Providing positive care

Lightening the burden of home-based care in rural Zimbabwe



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A case study of the Combined Oxfam Gender and HIV and AIDS Program in Zimbabwe





Above: ZWAAPV staff and caregivers. Photo: William Nyamuchengwa/Oxfam AUS.

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Front Cover: Chenjerai Zaza, ZWAAPV caregiver supervisor. Photo: William Nyamuchengwa/ Oxfam AUS.

INTRODUCTION

This case study explores how two community organisations supported by the Combined Oxfam Gender and HIV and AIDS Program have successfully provided home-based care programs for people living with or affected by HIV in Zimbabwe.

Zimbabwe Women Against AIDS, Poverty and Violence Trust and Batsiranai Home Based Care operate in Mashonaland East province which has the highest HIV transmission rate in Zimbabwe. In response to this devastating epidemic, these organisations have trained volunteer caregivers, among them sex workers and men, to provide home-based care to people living with or affected by HIV.

Sex workers and men have not traditionally been involved in such care and this innovation has challenged traditional gender roles and community attitudes, and enhanced the delivery of care services to families and the broader community. As this case study illustrates, sharing the burden of care for the ill and dying in Zimbabwe has resulted in community perceptions changing, and the inclusion of social groups traditionally marginalised from formal community care structures.

As well as providing desperately needed care and support, these organisations have helped to empower individuals, and this case study explores how individuals have confronted issues of culture, economic hardship, gender stereotyping and their own behaviour to share the burden of home-based care. The study also highlights the numerous challenges these two organisations have faced working within an extremely difficult socio-economic context and resource-poor country and the innovative strategies they have employed to overcome them.

It is hoped that in documenting and sharing their work, the Combined Oxfam Gender and HIV and AIDS Program will contribute to the quality and effectiveness of civil society's response to the impact of HIV and AIDS.

BELOW: A beaded pin featuring the AIDS ribbon. Photo: Lara McKinley/OxfamAUS.

COGENHA

The Combined Oxfam Gender and HIV and AIDS Program (COGENHA), based in Harare, Zimbabwe, provides funding and technical support to nine non-government organisations that are responding to Zimbabwe's HIV and AIDS epidemics.

These organisations are working in Mashonaland East, Midlands and Matabeleland North provinces to achieve gender equity and behaviour change in relation to HIV prevention as well as care and support for those infected or affected by HIV.





HIV AND AIDS IN ZIMBABWE

Zimbabwe has an estimated 1.3 million people, including 120,000 children, living with HIV¹. It also has the seventh-lowest life expectancy in the world — 43 years for women and 44 years for men² — largely due to the country's HIV and AIDS epidemics. Despite these statistics, Zimbabwe is the first country in Southern Africa to show a drop in HIV prevalence, down from 26.5% of adults in 2001 to 15.3% in 2007³.

The HIV and AIDS epidemics have created a tremendous need for care, prevention and education. In addition to the 1.3 million people living with HIV, an estimated 1 million children have been orphaned by HIV⁴; these children are also vulnerable to HIV infection. This indicates there are large numbers of Zimbabweans who require care: those who are ill or infirm and the young and older family members left behind.

Moreover, Zimbabweans are in the midst of an extreme crisis, lacking access to food, healthcare, clean water and safe sanitation. One million people have been affected by cholera and hunger is being experienced by millions across the country, which is increasing their likelihood of HIV infection as they are driven to adopt risky strategies to survive. For those already infected with the virus, malnutrition exhausts the immune system, which makes people more susceptible to other diseases and leads to faster progression from HIV to AIDS.

Zimbabwe is also experiencing economic stagnation, and displacement of people due to land reform. Given the political and socio-economic situation, and that just 8% of central government expenditure in Zimbabwe is allocated to health⁵, the population cannot rely on government to provide medication and the continuum of care required for HIV and AIDS. Consequently, the burden for providing care in the home for the ill, bedridden or dving lies with individuals, family members and communities.

The Government of National Unity (GNU), formed in February 2009, has made some headway, launching the Short Term Economic Recovery Program, securing some donor funding, and instituting economic policy reform. However, multiple governance challenges remain.

This, together with continued reports on human rights abuses, the failure to reform media laws, an upsurge in farm invasions, the uncertain allegiance of military commanders and uniformed forces to the GNU, and limited freedom of expression has given little credence to the GNU. As such, the international community maintains a "wait and see" attitude.

As a consequence, much needed international aid is not flowing in as initially anticipated and basic infrastructure such as roads and water and sanitation services remain in a state of disrepair. Social services, too, remain in a state of dysfunction, affected by the lack of resources and the continued exodus of health and education professionals.



THE BURDEN OF CARE: HEALTHCARE IN ZIMBABWE

Zimbabwe's HIV and AIDS epidemics have ravaged villages and towns, orphaned one million children and crippled the country's already vastly under-resourced healthcare system.

As a consequence, Zimbabweans are facing enormous challenges in accessing health services. In rural areas, those in need of medical services must travel long distances to attend the clinic, and for many families the cost of this journey means that the entire family will go hungry. Many cannot afford to buy food, especially as HIV has affected the incomeearning capacity of many families. Amid Zimbabwe's current economic crisis, there are extremely grave consequences for people already living with HIV. Out of the 1.3 million people estimated to be living with HIV, only about 100,000 are accessing antiretroviral treatment⁶ and most do not have access to the health services, psychosocial support and nutrition needed to remain healthy.

44 THERE WERE SO MANY PATIENTS THAT FAMILIES ACCEPT US AS CAREGIVERS, IT DOESN'T MATTER IF WE ARE MALE OR FEMALE. IN OUR CULTURE, IT USED TO BE THAT MEN CAN'T TAKE CARE OF THEIR ILL WIFE; HIS SISTER WOULD HAVE TO COME. BUT NOW THIS HAS CHANGED BECAUSE OF THE WAY THE HOME-BASED CARE IS STRUCTURED. WE WERE IDENTIFIED THROUGH THE TRADITIONAL LEADERS AND VILLAGE, AND REPORT THROUGH THE SAME STRUCTURE ON WHAT WE DO. **77**

GARIKAI KATIYO, BATSIRANAI CAREGIVER

For most Zimbabweans with HIV, AIDS or related illnesses, traditional remedies and homebased care are their only forms of support. With increasing rates of illness and death among young adults (who are also parents), there is a terrible impact on children who may have been orphaned or have to leave school to care for their parents.

In Zimbabwean culture, traditionally the burden of care for the ill and dying rested with women, who are also the most vulnerable to risk of HIV infection. However, given the extent of the epidemic, the impact of HIV, and the impact of bereavement on families and communities, men have become involved in the care and treatment of those infected or affected by HIV. Consequently, as illustrated in this case study, community perceptions of care for those who are ill or are living with HIV have changed, and men have had to redefine their role and understanding of what it means to take care of one's family and community.

OPPOSITE: Batsiranai caregiver supervisors Peter Zazembe and Louis Chikoto care for client Agnes Matsika. Photo: William Nyamuchengwa/Oxfam AUS.

Home-based care is recognised in the Zimbabwe HIV and AIDS Policy Framework as an essential element of the continuum of care. The objectives of providing homebased care for people living with HIV in Zimbabwe include to:

- ensure good quality care of an individual after being moved from a health facility to the home;
- promote family and community awareness of HIV prevention and care;
- provide the family and the community with the knowledge and skills needed to ensure long-term care and support;
- reduce the stigma associated with AIDS:
- make referrals from health facilities to the community and from the community to appropriate health and social facilities; and

facilitate quality community care for the infected and affected.

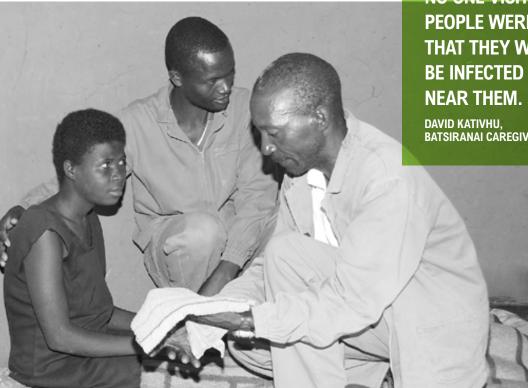
The principles of home-based care according to the framework are to:

- provide the best possible quality of life for the ill irrespective of age, gender, race, economic, socio-cultural or religious background;
- offer a support system that enables individuals to live as actively as possible until death;
- involve the individual, his or her family members and significant others in the decision-making and planning of care;
- implement home-based care in a multi-disciplinary, multi-sector approach;

- protect confidentiality, individuality, "doing no harm" and privacy;
- provide information. education and communication materials to individuals, community members and healthcare providers; and
- monitor and evaluate the care provided to ensure quality control.

66 IN THE BEGINNING, **THERE WAS A LOT OF STIGMA IN THE COMMUNITY. IF** SOMEONE THOUGHT **SOMEONE HAD HIV** THEY WERE EXCLUDED, THEY HAD TO STAY IN THAT HOMESTEAD AND NO ONE VISITED THEM. PEOPLE WERE SCARED THAT THEY WOULD **BE INFECTED BY BEING** NEAR THEM. **J**

BATSIRANAI CAREGIVER



ZIMBABWE WOMEN AGAINST AIDS, POVERTY AND VIOLENCE TRUST AND BATSIRANAI HOME BASED CARE

Zimbabwe Women Against AIDS, Poverty and Violence Trust (ZWAAPV) and Batsiranai Home Based Care have both developed unique approaches to providing home-based care in Mashonaland East province.

ZIMBABWE WOMEN AGAINST AIDS, POVERTY AND VIOLENCE TRUST

Zimbabwe Women Against AIDS, Poverty and Violence Trust (ZWAAPV) was founded in 2001 by Beatrice Karimanzira in response to the plight of rural women living in Murewa district, Mashonaland East province.

The organisation initially targeted single and widowed women who, having lost their husbands and breadwinners, resorted to sex work to sustain their families. Sex workers are often marginalised from the community and are subject to violence and disrespect. Given the nature of their work, they are also more at risk of HIV infection.

Starting with 132 sex workers in 12 wards in Murewa district, ZWAAPV provided women with opportunities for other sources of income and promoted safer health practices such as condom use. Some of the sex workers, however, were already infected with HIV and many became ill. Despite their need for care and support, they were stigmatised within the community and shunned by caregivers in the villages. ZWAAPV addressed the issue by training sex workers as caregivers so they could care for each other, and so its home-based care program began.

ZWAAPV has since expanded the reach and scope of its program to offer a range of services to the broader community. Operating in 24 wards in Murewa district, ZWAAPV now supports 300 sex workers, 2,000 people living with HIV and 1,000 orphaned and vulnerable children. They are cared for by 105 volunteer caregivers who include sex workers and other men and women selected from the community. ZWAAPV has also recruited and trained young men as peer educators to encourage men in the community to talk about HIV prevention, condom use and the need to change risky sexual behaviours.

ZWAAPV's support for orphaned and vulnerable children and their guardians has become a significant aspect of its work. Children are provided with food packs, school fees, uniforms, and stationery and ZWAAPV renovates homes to ensure that children have access to safe water and secure homesteads. To ensure that guardians are well supported, ZWAAPV funds the training of ward-based committees which help to identify orphaned and vulnerable children who should receive support from other donors and government agencies.

As part of its integrated approach to HIV prevention, support and care, ZWAAPV has also introduced income-generating projects into the target communities in recognition of people's struggle to earn a living and access affordable, nutritious food.

OPPOSITE,TOP LEFT: ZWAAPV caregiver Eunice Madzimbamuto works in a vegetable garden the ZWAAPV has established so caregivers can grow food to eat and sell. Photo: Maureen Bathgate/Oxfam AUS. TOP RIGHT: Batsiranai caregiver Mrs Kapondoro with a child who was treated in the district hospital. Photo: William Nyamuchengwa/Oxfam AUS. BOTTOM: Batsiranai Founder and Director Anna Karimanzira speak with caregivers. Photo: William Nyamuchengwa/Oxfam AUS.





66 AFTER MY DIVORCE IN 1998 I WAS ROAMING AROUND SELLING MY BODY UNTIL 2004 WHEN I JOINED ZWAAPV. THEY CAME AND TALKED TO US YOUNG LADIES, AND SAID, 'PLEASE LEAVE ALL THOSE THINGS BEHIND'. I WAS SEEING MOST PEOPLE GETTING ILL, GETTING TIRED AND REALISED THIS WAS NOT GOOD FOR ME, THAT I MUST CHANGE, AND THAT MY CHILDREN MUST HAVE SOMEONE AT HOME. **39**

TENDAYI CHOTO, ZWAAPV CAREGIVER



44 I DREAMT THAT ONE DAY I WOULD HELP PEOPLE. THE COMMUNITY IS PLEASED WITH MY WORK. I TALK TO THE COMMUNITY ABOUT CARING FOR OTHER PEOPLE, THAT IT IS IMPORTANT TO BEFRIEND THEM. PEOPLE LOOK UP AND LISTEN TO US. WE HAVE STANDING THAT IS RECOGNISED IN THE COMMUNITY. I ENCOURAGE OTHERS TO BECOME CAREGIVERS. EVERY EVENING I DISCUSS HEALTH WITH MY FAMILY. I HAVE GIRLS AND BOYS AND I TELL THEM THE TRUTH ABOUT SEX, LIVING WITH HIV, THE DANGERS AND HOW TO PROTECT THEMSELVES. **99**

DIXON VIYEANO, BATSIRANAI CAREGIVER

BATSIRANAI HOME BASED CARE

Batsiranai Home Based Care was founded by Reverend Anna Karimanzira who was concerned by the absence of home-based care services to care for men and women living with HIV in Mashonaland East's Uzumba Maramba Pfungwe district.

Following her discussions with local leaders, including the chief, kraal (homestead) heads, local councilors and village health workers, Batsiranai Home Based Care was established in 2001 to provide people infected and affected by HIV with emotional, physical and spiritual support.

TOP: Batsiranai caregiver Felder Gweshe helps to pick maize from the fields of one of her clients. Photo: William Nyamuchengwa/Oxfam AUS. BOTTOM: Most people have to walk long distances to access health services and markets due to the lack of transport in remote parts of Mashonaland East province. Photo: William Nyamuchengwa/Oxfam AUS. Using existing communitybased structures, local leaders nominated people within their community to be trained as caregivers. The first training was held in 2001 with 63 women and 37 men taking part. A second group of participants was trained in 2003 in response to the increased demand for homebased care, and the expansion of the program into new districts. With the assistance of traditional leaders and the church, Batsiranai actively encouraged men to participate in the training so that they could help to share the burden of care for those living with HIV. Batsiranai now has 242 caregivers, 75 of whom are male. Batsiranai has also begun to expand the scope of its work to include a nutrition gardens project and other income-generating activities.



THE HOME-BASED CARE PROGRAMS

In the current Zimbabwe context, with deteriorating socio-economic conditions, a crumbling health system and mature HIV and AIDS epidemics, home-based care programs are often the only source of support for people living with HIV and those who care for them.

OBJECTIVES

ZWAAPV's objectives are to:

- provide comprehensive quality care and support to those who are ill, orphans and vulnerable children, and target communities, through training and support to child protection committees, orphan guardians and primary and secondary caregivers;
- strengthen behaviour change initiatives among people living with HIV, sex workers and outof-school youth;
- provide nutritious food by promoting sustainable income-generating activities targeting orphaned and vulnerable children, sex workers and other vulnerable women in the target communities;
- promote and support conflict resolution and peace-building initiatives within communities in Murewa district; and
- strengthen the project's sustainability, monitoring and evaluation processes.

Batsiranai's objectives are to:

- teach caregivers and immediate family members how to care for HIV patients and seriously ill people;
- improve the nutritional diet of patients through nutrition gardens and supplementary feeding;
- provide standard replenishment kits to people infected and affected by HIV;

- provide care and support to people living with HIV and those affected by the disease;
- complement the government's efforts to contain the spread of HIV through educating communities within Uzumba Maramba Pfungwe district; and
- mitigate against the effects of HIV and AIDS.

66 THE TRAINING TAUGHT US HOW TO APPROACH A HOMESTEAD, HOW TO WORK WITH A PATIENT, INTRODUCE OURSELVES AND HOW TO SHARE OUR SKILLS WITH THE FAMILY MEMBER. IT ALSO TAUGHT US HOW TO BATH PATIENTS, TO CHECK ON A PATIENT'S INTAKE OF MEDICATION, TREAT BED SORES AND CHANGE BED LINEN. **37**

MARGARET CHINYERERE, ZWAAPV CAREGIVER

TARGET GROUPS

The organisations' home-based care programs primarily target people living with HIV in Zimbabwe's Mashonaland East province. Between them they also support the families of people living with HIV, sex workers and their clients, primary and secondary caregivers, peer educators, orphans and vulnerable children and their guardians, and the wider community through outreach activities and awareness campaigns.

PROGRAM ACTIVITIES

1. Training caregivers

ZWAAPV and Batsiranai involve community leaders and members to help with the selection and recruitment of volunteer caregivers. This consultative approach contributes to the organisations' credibility within the community and at a practical level means that caregivers do not have too far to travel to provide care as they live in the project area. ZWAAPV and Batsiranai train their caregivers according to national home-based care standards as outlined in the Zimbabwe HIV and AIDS Policy Framework to ensure quality of care. Training is conducted by trained trainers accredited by the Zimbabwe Health Department and typically runs for several weeks. Caregivers learn how to provide home-based care and basic health services to patients as well as how to support and train the primary caregiver in the family to care for the patient.

After this initial induction, caregivers receive ongoing training opportunities in additional skills such as counselling, will writing and drug dispensing so they can dispense painkillers and other analgesics as well as refresher courses in home-based care, mentoring programs and exchange visits to other organisations providing care.

As a result of their training and subsequent volunteer work, caregivers from both organisations have said they have:

- increased their knowledge about HIV and AIDS, sexually transmitted diseases, safer health practices and improved health practices such as nutrition;
- developed specific skills in home-based care, HIV prevention, counselling and in ZWAAPV's situation, income generation;
- engaged with community attitudes and their own attitudes towards issues surrounding HIV, illness and death, and sex work;
- confronted traditional gender norms associated with care for the ill and dying and traditional and political hereditary laws, as well as local governance structures; and
- responded to a real need in the community and within families by providing home-based care skills and resources.



44 I HAVE CHANGED AND GROWN SINCE BECOMING A CAREGIVER. BEFORE, I WAS SCARED TO KNOW WHAT TO DO WITH A BED-RIDDEN PATIENT, OR HOW TO FEED SOMEONE. NOW I REALISE I CAN DO IT AND AM ABLE TO PASS THE SKILLS ON. I AM NOW PREPARED FOR LIFE, ITS CHALLENGES, CHOICES AND WAY OF RELATING TO PEOPLE. **37**

DAVID KATIVHU, BATSIRANAI CAREGIVER



IN PROFILE

CLOUD CHIVANZA A male caregiver with ZWAAPV

Mr Chivanza was born in 1984 and is married to Ottilia. They have a daughter who is 16 months old. Mr Chivanza trained as a caregiver in 2006.

Mr Chivanza joined ZWAAPV as a peer educator and was then invited by the organisation to train as a caregiver. Through the training, he gained an appreciation of the challenges faced by some members of the community, especially the disclosure of one's HIV status. He was thus inspired to do something to change his community's attitude towards people infected with HIV.

"This job is interesting if you know how to do it, but if you are a coward ... you need to be a caring and patient person and you also need to be committed. The way you treat your own family is how you should treat those who are ill."

While Mr Chivanza finds his role rewarding, it is not without its challenges. "I can never get used to bathing an elderly person. At one point, I had to bathe my grandfather, because my family said 'Ah! The caregiver has arrived. You are the ones who know how to do this job, so here is your opportunity'. It took me some time to get used to the idea. I said to myself, 'Eh! How can I bathe my mother's father?' I found it really hard to do, but I realised that I had no choice, so I bathed him. One does not get used to such situations, though!"

Another challenging experience involved caring for his aunt who was seriously ill. She had been discharged from hospital and Mr Chivanza was called on to transport her back to her home. "It is very difficult to watch someone who has reached their last point [moment of death]."

Mr Chivanza has also had to grapple with the community's attitude towards male caregivers. "The first thing is that you lose your dignity. Some of the comments people made were that 'this is a job for women, what are you doing there? Are you now a woman?' That is the first thing. Next, you might find yourself with a female client [as a male caregiver]. This can be a problem depending on the family's level of understanding. However, the biggest challenge is losing your dignity among other men."

Mr Chivanza says he tries not to dwell on the stressful events and aspects of his work by spending a lot of time with his friends. Life is generally stressful, he says, and one should therefore not focus on the negative.

"Even at church you encounter problems. In the family you also encounter problems, so if you let it get to your head, you will be stressed. When I hear something, I don't want to think about it too much, so I find a friend to spend time with and we talk and this helps me forget."

OPPOSITE: Batsiranai caregivers collect water for one of their home-based care clients. Photo: William Nyamuchengwa/ Oxfam AUS. TOP: Photo: Penny Gorman/ Oxfam AUS.

2. Providing primary care

Patients are referred to Batsiranai and ZWAAPV by the hospital or district clinic. The nominated caregiver for that village then introduces themselves to the family and explains how the homebased service works. The patient may request the caregiver to be male or female, and wherever possible the request is honoured.

Caregivers typically visit their patients two to three times a week to provide basic healthcare, from pain control and treatment of opportunistic infections to bed bathing. As part of the healthcare plan they provide their patient with a "replenishment kit" each month which contains latex gloves, a bar of soap, bicarbonate of soda, Vaseline/lotion, linen saver, draw sheet, mattress, a bucket, cotton wool and tissue papers.

Caregivers also dispense medicines, deliver food, provide companionship and emotional and spiritual support, and help with household chores such as fetching water and preparing meals, especially in childheaded households.

3. Building family capacity

When home-based care programs were first introduced into communities, caregivers reported that many families hid the person living with HIV as they feared they too would become infected. Such attitudes and behaviours made it clear that engagement between the caregiver, patient and family is critical to the family's long-term ability to care for its members. As such, a key principle of a sustained home-based care intervention is transferring skills and building capacity within a family to provide care for the patient.

Caregivers train family members in how to provide basic healthcare for their loved ones; educate them in HIV prevention and nutrition; offer respite so family members can attend to other duties; and provide counselling and guidance to the entire family. Through their counselling work, caregivers have played a critical role in helping families confront attitudes and beliefs that may have compromised their ability to provide a supportive environment for those living with HIV. From dispelling myths surrounding HIV and AIDS to encouraging family members to address hereditary laws, caregivers work to ensure the family's future wellbeing.

Caregivers also create important links with the wider community to assist the family. For example, they help to build supportive networks for orphans and vulnerable children and activate communitybased circles of support to embed sustained care for the family firmly within the community.

BELOW: Gogo Karonga, mother of Batsiranai caregiver Felder Gweshe. Photo: William Nyamuchengwa/Oxfam AUS. OPPOSITE: Photo: William Nyamuchengwa/ Oxfam AUS.

66 MY MAIN DUTIES ENTAIL HELPING CLIENTS TO TAKE MEDICATION ON A REGULAR BASIS, PROVIDE INFORMATION ON INFECTION CONTROL AND POSITIVE LIVING, TEACH PRIMARY CAREGIVERS ON HOW TO CARE FOR HIV AND AIDS PATIENTS AND ON HOW TO AVOID CROSS-INFECTION, REFER PATIENTS TO CLINICS AND PROVIDE PSYCHO-SOCIAL SUPPORT. **99**

GARIKAI KATIYO, BATSIRANAI CAREGIVER





IN PROFILE

GOGO (GRANDMOTHER) KATSANDE*

Gogo Katsande lost her daughter to an AIDS-related illness and is now looking after five grandchildren, one of whom is HIV positive. Gogo Katsande stays with a daughter-in-law who is helping her to manage the household.

"I realised that my daughter was ill because she was losing a lot of weight. She also had diarrhoea and was coughing badly. She was diagnosed with TB and this is what she was being treated for when she died. People say my daughter died of this disease — HIV — because her husband died first and then she followed. So, what can I think, except that this is the disease of the times? I suppose then that what took the husband is also what took the wife.

"The nurses told us that it was not necessary for us to come back when her medication ran out. They said we now had to look after her from home as there was nothing else that they could do for her. At home we explored other options. My daughter urged me to go to faith healers for help. We tried but in the end all our efforts failed. God did what he did.

"In the end she died of diarrhoea. I would go off to do some laundry and when I came back she would say, 'Mother, it has happened'. I would then remove the soiled clothes and go off to do more laundry. When I returned she would have soiled herself again.

On the day that she died, she complained of a headache. She said, 'Mother, my head has split open!' and when I investigated, there was pus coming out of her ear. If you did not wipe it off, it would flow all the way down her body. She was once diagnosed with sores in her chest and these were treated but they returned after a while. So, I am not sure if these sores advanced from her chest to her head ... I don't know ... that is what eventually took her.

"I used to go with her to the hospital. On most days, she would make a head-start and I would follow her as soon as I had finished my morning chores. I had to go to the social welfare offices as I could not pay any of the hospital fees. The social welfare people wanted to know if my daughter was married or not, and I told them that her husband is late [dead] and that I was the one now looking after her. I also told them that I had no money to pay for her treatment. They gave me a letter which I then took back to the hospital. That was when my daughter started receiving treatment.

"My daughter was the one who was providing for me and she also helped with taking care of these children. Now there is no-one. Mrs Kangara [a caregiver] helped me a lot when my daughter was ill. She would bring some soap and assist with the laundry. She also assisted with food. If I happened to bump into some of the caregivers, they would also assist me. They also showed me how to care for my daughter, especially how to make her comfortable. They also showed me how to wash her soiled bedding. They were quite helpful.

"I am hopeful that my granddaughter's health will improve because her measles have disappeared. Some people think that she might have picked up her mother's illness, but given her recovery from the measles, I think that the disease has been cured. After her measles were cured, only a cough remained. I am not aware how badly she coughs these days because she now sleeps with my daughter-in-law."

* A pseudonym has been used to protect identity.

4. Providing nutrition support

Nutrition is of great concern to all the caregivers, and to patients and their families. Good nutrition is essential to good health, whether or not a person is infected by HIV. However, given the poverty levels and socio-economic situation in Zimbabwe, many families cannot afford to buy food.

As HIV has reduced families' earning capacity and productivity, the burden to provide food has rested on the younger or older generation. In response to this situation, ZWAAPV and Batsiranai have established community vegetable gardens. Community members are encouraged to work in the gardens in exchange for vegetables and maize as well as establish their own family vegetable plots. The main vegetables grown in these gardens include onions, tomatoes, butternuts, cucumbers, green beans and peas.

As well as providing people with nutritious food, produce from the medicinal herb gardens has helped people living with HIV to cope with shortages of medicines and antiretroviral drugs.

5. Developing people's livelihoods

In addition to their core business, ZWAAPV and Batsiranai have introduced income-generating projects as they have recognised that many people living with HIV as well as their volunteer caregivers are struggling to access affordable, nutritious food.

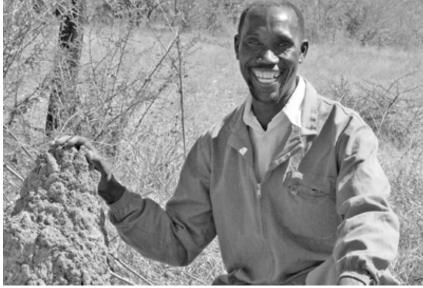
In response to the failure of traditional crops such as maize and groundnuts, ZWAAPV has introduced sunflower cropping as an alternative source of vegetable oil. The organisation has also acquired small livestock such as goats, chickens and rabbits to provide carers, patients and their families with a ready source of protein and income. ZWAAPV also offers its volunteer caregivers and their families access to a revolving credit fund to help them establish their own income-generating projects.

Other income-generating projects on offer through both organisations include peanut butter-making, oil-pressing, soapmaking and vegetable and herb gardens. These projects have empowered women in particular: as their access to finance has been improved through the projects, women have felt able to reduce their dependency on sex work as a source of income.

BELOW: ZWAAPV caregivers at work in the garden where they grow vegetables to sell and plants to use in traditional medicine. Photo: William Nyamuchengwa/Oxfam AUS. OPPOSITE, TOP LEFT: ZWAAPV finance officer Cain Nyakudziguma. Photo: Maureen Bathgate/ Oxfam AUS. TOP RIGHT: Batsiranai's caregiver supervisor for the Nyamhara area Taurai Hwema. Photo: William Nyamuchengwa/Oxfam AUS. BOTTOM: Batsiranai Mukuruanopamaenza area supervisor Serudzai Mutanga (right) speaks with colleagues Maud Murembu (left) and Moulid Choto (centre) about their duties as caregivers. Photo: William Nyamuchengwa/Oxfam AUS

11 THE VEGETABLE GARDEN WAS STARTED HERE IN AUGUST 2005. IT WAS STARTED BY SIX LADIES. VEGETABLES WERE IN DEMAND THEN. I SAW IT AS A GOOD THING BECAUSE I COULD EARN MONEY IN A GOOD WAY — NOW I AM FEELING VERY GOOD. **37** TENDAYI CHOTO, ZWAAPV CAREGIVER





44 AS I BEGAN TO WORK AS A CAREGIVER, I REALISED THE GAP BETWEEN THE FAMILY CAREGIVER LOOKING AFTER THE PATIENT AND HOW WE WERE TRAINED. IN THE BEGINNING, THE FAMILY MEMBER WOULD NOT EAT OFF THE SAME PLATE, OR WASH HANDS IN THE SAME CONTAINER, AND THEY FEARED THIS AIDS. WE WORK HARD TO ADDRESS THIS, AND TO TEACH THEM ABOUT HOW ONE CONTRACTS HIV. **37**

PATIENCE MUZVIDZWA, ZWAAPV CAREGIVER

NOME BASED CARE

DEFINING FEATURES OF HOME-BASED CARE

ZWAAPV and Batsiranai have both used a range of innovative strategies that set them apart from other community-based organisations providing home-based care in Zimbabwe.

1. Involving traditional leaders

Both organisations actively involve communities in the selection of individuals to be trained as caregivers. Village leaders, kraal heads (heads of family homesteads) and community members nominate individuals whom they consider to be trustworthy and of high integrity. This vote of confidence in one's character and capabilities appears to be a strong motivation for male caregivers in particular, many of whom do not turn down their nominations.

In Zimbabwe, village leaders and kraal heads are accorded great

respect in their communities and hence their involvement in the program has been a critical factor in recruiting male caregivers. As a case in point, most of the men who are involved in care work at Batsiranai were either appointed or nominated by the village leadership or kraal heads.

Traditional leaders remain committed to supporting caregivers beyond the nomination process by providing them with opportunities to address the community at local leadership gatherings. The purpose is twofold: to increase community awareness about HIV and care and to integrate the community's response to HIV within local decision-making structures.

The role of local leadership in changing community perceptions and bringing marginalised people into the continuum of care — as patients and caregivers — can be a slow process. However, given the urgent and overwhelming need for care in Mashonaland East province, community leadership has responded swiftly.

Indeed, claims from local leaders that ZWAAPV's home-based care program was discriminatory (ZWAAPV initially only provided care for sex workers) suggests that the severity of the impact on those in need in the community was overwhelming. This consequently "forced" a response which traditional norms would not have supported.

2. Using male caregivers

As in many other African countries, care work in Zimbabwe is typically viewed as "women's work" as it involves chores that are already part of women's daily repertoire, such as cleaning, cooking and washing.

Additionally, women and girls have traditionally been responsible for visiting and caring for the sick in their communities and households.

66 AS A CAREGIVER IT IS IMPORTANT TO ... WORK WITH FAMILIES TO LINK TO TRADITIONAL LEADERS AND LOCAL COUNCILORS IN THE COMMUNITY, LOCAL GOVERNMENT STRUCTURES, AND TO LOBBY FOR FOOD FROM THE GRAIN MARKETING BOARD. BY WORKING WITH THE COUNCILORS AND TRADITIONAL LEADERS, WE HELP IN ALLEVIATING THE PLIGHT OF FAMILIES THAT NEED ASSISTANCE. **99** It is therefore not surprising that the overwhelming majority of caregivers are women and that this work is typically not remunerated.

From its inception, Batsiranai encouraged men to participate in its home-based care program. This approach was innovative in that it challenged the accepted gendered role of care. According to Batsiranai Founder and Executive Director, Reverend Karimanzira, her organisation decided to train male caregivers for two reasons. First, some male clients were reluctant to be attended to by female caregivers and preferred men as carers. Second, the organisation responded to community pressure to include men in its training program.

Interestingly enough, this pressure only came about when men started seeing some of the material benefits that came with caregiving, such as bicycles for supervisor caregivers, uniforms, and increased status in the community. As one male caregiver commented: "Men first want to see if there is a future in this ... now they see us being called upon at community functions to speak and they now want to be involved."

ZWAAPV, on the other hand, began training male caregivers as a specific gender mainstreaming strategy aimed at lessening the burden of care on women. Both Batsiranai and ZWAAPV are among the minority of organisations whose home-based care training workshops actively target men.

Currently, men make up approximately 30% of the Batsiranai trained caregivers, while men constitute 10% of the 105 trained caregivers volunteering for ZWAAPV. **44** IN THE BEGINNING THERE WERE NO MALE CAREGIVERS, NOW THERE ARE MANY. THERE IS NO DIFFERENCE BETWEEN WHAT WE DO, WE DO JOINT HOME VISITS. IT IS POSSIBLE FOR MALE CAREGIVERS TO GIVE A BED BATH TO A FEMALE PATIENT; WE HAVE NO PROBLEM WITH THAT. BUT THE PATIENT MAY PREFER ONE OR THE OTHER, ESPECIALLY IF THE HUSBAND OR WIFE OR SISTER IS NOT AT HOME TO DO IT. THEY ARE HAPPY FOR US TO BE THERE. **97**

MARGARET CHINYERERE, ZWAAPV CAREGIVER

3. Linking to local health services

Strong links between government and community-based services and resources are critical to providing a continuum of care and creating a supportive environment for people living with HIV.

To this end, leaders within ZWAAPV and Batsiranai as well as within communities have worked hard to coordinate and integrate community home-based care programs with other health services. This is evident in the incorporation of caregivers into the continuum of health services in the community.

For example, caregivers are given the authority to provide patients with health kits from the District Health Service and coordinate patient access to food relief.

ZWAAPV works in close collaboration with the local district hospital to ensure that caregivers are trained according to national home-based care standards. It has also negotiated free medical treatment for its volunteer caregivers from the district hospital and clinics. The caregivers in turn perform some duties in the hospital and clinics such as baby weighing with support and mentoring from the local nurses. As a result, ZWAAPV's caregivers are now integrated into the health delivery system's discharge plans.

Embedding its program into local health delivery structures has also resulted in ZWAAPV caregivers becoming part of the health delivery referral system. The organisation's caregivers now conduct joint home visits with village health workers which have improved coordination and strengthened the support provided to people living with HIV. **66** ZWAAPV HAS ORGANISED FREE TREATMENT FOR US AS CAREGIVERS AT THE CLINIC AND HOSPITAL BECAUSE OF THE CARE WE GIVE TO OTHERS. **77**

PATIENCE MUZVIDZWA, ZWAAPV CAREGIVER

4. Caring for the caregivers

Providing home-based care requires a significant emotional and spiritual commitment from caregivers and potentially results in fatigue and burnout. In both organisations, caregivers have developed networks of support among themselves and within the organisation to address this concern.

ZWAAPV has taken it a step further by ensuring its caregivers receive free treatment at the local clinic or hospital in return for the services they provide to patients at home.

HIV positive volunteers and their families are now guaranteed of care and support through improved access to medication for opportunistic infection, antiretroviral therapy and condoms, reducing their vulnerability to re-infections. Nurturing the passion and pride of individuals in home-based care is critical to sustaining the service of caregivers. ZWAAPV and Batsiranai provide caregivers with uniforms and shoes to help foster their sense of identity and belonging to their respective organisations. Supervisors also receive bicycles to help them travel within the project areas.

Both organisations include community leaders in the volunteer recruitment process which ensures caregivers receive community recognition for their work from the outset.

In addition, ZWAAPV and Batsiranai offer caregivers ongoing training and support and ensure as far as possible that they have all the resources they need to undertake their work, such as the replenishment kits, as lack of resources can be one of the most demoralising aspects of home-based care work.

Caregivers work on a voluntary basis, so they must find other sources of income to feed themselves and their families. In recognition of this, ZWAAPV offers caregivers and their families access to its revolving credit fund so they can establish their own income-generating projects. The organisation also mentors its caregivers, helping them to learn skills in administration to effectively run their projects.

ABOVE: Batsiranai caregiver Felder Gweshe gives a cup of fruit juice to her daughter Victoria Gweshe. Felder cared for her daughter, who was living with HIV, until she passed away. Photo: William Nyamuchengwa/Oxfam AUS. OPPOSITE: Batsiranai caregivers sing traditional songs at the start of a group meeting. Photo: William Nyamuchengwa/Oxfam AUS.

5. Empowering sex workers

From its inception, ZWAAPV has targeted sex workers and other single marginalised women to engender behaviour change that will reduce HIV prevalence in Murewa district.

Initially, women were reluctant to abandon sex work despite the risks of HIV and sexually transmitted infections, and their vulnerability to abuse. The women explained it was difficult to find other sources of income that could immediately meet the demands of providing food and shelter for themselves and their children. They also struggled to learn to value and respect themselves and hence believe that change was possible.

With the support of ZWAAPV, the women came to realise that the reality of reducing HIV in their community meant that the change was not only about themselves, but about all women gaining the right to practice safer sexual relationships. As a result, the women of ZWAAPV spoke to all the sex workers on the trucking route through the province, and collectively they agreed to use condoms. Consequently, if a truck driver stopped anywhere along the route, he was told the same thing: "No condom, no sex". Over time, and as income-generating projects were established, the sex workers moved away from providing sexual services. To a large extent, this shift was accelerated through the provision of home-based care services to each other, and then to the broader community. The now former sex workers affirmed their increased self-esteem, respect for themselves and each other, and the affirmation from the community for the work they now do. They wear the uniform with pride and it has become an outward symbol of the principles of home-based care that they now strive to live by.

The involvement of the sex workers in providing a valuable communitybased health resource to address a critical need has contributed to the improvement of relationships between traditionally marginalised women and the broader community. Through working within existing health delivery structures, the organisation has made tremendous efforts in ensuring that sex workers are now accepted back into the communities that used to shun them.

6. Embedding home-based care in the community

In both organisations there has been a deliberate strategy to embed home-based care in the community. As a result, those traditionally marginalised from community health, such as men, or those who were shunned by the community, such as sex workers and people living with HIV, have been given an opportunity to become directly involved in service delivery.

Now they are accepted as caregivers in their community, have gained respect and dignity through this process, and have become the leaders of a new tradition and culture of care.

Both organisations have also deliberately sought to include community members in many of their processes, from recruitment and selection of caregivers to forums and discussions on HIV prevention and care. For example, caregivers have been encouraged by both organisations to address the community at local leadership gatherings to increase awareness about HIV and seek to integrate the community's response to HIV into local decision-making structures.



66 MY FAMILY WAS VERY SUPPORTIVE AND HAPPY THAT I WAS NOW DOING WHAT I WANTED TO BECAUSE THEY COULD NOT AFFORD TO KEEP ME AT SCHOOL. THEY KNEW THAT THE FIRST TRAINING WAS FOR COMMERCIAL SEX WORKERS, AND THE TRAINING I ATTENDED WAS FOR CAREGIVERS NOMINATED BY THE COMMUNITY.**37**

NEVER NYAKATSA, ZWAAPV CAREGIVER





44 AT FIRST, IT WAS DIFFICULT TO BE A CAREGIVER BECAUSE THE COMMUNITY SAID THIS GROUP WAS ONLY FOR THOSE WHO SELL THEIR BODY, BUT AS TIME WENT ON, THEY SAW THE HEALTH KITS AND HOW THE PROBLEM STARTED TO DECREASE. THOSE PEOPLE THEN SAW THIS AS A VERY GOOD THING AND THE HEADMAN SAID WE NEED TO CARE FOR EVERYONE. NOW HE HAS A LONG LIST OF THOSE WHO WANT TO JOIN THE GROUP. PEOPLE NOW LOOK AT ME VERY DIFFERENTLY. **37**

TENDAYI CHOTO, ZWAAPV CAREGIVER



IN PROFILE

JESSIE TAVAKADA A female caregiver with ZWAAPV

Jessie is 47 years old and has three children. Following the death of her husband she became a sex worker to support her family.

In 2004, ZWAAPV trained Jessie in home-based care and she now volunteers as a caregiver in Nyekete village in Murewa district, Mashonaland East.

"My husband died when I was 25 and three years after, I embarked on sex work because I felt it was the only way I could look after myself. As one of the commercial sex workers, I used to go into the pubs, drink beer, and have multiple partners.

"ZWAAPV ... told me that they had a course which was going on for the peer educators. Initially in the village there were two caregivers who ... would go around the village talking about the need for the reduction of HIV and AIDS, and so when I was approached I was really delighted.

"[At the time] the impression I had was the moment you were diagnosed as HIV positive, it was a death sentence; it meant that you were immediately going to die. I only realised through the training that I was given that it didn't mean [this]. That if you took ... medicine ... and you are going to abstain from sex and sex work you were going to live for much longer. "I went for [an HIV test] after visiting ZWAAPV and ... before I became a caregiver. I am positive; I am living with the virus ... I am happy because I am surviving ...and now it is easy for me to tell others how it is and how I can survive.

"As soon as I found out my [HIV] status and after the peer education training, I immediately stopped [sex work] and since then I have been abstaining from sex work. As a result I realise even when I have sores and wounds all over my body they are healing very quickly. My nutrition is good, I am eating food and have a healthy appetite and of course I may still get sick now and then but this is the usual flu and I get treated for it.

"If I've gone to visit a patient, I tell them what to do and I go back after a few days to find that they are happy to see me. I feel very rewarded but most of all because I'm also a patient so I also confide in them about my status which I use to encourage them to not give up hope because of their status.

"I am happy because I have got the [home-based care] kits which have [disinfectant] and medication that can help to look after the patient.

"There are some challenges we are facing, which is [lack of] food. Red Cross is giving food. When you visit a patient here, he or she expects you to bring something. But when we say, 'We've come to see you. How are you? Is everything OK?' they think maybe the caregiver has been given the food packs and is not giving them. The patients are also asking for pain killers, for paracetamol.

"I also [benefit from] the revolving fund which ZWAAPV is giving [for income-generating activities]. I was given ZWD \$5,000 to start a project on soap-making. At that time it was a lot of money. I am also into gardening. I have onions and tomatoes but I come to ZWAAPV to get money from the revolving fund so that I can buy the fertilisers for my garden."

OPPOSITE, TOP LEFT: ZWAAPV caregiver Fennie Shungu. Photo: William Nyamuchengwa/ Oxfam AUS. TOP RIGHT: Batsiranai caregiver supervisors are given bicycles to travel the long distances to clients' homes. Photo: William Nyamuchengwa/Oxfam AUS. BOTTOM: The granddaughter of Batsiranai caregiver Felder Gweshe helps to pick maize. Photo: William Nyamuchengwa/Oxfam AUS. ABOVE: Photo: William Nyamuchengwa/Oxfam AUS.

KEY CHALLENGES

Working within a deteriorating economy and crumbling health system, ZWAAPV and Batsiranai have both faced significant challenges but are deploying a range of innovative strategies to overcome them.

1. Keeping caregivers motivated and preventing burnout

Testimonies shared by caregivers illustrate the dedication and motivation that drive them to continue to provide care for those living with HIV. Underpinning their motivation is a deep, often religious belief in the worthwhile nature of the work, a need to come in from the edge of the community, or the fulfillment of a dream to give care and support.

This dedication is threatened by a range of difficulties faced by caregivers, among them lack of remuneration, lack of emotional support, demanding workloads with limited resources and the attitudes of some community members who take issue with men, sex workers or people living with HIV providing care services. Both ZWAAPV and Batsiranai have deployed a number of strategies to encourage their caregivers to continue to provide care and remain motivated. These include providing ongoing training and support networks, actively seeking community recognition for caregivers' work and providing caregivers with access to income-generating activities to help them sustain themselves and their families.

2. Ensuring the sustainability of home-based care programs

Emerging practice from ZWAAPV and Batsiranai suggests that increasing their effectiveness and ensuring their longevity requires a commitment to involving caregivers to a greater extent in day-to-day operations; responding to the needs of the caregivers to maintain standards and practice; strengthening links with government and other community-based health services; a continued emphasis on community involvement in programs; and ensuring organisational infrastructure is not dependent on one person (in particular the founding member). ZWAAPV has stated that its strategy has been to use a community-based approach in its activities and to achieve its goals through effective networking, good governance, institutional development and transparency. Moreover, it has sought the involvement of all stakeholders, including hospitals, government agents, nongovernment organisations and local leaders, to create a positive environment which it hopes will continue and expand.

66 BEING A CAREGIVER MEANS I AM A PERSON CONTRIBUTING A VALUABLE SERVICE TO THE COMMUNITY, A TASK I ACCEPT WHOLEHEARTEDLY. **99**

HAMADZIRIPI MHAKAYAKORA, BATSIRANAI CAREGIVER



3. Improving access to medicines

At the time of writing, painkillers were not readily available in the district hospitals and clinics, and when available, the patients had to buy them. In response to this need, many of the caregivers have turned to traditional plants and herbs to alleviate their patients' suffering or symptoms. While these traditional medicines have helped in some patients' treatment, improved access to mainstream medicines and antiretroviral therapy would help many people infected with HIV to maintain good health for longer.

Certainly lack of access to these mainstream medicines remains a major issue for patients and caregivers participating in ZWAAPV's and Batsiranai's homebased care programs. Although patients have indicated that they are satisfied with the services they are receiving, most feel that the crucial aspects affecting their health and wellbeing are not getting enough attention, namely access to medicines, transport to clinics for regular check-ups and supplementary feeding.

4. Meeting community need in a deteriorating economy

With their economy crippled by inflation and political strife, Zimbabweans are finding it increasingly difficult to earn a decent living and provide nutritious food for their families. Recognising that hunger levels in the country are unlikely to be significantly reduced in the short term, ZWAAPV has applied for and obtained a food import permit from the government. ZWAAPV can now ensure that its members benefit from any food import schemes that donors may be willing to fund. ZWAAPV can also enter into a strategic relationship with external non-government organisations which may have the food or funds but are unable to obtain the necessary import permit.

In addition to the food crisis, Zimbabwe has also been grappling with a cholera outbreak that has resulted in the death of more than 4,000 men, women and children. In response, ZWAAPV has deployed its care-giving structures and networks to distribute cholera prevention information within the community. ZWAAPV has also participated in the Murewa district "cholera blitz" meetings and activities. This level of engagement has enabled the organisation to plug into any support that the district is able to provide.

OPPOSITE: Batsiranai caregiver supervisors from the Nyamhara area, Taurai Hwema and Eunice Katiyo. Photo: William Nyamuchengwa/ Oxfam AUS. BELOW: ZWAAPV field worker Sitheni Mutufura explains the contents of home-based care kits to caregivers. Photo: William Nyamuchengwa/Oxfam AUS.

66 THEY THINK THIS GROUP ZWAAPV IS DOING VERY WELL SO THEY SAY: 'LET US DO IT TOGETHER'. **77**

TENDAYI CHOTO, ZWAAPV CAREGIVER





IN PROFILE

SEKURU (GRANDFATHER) MOYOSVI

Sekuru Moyosvi was born in 1932 and is a peasant farmer. He is widowed and of his nine children, only three are still alive.

Sekuru Moyosvi lives with his grandson, 12-year-old Nicodemus, whose father passed away six years ago. Both of them are visited by volunteer caregivers from Batsiranai.

"I have no wife. I have also recently lost my only surviving son and I have also lost a daughter. They both left kids and I am now staying with a grandson.

"My grandchildren and I have nothing to eat. Last year I only harvested 50 kilograms of maize. I have no one to help me work in the fields. Without these girls [the caregivers] I do not know how I would be managing. They help me with soap, cooking oil and even food.

"We are extremely grateful for the services provided by these girls. When they pay you a visit, you just wish they could stay longer because the assistance they give is invaluable. These girls do a lot of work in the community. You see them assisting at funerals ... may God continue to use them so that they bring about change. They still have a lot of work to do because this disease is terrible.

"This disease they call AIDS is real. And it is now out of control. The days of associating the disease with witchcraft are long gone. Look, I had nine children and now I am left with only three girls. They are all buried right here [in the homestead].

"If the government was working as hard as these girls [the caregivers] are, we would be better off by now. The government talks about free access to health services for people my age, but it is really only the first treatment that is free. After that you have to pay for subsequent treatments. We have also been told that if we show our identity cards to transport operators, we will be transported for free. I have not seen this happening. We pay for transport.

"Even when the government sends fertiliser to our areas, some of us do not get any. Instead, it is these girls who help us with our needs. The government should therefore do follow-ups to ensure that the instructions it gives are being followed because there are nurses who are stealing medicines and selling them privately. This has led to the scarcity of medicines even in the hospitals.

"I pray that if I get really sick and it's obvious that God is about to take me, I am not taken to a clinic because if I die there, there will be no-one to collect me. That is what I pray for all the time."

Nicodemus Moyosvi, grandchild

The second eldest in a family of six boys, 12-year-old Nicodemus is in Grade Five. Despite his tender age, Nicodemus has assumed adult responsibilities and manages the household for his grandfather, fetching water, collecting firewood, washing dishes and preparing the morning and evening meals.

"It was very painful [when my father was ill] ... some of the things that he did when he was ill made me wonder if he would ever get well. I was often sent to the shops to buy some medicines so that he would get better. Life was really tough then.

"When he died, that is when we started suffering. We had no means of making money. There were days when I could not attend school because there was no money. Sometimes I would fail to attend school because my clothes were so dirty because we had no soap. There was also no food. Life was tough.

"If I had shoes and clothes I would do better at school. Also we don't have enough blankets at home. I have only one blanket."

66 THERE MAY BE PEOPLE IN THE COMMUNITY THAT SEE THIS AS WOMEN'S WORK, BUT IN THIS AREA MEN ARE FIGHTING TO BECOME CAREGIVERS, SO THIS IS SHIFTING HOW WE SEE OURSELVES AS MEN. **77**

DAVID KATIVHU, BATSIRANAI CAREGIVER

5. Remaining responsive to changing community needs

ZWAAPV has continually sought to identify ways to strengthen its capacity to respond to emerging needs in the communities and over its seven years of operation has introduced a range of new initiatives. For example, to reach sex workers' clients and other men in the community, ZWAAPV recruited and trained male youths as peer educators to teach other men about HIV prevention and the need for behaviour change.

Recognising the need to go beyond advocacy for behaviour change among sex workers and youths, the organisation has also extended support to orphaned and vulnerable children and their guardians. While its initial focus was to support the children of its late members, this project has now been extended to benefit the rest of the community.

This evolving program demonstrates well how small community based organisations can remain relevant and responsive to local needs by being adaptive and using an integrated approach.

6. Challenging community attitudes to male caregivers

Many male caregivers have encountered various forms of resistance to their work. For David Kativhu, resistance came from his mother, whom he says "was worried that if I took this up I would succumb to the virus and then there would be no-one to look after her". For other male caregivers, resistance came from wives who were concerned that the job was not remunerated. This continues to be a bone of contention in most male caregivers' households.

Indeed, part of the ridicule that male caregivers initially face from other men stems from the fact that care work is voluntary. According to Cloud Chivanza, the greatest challenge associated with being a male caregiver is "losing your dignity among other men". Male caregivers were, and still are, viewed by some as "lazy and irresponsible". Attitudes appear to be slowly changing, which is a positive result of the program but also an ongoing challenge.

7. Addressing the challenges of location

ZWAAPV's project area straddles the main highway to the Mozambican border, providing numerous points for truck drivers to stop overnight. Acknowledging the role that the stop points play in fuelling the spread of sexually transmitted infections and HIV, the organisation embarked on reproductive health training and condom distribution in an effort to ensure that sex workers transact safely.

While the organisation has used the ABC (Abstain, Be Faithful, Use Condoms) approach in its prevention and behaviour change messages, other practitioners are also starting to use the SAVE approach. This advocates for safe practices (such as abstinence, faithfulness, condoms and safe transfusions), available medications, voluntary testing, and empowerment. This approach may help to strengthen ZWAAPV's response to HIV prevention in this context.

OPPOSITE: Photo: Annie Bungeroth/Oxfam. ABOVE: Batsiranai supervisor Lois Chikoto explains how he became a caregiver while still a single man. Photo: William Nyamuchengwa/ Oxfam AUS.



IN PROFILE

GARIKAI KATIYO A male caregiver with Batsiranai

Garikai Katiyo was born in 1971 and is married with two young sons. Mr Katiyo was among the first group of men to be trained as caregivers by Batsiranai in 2001.

Mr Katiyo has six clients, three of whom are bedridden. His furthest client lives an hour's walk away. In his village, there are five trained caregivers — three women and two men.

An illness in the family motivated Mr Katiyo to volunteer to be a caregiver. "My sister's child was ill and they came to stay with me. We had very little information on how to care for such a person and I also realised that some family members distanced themselves from him when he was very ill. So when I heard that Batsiranai was looking for people to train as caregivers, I decided to try it out."

Mr Katiyo found the training informative and immediately applicable. "The training was very useful because I was able to show my relatives how to care for my sister's child, and how to bathe him. I also explained to them that even though he is sick, he still has rights which must be respected. I pointed out that he had the right to live and that it is important to keep him company and talk to him and not shun him."

Mr Katiyo has attended additional training with Batsiranai, most recently a wills and inheritance workshop.

"There are many sick people who want me to assist them draw up their wills," he says. "Right now there are three who have told me what they want done when they die. Others ... simply tell me verbally that they want this and that done when they die and they also tell me the specific individuals I should disclose their HIV positive status to when they die."

Being a male caregiver has its challenges. Mr Katiyo says male caregivers were initially mocked by other men in the community who accused them of "being lazy for wanting to do women's work, rather than going out to look for proper jobs or finding other means of generating their own income". They were also mocked when they expressed views in support of gender equality, especially when they challenged men to care for their wives and not send them back to their maiden homes when they were ill, as often happens.

This initial resistance has waned and more men now want to be trained. According to Mr Katiyo, part of the reason for this shift in attitudes is the high status that caregivers enjoy in the community.

"People now know that if there is an illness in their family, we are the ones who can assist them, so I am encouraged by this community support. Even in the community, we are now invited to meetings and given time to talk about HIV and AIDS."

Another challenge that Mr Katiyo has encountered are difficult patients and families who abdicate their responsibility of care to the caregiver. "Some families want us to care for their sick 100% of the time and they forget that we also need time to engage in income-generating activities," he says. "This puts a lot of pressure on us as caregivers."

Being involved in caring for the sick has encouraged Mr Katiyo to change his sexual behaviour "because I could see for myself just how sick people were and I realised that this game [sleeping around] is dangerous."

His involvement in care work has also changed his attitudes to sickness and death. "In the past I used to be afraid of seeing someone who is seriously ill, or even bathing them or bathing someone who has died. But as I have gained experience through my work I am no longer afraid."

ABOVE: Photo: William Nyamuchengwa/Oxfam AUS. OPPOSITE, TOP LEFT: Batsiranai caregiver Spiwe Maulidi. Photo: William Nyamuchengwa/Oxfam AUS. TOP RIGHT: Traditional leaders at village meeting with Batsiranai caregivers. Photo: William Nyamuchengwa/Oxfam AUS. BOTTOM: ZWAAPV field workers Ann-Mery Nayakabau and Sitheni Mutufura. Photo: William Nyamuchengwa/Oxfam AUS.



domen Against HIV/AIDS and Violence



I USED TO FREQUENT THE BEER HALLS WHERE THE TRUCK DRIVERS VISITED ON THEIR WAY TO MALAWI OR SOUTH AFRICA, **AND WOULD GET BUSINESS** AS A SEX WORKER. MRS K **[A ZWAAPV CAREGIVER] USED** TO VISIT THE BEER HALLS AND SHE HAD A DIFFICULT TIME TO PERSUADE US TO JOIN ZWAAPV. I WAS NOT AWARE THAT I **COULD EARN MONEY FROM OTHER SOURCES IN THE COMMUNITY AND THOUGHT** I COULD ONLY GET IT FROM **SEX WORK. EVENTUALLY WE DECIDED TO LINK UP WITH HER BECAUSE SHE SHOWED HER** WILLINGNESS TO SUPPORT US: SHE FELT FOR US AND WANTED TO HELP US. SHE TALKED ABOUT HOW WE COULD SUSTAIN Poverty "OURSELVES WITH OTHER SOURCES OF LIVELIHOOD. AND ORGANISED TRAINING. 77

JACQUELINE CHINGWERE, ZWAAPV CAREGIVER

Zimbaby

CONCLUSION

Within the context of providing home-based care in Zimbabwe, a number of innovative practices are emerging from the experience of Batsiranai and ZWAAPV. These practices, which include involving more members of the community, illustrate how home-based care work can promote cultural and social norms and practices that foster gender equity, decrease women's vulnerability to HIV and AIDS, promote improved integrated care and support services, and provide a supportive environment for people living with HIV.

The response by the organisations, individuals and the community further suggests that there is a shift in dependency from state healthcare to community-based healthcare. As highlighted by the World Health Organization, innovative care at the micro levels requires the integration of not only health services, but families, patients, community structures and healthcare teams. The example of the work of Batsiranai and ZWAAPV suggests the achievement of positive outcomes relating to increased awareness, reducing stigmatisation, encouraging positive outcomes in individuals and community relationships, and in building sustainable care in the family.

A number of features have contributed towards these positive outcomes. These include the importance of integrating healthcare services in community structures to facilitate community ownership; leadership that responds to community health needs and raises awareness of needs; and empowering individual caregivers to take initiative in healthcare and removing stereotypes. The goal is to ensure that the practical delivery of healthcare encourages and facilitates a better reality for all.

The testimonies provided in this case study suggest that the community-based organisations and caregivers are meeting the stated objectives of home-based care, and recognise and uphold the principles of home-based care for Zimbabwe. It appears that the caregivers are providing a sound quality of care to patients after release from hospital; promoting family and community awareness; providing the family with the knowledge and skills for long-term care; reducing the stigma associated with HIV and AIDS; and facilitating quality community care for the infected and affected. The socio-economic situation in Zimbabwe limits the ability of the caregivers to refer patients to appropriate health and social facilities, and adds to their burden of care as families require and are challenged by providing basic food and health needs.

The challenge will be for the organisations and individual caregivers to maintain and sustain the level of care, and to continue to mobilise community support, despite the lack of resources in Zimbabwe.

BELOW: The grandchildren of Batisiranai caregiver Felder Gweshe. Felder now cares for the children since her daughter passed away. Photo: William Nyamuchengwa/Oxfam AUS.





ABOVE: Batiranai caregivers prepare to set out on their client visits. Photo: William Nyamuchengwa/Oxfam AUS.

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The opinions of authors or participants in this document do not necessarily reflect those of Oxfam Australia, Oxfam affiliates, COGENHA or its staff. BACK COVER: ZWAAPV Founder and Executive Director Beatrice Karimanzira joins caregivers in a song of celebration. Photo: William Nyamuchengwa/Oxfam AUS.

References

^{1& 3} UNAIDS www.unaidsrstesa.org/ countries/zimbabwe

² World Health Organization www. who.int/whosis/en/index.html

^{4 & 5} UNICEF 2007 www.unicef.org/ infobycountry/zimbabwe_statistics. html

⁶ UNAIDS Zimbabwe 2008 Country Progress Report

⁷ National Home Based Care Training Manual. Zimbabwe.

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Telephone: +61 3 9289 9444 Facsimile: +61 3 9347 1983 Website: www.oxfam.org.au Email: enquire@oxfam.org.au

Chief Contributors: Margaret Roper and Tsitsi B Masvaure Editors: Melanie Scaife Maureen Bathgate Christine Graunas Picture editor: Chris Parkinson Proofreaders: Christine Graunas and Talia Elion Print coordinator: Kim Hayes Design: Paoli Smith Print: Work & Turner

Contributors: Maureen Bathgate Leo Wamwanduka Bridgette Thorold Doreen Mukwena Benny Mushowo Skye Windebank



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