

SPOTLIGHT ON

# GRASSROOTS

SPRING 2016

## Home-Based Care

*"Now is the time to do more, not less!"*



*the Stephen Lewis*  
FOUNDATION

**S**INCE THE EARLIEST days of the AIDS epidemic, home-based care has saved countless lives, restored hope and dignity to the sick and dying, and provided care to families and communities all across sub-Saharan Africa.

The frontline workers at community-based organizations in sub-Saharan Africa live with the reality that their region is home to almost 70% of those living with HIV, while some countries still have fewer than two doctors for every 10,000 people. In the early years, when families and communities were being devastated by the harrowing combination of poverty, hunger, and HIV & AIDS, these community-based organizations quickly understood that it was going to take a powerful grassroots response to fill the gap left by beleaguered and often inaccessible national healthcare institutions.

As a result, home-based care has become one of the most effective treatment and prevention strategies in the struggle to subdue the AIDS epidemic since its devastating emergence. The solace, emotional support, and medical care offered by home-based care workers are core elements of survival and hope for the future. Home-based care workers—primarily women volunteers, many HIV positive themselves—often walk for miles, ensuring that medicines are taken properly and consistently, nutritional needs are met, stigma is reduced, food packages are delivered, and emotional support is provided to women and children coping with trauma and illness. Their deep connection to the communities in which they work gives grassroots organizations invaluable insight into the needs of the families they visit.

Alexis Marchand/AGF

Globally, there is an increasing focus on getting lifesaving antiretrovirals (ARVs) to Africa. This is absolutely vital—currently only 50% of those who need ARVs have access to them. However, drugs do not deliver nor administer themselves. Community-based organizations engaged in home-based care play an indispensable role in ensuring the full life-saving potential of these medicines.

Recently, we were privileged to have a conversation with a group of our partners about the ways in which home-based care has resulted in unprecedented insight, trust, access, and evolution on the path from diagnosis to positive living, and from awareness to prevention.

### Time to do More

**Ndinini:** We have miles and miles to go. If home-based care were to disappear, we would go backwards; we would lose ground. When this kind of thing does happen, people go back to not trusting what you have been preaching. This is not the right time for the internationals or the nationals to write off home-based care. But they are doing that. Even with HIV in our country, you can see that it is becoming less and less of a priority in terms of funding. Meanwhile, people are just starting to understand the risks. Now is the time to do more, not less!

**Lorenz:** We certainly cannot deny that ARVs are doing a lot of good. People are up and running again. But we also cannot deny that even the up-and-running clients can fall sick once more. And when they fall sick they will need our support to get better... In particular, we are aware that we are the fragile link between the health facilities and the community. Because we know the health facility will not come pick people up and say, “Hey, why haven’t you taken your treatment?” Only the home-based care providers will do that.

**Grace:** In Kenya today, the govern-



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*“The people who are saying that HIV is coming to an end certainly haven’t asked me.” —GRACE WARUGURU*

ment has actually done a reasonably good job of securing ARVs. So the drugs are there, but so is stigma. The drugs are there, but so is poverty. And until the stigma and the poverty are gone, we are still talking. We are still dealing with issues around access, adherence, and much more... The people who are saying that HIV is coming to an end certainly haven’t asked me. If we say that AIDS is over then we are going to

go back to 2003, and it will be as though all the achievements we have made over the past two decades will disappear. It’s a challenge for us in the grassroots community to be able to articulate that: Yes, we have made progress, but still we have a long way to go!

**Ndinini:** In many ways, home-based care has always been there. In fact it was probably the *only* care that many people received. There were no alter-



A home-based care worker with Catholic AIDS Action in Namibia visits a community member in her home.

natives. Even though they were not always called “home-based care workers,” those same people continue to take on the job of caring for community members affected by HIV & AIDS, and they also provide other kinds of care for the sick. So the support we offer is very traditionally-rooted. It’s something that has always been there and needs to continue. We cannot afford to have less of it just because we’ve seen some specific improvements here or there. This is something that has existed for generations.

### Stigma Can Be Broken!

**Lorenz:** Home-based care is very useful in terms of reducing stigma. If there is a person who has just moved into a new settlement, it can be such a burden for them to go to a health centre and get their ARVs, because they will be drawing attention to their status. But home-based care allows us to reassure that person and say: “It’s okay. There are other people here accessing ARVs. There’s a support group.”

**Ndinini:** Fortunately, we are finding that more and more people feel comfortable and are willing to participate in testing. But we also encounter people who say, “We will be tested, but we don’t want to have our results back.” So wanting to be tested doesn’t necessarily mean wanting to know your results. And home-based care has to bridge that gap.

**Lorenz:** It can also take quite a lot of work for someone to agree to testing. That’s why we believe we need to have door-to-door community counsellors and testers that are working *with* our home-based care providers. That way, if you’ve agreed to testing, you don’t need to take another trip to the testing site. Perhaps in urban areas or towns it is easy for a person to walk to the clinic and wait in a long line, but in rural areas it’s much more difficult. People living here make a trip to town maybe once per month, and if this trip has to include testing, it can be quite a long wait.

**Grace:** I agree. We have an HIV & AIDS counsellor and we concluded that she needs to be going on home-based care visits because she is trained on testing. That way, if somebody decides they want to be tested, we can test them right on the spot! We have also decided that the office should have a testing kit, because someone might walk in and say, “I want to be tested.” But if you have to say, “Okay—I’ll take you to the hospital,” then you’ve lost them.

### Keeping People on Treatment

**Lorenz:** One of the things we track very carefully is treatment adherence, and instances of defaulting. But we also try to do away with the word ‘defaulter.’ Instead we ask: What is the number of days in the month when ARV or treatment was not taken by the person? Only once it’s clear that someone is *consistently* not taking their drugs do we use the term ‘defaulting.’ We also work to develop a summary of



*Since the emergence of the global AIDS epidemic, 17 million children have lost one or both parents to AIDS. Across sub-Saharan Africa, home-based care workers help ensure that caregivers receive support, and that children remain healthy and are able to continue attending school.*

reasons why the drugs were not taken, and use this to help develop further interventions.

**Grace:** Yes. We need to understand why people are defaulting and then take an active role in addressing those issues. For example, two years ago there were three teenagers who actually died because they had stopped taking their drugs, and we wanted to know: *What can we do?* So now we have adolescent support groups so that we can understand what teenagers are thinking. And we have learned that a lot of it is stigma-related. They don’t want their peers to know that they are HIV positive. So we are helping to work against that and protect confidentiality.

**Ndinini:** In our organization there is a community tracer who goes into the community to determine if people are defaulting. And they’ll ask: “*Why are you defaulting?*” In some cases people need to go to clinics to access the drugs, and then you’re dealing with the issue of long distances. Say you’re told you can have the drugs, but you have to access them at a hospital, 30 km from where you live, often on foot. Who’s going to walk 30 km away? Definitely not some sick person. The clinics also have a lot of checks and balances and procedures. The process is *not* straightforward. Many patients need a home-based care worker to help them navigate that system. In my view, there’s no way the government can provide drugs effectively without the human element.

### Children and Youth: Home-based Care and Hope

**Lorenz:** We are always keenly invested in knowing the HIV status of the children who are registered in our programmes. But in addition, we look carefully at their school attendance. We try to find out: Does the child go to school? Is there a role

the home-based care provider could play in keeping the child in school?

**Ndinini:** Oftentimes, community workers are able to alleviate the work load of children in their homes. Many of these kids would normally be the ones taking care of their parents, taking care of the sick. Now there is someone else helping and the kids get a chance to enter into primary school and secondary school... and the ones who do well go on. So part of the connection is that when there is extra support from the home-based care programme, more kids have a chance to get an education.

**Grace:** Because of the home-based care services KIPEWA has been offering, four children in the communities where we work are actually going to university! Four is a lot. It's a major, major achievement. And if they had not been in the home-based care programme, this would not have been achieved.

### The Key: Trust and Community

**Ndinini:** The work we do at the community level is all about trust. The traditional birth attendants and other community workers could not do their work if they didn't have the trust of community members. In



Alexis Macdonald/SIF

*Community-based organizations like MWEDO in Tanzania serve hard-to-reach communities such as the Maasai, who often live in remote areas, far from the nearest hospitals.*

Maasai communities, for instance, you will find that you can sit with someone under a tree and have a long meeting with them, and you may think they got the message when in fact they think you're wrong. But if you *know* the community, you can tell if they are with you or not. That's something the government has had problems understanding.

**Lorenz:** In the same way, the organization itself should be trusted and

well-known to the community. In most cases, the entire organization is made up of community members. They build it. So the work is always rooted in the community, or aligned to existing community structures—such as church or traditional authorities... Consistency is also very important. Volunteers and paid staff alike must be consistently available. They are committed to providing care for the long run, not merely for a month or two. ✨

**Home-based care is a lifeline keeping communities healthy and vibrant!  
Your donation has a powerful impact in the hands of our grassroots partners.**

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