Volunteers with Afya Women Group, Mufindi. From left: Veronica Mwila, Benjamini Chumi, Rhoda Mgowe, Augustine Mbedule, Faith Mwakanyamale

Spotlight on TUNAJALI's Community Volunteers

TUNAJALI
WE CARE

TUNAJALI, a Swahili word that translates as "We Care," is a highly appropriate name for the US Government-funded program that provides home-based care for people living with HIV and for orphans and vulnerable children across Tanzania. It is also a fitting motto for over 3,400 volunteers who deliver these crucial services for thousands of adults and children.

The TUNAJALI home-based care program is managed by Deloitte Consulting Limited. Family Health International, one of four core partners, provides training for the volunteers and technical leadership for over 30 local organizations to which they are attached, always working closely with the Government of Tanzania and local governments to ensure a continuum of care.

COMMUNITY VOLUNTEERS are the heart and soul of the US Government-funded TUNAJALI Project in Tanzania, which provides home-based care for people living with HIV and for highly vulnerable children. Indeed, without the volunteers, who are engaged and supervised by 32 non-governmental or faith-based implementing organizations, there could be no program.

This fact—and the crucial services that TUNAJALI volunteers have been delivering for more than 60,000 people living with HIV and nearly 75,000 children who are orphaned or otherwise highly vulnerable—demands more than a recitation of numbers.

Instead, a personal and human perspective is needed: one that sheds light on who the volunteers are; how they are selected, trained, and supervised; what they do for their clients; and what a week's schedule may entail. Such an account can inform future and current home-based care programs that support people living with HIV and the children and families who have been made vulnerable by the epidemic.

Instead of generalizing about nearly 3,400 TUNAJALI volunteers across 34 districts of mainland Tanzania and 10 districts in Zanzibar, this document focuses on a representative cross-section of volunteers employed and supervised by four TUNAJALI local implementing organizations: WAVUMO in Morogoro, Alpha Dancing Group in Kilolo, Afya Women Group in Mufindi, and Allamano Centre in Iringa. The last three are working in the Iringa Region, which has one of the country's highest HIV prevalence rates and a high rate of orphaning: about one in four of all children under 18.

Who the volunteers are

Not surprisingly, most TUNAJALI volunteers are women. They constitute 85 of 121 (or 70 percent) of WAVUMO's volunteers and nearly 60 percent of

Alli Ramadhani

Veronica Havu

Flora Mbuna

Helena Osiah

Sophia Makweta

those currently working for the three organizations in the Iringa Region. The kind of services the volunteers offer is often considered to be women's work, but an admirable group of male volunteers are countering gender stereotypes.

Most volunteers are in their 30s and 40s; at least one is in his 70s. Each receives a bicycle to facilitate their home visits, a small monthly stipend of about US$20 (or TZS 25,000), and bus fares when needed. The volunteers require other income, so they are typically engaged in small-scale vending, farming, or livestock-keeping. A few are teachers, nurses, or evangelists, but the project's preference is that volunteers not hold demanding jobs that allow little time for visiting clients.

All volunteers fight stigma and discrimination against people living with HIV by giving health talks in the community, so they cannot be shy and retiring or too squeamish about talking about sex or "private matters" in public.

Because volunteers become enmeshed in the personal lives of some of the most vulnerable individuals in their communities, they must be compassionate, loving, and dependable, as well as iron-willed keepers of confidences. They must be able to communicate effectively with people of all ages and from all walks of life, including clinicians and other caregivers; community leaders and village elders; traumatized children; spouses and adolescents who may be angry or in denial; and people who need to be convinced to take an HIV test or to stop stigmatizing people living with HIV. The volunteers also need to be resilient: they must exhibit patience when clients stop taking their drugs or drink too much alcohol, but they must also quickly devise strategies to help bring an end to these behaviors.

Given these heavy demands, the optimum number of clients for a given volunteer is 15. However, most who work for the organizations in the Iringa Region have considerably more, since funding is not currently available to match the region's high rates of HIV prevalence and orphaning.

From left: Juma Gumbo, community volunteer with the Alpha Dancing Group, Iringa Region, with a widowed client and Atuselye Nyagawa, his supervisor.

Jakomina Mbangwa

Christopher Sanga

Hilda Ioga

Celestine Mziwanda

Edward Sambala

How volunteers are selected, trained, and supervised

Because of their vital work and their access to confidential information, volunteer selection is a meticulous process that involves village councils and governments. Individuals who have a respected record of community service and activism are recommended to implementing organizations by ward-level officials and by village and community leaders.

The selection adheres to standards set out in *Guidelines for Home Based Care Services* published by Tanzania's Ministry of Health, which state that community volunteers be based in and accepted by the communities they serve, and possess the ability to read and write and to keep confidences and build good interpersonal relationships with others.

Family Health International, which provides technical support for the TUNAJALI Project, is responsible for a comprehensive, 22-day training program that covers the care needs of adults with HIV in 18 days and spends 4 days on care for highly vulnerable children.

The program, offered to 30 to 40 new volunteers at a time at a district headquarters, teaches the basics on HIV and antiretroviral treatment and equips volunteers to support their clients' adherence to drug regimens and make appropriate referrals. The training also puts considerable emphasis on counseling and communication skills and on helping family members to

From left: Wilson Mwakibete, home-based care supervisor with the Allamano Centre, confers with volunteer Juma Gumbo. Among other tasks, supervisors advise volunteers, review their reports, and take a leading role at monthly meetings that discuss general issues and problems.

Leah Ngumbi

Halima Mbaga

Claude Kindole

Rehema Msola

Eme Lupembe

become primary caregivers, even when patients are bedridden.

A new curriculum being piloted has added materials on "positive prevention" that help volunteers talk about sex and condom use with sexually active clients and provide more detailed advice on preventing ongoing HIV transmission. Another new session focuses on healthier lives and the benefits of reducing alcohol and cigarette use, exercising regularly, sleeping under mosquito nets, joining a support group, and ensuring hygienic surroundings and clean water.

TUNAJALI volunteers receive supportive supervision by trained nurses and social workers who are on the staff of implementing organizations and specialists or "focal persons" in home-based care or in support for vulnerable children. These supervisors make routine home visits to clients as well as visiting those who are sick. They also conduct HIV tests at home and post-test counseling for clients after pre-test counseling by volunteers.

Afya Women Group volunteer Faith Mwakanya visits one of her clients, a widow with three children. Of her 17 clients, 14 are women.

Who their clients are

Anyone who is HIV-positive in the districts where TUNAJALI volunteers work is eligible for home-based care. Most adult clients are women. On WAVUMO's 2009 register, there are 631 men and 1,584 women, and women constitute 65 percent of all adults ever enrolled in home-based care in the Iringa Region. (Many of these women are widows, a group whose overall HIV prevalence in Tanzania is an astonishing 27 percent.)

Often, volunteers find their clients by going door-to-door in communities where they live. Clients who live nearby are also referred by neighbors and local leaders and by health facilities, including care and treatment centers, district hospitals, reproductive and child health clinics, and voluntary HIV testing centers.

Volunteers develop good relationships with health facility staff. They provide referrals to facilities and accompany their clients on their clinical visits to facilitate better service and treatment compliance. In turn, health facilities rely on volunteers to track down clients

Benjamini Chumi

Veronica Mwila

Shabani Mahulu

Margareth Charles

Said Shija

lost to follow up, including by calling on their relatives. Some 2,000 patients in the Iringa and Morogoro regions have been located and brought back to care by volunteers. These are among their most important tasks, since non-adherence not only compromises health but allows drug-resistant strains of the virus to develop.

Volunteers take on responsibilities for children who are referred to them by local "most vulnerable children committees," bodies on which the volunteers themselves often serve.

The committees use the Government of Tanzania's definition of a most vulnerable child: one who lives in a child-headed household, with a chronically ill guardian, or with a disability, or in very poor conditions and without one or both parents. Volunteers are tasked with overseeing the delivery of the "service package" promised to these children in the areas of health, nutrition, psychosocial support, education, child protection, shelter, and training in income-generation and life skills.

Mary Mbosa, home-based care supervisor with the Allamano Centre, talks with a motherless child. The child's father, visible in the background, is on antiretroviral treatment.

Jane Luganga

Kellen Mpesa

Augustine Mbedule

Rhoda Mgowe

Juma Gumbo

What TUNAJALI volunteers do for their clients

Though some volunteers look in on their clients at any convenient time they are passing by their homes, many schedule their visits, since now nearly all clients are ambulant and may not be home. Saturday and Sunday afternoons are the most popular times for home visits, followed by early morning or evening visits on two or three weekdays. The number of clients that a volunteer sees in a week will vary; it may be as many as 10 or 20 for some. Most volunteers visit each client at least twice a month and more frequently if the client is not doing well.

For clients who are in reasonably good health, a typical visit lasts 15 to 20 minutes. A third or more of the volunteers' HIV-positive clients maintain high CD4 counts and are not on antiretroviral treatment, lessening side effects, complications, and the need for nursing care. For clients on treatment, the volunteer reviews forms kept in their homes that outline their prescription and adherence and looks at their pill supply. The volunteer may even bring along prescription refills for clients who have trouble getting to a clinic.

These medications will be carried in kits provided to each volunteer that are equipped by the TUNAJALI Project with items they need to examine clients, treat simple opportunistic infections, dress wounds, and alleviate pain and drug side effects. The kits usually also contain vitamins to boost immune systems as well as condoms to prevent onward transmission of HIV.

During their visits, volunteers pay close attention to clients' nutrition, since it affects their response to antiretroviral treatment and their general health. In addition to nutrition counseling, volunteers advise clients and their families on how to alleviate side effects. They also look for symptoms of common opportunistic infections and danger signs that call for an immediate clinic visit. As they perform these tasks, they mentor family members so they can provide basic nursing care and adequate hygiene.

During home visits, volunteers may also need to convince some of their clients to change risky behaviors (including

WAVUMU volunteer Celestine Mziwanda (left) visits one of her clients, a widow on antiretroviral treatment who supports herself and her daughter by selling vegetables.

Melania Msigwa

George Mwalo

Triphonia Dugange

Angela Sambala

Richard Kisegelo

excessive drinking) and to disclose their HIV status to their partners. The volunteers may assist with this disclosure as well as with convincing partners to be tested for HIV. Volunteers may even conduct pre-test counseling for family members and potential clients who cannot or do not want to go to a testing facility, in preparation for at-home HIV testing by home-based care supervisors.

Volunteers must spend sufficient time during home visits to become confidantes of the vulnerable children who are their clients and to be aware of how they are doing in school. The volunteers are tasked with monitoring the delivery of TUNAJALI support by way of paid-for school fees, school materials, and uniforms. In addition, about once a month or more frequently, volunteers take part in weekend children and youth clubs that constitute part of the service package referenced earlier. There are 325 such clubs supported by TUNAJALI, which are open to all children. They offer opportunities for children in the program to play and enjoy peer and psychosocial support and obtain valuable life-skills training and age-appropriate HIV prevention education.

The provision of psychosocial support is a crucial part of the volunteer's work. It encompasses counseling clients and family members who are anxious about the future or feeling stigmatized, as well as those who are depressed, despairing, dying, or bereaved. When needed, volunteers call in spiritual advisors.

But, for the most part, the volunteer's visit and its comforting and friendly interactions comprise the psychosocial support that their clients require. Even relatively short visits convey to clients that they are far from alone, especially since volunteers inform them about the range of help available from a network of caring community organizations, including those supporting people living with HIV, providing food or paralegal support, or offering income-generating and microcredit opportunities—often the same organizations in which the volunteers are deeply engaged.

Volunteer Jakomina Mbangwa with the Alpha Dancing Group has been trained to address the care needs of vulnerable children like this one.

WAVUMU volunteers Margareth Charles, Melania Msigwa, and Said Shija enjoy each other's company. The close relationships and camaraderie between volunteers are part of the reward for their work.

Why volunteers do this work and what keeps them going

Some volunteers are drawn to the work because they themselves are HIV-positive. Those who are boost the morale of clients by being robust and active exemplars of life with HIV and by sharing their own experiences with HIV testing, disclosure of their status, and adherence to antiretroviral drugs.

Others became volunteers because of their experiences with HIV-positive family and friends and their awareness of their need for home-based care. Still others had received prior training in nursing and home-based care and want to apply their skills.

All volunteers are driven by the mission of helping others. As one put it simply, "The burden of HIV/AIDS is for every one of us."

When asked what keeps them doing the work, volunteers responded:

"I feel proud and good about what I do. I'm accepted by the community."

"I'm happy about the education the program has given me. It has allowed me to go to the community and sensitize them."

"At the start, many patients were bedridden. They are now ambulant. Some who were bedridden are now volunteers."

"Even the government is recognizing our work. We are invited to join health committees and committees for orphans and other vulnerable children."

"My clients are family. It becomes a joy to meet them."

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Funded by the US President's Emergency Plan for AIDS Relief through the US Agency for International Development, TUNAJALI has two components: a five-year, $30 million initiative that provides home-based community care for people living with HIV and for orphans and other vulnerable children; and a four-year, $26 million initiative that supports HIV/AIDS care and treatment. Family Health International provides technical leadership for both initiatives.

The home-based care initiative is managed by Deloitte Consulting Limited; Catholic Relief Services and Africare lead implementation in certain provinces. Tanzanian partners provide technical assistance in the following areas: nutrition (COUNSENUTH), stigma reduction (MUCHS), involvement of people living with HIV (NETWO+), and legal support (TAWLA).

Text and photos by Hilary Russell.

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