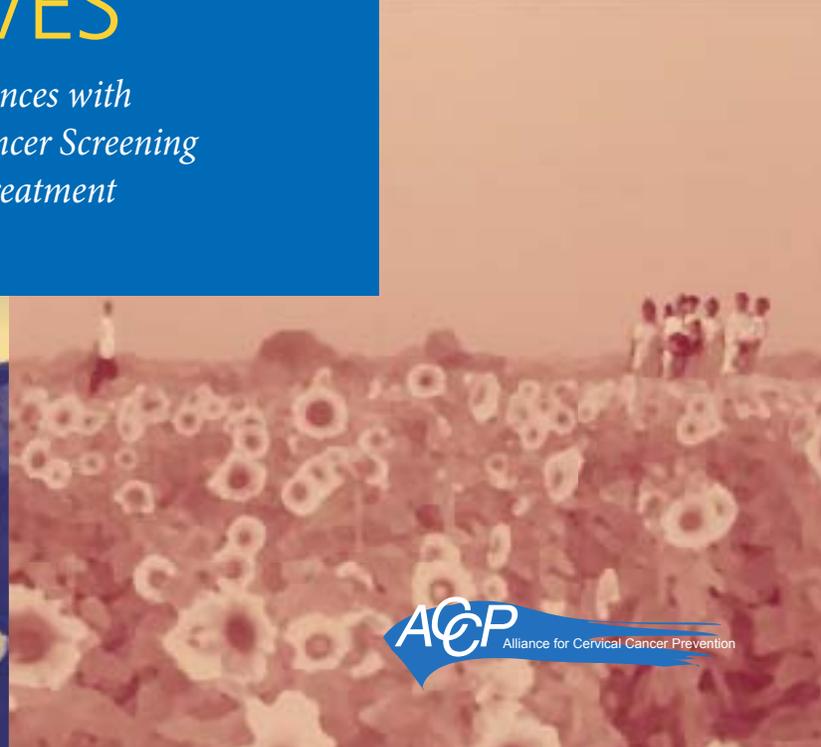




WOMEN'S STORIES, WOMEN'S LIVES

*Experiences with
Cervical Cancer Screening
and Treatment*



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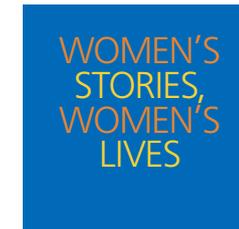
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Introduction



Cervical cancer is a preventable disease. Each year, however, close to a half million women are diagnosed with cervical cancer, and nearly a quarter million women die from the disease.¹ The vast majority of these women live in developing countries, where effective prevention programs—and awareness of the problem—are often in short supply. In fact, in most developing countries, cervical cancer is the leading cause of cancer deaths among women.² The stories in this collection illustrate the unnecessary suffering cervical cancer can cause women and their families, and how prevention programs can save women’s lives.

Cervical cancer develops slowly after initial infection with human papillomavirus (HPV). Although women often do not experience symptoms until the disease has advanced, simple screening methods can detect precancerous lesions. If such lesions are detected, a range of treatment approaches can be used to prevent the disease from progressing. Women in their thirties and forties are at highest risk for the treatable precancerous lesions that can progress to cancer; cervical cancer rates peak among women in the fifties and sixties.³⁻⁵

Alliance for Cervical Cancer Prevention (ACCP) demonstration and research projects offer

important insights into the potential effectiveness of different screening and treatment strategies under a range of conditions. Focusing on the regions in which cervical cancer incidence and mortality are highest—sub-Saharan Africa, Latin America, and South Asia—ACCP studies have examined visual inspection with acetic acid (VIA), visual inspection with Lugol’s iodine (VILI), cytology (Pap smears), and HPV DNA testing. The ACCP has also explored protocols and methods for treating women with suspected precancerous lesions, including cryotherapy and LEEP, both in single- and multiple-visit approaches. While assessing these methods and contributing to knowledge about alternative prevention approaches, the ACCP’s work has also touched—and saved—many women’s lives.

The stories on the following pages reflect the experiences of women and their families in Africa, Asia, and Latin America and the Caribbean as they undergo screening and, when necessary, treatment for precancerous cervical lesions or cancer. Each story describes the unique perspectives, fears, and circumstances that the women and their families face. Collectively, the stories highlight the importance and common challenges of increasing understanding of and access to cervical cancer screening and treatment measures.

For more information, visit the ACCP website at www.alliance-cxca.org.

About the project

In Kenya, PATH worked with the Kenya Cancer Association (KECANS), Maendeleo ya Wanawake Organization (MYWO), and the Kenyan Ministry of Health on the Western Kenya Cervical Cancer Prevention Project, (WKCCPP), which developed and evaluated a model cervical cancer prevention program for rural, low-resource settings in Africa.

Dawn

K E N Y A

A spring of determination



By Jemimah Mwakisha

She remembers the two-hour walk to the nearest dispensary as if it were yesterday. Through valleys and along the hills, Dawn kept on the familiar narrow path. She recalled the many times she had walked the same path because she felt ill or one of her five children had fever, malaria, or other ailments; sometimes

she had to carry a child on her back the whole way.

On one occasion two years ago, it was different. Dawn, a 32-year-old Kenyan woman, was not sick. In fact, she was in high spirits. Shortly before, a community health worker's announcement at a funeral had inspired her. He had spoken about a chronic disease that affects women—cancer of the cervix—and explained that the disease is preventable. If cervical precancer is not detected early and treated, a woman can lose her life.

These comments stirred Dawn. “For some reason, I felt a sense of urgency and needed to respond to the announcement,” Dawn reminisces. “I felt it was important for me to know my status because, after all, I could get help.”

“I felt a sense of urgency and need to respond to the announcement. I felt it was important for me to know my status because, after all, I could get help.”

That morning, Dawn walked to the community worker's home to seek more information. He gave her a card and told her to go to the dispensary at Sio Port, near Lake Victoria, where a project was testing and treating women to prevent cervical cancer. When Dawn arrived at the clinic, she waited for the women ahead of her to be seen. “At that point, I started wondering about . . . the possibility of having the disease. ‘What if I was sick? Could it be at an advanced stage?’”

The initial examination

When Dawn's turn came, a nurse asked her to go into the examination room and lie on the bed. Two nurses examined her. Dawn recalls that the examination was uncomfortable but not painful. After the exam, the nurses told Dawn they had detected a lesion and that she needed to go for further analysis and treatment at the district hospital in Busia, which has better facilities.

“The nurse . . . told me I had done a great thing going to the hospital early because now I would be treated. If I had gone later, it could have been too late.”

Dawn described her reaction when she heard the news. “I felt at peace and grateful to God for making me come to the dispensary to learn about my condition. In fact, my prayer then became, ‘God, help me to be completely healed.’”

Dawn then made the difficult decision not to tell her family about her condition. Her voice had a tinge of sadness as she recalls, “. . . my husband had died in a road accident just a few weeks earlier. In fact, I was still mourning. But I was not going to tell the children. I didn’t want them to worry about me. I wanted them to know all was well. In any case, I believed the reason I had responded to the [community health worker’s] information was so I could get treatment.”

Finding her way

Dawn could not get treatment immediately, however. “The hospital is much further from where I live, so I had to find money to enable me to go there.” Her husband had been the family’s main source of income, so Dawn had to find ways of supporting the family.

In the mornings, she worked on her small *shamba* (piece of land), which provided her family with food—mainly cassava, maize, beans, and

vegetables. In the mornings when she was not working on her *shamba*, Dawn worked on her neighbor’s farm for extra money. In the afternoons, she bought fish from a dealer and sold it in the nearest shopping center. After about a month, Dawn was able to save enough money—approximately 200 shillings (US\$2.50)—to get to the hospital.

At the hospital

The procedure at the Busia Hospital was a little different from the first examination. The nurse used a method called visual inspection with acetic acid (VIA) to detect the precancerous lesion on her cervix. This was followed by a biopsy, in which the nurse removed a small piece of the lesion to confirm Dawn’s status. “The nurse was very nice and she explained everything to me. She told me I had done a great thing going to the hospital early because now I would be treated. If I had gone later, it could have been too late.”

Dawn was given a second appointment for cryotherapy, a procedure in which extremely low temperatures are applied to precancerous lesions to freeze and destroy the abnormal cells. Dawn was asked to return for follow-up care to ensure that the treatment had worked and that the site was healing. “There was some pain,” Dawn remembered, “but the nurses gave me some pain killers. They also told me to avoid sex for a month.”

Dawn’s motivation

After learning that she had a precancerous lesion, Dawn refused to sit at home and feel sorry for herself. “I realized that death is the path we all have to go through and, since my husband had

gone ahead of me, I needed to live meaningfully with the children, and I could only do that by being positive about life,” she says.

Looking back at the treatment and the follow-up appointments, Dawn says the fact that she responded to the health worker’s information in the first place was a miracle. “At the end of it, I realized my life had been saved. I told God, ‘please heal me completely because I have these children to bring up.’”

When Dawn reflects on what motivated her to keep all the appointments, she explains, “Well, it is all about knowing where you are going. You can’t stop midway. Even for a child, unless you strive to take them to school by paying their fees and meeting their needs, that child will not achieve anything in the end.”

Sharing her experience

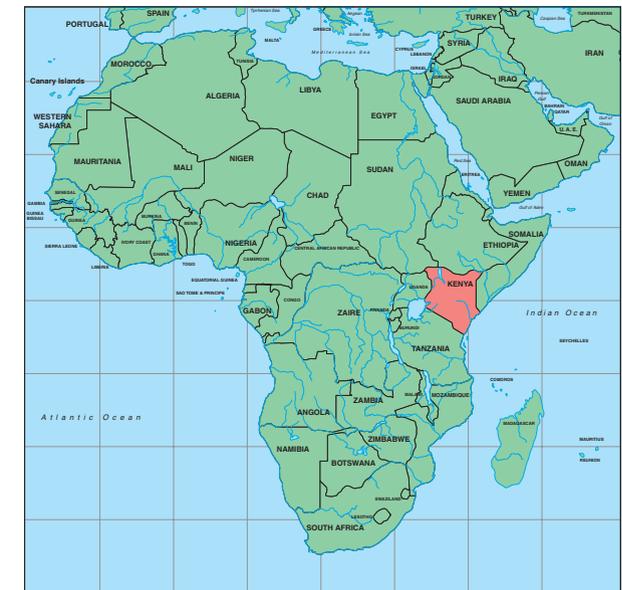
During the screening and treatment, Dawn kept her condition secret, only informing a female relative who worked as a nurse at the Sio Port dispensary.

After her one-year appointment, when the nurses assured her she was fine, Dawn began to speak publicly about her experience. One day, she stood up in her church and spoke to the women about cervical cancer. She described the disease and explained the importance of being tested early. She also revealed that she had tested positive for precancerous lesions and had gone through treatment.

Many who knew Dawn were surprised at this news and expressed sympathy. They wondered how she

could have kept her worries to herself. But the last thing Dawn wanted was sympathy. “For me, the issue was that they know the disease exists and that they can save their lives by being tested [early] and treated.” She explained that the testing and treatment were especially important for women in their thirties, and that waiting too long could lead to death.

Dawn continues to speak to groups about cervical cancer prevention wherever an opportunity arises, including at funerals and other events. Her courage has had an impact; women she has spoken to have followed up with her and been tested. “At least 10 of them have turned out to be positive, and many more are now going for check-ups.” Dawn is happy to be helping others. “I don’t want anyone to die when God has provided an opportunity for us to live longer,” she says.



About the project

The International Agency for Research on Cancer (IARC) works on several cervical cancer prevention projects in India, including a randomized, controlled intervention trial initiated in Osmanabad, a rural district in India's Maharashtra state. The Tata Memorial Cancer Hospital (Mumbai), the Nargis Dutt Memorial Hospital (Barshi), and IARC are collaborating on this project, which is evaluating the efficacy and cost-effectiveness of visual inspection with acetic acid (VIA), cervical cytology (Pap smear), and human papillomavirus (HPV) DNA testing in reducing cervical cancer incidence and mortality in Maharashtra state.

Pratibha

I N D I A



Screening, treatment, and community support



By Silvina Arrossi, Kasturi Jayant, and Bhagyashree Virupaksha Rajeshwar

As usual, Pratibha's morning in Maharashtra state began early. After she lit the fire, she went out to get fresh water from the village tap and found a group of women talking anxiously.

As she approached the group, she listened to what they were saying. "They had come to my house," her neighbor said. "They were telling me about cervical cancer and that I should get myself tested."

Pratibha, 37, said to herself, "Well, this is not for me, I am perfectly well." She would have liked to linger and listen to what the women had to say, but she had to hurry back since her mother-in-law was waiting for her.

An initial meeting

When Pratibha arrived at her house, two women were talking to her husband. She learned that they were workers from the cancer hospital. Pratibha felt frightened, although she was not sure why. She wondered why they were there.

"I was pleased to hear my husband approving my being screened, and I realized that Mr. Shinde [a political leader] had done a good deed by talking to husbands in the village."

The health workers approached Pratibha and asked to talk to her. Together, they sat down in the only room in the house. In the corner, Pratibha's two-year-old son was still sleeping. The health workers asked Pratibha many questions, such as how old she was, when she married, and how many children she had. Then they told her about cervical cancer—that it is common in women in her region, and that it is a preventable disease. They also told her about an opportunity to be screened in the village.

Pratibha asked why she was selected for this interview. She was relieved to learn that they were visiting every house in the village. She still didn't understand why she should go for the test, but when the health workers invited her to the schoolteacher's house for a talk on cervical cancer prevention, she was curious about what the other women would say.

“These people saved my life. They have not only saved the woman but they have saved the mother of a small child.”

A spirited gathering

When Pratibha arrived at the teacher’s house, it was already full of women and their children. Everybody was talking. As soon as the health worker began speaking, however, the room fell into silence. The health worker explained that testing women for precancerous lesions—even if they feel well and have no abnormal symptoms—can prevent cervical cancer and death.

“I found it difficult to understand all the things that were being said, as, unfortunately, being a girl child my parents educated me only up to primary level,” said Pratibha. “I was happy to hear that a video show would be organized in the evening. I would understand better by seeing the pictures. In the end, the health worker said if a woman is healthy, then the family will be healthy. When I heard that, I remembered how difficult it had been for me to look after my son during the last monsoon season when I got seriously ill with typhoid. When the meeting was over, I thought I should attend the clinic if my neighbor who is more educated than me also attends.”

That evening, Pratibha and her husband attended the function organized by the cancer hospital, and they heard senior hospital staff speak about cervical cancer screening. After hearing this and viewing the video, Pratibha thought that the procedure seemed simple and noted with relief that female health care providers perform the exams. As she spoke with other women, she found their concerns were also alleviated and that they felt good about participating in the screening.

Family concerns

Pratibha was still worried about talking to her husband about going to the clinic, however. “I wondered whether he would allow me to have a gynecological test since I have no complaints,” she said. “One of the advantages of participating in the program was the testing and treatment were all for free. There was no financial burden. If any expense was involved, I would never have thought of participating or discussing it with my husband.

“Now as there was no such problem, I asked my husband if he would allow me to go to the clinic. My husband informed me that Mr. Shinde had said that all women from this village should go and avoid getting cervical cancer. Mr. Shinde is the political leader of the village—a well-respected man. His mother had died of cervical cancer when he was 10 years old. I was pleased to hear my husband approving my being screened, and I realized that Mr. Shinde had done a good deed by talking to husbands in the village. My husband was also able to convince my mother-in-law about the benefit of my getting tested.”

Taking the next steps

Pratibha said that almost all of the women in the village attended the clinic and found that the test was fast and painless, as the health worker had said. Although the women had to wait in a long line, Pratibha said they were happy with how the clinic was organized.

As Pratibha explained, “After examination, the [health] worker said that they would inform me about the report. Then, after some days I got my report. It was positive. I thought, ‘I am not suffering from any symptoms. How then is my report positive?’ I was very upset. My neighbor, a woman I respect, consoled me. She told me, ‘Don’t worry, my report is also positive. We will take treatment. There is no need to worry.’

“Then I attended the cancer hospital. The doctor examined me and advised LEEP [loop electrosurgical excision procedure] treatment. I thought that this would be sufficient treatment, but, unfortunately, again the report of LEEP was positive [for cancer] and the doctor advised hysterectomy. It was very shocking; it disturbed me a lot.

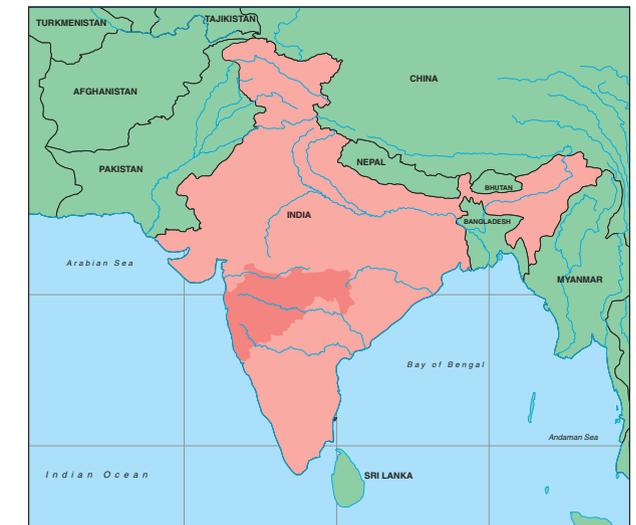
“My husband and I decided that I should take the treatment but I had a problem. There was nobody to look after my son, who is just two years old. But happily, I solved it with the help of my neighbors and attended the hospital for hysterectomy. The doctor has done my operation successfully and now I don’t have any problems.

“Previously, I thought that I am a very unlucky woman because there was a positive report. But now I feel how lucky I am! My disease was detected in the earlier stage. And I got treatment

for free. These people saved my life. They have not only saved the woman but they have saved the mother of a small child.”

Reflecting on her experience

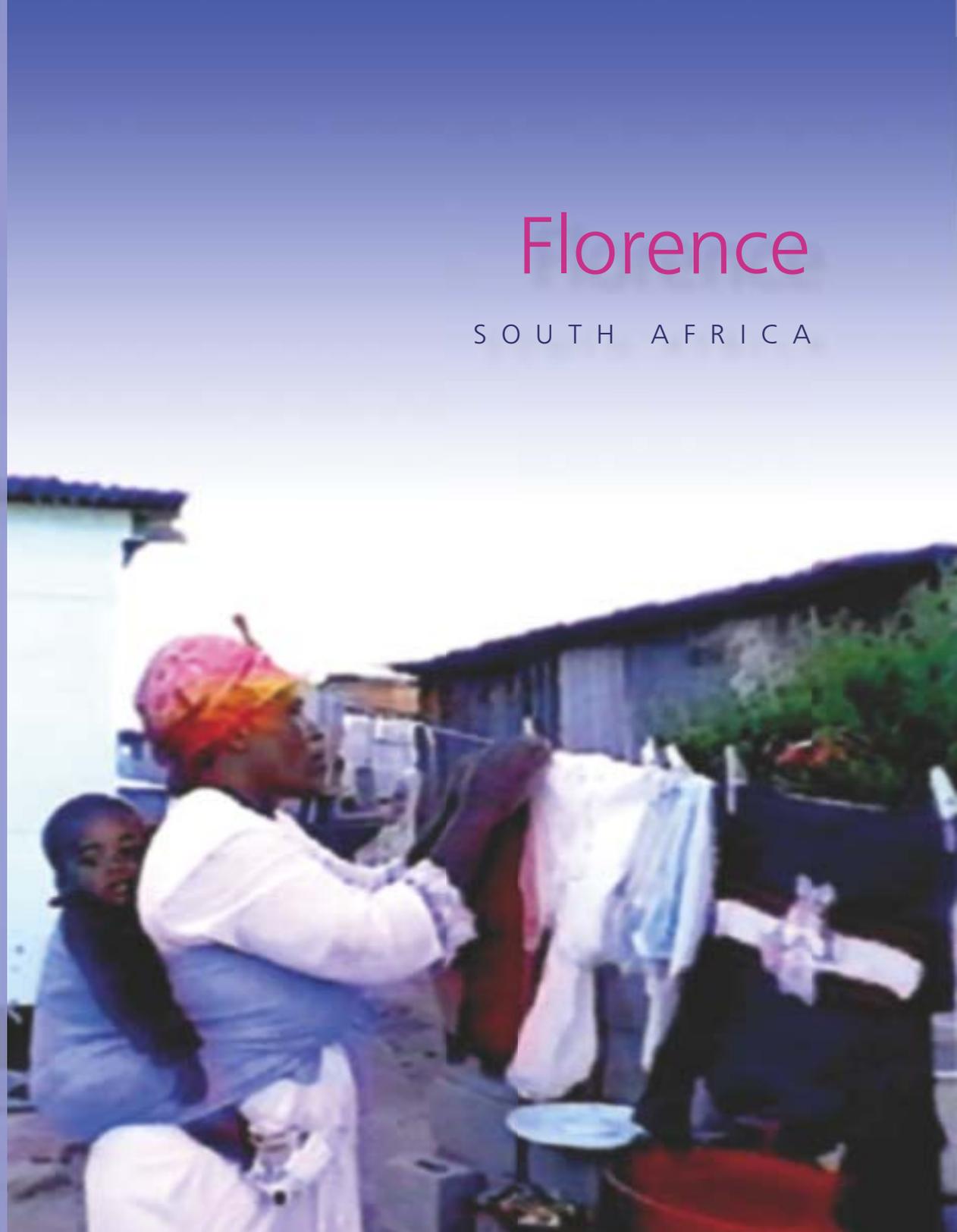
Pratibha recalls talking to another woman with advanced cancer in the hospital. The woman was very upset, worried about what would happen to her children if anything happened to her. “Listening to her, I thought how lucky I was to get the opportunity to attend the program. I was saved. If I did not attend the clinic, what would have happened to me? This thought frightens me even now. I am lucky that I live in the village of Osmanabad District, which has been selected for this program. I am thankful to these people, who put in so much effort to convince me to get tested and prevent cancer. They saved my life and my family.”



About the project

The University of Cape Town, Columbia University, and EngenderHealth have collaborated to conduct a randomized clinical trial in three sites in Khayelitsha, a squatter community outside of Cape Town, South Africa. The team is exploring the safety and efficacy of cervical cancer screening using visual inspection with acetic acid (VIA) or human papillomavirus (HPV) DNA testing followed by treatment with cryotherapy for women with positive results. This “screen-and-treat” approach may provide an alternative to cervical cancer prevention strategies for countries that cannot carry out successful cytology-based programs.

This story was adapted from the documentary “Silence of the Wombs,” directed by Athalie Crawford and supported with funds from the Alliance for Cervical Cancer Prevention.



Florence

SOUTH AFRICA

Surviving cervical cancer and preserving health and family unity



By Ilana Dzuba

Another day comes to a close. The setting sun spreads red and orange hues across the South African sky, casting a glow on Florence, age 51, as she chops wood for the evening fire. The rolling hills of the former

Transkei, now the Eastern Cape Province, are covered with mustard-colored grass and sparsely dotted with trees, bushes, and dwellings.

Florence, a Xhosa woman, lifts the ax high above her head and brings it down forcefully to split the log at her feet. “I have never been a sick person—doesn’t matter if it’s raining, I collect my wood, do the washing, do my work,” she says. This was the case until she began to experience pain in her abdomen. “I would finish menstruating and then the discharge would start. It was as if I’d just given birth—always pain and blood.” Even though Florence knew something was wrong, she delayed seeking medical help for several months.

Heeding the signs

Florence’s adult daughter, Priscilla, understood the seriousness of physical symptoms—and the problems that can arise when they are ignored. “I had my aunt in my husband’s family . . . passed away in 1998 because of cancer.” Her aunt reportedly did not heed the warning signs.

“I’m ready—I’m not afraid to tell them about it because it’s good to hear about it from someone who’s gone through it themselves . . . Let us check our wombs!”

To help Florence avoid a similar fate, Priscilla encouraged her mother to go to a clinic in distant Cape Town, where she received a Pap smear. The result indicated that Florence had cervical cancer. “My heart was sore when I heard I had cancer,” remembers Florence. Like most women in Transkei, she assumed death was inevitable.

Selecting an approach to care

The Xhosa people of the Transkei typically go to a *sangoma* (traditional healer) for care before resorting to Western medicine. Many harbor feelings of distrust toward the Western approach to disease management, including cancer. Florence admits, however, that although “our belief is in the sangoma . . . I never thought of going to a sangoma . . . A sangoma can give you medicine but he can’t examine you internally.”

As with practitioners of Western medicine, *sangomas* can sometimes help a person get well; sometimes they cannot. In this case, Florence opted to seek care from a doctor trained in Western medicine.

“My heart was sore when I heard I had cancer.”

Pursuing treatment for the sake of her family

Priscilla was very concerned for her mother’s health. “It will affect my life if she won’t get any better . . . if she can die . . . We lost our father when we were young. Now she’s the only one [we have],” said Priscilla.

With her children and grandchildren in mind and in spite of her fear, Florence agreed to go to the university-affiliated reference hospital in Cape Town to see a radiation oncologist and learn about her treatment options. “I had faith that they’d help me at Groote Schuur Hospital.”

The sight of the large hospital building overwhelmed Florence and she briefly considered missing her appointment and returning home. “I was scared when I saw how big Groote Schuur Hospital was. I didn’t know how I was going to find my way.” Overcoming her fear, Florence entered the hospital and waited for her first meeting with the doctor.

During the visit, the doctor told Florence where the cancer was located in her body. He explained that when cervical cancer is detected in its early stages, it can be treated by surgically removing a woman’s uterus. When detected in more advanced stages, such as Florence’s, surgery is no longer possible. Radiotherapy is one option for shrinking

the tumor, relieving pain, stopping bleeding, and enhancing quality of life. Because Florence’s cancer extended to the surrounding tendons from the cervix, her uterus could not be removed and the doctor recommended radiotherapy.

Among the Xhosa people, radiotherapy has a negative connotation. It is commonly referred to as “burning” or “ironing” because of a slight darkening effect on the abdomen following treatment. If a woman dies after receiving radiotherapy, her death is often attributed to the therapy. “Some people tried to scare me saying I shouldn’t agree to being burned, being ironed,” Florence said. “They said it’s dangerous and you die covered with sores over your whole body. I said, ‘well, if I die, I die. If I live, I live.’” Typically, however, women do not die from the “ironing,” but because they arrive for treatment too late.”

Maintaining her faith

Florence did not believe the unsubstantiated myths about her treatment options and instead relied on faith and prayer to help her through recovery. “They told me this ironing helps us and you don’t feel anything when you are being ironed. I pray to God to help me get well because this doctor has been placed here by God, and God is guiding his hand. I felt frightened, but even in my fear . . . I have faith that I’ll get better.”

To complete her treatment regimen, Florence was required to go to the hospital several times to receive radiotherapy. “You know, when you do something for the first time, you feel worried . . .

I worried that it might be painful . . . There is nothing in your mind except death when you see a machine as big as that.”

Florence quickly realized that there was no pain associated with the procedure. “It’s not hot, you don’t feel it!” She became dedicated to honoring her scheduled appointments and following through with her treatment until it was completed. “Clearly I would be wrong not to go to the ironing.”

Raising awareness

Florence’s road to health has not been easy, but she feels fortunate that she had the opportunity to undergo screening and treatment. As her health improves, her interest in advocating for cervical cancer prevention among the women in her community is growing. She notes that women tend not to talk about intimate health problems, particularly those related to the genitals, because they do not want to be the subject of gossip. Florence does not let this deter her, however. She feels that she has an important role to play as a cancer survivor.

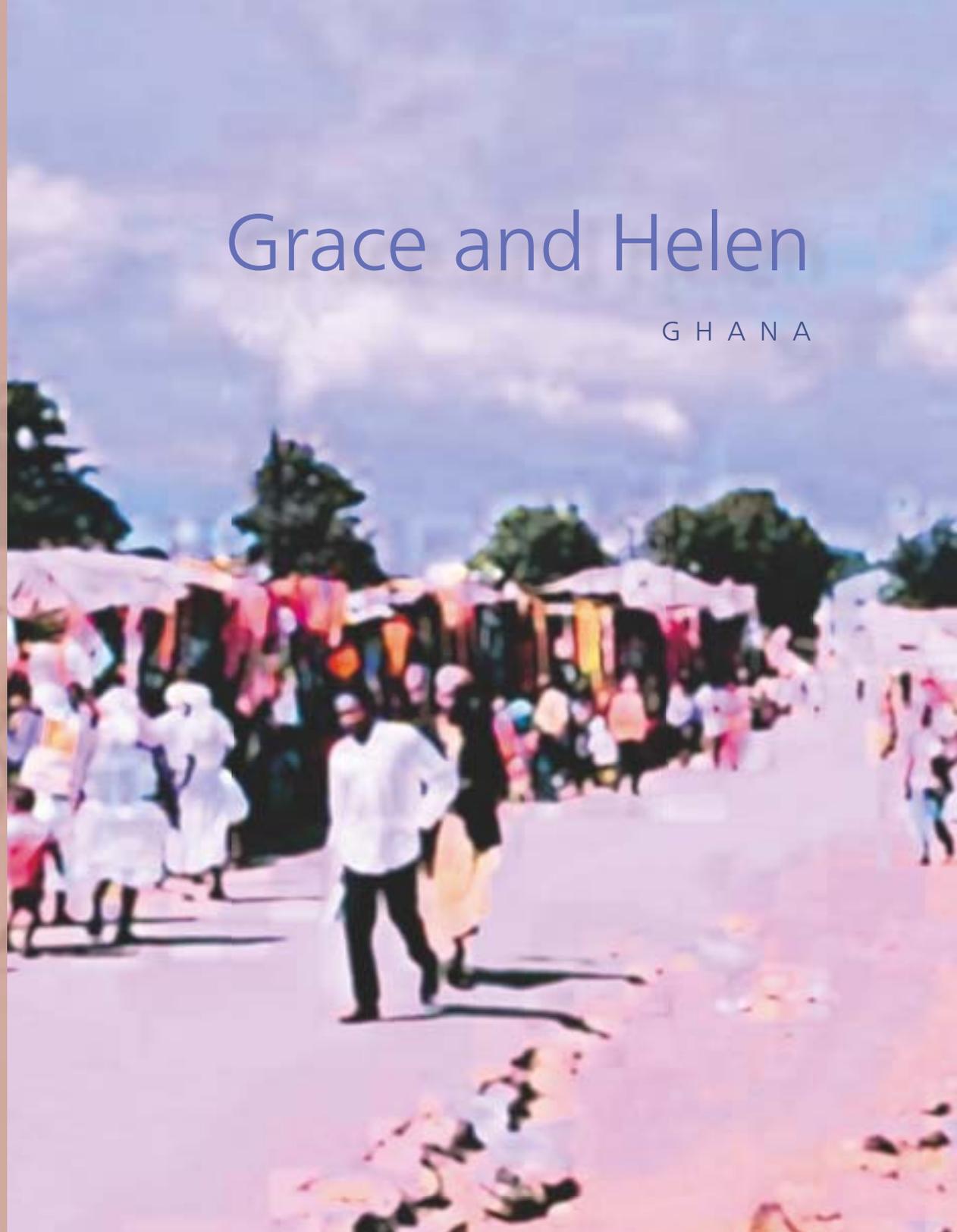
“I’m ready—I’m not afraid to tell them about it because it’s good to hear about it from someone who’s gone through it themselves . . . Let us check our wombs!”



About the project

In Ghana, JHPIEGO partnered with the Ministry of Health (MOH) and Ghana Health Service for two projects sites: Ridge Hospital, an urban regional hospital, and Amasaman Sub-district Health Center, a semi-rural facility. At both sites, the team trained and supervised nurse-midwives delivery services. Currently, supervision is provided by trained ob-gyns, who also perform biopsies for referred suspect cancers. Women with biopsy-confirmed invasive cancer are referred to Korle Bu Teaching Hospital for advanced diagnosis and management. Women needing advanced services are offered surgery or radiotherapy, as indicated.

While the television program featured in this story described the components of this project, it is not affiliated with the project.



Grace and Helen

G H A N A

A husband's encouragement leads to screening



Two stories by Amanda Adu-Amankwah and Amy Kleine

Born in a village in the Brong-Ahafo region, Helen moved to Accra's Abeka Lapaz neighborhood many years ago. She is happily married and has three children aged 4, 10, and 17. Although her mother left the country, Helen maintains a close and supportive relationship with her and her sisters.

Helen, 37, had no reason to worry about her health. As she explained, "I am physically sound in health and do not have any problems currently." But when she learned about visual inspection with acetic acid (VIA) through a popular television program, her interest was piqued.

Her husband recalls that, "One evening, I was watching the GTV when the popularly known 'Nmaa Nkomo' program started and I heard them talking about cervical cancer. I quickly called my wife who was then preparing a meal for me in the kitchen to come and listen, since it concerned women." Helen decided to participate in the testing, which has been offered at Accra's Ridge Hospital since the middle of 2001.

Unprecedented demand

After the program aired, hundreds of women flocked to Ridge Hospital for testing. So many came, in fact, that the line extended out the door and around the building. The nurses had to send

women away with appointments for another date because they were overwhelmed by the number.

This level of demand was unheard of. Previously, the hospital had tested as few as five women over the course of a day. Now more than 300 women were requesting screening each day.

A husband's encouragement

Unlike many of the women, Helen did not rush to the hospital immediately after seeing the program. As she explains, "My husband had been pressuring me to go for screening, but I was always postponing it until I finally decided to take the opportunity. I even came to talk with [a doctor] about it and he recommended I come for screening." It was the combination of her husband's support and the doctor's recommendation that finally pushed Helen to attend the VIA clinic.

In Ghana, women are commonly required to have permission from their husbands to seek health care. This was the case for Helen. Her husband's approval and encouragement were the most influential factors on her decision to be screened, and when she announced she was ready to attend the screening clinic, he gave her permission to go.

On the day of her screening, Helen said she felt "... scared because I did not know what the screening entailed, and I am the type who cannot endure pain." After the procedure, which Helen described as "painless, simple, smooth, and comforting," she

was informed that her test result was negative. Naturally, she was very happy to receive this news. Her husband was pleased as well: “I am happy that my wife has been screened and her result is negative.”

Educating other women

As a result of their experience, Helen and her husband are encouraging other women to take part in the screening program. He said, “I feel women

should be educated on some of these important issues because they are vital to their health. I will speak to and encourage the women and youth in our church so that they can also take advantage of the program.”

Thinking about her experience, Helen explains that, “I was not worried about the decision I took to undergo screening at all because I think life is too short for one to take for granted, so I made up my mind to make use of the opportunity.”

Screening keeps death at bay



At age 42, Grace hadn't thought that death could be knocking on her door. Instead, she was focused on her full family life as a daughter, sister, wife, and mother of two children.

When she noticed unusual bleeding from her vagina, however, Grace became concerned and decided to seek medical

advice. She visited the cervical cancer prevention program at Ridge Hospital in Central Accra, where she was referred to a nurse for visual inspection with acetic acid (VIA). The VIA testing could determine whether the bleeding was an indication of cancerous lesions forming on her cervix.

“I was screened and a specimen was taken to Korle Bu for further tests,” Grace recounts. Her specimen

was positive and her laboratory records reported “diffuse large-cell malignant lymphoma of the cervix.” In other words, Grace had invasive cervical cancer.

Acting on the diagnosis

When she received the results, Grace was surprised. “I was really disturbed and confused because I least expected it.”

A staff member from the screening site accompanied Grace to Korle Bu Hospital and ensured that she received appropriate services. As the largest teaching hospital in Ghana, Korle Bu is well known for treatment of later-stage illnesses. The physicians at Korle Bu work closely with the cervical cancer project at the hospital, providing advanced care to women diagnosed with cancer or other gynecological conditions.

“I was afraid I would die, so I wanted to know what brings about the disease.”

Because the cancer was detected at a later stage, Grace required radiotherapy treatment and invasive surgery. Radiotherapy is not normally available to people in Ghana, but Grace fortunately had access to it through this program.

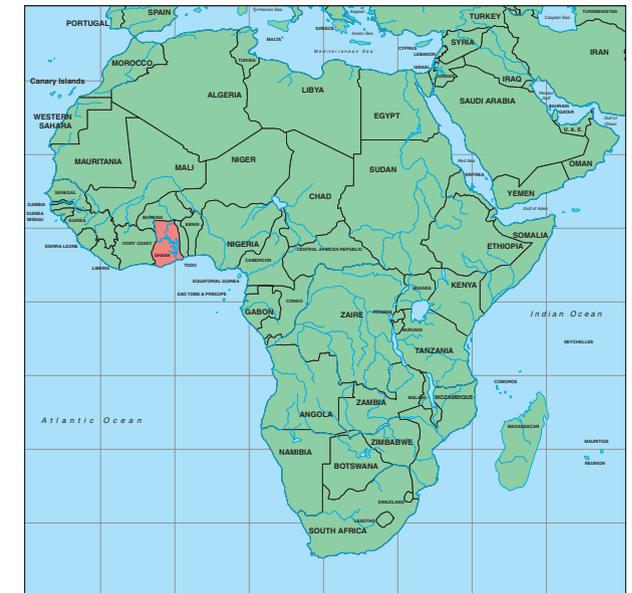
While she now says that her treatment was successful, it brought several hardships during the process. “Sometimes I was in so much pain that I really did not know what to do, and still today I feel pain where the radiotherapy treatment was done.” In addition to the physical discomfort, Grace was distressed about the costs of treatment and transportation to the hospital. She was fortunate to be a participant in the cervical cancer prevention project, Cervicare, which reimbursed her for her expenses and provided the radiotherapy free of charge.

Relying on family support

In addition to support from the project's staff, Grace received comfort from her family. “During the time I was sick, even though my family could not visit me, they always sent me words of encouragement.” She told the staff that her mother had been very worried about her daughter's health and was grateful to them for their intervention.

A key to prevention

Even with the many hurdles she had to overcome, Grace feels fortunate. “I have begun talking to some women about cervical cancer and its associated problems,” she explains. Grace does not want other women to face the disease unnecessarily, so she encourages them to take advantage of early screening and treatment which can prevent the disease. “I was afraid I would die, so I wanted to know what brings about the disease.” As Grace discovered, awareness is one of the most important keys to prevention.



About the project

The Pan American Health Organization (PAHO) is working through the Caribbean Epidemiology Centre (CAREC) in Trinidad and Tobago to strengthen cervical cancer programs in the Caribbean. High-priority areas include development of screening and treatment guidelines, quality improvements for cytology laboratories, and the implementation of advocacy and educational initiatives.

Ava

TRINIDAD AND TOBAGO

Considering her options



By Clare Forrester

“I started to curse,” Ava admitted with a rueful smile and shake of her neat, long braids. She appears much younger than her 42 years. “I might have been expecting it at the back of my mind, but to hear the word ‘cancer’ [in precancer]—the big ‘C’—was still traumatic.”

Several years before she learned she had a precancerous condition, Ava had been told that she had a polyp that should be removed. “That was in 1995,” she explained, “but I kept putting it off. I am a single mother with lots of responsibilities. It remained at the back of my mind as something I should do but I didn’t do anything about it until much later.”

Finally, Ava decided she should have a cytology (Pap smear) test. She was getting older and some of her friends and colleagues were being advised by their doctors to get the test. After the test, Ava got a call from her gynecologist. He explained that there was “a slight irregularity” in her test result. Taking a female friend with her, she went to see him.

When the doctor broke the news that Ava might have cancer of the cervix, she worried about how long she would have to live, and asked, like so many other women in her situation, “Lord, why me?”

“. . . I kept putting it [treatment] off. I am a single mother with lots of responsibilities . . .”

A troubling diagnosis

The doctor explained that he would have to do a biopsy to determine the seriousness of the problem. The biopsy would entail removing a small tissue sample from her cervix. He also told Ava that it was possible that she would need a radical hysterectomy.

After the biopsy, Ava anxiously waited for the results. A week later, her worst fears were confirmed. The doctor called and said he had consulted with several colleagues who agreed with his diagnosis of a high-grade lesion, a precancerous condition. He told her she needed a hysterectomy—quickly, before her condition worsened. The doctor said that she did not really need a womb and would not miss it.

Ava was shocked. She considered the doctor’s words callous, and believed that physiological and psychological problems must be associated with a hysterectomy. She had heard stories about women having hysterectomies and finding themselves with a host of other problems, including early menopause and depression.

“Prevention is better than cure . . . the earlier you find out, the greater chance you have of treating it. That is what I discovered.”

A second opinion

The friend who accompanied Ava on her first gynecological visit told her about someone she knew who had cancer and saw a gynecological-oncologist. Ava was flabbergasted. Here she was—an educated, intelligent, and informed person—and yet she did not know that there were doctors who focused on both gynecology and oncology. Desperate for another option, Ava made an appointment with the specialist recommended by her friend.

This doctor immediately calmed her fears about a hysterectomy, telling her it was not necessary and there was no immediate need for drastic action. Cancer of the cervix develops slowly, he explained; the high-grade lesion stage preceding cancer is treatable. After a thorough examination, the doctor said that only a slightly deeper cut into the cervix was needed to remove the abnormal cells. The doctor further alleviated her concerns by explaining that the polyp found in 1995 was not the cause of this lesion.

He explained that she would not need to be put under general anesthesia during the surgery, which alleviated her concerns about associated health risks. Instead, he planned to use a local anesthetic, so Ava would be out of the hospital in a day. “You and I will leave the hospital at the same time,” the doctor joked.

Ava decided to follow the new doctor’s advice. It is a decision she has not regretted. Ava had follow-up tests for a year; after the first three months, six months, and then twelve months later. All of the tests came back negative. A year after the surgery, she is feeling much better and can laugh about the anxiety and initial shock of her diagnosis.

The need for more information

Ava believes women need more information about the resources available for those who suspect or are told that they have cervical cancer or precancer, including the names of doctors who specialize in gynecology and oncology. “We must know our options, all our options,” she says.

She also feels women need to know where to go for information and treatment and with whom they should speak. She stresses that a woman who is told that she has a problem with her cervix should be sure to work with a doctor she trusts. “Education,” she said, “that is the key. More education.”

“Education,” she said, “that is the key. More education.”

A need for privacy

Ava notes that, in her region, people do not have access to state facilities that guarantee the confidentiality of the patient. “This is a small country, and the problem [of cervical cancer] . . . is a very private problem that you want to keep private . . . This would add more pressure to what is already a distressing and embarrassing situation.”

Ava says women must be proactive in their approach to cervical cancer and protect their future health. “Prevention is better than cure,” Ava repeats. “It is. It is better to spend \$200 for a Pap smear than to have to spend \$20,000 for surgery. In any case, the earlier you find out, the greater chance you have of treating it. That is what I discovered.”



About the project

Tamizaje con Tratamiento Inmediato (TATI) is a cervical cancer prevention project carried out in San Martín, Peru, by PAHO, PATH, and the Peruvian Ministry of Health (MOH). Women are screened with visual inspection with acetic acid (VIA) and cytology (Pap smears), and offered immediate treatment of pre-cancerous lesions with cryotherapy when indicated.



Gloria and Bertila

P E R U

Navigating myths and reality



Two stories coordinated by
Irene Agurto

On the outskirts of Tarapoto, a city in the Peruvian rainforest, a handful of women in their late thirties sit in the shade of the palm trees, waiting to see a midwife at the medical center.

They appear anxious. They are about to enter the clinic to be screened for cervical abnormalities—one of the leading causes of mortality among women in Peru.⁶

“Gloria!” calls the midwife. It is Gloria’s turn. A woman who devotes herself to her home and to gathering and selling firewood, 36-year-old Gloria gave birth to her three children in her adobe and thatch home, attended by the community midwife. Gloria usually consults the midwife for gynecological problems, which are generally treated with herbal remedies.

This time, however, she decided to have herself screened because she was afraid of developing the same disease that she believes killed her mother. “At the end, my mother, who had 13 children, bled from her private parts and shriveled up like the snakes that sleep in the sun,” she recalls.

A simple screening exam

Once Gloria enters the clinic, the midwife asks her to lie down on the cot for the examination. “Don’t be afraid, Gloria, this won’t hurt,” she says while she proceeds with the examination.

To detect lesions that could become malignant over time, the midwife applies acetic acid (vinegar) to the cervix. Gloria is embarrassed, but the discomfort is minimal. After the vinegar is applied, whitish spots appear on the pink surface of the cervix, revealing potential precancerous lesions.

To corroborate the midwife’s visual diagnosis, a general practitioner performs a second assessment. He uses an instrument that consists of a flashlight and a magnifying lens. The instrument confirms the presence of the whitish spots.

“You have a small lesion that, if not treated in time, could cause you a great deal of harm,” the practitioner tells Gloria. If left untreated, the abnormal cells could proliferate, destroying other parts of her body and eventually causing her death. Although this process can take more than 10 years, treating the lesions early is essential to maximizing the likelihood of success and preventing death.

Searching for the cause

It is common in San Martín for women to have false notions about the causes of cervical cancer. When asked what she believed was the cause of

her lesions, Gloria said, “My neighbors have told me that you get cancer from lycra underwear, IUDs, too much sex . . . But I think that if it’s not inherited from my mother, it’s God’s punishment for something bad I must have done in the past.”

Despite her fears, Gloria listened to the specialists’ explanation of the treatment for these lesions, and she decided to trust their approach. She underwent cryotherapy, a simple procedure in which extremely cold temperatures are applied to the precancerous lesions to freeze and destroy them. By treating these lesions, cryotherapy greatly reduced Gloria’s risk of developing cervical cancer—and her risk of dying from the disease.

The mythology of the rainforest is a major obstacle for health professionals in the San Martín region. In this majestic area, many women still shudder

when vultures fly overhead because they believe the vultures bring bad health. Many people also believe that, during a gynecological check-up, the doctor who takes a sample of cells for examination is the “pistaco” himself—that is, a mythical being who takes the fat from dead bodies to use as fuel for flying machines.

In the context of myths, community health workers struggle to convince local people to trust health professionals more than the *phantasmas* (ghosts) of the rainforest. The people of the Peruvian rainforest do not have a culture of preventive health care amid their other beliefs. It seems more important to focus on daily chores than to go to the doctor when one is feeling fine. When the pain becomes severe, they may see a doctor—but, in the case of cervical cancer, they often go too late to start effective treatment.

Medicine versus myth



Learning about preventive care
“Bertila Vela!” calls the midwife. Bertila, 42, has four children and grows rice, beans, bananas, manioc, peanuts, and sugarcane to feed her family. She attended only five years of schooling. Television and telephone service reached her community only 15 years ago, and women have to walk for hours to get to the nearest health post.

After attending an educational talk near her home, Bertila recognized the value of preventive health care and was in fact experiencing some symptoms that concerned her. Although transportation to the health center was no simple matter and she would have to put off household responsibilities such as cooking, washing her children’s clothes, and treating an injured mare, she decided to visit a clinic that offers visual screening with acetic acid (VIA) screening for cervical cancer.

“The mythology of the rainforest is a major obstacle for health professionals in the San Martín region.”

During the screening process, Bertila learned more about cervical cancer prevention. She believed that the pain and discharge she was experiencing from her vaginal infection were symptoms of cancer. “It hurts more in the morning, when I’m working on the farm. If it rains, the pain is worse,” she complained to the midwife.

Confirming her health

Fortunately, the screening alleviated Bertila’s concerns that she had cancer; the VIA examination was negative. Bertila had no precancerous lesions—only a vaginal infection that could be cured with some pills.

When she got home, Bertila found that her children and husband had been worried about her absence. Relieved, she hugged them and told them not to worry. “Bertila will be around for awhile,” she said.

As Bertila’s and Gloria’s experiences show, some local misconceptions are being left behind. Through educational talks, health professionals are promoting a culture of preventive health and helping women—some of whom have never visited a health post—get an early chance of ensuring their cervical health.



About the Bolivian project

EngenderHealth works with the Caja Nacional de Salud in Bolivia (the country's social security system) to strengthen the quality of cervical cancer prevention services in their facilities nationwide and enhance screening coverage.

Other perspectives

KENYA AND BOLIVIA

A daughter's story, Kenya



By Jemimah Mwakisha

I remember the call. It was as alarming as it was shocking. Mummy had taken ill and needed urgent medical attention at the Kenyatta National Hospital, the national referral hospital in Nairobi.

My brother Jerry wouldn't explain much except that Mum had fallen sick and he had made arrangements to move her, as the doctors in Mombasa made the urgent referral to the national hospital, some 500 kilometers away. All this happened in just a few days, which left me wondering what would be next.

A family's response

My first reaction was to get to the hospital, but my brother, Jerry, said that would not be necessary. He would accompany Mum to the referral hospital in the city and I could meet them there. "But what is wrong with her?" I asked. I received no clear explanation.

Then, my other brother Willie called, devastated. I knew I could get information from him. "The doctors have said that Mum has cancer of the cervix," he said with caution. "You must get to Nairobi to see her as soon as possible because the problem is serious." After hearing this, I knew there was trouble. As his wife is a nurse, I wondered if perhaps he was privileged to more detail.

That night a blanket of uncertainty and fear enveloped me and, I believe, all of my family members. I had read bits about cancer in newspapers. I knew it was an incurable disease, but that was about it. I had never known anyone with cancer. I kept asking myself, "... what is cervical cancer? How did it manifest itself? Why Mum? Is she going to die? How could God let this happen? Would He take her even after the death of my father?" My mind raced back and forth in a desperate effort to understand it all. I could not think of her suffering from such a dreadful disease. She was so central to our family, especially after my father's death. She was a loving mum and not just to us—our home was the central place for my age-mates and cousins.

Early signs

As the only girl in the family, I was very close to Mum and knew her every pain and experience. For at least two years, she kept telling me about her resumed periods, which I found rather strange. After all, she was over 55. I encouraged her to see a doctor, which she did several times, but on almost all occasions she received no significant information or treatment. The word "cancer" never came up. Instead, she was given various pills that seemed to be a temporary measure. Now I wondered, could the bleeding have had anything to do with it? Would Mum actually die?

Beginning treatment

At the hospital we learned Mum not only had cervical cancer, but that it was advanced. She needed immediate radiotherapy to reduce the spread and bleeding and prolong her life.

“It was all too much to bear,” Jerry reminisces. “In less than a week, we had realized just how close death could be and that our dear Mum was threatened with death. It was such a helpless and harsh situation.”

After a few days at Kenyatta National Hospital, Mum was discharged. Each day she was rolled to a radiotherapy session and came out looking tired. She did not seem worried, as she had not yet been told. It is common for doctors to only inform close relatives when a patient is terminally ill.

The radiation was followed by several appointments, which meant she had to make the full day’s journey by bus from Mombasa to Nairobi, with one of my brothers accompanying her. The process of moving our sickly Mum hundreds of kilometers to Nairobi and observing her getting weaker and weaker each time was traumatic.

For several months after the first radiotherapy sessions, Mum stayed with my brother’s family in Mombasa. The bleeding never completely stopped and she had to have blood transfusions, but the fact that she was surrounded by family and had regular check-ups encouraged her.

Caring for our mother

After about six months of regular check-ups and treatment, Mum’s condition worsened; she was weaker and experiencing so much pain she could hardly do anything for herself.

“We literally had to help her stand up because one of her limbs and one side of her hips had become very weak and painful,” recalls Mbori, Jerry’s wife. They also had to keep her clean and dry since she could not do this herself.

Seeing her worsen over time caused me such misery. I remember the last time she came to Nairobi for a radiotherapy session; she was extremely weak and fragile. In fact, we had to carry her from the car to a chair. I still believed in a miracle and kept praying for God to heal her. We all did. But by then, we had come to accept the problem. We hung onto prayer, waiting for God to do something.

Preparing for death

The doctor finally advised transferring Mum to Voi District Hospital, which was closer to home. This meant she was close to her death. I didn’t understand the meaning of the move; if it crossed my mind, I must have wished it away.

Mum was bedridden and quite distant. She hardly spoke, but was keen to find out about my welfare. I was at a loss for words. The fact that several relatives stayed in our house to assist her made it clear how much she needed help and how near was her death.

It was only about a year from learning of her condition to her death. What a dreadful year. What a dreadful disease cervical cancer is! And yet it can be prevented. If only Mum had received earlier detection and treatment.

A clinician’s story, Bolivia

By Ilana Dzuba

Dr. Oscar Niño de Guzmán Peña calls the first of 20 clients he will see throughout the day. “Good morning, Madam. How are you feeling today?”

Dr. Niño is an important resource in Bolivia, which has among the highest cervical cancer rates in all of the Americas.⁷ As director of the gynecological-oncology clinic and cervical pathology unit at the Hospital Obrero No. 2 in Cochabamba, he works to reduce women’s pain and suffering from cervical cancer—the leading cause of cancer death in Bolivian women—and educates future specialists by training and working with medical residents.⁷

Supporting women and their families

In the last four years, Dr. Niño has treated about 80 women with cervical cancer. He noticed that most became very depressed, angry, and hopeless after being diagnosed; many feared death and the effects it would have on their families, particularly their children.

To respond to these emotional needs, Dr. Niño helped establish counseling and psychological support services at his hospital. Cervical cancer affects families in different ways, and patients’ relatives also require support with coping strategies. His program emphasizes the importance of family counseling to maintain unity, strength, and encouragement.

Because many health care providers find it difficult to talk with women about their cancer diagnosis

in a sensitive, caring manner, they benefit from training in interpersonal communications, especially when they have to deliver warnings of imminent death. “The provider should always transmit warmth and caring. She or he needs to have the patience to listen, listen, and listen some more, even if medically there is nothing more that she or he can do,” Dr. Niño explains.

Reason for hope and despair

Cervical cancer can be prevented easily and economically where effective screening programs are available, therefore, Dr. Niño is disheartened each time he diagnoses a woman with advanced cervical cancer. “There are some frustrating and upsetting days when I want to hang up my white coat because of all the sadness, pain, and devastation that cancer provokes. Some days are so difficult, I feel like I age 10 years. But then I regain perspective and remind myself how important this work is and how much I love to treat these women and try to ensure them a good quality of life.”

Dr. Niño’s greatest moments of satisfaction are when he is able to tell women they have been successfully treated. “These are the moments that bring greatest happiness because not only the patient [is reborn], but also her entire family.”

High-quality cervical cancer prevention programs can ensure that no woman experiences the pain and suffering associated with advanced cervical cancer, and that nobody loses a mother, sister, wife, daughter, or friend to this disease.

Reflections

Each of these stories is unique, and yet the collection illustrates some of the common experiences and issues women encounter when they are screened or treated for cervical cancer. As women and other key stakeholders—policymakers, donors, program planners, communities, health professionals, and researchers—confront the challenges of cervical cancer screening and treatment, these experiences can help guide the way.

Early detection and treatment saves lives

Both Dawn's and Pratibha's experiences illustrate how critical it is for women in their thirties and forties to be screened for precancerous lesions, even if they are not experiencing symptoms. Given cervical cancer's slow progression, screening to identify precancer before it becomes cancer is critical to preventing illness and death.

Cervical cancer is treatable when caught in early stages, and women such as Florence and Grace can recover. Women have a tremendous unmet need for access to treatment options in many parts of the world, particularly in low-resource settings. When women do experience symptoms that remain unaddressed—as Jemimah's mother did—their cancer has often progressed beyond treatment. This underscores the need to screen women in their fifties who have never been screened—in addition to women in their thirties and forties—as they are at high risk for cancer.

ACCP research findings suggest that it is possible to implement organized cervical cancer prevention programs in low-resource settings that will reduce the burden of disease. The Alliance's demonstration and research projects—particularly those focusing on a screen-and-treat approach, which involves just one or two visits to a clinic where test results and treatment can be provided—hold great promise for increasing women's access to more feasible cervical screening programs in developing countries. In Kenya, Thailand, India, South Africa, and Peru, ACCP projects have integrated cervical cancer prevention services into existing health systems.

Family and community involvement is key to programmatic success

Families and communities play an important role in cervical cancer prevention. Understanding and support from husbands, other family members, and communities are critical to women's participation. In Pratibha's story, for example, the community leader's approval was essential to her decision to be screened. Similarly, Helen's husband was the key influence on her decision to seek services.

Women are often advocates for one another as well. As shown in Dawn's and Florence's stories, cervical cancer survivors—as well as women who have simply undergone screening or treatment of precancerous lesions—can provide crucial encouragement to other women considering screening.

Service delivery barriers are significant but solutions do exist

The many difficulties that women face—getting to clinics and hospitals, balancing their own care with the demands of work and childcare, and cost concerns—are common threads throughout these stories. In low-resource settings, some women must walk for hours or take a long bus ride to get to a clinic, provided that they have the funds needed to get there. Once at the clinic, they often must wait in long lines for screening. Efforts to remove or mitigate these barriers can greatly increase women's use of services. Indeed, the convenient location and lack of fees at the ACCP's clinic in rural India facilitated Pratibha's access to screening and treatment.

In addition to logistical challenges, women face very real emotional hurdles as well. Ava's need for confidentiality, Pratibha's relief that a woman would conduct her examination, and Helen's fear of pain highlight some of the issues that programs should consider when providing women with information about the screening process.

Confronting misperceptions and raising awareness is imperative

Fears and misperceptions often prevent women from seeking screening and treatment services. In addition, cancer is considered a death sentence in many regions; people would rather avoid a test that could prevent it than investigate their status.

Raising public awareness to curb misperceptions and promote understanding—for example, by showing videos and having prominent people give speeches on cervical cancer—is an important part of cervical cancer prevention efforts. By increasing awareness, programs can encourage early screening and strengthen the likelihood that lesions can be successfully treated.

Call to action

One of the most poignant aspects of these stories is the extreme hardship that women and their families in developing countries face and the compounded adversity cervical cancer presents. When women have cervical cancer, families must confront the illness itself—and the potential loss of a cornerstone of their families' well being. When women have already lost their husbands—such as Dawn and Florence—their role as caregivers and wage earners becomes even more critical.

Raising policymakers' and donors' awareness that cervical cancer is a preventable disease can help ensure that all women have an opportunity to access services. Increased awareness can lead to actions that support cervical cancer prevention programs. Even in the most remote settings, these programs can save the lives of tens of thousands of women each year.

What can you do?

Everyone can promote cervical cancer prevention, especially by raising awareness among colleagues, friends, and family. In addition:

- *If you are a global or national policymaker*, you can help prioritize cervical cancer prevention, become familiar with current research on best practices, confirm that global guidelines and policies are consistent with this research, and encourage local community leaders to promote cervical cancer prevention in their regions.
- *If you are a donor*, you can invest in cervical cancer prevention programs and research and encourage decision-makers to prioritize cervical cancer prevention.
- *If you are a researcher*, you can communicate with other researchers about new research findings and explore conducting such research in your region.
- *If you are a program planner or health professional*, you can explore whether your programs and services are consistent with the latest research findings and programmatic evidence and lobby local policymakers to prioritize cervical cancer prevention.
- *If you are a woman over 30*, you can get screened and encourage your mothers, sisters, and friends to do the same!

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The women appearing in this publication are not necessarily the women interviewed for these stories.

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For more information on ACCP’s work and publications, please visit www.alliance-cxca.org.

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