Towards an inclusive cervical cancer screening strategy: Approaches for reaching socioeconomically disadvantaged women

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Abstract

Barriers to prevention and early detection of cancer among the socioeconomically disadvantaged are important areas for public health focus. A community coalition was established in North York, Ontario, to identify a suitable primary prevention initiative, cervical screening among young women of lower economic status. Two pilot communities were selected for the project. Community members, key informants and service providers participated in a series of individual and focus group meetings to identify barriers that impede cervical screening. The benefits and challenges of such a project will be of importance to practitioners eager to work collaboratively on primary prevention initiatives. This article will be of interest to nurses wanting to foster a community coalition approach to program design, planning, implementation and evaluation. It will also assist nurses with utilizing needs-based assessment in their work. Although the findings relate to a population of women in a large urban centre, the results will be useful for nurses and other health professionals planning to engage in work related to cervical screening.

Introduction

An important public health issue is prevention and early detection of cancer among the socioeconomically disadvantaged. The literature indicates a disproportionate number of people who develop cancer and die of the disease are among the socioeconomically

disadvantaged of all races (Freeman, 1989). In Canada, there is a clear relationship between income and mortality regardless of race, with cancer incidence and mortality increasing as income decreases. Selected cancers have considerable differences in incidence and mortality rates in relation to socioeconomic status (National Cancer Institute, 1991).

This paper discusses the processes related to the formation of a coalition which focused on cancer among the socioeconomically disadvantaged. Strategies used to reach two communities, a summary of the results of discussions with women, discussion of some of the program strategies implemented, and issues related to the overall project design and management will be described. Suggestions will also be made for health care professionals who may wish to embark on similar projects.

Forming a coalition

A health promotion team at the Toronto-Sunnybrook Regional Cancer Centre envisioned bringing together community partners and forming a coalition with representatives interested in working together to study poverty and cancer in North York. A grant proposal was submitted to initiate a project, a list of potential partners who could form a coalition was identified by the team, and letters of invitation were sent. The team anticipated this coalition would meet for a period of six months to determine an area of focus and a project they could work on. Each organization was asked to name an

ABRÉGÉ

VERS UNE STRATÉGIE GLOBALE POUR LE DÉPISTAGE DU CANCER DU COL UTÉRIN: MÉTHODES PERMETTANT DE REJOINDRE LES FEMMES DÉFAVORISÉES SUR LE PLAN SOCIOÉCONOMIQUE

Les obstacles à la prévention et au dépistage précoce dans les milieux démunis sur le plan économique sont des cibles prioritaires en matière de santé publique. Une coalition communautaire a été mise sur pied à North York, Ontario, dans le but de choisir une initiative valable en matière de prévention primaire, à savoir le dépistage du cancer du col utérin chez les jeunes femmes à faible revenu. On a sélectionné deux villes pilotes pour le projet. Des membres de la collectivité, des dispensateurs de soins et des répondants clés ont participé à une série de réunions individuelles et de groupes de réflexion afin de dégager les obstacles qui freinent le dépistage du cancer du col utérin. Les avantages et les défis d'un tel projet revêtiront une grande importance pour les cliniciennes qui sont prêtes à travailler en collaboration avec d'autres organismes dans le cadre d'initiatives de prévention primaire. Cet article intéressera également les infirmières qui souhaitent utiliser l'approche coalition communautaire dans le cadre de l'élaboration, de la planification, de la mise en oeuvre et de l'évaluation des programmes. Il sera aussi utile aux infirmières qui sont appelées à utiliser, dans leur pratique, des évaluations fondées sur les besoins. Bien que les résultats portent sur une population féminine dans une grande agglomération urbaine, ils n'en seront pas moins utiles aux infirmières et autres professionnels de la santé dont le travail se rapporte au dépistage du cancer du col utérin.

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individual to be its representative on the coalition. Agencies which participated included the cancer centre, three community health centres, health department, local food bank, housing authority, municipal government, social service agencies and organizations with a primary focus in cancer.

During the first six months of the project, the coalition reviewed the literature related to poverty and cancer, and heard from key informants about specific research being done related to the socioeconomically disadvantaged and cancer. The criteria the coalition used for selecting a program focus were availability of data, scientific evidence that a problem existed, the existence of an intervention, and a measurable outcome. The coalition decided to focus on cervical screening among young, low-income women based on what key informants recommended and the information from the literature, which indicates a high proportion of cervical cancers can be prevented by screening and early detection. The coalition identified issues such as language/literacy, social barriers, access, culture, and lack of incentives which needed to be taken into account when working with people living in low income neighbourhoods. Coalition members also felt that the project should be innovative, target North York communities, find consumer representatives to contribute to the decision-making process, and access target groups.

Background literature

The focus in the cervical screening literature addressing low income or vulnerable populations is specific to issues of access, barriers and attitudes towards screening. Another segment of literature speaks to those strategies which may increase Pap screening within these specific low income populations.

Access

Despite the increased opportunities for cervical screening, many women with low socioeconomic status are less likely to seek screening than their more affluent counterparts (Hayward, Shapiro, Freeman & Corey, 1988; Stern, Misczynski, Greenland, Damus & Coulson, 1977; Helsing & Comstock, 1978). As well, several other authors have documented a decrease in Pap testing with decreasing income (Hayward et al., 1988; Stern et al., 1977; Helsing et al., 1978 & Kleiman & Kopstein, 1981). Thomas and Frick (1994) and Kisuk (1994) report that there is underutilization of the Pap smear by women of low income.

In a review paper, Norman, Talbott, Kuller, Krampe and Stolley (1991) reported on several studies which found that decreasing income was associated with less chance of women ever having had

a Pap test, as well as in the frequency of Pap testing. Marcus et al. (1990) reported that a large percentage of unscreened low-income women had received medical care within the previous five years, but that hospital emergencies and STD clinics did not give priority to cervical screening.

Goel (1994) reviewed the determinants of Pap smear utilization in Ontario and identified factors related to low utilization of cervical screening among recent immigrants, less-educated women and women whose mother tongue was not English or French. Fruchter et al. (1990) report that factors consistently associated with high prevalence of cervical neoplasia include early sexual activity and low socioeconomic status. As well, community and hospital studies of select populations have consistently reported lower screening rates in immigrants than US-born women. In another study by Anderson and May (1995), trends in cervical cancer screening indicate that women with more than a high school education, women residing in urban areas and those living above the poverty line continue to report more cervical screening than their counterparts.

Barriers

Kirkman-Luff and Kronenfeld (1992) found that US women without health care insurance or those without a usual source of care were less likely to have cervical screening than other women with conventional insurance. Deschamps et al. (1992) reported that women's lack of knowledge of Pap tests and their importance, feelings of embarrassment and shamefulness were reasons for not attending Pap screening clinics. Similarly, Lantz, Dupuis, Reding, Krauska and Lappe (1994) reported that Hispanic migrant farm workers avoided screening due to embarrassment, shame and discomfort with male clinicians.

Other barriers cited by Norman et al. (1991) included misunderstanding the purpose or importance of the Pap test, fear of embarrassment, and pain. Murray and McMullan (1993) found that beliefs and attitudes about the procedure and possible outcomes predicted participation in screening. Issues such as dislike of doctors/hospitals, worrying that complaints would be seen as minor by doctor, embarrassment by the tests, fear of results, or of needing further surgery, of disfigurement or of being a burden to family, and finally fear of losing job or becoming disabled were also cited.

Strategies

Black and Ades (1994) reviewed several demonstration projects which were intended to increase screening in the socio-economically

Figure One: Program goal and objectives

disadvantaged and underserved. They offered seven suggestions or strategies to assist these groups. The strategies include employing outreach staff indigenous to the community, combining cancer information along with other relevant community issues, keeping messages simple, being positive about people's ability to affect health, delivering education through existing programs, developing culturally sensitive and community-specific resources, and focusing on wellness and health rather than cancer and fear.

Sung et al. (1992) used trained lay community workers to recruit low-income inner-city black women in the US to screening programs. Less than half of women who were asked to participate did so, which led the authors to conclude that greater attention be paid to developing successful intervention strategies.

How the project evolved

Initially, members of the coalition decided to conduct several key informant interviews and focus group meetings to determine if the literature was an accurate reflection of what was occurring within our urban setting. These meetings also gave the coalition members an opportunity to assess whether there was interest in the topic of cervical screening and if pursuing a project was deemed appropriate within the community. The coalition determined that the information contained in the literature did hold true for their particular setting and that there was interest in pursuing a project which focused on the area of cervical screening (Fitch, Greenberg, Cava, Spaner and Taylor, 1996).

Identification of an overall goal, and more specifically a program goal and objectives was an initial task of the coalition. The program goal was to develop a program with young, low-income women which would reduce barriers to Pap screening. The objectives identified were categorized into five areas; community participation, education with women, supportive environment, education of health care professionals, and advocacy (see Figure One).

The coalition members then proceeded to identify two communities within North York that had populations of low income women. The community health centres in both these communities expressed a commitment to being involved in a program which focused on cervical screening. Representatives from these two centres were also coalition members. It was at this time also that other coalition members decided to become more actively involved in the project and a smaller "working group" was formed to move the project forward. This working group

consisted of coalition members representing the two target community health centres, the public health department and the regional cancer centre.

The working group members felt it necessary to have a dedicated person involved with the project in order for it to gain momentum and achieve results. A program development grant was awarded by the Ministry of Health. The grant facilitated the development of a job description and interviewing for a community outreach coordinator. Once hired, this coordinator began to profile the two target communities, and as well met with the women and key informants in the communities. The resulting information from the communities consisted of the existing community resources, demographic characteristics of the women, key informants and relevant service providers. The coordinator also consulted with women about developing a community strategy, identified barriers and opportunities to access women in each community, conducted individual and group meetings with women and identified women who were interested in becoming involved in developing the project further.

In total, more than 110 women participated in group meetings and identified several key issues (Fitch et al., 1996). The issues included being treated like a person, talking with doctors, having questions about cancer, and experiencing concerns about the Pap smear. Most participants had little awareness of the Pap test or its role in the early detection of cervical cancer. They did not feel that they had received adequate explanations of the procedure, and the meaning of the results. The majority found the experience to be embarrassing, uncomfortable, humiliating and degrading. Recent immigrants had limited understanding and experiences with Pap tests. Participants suggested that the procedure and results need to be explained in simple terms, perhaps with the aid of pictures or video.

Women in both communities identified a number of strategies which they felt would work in their community in relation to a cervical cancer screening program. The working group categorized the action strategies according to the project objectives. There were several strategies listed under each of the following areas: community participation, education with women, supportive environment, education of health care professionals, and advocacy (see Figure 2).

Three of the objectives which the working group did develop further in this project included education with women, supportive environment and education of health care professionals. Education

Figure Two: Strategies for cervical screening

Subsequent to the second Women's Health Day, a parent-child, well-woman drop-in group was initiated. An advisory group of women from the community were helpful in determining the format and structure of the drop-in. During a designated time women from the community could come to the centre (with their children if they wished) and meet with other women. A community outreach worker was always present at the drop-in, and another professional staff (i.e. nurse, physician) would be available for consultation with the women. The drop-in group was evaluated after one year of operation. Attendance remained fairly constant at 20 participants. This was largely due to the committed work of the community outreach workers, particularly over the summer months when typically participation could decrease. The women appreciated the clinical component of the drop-in and issues which have been raised relate to psycho-social issues, parenting issues and health concerns of their children. One positive outcome of the drop-in has been that the

Both the community health centre's professional staff and nursing staff at the public health department and the cancer centre attended educational sessions which outlined the results of this project. The data which was gathered from the focus groups and dialogue sessions were shared with these professionals with the aim of increasing their

Building coalitions and collaborating on key issues relevant to stakeholders and the community are necessary strategies in the current economic realities of limited resources (both financial and human). However, these are not easy tasks and pose many challenges. The challenges of coalition building and working in coalitions include determining the appropriate size of the coalition for effective functioning, defining expectations of coalition members, and achieving clarity of purpose in the coalition work. The participating stakeholder organizations need to identify key individuals who can participate. Coalition meetings often require decisions to be made and the individuals present need to have the power to make these decisions. Open communication, dialogue and trust are essential elements for a coalition. It is very important for all members of a coalition to have their opinions heard and valued. Other challenges relate to the

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M U N Y E O D C L I N R C A E T L A

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N A O E R I E R A E S B R E T A S D

O T L G P C L I R A D I C A L T I A

B I O P S Y D Y T A M O X I F E N R

E O G M A Y C N A N G I L A M M O G

N Y N R E V I T A I L L A P O L

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N P L A E V I S S E R G O R P N E O

A C E R U C A T S U F F E R I N G L

E R E M I S S I O N E Y P A R E H T

T L A C I G O L O H T A P O H T A P

participants being unable to give long-term commitment to the project, time scheduling, and coalition members having other work commitments which preclude active involvement in the work of the coalition. Deciding on which strategies a coalition should pursue is not without challenges also. Members often have varying opinions and reasons for wanting to move in a particular direction. Arriving at a consensus can be time-consuming and labour intensive for all members of the coalition.

Community partnerships can have benefits. When a group of agency representatives identify a common need and plan a program together, the subsequent commitment to the program can be high. A sense of ownership grows as plans are made and individuals participate in implementation. Having several agencies working collaboratively increases the amount of resources, both personal and financial, being available for the project. Any single agency may not be able to support a program on its own, but by each one contributing a portion of the support, the program goal can be realized. Finally, working in partnerships means many perspectives can be brought to bear on the discussions and decisions, as many different disciplines are represented. It is imperative not to impose a program agenda on the community as this may be a hindrance to the program's success. Multiple perspectives are critical in understanding the community's priorities.

The hiring of a community worker was a very important step in moving this project ahead and engaging the women of the community. The community worker was able to engage women in group discussions which seemed to sensitize women to the issues related to cervical screening, and also provided those women not being screened a place to discuss their fears. Feedback from the women indicated that they found the discussions helpful. Women also felt that a stand-alone program for cervical cancer would not likely

be of high priority in their lives, and information on cancer and prevention needed to be incorporated with other events or activities which target women's health. Being flexible and responsive to the needs of the community is important to the success of such a project. Accessing women to participate in group discussions posed some challenges which included women having more family obligations in the summer, few organized summer community activities, isolation of some women, language/cultural barriers, and lack of control of certain life events.

Effective implementation of a cervical cancer screening program in these two low-income communities does require a multiple strategy approach which works with the community. A comprehensive cervical cancer screening program should address: community participation, public and professional education, a supportive environment, advocacy and outreach screening activities, in order for it to be successful. Incorporating the principles of health promotion, communication, social marketing and community development are important elements for these strategies. It is critical that these activities take place and are reinforced in diverse community settings. As well, fostering ongoing community participation with low income women is essential in order to mobilize and build on existing community knowledge, skills and resources. ♥

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