the psycho-social well-being among retirees in the United States a study by Moen & Fields (2002) showed that community participation may be less important for the well-being of married, as opposed to unmarried because married people are less socially isolated than are those who are widowed, divorced, or never married. Authors also argued that married retirees would both be more suitable to participate in their communities and to benefit from that participation (Musick et al., 1999). They added that marriage itself is an integrating role, one with obvious emotional benefits to health (Pienta et al., 2000; Waite & Gallagher, 2000).

A recent study by Ahmadian et al., (2011) exposed that there is not a significant relationship between marital status and voluntary participation in breast cancer prevention activities among women attending outpatient clinics in Iran. Iranian women, particularly married ones may have no tradition of extensive involvement in community networks, especially in health programs. However, they support survival groups, after being healed from breast cancer, which shows that specific personal experience on medical issues will be an incentive to mobilize people against diseases such as breast cancer and to encourage them to voluntarily participate in health activities.

Occupation

There are some inconsistent results between the researches about the importance of occupation as a socio-demographic factor. It seems working people tend to participate in community based health programs which might drive from their communication with other people in the society or education. These people can be informed of their relevant medical programs such as those available work-place programs. Besides, they are less conservative than the other unemployed ones. For example, the employed women are able to consider the reality that their own health is equally important to the whole family health (Ahmadian et al., 2011). In a recent research which was conducted in Iran by Ahmadian (2011), women with full-time jobs have participated in health promotion programs such as breast cancer prevention programs more than those having part-time jobs, being unemployed and housewives. It can be concluded that participating

women with full-time jobs have less socioeconomic dependency (Ahmadian et al., 2011). In contrast, association between occupation and participation in cancer support group was not significant in a study in the United States (Sherman et al., 2008).

Income level

According to Boyce (2001) community members with the low-income levels had little participation usually as clients and volunteers, and showed no concern in taking responsibility at project management situations. Boyce (2001) also discovered that community members with low incomes had minimal levels of participation in health promotion projects in Canada. Similarly, Green and Kreuter (1991) indicated that economic status as an individual characteristic influences voluntary behavior in health programs, such as getting vaccinated and complying with a treatment schedule.

Likewise, income was not found to be a significant contributor in a recent study in Iran regarding women's participation in health promotion programs such breast cancer prevention (Ahmadian et al., 2011). Rich women including the old ones in Iran are keen on voluntary group programs, like charities or elderly care, but they do not appreciate the need for health seeking behaviours (Ahmadian, 2011). No matter how clear the benefits of a designed intervention may appear to those initiating it, the socioeconomic context may affect whether community involvement is made possible or delayed (Zakus and Lysack, 1998).

Psychosocial Factors

The effect of psychosocial factors on community participation or public participation in health and health inequalities has been characterized significantly in human and social capital research literature. Egan et al., (2008) cited from previous literature that psychosocial theories have persuaded policy-makers to develop public health strategies that take into account people's support networks, sense of control and empowerment, and the extent to which people participate in the local community.

We carried out a literature review of recent studies looking at how psychosocial factors such as attitude, beliefs, self-efficacy, social influence and perceive barriers, may relate to community participation in health programs, particularly preventive disease programs like breast cancer prevention community settings. We also found some specific psychosocial factors associated with community participation in health programs. However, more robust reviews should be done to make possible a better understanding of psychosocial factors and its effects on community participation in prevention programs within health care structures. Here, we began to emphasize the influences of

psychosocial factors on people's behavior with regard to their participation in health programs. Nevertheless, understanding the psychosocial determinants of community participation in health programs could be a difficult endeavor in practice. As we are interested in community participation in health promotion programs, concerns must be drawn out for individual and structural factors which have been reviewed in the paper.

Attitude

The concept of community participation is not explicit to health because it underpins rural community development (Cheers, 1998), and social development (Midgley et al., 1986). In terms of health prevention programs, literature showed that community members' attitudes influence their participation in programs. When local community people change their attitude and behaviours, they would obtain a sense of program ownership and sustainability. For instance, in Uganda a health program develops community support through the use of participatory techniques to promote dynamic reflection on HIV/AIDS and to change local community attitudes. This program was successfully used to educate and mobilize entire communities to reduce their risk of becoming infected with HIV due to behavioural change at the community level (Welbourn, 1998).

Community involvement in the diagnosis and seeking solution of health problems is an old opinion of public health. But listening to the concerns of the community is important (Minkler, 1990). Beeker et al., (1998) also stated that public health practitioners should recognize environmental and community factors which influence health issues. The results of a research which was carried out in Iran showed that local people could acknowledge their own health needs and request more information from professionals to improve their own health based on their cultural attitude and historical roots (Behdjat et al., 2009).

Another study by Sharma (2007) in India showed that understanding participation in the community-based rehabilitation is referred to the attitude and behaviours of all actors involved in the community-based programs. Sindato et al., (2008) also noted that it is important to comprehend the people's attitudes before their involvement in a health program. In contrast, attitude regarding dengue fever prevention among Brazilian communities was not associated with effective dengue control actions (Claro et al., 2006).

With regard to breast cancer, women's participation in prevention programs at the community level was significantly related to their attitude (Ahmadian, 2011). We believe that more social scientist should come to assist local communities to

outline their own health needs, particularly about preventive diseases and to develop initiative approaches and solutions for meeting them. In a way, attitude towards participation in health programs may potentially explain some health outcomes.

Self-efficacy

Handy & Kassam (2004) indicated that individuals with low self-efficacy regarding health behaviour restrict their participation in rural NGOs in India. Smith-Morris (2006) also stated that non-participation in successful community-based diabetes program attributed to insufficient self-efficacy. Smith-Morris (2006) believed that program revision must be tied to certain psychosocial factors due to the importance of people's voluntary participation in community-based health programs. With regard to social capital and health programs, Kawachi et al., (2004) identified inconsistent evidence of relations between collective efficacy and social cohesion with health outcomes such as general health and child health. However, publication bias may influence our literature review.

Another study revealed that self-efficacy is not a salient factor for participation in breast cancer prevention programs among Iranian women (Ahmadian et al., 2011). The result of the study demonstrates a trend of community participation in health programs in less developed countries such as Iran. This trend includes lack of a strong sense of community among participants and low numbers of active participants since there is no actual formal program regarding breast cancer prevention in developing or less developed countries.

Belief

Previous study showed specific cultural belief and ethnic contexts had association with voluntary participation in health program (Boyd-Franklin, 1991; Guidry, et al., 1997; Mathews, Lannin, & Mitchell, 1994). Health belief is a vital part of community-based control program. Positive belief encourages people to control the diseases such as malaria individually and to increase their voluntary participation in control activities or programs (Grantham, 2009). Similarly, Zaim (1997) mentioned that in malaria control campaigns in southern Iran, health care professionals should take into account people's beliefs towards national malaria control programs in the region. He also mentioned that malaria control activities have been integrated into the primary health care system (PHC) in Iran. According to him, people's beliefs and behaviour towards national malaria control programs in southern Iran lead to control the disease and increase community participation in malaria control activities, particularly those measures aimed at reducing human-vector contact. Another study showed that belief is a prominent factor for participation in breast cancer

prevention programs at the district level among Iranian women (Ahmadian et al., 2011).

Social Influence and Social Support

Social influence and social support within familial, marital relationship and social network can affect public participation in health programs. In fact, these factors mediate community involvement in health programs. With regard to women's participation in breast cancer support group, literature showed higher level of participation in support groups was associated with potential benefits of participation in support groups and consistent support over time (Stvens, 1998). Community participation or activity may reveal a general readiness for social engagement (Bauman et al., 1992; Taylor et al., 1986). Similarly, previous studies showed that social influence and social support are associated with participation in breast cancer prevention programs or cancer support groups (Ahmadian et al., 2011; Sherman et al., 2008). Previous literature has also shown that it is crucial to foster social support from partners and families both before and during interventions in order to facilitate program goals (Leonard et al., 2001). Taylor et al. (1986) similarly found that encouragement from spouses to attend a group was tied to greater participation.

Stevens & Duttlinger (1998) identified that demographic, medical, and psychosocial factors affect women's participation in breast cancer support groups. According to them, the most important barriers causing non-participation were anxiety, depression, stress, non-support, and aggression which were lower in established participants with higher participation. Furthermore, established participants were most educated, and most of their friends were diagnosed with cancer which supports the view that social influence is linked to better health and active participation. According to (Bauman, et al., 1992; Taylor et al., 1986), volunteer or community activity has been linked to the use of social influence and may reflect a broader readiness for social engagement.

Similarly, social networks influence health behavior, directly through normative pressure to change individual-level characteristics such as frequency of condom use, and indirectly through collective action to change community-level characteristics such as restrictive gender roles regarding HIV (Beeker et al., 1998). In practice, identifying social network factors affecting community participation in health program can be a difficult task. For example, Media attention to the disease such as breast cancer compared with other cancers may affect participation in the community support group (Sherman et al., 2008). Other researchers (Eakin & Strycker, 2001; Krizek et al., 1999) similarly stated that the level of awareness and

utilization of community support groups are higher among breast cancer patients than among those with other types of cancer.

Perceived Barriers

Theoretical perspectives rarely have been employed to investigate the use of community participation in community-based disease prevention programs. A recent study by Sherman et al., (2008) utilized the Health Belief Model (Rosenstock, 1974; Stretcher & Rosenstock, 1997) to identify the determinants of women's participation in a community-based cancer support group in Arkansas, USA. Authors suggested that the perceived barriers were associated with women's participation in cancer support group.

Martinez et al., (2001) examined the barriers to the physical activity of a faith-based community among churchgoers in a border region. They found some individual barriers to participation in the community-based physical activity program including lack of motivation, time, language, money, social support, family or household responsibilities, socio-cultural (fear) and environmental (traffic-related) barriers which reduce people's attendance in community-based health programs.

Likewise, Kapiriri et al., (2003) found that at the structural level, social, economic and cultural barriers influence local community participation in health in Uganda. In addition, Boyce (2001) also mentioned similar barriers in a study on community participation of disadvantaged groups such as poor women, street youth, and disabled persons in health promotion projects in Canada. In addition, Smith-Morris (2006) noted that non-participation in health programs such as diabetes program can happen due to barriers like lack of knowledge, income, social or family support.

Similarly to other authors' findings, Beeker et al., (1998) argued that public health practitioners have recognized that health is influenced by environmental and community factors. They added that community involvement in the diagnosis and solution of health problems is a long-standing opinion of public health. It encourages listening to the concerns and problems of community residents (Minkler, 1990). Green & Kreuter, (1991) also mentioned that despite early recognition of health behaviour in culture, geography, economic and political circumstances, health interventions should focus on individual characteristics, like motivation and skill, to change voluntary behaviours in health programs such as getting vaccinated. With regard to breast cancer, Sherman et al., (2008) cited that some practical barriers were associated with participation in support groups such as breast cancer groups.

As underlined by previous investigations (Eakin & Strycker, 2001; Plass & Koch, 2001), limited

awareness of where to find a group was tied to lower participation. Moreover, as expected, those who lived in distant or rural areas reported less participation in support groups. Mostly, these individuals have fewer group services available in their local communities and appear reluctant to travel long distances to seek them. Geographical or transportation barriers have been cited as important obstacles by several investigators (Duncan & Cumbia, 1987; Thiel de Bocanegra, 1992; Llwyn et al., 1999; Fukui et al., 2001).

Regarding women and breast cancer activity, a recent study showed that they overcame their barriers towards preventive behaviors such as mammography for higher level of participation in any community-based breast cancer prevention program in Iran (Ahmadian et al., 2011). However, they observed that those who participated in the programs lived nearby as well.

Thus far, we have discussed the specific barriers to public participation or community participation in health programs and the fact that community participation in health needs a pragmatic solution to identify these barriers prior to the success of community participation activities and process in health programs.

Structural Factors

This section introduces structural factor as one potentially useful determinant of community participation in health programs. Recent perspectives proves that community participation in health programs has appeared to be understood as relying more on structural factors in health care structures than on cultural factors in local communities. There is an increasing emphasis on political factors within and between health agencies, governments, and different levels of national health care systems. These perspectives put up new inquiries for community health programs and the strategy of community participation (Stone, 1992).

According to Sherman et al., (2008), structural factors influencing participation in health programs might incorporate practical problems such as transportation or distance (Bauman et al., 1992; Duncan & Cumbia, 1987; Fukui et al., 2001; Llwyn et al., 1999; Thiel de Bocanegra, 1992), and include functional capacity (Duncan & Cumbia, 1987), financial obstacles, or competing family or care giving responsibilities (Fukui et al., 2001). Geographical or transportation barriers have been mentioned as important obstacles by several researchers (Duncan & Cumbia, 1987; Llwyn et al., 1999; Fukui et al., 2001).

A structural perspective was utilized in another study on community participation of disadvantaged groups such as poor women, street youth, and disabled

persons in health promotion programs in Canada. This study showed the relationship between various dimensions of structure like social-cultural, organizational, political-legal-economic, and the community participation process. Participation was controlled by structural factors such as bureaucratic rules, perceived minority group relations, agency responsibilities, available resources, and organizational roles. The study came up with a conceptual model based on structural factors that is practical in explicating how key factors from federal and local levels can limit or ease the community participation process (Boyce, 2001).

With respect to patients participation in health program or groups, one should bear in mind that understanding patient preferences might also be an important structural questions regarding group composition and group format. Many groups are directed toward specific diseases (e.g., breast cancer) and these focused groups assist participants distinguish more readily with other members and hasten group cohesion (Leszcz et al., 2004; Cameron et al., 2005). Previous literature also cited by Sherman et al., (2007) in a study regarding cancer group psychotherapy interventions. In the same way, health care providers should clarify to people about the importance of common diseases and the reality of prevention programs in a small scale approach, as well as the benefits that participation in these programs can offer (Ahmadian and Abu Samah, 2012).

Limitations

This review explores the evidence of demographic, psychosocial, and structural factors and their associations with community participation in health programs, particularly breast cancer prevention or support programs in community setting. However, the review provides little proof on the factors inspiring community participation in health programs based on local community geography around the world. The overall lack of robust data on factors influencing community participation in health programs, this paper may reflect the deprived quality of some previous studies on these factors.

The literatures regarding socio-psychological attributes on community participation in health programs are relatively limited in theoretical depth. The present review cannot be addressed directly to previous literature review and much of this limitation may be linked to our approach to scoping the previous studies. Some of these limitations have also been cited in a systematic meta-review on psychological risk factors and health inequalities by Egan et al., (2008). Nevertheless, the benefit of factors influencing participation in health program can be concluded by highlighting the importance of specific factors in this review.

A review of 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. The problem is that presence does not mean participation. People may be present, but have no commitment or understanding of what is going on (Rifkin, 2001). Therefore, it is a further limitation for studies related to community participation purpose. Another limitation is designing a framework for community participation to increase participation in health which might lead to unrealistic assumptions about participation in health programs.

Conclusion

Community development strategies emphasizes communities to take greater responsibility for their own health and changes in people's attitudes to improve their optimal health. However, a major contribution to this change is the attitudes of the professionals involved in health promotion programs.

It is clear that changes in people's behaviour and attitudes are a long-term process and should address questions about whether the specific demographic, psychosocial, and structural factors are effective to active community or public participation in health plans. Since people know what is going on, their positive attitude can reduce their suspicion about health promotion programs and simplify their accountability to the existing diseases prevention programs.

This review provides some information about demographic, psychosocial, and structural factors and community participation in health programs. We found some evidences of factors associated with breast cancer prevention programs or support groups to appraise the importance of breast cancer prevention in the public health setting. These factors may be useful determinants for public health intervention agendas in future.

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