Involving the community in cervical cancer prevention programs

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Abstract
Underutilization of cervical cancer prevention services by women in the high-risk age group of 30—60 years can be attributed to health service factors (such as poor availability, poor accessibility, and poor quality of care provided), to women’s lack of information, and to cultural and behavioral barriers. The Alliance for Cervical Cancer Prevention (ACCP) partners have been working to identify effective ways to increase women’s voluntary participation in prevention programs by testing strategies of community involvement in developing countries. The ACCP experiences include developing community partnerships to listen to and learn from the community, thereby enhancing appropriateness of services; developing culturally appropriate messages and educational materials; making access to high-quality screening services easier; and identifying effective ways to encourage women and their partners to complete diagnosis and treatment regimens. Cervical cancer prevention programs that use these strategies are more likely to increase demand, ensure follow-through for treatment, and ultimately reduce disease burden.

1. Introduction
Increasing access to and improving quality of screening programs in the high-risk age group of 30—60 years has been identified as a key compo-
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technique. Effective programs for early detection of cervical cancer in low-resource settings [1,2]. However, programs have not been able to achieve a high coverage of women and disease reduction in many low- and middle-income countries. In developing countries, variation in coverage is wide, with rates of Pap smear within the past year in Latin America ranging from lows of 15%–20% (Jamaica, Nicaragua) to highs of 65%–80% (Costa Rica, El Salvador), and very low or nonexistent coverage in most Asian and African countries [3,4].

Available, affordable, and high-quality screening, diagnostic, and treatment services are essential for cervical cancer prevention programs to achieve the high coverage necessary for effective disease reduction in the population. At the same time, health care providers need to be aware of the socioeconomic, cultural, and behavioral characteristics of the target population that influence participation in prevention programs.

Underutilization of cervical cancer prevention services in developing countries may be explained by the health behavior patterns of women in the high-risk age group, as well as the poor quality of services in low-resource settings. The disease affects mainly older women, between the ages of 30 and 60 years, a group that is harder to reach than younger women, who may frequent family planning and pediatric services and are often opportunistically screened. The short-term and pressing issues that low-income women face every day, along with lack of information, may prevent them from being concerned about or taking preventive action for an asymptomatic disease that develops over a long period of time. Furthermore, in many women, cervical cancer evokes images of death, and many fear the possibility of obtaining positive results and undergoing costly diagnosis and treatment if lesions are detected. Women may also have to overcome their sense of modesty to have a speculum examination, particularly in situations where clinics do not offer adequate privacy.

The Alliance for Cervical Cancer Prevention (ACCP) partners have been working to identify effective ways to increase women’s voluntary participation in prevention programs and to improve the overall coverage of screening programs. The ACCP partners based their projects on the main principles of the ACCP community-involvement framework, namely, listening to and learning from the community, involving community stakeholders in program development and implementation, and responding to the needs of the community. ACCP experiences in developing countries illustrate how listening to and learning from communities and involving local stakeholders can contribute to an effective response to the needs of the target population. This may increase and sustain demand and improve the quality of preventive services, resulting in increased participation in screening and compliance with treatment recommendations.

This article presents ACCP experiences in involving communities in cervical cancer prevention. Four approaches are described: (1) developing community partnerships to facilitate project implementation and enhance appropriateness of services; (2) responding to the community need for information through culturally appropriate messages; (3) increasing easy access to quality screening services; and (4) identifying effective ways to encourage women and their partners to complete diagnostic and treatment regimens. Country vignettes are given to illustrate each approach. The examples are drawn from a broad range of cultural settings and geographical locations that cover most of the ACCP projects; they represent particular settings and may not be generalizable to other countries.

2. Listening to and learning from the community through partnerships

Involving stakeholders in the development and implementation of prevention programs and anchoring a program on existing social networks and institutions may facilitate women’s ability to make informed decisions about their health. In addition, working with the community at large encourages local ownership of prevention programs and may enhance their sustainability.

Community partnerships have been found to be beneficial in public health through means such as peer support among patients [5], overall recruiting of populations and helping to sustain projects over the long term [6], and reaching out to high-risk populations and areas [7]. In addition, the ACCP partners found that women were more likely to attend screening services when respected and trusted community stakeholders were involved in the project.

2.1. Involving key stakeholders

Key stakeholders include representatives from local women’s organizations or community-based organizations; local and regional government officials; representatives from local religious and educational institutions; community leaders, such as village elders; and health workers and local health institutions. Because cervical cancer prevention
programs must address the cultural, emotional, and practical factors that influence whether women use screening services, key stakeholders can provide critical input in the design and implementation of program activities to make the activities culturally relevant.

In ACCP projects, community partnerships were developed with many existing groups and institutions. For example, in the project site in Ambilikai, India, meetings were held with district administrative and health authorities, members of the local civic bodies, village community leaders, teachers, and other local organizations to discuss the project objectives and ways of reaching women before the start of project activities. In Ghana, the main partnership was developed with one existing organization, a local Rotary International club. In Peru, community members were invited to form advisory groups to help strengthen the linkages between communities and health services. Results from these projects indicate that an increase in the frequency of advisory group meetings was one of the independent positive predictors of screening coverage [8].

2.2. Involving community health workers

ACCP experiences have shown that approaches involving community health workers can be highly effective for raising awareness and carrying out systematic recruitment. This is a result of the profound knowledge that community health workers have about their communities.

In the Cabañas project in El Salvador, community health workers from the Ministry of Health were involved in increasing demand for services. They were trained in basic issues related to cervical cancer prevention, including risk factors and El Salvador’s guidelines for priority-screening age groups, to ensure that they were sufficiently informed to educate women in their communities. In addition, the community health workers took a census of women in the priority-screening age group in their communities so that the workers could focus promotion efforts on women who had never been screened. The community health workers participated in a plan to mobilize community resources to assist at-risk women in accessing often-distant services.

In Thailand, village health volunteers were key to generating demand for cervical cancer screening services. The volunteers themselves were screened, as a positive example in their communities, and they spoke to women directly about their experiences and distributed information. Results from 79 semi-structured interviews with 132 participants at the national, provincial, district, and village levels in Roi Et Province suggested that increased activity of health center personnel and village health workers led to increased clinic attendance. Higher rates of screening were associated with effective coordination between health center staff and community health workers in recruiting women; a larger number of days and teams available for screening; and support from local government [9].

2.3. Partnership with a women’s organization: Kenya experience

The ACCP project in Kenya was initially conceived through a partnership with the Maendeleo Ya Wanawake Organization, a national grassroots women’s organization with an estimated individual membership of 2 million women and more than 25,000 women’s groups. Thirty-five members in the project area volunteered to act as community health workers to inform and motivate women in the community to come for screening. Group-based approaches included addressing women’s groups, religious groups, school-based parent groups, and barazas (local administrative meetings). Individual home visits were also organized to provide a more private setting in which women could discuss any concerns or confusion around the screening service and what to expect and in which women could receive additional encouragement from trained community health workers. Subsequent analyses showed that group-based approaches were at least as effective in stimulating screening participation as home visits and were logistically easier to organize [10].

3. Responding to community needs through culturally appropriate messages

The ability of women to make informed decisions about their reproductive health is a human right and falls under the United Nations Millennium Development Goal of promoting full and equal participation in all aspects of life for women. However, fear and anxiety, coupled with a lack of information and counseling, may prevent women from seeking out screening services and from complying with needed follow-up that can prevent disease progression. The communication of appropriate messages that address women's concerns and correction of misconceptions may enhance the likelihood that women will adopt prevention behaviors [11].
To develop culturally appropriate materials, ACCP projects explored the informational needs of their target audiences by carefully considering women’s myths and misconceptions, their reasons for not undergoing cervical cancer screening, and their motivations to address important health issues through formative research. The intended audience was incorporated into the development of messages and materials, through focus groups and interviews, to examine local issues, and to pretest materials.

Various materials were developed and distributed by ACCP projects, including brochures, posters, and manuals for community health workers and counseling flipcharts and other types of job aids for health personnel [12]. Local volunteers and personnel involved in ACCP projects were trained to use these materials to raise public awareness and educate populations.

3.1. Developing educational materials and training health providers: El Salvador experience

El Salvador is currently among the countries in Latin America with the highest cervical cancer incidence and mortality. Estimated cervical cancer incidence is 40.6 cases per 100,000 women. More than 50% of the population lives in poverty, with close to one-quarter living in extreme poverty, and 54% of the total population resides in rural areas.

ACCP staff conducted a review of the material formerly used by the El Salvador Ministry of Health, assessing language use, graphics, suitability for the space constraints of a small clinic, and women’s understanding of key messages. It was found that existing material used fear to persuade women and contained inaccurate and out-of-date information. Focus groups were conducted in both urban and rural areas to develop and refine key messages, and a logo and graphics were designed and tested that highlighted the benefits women expected to receive from screening. Using this approach and incorporating technical information from the ministry of health’s new guidelines for cervical cancer prevention, new materials were produced: a prevention brochure for women, a counseling job aid for health personnel, and a posttreatment instruction sheet. To introduce the materials, ensure their proper use, and reinforce the ministry’s new guidelines, training workshops for health providers were offered throughout the country. An evaluation of the use of these materials is currently under way.

4. Listening to, involving, and responding to the community to increase access to high-quality services

Low rates of attendance at screening services by women in the high-risk age group can often be attributed to problems with health services, including poor availability, poor accessibility, and/or poor quality of care, as well as to lack of information and cultural and behavioral barriers [13,14]. Health services may also have difficulties reaching underserved populations, given these populations’ tenuous social integration in terms of their connectedness with different institutions that may give them a stronger sense of belonging. For instance, in South Africa, underserved populations were identified as older, poorer, less educated, unemployed, living in nonpermanent dwellings without a partner, and not likely to seek health care [15].

Improving the supply of cervical cancer prevention services includes addressing accessibility to services, the quality and structure of health services, and approaches to staffing and scheduling. It requires that providers listen to and learn from clients about what the clients perceive as high-quality services and how the health system might better meet their needs. Improving the quality of care also has a positive effect on increasing coverage; women who are satisfied with the overall quality of the services that they receive are more likely to relate their positive experience to family members and friends and encourage them to seek services. For example, nearly 12% of 32,839 women screened in Peru reported that their decision to be screened was most influenced by a family member or friend who had also been screened [16].

“High quality” in health care can be defined as the provision of client-centered services that meet clients’ needs. Typically, these include [17]:

- Ensuring that all providers (not only doctors) are well trained and experienced in performing pelvic examinations and cervical screening tests.
- Guaranteeing that staff are respectful of and responsive to clients.
- Ensuring continuous access to supplies and equipment.
- Establishing linkages to a reliable laboratory and ensuring that the means of transporting specimens and results to and from screening facilities exist (in the case of cytology-based screening).
Developing systems for communicating test results to women in a timely manner (in the case of a multivisit approach).

• Setting up effective referral systems for management and treatment.

4.1. Improving quality: client-centered services

Participatory quality-improvement methods were used in ACCP projects in Peru, Bolivia, and El Salvador to address issues in the delivery of services that are relevant from the community perspective. A client feedback process was established in Peru, where women who received screening or treatment services were interviewed about their satisfaction with care. This was based on the quality of the physical setting, the quality of the provider interaction, aspects of informed consent, and overall satisfaction. The results from these interviews were shared with health center staff, who examined the strengths and weaknesses of service delivery and developed an action plan to address any aspects of service delivery with which more than 5% of clients expressed dissatisfaction. After several rounds of this interactive process, quality significantly improved, as evidenced by women reporting increased satisfaction with care [18]. For example, women reported that examination rooms were more private and that they received explanations of the informed consent form, as well as the clinical procedures.

The COPE* method (client-oriented, provider-efficient) for quality improvement has been adapted for use with cervical cancer prevention services and is currently being implemented in four sites in Bolivia. COPE is a process used by health care staff to continuously assess and improve the quality of care that they provide [19], bearing in mind the client’s needs and perceptions of care. The COPE process has four tools: (1) self-assessment guides, (2) a client interview guide, (3) client flow analysis, and (4) the action plan. These tools enable supervisors and their staff to discuss the quality of their services, identify problems that interfere with the delivery of quality services, identify the root causes of those problems, recommend ways to solve the problems, implement the recommendations, and follow up to ensure resolution of problems. Elements addressed through COPE’s set of tools include screening tests and examinations, laboratory services, treatment of precancerous lesions, follow up and management of clients, referral and feedback, and equipment and supplies.

A continuous quality-improvement method was used in 16 clinics and two hospitals in El Salvador. An external baseline study that included user-satisfaction surveys identified priority areas for improvement, such as focusing on women who had never been screened, focusing services on those in the target age group, reducing laboratory turnaround time, and improving the availability of equipment and supplies. Action plans were prepared by health providers and peer reviewed. These plans were carried out by local officials, using existing resources, and later evaluated. The intervention greatly increased women’s attendance to routine screening services, particularly among those who had never before been screened [20].

4.2. Staffing and scheduling

Maintaining a staffing pattern and scheduling services that meet the expectations of the community are important aspects of improving screening participation. Evaluations of opportunistic cancer detection clinics in Osmanabad, India, carried out between 1982 and 1987 highlighted the importance of staffing clinics with female doctors and nurses. Based on these results, ACCP projects in India employed female doctors and nurses for cervical cancer screening clinics. On the other hand, both male and female staff are needed for effective communication with women and men in the community. Female health workers had primary responsibility for providing counseling to women, while male health workers participated mainly in community educational and promotion activities. Male health workers also had responsibility for communication with husbands and male community leaders, because these audiences are likely to accept information more easily when other men provide it.

ACCP project experience showed that services should be offered according to a fixed schedule that women can count on and that appointment dates and times for follow-up visits should be flexible and adapted to women’s scheduling needs.

4.3. Improving accessibility

In ACCP projects in Thailand, India, Peru, and El Salvador, screening services were offered closer to where women lived and provided free of charge, to improve accessibility and alleviate geographic and economic constraints. This improved accessibility of services, particularly among women who live in remote areas.
4.4. The mobile clinic: experience in Osmanabad, India

The ACCP project in the Osmanabad district in India took place in 722 villages with a total population of 1,239,009 inhabitants. The female literacy rate in this area is 39%, and the cervical cancer incidence rate ranges from 55 to 77 cases per 100,000 women among women aged 30—69 years.

A fully equipped van was sent out to 32 primary health care clinics, as well as other settings such as municipal offices, classrooms in local schools, and women’s club buildings that could be used for screening women using visual inspection. Project staff met with district administrative and health authorities, the president and members of the local civic bodies (panchayaths), village community leaders, teachers, and others to explain the details of the project and to seek their cooperation. On the evening before the services were to be available, eligible women, their partners, and elders in the village were invited to a meeting where a film about cervical cancer prevention was shown. On the screening day, medical social workers were on hand to explain the screening and treatment procedures to women waiting to be screened. Afterward, female health workers explained screening results and organized appointments for women with positive results of screening tests. Of the women invited, 63.4% attended and were screened through mobile clinics.

5. Encouraging women and their partners to complete diagnostic and treatment regimens

Ensuring that women who have abnormal screening test results undergo diagnostic testing (colposcopy and/or biopsy) and/or treatment if there is no diagnostic step (i.e., screen-and-treat approaches) is an essential element for disease reduction [21]. Some women do not return for diagnosis or treatment visits because health services may keep poor records that do not allow tracking of progress through the diagnostic and treatment protocols, or women may be unable to follow provider recommendations for management. Most of the challenges women face when attending screening services are also encountered, and sometimes exacerbated, at the diagnostic and treatment phases [22]. Women may have a poor understanding of the importance of follow-up tests and treatment, which may lead them to discontinue care. In addition, they may lack family support to seek further care or may be unable to pay the associated expenses.

All ACCP projects offered counseling for women referred for follow-up care. Counseling sessions were developed from the perspective of the woman, addressing her concerns and her perceived needs, her understanding of what she was being asked to do, and her particular circumstances. It often takes only an additional 5—7 min to counsel the patient, and this can have a significant impact on the uptake of services, improve follow-up rates, and enhance a program’s success. Information sheets and reminder cards, along with community support, were provided to address the potential barriers to follow-up care.

In many instances, ACCP project staff found it useful to involve the male partners of clients in counseling sessions, particularly if the client required treatment. Engaging partners was found to be important in ensuring compliance with posttreatment abstinence after cryotherapy.

5.1. Men and women working together to prevent cervical cancer: Khayelitsha, South Africa experience

Khayelitsha is a large settlement outside Cape Town. Before ACCP involvement, Khayelitsha did not have an organized cervical cancer prevention program, and there had been a significant decrease in Pap screening from 1988 (5000 smears) to 1995 (1332 smears). The ACCP project in Khayelitsha recognized the important role that men can have in improving women’s participation and compliance with screening and precancer treatment, and the project staff implemented several interventions to mobilize male community members.

A curriculum was developed to train peer educators to inform men about cervical cancer prevention and motivate them to support women in seeking screening and complying with posttreatment instructions [23]. An evaluation of the training demonstrated that it had a substantial impact on men’s knowledge, particularly immediately after the course. Male attitudes were also positively affected by the training [24].

6. Conclusions

Stimulating demand for cervical cancer prevention requires that providers and program planners listen to, learn from, partner with, and respond to the community in ways that encompass not only active recruitment but also the empowerment of women
in low-resource settings to use health services based on the information available to them. Concomitantly, this demand may stimulate the improvement of the supply of health providers to shape their services to meet the specific needs and concerns of their users.

Building partnerships with local institutions, organizations, and respected leaders may help build trust and confidence in the service. It may also help to tackle logistical issues, such as transportation, identifying hard-to-reach populations, and preparing the setting for a mobile campaign. Working with local partners and involving target audiences, as well as forming advisory committees, proved useful in guiding, supporting, and facilitating community-based awareness-raising and educational activities [10].

Hard-to-reach women, such as those living in isolated geographic areas or in temporary dwellings, can be identified through local census or referred by other women who have had a positive experience with cervical cancer prevention services. Interventions need to be tailored both for accessibility and acceptability.

Devising communication strategies that speak to women who have low literacy rates and who live in low-resource settings is a challenge in itself. Activities and materials have to be custom-made for the target audience; however, there is also a risk of patronizing women by using plain and simple images. Although culturally competent communication should improve health outcomes and reduce disparities, there is no standard for how or when to implement such communication strategies properly [25]. Although studies have shown that a combination of direct communication and mass media can significantly increase uptake of Pap smears [26], this may not be true in all settings—for example, in South Africa, the effect of adding mass media was insignificant in screening uptake [27].

Health providers are a powerful influence in promoting use of preventive services, both through actions in communities (outreach) and recruitment within their own clinics (inreach). Women’s needs, both physically for screening or treatment and socioculturally for ownership and empowerment, need to be built into the service-delivery modality [9].

To establish a productive client—provider relationship and evaluate progress, the ACCP found it beneficial to obtain feedback from clients, as well as from the health care providers, and to use this information to improve the delivery of services and the quality of care. This requires support from top management, as well as a certain degree of accountability to the community, to ensure an ongoing and sustained effort.

Cervical cancer prevention programs that listen to and learn from the community and that involve community members in program implementation and materials development are more likely to increase demand, ensure follow-through for treatment, and, ultimately, reduce disease burden.

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