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In Zambia, a formula to fight AIDS

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Karisa King
Express-News

MONGU, Zambia — In the moments after Pumulo Sipatonyana learned the sickness attacking her weak and pregnant body was AIDS, she silently pictured her own death, then asked a desperate question: What about my baby?

A nurse told her medicine might spare her newborn, but her breast milk still could carry the AIDS virus.

There was an alternative, the nurse said. A new clinic soon would be giving free infant formula to mothers with HIV.

In this hot and sandy outpost of thatched huts where women face beatings and abandonment for disclosing they have the virus, the program offered a rare but stark choice: Pumulo could breastfeed and risk infecting her baby, or nurse the child from a bottle, a practice so uncommon here that she would draw certain suspicion of her disease.

"I wanted to do everything I could," says Pumulo, who is 37 and soft-spoken, her stick-thin body slowly wasting to AIDS. "I made a promise to myself."

Pumulo steeled herself against the consequences and became the first of 78 women to join the program, run by San Antonio's Sisters of Charity of the Incarnate Word.

The clinic, barely a year old, reaches women from the lowest rungs of Mongu, a remote town with deeply rutted roads, set in the poorest region of one of the poorest countries in the world.

The project tackles one of the most complex and intractable problems of the AIDS pandemic. In southern Africa, the epicenter of the crisis, the disease killed more than half a million children last year, nearly all of them infected at birth or through breastfeeding, according to the United Nations Children's Fund.

In Zambia, a country with half the population of Texas, an estimated 30,000 children each year are newly infected by their mothers. Half of them will die by age 2.

Yet few charities or relief groups in Zambia attempt to navigate the risks and costs of providing formula to HIV-positive mothers. Bad sanitation and dirty water often make powdered milk deadly for infants, and the conspicuous baby bottles mark the women just as surely as a scarlet letter.

For Pumulo, her resolve to join the clinic came with a decision to tell her husband that she had AIDS. "He told me: You're sick. I'm not sick. You brought this," she

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INTERACTIVE GRAPHIC

A San Antonio program brings infant formula to Zambia in an experiment to stem one of the growing crises in the AIDS pandemic -infection through mother's milk.

Sisters long have offered aid to the poor, dying

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He was gone within weeks, returning later only to pick up a pair of trousers and their oldest child, a 6-year-old daughter. Pumulo hasn't seen her since. Her baby girl, Naomi, who has delicate features and short braids with rainbow-colored beads, stayed with her only because Pumulo frantically argued that she was too young for him to take.

"We're aware that these women are risking a lot," says Incarnate Word Sister Walter Maher, the San Antonio nun who spearheaded the project. "They have tremendous courage."

Maher was inspired to start the clinic during a visit to Mongu where the progressive order of nuns began their most recent mission in 2001. The five sisters posted here teach at Catholic schools, run an AIDS hospice and give food and financial help to orphans.

The growing milk program cuts to the core of a bitter controversy over how women like Pumulo should feed their babies.

The project contradicts decades of the "breast is best" philosophy that a mother's milk is far safer and provides better nutrition than any other type of food — an ideology that prevails in much of Africa even in the face of HIV.

Because infected women face only a 10 percent to 20 percent chance of passing along the virus in their breast milk, proponents say the benefits of breastfeeding outweigh the risk of HIV.

The U.S. has all but eliminated the spread of HIV from mother to child by cutting out breast milk and using sophisticated medicines that keep the virus at bay.

In African countries like Zambia, the recent arrival of a cheap and easy drug treatment has underscored the breastfeeding dilemma. Women take a single pill of a drug called nevirapine during labor, and babies are given a few drops of it after birth. The treatment reduces the chance of infection by nearly half. But the very same babies who are saved from HIV may become infected months later from breastfeeding.

"As we expand these programs, the next question that concerns all of us is how do we deal with the breastfeeding risk," says Chewe Luo, the senior HIV adviser for United Nations Children's Fund.

For women in Mongu, where nearly one in four expectant mothers has HIV, the Incarnate Word sisters hope to provide that answer.

As the earliest babies to enter the program now grow old enough to test for HIV, Pumulo would be among the first to know her child's fate.

Filing into the clinic

Sheltered from the harsh sun, the women wait outside the one-room clinic in the shade of a muzauli fruit tree. It's Friday, and just as they do every week, the women have come to pick up the yellow tins of powdered formula for their children. The women sit close to each other on straw mats in the sand, chatting softly, sandals kicked off. There are no men here.

Like Pumulo, many of the women have been rejected by their husbands or boyfriends after revealing they have HIV. As the women wait for their numbers to be called, they swap babies freely between their laps and tell their stories.

There is Precious Kashweka, 17 years old and wearing pigtailed. She deeply wants to finish high school, but can't afford the \$27 tuition. Three years ago, AIDS killed her older sister at age 15, then took both of her parents last year. When her boyfriend learned she had the virus, he refused to be tested and left. She lives with her 1-month-old baby girl and her grandmother.

"I'm alone," she says.

There is Penelope Mundimba, who was six months pregnant when she found out she was infected with HIV. When she told her husband, he handed her \$50 and she was thrown out of her brother-in-law's house.

And there is Nyambe Muimui, who has a full-throated laugh and carries herself with confidence. Rejected by her boyfriend and her own family, she lives with her five sons in a leaky grass hut and worries about their future if she dies.

"My cousins just laugh at me. They won't take them in," she says. "They told my sons: You'll be like psychiatric patients, going and picking food. They'll just leave them like that."

One by one, the women file into the clinic in a low-slung concrete building. The tiny patients, strapped to the backs of their mothers with brightly colored wraps, are pudgy-cheeked, with meaty little arms and calves. The women ladle the babies onto a small white scale, and volunteer nurses from the local clinics weigh each child and chart their growth.

"They all seem to be right on their growth marks," says Dorinda Escamilla, the Christus Santa Rosa nurse who designed the program for the Incarnate Word Sisters.

She has come on one of her frequent visits to oversee the project, which she tailored to meet the greatest risks the babies face. For women who take part in the government's nevirapine treatment and are referred here, the clinic provides the formula for a year when the infants are tested for HIV.

It also gives the women a year's supply of medicine to guard their babies against pneumonia, the No. 1 killer of children under age 5.

One of the most immediate dangers is the water used to mix the formula. Water tainted with intestinal bugs can cause diarrhea, and infants who don't exclusively breastfeed are 25 times more likely to die from it, according to UNICEF. The women receive chlorine and plastic containers to treat the water, along with bottles, sippy cups and soap. Nurses examine the babies each week and teach the mothers how to safely prepare the milk.

"We work really hard on education and follow-up. This is a complete package," Escamilla says. "We're the only ones doing this."

The project isn't the first to give formula to HIV-positive mothers. Between 1999 and 2002, UNICEF provided formula in eight African countries, including Zambia. But the pilot programs, which were short on counseling for the mothers, soon closed amid questions about whether formula was safe and cost-effective.

Escamilla hopes the project will become a template for a government program that would give formula to larger numbers of Zambian women. As more babies in the program are tested for HIV, the clinic also may become grounds for study in an area where answers have been elusive.

But much of the clinic's success hinges on the ability of the women to learn something that is far more difficult to teach — standing up to the stigma of AIDS.

The danger is that mothers may sometimes breastfeed to avoid suspicion of HIV, a decision that can be deadly for their babies. Experts say the pressure to breastfeed, in a culture where men and mothers-in-law make the decisions, poses a risky hurdle for projects like this.

The persistent stigma

In the early months of the clinic, two mothers had been missing their weekly visits, and when they eventually returned to pick up their milk, they told nurses that they had been breastfeeding. The women were kicked out and Escamilla polled the first 17 mothers in the program. All but six of them admitted to breastfeeding once or twice to appease family members.

Since then, the nurses have begun checking on the mothers at home and lead group talks about coping with the social stain of HIV.

In a country where AIDS killed 98,000 people last year and 1.1 million people live with the disease, the persistence of the stigma can be puzzling.

The devastation wrought here by AIDS is staggering, yet it has become an ordinary part of life. It has left nearly a million children without one or both parents, ravaged an entire generation of adults in their prime and reduced the average life expectancy to 40.

But the pervasiveness of the virus has not blunted the stigma surrounding it. AIDS remains entangled with the darkest of taboos — death, sex and infidelity. Rather than name the disease, Zambians often call it "slow puncture," a reference to the way life slowly leaks from the afflicted.

So strong is the secrecy and denial surrounding AIDS that many who are sick won't seek the free, lifesaving drugs that have become available in Zambia in the last two years.

Against that backdrop, the simple act of bringing the women together offers a release from the isolation of HIV.

"When we come here we look at each other. We're all the same," says Joyce Kaongolo, who relies on the support of the other women even though her husband has remained by her side. "Without the program, I wouldn't know what to do. It

has changed my life completely."

The luxury of being able to choose how to feed their babies also has imbued them with a sense of control. Kaongolo says she felt the weight of her decision, but did not agonize over it.

"I said I want my child to live, not to die," she says. "I thought hard and at last I said I can't ignore it. I knew what I was doing."

Informally, as the women wait outside the clinic, they confide in each other. They talk about the whispers they hear when they feed their babies on the street. They talk about intimate things like how to convince their partners to wear condoms. They talk about dying and what it would mean for their children. Mostly, they talk to each other when there is no one else to listen.

The first HIV tests

Pumulo anguished over the question for more than a year. Countless times she looked into the watchful brown eyes of her baby girl, Naomi, and searched for signs of whether she has escaped the virus.

Pumulo scrutinized the baby's every cough and couldn't help but compare Naomi's growth to her three older children.

"This one, she's smaller than the others," she says. "She's late on walking."

More unsettling were the girl's frequent bouts with malaria, diarrhea and skin rashes, which sent her to the hospital four times.

Two weeks ago, shortly after nurses told her that Naomi was old enough to test for HIV, Pumulo resigned herself to whatever the results might be. A few days earlier, two other babies in the program had been tested for the virus — one was negative, one was positive.

Pumulo dressed Naomi in a pretty black skirt and white blouse, which she had bought at the market, and carried the girl 40 minutes to the hospital for the test. A nurse led them into Room No. 7. She asked Pumulo if she was prepared to learn the results.

"I'm ready," she told the nurse.

As Naomi sat on Pumulo's lap and cried, the nurse stuck a needle into the girl's lower left arm. Pumulo silently watched the girl's red blood rise into the syringe. The nurse set the needle on a tray and then told Pumulo to come back in a week for the results.

On Thursday, she returned to the hospital and the same nurse delivered the answer: Negative for HIV.

Still, Pumulo is left with fears about how long she herself will survive. Although she takes medicine to stave off the disease, malaria and pneumonia have withered her body to a gaunt 115 pounds.

On bad days, she is too sick to leave bed. Then, her two older sons, who are 16 and 11, fetch water and take care of Naomi. On good days, she sells pastries at a roadside market and finds inspiration in her best friend who she met through the milk program.

"We do encourage each other," she says. "Together we decided: Let's live the life we used to have."

In that life, she recalls, she married for love when she was 21 and headstrong enough to defy tribal traditions. She came from the Lozi tribe, he was a Bemba, and her mother-in-law never accepted the marriage. Eventually, his family insisted on another bride, forcing her and the boys out of the house.

She met her second husband at a restaurant where she worked as a cashier. He told her he already had a wife, and wanted her to be his second. He promised to help her start a business, and though he never followed through, he supported her and they had a daughter. He accepted her second pregnancy and continued to support them. Then she tested positive for HIV.

"That's when he stopped coming to the house," she says.

He accused her of having sex with other men, took their 6-year-old girl and sent her to Livingstone to live with an aunt.

Four months ago, his first wife died, apparently from AIDS.

Now, Pumulo lives in a cramped apartment with no water, a food cupboard that often is empty and a single light bulb that goes on at dusk when the landlord flips

the switch. When she is gravely ill, her parents make the long trip from their village to see her, a five-hour walk through the bush and another hour by bus.

Recently, she asked if they would take care of the children if she dies.

"Don't say that, you'll be OK," her father told her, crying.

"I just said, 'Yes, I'll be OK.'"

No good answers

Only a few years ago, helping mothers like Pumulo was considered a lost cause.

The drug treatments that had proven so effective in wealthy countries were too expensive and complicated for the developing world.

But in 1999, a breakthrough study found that if mothers and their babies each took a single dose of the antiretroviral drug nevirapine, the transmission could be cut by nearly half. Since then, the growing availability of the drug in poor countries including Zambia has become one of the greatest victories against AIDS.

The treatment, which costs only a few dollars and appeals to women because it's easy to conceal, has shielded thousands of newborns from infection since it began here in 2001.

That success, however, opens questions about how to continue protecting babies spared at birth, especially in countries like Zambia where few women can afford formula and often breastfeed for up to two years. Some of the brightest minds fighting AIDS disagree on the best approach. And United Nations guidelines on the issue are vague.

The recommendations tell mothers with HIV to avoid breastfeeding as long as formula or other substitutes are safe, affordable and culturally acceptable. But in Africa, where contaminated water and bad hygiene prevail, many say giving out formula is too risky.

"It's not feasible to do that here. Plus, it could be harmful," says Dr. Elizabeth Stringer, an investigator at the Centre for Infectious Disease Research in Zambia (CIDRZ), which supports the Zambian government's distribution of nevirapine.

While formula guards against HIV, more babies may end up dying from diarrhea and other diseases.

Breastfeeding became more appealing with the results of a 2001 study. It showed that babies who strictly breastfed — with no other foods or liquids — were about as likely to contract HIV as infants who had no breast milk at all. The results also showed newborns who fed on a mixed diet of breast milk and other food were much more likely to become infected.

The scientific reason for the finding is not clear, but the speculation is that other foods irritate a baby's gut, making it easier for the virus to be absorbed.

The study lends support to the most common recommendation for women in most African countries, including Zambia, to exclusively breastfeed for six months.

But exclusive breastfeeding brings its own risks. Although African women typically breastfeed, they also give their babies porridge and water, a practice that is difficult to break. The advice also clashes with a grim reality in Zambia: women who breastfeed often don't want to stop after six months because they have nothing better to give the baby.

"The bottom line is that neither option is really good. That's the whole conundrum," Stringer says. "It's just a big thorny problem and I admire the people who are trying to solve it because it is so complicated."

Some, including Stringer's husband, Dr. Jeffrey Stringer, the director of CIDRZ, question the reliability of the study and believe that the push to strictly breastfeed stems from a lack of alternatives.

"It's whistling in the dark," he says. "There's nothing to do for these women, so let's give them something and tell them to do exclusive breastfeeding."

To Dr. Arthur Amman, a pioneer in the field, there is little scientific question that formula feeding is the best option.

"This isn't an issue of science any more. We know what to do. It's a matter of economics," he says. "If you have the funds to provide sustainable formula and it can be done safely, then that's what you should do."

For now, it's not clear whether the approach of the Incarnate Word Sisters will prove to be effective. So far, seven babies have died, apparently from pneumonia

and diarrhea, a number that's not high enough to set off alarms about safety.

"It doesn't appear to be a problem," says Njahi Sitali, who works with CIDRZ in Mongu and has watched the program up-close. "To me, it's really the answer for these mothers."

The biggest challenge for the project, if it is to expand, remains the fear and denial surrounding HIV. For every woman who joins the program, many more refuse the option.

"We believe the stigma is the problem," Sitali says.

Escamilla, the nurse overseeing the project, had hoped that by now the project would be twice its size. At the local clinics that refer women to the program, breaking through to expectant mothers had been hard. During her visit to Mongu in November, Escamilla decided to try something new. She asked if any women in the program would speak about her decision to not breastfeed. One woman volunteered.

Breaking the silence

Outside the Liyoyelo clinic, run by the government in Mongu, a dozen pregnant women sit in a circle of chairs. The small clinic serves as a prenatal counseling site and the women are here, in part, to decide whether they want to take HIV tests.

Nyambe Muimui, who joined the milk program two months earlier, readily agreed to speak here out of conviction, though she'd never publicly revealed her disease. Talking about it can bring brutal consequences, she knows. She was two months pregnant when she told her boyfriend she was sick. He left her and her first four sons from a previous marriage. Many in her own family have turned their backs.

Without help and too sick for stable work, she and the boys often go hungry for days. When it rains and her small grass hut leaks, she sets out plastic bowls to catch the water and lays the baby under a rainbow-colored umbrella.

To survive, her two oldest boys, who are 15 and 11, carry fruit to the market and sell it. Half the profit goes for porridge for the boys and the other half goes to buy the fruit, which her boys then resell at the market.

Despite it all, she is fervent about being open. She is poor, African, uneducated and marginalized, but she also is more than her statistics might suggest.

"I'm not going to hide my (HIV) status," she says about her decision to speak to the group. "They can learn from me."

Muimui surveys the group, which includes two husbands. The nurse in the middle of the circle is struggling to lead a discussion about AIDS.

"What is HIV?" the nurse asks.

Blank faces stare back in painful silence.

A few minutes later, Muimui takes the stage. She speaks forcefully about her life. She talks about how she escaped death from tuberculosis, only to learn she had AIDS. She talks about how she and others can live with the virus, thanks to new medicine, and she urges them to not let shame keep them from getting help.

"I'm together with my sons, rather than I'm dead," she tells them.

Then she talks about her choice to bottle feed, and how she has grown accustomed to the stares.

"Why should I hide?" she asks them. "I'm free. I'm open."

After her talk, some of the women tell her that the most astonishing thing was not what she said, but that she said anything at all.

Two days later, Muimui returns to the Incarnate Word Sisters clinic for the group's last gathering before the nurse Dorinda Escamilla returns to San Antonio.

The women in the program had talked about doing something special for her as a way to show their gratitude. Muimui suggested writing a song and singing it. But the suggestion touched off a debate.

"Some of them refused to sing because people are walking by and they'll hear it," she says. "And then from there they will start asking so many questions."

As Escamilla leaves, Muimui prompts the other women and they launch into the song in their native Lozi tongue.

Translated, it goes like this:

"Dorinda, continue your talent for the work you are doing," they sing. "Come and see the work you are doing."

As they sing, they raise their voices loudly together in soft harmonies, stomp their feet and sway their hips to the beat.

Their voices carry over the walls of the clinic's compound and into the street, for everyone to hear.

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