

Home-Based Care: The Healing Power of Human Connections

# Spotlight on Grassroots

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mothers2mothers, Lesotho; Photograph by Ryan Tantuan



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# Life-Saving Work from the Heart

**F**or communities living through the AIDS pandemic, trust means everything. Recently, one of our partners in South Africa told us why communities trust them so deeply. “We know about sickness. We have love and passion, and are well-trained on home-based care. We’re doing home-based care from the bottom of our hearts. Actually, it’s in our veins.” Some of the staff and volunteers are HIV positive or have lost family members to the illness.

It’s extremely difficult to quantify “love,” and “care from the bottom of our hearts,” but hundreds of grassroots organizations that are turning the tide of HIV & AIDS have done just that. Over the past 16 years, our community-based partners have shared more than 10,000 pages of documentation about their work. Most refer to resources—antiretroviral (ARV) medication, health clinics, school supplies, and job training—but at the core of their stories are the real reasons for their successes: increased resilience, psychosocial wellbeing, family solidarity, community engagement, and human rights.

As the Maasai Women Development Organization (MWEDO), in Tanzania, told us: “Our carers make sure that information about health and HIV reaches the community.” That community typically lives in a rural area poorly served by mainstream healthcare facilities where being HIV positive is too often associated with stigma and discrimination. This is where MWEDO steps



Siyanqoba, South Africa; Photograph provided by Siyanqoba

in. “They take our needs to heart,” said one of their clients living positively with HIV. MWEDO’s home-based caregivers start in homes, but they spread the word at church gatherings, marketplaces, and village meetings. “People listen to the carers because they’re connected to a trusted organization,” MWEDO said. “The women now speak with confidence about issues that in the past they could address only in secret.”

How does this trust and confidence develop? “It’s the individualized care that we’re able to provide in a loving, compassionate and positive manner,” said Hillcrest AIDS Centre Trust, in South Africa. “The majority of our home-based carers are impacted by HIV & AIDS themselves, either directly or within their families... They have huge hearts, are incredibly humble, feel they are called to care for the sick and the dying, and are incredibly strong and courageous – able to witness heart-wrenching tragedies and yet, somehow, still smile and carry on loving the next patient.”

## “The women now speak with confidence about issues that in the past they could address only in secret.”

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Because of organizations like these, the despair underlying the HIV & AIDS pandemic a few decades ago has given way to hope. Recently, speaking with 40 community-based organizations engaged in home-based care (out of the hundreds with whom we’ve partnered), we heard that they work with 50,000 people and their families, nearly half of whom are grandmothers, children and teenagers. For many people living with HIV, home-based caregivers help to move to a place of optimism and resilience. Tens of thousands of home-based caregivers provide this critical support across sub-Saharan Africa, the vast majority of them women, usually working as volunteers.

Kiambu People Living with HIV/AIDS, in Kenya, summarized it concisely when the organization said that becoming healthy is as much a “battle of the mind” as it is a physical struggle. “One of the most important changes we see in our clients is that they start to actively engage in the routine of their daily lives again,” added Catholic AIDS Action, in Namibia. “Our beneficiaries are facing all kinds of stigma and discrimination, and they’re finding the courage to accept the challenges of their lives and to continue living. We’re also seeing that they can disclose their HIV status to family members without fear, and are willing to join the mutual support groups we run for people who have been diagnosed positive for HIV.” Beyond the will to live, these stories show the will to reach out.



Swaziland Nurses Association Wellness Centre for Health Workers and their Families, eSwatini;  
Photograph by Claudia Ramos

# Trust Grows through Home-Based Care



Trainees at a workshop for Traditional Birth Attendants (TBAs) learn how to support and care for their clients. Maasai Women Development Organization (MWEDO) in Tanzania, trains these community volunteers who support and take care of young women during and after birth and refer women to clinics and hospitals; Photograph by Alexis MacDonald/SLF

**T**he stories from our partners point to trust again and again. They work in 15 countries in sub-Saharan Africa, providing care and support to women, grandmothers, children, and communities living with HIV & AIDS. “They’re trusted because they’re part of the community and they reside in the community,” explained Action for Rural Women’s Empowerment in Uganda. “Some of them are HIV positive, so they really understand the needs of clients. They’re within reach whenever they’re needed.” Today, after the widespread introduction of ARV medication, partners tell us that the primary challenge isn’t caring for the terminally ill; it’s supporting people and their families to lead full, healthy lives.

Home-based care has been key in supporting people, especially in helping them to access and undergo ARV therapy. Some people are malnourished or live with nutritional deficiencies, due to poverty, which means their bodies can’t easily absorb the ARV medicines or possible side effects. Other people, mainly in rural areas, can’t afford the transportation costs to get to faraway health centres: “This keeps them from getting treatment, as the walking distance from their homes to the hospitals

and clinics is just overwhelming,” explained Hope Tariro Trust (HTT), in Zimbabwe. Still others are terrified that their husbands or families will target them if they find out they have HIV, so they don’t access the medicines in the first place. Also, many teenagers and children living with HIV contend with social and emotional traumas in taking multiple pills many times a day in communities that shun them or discriminate against them. For all these reasons and more, ARV adherence is one of the biggest challenges in the response to HIV & AIDS. With home-based care, HTT and our other partners support people as they try to overcome these barriers and traumas.

An estimated 25 million people in sub-Saharan Africa live with HIV, more than double the number in the rest of the world, according to UNAIDS. Just over half of those individuals are maintaining successful ARV therapy. Our partners report ARV adherence rates in their communities that are well above averages in their regions. And more than half of the organizations report adherence rates above 95%, which are astonishing, inspiring successes.

# “We Have a Saying: If You Have Hope, You Have Everything”

**L**istening to our partners, we hear the theme of human connection over and over – connections that overcome personal isolations that can arise with HIV & AIDS, connections between homes and healthcare facilities, connections to job training and employment opportunities, and connections to counsellors, to grandmothers with parenting advice, to male role models who work with men living with HIV, and to child-protection agencies if needed.

Organizations report tremendous results, primarily because of home-based caregivers, who:

- 1. take a holistic approach to physical, mental and emotional wellbeing, while addressing challenges related to education, employment and family and social ties; and**
- 2. create continuity of care between people's homes, communities, and government health services.**

As with the work of MWEDO in Tanzania, the initial reason for a home visit in Botswana, Congo, Lesotho, Namibia, Rwanda or Zambia may be to assess an individual's health, but that visit will likely expand to discussing difficulties with family, the need for school assistance, or fear and anxiety related to ARV treatment. Caregivers take a holistic approach to complicated situations. For example, hunger and nutritional deficits can be serious problems, so community-based organizations often provide food baskets, as well as guidance on food preparation and creating vegetable gardens. In addition, the stigma and shunning that people living with HIV face can be emotionally isolating and devastating, so home-based caregivers help to restore supportive, loving family environments. On top of that, financial pressures can be catastrophic; home-based caregivers respond by linking families to income-generation and training opportunities, including small-business-development groups.

Deep connections and trust are also developed when community-based partners, such as Kimara Peer Educators & Health Promoters Trust Fund, create continuity of care between schools, job-training centres, mothers groups, kids clubs, savings-and-loans groups, and formal healthcare systems. With Kimara Peers, savings-and-loans initiatives were initially set up for people in HIV support groups, but all 26 initiatives are now open to anyone who needs them.



Kimara Peer Educators & Health Promoters Trust Fund, Tanzania; Photograph by Alexis MacDonald/SLF

**“We encourage our clients never to give up hope no matter what the situation, and our saying is that ‘If you have hope you have everything.’”**

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Swaziland Nurses Association Wellness Centre for Health Workers and their Families, eSwatini; Photograph by Claudia Ramos

Continuity of care also includes connections to regional healthcare systems, so that clients can receive the best possible care. When someone can't make it to a treatment clinic, home-based caregivers visit to find out what happened, and to offer medicine, first aid, counselling, or referrals. “Our care workers do all of the above in close consultation with the health workers at the nearby accredited health facility,” explained Action for Community Development (ACODEV), in Uganda. Also, ACODEV's staff and volunteers work in out-patient departments, antenatal-care clinics, and ARV clinics; they weigh patients, offer health education, assess emergencies, and manage referrals between facilities. Clients thrive when they're connected to both formal healthcare systems and community-based organizations. “We work as partners with each other,” added mothers-2mothers, in Lesotho. It's similar with organizations in Kenya, Ethiopia, eSwatini, and Tanzania, as explained by

Ekwendeni Hospital HIV/AIDS Programme, in Malawi: “A referral system has been established between the hospital and our organization that's well known by both our community volunteers and the health-facility staff. When a home-based care patient needs further medical help, the volunteers refer them to the hospital, and the hospital will also refer people to us for ongoing support.”

The goal is hope, health and a vibrant life. “We encourage our clients never to give up hope no matter what the situation, and our saying is that ‘If you have hope you have everything,’” said Kyetume Community Based Health Care Program, in Uganda. “When we carry out our home visits we meet with different kinds of families who are facing so many different problems, but, with the psychosocial support we provide, these families always find a way to get through everything that's disturbing them. The ones who went astray bounce back fully, energized and ready to live.”

# Pilly - From Home-Based Care to Peer Mother Counsellor

Three years ago, in Tanzania, when Pilly and her husband found out they were HIV positive, they didn't tell their families or community, but Pilly needed to talk to someone. Her husband refused to take his antiretroviral (ARV) medication, they faced serious financial problems, and she was raising two teenagers. One day, she connected with Rose, a home-based carer with Kimara Peers, but Pilly's husband continued to refuse to take his medication, and he passed away. Pilly was devastated, and Rose stood by her.

Pilly's family abandoned her when they found out she had HIV, leaving her with no income or social support. She felt abandoned twice: by her husband and her own family. However, Rose and other caregivers continued visiting, offering counselling, food, and support for school fees, books, bags, and other materials for her children. The Kimara Peers team also worked with Pilly on entrepreneurship training, and she started a home-based business making liquid soap and selling kitenge fabrics. Over time, the team started to feel like Pilly's family.

Pilly never dreamed she would join Kimara Peers as a caregiver. During her first workshops with the organization, she'd been at the point of despair and afraid to talk. But as she became more involved, she made friends, and people were drawn to her personality and joyful energy.

Last year, she trained as a Peer Mother and began working with women who were diagnosed with HIV. It was a remarkable turning point. She counsels mothers about safe breastfeeding habits and HIV testing, and she provides referrals to home-based care. She also reaches out to mothers who don't show up for appointments, helping them through anxiety and fear.

Life is good now: Pilly's new businesses generate a steady income, her children are getting an education, and many women are benefiting from her skills. Now on ARVs, Pilly is fit and healthy, and the HIV virus is virtually undetectable in her system. Three years ago, this wasn't what she foresaw for herself and her family. Today, she's a community leader.



L-R: Pilly's teenage daughter, Wiso, Janeth, Pfiraeli and Pilly Kimara Peer Educators & Health Promoters Trust Fund, Tanzania; Photograph provided by Kimara Peers



Catholic AIDS Action (CAA), Namibia; Photograph by Alexis MacDonald/SLF

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