

Cervical Cancer Prevention Issues in Depth 2

ACCP Strategies For **Supporting Women With Cancer**



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Cervical Cancer Prevention Issues in Depth #2

Alliance for Cervical Cancer Prevention (ACCP)

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About the Alliance for Cervical Cancer Prevention

The Alliance for Cervical Cancer Prevention (ACCP) consists of five international health organizations—EngenderHealth, the International Agency for Research on Cancer, JHPIEGO, the Pan American Health Organization, and PATH—with the shared goal of preventing cervical cancer in developing countries. Alliance partners work to identify, promote, and implement cervical cancer prevention strategies in low-resource settings, where cervical cancer prevalence and mortality are highest. For more information on ACCP's work and publications, please visit www.alliance-cxca.org.

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ACCP Strategies for Supporting Women With Cervical Cancer

Overview

Public health interventions that focus on increasing rates of screening for cervical cancer among at-risk populations will inevitably discover advanced stages of the disease among a small minority of women. Practical and ethical questions arise in these instances regarding how much financial and psychological support can and should be provided for women and their families. In some countries, an infrastructure of support already exists, provided by government programs, local organizations, or volunteer networks. In most developing countries, however, there is little or no support for women with cervical cancer, and women who have been diagnosed with the disease struggle to access treatment and cope with its physical and psychological impact.

In 1999, five international agencies launched a major new effort to prevent cervical cancer in low-resource settings. This group—the Alliance for Cervical Cancer Prevention (ACCP)—works to clarify, promote, and implement strategies for preventing cervical cancer in developing countries. The Alliance comprises EngenderHealth, the International Agency for Research on Cancer (IARC), JHPIEGO, the Pan American Health Organization (PAHO), and PATH. Alliance projects focused on regions in which cervical cancer incidence and mortality are highest: Africa, Latin America, and Asia. The five partner organizations in the ACCP worked independently and with local institutions to provide support for women who have been diagnosed with cancer in the course of prevention-based projects. The focus of ACCP projects was on early detection and treatment of lesions, rather than on treatment of cancer. For this reason, comprehensive strategies to assist women with cancer were not included in project protocols. For ethical reasons, however, all Alliance partners offered some degree of assistance in the areas of counseling, access to treatment, and support for women with cervical cancer.

This report provides an overview of current issues relating to cancer treatment in developing countries, followed by descriptions of existing support for cancer patients in countries where ACCP has worked and the support provided by ACCP projects. Finally, this report provides recommendations, based on ACCP experiences, for the provision of basic assistance at the national or local level to women with cervical cancer, within the context of a prevention-based intervention in low-resource settings.

Cancer treatment and palliative care in developing countries

Although the total cancer burden is highest in affluent societies, the number of cancer cases in developing countries is increasing. Cancers associated with chronic infections (stomach, liver, and cervical cancer) are more common in poorer countries (see Figure 1).¹ The incidence of other cancers is on the rise as well, due to the adoption of unhealthy diets and other risk factors such as tobacco use. While levels of existing infrastructure and services vary by country, people with cancer in all less-developed countries are more likely to die from the disease than those in the industrialized world.

According to the 2003 World Cancer Report, 80 percent of cervical cancer cases occur in developing countries, where in many regions it is the most common cancer among women. In fact, it is the second most common cancer among women worldwide. In countries such as South Africa, the problem is exacerbated by a high incidence of human immunodeficiency virus (HIV). Studies have found that HIV-infected women have a high rate of persistent human papillomavirus (HPV) infections, and that cervical cancer progresses more rapidly in HIV-positive women.²

As with all cancers in developing countries, cervical cancer is usually diagnosed at an advanced stage. This is in part because of the paucity of effective screening programs. The infrastructural, technical, and organizational requirements of cytology (the conventional test used in most developed countries) make it extremely difficult to screen women effectively. In places where they do exist, effective screening programs are frequently inaccessible to women for geographical, financial, or cultural reasons. Finally, women with cervical cancer tend not to have symptoms in the early stages of disease, and most women seek care only once they have become symptomatic.

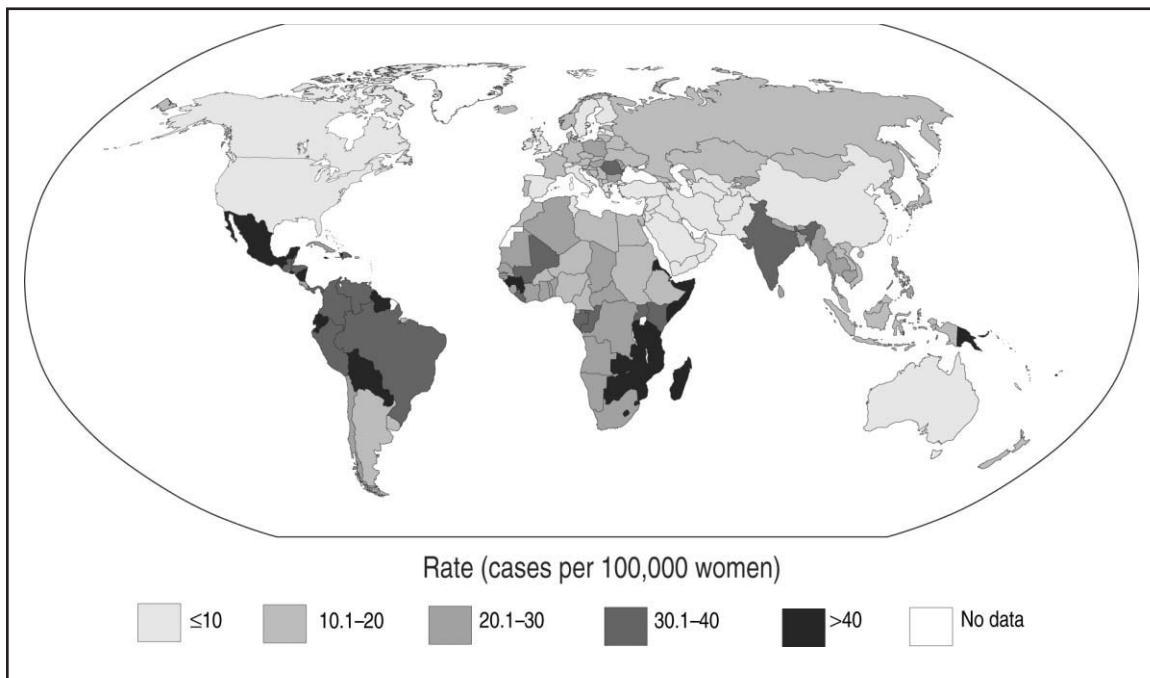


Figure 1. Estimated age-standardized incidence of new cervical cancer cases.³

Cancer treatment options

In developing countries, surgery is generally the most readily available treatment modality for cancer.⁴ It can be an effective treatment option for earlier stages of cervical cancer; for treatable advanced disease, however, radiotherapy is normally used (see Appendix). According to the International Atomic Energy Agency (IAEA), as many as 80 percent of cancer patients in developing countries would benefit from radiation therapy. But in developing countries, the availability of radiotherapy does not match the demand, as many of these countries lack the technology and expertise to provide such treatment. Some countries in Africa and Asia have no radiotherapy available to cancer patients; others only offer it on a limited basis.⁵ International organizations such as the IAEA are currently working to mobilize funding and provide training for treatment of cancers in countries with limited access.

Even when cancer treatments exist in poor countries, access to services can be extremely difficult for the majority of the population. As a result of lack of services, lack of education, or the desire for a less-invasive treatment associated with fewer side effects, many cancer patients and their families turn to alternative medicine. One study in India found that 38 percent of patients visiting a cancer hospital during the time of the study had attempted alternative anticancer treatments before coming to the hospital. Most of these patients were women, and most were from rural areas.⁶ Some alternative therapies, such as acupuncture and meditation, when used as a complement to medical interventions, have been found to be beneficial for pain relief and to improve strength and stability. Other alternative treatments, such as high-dose vitamin C and shark cartilage, have been studied and found ineffective. Patients using ineffective treatments risk delaying diagnosis, causing physical harm, and wasting family resources.¹

Palliative care and pain management

In settings where curative treatments for cervical cancer are not available, or in untreatable cases, palliative care can be invaluable to women facing a lengthy illness with unique medical and psychological conditions. Palliative care can be defined as “the active total care for a person with terminal illness who is near the end of his or her life. [It] involves support of patients whose disease is in advanced stages and does not respond to curative treatments; this includes the provision of terminal care.”⁷ Palliative care addresses the medical, emotional, social, and spiritual needs of terminally ill people and is particularly important in developing countries, where cervical cancer is common and curative services are unavailable. Since long-term residential hospice care is not available in most low-resource settings, women with cancer usually are cared for at home by family members. They and their families can benefit greatly from home-based palliative care provided by a trained doctor, nurse, or health care worker.

Due to a lack of available drugs and methodology for pain management in poor countries, most people with cancer do not have access to pain relief. Although medical access to opioids such as oral morphine has increased in the United States and Europe during the last decade, opioid availability has remained very low in developing countries.¹ International organizations are working at the policy level to improve opioid accessibility in countries where they have not been available and to facilitate their appropriate distribution.

Psychological support for cancer patients

Aside from pain relief, the needs of cancer patients can vary according to culture. A comparison of cancer patients in Kenya and Scotland found that while physical pain and financial worries dominated the lives of patients and their caregivers in Kenya, Kenyan patients felt that families and communities met their psychological and spiritual needs. In contrast, terminally ill patients in Scotland received adequate pain relief, but their nonphysical needs went unmet.⁸

Very little formal psychological support, such as group or individual therapy, is available to cancer patients in developing countries, although evidence from developed-country settings has shown that it can be an important aspect of cancer care. Psychological support has been found to reduce distress and show beneficial effects on anxiety and depression among patients with cancer.^{9,10,11,12} Although results are not consistent, some randomized studies examining the effects of psychosocial interventions on survival time of cancer patients have documented improved survival rates.¹³

Psychological interventions can play an important role in women's lives at what is often a particularly stressful time. These interventions, particularly group techniques, are inexpensive in contrast to invasive medical procedures.¹⁴ Systematic reviews of the literature suggest that group therapies, education, and counseling are among the psychological therapies found to be most effective for medium- and long-term benefits among patients with cancer.^{15,16}

ACCP project experiences in supporting women with cancer

Barriers to cancer treatment

ACCP partners have developed research and demonstration projects offering various cervical cancer prevention strategies in Burkina Faso, Congo, El Salvador, Ghana, Guinea, India, Kenya, Mali, Niger, Peru, South Africa, and Thailand. In all ACCP projects, women with cancer and their families faced formidable barriers to accessing cancer treatment, including limited affordable transportation options, limited funds to cover service fees, and the need for temporary housing where treatment is offered. Below is a description of existing support for cancer patients in these countries and a summary of the measures taken within projects to assist participants found to have cancer.

Transportation

In most countries where ACCP partners are working, project participants who have been diagnosed with cancer often must travel considerable distances in order to receive treatment. In many settings, cancer treatment centers are only available in capital cities, and frequent travel from rural areas is generally not affordable for low-income families. Support to cover the transportation costs of cancer patients generally is not available, although there are several exceptions. In South Africa, eligible women may apply for a government disability grant that helps alleviate financial strains that families face when dealing with a disabling health condition. Free travel is offered to patients and a family member in India, and in El Salvador, coordination is currently under way between the national and regional levels of the Ministry of Health to provide transportation between hospitals in San Salvador and rural areas.

In most cases, ACCP partners have subsidized the costs of transporting women to treatment centers. In El Salvador, Ghana, Peru, South Africa, and Thailand, projects provided free transportation (for example, by paying for public transit in El Salvador, contracting with local transport companies in Ghana, or making the project car available when needed in South Africa). In Burkina Faso, Congo, Guinea, Mali, and Niger, all participants lived in an urban area where access to cancer treatment did not require long-distance travel. Although the project in Kenya did not provide transportation subsidies for women with cancer, the project worked with local resources to raise money and assist families.

Providing for assistance with transportation is a crucial component in ensuring that women who require treatment are able to access it. While direct subsidies of travel costs may not be feasible outside of special project situations, national programs can explore alliances with existing institutions and organizations to find creative solutions for helping women access treatment.

Cost

In many countries where ACCP projects were located, only limited treatment is generally available to women with cervical cancer. In Ghana and Thailand, major surgical services are scarce or nonexistent; in most West African project sites, there is no radiotherapy available and surgical services are limited. Where treatment exists, cost presents a barrier for many patients, and there is a wide variation in the amount of local subsidization available to defray these costs. All cancer

treatment in South Africa is free for anyone who earns less than an established minimum income and can access care. In Peru, oncology centers offer subsidies for low-income patients, and in Kenya, community organizations raise money to cover some costs. All cancer treatment in El Salvador is subsidized either by the Ministry of Health or through private donations to the Instituto del Cáncer, and therefore, is free for all patients. In Ghana, however, there are no national subsidies, and the system requires cash payment for services. Under the national health care reform in Thailand, prevention and treatment services are provided by the government, though women needing follow-up may be required to pay a nominal fee. Surgical, radiotherapy, and chemotherapy services exist in India, and treatment is partially or totally subsidized by the government, depending on income level.

Given the challenges described above, many ACCP projects incorporated cervical cancer treatment subsidies into project activities. In Ghana, India, Peru, Thailand, and the West African sites, projects subsidized the cost of treatment. The project in Kenya did not pay treatment costs, but did hire a nurse to provide support to women with cancer. In both Ghana and Thailand, costs associated with treatment were fully covered by the project. Without such subsidies, poor women may not have been able to seek cancer treatment. During planning, new programs need to consider treatment subsidies as one component of their activities.

Temporary housing

When treatment facilities are located far from their homes, women may require lodging near the treatment center during the course of their care. ACCP projects that assisted families with room and board during treatment did so by linking with existing organizations. For instance, in Peru the Tamizaje y Tratamiento Inmediato de Lesiones Cervicouterinas (TATI) screening and immediate treatment project contracted with the Peruvian Cancer Foundation; in El Salvador, the project made an agreement with Divina Providencia hospital to provide free temporary housing while women underwent cancer treatment.

State-subsidized temporary housing support for indigent patients also exists in South Africa, where women are admitted to hostels sponsored by the local cancer association, and in Kenya, where a local hospice provides support to women needing end-of-life care. Several projects offered partial support to work with existing services. For instance, in India an existing dormitory service was available to all women in the project setting, and the project supplemented that support by providing meals to project participants. In Kenya, the project assisted women in applying for entry into hospices. ACCP members did not pay housing costs in either Thailand or Ghana.

The provision of temporary housing can make it feasible for low-income women to travel to national or regional treatment centers far from their homes and stay long enough to receive a full course of treatment. National-level programs may be able to replicate the experience of ACCP projects in providing lodging to women near treatment facilities by networking with existing programs that provide this service.

Supporting women with cervical cancer in South Africa

The primary objective of the Khayelitsha Cervical Cancer Screening Program in South Africa (a collaboration among the University of Cape Town, Columbia University, and EngenderHealth) was to test screening methods for the prevention of the disease. The project also was committed to facilitating access to treatment for those project participants found to have cervical cancer. Of 7,123 women screened in the Khayelitsha project, 28 cases of cancer were detected. To assist these patients in accessing services and maximizing available resources, the project coordinated closely with existing local institutions and organizations. The Groote Schuur Hospital in Cape Town, which offers radiotherapy and other types of cancer treatment, shared resources and expertise with the project. The project also collaborated with the Cancer Association of South Africa and St. Luke's Hospice, local nongovernmental organizations (NGOs) that provide services and support to cancer patients in poor communities. Women were referred to these organizations and provided with specific contacts.



Women waiting to receive cervical cancer prevention services in Khayelitsha, South Africa.

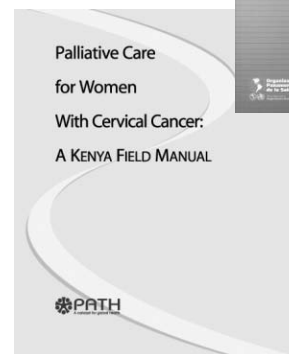
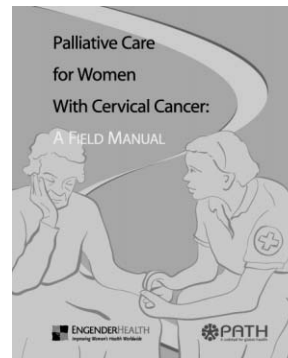
Though cancer treatment in South Africa is free for very low-income patients, women must take multiple steps to access care, and the process can take several years. The main role the project has played regarding treatment access is to expedite the process by bringing patients directly to treatment centers and seeing to their immediate care. This type of assistance speaks to the need for advocacy for cancer patients and the necessity of streamlining services for optimal accessibility.

Palliative care support

Though the lack of treatment options in many ACCP countries makes palliative care particularly necessary, long-term care and pain-relieving drugs are not available in most settings. In response to the need for the development of palliative care programs, ACCP partners have produced three palliative care manuals that suggest how caregivers can use readily available resources to provide clinical and emotional support for women in terminal stages of cervical cancer. Information provided is a combination of regionally specific recommendations and general principles for providing optimal palliative care.

The following palliative care publications are available:

1. *Palliative Care for Women With Cervical Cancer: A Field Manual* offers guidelines for provision of home-based palliative care by community nurses and mid-level health care providers. The manual emphasizes the provision of symptom relief and emotional support for patients and their families. It was published by PATH and EngenderHealth and is available in Spanish and English.
2. *Cuidados paliativos: guías para el manejo clínico (2nd edición)* is a Spanish-language guide to clinical and psychological aspects of palliative care that was developed by PAHO and the International Association for Hospice and Palliative Care (IAHPC). It is being distributed primarily in Latin America.
3. *Palliative Care for Women With Cervical Cancer: A Kenya Field Manual* is a country-specific field manual that provides guidelines for relief of symptoms and emotional support for patients, their families, and visiting nurses. It was produced by PATH.



For more information on these publications, see the ACCP web site www.alliance-cxca.org.

Psychological support

Emotional support and counseling are important components of cancer treatment programs. These kinds of support include counseling prior to cancer treatment, emotional support during treatment, coordination support (to negotiate various agency needs), and provision of post-treatment counseling and educational materials for women with cancer. ACCP project countries demonstrate a wide range of availability of counseling and emotional support services.

Counseling

In most countries where ACCP projects were located, women suspected of having invasive cancer are referred to a central cancer hospital for treatment, and information and counseling regarding clinical concerns are generally given at this facility. Apart from this tertiary-level counseling, routine ministry of health programs generally provide little emotional support for women in preparation for treatment. Support consists primarily of referral to clinical services and clinically-based counseling or informed consent prior to treatment. In El Salvador, for example, women are counseled about their diagnosis,

but no standard protocol exists, and the information provided depends largely on the initiative of the hospital staff. Beyond referral and counseling prior to clinical services, no programs or systems are in place to provide emotional preparation for women about to undergo cancer treatment.

In ACCP projects, health professionals (either ministry of health or project staff) generally counseled women prior to their travel or referral for treatment. The content of patient counseling tended to be focused on clinical issues rather than emotional concerns; standard protocols do not exist regarding the information to be covered in these counseling sessions. In Peru, a protocol was developed by the Ministry of Health regarding cancer treatment, suggesting that women be counseled about the disease and possibilities for treatment both at the local health center and at the regional referral hospital. In El Salvador, a flowchart detailing the steps a woman in the public health system should follow was developed, but it has not yet been introduced. In the ACCP South Africa project, women received counseling by one of the project doctors and a senior nursing sister before treatment. This generally included an informed consent procedure with a full clinical discussion of the treatment options, treatment intent, side effects, and possible outcomes. The project encouraged women to bring family members to these sessions to explain the disease and its implications. In India, ACCP health professionals provided detailed information on the type of treatment women would receive, the likely treatment outcome, and the consequences of choosing not to undergo treatment; there was, however, no counseling related to emotional concerns. ACCP project experiences demonstrate that developing and incorporating protocols with key messages and counseling steps, including emotional aspects of treatment, can be integrated into existing systems.

Emotional support

Availability of emotional support services during or after treatment is extremely limited in most countries where ACCP implemented projects. In some settings in Peru and South Africa, special psychological counseling services are available to patients who present clear signs of anxiety, depression, or extreme distress; these services are not offered or available to the vast majority of patients. In El Salvador, community health workers and clinicians from local health centers normally make home visits and coordinate the woman's follow-up appointments when they are informed by the cancer hospital about a local woman who has received treatment, but loss of follow-up can occur when local health centers do not receive this information.

Emotional support for women during their cancer treatment was not a component of most ACCP projects, but some projects did develop linkages to other groups offering this type of support to women. In South Africa, the ACCP project referred women in need of additional emotional support to state and local nonprofit organizations that specifically provide care to cancer patients in poor communities. In India, a dormitory was available for accommodation of relatives as well as patients. These family members may be able to provide some level of emotional support to cancer patients. The project in El Salvador worked with the Ministry of Health to develop a program to provide support to cancer patients through psychiatric interns. Supportive steps also were taken in Peru (see text box, next page).

In many cases national programs will not have the resources to provide emotional support, but they can link women to independent services that have the capacity and experience required to offer this type of support.

Supporting women with cancer in Peru

While the cervical cancer prevention project in San Martín, Peru, was aimed at screening for and treating women with precancerous lesions, screening implemented in the region identified more than 100 women with invasive cancer. Project staff sought local solutions to advocate for women found to have invasive cancer who were referred for curative treatment. To

facilitate women's access to treatment, PAHO provided funding for women's transportation from the project site in Tarapoto to the cancer hospital in Lima. There, the project contracted with the Peruvian Cancer Foundation (Fundación Peruana de Cáncer) to provide room and board for San Martín women who needed to stay in Lima for the duration of their cancer treatment. PATH made project funds available to strengthen the technical capacity of the foundation's volunteers to provide education and support to patients, to train patients (who so desired) to become health promoters, to train patients in handicraft activities, and to provide psychological support to patients. The foundation made these activities sustainable by coordinating with a group of volunteers from the National Cancer Hospital (INEN—Instituto de Enfermedades Neoplásicas). Volunteer activities are administered through INEN out of an office at the hospital that also coordinates hospital-based volunteer activities. Volunteers continue to provide education and health promotion as well as handicraft training to patients staying at the foundation's cancer patient hostel. The foundation has continued to support a psychologist who works with patients at the hostel on a weekly basis.

With assistance from the Ministry of Health, a group of women who returned from cancer treatment in Lima formed the "Alianza Nueva Esperanza" (New Hope Alliance), a local association for cervical cancer survivors. With their motto, "We want to share strength and hope," framing their activities, the organization has three objectives: to provide education to women about cervical cancer prevention, to raise funds for women who have returned from cancer treatment (since medications are expensive and many women cannot afford the medication they need), and to organize social exchange among women living with cervical cancer and those who have been treated successfully. PATH and the Ministry of Health have supported this organization through training about cervical cancer and its prevention. PATH staff also are supervising a local volunteer who is coordinating with the New Hope Alliance and with local public and private institutions to develop a regional volunteer network in San Martín that will raise funds and help provide logistical support for cancer patients who need to travel to Lima for treatment.



Cancer survivors from the "Alianza Nueva Esperanza" (New Hope Alliance) plan activities for the organization.

Photo: PATH

Support at the service delivery level

Treatment planning

One aspect of supporting women undergoing cancer treatment is to ensure that they receive consistent messages and appropriate care from various providers. In Ghana, a Multidisciplinary Cervical Cancer Care (MC3) group was established to improve coordination of care and treatment planning for patients with known or suspected cervical cancer. The MC3 group brings together obstetricians/gynecologists, pathologists, and radiation oncologists, creating a direct link between community-based screening services and tertiary care—a connection that did not exist before the project and may not survive now that the project has concluded. Ideally, such efforts will be adopted by countries and maintained at the local or national level. The low level of investment required to construct networks for care and treatment and the high level of potential benefit to cancer patients merit sustained efforts in coordination support by governments and organizations.

Educational materials

South Africa is the only ACCP project country where printed educational or support materials related to cervical cancer treatment are available to women. Although the majority of counseling that takes place there is done on a personalized basis, some brochures about cancer treatment are available. These brochures, however, were not developed with the specialized needs of the country's ethnic groups, such as the Xhosa, in mind. Aside from the palliative care manual described earlier, formal materials regarding counseling, details of cancer treatment, or follow-up were not developed for ACCP projects.

Conclusion and recommendations

The experience gained by ACCP partners in ensuring that participants with cervical cancer received available treatment provides insight into important components of cancer treatment systems in low-resource settings. The frequent late-stage diagnoses of cervical cancer in developing countries can be reduced through implementing screening programs that reach women before cancers have a chance to develop. The ACCP provides guidance and lessons learned from its project sites regarding the implementation of such programs in *Planning and Implementing Cervical Cancer Prevention and Control Programs: A Manual for Managers*. This guide aims to help program managers design, plan, implement, and monitor cervical cancer prevention services.¹⁷

Access to cancer treatment is difficult for low-income women around the globe. ACCP partners' experiences highlight this difficulty as projects have identified cases of cancer far from national or regional sites where cancer treatment services are available. ACCP partners have addressed this issue by subsidizing transportation, medical, and other costs in order for women with cancer to receive treatment. These types of subsidies were available only for the duration of ACCP projects, so the need remains for long-term solutions. Direct subsidies for women are not likely to be a viable alternative for many ministries of health. Instead, national programs may need to consider building local alliances with institutions or organizations that support cancer patients and explore opportunities for meeting women's travel, treatment, and temporary housing needs during cancer care. Countries without radiotherapy may also consider collaboration with international organizations that can facilitate the provision of technology and training.

Palliative care is an important component of all programs that will identify untreatable cases of cancer, especially in settings where curative treatments are not available. ACCP experience highlights the lack of resources devoted to women in need of end-of-life care. The global and Kenya-specific field manuals and the Spanish-language clinical and psychological guide were developed in response to this identified need, and can provide guidance for incorporating these complex issues into a local program.

Psychological interventions have the potential to reduce distress, anxiety, depression, and perhaps costs as well, yet are extremely limited in most developing countries. One way to encourage counseling of cancer patients in local clinics and treatment centers is to design and distribute a protocol entailing key messages and counseling steps to be delivered to women or implemented at specific points during diagnosis, treatment, and follow-up. Collaboration with nonprofit organizations and groups working on cancer care issues to provide further emotional support may be an alternate approach to ensuring that women receive needed assistance.

In many countries effective cancer prevention and treatment programs require significant infrastructure investments. However, intermediate steps requiring limited resources can and should be taken to improve clients' access to and experiences with treatment. A summary of recommendations is included below.

Recommendations

1. Increase coordination between cancer treatment organizations, medical associations, ministries of health, community organizations, and other groups that support cancer patients. Local coordination allows for the formation of networks to provide sustainable support for transportation, to help raise funds to assist families with cost of treatment and other expenses, and to facilitate the establishment of room and board while women are receiving treatment. Multidisciplinary cancer treatment groups can create linkages between screening services and treatment services, thereby providing more consistent messages and care to women.
 2. Integrate psychological support into cervical cancer treatment programs at the local level. Staff with adequate training should be available to provide psychological support or linkages to appropriate counseling services. Additionally, networks or support groups can be formed among cervical cancer survivors.
 3. Standardize clinical counseling information, incorporating international guidelines and implementing protocols describing pre- and post-treatment instructions. This step helps to ensure that women with cervical cancer receive the information they need in order to make informed choices to protect their health and peace of mind.
 4. Develop educational material for women undergoing cancer treatment. Project countries have actively integrated materials regarding cervical cancer prevention developed by ACCP partners and are likely to be interested in this type of additional support. These materials should include information about the disease, what women can expect from treatment, and post-treatment instructions.
 5. Increase cancer treatment options such as radiotherapy in countries where they are lacking. Explore opportunities for coordination with international organizations that provide technology and training to countries without radiotherapy.
 6. Increase women's access to end-of-life care. Explore the roles that community and women's or religious groups can play in helping sick women and their families cope with the disease. Encourage local health organizations to train health workers in principles of palliative care so that home-based care is made more accessible.
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References

1. Stewart BW, Kleihues P, eds. *World Cancer Report*. Lyon: IARC Press; 2003.
2. Moodley M, Moodley J, Kleinschmidt I. Invasive cervical cancer and human immunodeficiency virus (HIV) infection: a South African perspective. *International Journal of Gynecological Cancer*. 2001;11:194–197.
3. Ferlay J, Bray F, Parkin DM, Pisani P, eds. *Globocan 2000: Cancer Incidence and Mortality Worldwide (IARC Cancer Bases No. 5)*. Lyon: IARC Press; 2001.
4. Sandelin K, Apffelstaedt JP, Abdullah H, Murray EM, Ajuluchuku EU. Breast Surgery International—breast surgery in developing countries. *Scandinavian Journal of Surgery*. 2002;91: 222–226.
5. Millions of cancer victims in developing countries lack access to life-saving radiotherapy [press release]. Vienna: IAEA; June 2003. Available at: <http://www.iaea.org/NewsCenter/PressReleases/2003/prn200311.html>. Accessed July 20, 2004.
6. Chaturvedi P, Chaturvedi U, Sanyal B. Alternative medicine and cancer patients in less developed countries. *Lancet Oncology*. 2002;3(1):10.
7. PATH/EngenderHealth. *Palliative Care for Women With Cervical Cancer: A Field Manual*. Seattle: PATH/EngenderHealth; 2004.
8. Murray SA, Grant E, Grant A, Kendall M. Dying from cancer in developed and developing countries: lessons from two qualitative interview studies of patients and their carers. *British Medical Journal*. 2003;326(7385):368.
9. Classen C, Butler LD, Koopman C, et al. Supportive-expressive group therapy and distress in patients with metastatic breast cancer: a randomized clinical intervention trial. *Archives of General Psychiatry*. 2001;58(5):494–501.
10. Goodwin PJ, Leszcz M, Ennis M, et al. The effect of group psychosocial support on survival in metastatic breast cancer. *New England Journal of Medicine*. 2001;345(24):1719–1726.
11. Fawzy FI, Fawzy NW, Hyun CS, et al. Malignant melanoma. Effects of an early structured psychiatric intervention, coping, and affective state on recurrence and survival 6 years later. *Archives of General Psychiatry*. 1993;50(9):681–689.
12. Fawzy FI, Cousins N, Fawzy NW, Kemeny ME, Elashoff R, Morton D. A structured psychiatric intervention for cancer patients. I. Changes over time in methods of coping and affective disturbance. *Archives of General Psychiatry*. 1990;47(8):720–725.
13. Spiegel D. Effects of psychotherapy on cancer survival. *National Review of Cancer*. 2002;2(5): 383–359.
14. Spiegel D. Psychosocial support for patients with cancer. *Cancer*. 1994;74:1453–1457.
15. Newell SA, Sanson-Fisher RW, Savolainen NJ. Systematic review of psychological therapies for cancer patients: overview and recommendations for future research. *Journal of the National Cancer Institute*. 2002;94(8):558–584.

16. Ross L, Boesen EH, Dalton SO, Johansen C. Mind and cancer: Does psychosocial intervention improve survival and psychological well-being? *European Journal of Cancer*. July 2002;38(11): 1447–1457.
17. ACCP. *Planning and Implementing Cervical Cancer Prevention and Control Programs: A Manual for Managers*. Seattle: ACCP; 2004.

Appendix: Stages of cervical cancer

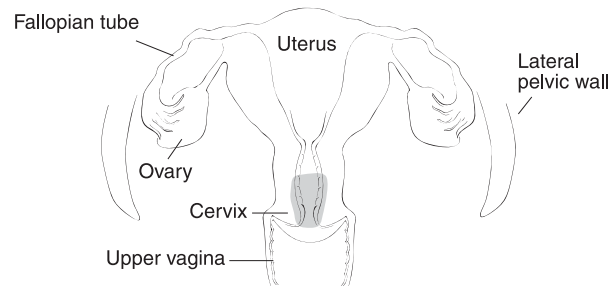
Stage I A

Carcinoma is strictly confined to the cervix, but can be only diagnosed by microscopy (not clinically visible).*

Usual Symptoms: None (asymptomatic).

Optimal Treatment: Total abdominal hysterectomy.

5-year survival (with optimal treatment): 90%–100%.



* All staging descriptions based on International Federation of Gynecology and Obstetrics (FIGO) nomenclature.

Stage I B

Carcinoma is strictly confined to the cervix, and a macroscopically (clinically) visible lesion is present.

Usual Symptoms: May be a watery, pale, straw-colored vaginal discharge and postcoital bleeding.

Optimal Treatment: Radical surgery (radical hysterectomy with bilateral pelvic lymphadenectomy or radical radiotherapy).

5-year survival (with optimal treatment): 80%–90%.

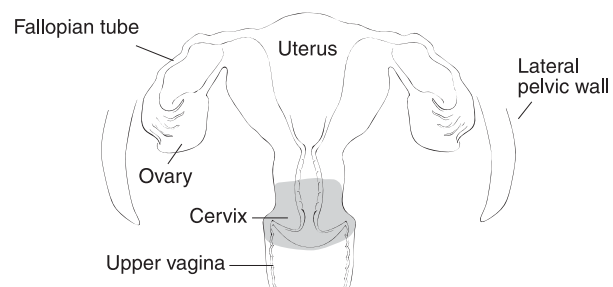
Stage II A

Cancer has spread beyond the cervix, but does not involve the pelvic wall, lower third of the vagina, or the parametrium.

Usual Symptoms: Vaginal discharge may be serous, mucopurulent, blood stained, and sometimes foul-smelling. Recurrent vaginal bleeding including postcoital.

Optimal Treatment: Radical radiotherapy with or without concurrent chemotherapy; in selected cases, radical surgery plus radiotherapy.

5-year survival (with optimal treatment): 75%.



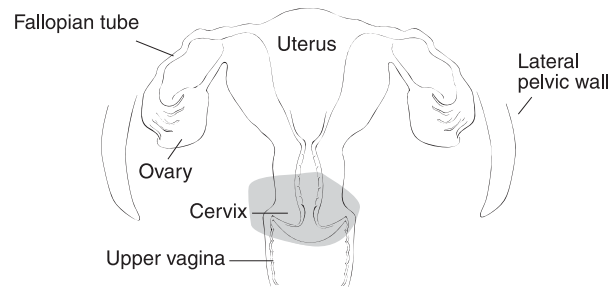
Stage II B

Cancer has spread beyond the cervix, but not as far as the pelvic wall or the lower third of the vagina. There is obvious parametrial involvement.

Usual Symptoms: Similar signs and symptoms as II A, often with pain in lower pelvis and lower back.

Optimal Treatment: Radical radiotherapy with or without concurrent chemotherapy.

5-year survival (with optimal treatment): 50%–60%.



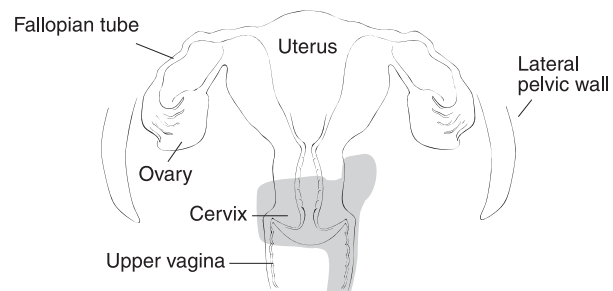
Stage III A

The tumor invades the lower third of the vagina, with no extension to the pelvic wall.

Usual Symptoms: Similar to II B, often with painful intercourse.

Optimal Treatment: Radical radiotherapy with or without concurrent chemotherapy.*

5-year survival (with optimal treatment): 20%–40%.



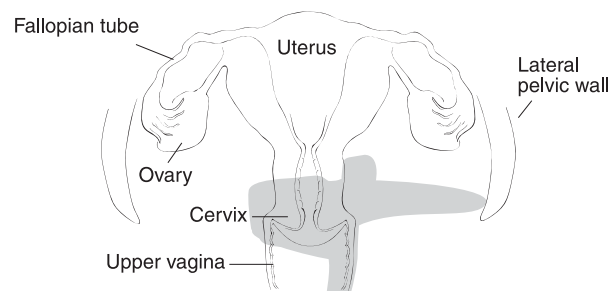
Stage III B

The tumor involves the lower third of the vagina and extends to the pelvic wall or hydronephrosis or nonfunctioning kidney occurs.

Usual Symptoms: Similar to III A, severe pain in lower abdomen and lower back, often one or both legs swollen. May be signs and symptoms of uremia (chronic renal failure) due to obstruction of one or both ureters.

Optimal Treatment: Radical radiotherapy with or without concurrent chemotherapy.*

5-year survival (with optimal treatment): 20%–40%.



* These are radical treatments with curative intention, not palliative treatments. One-third of Stage III patients are cured with radical radiotherapy with or without concurrent chemotherapy.

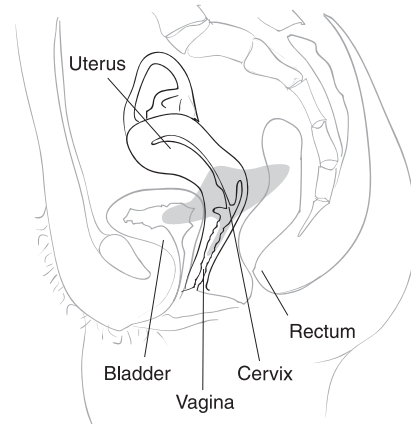
Stage IV A

Cancer has spread beyond the pelvis to the adjacent organs (bladder and/or rectum).

Usual Symptoms: Similar to III B, often with hematuria (blood in the urine), dysuria, anemia, weight loss, and sometimes vesicovaginal fistula or rectovaginal fistula.

Treatment: Palliative radiotherapy and/or palliative chemotherapy and symptom control; radical radiotherapy with or without concurrent chemotherapy in selected cases.

5-year survival (with optimal treatment): 5%–10%.



Stage IV B

Cancer has spread to distant organs.

Usual Symptoms: Same as IV A, but with additional signs and symptoms according to site of metastatic spread:

- Kidneys – severe midback pain.
- Lungs – intractable, nonproductive cough.
- Liver – abdominal swelling (right upper quadrant pain and tenderness), jaundice.
- Skin – large, nontender, nodular skin swellings.
- Lymph nodes – enlarged lymph glands.
- Brain – convulsions, confusion.

Treatment: Palliative radiotherapy and/or palliative chemotherapy and symptom control.

5-year survival (with optimal treatment): 0%.