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# Where there's a will there's a way

Nursing and midwifery champions  
in HIV/AIDS care in Southern Africa



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## BEST PRACTICE COLLECTION

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Cover photos by Guy Stubbs

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Nursing and midwifery champions  
in HIV/AIDS care in Southern Africa



The document was written by Sue Armstrong at the request of UNAIDS and the Southern African Development Community (SADC) AIDS Network of Nurses and Midwives (SANNAM).

The UNAIDS responsible staff member was Sandra Anderson of the UNAIDS Intercountry Team for Eastern and Southern Africa.

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This research would not have been possible without the hard work and enthusiasm behind the scenes of the nursing associations of the countries visited, and we wish to express our sincere appreciation for their vital contribution. We would like to thank the following individuals from the nursing associations and SANNAM who took time out to guide and accompany Sue Armstrong on her visits to their countries. They are, in alphabetical order:

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## Foreword

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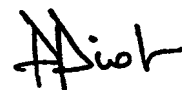
HIV/AIDS needs champions. In the face of the cruellest epidemic humanity has ever known, we need the champions who lead by example, who keep hope alive that the epidemic can be defeated, and who are unstinting in their care.

This report celebrates just a few of those champions: some of the many thousands of nurses and midwives who are at the front line of HIV/AIDS care in Southern Africa. The global community owes these champions an incalculable debt for their service to humanity, but it also owes it to them to do all that is possible to lighten their burden.

We must do all in our power to overcome the global divide that denies HIV treatment to 99% of the people living with HIV/AIDS in Southern Africa, whose lives it would save. The lack of access to vital medicines is not only a tragedy for those with HIV/AIDS, it is also deeply disempowering for the health professionals who care for them. They must do the best they can for their patients, knowing that it falls far short of what is possible. And they must bear the shame and frustration of being part of a system that fails most of those for whom they care.

We must applaud those nurses and midwives who refuse to give up, despite the huge challenges they face, and who remain committed to the ideals of their profession as caregivers. The nurses and midwives of Southern Africa deserve our recognition, support and encouragement for what they are managing to achieve in the face of desperate odds.

UNAIDS, through its support to the SADC AIDS Network of Nurses and Midwives, and many other partners, honours these specific champions, and thereby recognizes the many others in Southern Africa and throughout the world. Nurses and midwives are at the forefront of prevention, care and treatment, and in fighting stigma and discrimination. Their leadership must be praised, their compassion rewarded, and their commitment nurtured.



Dr Peter Piot  
Executive Director  
UNAIDS

## Introduction

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***HIV/AIDS affects us in our workplaces and also at home, in our families. We are the first point of contact for patients—and sometimes these patients are members of our own families.***

— Beauty Mahatelo, Botswana nurse

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Sitting in her office in Lusaka's sprawling University Teaching Hospital (UTH), the director of nursing, Mercy Mbewe, reflects on the effect HIV/AIDS is having on her staff. "Usually, patients come in, they get better, and they go home. But, with HIV/AIDS, the patient doesn't get better and doesn't go home. Or else he goes home and comes back and keeps returning to the hospital. This is not what nurses are trained to expect, and for some it's just too much; they can't cope."

The strain is obvious, says Mercy, in the high levels of absenteeism; in the faces of young nurses working in wards that are understaffed and where almost everyone is bedridden; and in the fact that some of her staff are not sleeping well or eating properly.

The picture is similar throughout Southern Africa, where the HIV/AIDS pandemic is at its worst. With only 5% of the world's population, this region is home to approximately 30% of all people living with HIV/AIDS. Moreover, the pandemic continues to grow at a staggering rate, putting tremendous pressure on health services already struggling with tight budgets and scarce resources to meet the basic needs of their people. Among health professionals, the biggest burden is shouldered by nurses and midwives, who are the first point of contact for patients and the staff members who bear greatest responsibility for their on-going treatment and care. But lack of recognition or respect for their contribution is intensifying the burden and undermining countries' efforts to control the HIV/AIDS epidemic.

HIV/AIDS affects every aspect of nursing practice, yet nurses and midwives have to take on responsibilities for which many are ill-prepared. Often they qualified before HIV/AIDS was on the curriculum and they have not received specialist training in the syndrome since. In many places, nurses and midwives are bypassed by public information programmes because their central role in combating the epidemic and their need for specialist knowledge and skills are not recognized. A survey by the Centre for Health Policy at the University of the Witwatersrand in South Africa, for example, found that only 10% of nurses canvassed had received specific training in clinical management of HIV/AIDS (1). Fifteen per cent of the sample could not recognize oesophageal thrush—one of the most common HIV/AIDS-related complaints—and only 7% knew how to treat it. Only half of 215 nurses surveyed knew how to treat diarrhoea in HIV-positive children.

Excessive workloads—caused by ever-increasing numbers of patients, the time and energy required to care for people living with HIV/AIDS (PLWHA), and the mass emigration of nurses and midwives from all over sub-Saharan Africa in search of better pay and conditions in the developed world—are one of the biggest strains on those who remain to practise their profession in their home countries. Whereas a ratio of 1 nurse to 10 patients (or 1-to-4 in busy wards) is the ideal, many are single-handedly caring for 30, 50, 60 and even more patients, most of whom are bed-ridden and need everything done for them. In addition, staff members often have to contend with widespread shortages of medical supplies and equipment, including the

most basic necessities for protecting against hospital-acquired infection, such as rubber gloves, gowns and masks.

One young nurse working on a medical ward in UTH, Lusaka, with 60 patients to look after, stopped at a bedside briefly to describe the conditions with which she contends. There were only two thermometers on the ward, she said, and there had been no water in the taps for 12 hours the night before. She told also of how, sometimes, drugs run out when a patient is halfway through treatment, and of the defeat she feels as she watches someone who was getting better decline again. “I sometimes don’t want to come back to work,” she said, her eyes brimming with tears.

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***I can’t just watch a patient die because I don’t have gloves. Every time I see someone in that situation, I think of what I learned—that the patient comes first and my safety next (2).***

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For many nurses and midwives working in such conditions, there is the constant fear of contracting HIV from their patients. Studies of occupational risk conducted in the United States of America and Europe suggest that less than 1% of HIV cases among health workers are contracted in the course of duty. However, data from the developed world are not convincing to people working in poor countries, and fear is badly affecting morale throughout the health services. “Two years ago, the obstetrics and gynaecology ward used to be a fun place to work. But not now,” says Mercy. “Midwives are very proud people—proud of their work—but even they are demoralized.”

For those health workers who know, or suspect, that they are already infected with HIV, there is the fear of detection and marginalization by colleagues, fear of losing their jobs, and the fear of confronting their own possible fate as they witness daily the ravages of AIDS and the constant cruelties of stigma and rejection. Besides undermining a health worker’s capacity to do his or her job properly, fear itself is an emotional burden that eats away at self-esteem.

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***If you suffer fear and prejudice towards your patients, you don’t get any job satisfaction and it’s demotivating.***

— Jennifer Munsaka, Executive Director of the Zambia Nurses Association

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Even after two decades of HIV/AIDS, stigma remains one of the most obstinate and damaging features of the pandemic, and it adds to the difficulties faced by health workers. Forced to deal with a condition that few dare to name, and governed by unusually strict rules of confidentiality, nurses find it hard to discuss important issues of prevention and care with patients and their families. Many fret that they are failing in their duty towards vulnerable people.

Everyone is unnerved by the silence surrounding HIV/AIDS, and front-line health workers are frequently subjected to aggression from scared and overwrought patients and their relatives. There is the problem, too, of ‘secondary stigma’: members of home-based-care teams sometimes find themselves shunned by people who fear that a visit from them will reveal their painful secrets to the neighbours. And even the wearing of gloves, especially in the home, has become a sensitive issue because of the association with HIV.



**Box 1. Infectious and non-infectious body fluids**

Infectious body fluids:	Non-infectious body fluids:
<ul style="list-style-type: none"> <li>• all body fluids containing visible blood</li> <li>• vaginal secretions</li> <li>• semen</li> <li>• amniotic fluid</li> <li>• pericardial, peritoneal and pleural fluid</li> <li>• cerebrospinal and synovial fluid</li> </ul>	<ul style="list-style-type: none"> <li>• tears</li> <li>• feces</li> <li>• urine</li> <li>• saliva</li> <li>• sputum</li> <li>• nasal secretions</li> <li>• vomit</li> <li>• sweat</li> </ul>

Source: US Department of Health and Human Services, Centers for Disease Control and Prevention. Updated US public health service guidelines for the management of occupational exposures to HBV, HCV and HIV, and recommendations for post-exposure prophylaxis. *Morbidity and Mortality Weekly Report (MMWR)*, 29 June 2001: 50(RR11); 1-36.

In most of Africa, the frequent lack of necessary treatment for HIV/AIDS-related diseases, including antiretrovirals, means that nurses must face patients day after day without life-saving medicines that are readily available in some parts of the world. This void contributes towards nurses feeling helpless, depressed and disempowered.

The excessive burden imposed by the epidemic on nurses and midwives in Southern Africa is exacerbated by the fact that they are working in an environment that is unresponsive of their efforts and inherently stressful. In a number of countries, their wages are extremely low, their career prospects poor and their jobs insecure, and there are no regular supplies to protect them from infection in the workplace. Everywhere, nurses and midwives lack appreciation for their pivotal role in combating HIV/AIDS, and there is little recognition of the stresses they face or official concern for their psychological welfare. Moreover, these important front-line workers have no voice in policy- and decision-making and no listening ear in high places.

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***Today, many people see nursing as a dirty job for nothing.***

— Jennifer Munsaka

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Sadly, it is the failures of nurses and midwives under such conditions that receive most attention, and a negative image of these health workers prevails in the public mind. This is enormously damaging: not only is it often unfair and unkind, but it helps to further undermine the morale and contribution of some of the most important people in the fight against HIV/AIDS. No country can afford to squander such a precious resource, and it is the purpose of this report to challenge negative public perceptions, and to encourage the confidence and stimulate the initiative of nurses and midwives working on the front line of the epidemic everywhere.

The report describes some of the many ‘champions’ of the profession—individuals who, with singular commitment and resourcefulness, are delivering good-quality care to people with HIV/AIDS, or who are otherwise helping families and communities to understand the epidemic, to come to terms with their own fears and prejudices, and to protect themselves from infection. However, this is not some kind of league of heroines and heroes of the epidemic. The

champions featured here are just a few of the ordinary nurses and midwives who are simply doing their job well, under difficult circumstances. There are, without doubt, very many more of them. In describing the work of a few, the intention is to pay tribute to all who are doing a caring, committed job in the face of great odds, and to share as widely as possible the valuable lessons they have learned from experience.

The report was commissioned by the SADC AIDS Network of Nurses and Midwives (SANNAM) in collaboration with UNAIDS. It involved original investigation in the field by a consultant who, over the course of one month, visited five countries in Southern Africa—namely, Botswana, Lesotho, Namibia, South Africa and Zambia—to link up with the national nursing associations and speak to a wide range of people. In addition to nurses and midwives, these included some of the people they work with in communities, such as volunteer caregivers, members of youth groups, and PLWHA and their families, as well as people working within ministries of health, and relevant United Nations agencies and nongovernmental organizations.

Besides being aimed at nurses and midwives themselves, the report is addressed at all those with an interest in improving the quality of care and support of people living with HIV/AIDS (PLWHA), especially those responsible for training, managing and supervising nursing and midwifery staff, and policy-makers within the health services.

## The HIV/AIDS epidemic in Southern Africa: an overview

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***I just look at that person in front of me, and I try to put myself in their shoes. I think of what it must feel like to know that nurses are frightened to care for you, or your family not to visit you, and to know that you have something that cannot be cured, and I feel so sad.***

— Olive Ng'andu, Zambian nurse/midwife

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Olive Ng'andu

There is virtually no one in Southern Africa who does not have personal experience of HIV/AIDS. If the epidemic has not touched their own families, it is more than likely to have taken friends or neighbours, for the virus has spread faster and further in this region than anywhere else on earth. Hopes that HIV might reach some natural limit in populations and 'plateau out' have been dashed, as infection rates have continued to climb beyond expert predictions.

Among 15–49-year-olds, 39% are infected with HIV in Botswana, compared with 31% in Lesotho, 22.5% in Namibia, 20.1% in South Africa and 21.5% in Zambia (3). But national prevalence rates hide

significant variations between population groups. While some of the more remote rural corners of the region still have infection levels in single figures, HIV infection rates of more than 50% have been recorded among pregnant women in urban Botswana, and more than 60% among male patients attending clinics for sexually transmitted infections (STIs) in Botswana, Lesotho, South Africa and Zambia. Extremely high rates of infection have been recorded, too, among female sex workers in Southern African cities. Globally, HIV/AIDS ranks fourth among the causes of death, but in Southern Africa it is now the leading cause of death, outstripping other major killers such as malaria and tuberculosis (4).

The impact of the epidemic is devastating. HIV/AIDS is overwhelming services, deepening poverty, crippling already-fragile economies, and playing havoc with population dynamics across the region. In Namibia, the number of people hospitalized for HIV-related illness increased from 355 in 1993 to 6878 in 1999 (5). In Zambia, too, hospital admissions are overwhelming resources: the cost of treating a patient in hospital is about US\$200, whereas the annual per capita expenditure on health care is just US\$3 (6). Everywhere, hunger is an increasing threat as food production has declined with the illness and death of agricultural workers. At household level, HIV/AIDS has pushed even once-thriving families into destitution as breadwinners have succumbed to the virus or else have had to give up work to care for sick relatives. Often, there are extra mouths to feed as families take in orphaned children. In Botswana, for example, it has been calculated that every income-earner in the poorest sector of society can expect to take on four extra dependents as a result of HIV/AIDS (7).

At the demographic level, HIV/AIDS has knocked years off the life expectancy in all countries visited. In Botswana, life expectancy at birth has dropped from 67 to 42 years, and is

expected to fall below 30 years by 2010 (8). In Zambia, it declined from 55 years in the early 1980s to 37 years by 1998, and is still declining (9). And, in Namibia, life expectancy at birth is projected to drop from a high of 60 years in 1994 to just over 40 by 2005 (10). Within the next few years, people will be dying at a faster rate in Botswana, Lesotho and South Africa than babies are being born (11).

Namibia has tried to bring home the reality behind these mind-numbing figures by looking at the prospects for 100 boys and 100 girls aged 14 today and still uninfected (12). According to existing trends, over half of the boys (55%) could expect to be HIV-positive before the age of 50, with 38% of them dying before their 40<sup>th</sup> birthday. Among the girls, 60% are likely to be HIV-positive before their 50<sup>th</sup> birthday, and nearly half of them will have died before reaching 40. And because females in Namibia tend to become infected at earlier ages than males, one quarter of the girls in the hypothetical sample are likely to die before their 30<sup>th</sup> birthday.

A complex mix of political, economic and cultural factors is driving the epidemic in Southern Africa. Poverty, which is widespread in the region, makes individuals vulnerable to infection by encouraging risky behaviour such as prostitution, or the exchange of sex for food, shelter or financial support, in the desperate bid to survive. It drives many young women into the arms of 'sugar daddies' as their only hope of finding the money for school fees and decent clothes. It disrupts family life and stable relationships as people scatter in search of work, often acquiring new sexual partners during their long absences from home. And, in a vicious twist, HIV/AIDS exacerbates poverty, rendering families and communities ever more vulnerable to the virus. Research in Zambia, for example, revealed that the majority of families in which the father had died of AIDS saw their monthly income fall by up to 80% (13). The majority of households in which the mother had died simply disintegrated, precipitating family members into a personal survival crisis.

Gender inequality is also driving the epidemic in this region. For women who are dependent on men for their financial support and social status, it is especially difficult to broach the subject of safe sex, even with their regular, committed partners. Negotiating the use of condoms implies that the woman has been unfaithful or that she does not trust her husband or partner, either of which might result in her being rejected, beaten up or thrown out of her home. Thus, even when people know the risks they are taking with HIV and what they could do to protect themselves, fear of the immediate consequences often stifles discussion between couples.


Lack of knowledge is a factor, too. The idea that people with HIV/AIDS have been bewitched is still strong in some communities. And surveys show that, among those who do accept the virus theory, there is a significant proportion who are still not sure exactly how it is transmitted or how to protect themselves.

One of the most powerful forces at work behind the epidemic, however, is stigma, which has thrown up a wall of silence around the virus and inhibited every effort to combat the epidemic. In every town and rural village visited, there are families hiding away their sick sons and daughters, husbands and wives, for fear of the harsh judgement and rejection of neighbours. There are sick people afraid to be visited by home-based-care teams because of the risk of disclosure. And there are people with tuberculosis (TB) who are not prepared to attend the TB clinic because of its association with HIV/AIDS.


The vast majority of people in Southern Africa do not know their HIV status. Voluntary counselling and testing (VCT) services are nowhere widely available, especially outside the main centres. There are shortages of trained counsellors and laboratory facilities. Often blood samples have to be sent away for analysis, so that results are a long time coming and people tend to lose courage or motivation to return for their results. But even where VCT services are available, people may be reluctant, for a variety of reasons, to take a test. In Zambia, for example, the nurses association is keenly aware of the need for greater openness, and encourages nurses and midwives to go for VCT, but only about 20% have done so. "They ask: 'What's the point? What help is there if I find I am positive?'" explained Zambia Nurses Association (ZNA) president Dorothy Chikampa. Some are worried about confidentiality because it is their own colleagues who run the counselling and testing services. Some fear they will lose their jobs. But some reject VCT because, as professionals who are looked to for care and support, they find it hard to accept their own vulnerability and would rather deny it. On the other hand, a recently opened VCT centre in Lusaka, called New Start, is doing brisk business. Churches, in particular, are promoting the value of knowing your serostatus, especially for couples about to get married, whom they urge to be faithful to one another. Priests say they have buried too many husbands and wives, and they don't want to be burying the next generation.

The provision of care and support services is an important element in encouraging people to find out their HIV status, and countries are slowly taking steps to provide such services. In Botswana, every HIV-positive pregnant woman is now offered AZT to protect her baby from infection, and is provided with free infant formula if she wishes not to breastfeed. Antiretroviral treatment for the prevention of mother-to-child-transmission is being piloted in a few urban centres in Namibia and Zambia, too, with the intention of eventually expanding the programmes nationwide. And, in Botswana, a programme to offer antiretroviral treatment to everyone with advanced HIV infection has recently begun with a pilot project in Gaborone.


The availability of these services will make it even more important for people to find out their status and will give a boost to VCT. But, in the end, stigma and silence will only be overcome when many more of those who test HIV-positive have found the strength to live openly with their diagnosis. Encouraging this process among nurses and midwives as well as the general public was a key objective in the founding of SANNAM in May 2001.




**Zambia**  
 Total population: 10.4 million  
 Population urbanized: 39.6  
 Adult literacy rate: 78.1%  
 Infant mortality rate (per 1000 live births): 112  
 Child mortality rate (per 1000 live births): 202  
 GDP per capita (PPP\* US\$): US\$780  
 Population living on less than US\$2 per day (PPP): 87.4%  
 Per capita health expenditure (PPP US\$): \$23  
 Physicians per 100 000 people: 7




**Botswana**  
 Total population: 1.5 million  
 Population urbanized: 49%  
 Adult literacy rate: 77.2%  
 Infant mortality rate (per 1000 live births): 74  
 Child mortality rate (per 1000 live births): 101  
 GDP per capita (PPP\* US\$): US\$7184  
 Population living on less than US\$2 per day (PPP): 61.4%  
 Per capita health expenditure (PPP US\$): \$127  
 Physicians per 100 000 people: 24  
 TB rate per 100 000 people: 513

**Namibia**  
 Total population: 1.9 million  
 Population urbanized: 30.9%  
 Adult literacy rate: 82%  
 Infant mortality rate (per 1000 live births): 56  
 Child mortality rate (per 1000 live births): 69  
 GDP per capita (PPP\* US\$): \$6431  
 Population living on less than US\$2 per day (PPP): 55.8%  
 Per capita health expenditure (PPP US\$): \$142  
 Physicians per 100 000 people: 30  
 TB rate per 100 000 people: 469



**South Africa**  
 Total population: 43.3 million  
 Population urbanized: 56.9%  
 Adult literacy rate: 85.3%  
 Infant mortality rate (per 1000 live births): 55  
 Child mortality rate (per 1000 live births): 70  
 GDP per capita (PPP\* US\$): \$9401  
 Population living on less than US\$2 per day (PPP): 35.8%  
 Per capita health expenditure (PPP US\$): \$230  
 Physicians per 100 000 people: 56  
 TB rate per 100 000 people: 323



**Lesotho**  
 Total population: 2 million  
 Population urbanized: 28%  
 Adult literacy rate: 83.4%  
 Infant mortality rate (per 1000 live births): 92  
 Child mortality rate (per 1000 live births): 133  
 GDP per capita (PPP\* US\$): US\$2031  
 Population living on less than US\$2 per day (PPP): 65.7%  
 Physicians per 100 000 people: 5  
 TB rate per 100 000 people: 291

(Source of all country information: UNDP, Human Development Report 2002)

\* PPP stands for 'purchase price parity' and is a more accurate way of measuring income and expenditure for the purposes of comparison between countries than using the currency exchange rates. It takes into account what can actually be bought with the US\$ equivalent.

## SANNAM and the national nursing associations

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The SADC AIDS Network of Nurses and Midwives (SANNAM) was launched officially on 23 May 2001. It has its roots in the International AIDS Conference held the previous year in Durban, and a unique partnership between diverse organizations with a shared vision. In advance of the conference, and with the encouragement and guidance of UNAIDS, the nursing associations of the Southern African region were hosted by the Democratic Nursing Organisation of South Africa (DENOSA) to plan a satellite nursing meeting before the conference and to discuss the opportunities for synergy through networking. All faced similar challenges as they struggled to cope with rampant epidemics, and they quickly realized the immense value of sharing their experiences with each other.

The idea for a formal network of national associations to address issues related to the epidemic—inspired originally by UNAIDS—took off and quickly found support from a number of organizations. It won the approval of the health desk of the Southern African Development Community (SADC), giving the new organization a political platform and foundation in a strong existing regional community. DENOSA, under the leadership of their Executive Director, Thembeke T. Gwagwa, generously offered the network a home in Pretoria. The Canadian International Development Agency (CIDA) and the Canadian Nurses Association, through June Webber, the Director of International Policy and Development, gave financial and technical resources for institutional development and capacity-building. The Baylor College of Medicine in the USA gave financial and technical resources, with support from the Bristol-Myers Squibb 'Secure the Future Initiative', as well as providing an HIV nursing curriculum, which had been developed collaboratively within the region, under the leadership of Nancy Kline, Meg Ferris and Lorraine Cogan.

"The purpose of forming the network was to empower nurses to break the silence on HIV/AIDS, and also to explore the impact of the epidemic on nursing and midwifery, and the expanded role it has meant for us," says Jabu Makhanya, DENOSA Communications and Corporate Manager and organizer of the nursing satellite meeting. "It also gives us more of a voice and a better opportunity to influence policies in our various countries."

Apart from the coordinator and the administrative secretary, everyone works for SANNAM on a voluntary basis. The national nursing associations are represented by their presidents, who meet regularly to discuss common concerns and plan the way forward. Major activities so far have been:

- the launching of *Fact Sheets for Nurses on HIV/AIDS*, developed jointly by UNAIDS, WHO and the International Council of Nurses;
- the organizing of training workshops in all of the 14 SADC member countries in the use of the *HIV Curriculum for the Health Professional*, from Baylor College (see 'Recommended further reading');



SANNAM members from 14 SADC countries, plus their supporters from SADC and UNAIDS

- the development of a SANNAM website; and
- the commissioning of this report on best practices.

In addition, a needs assessment survey has been carried out in each of the member states. This will form the basis of future action by SANNAM to enable nurses and midwives in the region to respond more effectively to the HIV/AIDS epidemic (see Annexes 1 and 2).



SANNAM/Baylor Training of Trainers Workshop with the Zambia Nurses Association, 3-6 September 2002.

### **Box 2. Summary of recommendations from the SANNAM Needs Assessment Survey, 2002 (14)**

- More training on HIV/AIDS, especially in counselling, management of opportunistic infections and antiretrovirals
- Exploration and action to decrease negative attitudes about HIV/AIDS, stigma and discrimination in health-care settings
- Protective equipment and methods for disposal of 'sharps' for infection control
- Better recruitment and retention of nurses
- More data on the impact of HIV/AIDS on the nursing population and their morale
- Health care and treatment for HIV-infected nurses, and support for affected nurses
- More input into national and institutional HIV/AIDS plans and policies related to HIV/AIDS
- Increased regional and local networking for quality of care and making nursing contributions more visible, including with nongovernmental and community-based organizations, associations of people living with HIV/AIDS and faith-based organizations.

### **National nursing associations**

National nursing associations (NNAs) exist in all the SADC countries. Their prime purpose is to look after the interests of nurses and midwives, to enhance their professional knowledge and skills in the pursuit of high-quality care, and to give them a collective voice in public affairs. Most NNAs are affiliated to one or more supranational professional organizations, such as the International Council of Nurses (ICN), the Commonwealth Nurses Federation (CNF), and the East Central and Southern African College of Nurses (ECSACON), which help to enhance their authority and political influence. Most are also represented in a number of national organizations and work in close partnership with international bodies, such as WHO, UNICEF and UNAIDS.

The role of the national associations in speaking up for their profession is very important, says ZNA President Dorothy Chikampa. "Policy-makers are almost invariably recruited from among physicians. Nurses and midwives are not consulted on policy issues as a matter of course. Our knowledge and experience aren't widely recognized."



NNAs are nongovernmental organizations and they each have their own characteristics, priorities and activities. At a time when health services and their staff are facing new and increasingly complex challenges, they have a particularly important role to play in maintaining morale and commitment to the profession, and standards of care.

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***Policy-makers are almost invariably recruited from among physicians. Nurses and midwives are not consulted on policy issues as a matter of course. Our knowledge and experience aren't widely recognized.***

— Dorothy Chikampa, ZNA President

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Dorothy Chikampa, President of ZNA, with the Honourable General Brian Chituwo, Minister of Health and Dr Muti, Permanent Secretary, Ministry of Health.

- **The Nurses Association of Botswana (NAB)** was founded in 1968, with assistance from the International Council of Nurses, and with the express purpose of advancing the nursing profession, enhancing the quality of nursing care, and promoting the welfare of nurses and midwives. The NAB has 20 branches countrywide and a membership of about 2500 people. It employs 12 staff members who operate out of modern, well-equipped offices in Gaborone. The NAB headquarters are set in their own gardens and include a hostel, a cafeteria and a day-care centre, which help to generate income for the association. The NAB also believes in networking, and is involved in a wide range of programmes and activities, alone or in partnership with other organizations. Like its Zambian counterpart, the NAB has adapted the UNAIDS/WHO/ICN fact sheets to reflect the local situation. It is undertaking research into the impact of the epidemic on the professional lives of nurses and midwives, and has developed a 'caring for the carers' programme to cater for their psychosocial and welfare needs. The NAB has secured a piece of land in the village of Molepolole to establish a day-care centre and other projects for orphaned children. In addition, the association is exploring the possibilities of taking information and education on HIV/AIDS directly into homes and schools. The principal aim is to reach children, who are often silent and fearful witnesses of the devastation of AIDS in their own families, and adolescents who need knowledge and skills to avoid infection as they become sexually active.
- **The Lesotho Nurses Association (LNA)** has a membership of around 380, out of a total workforce of 800 registered nurses and midwives. Its key responsibilities are to enhance the development of the profession, and to look after the legal, health and welfare needs of nurses and midwives practising and/or training in Lesotho. The association has branches throughout the country, which is divided into 19 Health Service Areas, each of which has a hospital providing core services to the local population and referrals to Queen Elizabeth II Hospital in the capital city, Maseru. The LNA is run by a president and an executive committee whose seven members are elected every four years at the annual general meeting. At present, all office-bearers serve as volunteers in their spare time, and have to rely on the goodwill of their employers for office space and other resources. However, the association has recently acquired a site in central Maseru to establish its own offices, and is busy

raising funds for the project. It publishes a newsletter, *Mooki*, twice a year to keep its members informed of its activities and other relevant issues. Research reported in *Mooki* shows that nurses and midwives in Lesotho are under considerable stress from the HIV/AIDS epidemic. High bed occupancy, a high mortality rate among patients, and overwork are undermining the morale of nursing staff. The LNA has, to date, run two training workshops for its members on counselling PLWHA and their families, and it continues to research HIV/AIDS-related topics. The association is represented within a number of national organizations, and works in close alliance with nurses associations in many other countries.



Meeting of the SADC National Nursing Associations at the Democratic Nursing Organization of South Africa (DENOSA), where the SANNAM Secretariat is housed.

■ **The Namibia Nurses Association (NNA)**, founded in 1980, currently faces enormous challenges. Until Namibian independence in 1990, the NNA had compulsory membership. “Since joining the association became voluntary, we have lost a lot of members,” said NNA secretary, Olavi Iyambo, who puts today’s membership at less than 100 out of a total workforce of about 6000. He believes nurses and midwives in Namibia are generally unaware of the advantages of belonging to the association, such as the opportunities for networking, attending educational courses and workshops, sharing experiences, and having representation in high places. But there are huge difficulties in communicating with a workforce that is widely scattered and with many people working in remote places. Besides, he and his fellow office-bearers have to contend with shortages of funds and equipment and the pressures of their regular work. The association is run from one small office in the northern town of Oshakati and employs one part-time clerical worker. Despite the constraints, however, some members show great commitment in undertaking research and other activities on their own initiative.

■ **The Democratic Nursing Organisation South Africa (DENOSA)** was launched on 5 December 1996. In the apartheid years, there was no single professional association for nurses and midwives, but a separate association for each of the racial groups and each of the tribal ‘homelands’. A nationwide debate among nurses during the transition to majority rule in the early 1990s concluded that transforming the fragmented system from the inside would be too difficult; the existing associations should be dissolved in favour of a completely new and unified body. Today, DENOSA has some 70 000 paid members out of a total population of 176 000 nurses and midwives. Another 100 000 have expressed an interest in the association and many are in the process of joining up. DENOSA has a head office in Pretoria and 9 provincial offices, which together employ a staff of 86 people. It has separate departments dealing with professional development, communications, finance and administration, human resources, and publications. The association also has a department of industrial relations since it is a member of the Council of South African Trade Unions (COSATU) and active in trade union affairs. In response to the epidemic, DENOSA has run a joint workshop with the national Department of Health (DoH) for the empowerment of health professionals in dealing with HIV/AIDS. Also in conjunction with the DoH, it has run

workshops in the workplace to introduce the UNAIDS/WHO/ICN *Fact Sheets for Nurses on HIV/AIDS* and to make health-care providers aware of the policy guidelines on HIV/AIDS in their institutions. With COSATU, the association has helped develop a booklet on HIV/AIDS in the workplace. And it has formed a partnership with the Canadian Nurses Association, which is funding a five-year programme on HIV/AIDS that will include research into the impact of the epidemic on nurses and midwives, development of a curriculum on HIV/AIDS to be integrated into their basic training, a 'caring for the carers' project aimed at addressing the welfare needs of nursing staff, and programmes to challenge stigma.

- **The Zambian Nurses Association (ZNA)**, was founded in 1950 by Dora Norman (a British nurse working in what was then Northern Rhodesia), and is the oldest professional body in the country. The association has a membership of about 700 out of a total workforce set officially at 12 000 nurses and midwives, although people are emigrating or leaving the profession at an unprecedented rate, and much faster than they are being replaced. It has branches throughout the country, and a core of full-time staff, led by an executive director, based at its headquarters in Lusaka. The president of the association and her two vice-presidents are all volunteers. The ZNA has carried out research into the effects of HIV/AIDS on the profession and the needs of nurses and midwives in responding to the epidemic. Besides the special HIV/AIDS project that is described in detail later in this report, the association has piloted a weekly HIV/AIDS radio drama targeted primarily at health workers. It has adapted the UNAIDS/WHO/ICN *Fact Sheets for Nurses on HIV/AIDS* to include information on healthy nutrition using locally-available foods, home-based care, and HIV/AIDS-related legal issues. A ZNA newsletter is in the pipeline to disseminate information and research findings to members on a regular basis. Between September 2001 and 2002, the association conducted capacity-building workshops for nurses and midwives in the nine provinces countrywide. It has also undertaken two research studies and published the results (15). The ZNA believes in the value of networking. It has formed cooperative partnerships with a number of local organizations with shared interests, such as Youth Media—an NGO for youth, specializing in information, education and communication, which publishes a newsletter on sexual and reproductive health (*Trendsetters*) and which has made a video with ZNA and participated in workshops run by the association. The ZNA also has a special relationship with the Norwegian Nurses Association, which dates back to 1988.



Launch of the SANNAM/Baylor Training of Trainers Workshop. Left to right (ZNA leaders): Jennifer Munsaka, Executive Director; Dorothy Chikampa, President; Thom Yunaana, First Vice-President; and Patricia Kohawa, Second Vice-President.

- **The Zimbabwe Nurses Association (ZINA)** was inaugurated in 1980, after Zimbabwe's independence from Britain. Its main purpose was to promote the development of the nursing profession. The association has a membership of around 6000; however, their numbers are declining as nurses and midwives leave the country for

greener pastures. ZINA draws its members from all health institutions in Zimbabwe—that is, the public and private sectors, local authorities and missions. Qualified nurses who join the association receive full membership status, while student nurses are entitled to associate membership. ZINA is a participatory, nongovernmental organization, and is apolitical. It has a standing committee of six members who manage the day-to-day affairs of the association, and a national executive, headed by a president, that is responsible for monitoring and evaluation of ZINA's activities. The association participates in the national and provincial planning process for HIV/AIDS prevention, care, support and impact-mitigation facilitated by the Zimbabwe National AIDS Council. In addition, it is currently undertaking a survey of NGO activities in the field of HIV/AIDS with the aim of improving cooperation and collaboration between the various programmes, and forming a network that can offer efficient, comprehensive care to patients, families and communities.

## Champions of care

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When the idea for this report was first suggested, SANNAM invited the nursing associations of its 14 member countries to present examples of good practice that might be included in it. The country representatives were then asked to prioritize the examples on their lists, but there were still many more potential stories than could be told in this one brief document. An attempt has been made, therefore, to select examples of best practice that give an idea of the diversity of activities in which nurses and midwives are involved, and that offer a wide variety of messages. The wealth of information and insights given by interviewees whose personal stories do not appear here, for reasons of space, have been used to enrich the description and analysis of the situation facing nurses and midwives working in Southern Africa today.

### Beatrice Chola

The headquarters of Bwafwano is reached after a bumpy ride through the potholes and dust of Chipata compound on the outskirts of Lusaka. A collection of low, white-washed buildings set in a walled courtyard, it sits at the heart of this bustling community of some 250 000 people. Most are extremely poor. They have come from all over Zambia to look for work, and have built themselves houses of bricks or traditional mud, planted small patches of food crops and vegetable gardens, and set up businesses wherever they have seen an opportunity. The wide dirt streets of the 'township' are lined with kiosks, workshops and bars.

Bwafwano, meaning "to help each other" in Bemba, was started in 1996 by Beatrice Chola who was then working as a registered nurse at the Chipata Clinic. "I came up with the idea for Bwafwano because of the chronically ill patients I saw coming to the clinic in increasing numbers," she says. "They were being brought by relatives in wheelbarrows or carried on bikes or on people's backs. While I was taking their medical histories, many revealed they were suffering stigma and discrimination. I felt so sad for them."



Members of the Bwafwano Youth Group

But Beatrice's idea to work with the community to set up a home-based-care programme was met with derision by her colleagues at the clinic. "They laughed and said: 'what can you do for these people? You are joking!'" Her first efforts were obstructed by her employers and fellow nurses who did not give her time to work with the community. "Their attitude was: a nurse can never do this. Because I failed to convince my matron, I went direct to the District Health Management Board (DHMB). I gave them a written description of what I wanted to do. They accepted and said they'd help. They advised me to write a project proposal."

With encouragement and support from the DHMB, Beatrice appealed to the community and church leaders. The response was enormous. "They were seeing this thing, HIV/AIDS, in their

own homes, and they came in large numbers to Chipata Clinic.” Drawing on the experience of community mobilization that she had gained while working in outreach at Chikankata Hospital, Beatrice carried out a needs assessment with the community. She then selected 50 women to work with her as volunteers. With assistance from the World Health Organization (WHO) and the Ministry of Health, she found training for the women and they began visiting patients in their homes. Beatrice took early retirement from Chipata Clinic and rented a small house in the community from which to run Bwafwano and where they held their meetings.

The programme started with only about 100 patients. “At the beginning, people tried to hide away from us because the stigma of HIV was so strong,” says Beatrice. “We fought it through counselling and awareness campaigns—we worked flat out.” In those tough, early days, it was the enthusiasm and commitment of the community that kept her going, and the backing of her own family. “My husband, who’s a businessman, has been very supportive from the beginning. He knew I was a nurse and that he couldn’t stop me from doing what I thought was necessary. My mother and father were supportive too; they had brought me up with a sense of duty. We are all Christians and the Bible talks of such things.”

Beatrice was the only nurse in the programme for three years. She saw her role as that of teaching and passing on her skills to the volunteers rather than taking on the responsibility for doing the nursing herself. She would visit bed-ridden patients with the caregivers and show them what to do, and made a point of always involving the family. “I made it very clear that AIDS is everyone’s burden. I saw that, unless I involved the family, they would neglect the patient. They’d say: let’s wait till the home-care nurse comes. So you must involve the family. They’re the key people. You mustn’t take the responsibility yourself as a nurse.”

Medicines and equipment for home-based care were a big problem in the early days, “because no one knew me or about the programme,” says Beatrice. Caregivers used to improvise, using plastic bags fastened at the wrist with sticking plaster for protection from blood and body fluids because they had no gloves. WHO and the Japanese Embassy helped her with drug supplies, but she bought such things as medications out of her own pocket. “When the Ministry of Health gave Bwafwano their approval, other donors started to notice us and to help.”

From small beginnings in 1996, Bwafwano has grown into an organization with 280 community caregivers looking after about 1300 PLWHA in Chipata compound. It also has branched out in many other directions. As she visited homes, Beatrice became aware



A grocery kiosk in Chipata compound, Lusaka, acts as a ‘drop in’ centre for the Bwafwano Youth Group’s programme to distribute condoms and information on HIV/AIDS to the community.

of a host of other needs created by the epidemic. Families were hungry and impoverished; children were losing their parents and dropping out of school; teenagers were deprived of support and guidance. So she sought donor support for a variety of new services. Today, Bwafwano runs a skills-training programme teaching sewing, carpentry and carpet weaving; a feeding programme that caters for about 200 children daily; a clinic; and a youth centre. There is also a school for more than 220 orphaned and vulnerable children. When it was recognized that many of the children could not concentrate in class, Beatrice engaged a social worker to offer psychosocial counselling. Typically, children are not getting on with their guardians, who are often

overburdened by the extra mouths to feed, she explains. If appropriate, the counsellor speaks to everyone together. With the variety of resources and skills it has gathered, Bwafwano now offers HIV/AIDS-affected families a 'triple package' that consists of care for the sick adults, peer support for teenage children of the household offered by the organization's youth group, and care for the small children.



Bwafwano's TB programmes provide a much-needed service in the community.

The clinic at the centre was originally just for PLWHA and TB patients, but gradually others in the community started to attend, so Bwafwano decided to charge them a nominal fee. Most people are happy with this arrangement, says Beatrice. "It's a way of allowing them to contribute to the good of everyone."

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***I made it very clear that AIDS is everyone's burden. I saw that, unless I involved the family, they would neglect the patient. They'd say: let's wait till the home-care nurse comes.***

— Beatrice Chola, Zambian nurse

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Of course, not everything runs like clockwork. There is no limit to the needs Bwafwano is trying to meet, and the organization is always short of funds and staff. There is only one nurse, Sammy Chingombe, to supervise the home-based-care programme, and only one psychosocial counsellor with a big caseload of distressed children. And there are many people queuing for the seed money of 300 000 kwacha (about US\$66) offered to those on skills-training to get small businesses off the ground, but the revolving fund is empty. Beatrice, who puts enormous energy and commitment into Bwafwano, is undeterred by these challenges. As director and 'manager' of the programme, she sees it as her job to "run around looking for money, writing reports and proposals, and seeing that my staff are all right—that they don't burn out. A manager must be alert."

Beatrice has no worries that her skills as a nurse are not being used directly. "The point is for the community to take responsibility for solving its own problems," she says. "Our job as nurses is to empower the community with our skills. This helps ensure sustainability. When the funds run out, the community will still be there and it will have the skills to carry on. Our work in the community is to build capacity."

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***Our job as nurses is to empower the community with our skills. This helps ensure sustainability.***

— Beatrice Chola

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## **Sammy Chingombe**

Sammy Chingombe is the coordinator of Bwafwano’s home-based care programme. He began his career working for the Zambia Flying Doctor Service (ZFDS), where he started a programme to care for chronically ill patients in their own homes, having attended a training course in home-based care at Zambia’s famous Chikankata Hospital.

Sammy qualified as a nurse in 1992 and had been taught very little about HIV/AIDS during his training. But, despite lack of knowledge, he never felt the fear and revulsion towards HIV-infected people that some of his colleagues showed. “From childhood, I have wanted to help people. I remember at nursing school we had a patient who was HIV-positive. The other nurses were laughing and turning away from her. But I felt very sorry. There was a nine-year-old child, a boy, who was caring for the parent. He cooked the meals and brought them to the hospital. I felt the child had lost part of his childhood, and I wanted to help him. I arranged for some of us to see his mother at home.”

Sammy has never forgotten his own experience as a patient with malaria when he was a child. While some of the nurses attending him were very kind, others treated him badly. He was so affected by the behaviour of the nasty ones that he determined always to be nice to his patients when he became a nurse. “I used to plead with the nice ones to stay on the ward so that I wouldn’t have to bear the ill-treatment of the others,” he recalls.

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***I used to plead with the nice ones to stay on the ward so that I wouldn’t have to bear the ill-treatment of the others.***

— Sammy Chingombe, home-based-care coordinator

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Bwafwano’s Sammy Chingombe (seated) and Moses Mutale check the records of people to be visited in their homes.

When working conditions at the ZFDS deteriorated and staff payment became erratic, Sammy left the service and joined the Ndola Catholic Diocese as a home-care organizer. “At the beginning, I was very distressed when the person I had been nursing died. It was very hard. I was worried to see so many people dying.” Sammy got support and encouragement from Dr Piet Reijer, one of the mission doctors, who has remained his role model, inspiration and support ever since. Now, back in Germany, Dr Reijer communicates regularly and sends reading materials that Sammy, a thoughtful young man with an enquiring mind and hunger for information, values greatly.

At the Catholic Diocese, Sammy was working in three compounds with a population of about 50 000. There were about 400 patients and the stigma was terrible. Sammy felt there was a need for a support group for PLWHA, so he started an organization called ‘*Iluba Lipya*’ (new flower). Recognizing that HIV-positive people had skills and wisdom to share, the group’s role was to provide counselling to each



other, to be role models in the promotion of positive living, and to help each other avoid dependency. Members also helped each other with income-generating projects. Another role for Iluba Lipya was to give a voice to the clients of the home-based-care programme—to communicate with volunteers, nurses and the health department. Taking control of their own lives is very important for PLWHA, believes Sammy. “Doing nothing is killing them softly.” Of his decision to start a support group, he says, “I really wanted to help them accept their status as HIV-positive people, because I had seen that those who accepted it were much better able to cope than those who didn’t know what was happening to their bodies.”

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***I really wanted to help them accept their status as HIV-positive people, because I had seen that those who accepted it were much better able to cope than those who didn’t know what was happening to their bodies.***

— Sammy Chingombe

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Sammy ensured that the training of home-based-care volunteers was practical, relevant and continuous. And he encouraged caregivers to take their own initiative, be confident in doing things the way they saw worked, and to not be constrained by the ‘rules’ or theories. Because so many had difficulty raising the issue of HIV when they approached families, Sammy introduced a system whereby those who had been prepared to reveal their HIV-positive status would accompany volunteer counsellors in their visits. But there were not many who had disclosed.

What motivated those who were prepared to be open? They seemed to want to give back to the community something for the care they had received, says Sammy. He describes one woman, Ethel, who was particularly committed to confronting the stigma and denial and asked if she could speak to a gathering at church. This was very successful and it snowballed so that Ethel spoke on many different platforms. “She would come to staff workshops and talk about positive living. She’s an example, a model.” Ethel’s daughter was diagnosed with TB and then tested HIV-positive too. She joined her mother in the programme of fighting stigma. Sometimes she would visit people who were struggling to comply with their TB treatment because the drugs made them feel awful, and she would take her own drugs with them. “Being encouraged by someone who has personal experience of what you’re going through is very powerful,” says Sammy.

Sammy met Beatrice Chola when he was in Ndola. His home-based-care programme had won a silver award from the British Medical Association in 2000, and Beatrice asked him to join Bwafwano to help with their programme. He has started a support group modelled on Iluba Lipya, but called ‘*Tilimbikile*’, meaning ‘to hang on, remain strong’. There was already a support group in existence at Bwafwano, but it was having difficulties. Sammy considered it a drawback that people met at the Bwafwano headquarters rather than in their own homes. Also, he found that the main focus of the existing group was income generation, not confronting stigma. But he is gradually changing the focus. “Our duty is to encourage people to go for VCT. We discuss the benefits,” he explains. “There’s a lot a person can do if they know they are HIV-positive.” Tattoos, using the same razor blade, are a popular traditional practice in Zambia, believed to protect whole families from harm, and those who know they are positive can avoid such things. Sammy does pre-test counselling at Bwafwano and takes blood samples, as well as sputum samples from TB patients, which he sends to Chipata Clinic for analysis. Before he started offering these services, people themselves had to go to the clinic, which is a long distance for many of the township’s residents. Sammy realized that this was a powerful

disincentive to getting tested. His guiding principle in working with communities is to make everything as simple and easy as possible for people.

When he joined Bwafwano's home-based-care programme, he found that caregivers were struggling with paperwork and record-keeping. Moreover, there was a hierarchy among the volunteers, with those who could not read and write at the bottom, feeling inferior. Sammy believes it is crucial for a programme to be as flexible as possible so that it can make changes as and when they become necessary. Gradually, and with lots of discussion, he made changes at Bwafwano. To try to get rid of the stigma of poor education, he introduced information and other materials that do not require literacy. He started holding the caregivers' meetings in the community rather than always bringing people to the centre. He also realized that some people are not comfortable talking in big gatherings, so today he finds settings in which volunteers are confident to talk, such as in smaller gatherings in their own sections.

Sammy has also instituted a policy of inviting spouses and children of caregivers to some of the meetings so that they understand and can support the work the caregivers are doing, and are more tolerant of the time they spend in their work outside the home. This also has the effect of bringing the whole family into the 'circle of respect' that the caregiver enjoys in the community. It is also Sammy's belief that "education starts with the family of the caregiver. It shouldn't be something she targets at 'outsiders'." Sammy also thinks it is important to recognize all the activities and contributions a volunteer makes. He has therefore developed a questionnaire that makes the programme aware of what volunteers are doing beyond what is expected of them.

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***Inviting spouses and children of caregivers to some of the meetings has the effect of bringing the whole family into the 'circle of respect' that the caregiver enjoys in the community.***

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"Joining a programme as a volunteer is one thing; staying in and staying active is quite another," he says. "It requires a certain commitment." He did a survey on what caregivers felt about their work, what value they put on it, and what they got out of it. Some said their feelings towards HIV-positive people had changed and they had got rid of their prejudices and impulse to stigmatize. They felt more compassionate. Sammy believes that the negative feelings that many people harbour towards PLWHA are a psychological burden to them. He tells the story of a young woman who was a new caregiver on his team. He recognized that she was struggling with her feelings towards a very sick woman who was badly disfigured by AIDS. The volunteer was particularly disturbed by a picture hanging on the wall of the woman's home showing her when she was well. She had been very pretty. Sammy believes there is a need to share such feelings and misgivings in workshops and discussions. Those responsible for teams of caregivers—volunteer or otherwise—should remain alert to such personal struggles and help people to deal with them.

How does Sammy protect his own well-being and mental health? Besides his mentor, Dr Reijer, who gives him constant support, his religious faith is a source of strength. "I think I was made for this work," he says. "I also spend time on reflection and I talk to my colleagues." To avoid burnout among the volunteers, Sammy advises them to reflect on all their problems and then to put them all in an imaginary bin, close the lid and start afresh. He also believes in people taking time off and resting when they cannot cope. "You break up when someone you care about dies. I've suggested we have someone from the church to come to talk to us about

coping with stress, to help us with reflection. At the diocese, we had a pastoral care person looking after all the members of the teams.”

According to one of the community volunteers, Sammy is an inspiring leader of the programme. He is also observant and ready to try new things. Much of his inspiration comes from the community, he says, and it is important to involve as much of the community as possible in whatever you are doing. “There are lots of good ideas and potential out there,” he says, “which haven’t been tapped.”

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***Volunteers are advised to reflect on their problems and then to put them all in an imaginary bin, close the lid and start afresh.***

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### **Box 3. Taking care of the next generation: Bwafwano’s youth volunteers distribute condoms and information**

One of Bwafwano’s hallmarks is the way in which it recognizes the multiple effects of HIV/AIDS on the community and tries to cater for the needs of everyone, not just the sick who require nursing. When a small bunch of youngsters from Chipata compound approached the programme, hungry for information and guidance for themselves and their friends, Beatrice responded by appointing a youth project coordinator and offering them training as peer educators. AIDS is taking so many of their friends and they’re afraid, explains Gift Kanyambi as he leads the way through the labyrinth of dusty paths towards one of his drop-in centres. Passing a row of barber’s shops decorated with hand-painted pictures of funky modern hairstyles, he stops to greet one of the proprietors. Inside, beneath the unkind light of a neon tube, a small boy with a white towel draped around his shoulders is having his hair cut close with an electric shaver as he watches his reflection in a cracked mirror. The barber, a young man, is all smiles and enthusiasm as he reaches for a handful of leaflets and condoms from the counter.

At a bar further down the road, the owner keeps a wooden model of a penis under the counter so that she can show inexperienced youngsters how to use the condoms she hands out to those who come to her for supplies. The barber’s and the bar are 2 of about 18 drop-in shops set up in a variety of premises around the compound, where young people can go for information and condom supplies, knowing they will be helped and not judged for their behaviour. The plan is to have about 1 drop-in shop for every 20 houses in the compound, but the youth group is a long way from that target yet.

Besides supplying the drop-in centres, the peer educators encourage local schools to set up anti-AIDS clubs. They go visiting houses, door to door, in their allocated zones to raise awareness about HIV/AIDS and to check if there are families in need of help. Bwafwano relies on its youth volunteers to be its ‘eyes and ears’ in the community, and to alert the home-based-care workers and others to people in distress. The youth workers are called upon to help directly when there are teenagers or young people in an affected family.

The main purpose of all the youth group’s activities is to stop the dying by eroding the taboos around discussion of sex and breaking the silence surrounding HIV/AIDS. “We’re still young; we want to enjoy our youth,” says Gift Kanyambi simply.

## Olive Ng'andu

Olive Ng'andu's father and uncle were members of Zambia's first government after independence from Britain. The young Olive had all kinds of opportunities at her feet, so her family were disappointed when she turned her back on the idea of going overseas to study in order to become a nurse. "They couldn't understand why I wanted to involve myself



Olive Ng'andu

in the blood and dirt," she says with a gentle smile. "But I remember seeing nurses in their uniforms when I went to hospital as a child, and thinking: one day I want to wear that uniform and look after people who are sick."

Olive trained as a nurse/midwife in the 1960s and went to work at the University Teaching Hospital (UTH) in Lusaka. In the early 1980s, she got a bursary to attend a course in administration at the Royal College of Nursing in London, and subsequently spent six months training as a paediatric nursing officer at Booth Hall in Manchester. Returning to Zambia, Olive became a nursing officer in Livingstone. She had been a member of the Zambia Nurses Association since 1973, and her administrative skills soon saw her elected to the

executive, firstly as vice-president and then as president—a post she handed over in 2000 to Dorothy Chikampa. Today, she manages an HIV/AIDS project for nurses and midwives, which shares the offices of the ZNA in Lusaka and works in close cooperation with the association, but has its own budget, staff and objectives.

The project, which is the first programme of its kind in the region, started in early 2002, in response to growing concern about the effect of the epidemic on front-line health workers. In the early 1990s, Mercy Mbewe, Director of Nursing at Lusaka's University Teaching Hospital, had started to notice that her young staff members were losing confidence. "They didn't want to come to work, and were finding any excuse, often going off sick," she explains. "So I started to look at the records—who was sick and how many man hours were lost because of this. In 1995, it amounted to thousands and thousands of man hours lost. And I thought: we need to raise the alarm to those who can act." So Mercy wrote to the ZNA and the General Nursing Council.

The ZNA called a meeting of senior nurses from across the country. They were asked to gather information from nurses at all levels of the system in their home areas about what was happening—how many nurses and midwives were sick, how many had died—and to come back with the information to Lusaka. "That was a very fruitful meeting," recalls Olive Ng'andu. "When we saw how bad the situation was, we asked: 'what next?' At that time, we were still not really sure what we were dealing with. We thought maybe this AIDS was something that would come and go like other problems we had seen. We didn't know much about it. We felt maybe nurses were being careless on the wards, not practising infection control properly when they cared for patients with TB." It had been the practice that every nurse working on a TB ward was screened annually with X-ray. But the practice had been stopped, and the ZNA thought perhaps this had allowed standards to slip.

As it became clear to the ZNA that the epidemic posed a serious threat to their profession, the association undertook a survey of nurses' and midwives' needs (16) that concluded

that front-line workers were being left out of information campaigns directed at the community as a whole, and that they felt helpless in their ignorance. “Nurses were saying to us: ‘what am I supposed to do? I have a patient lying in secretions. Either I touch that patient and I risk my life, or I leave the patient lying in the secretions,’” says Olive. She could identify perfectly with the feelings expressed in the survey, remembering the desperation she herself had felt, both as a working nurse, and as a matron being challenged about what to do by her own staff.

Many respondents felt that information was what they most needed in order to be able to provide good-quality care. However, Olive believes it is equally important to address the lack of materials. “Nurses know what to do to care for a patient even if they don’t have special knowledge about HIV/AIDS. But what can they do if they have nothing? Sometimes they are running around looking even for a thermometer.” You can improvise for so long, she says, but after a while it wears you down. “As a matron, you feel like a useless person, not even worthy of standing before them [the nurses] because you are failing them. The demands are so high and the money has run out.” It was her experience of working under these conditions at UTH that led Olive in the late 1980s to seek secondment from the government to allow her to work full-time for the ZNA, where she felt she could be more effective in addressing the needs of nurses.

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***Nurses know what to do to care for a patient even if they don’t have special knowledge about HIV/AIDS. But what can they do if they have nothing? Sometimes they are running around looking even for a thermometer.***

— Olive Ng’andu, Zambian nurse/midwife

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Over Olive’s years in office, the ZNA had developed a close and trusting relationship with the Norwegian Nurses Association, and Olive took advantage of this to get the HIV/AIDS project off the ground, appealing to the NNA and the Norwegian Government for assistance. The purpose of the project, which is funded by NORAD and the Norwegian Nurses Association, is to give nurses and midwives essential information on HIV/AIDS, to develop their skills in clinical management as well as prevention of HIV infection, to challenge stigma and silence by encouraging nurses and midwives to go for VCT, and to offer support of all kinds to those who are infected.



Celebrating the partnership between ZNA, the Norwegian Nurses Association and NORAD in the HIV/AIDS Caring for Carers Project for Nurses and Midwives.

This last is especially important, says Olive. “We, as nurses, don’t support each other. I don’t know why, but we really don’t—that’s what we have observed and experienced ourselves. We stigmatize and turn our backs on our colleagues who are HIV-positive. We felt that, before we ask others to come and support us when we’re sick, we should start caring for each other.” One survey respondent commented, for example, that nurses only said nice

things about one of their colleagues at the graveside when she had died. She wished they could bring themselves to express those feelings when the person was still alive because it would be wonderful to know you were appreciated. It does not take a lot of money to make a difference, says Olive. “We ask what are the small things we can do for ourselves. Often, just visiting, going to see that children are okay and that there is food in the house makes people feel cared for by their colleagues.”

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***One person told the ZNA survey that nurses only said nice things about a colleague at the graveside when she had died. She wished they could bring themselves to express those feelings when a person was still alive because it would be wonderful to know you were appreciated.***

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At present, the project has a staff consisting of Olive as manager, two facilitators, a driver and a secretary. The plan is to appoint a coordinator and deputy for each province, and to have a number of provincial trainers to run workshops, as well as a corps of volunteers who will act as workplace facilitators within health-care settings. The project has a formal relationship with the Chief Nursing Officer, who is on the committee, along with representatives from WHO, the General Nursing Council, and the Central Board of Health. “We want everyone to know this is a specific project for nurses. We want them to feel a sense of ownership. That’s why we’ve involved all the important nursing organizations”.

At the start of the project, 10 people (including Olive Ng’andu, the 2 facilitators and the project secretary), were given an intensive two-week training to run workshops using the ‘participatory learning approach’ (PLA). While lecturing often sends people to sleep and touches on many things not relevant to workshop participants, she explains, PLA explores what the participants already know and builds on that through sharing information and experience. “This method of teaching addresses the issues nurses actually face. We are the ones who know best what goes on in our working environment and what we need.”

Ten nurses and midwives were chosen to be trained as trainers to ensure that the programme was not interrupted if someone fell sick. The facilitators have conducted three pilot training workshops and the project is now embarking on a programme of capacity-building workshops for nurses and midwives across the country (see Box 6). But, in taking responsibility for teaching nurses about HIV/AIDS and developing their skills, isn’t the ZNA project doing the government’s job for it? “We feel we are complementing what the government does,” says Olive. “The challenges we face are so enormous, and Africa’s resources are very few; if you wait to get what you need you will wait forever. We feel it’s better to sit down among ourselves and say, ‘Friends, how can we best solve this problem?’” Not only do nurses come up with all kinds of suggestions and ideas, she says, but such an approach makes them feel they are being heard, and that someone cares about them. And it relieves anxieties because it gives them an opportunity to talk and to share their experiences.

“Every day, there is something new in HIV/AIDS—new facts, new drugs, new ways of treating,” continues Olive. “As a nurse in a uniform, you are supposed to know things. People stop you and ask: ‘what is this thing we are hearing about HIV/AIDS?’ You just feel inadequate if you have no answer. This is what we are hearing from the nurses. This is a service from ZNA that they value.”

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***The challenges we face are so enormous, and Africa's resources are very few; if you wait to get what you need, you will wait forever. We feel it's better to sit down among ourselves and say, 'Friends, how can we best solve this problem?'***

— Olive Ng'andu

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Mercy Mbeve, Director of Nursing at Lusaka's University Teaching Hospital, believes whole-heartedly in the HIV/AIDS project for nurses and midwives. She tells the story of one young woman who brought home to her the reality of what was facing her profession. The young woman had been a good student—bright and committed. And she had started her career well. But Mercy began to notice her on the wards carelessly dressed and working with a distracted air. The director had felt irritated and impatient at the young nurse's behaviour. But, one day, she failed to turn up for work and when Mercy enquired of her colleagues why she was absent, they told her she was attending a funeral—her husband had died. “None of us had known what she was coping with at home. I felt so bad. It hit me how, as health workers, we put up walls and we don't reach out to each other.”

#### **Box 4. HIV/AIDS and Zambia's nurses: what the survey revealed**

The survey, entitled 'HIV/AIDS and the workplace: a case of nurses and midwives in Zambia', was carried out between May and August 2001 and funded by the Norwegian Agency for Development Cooperation (NORAD). It was conducted among nurses, other health personnel, health administrators and other relevant organizations and authorities in Zambia.

It revealed that:

- Zambian nurses, especially those in the hospital sector, are seldom offered specific training in HIV/AIDS and how to deal with it in a clinical setting;
- national plans do not mention the risk of infection in the workplace, and guidelines for prevention in the working environment are either non-existent or poorly developed;
- though there was no evidence of nurses actually being dismissed from work as a result of HIV/AIDS, there is no personnel policy to take care of infected nurses and midwives, to adjust their work commitments according to their state of health, or to offer support;
- because of shortages of protective equipment and heavy workloads, most nurses feel themselves to be at risk of infection in the workplace, and believe, too, that the risk they face at work is higher than the risk of exposure to HIV in their private lives;
- there is a general perception that infected health staff are more likely to suffer stigmatization and discrimination than the rest of the population; and
- the struggle to survive on poor wages leads some nurses to engage in activities that put them at risk of HIV infection in their private lives.

### Box 5. Two midwives speak

Jennifer Munsaka, Executive Director of ZNA, and Sarah Ngoma were among the original group trained in the participatory learning approach (PLA) to work with the HIV/AIDS project. Both are midwives with long-standing experience of working in maternity units—and both were moved by the conditions of service to find positions away from the front line where they felt they could do more to help develop the skills of nurses and midwives in coping with the epidemic.

HIV first impinged on Jennifer's consciousness in the early 1990s. She remembers the

first infected patient and how no one wanted to deliver her. It was Jennifer's responsibility, as head of the labour ward, to designate someone. The midwife chosen was dressed up like a Martian, with protective gown, gloves, goggles, and boots, for the delivery, she recalls. And afterwards, everything was sterilized and the room itself was disinfected. "We didn't know much about the disease then, so anyone with a chronic illness, such as diarrhoea or cough, was automatically isolated as a suspected case of HIV infection." They were demoralizing times, comments Jennifer. "If you suffer fear and prejudice towards your patients, you don't get any job satisfaction and it's demotivating."

As HIV began to overwhelm the health services, workloads increased and protective equipment was in very short supply. Sarah Ngoma was working as a district midwife and

remembers antenatal clinics where there was only one midwife to see maybe 200 pregnant women. She remembers, too, being the only person on duty overnight when several mothers were in labour at the same time. "Sometimes, there was time only to bring out the baby and lay it on the mother's abdomen, without even cutting the cord or delivering the placenta before moving on to the next delivery," she says. Sarah used heavy-duty rubber gloves she bought for herself, and would rinse them in bleach between deliveries. And she would never throw away an intravenous drip that was still half full. Jennifer remembers using incontinence sheets for deliveries where there were no rubber gloves. She and her assistants would lay the mother on the sheets and put their hands underneath, lifting up a flap to cover their hands as they pulled the baby out. "You're forced to use your initiative—there's no other way," agrees Sarah. "And there's a challenge and satisfaction in preventing maternal or child deaths."

But facing such challenges on a daily basis also leads to burnout, comments Jennifer—especially as the poor conditions in hospitals and the struggle to keep up standards of care have impacted directly on the image of nursing and midwifery. Whereas the profession once enjoyed high status and respect in Zambia, "today, many people see nursing as a dirty job for nothing," she says.



Sarah Ngoma facilitating the HIV/AIDS workshop in Serenje, Zambia.



The HIV/AIDS workshop in Serenje, Zambia.



### Box 6. HIV/AIDS training goes on the road

It is a chilly, overcast day in Serenje, a small town some 450 kilometres from Lusaka. A stiff breeze whips up dust and shivers the leaves on the trees as 28 nurses and midwives from the local hospital and from rural clinics all around the district make their way to the community centre for a workshop on HIV/AIDS. The hall is bright and welcoming, its walls covered with posters on which the thoughts, comments and ideas of the workshop participants have been scrawled in large letters. There is a 'mood metre' registering how people felt about the previous day's activities. And there is a 'post box' into which participants have pushed little anonymous notes of encouragement or praise to each other. These are read out, with much giggling behind hands, at the start of the day to introduce an element of fun and to help people to feel noticed and involved.

At the front of the room are two facilitators: Sarah Ngoma and Christine Mutati. Today's subject is mother-to-child transmission (MTCT) of HIV, and their job is to explore with the participants what they know about the topic, how significant it is in their working lives, and what experience they have of it. The letters 'MTCT' are scribbled on a big sheet of paper and everyone is given some time to reflect on what the letters mean to them, and to jot down their own thoughts and comments, before sharing them with the class. One nurse says she does not know what MTCT stands for; many say they are unsure exactly how the virus is passed between mother and child, and several are surprised to hear that breastfeeding poses any kind of risk. Soon the discussion is bubbling with personal insights and anxieties. One midwife, Charity, tells the workshop that, in her area, pregnant women are asked to bring rubber gloves with them when they go into labour, but most forget to do so. "Then you have no choice but to do the delivery without gloves, and you fear what will happen," she says. Another tells how they never know for sure who is HIV-positive because VCT services have broken down in her area: the laboratory has run out of supplies and there are not enough people to do the counselling.



Lindiwe and others at the HIV/AIDS workshop for nurses and midwives in Serenje, Zambia.

Lindiwe, a general nurse at the local hospital, says this is the first course she has had on HIV/AIDS, though the epidemic has touched her own life intimately. A single mother of five children, she is looking after the orphaned children of two colleagues who have died. Hungry for information, Lindiwe has read everything she could find, including children's school books on AIDS. But she has been confused by conflicting information, and feels that she risks losing credibility with the community if she does not have answers to their questions.

The discussion eventually comes round to practicalities—what can the nurses and midwives do, in the impoverished environments in which they work, to protect themselves and provide better care to their patients? They share stories of improvisation. Lindiwe says she takes care of her hands, and covers any scratches or blisters with sticky plasters. She advises relatives at the bedside of patients to use plastic bags from the local shops to cover their hands, if necessary. "Information is empowering. It makes us better carers," comments one nurse. Another says having knowledge will make her and her colleagues more confident in confronting management about lack of protective gear.



Sarah and Christine guide and prompt the discussions and gently correct myths and misconceptions without, at any time, discrediting the knowledge and personal experience of the participants. But this is the first workshop they have run and they are feeling their way. Christine, in particular, is wary of a possible 'credibility gap'. So many of the nurses and midwives who will be at the workshops will be so poor and so ground down by their working conditions, she says, that they may well harbour resentment against the organizers, seeing them possibly as getting good money from donors and just pushing the donor's messages. She also believes there will be people who attend workshops just to get away from the monotony of their work and for the small stipend, the food, the company and a good time; they won't necessarily be motivated by a desire to learn. Though she is excited by the challenges of the new project, and the programmes she and her colleagues are pioneering, Christine feels it is important to be aware of these things. "I will always ask myself why people have come for training and will be on the lookout for problems of motivation," she says.

Back in Lusaka, Olive Ng'andu acknowledges the risk of a credibility gap, but says that making people feel intimately involved in the workshop process is the key to avoiding it. By getting nurses and midwives to identify the issues that are important to them, and to search for their own solutions to their problems, the participatory learning approach is very effective, she says.



Participants at the HIV/AIDS workshop in Serenje could send each other anonymous messages of encouragement.

### Box 7. Making health services 'youth-friendly'

In 1997, the ZNA held a four-day workshop on youth and health as public concern grew about the high levels of teenage pregnancy and back-street abortion, and the obvious failure of the health services to meet the needs of young people. "Oh, I have never forgotten that workshop—the issues that came out!" exclaims Olive Ng'andu. Youngsters accused adults of not listening and being authoritarian. They claimed that the judgemental and aggressive behaviour shown them by nurses and midwives at clinics (especially if they were pregnant or suffering from sexually-transmitted infections) inhibited them from using health services. And they complained, too, of lack of privacy and fears for their confidentiality because clinic staff often knew their parents socially.

Following the workshop, the ZNA came up with the idea of creating 'Youth-Friendly Corners' in health institutions. It obtained funding from USAID for the training and reorientation of nurses and midwives in counselling and delivering family planning and reproductive health services specifically to young people. Those who attended training courses were expected to return to their workplaces and sensitize their colleagues about the needs of young people. The idea of youth-friendly corners has taken off and, today, they exist in a number of health institutions.

The one at Lusaka's Bauleni Clinic is considered a model. Set up in what used to be a kitchen at the back of the main clinic, the room is a drop-in centre for young people. Here, they can speak to other young people trained as peer educators and counsellors, who run the centre under the supervision of the clinic staff. The youngsters can come for personal consultations and be referred to a youth-friendly nurse or midwife, if necessary, for care. Or they can join in group discussions on health topics, or watch educational videos and films. To help break the resistance of young people to attending health institutions, Bauleni has involved the local churches and community organizations in publicizing their services and encouraging parents, too, to support the initiative. The clinic's records show that demand for condoms has increased dramatically, and that young people are attending the clinic earlier and in greater numbers than was previously the case when they have sexually-transmitted infections or pregnancy.

The role of youth-friendly services in sex education is one of their most important functions, comments Isaac Sulwe of the ZNA. Traditionally, it is not parents but uncles and aunts who are responsible for teaching young people about sex, he explains. But AIDS and other forces have broken up the extended family and left a gap in the information chain that is often filled by peers whose knowledge is slight and often inaccurate.



Bauleni Clinic's Youth-Friendly Corner.

## Wilhelm Akwaake



Wilhelm Akwaake takes some provisions when visiting a young woman with HIV/AIDS in a remote rural homestead.

Lifting aside some of the rough wooden stakes around the kraal, Wilhelm Akwaake steps into a compound with a cluster of small thatched rondavels. A skinny dog gives a low growl and a hen puffs her feathers and gathers her skittering chicks close. Wilhelm squats down to greet an old lady sitting on a mat in the sunshine, chopping pumpkins with a machete. After a few minutes' conversation, she leads him to the rondavel where her daughter, Grace, is bed-ridden, and she ducks before him through the low door into the darkness. As his eyes become accustomed to the gloom, Wilhelm sees the girl, 30 years old, lying on an iron bedstead, a blanket resting on the knife-blades of her legs and hips. She is holding a shard of mirror and delicately fingering a tight swelling on the side of her face. Grace was admitted to hospital with TB in 1996. She also has HIV (though no one speaks openly of it in the family) and has been ill almost constantly since. But the family has no income, their kraal is deep in the bush several kilometres from a road or a clinic, and they are already heavily in debt to a neighbour who transported them to hospital in one emergency. If it were not for the Katonyala Home-Based-Care Programme, the girl would probably have to endure the regular bouts of sickness without the benefit of modern treatment.

Katonyala means 'never give up' in the local language, Oshivambo, and Wilhelm is one of the founding members of the programme based at Onandjokwe Lutheran Hospital on the outskirts of Ondangwa in northern Namibia. Started in 1992 as a specialist programme for the care and prevention of sexually transmitted infections, which are a major problem in the area, Katonyala soon began offering counselling and testing for HIV. But the team encountered great reluctance among people to being tested, and they decided they needed to take information about HIV and how to prevent infection into the community, and to start home-based care for patients who were being hidden away. Members of the team, most of whom are nurses, went off to various places, including Zambia's Chikankata Hospital and to programmes in Uganda and the USA, for training. But getting their own programme off the ground back home has been an uphill struggle, with little time and equipment and an ever-increasing workload.

In Ovamboland, the HIV epidemic is marching hand in hand with TB, with this region experiencing some of the highest rates of both infections in Namibia. The dual epidemic is of special interest to Wilhelm. Early in his nursing career, he suffered from crippling back pain, which was finally diagnosed as a TB spine, and the disease has been the main focus of his work ever since. Today, he is a District TB Coordinator, and when he took a master's degree in public health at the University of Leeds in England, UK in 1999, the subject of his dissertation was improving community-based care for people with TB and TB/AIDS in his home district of Onandjokwe.

More than half the TB patients in the district are found to be co-infected with HIV. This makes the disease more aggressive and more difficult to shake off, and Katonyala keeps a close watch on patients. Unless they require hospitalization, TB patients are put on DOTS (see Box 8). They are given two months' supply of drugs at a time, but are asked to report to the nearest clinic monthly for follow-up checks. If they do not turn up, the home-based-care team visits them at their homes to see what is happening. Besides monitoring the patient's progress,

the team members investigate the home environment and instruct family and other members living there on how to protect themselves from infection. They emphasize the need for good ventilation and cleanliness, in particular, says Wilhelm.

There are high risks for non-compliance with the treatment regimen, he comments. “When people start to feel better and stop coughing, they often think they’re cured, so they stop taking the drugs.” This encourages drug-resistant strains of the bacterium to develop; indeed, Namibia has a growing problem with multi-drug-resistant TB, or MDRTB, which is extremely difficult, and sometimes impossible, to treat effectively. “We had one 36-year-old man who was confirmed to have MDRTB. He was failing to respond to second-line drugs so the doctors finally took him off treatment after eight months,” says Wilhelm. “We went to the family to advise them how to care for him—making sure that he had nutritious food, for example, that he avoid hard physical work, look after his personal hygiene, and seek treatment for minor ailments quickly.”

### **Box 8. What is DOTS?**

DOTS stands for ‘Directly Observed Treatment, Short-course’. It is the name for a comprehensive strategy developed by WHO and being used by primary health-care services around the world to treat people with TB in their own homes, in prisons and in workplaces. Patients are counselled about their treatment, which involves taking a powerful combination of drugs for six months or more. They are observed by a health worker (often a nurse or reliable and responsible relative or friend) actually swallowing their pills each day, and are monitored closely by the health services until they are cured.

Wilhelm and his colleagues encourage all their TB patients to be tested for HIV, but most are very reluctant. Wilhelm is convinced that the uncertainty exacerbates their illness, and he counsels them on the benefits of knowing their status. “I tell people they can avoid destructive behaviours such as smoking, drinking alcoholic liquors, and unsafe sex. And they can avoid catching other STDs [sexually transmitted diseases], or go for treatment early if they get them. Also, they can plan for the future,” he says.

Many people in Namibia believe that TB and AIDS are tantamount to the same thing, and that all those with TB have HIV. Realizing that lack of knowledge and understanding inhibits the efforts to control these two epidemics, Wilhelm has drafted a leaflet, which he hands out after speaking in churches and other public places, and which he plans to develop for use by others working in the community, such as counsellors, and community health motivators and educators. The key messages are that not everyone with TB also has HIV; that the two diseases have different pathogens and different modes of transmission; that dormant TB can be activated by HIV, and that the presence of HIV makes a person particularly vulnerable to TB. The leaflet also advises that behavioural change can protect against both infections, and that TB can be cured, whereas HIV cannot, although much can be done to improve the life of someone with HIV.

Wilhelm knows that the work he does—especially visiting people who may have active MDRTB in poor and overcrowded homes—puts him at risk of infection, and says, yes, of course, he is scared for his own health, at times. He has a wife and five young children to consider. But his wife, a teacher, is very supportive of his work and reminds him gently, when he gets home tired, to change his clothes and wash before relaxing. “Also, we at Katonyala make a point of looking after ourselves and keeping our immune systems strong,” he explains. “For instance, we try never to start the day without breakfast. And we also try not to miss tea and

lunch breaks. When we're very busy and have to leave patients waiting while we have lunch, we explain to them that it's important we protect our own health, or they won't have anyone to care for them." Wilhelm also makes a point of wearing a mask when caring for someone with TB, especially MDRTB, but says it is important to explain to the client that wearing a mask is for the protection of everyone—the patient as well as the nurse—so that the patient does not feel rejected or offended. "Sometimes, families ask us why we are wearing protective clothing; they ask: 'What about us?' But we are faced with shortages ourselves—shortages of gloves, masks, everything. We even have to re-use gloves, so we don't have anything to hand out. We tell people that they can use anything, even plastics from the supermarket to avoid touching blood."

Wilhelm's thesis for his master's degree was a plan for developing a comprehensive programme for the control and prevention of TB, and he has submitted it to the government, who is looking for funds to implement it. Rosalia Indongo, TB coordinator at the Ministry of Health and Social Services, is enthusiastic about his ideas. And she is impressed, too, by what he and his colleagues at Katonjala are doing with communities in his district. Historically, says Ms Indongo, health services in Namibia were focussed on care of the sick. Preventive and promotive health activities were neglected, so there is not a strong tradition of working with communities.

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***Volunteers are our right hands in extending health services to communities.***

— Wilhelm Akwaake, Namibian nurse

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A major objective of Wilhelm's plan is to raise awareness that everyone, from individual family members, business people and church ministers, to community organizations and public servants, has a role to play in preventing and treating TB and HIV/AIDS. In his district, he is keen to use existing resources—for example, community volunteers who are already doing health work, education or motivational activities—to spread information about TB, and intends to add to their training a component on TB and its relationship with HIV/AIDS. Such people could then be the 'eyes and ears' of the health service in the community, able to identify and refer suspected cases of TB. They could also be trained to supervise TB patients through DOTS.

"Volunteers are our right hands in extending health services to communities," says Wilhelm. But, echoing his colleague at the Ministry, he says that care in the community is a relatively new concept in Namibia, and he and his colleagues at Katonyala are trying to raise awareness and acceptance of the idea by speaking regularly at community meetings—in churches, market places, schools. Meanwhile, Wilhelm is planning, in his spare time, to write a manual on TB that can be used to provide information and guidelines on care by people at all levels.

## **Lischen Haoses**

Dr Lischen Haoses has no doubt that HIV/AIDS is destroying the fabric of Namibian society: she has seen colleagues and friends, including three fellow members of her church choir, die of the disease, and nursed her neighbour with HIV. "It was while I was on study leave, working for my doctorate, and for one whole month I never looked at my books," she recalls. "I was nursing her the whole time and I was very much touched by what I observed. I'm a nurse, but her suffering was too much for me psychologically, emotionally. Her husband was neglecting her; her family was calling to find out how she was; and all the time I had to

keep silent. She told me a week before she died that she was HIV-positive, but I knew already because of the symptoms.”

Dr Haoses is not personally fearful of HIV/AIDS and has no instinct to stigmatize. “Sex is something wonderful. Everyone wants to be involved with someone else, everyone wants intimacy at some point, and HIV can happen in a second,” she comments. “And I have learned from experience of difficult circumstances not to point fingers.” Instead, she feels compelled to use her knowledge, her skills and her personal experience to do what she can to help curb the epidemic. Dr Haoses is a senior lecturer of nursing studies and deputy dean at the University of Namibia (UNAM), and she is acutely aware of the fact that the young people she sees on campus today are the politicians, teachers, academics, lawyers, health professionals, and businessmen and -women of tomorrow—the people Namibia depends upon for its future development and prosperity. She is also aware that, as young people living away from home, in an environment of enquiry and experimentation, they are in special need of protection from HIV infection. More than half the students are believed to be already sexually active when they start college.

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***Everyone wants to be involved with someone else; everyone wants intimacy at some point, and HIV can happen in a second... I have learned from experience of difficult circumstances not to point fingers.***

— Dr Lischen Haoses, senior lecturer of nursing studies and deputy dean at the University of Namibia

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Dr Lischen Haoses

In 2000, Dr Haoses and two colleagues at UNAM—Marjorie Katjire and Kathe Hofnie—conducted research among the students to find out their levels of awareness and knowledge about HIV/AIDS. “The results were a matter of concern,” she says. The researchers found that most students were aware of HIV/AIDS, but few were knowledgeable. Ninety-six per cent of the 1363 students interviewed were aware that HIV/AIDS was the number-one killer in Namibia, and 86% believed they were well informed about HIV/AIDS. However, more detailed questioning revealed that as many as 78% of second-year students were uncertain about how the virus was transmitted and the same proportion required more information about prevention. Forty-three per cent of the sample was unsure about how HIV infection progressed to AIDS. Furthermore, a majority of students were unaware of anything the student representative council (SRC) was doing about HIV/AIDS. Most commented, too, on the lack of action by the university management and individual faculties.

Dr Haoses and her colleagues published their study’s findings in 2001, with a series of recommendations to set up education and prevention activities as well as a support system for affected students on campus. Meanwhile, she and Marjorie Katjire are busy developing education modules on HIV/AIDS to be used as part of the core curriculum for first-year students in all faculties at the university. Their action stems from a preliminary survey they did in 1999 that revealed many dangerous misconceptions among students about how to protect themselves from HIV. They realized that the university needed to do more than leave the subject of HIV/AIDS to the discretion of individual lecturers to touch upon in their courses. They took their idea of making it a substantial and integral part of the core curriculum to all interested parties, including the ministries of education and of health, other AIDS service organizations, and donors, as well as to all the faculty heads at the university. They also circulated a draft curriculum for comment. “Some

faculty members felt that what they were already doing was enough,” says Dr Haoses. “But most of the others welcomed the suggestion and were very positive.”

In addition to making HIV/AIDS part of the core education, she and her colleagues intend to run regular workshops and conferences on campus. Students are the opinion-formers of tomorrow, and they are likely to have a major influence on the course of the epidemic, believes Dr Haoses. “It is my aim that every one of them should leave the university with sound knowledge of HIV/AIDS.”

### **Diana Shilongo and Engelbert Mwanyangapo**

Working on the medical and paediatric wards at Oshakati Hospital, northern Namibia, in the early 1990s, Diana Shilongo watched the HIV/AIDS epidemic creep up on communities and begin to overwhelm the health services. “This wasn’t like anything else we’d had to treat,” she recalls. This was known as a ‘deadly disease’, and people needed much more than ordinary nursing; they needed counselling and someone to talk to and to answer their questions. “The hospital was so full of people with AIDS; it began to dominate the picture and I felt we had to do something.”

On her own initiative, Diana signed up for a training course on working with communities, conducted by the government and some nongovernmental organizations (NGOs) in the Namibian capital, Windhoek. “The Ministry of Health had realized they couldn’t cope



Diana Shilongo and Engelbert Mwanyangapo of TKMOAMS.

with the epidemic on their own and must involve communities,” explains Engelbert Mwanyangapo, who also attended a training course in Windhoek. Engelbert, too, was working as a nurse at Oshakati Hospital. He was losing members of his own close family to AIDS and, like Diana, was increasingly distressed by the suffering he saw around him. “People were coming in very sick and we were treating them and sending them straight back to their families, who didn’t know how to handle them. They were often rejecting them out of fear that they could be infected by casual contact at home,” he says. “I decided that, even if I had to give up all my free time, I had to do something to care for people better.”

Back in Oshakati, encouraged and motivated by what they had learned, Diana and Engelbert started to work with communities outside the hospital. In 1996, they set up an organization called TKMOAMS, which is an acronym for an Oshivambo phrase meaning, ‘God protect our nation from this disease AIDS’. But they have struggled mightily with lack of interest in their ideas from the hospital management, and opposition—even hostility—from some of their colleagues who accused them of doing the government’s job for it. Many nurses at Oshakati Hospital have been trained to do counselling, says Diana, but most say they are too busy to take on extra work, especially without extra pay.

Eventually, the two nurses won respect for their commitment and support for TKMOAMS from the ministry and the hospital administration. They have been given counselling rooms and office space at the hospital, where they have developed a grass-roots organization that today involves thousands of people in communities across northern Namibia.



However, getting permission for volunteer counsellors to work on hospital premises took a lot of energy: Diana and Engelbert had to counter arguments that the presence of lay counsellors would compromise the professionalism of the health services.

They had to do careful groundwork in the communities also, garnering the support and cooperation of community leaders, headmen and chiefs for their programme. The headmen identified the first group of volunteers to be trained as HIV/AIDS educators, but today volunteers come forward of their own accord. To date, TKMOAMS has trained 653 volunteers who work as educators to raise awareness and encourage prevention in 23 communities. Another 700 volunteers have expressed the desire to join the organization and are awaiting places in the busy schedule of training programmes. Around 540 of the existing volunteers have been given specialist skills in home-based care as well and, as of August 2002, they were looking after some 1300 patients in their own homes. "Home-based care is only for those who aren't seriously ill," explains Engelbert, who is responsible for this side of the programme, while Diana works as counselling coordinator. Volunteer caregivers can dress wounds, treat diarrhoea, vomiting and skin rashes, and deal with pain, he says. Anything more serious is referred to the hospital. But hospital appointments cost money that few families, impoverished by HIV/AIDS, can afford, and TKMOAMS is trying—so far, unsuccessfully—to negotiate a waiver of fees for their patients.

#### **Box 9. French Government helps with home-care kits**

In a small side room in Oshakati Hospital, two women in crisp white lab coats stand at a table, scooping pills from a large tub and counting them into envelopes. Behind them on the shelves are boxes of ointment and bandages, sacks of sugar and salt, tubs of vitamins, neat piles of face cloths, plastic aprons, tablets of soap, and bundles of scissors and rubber gloves. In early 2002, the French Government provided funds to equip 400 TKMOAMS volunteer caregivers with home-care kits for one year.

It is the job of volunteers Lovisa Andjamba and Lea Mumbala to make up the kits from the bulk supplies they get from a local pharmacy at trade prices. Both have been with TKMOAMS since 1996 and are trained as educators, counsellors and caregivers. They work Monday to Friday in the pharmacy and weekends in the community. They do not resent the time they spend, or the fact that they get no pay; that was never an expectation. HIV/AIDS is very visible in their communities, and the women value the skills and knowledge they have been given, and the opportunity to do something to challenge the killer in their midst.

The home-care kits include a T-shirt for the volunteer, as well as a notebook and pen, and they have made a huge difference to the effectiveness, status and morale of caregivers who have been working for years with minimal or no supplies. The kits have also helped encourage a spirit of openness, says Engelbert. In the early days of TKMOAMS, volunteers were marked with the stigma of HIV/AIDS and were often shunned by their communities. Today, however, they are greatly respected and sought out for advice. It helps greatly that caregivers have more to offer their patients than kindness and counselling.

It is hoped that, when the French funding runs out, the Namibian Government will be able to support the provision of kits. Engelbert has kept up a dialogue with the Ministry of Health about the necessity for home-based care, and has helped develop a training curriculum and a series of training manuals on working with communities. The Ministry now has a Community-Based Health-Care Unit, whose job is to facilitate and support organizations such as TKMOAMS, working at the grass-roots level.

Reaching the poorest of the poor and those who are too fearful of stigma to come forward presents a real problem, explains Diana, so volunteers don't just go to the homes of people known to be sick; they visit every home in their area from time to time. This allows them also to identify others in need, such as orphans and vulnerable children, and they have special monitoring forms to record the make-up of each household and determine whether or not they have an income or other source of subsistence. Some 2000 orphans and vulnerable children have been identified in the area, and there are plans to start an assistance programme for them by raising money from making and selling school uniforms.

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***Reaching the poorest of the poor and those who are too fearful of stigma to come forward presents a real problem, so volunteers don't just go to the homes of people known to be sick; they visit every home in their area from time to time.***

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The community counsellors generally carry out pre-test counselling, and they then refer clients to Diana and her team of four counsellors at the hospital for testing—taking blood, giving results and doing post-test counselling. At the hospital, Diana sees people who are referred by doctors as well as people who come of their own accord, and she follows up on a monthly basis with those who are HIV-positive. “At the beginning, demand for VCT was quite slow,” says Diana. There were concerns about confidentiality because the counselling room was not ideal. However, they now have better counselling facilities in the hospital, and the fact that they have something to offer those who are positive has been a big encouragement. Now they are overwhelmed with the demand. Diana opens her register and runs her finger down the list of 29 people who came to give blood for testing yesterday, and 25 others who came for their results, all of whom had to be counselled.

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***Even when you are sleeping, you see that distressed patient you've been counselling again in your dreams.***

— Diana Shilongo, Namibian nurse

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To cope with the large number of volunteers and the ever-expanding workload, TKMOAMS has developed a structure whereby each community has an AIDS committee, which does the day-to-day organizing of the volunteers in that community. Diana and Engelbert are responsible for supervision and support, and they sit on the executive committee, which includes a representative from each community AIDS committee. “We try to visit the volunteer groups on a monthly basis,” says Diana. “This is important to motivate them and to give moral support.”

TKMOAMS also has a technical committee, which helps with planning and strategizing. And, in early 2002, the programme set up a Business Advisory Group made up of local business people and representatives of development agencies. Its purpose is to give TKMOAMS advice on income-generating opportunities, help identify sources of funds and advise on how best to use existing resources. But it also serves the purpose of drawing the wider community into TKMOAMS' activities and gaining support and commitment from those who are economically powerful in the area. An Oshakati pharmacist in the advisory group, for example, has helped the organization obtain bulk supplies at trade prices for its home-based-care kits.

In 2002, the programme was joined by Martyn Price, a VSO volunteer from Britain, who helps with administration. Martyn says that, without the leadership qualities of Diana and Engelbert, TKMOAMS could never have got off the ground. “Diana,” he says, “is a gentle person, a listener, and very supportive of people. She makes them feel valued.” Engelbert is a

man with drive and vision, but his great strength is that “he’s able to break his vision down into steps and make it happen, and that’s very important.” Though TKMOAMS now has support from some major donors and is expanding fast, Martyn believes that one of the programme’s strengths is that it started small and grew slowly—and from the bottom up. For a long time, the volunteers were doing their own fundraising, selling things on the street and appealing to local businessmen for support. “TKMOAMS demonstrated that it had gained the commitment and support of the community by the fact that, for four years or so, it was operating on a tiny shoestring,” says Martyn. “The programme only had about N\$1000 (approx US\$100) in the bank when VSO started working with them, yet it was going strong.”

Despite the steps taken to spread the load of responsibility across the various committees, the emotional burden on Diana, Engelbert and their army of volunteers remains enormous. Diana gets comfort from her church and lots of support from her husband and four children, but says she finds it almost impossible to leave her work behind when she goes home. “Even when you are sleeping, you see that distressed patient you’ve been counselling again in your dreams,” she says. True to his commitment when he first started working with communities, Engelbert gives almost all his time to the programme. “We no longer think in terms of working hours and weekends!” he says with a smile. To recharge their batteries, they bring everyone together a couple of times a year, slaughter a cow, and have drinks and a big party. At the day-to-day level, there is a policy to share the emotional burden between volunteers: no one is assigned to look after a sick person exclusively, and sometimes volunteers work in pairs. Moreover, there are regular meetings to share experiences, and on-going training sessions and workshops. “These kinds of things make volunteers feel valued and cared for,” says Engelbert.



Diana Shilongo of TKMOAMS and Olavi Iyambo, secretary of the Namibia Nurses Association, watch volunteers Lovisa Andjamba and Lea Mumbala make up home-care kits in their small office at Oshakati Hospital.

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***At the day-to-day level, there is a policy to share the emotional burden between volunteers: no one is assigned to look after a sick person exclusively, and sometimes volunteers work in pairs.***

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Recognition also boosts and sustains morale and, in 2002, TKMOAMS drew the attention of some major donors at home and abroad. It has been given a four-wheel-drive vehicle by Namibia’s diamond mining company, NAMDEB, funds for 20 bicycles by a group of supporters in Austria, and a computer by VSO. With better transport and communications and streamlined administration, TKMOAMS is that much nearer to fulfilling its ambition—to extend its programme to communities throughout northern Namibia.

### Box 10. The Friendship Club

Wilima Johannes and Emilla Silas are members of TKMOAMS' Friendship Club for people living with HIV/AIDS. Most days, they can be found at a community centre close to the hospital, poring over trays of tiny coloured beads. They are members of an income-generating group that makes red-ribbon badges that they sell for N\$10 (US\$1) each to meet their basic needs and to support a food programme for Friendship Club members. Some 60 people belong to the club, and they all cook and eat together regularly at the centre. This gives them support as well as a good meal, and their health has improved a great deal since they started the programme, says Martyn Price.



Wilima Johannes and Emilla Silas are members of TKMOAMS' Friendship Club for people living with HIV/AIDS. They make red-ribbon badges from beads to earn money for basics.

While some members of the Friendship Club are still too anxious to be completely open about their HIV-positive status, 15 have been trained as counsellors and caregivers and are very active in the campaign to encourage openness. They address workshops and training sessions and always discuss the advantages of taking a test with clients they counsel. "They've really encouraged people to come out of their hiding places," says Engelbert. "It's much better to hear of the advantages of openness from people who have personal experience than from me." He believes that, most often, rejection is stimulated by fear bred of ignorance rather than prejudice, and says he has seen things change as people have gained greater understanding.

Wilima's own story confirms this view. When she tested HIV-positive, she went to Diana for support, and only felt ready to disclose to her family when they had been sensitized. "If the nurses hadn't given information to my family first, I'd have been too scared," she says. Openness has brought freedom to both young women. "Knowing your status gives you courage to change your behaviour. It helps you to live positively," says Wilima. Both she and Emilla have trained in home-based care. They have lots to do and a sense of purpose in their lives. But they shake their heads and laugh with dismay at the thought of what their lives would be like if TKMOAMS did not exist.

### Letsema Oagile

Letsema Perpetua Oagile is a lecturer in midwifery at Botswana's Institute of Health Sciences. She grew up in the village of Gabane, which is some 20 kilometres from the capital city, Gaborone. But, today, Gabane has been engulfed by the urban sprawl of Gaborone so that you never really leave the big city before reaching the village. The influence is plain to see in the small, busy bars that fringe the dirt roads of the village, and the fashionable clothes of the youngsters who cluster round them, listening to loud music. There is much socializing with Gaborone and, today, Gabane is a regular haunt of different groups of people, explains Letsema. Casual sex following the consumption of alcohol is the name of the game, and the quiet, traditional village she remembers from her childhood is being ravaged by HIV/AIDS. The graveyard is filling fast with new graves. The dates on the headstones bear witness to pathetically brief lives: people here are dying in their 20s and 30s. Gabane can no longer hide the tragedy of what is happening.

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***The dates on the headstones bear witness to pathetically brief lives: people here are dying in their 20s and 30s. Gabane can no longer hide the tragedy of what is happening.***

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It was the shock of so many funerals and deaths among families she knew that stimulated Letsema to do something for her community and, in 1998, she set off on foot along the dusty paths of the village to address children in schools and people spilling out of churches on Sunday mornings. Her purpose was to challenge what she believed was widespread denial and ignorance about HIV/AIDS and to encourage behavioural change.

Accompanying her student midwives during practical work in the communities has given her invaluable insights into the dynamics of sexual relationships in Botswana and greatly influenced her thinking, she says. “One thing I’ve learned is that people act according to the logic of their immediate circumstances, not necessarily in their long-term interests.” Many of the women she spoke to at antenatal clinics, for example, had relationships with several men for the sake of financial security. They spoke of the difficulty of negotiating safe sex and how, if their partners disliked condoms, they dared not insist for fear of rejection and abandonment. Pregnant teenagers told of the psychological pressure they were put under by boyfriends, and sometimes sugar daddies, to have sex. And Letsema also learned that traditional married women tended to believe that there was no need to consider the use of condoms with their husbands, because they were protected by his payment of bride price.

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***One thing I’ve learned is that people act according to the logic of their immediate circumstances, not necessarily in their long-term interests.***

— Letsema Oagile, lecturer in midwifery at Botswana’s Institute of Health Sciences

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But as well as these cultural and socioeconomic obstacles, Letsema is also up against widespread superstition. HIV/AIDS is a complex phenomenon and information surrounding it can be confusing, she says. “People still like to explain what they see as witchcraft,” she adds. Belief in witchcraft has deep roots and a strong hold over the population. The majority of people still go to traditional healers regularly for ritual practices designed to protect families from harm. The practices themselves, which include cutting each member of the family and applying a paste to the wound, and sometimes giving enemas, can pose a risk of HIV infection. But it is the hold over the mind that is of particular concern. “The belief in witchcraft, with its tendency to blame others for your misfortune, makes people slow to respond positively to information about HIV/AIDS,” she says. And it makes the stigma of HIV/AIDS particularly difficult to challenge: people are afraid to be identified with someone with HIV because of its connotations. Sometimes, relatives or friends are chased away from funerals, accused of causing the death. Such accusations of bewitching the sick serve to weaken and destroy the extended family system, just when unity is most needed to meet this mammoth challenge, says Letsema. Families may be reluctant to care for sick members at home for fear of being held responsible for their fate. And those who do look after a sick relative may not take measures to protect themselves if they believe that what they are dealing with is witchcraft rather than an



Letsema Oagile, lecturer in midwifery at Botswana’s Institute of Health Sciences



Angelina Morapedi, Nurses Association of Botswana, and Letsema Oagile (right) visit the graveyard in Letsema's home village of Gabane, outside Gaborone.

infectious disease. "I was born here and spent a lot of my life in Gabane, so I know how my people think and what they believe," Letsema says. "These are the things I have to challenge."

She makes contact with the guidance and counselling teacher at schools and then goes along to address large groups in the school hall. Aware that people are bored by the subject of HIV/AIDS, even if they badly need the information, she uses teaching aids as much as possible to make her presentations interesting and personally relevant. She starts by showing a video distributed by the Ministry of Health and produced in Kenya, called 'Silent Epidemic'. This follows the life of a young woman infected by HIV as she sickens and dies. It also looks candidly at the signs and symptoms of HIV/AIDS. For many youngsters, this is the first time they have looked closely at genitalia, which, in the film, are larger than life for the sake of clarity, so Letsema takes pains to prepare them in advance for what they will see.

The video raises many issues and invariably stimulates the debate. Letsema guides the discussion, and makes sure that, as well as imparting the basic information about HIV/AIDS, she brings home to people the fact that it is a threat to them personally, as well as to their families and friends. She looks at the statistics and reminds her audience that at least a quarter of them are likely to be infected. And she uses the example of a relay to discuss how the baton of HIV is passed from one to another in a linking chain, explaining that two people having unprotected sex are effectively linked to all the other partners each has had. She also discusses with her young audiences the kind of social situations in which they are vulnerable, and possible ways of avoiding them.

Letsema has spoken to many school children, from primary to senior secondary, and to church congregations throughout her community. But she is concerned, too, about the young people who are not in school and do not go to church. She is trying to reach them through the traditional community meetings—the *kgotla*—and through the local clinic while they are waiting to see the nurse. As a teacher, Letsema believes implicitly in the power of education to expand the mind and weaken the hold of superstition and fatalism. Her hope is that the messages she takes to her community will be powerful enough to change people's behaviour.

## Patricia Hirschfeld

With a tiny population and one of the strongest economies in sub-Saharan Africa, Botswana is better placed than most countries in the region to deal with the HIV/AIDS epidemic. It has set up a home-based-care programme in the STI/AIDS unit of the Ministry of Health, in which nurses work alongside social workers, family welfare educators, and community volunteers to give comprehensive services to PLWHA and their families. And it is the first country in sub-Saharan Africa to introduce antiretroviral therapy for PLWHA, with a pilot project set up in January 2002 at Gaborone's Princess Marina Hospital. But the growing demand for home-based care is putting tremendous strain on the country's welfare infrastructure and the government has coaxed a number of nurses out of retirement to help run the programme.

Patricia Hirschfeld is one of them. She works with a team of volunteers out of a brand-new purpose-built centre that has a kitchen, counselling room, and a treatment room for such things as the rehydration of patients. Outside, there are the beginnings of a vegetable garden. Patricia intends to start day care for patients at the centre. And there are plans to add on a skills-training room and to help the volunteers set up income-generating schemes. The Ministry of Health, which is keen to discourage dependency and to promote the sustainability of community care activities, has a budget to support these efforts with small grants.

HIV-positive people with a CD4 count below 200 or who are co-infected with TB are eligible for antiretrovirals, as are babies born with HIV infection. The government estimates that about 110 000 people nationwide fit these criteria. Ten of the 65 patients in Patricia's home-based-care programme are on the treatment. Twenty-six-year-old Kagiso, who lives with his grandmother in a Gaborone suburb, is one of them. He has TB and has found it hard to comply with his treatment, says Patricia, as the young man, painfully thin and weak, shuffles from his bedroom into the living room and sits down beside her. He has to take five tablets at specific times during the day, but the trouble is that neither he nor his grandmother can read or write, and they did not know what was expected of them, she explains. Kagiso's mother died when he was very young, leaving five orphaned children, and there was no money to send them to school. Patricia says it was the responsibility of the dispenser to see that Kagiso understood his treatment regimen, but she has now taken it upon herself to supervise his therapy and is watching him improve slowly. Taking ARVs "is a very heavy burden to bear alone," she comments. People need support from someone who will ensure they take their medicine even when they have no appetite and don't feel up to it, so she gradually drew Kagiso's whole family into the treatment plan through intensive counselling.



Patricia Hirschfeld (second from left) and colleagues outside their new, purpose-built centre in Gaborone.

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***Taking antiretrovirals "is a very heavy burden to bear alone." People need support from someone who will ensure they take their medicine even when they have no appetite and don't feel up to it.***

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Patricia visits the young man weekly to assess the situation and his treatment. This cannot be done by volunteers, she says, though they come to help his grandmother with household chores. She explains that people on ARVs must have a nutritious diet, which often needs to be assessed on an individual basis. Kagiso is on welfare and Patricia liaises with the dietitian and social workers to make sure he gets what he needs in his monthly food basket. She has taught infection control to family members, and provides them with gloves and linen-savers too, when necessary. It is her job to assess these needs and to make sure that supplies are delivered by the welfare department.

Next on her list of visits for the day is a young woman whose only ally in a hostile family is her sister, who cares for her and supports her ARV treatment. The girl is sitting outside her home against a wall, soaking up the warmth of the sun, and making a patchwork cover from scraps of material. She looks up and smiles as Patricia enters the yard. A few weeks back, she could only walk with a frame, says Patricia. Now she gets up without problems, though her limbs are stick-thin. The girl has dark patches on her face and neck from the treatment. Her mother has not yet been told of her daughter's HIV status, because she is angry and dismissive. Patricia explains that, nowadays, many youngsters with a bit of education leave home for the bright lights and often neglect their families. When they return home very sick and looking for care, they are resented, and time and counselling are required to work through this. Patricia and the girl's sister are working on her mother, and the sister feels it will soon be time to tell her—but not quite yet. So Patricia does not mention HIV/AIDS as she hunkers down in the sunshine to speak to the girl.

Patricia's workload is heavy and she categorizes her patients according to how needy they are. Those on ARVs she visits weekly, "because I have to see that they're eating well and that they're supported by the family". Others she visits once a fortnight or once a month, though her volunteers visit everyone more regularly.



Mavis Kewakae is a nurse who works in community health and home-based care.

Patricia explains that she came out of retirement to do this job because the programme was short of manpower. Before she retired, she had been a matron in the operating theatre at Princess Marina Hospital, where she used to see AIDS patients when she visited the medical wards. "But I only really understood what AIDS does to a person when I started this home-based-care work. And I felt such sympathy."

According to people in health management behind the scenes, as well as those on the front line, pressure of overwork is the Achilles heel of the home-based-care and antiretroviral programmes. "We're able to cope at present, but we wonder how long we can sustain all these programmes," says Mavis Kewakae, who works in home-based care at the Ministry of Health. This is a familiar story wherever people are running programmes to combat HIV/AIDS. But because a government programme theoretically offers a service to everyone who is eligible, it is likely



to raise expectations that are difficult to meet, meaning that 'failure' of sorts is inevitable, no matter how much staff put into their work. Demoralization and despair are far more apparent among people working in HIV/AIDS programmes within the system than in those working for nongovernmental organizations.

Patricia finds her work with patients rewarding but the job itself thankless, and she does not feel adequately supported by the system. No one—not even colleagues at the clinic—understands what this work entails, she comments. “They think it’s a luxury to be going around in a vehicle; they don’t realize what we’re doing.” When one of her patients dies, she agonizes about what she could have done better, and feels there is a pressing need for counselling and support services for those on the front line who carry such huge responsibility. Meanwhile, her religion is a great strength, she says. “And the community has really supported me. I have made friends and know they will stand by me.”

### **Box 11. Hospice offers specialist care for the terminally ill**

Twenty years ago, Mary Mphafe was diagnosed with terminal cancer, and was expected to die quickly. But, miraculously, she recovered. Keen to help other terminally ill people avoid the dreadful pain and suffering that she went through, Mary works at a hospice run by the Bamalete Lutheran Hospital in Ramotswa village, Botswana. The wall of her small office bears a number of framed certificates for palliative care and bereavement counselling.

With palliative care, you are not aiming to treat but to comfort patients so they can die with dignity and peace, explains Botho Moreko, a nurse at the centre. Its main elements are pain relief, comfort, and psycho social support. The hospice, which opened its doors in 1992, consists of a large, bright day-room equipped with television, radio, games, books and a sewing machine, a kitchen, counselling and consulting rooms, and a chapel. There is also a small dormitory where patients who are bedridden can come for the day to relieve the burden on caregivers. Respite care was begun only in 2002, but is already one of the most valued services of the hospice. “Most patients are cared for by elderly relatives, and it’s very difficult for [the relatives] to be responsible for them 24 hours a day,” comments the nurse.

The hospice offers day care to terminally ill patients, who are predominantly people with cancer and HIV/AIDS. A vehicle goes to fetch them early on Tuesdays and Thursdays, and delivers them home at the end of the day. Patients have meals together, share prayers in the chapel, and socialize with each other and the staff. Sharing experiences with other terminally ill people is almost like group therapy and it boosts the morale, says nurse Moreko. But the hospice staff visit people in their homes, too, and they run training programmes in care for the terminally ill for community-based volunteers. When the hospice first opened, it was the only alternative to hospital care for people with HIV/AIDS, and it was overwhelmed by the demand. But the government’s home-based-care programme has relieved the pressure, and the hospice has found itself playing a more comfortable, complementary and supportive role.

## Margaret Mokhothu

Margaret Mokhothu is larger than life. She is a big lady with a bright, strong face and a halo of white hair, who talks fast, smiles a lot and is brimming over with ideas. She also has a generous spirit. Monapathi Maraka, secretary of the Lesotho Nurses Association, is one of a number of people she met as bright youngsters caught in a limbo of poverty and limited opportunities, and she encouraged him to follow a nursing career. ‘Ma Mokhuthu’ is his mentor. When she began to witness the silent suffering of families affected by HIV/AIDS, she turned her compassion and her considerable energies in their direction.

Margaret trained originally as a nurse in the 1960s and subsequently took courses in mother-and-child health and family planning in the United States before returning to Lesotho to work in public health. In the early 1980s, she went back to university to study sociology and thereafter worked as a researcher in the Lesotho Housing and Land Development Corporation. It was while she was doing her research in villages across Lesotho in the late 1980s that she first became aware of HIV/AIDS. Her curiosity kindled, she began attending courses and workshops run by NGOs to learn about the subject, and began to try to raise awareness among her colleagues.

What concerns her most is the isolation and neglect of those who are sick. For a long time, she directed her energies towards befriending people living with HIV/AIDS and their families. Her great skill is in making contacts and using her networks to find the help she needs. She was, for many years, president of the National Council of Women in Lesotho—an NGO that champions women’s rights. This afforded her rich opportunities for meeting people, and today she uses her contacts to find hospital beds for those who are very sick, nursing care at home for those who need it, and support for orphaned children she finds in the homes that she visits. She seeks the help of lawyers, local chiefs and police officers to see that vulnerable people, especially women and children, are not dispossessed of their property by greedy and uncaring relatives. And she encourages and assists those who are dying in making a will to protect their dependents. “It’s all just small things that I do,” she says with a dismissive wave of the hand. “It’s all just networking and using my contacts.”

One of the biggest obstacles Margaret faces in her work, she says, is stigma. “It’s terrible!” She tells the story of one of her close friends whose daughter has HIV/AIDS, which she refuses to acknowledge. When Margaret suggested finding the girl a place in hospital when she became seriously ill, her mother refused. “She knows what I do and she didn’t want me taking her daughter to hospital because it would make the neighbours suspicious,” says Margaret. One day, the girl revealed that she had been beaten by her mother for disgracing the family. She lifted her jersey to show the welts across her back. “That’s the degree of stigma we’re talking about,” says Margaret vehemently. “We’ve got to start digging down, down, down; talking and talking.”

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### ***Denial and anxiety are swift killers of people with HIV.***

— Margaret Mokhothu, Lesotho nurse

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Not surprisingly, she starts at the personal level, encouraging people who have tested positive to accept their condition and fight the negativity and fatalism surrounding the diagnosis. “I tell them, the first thing to do is realize it isn’t the end of the world, but the start of something new.” Denial and anxiety are swift killers of people with HIV, she believes, and she stresses the advantages of being open. She tells PLWHA: “If you accept who you are and map out a plan for your future, and for your children, it’ll give you peace of mind and protect your health”.

Having worked alone for years befriending individuals and families affected by HIV/AIDS, Margaret feels it is time to start involving others in her activities and is busy creating a more formal structure. She has selected 10 volunteers from her own community, Mohalalitoe, and 10 from the neighbouring community of Khubetsoana to be trained to run HIV/AIDS support groups. There are so many people suffering from HIV/AIDS in these communities, she says. "We see them; we know them; we want to help them. We have to do something because this damn thing spreads like wildfire!" The plan is to divide the area into cells, and give each volunteer responsibility for a cell. Margaret will encourage them to join NGO groups or national forums, and to make contact with local representatives of WHO and foreign missions. She will teach them to network, she says. The volunteers will be supervised by a technical team, including herself, and three other trained nurses working as volunteers.

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***If you take an old lady staying alone, not knowing where her next meal will come from or what to look forward to, and put her into a household with children who are also lonely and lost, what a transformation there could be!***

— Margaret Mokhothu

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Meanwhile, another plan is taking shape in her head. Margaret is a member of an old people's group, where she sits on the 'communications' committee. Radio Lesotho sets aside a few minutes of air time for public service broadcasting, and she intends to suggest a programme on HIV/AIDS and the elderly—a regular slot over some time that will raise the issues of their vulnerability, and the role they are playing as caregivers of PLWHA and as guardians of orphaned children. Margaret feels that elderly people have been very much neglected in the information campaigns as a target audience. Many of them are ignorant of how to protect themselves as caregivers and are therefore at serious risk of infection, she says.

Always sensitive to those pushed aside by society, she is also concerned that many elderly people in Lesotho are isolated and lonely. Breakdown of the extended family system has deprived them of the traditional role they played in the home, she says. The smallest children whom grandmothers once expected to look after are now being sent to nursery schools. But, at the same time, there are growing numbers of children with no one to care for them—children whose parents have died of AIDS. "Why can't our government subsidize elderly people to be surrogate mothers to these children?" asks Margaret. "If you take an old lady staying alone, not knowing where her next meal will come from or what to look forward to and put her into a household with children who are also lonely and lost, what a transformation there could be!"



Thembi Zungu, South African nurse

### **Thembi Zungu**

Thembi Zungu first became aware of HIV/AIDS as a student nurse in the late 1980s. "We were doing psychology and we had someone in to talk to us," she recalls. "We were asked the question: 'how would you deal with an HIV-positive patient that's admitted to your ward?' I was very blank. At that stage, the only thing I knew was that you get HIV when you sleep around. I didn't know that 'sleeping around' means having sex with your own partner. The message didn't have much meaning to me. I was very young, in the prime of my life. I never thought I'd get HIV/AIDS then."

Thembi qualified in 1991, but because she had received no specific training in the clinical management of HIV/AIDS, she was unprepared when she began to encounter the disease in her first job at the hospital's dermatology clinic. "The epidemic was advancing and there were all these young kids coming up with herpes zoster. At that time, the doctor would just say: 'Go to room number so and so; the sister will take your blood'. These were people very young—23, 24 years old—and the results were coming back positive. The way they were told, it was just like: 'Your results are positive; you have AIDS and there is nothing that we can do for you.' It was terrible!

"At that time, I was in charge of the clinic. I had a group of student nurses doing a fourth-year course, and we used to take the blood. We decided [to] just test our own blood for HIV. It was just out of curiosity.

"I waited for my results...I waited, and they didn't come back. And then the doctor came in and said to me: 'There's something wrong with the blood in the lab, and they want you to give a second specimen'. I said, 'What?' He said, 'They want a second specimen'. So he took the second specimen...I remember it was August, just before my graduation. They phoned me after two days and just said, 'Let us go to the lab'. I was following after this doctor, very worried and not knowing. Remember, I had not had any sort of pre-test counselling; it was just out of curiosity that I was taking this blood test. We went to the lab, we took this envelope, and then we went to a quiet place. It was only the two of us, and he said, 'Your results are positive'. And that was that. That's how I knew about my positive status.

"It never occurred to me that it would come back positive, and I was shocked. I didn't know how to react at that particular moment in time. I had to go back to work because I was in charge of the clinic—in charge of this same clinic that would make me test people for HIV!

"It was the day before my graduation party, and I didn't sleep that whole night. I was asking all these questions: 'Why me? Why is it happening to me?' I was the first person in my family ever to graduate at tertiary level. My mother and father had passed away and I was the only breadwinner at home. My sisters were still at school.

Maybe after 3 o'clock in the morning I decided, 'I think I have to keep this inside me. I have to behave as if I am normal, as if nothing has happened to me'. My thoughts were that I had to be alive for these kids to finish school.

"It's only today that I realize I was in deep denial, because my life went on as if nothing had ever happened. I was afraid to tell my partner about the positive test result at that time. We didn't practise safe sex at all—which is why I always understand if a person is in denial and there are problems cropping up in a relationship, because I am coming from there. If your partner doesn't say, 'I am going to use a condom,' then you are not going to be strong and say, 'Use a condom'. I remember it myself. I couldn't say anything, because I was not used to saying the words 'I am HIV-positive.' I didn't know what was in me and I didn't know what was going to happen to me."

So how did Thembi emerge from the denial and actually start to face her diagnosis? "It was a long trip out of that denial; it took me from 1991 till 1996. I got married in 1995. I already knew that I was HIV-positive, but I didn't talk about it. We sometimes practised safe sex, sometimes not. To me, it was as if the virus did not exist. I think that, from the very beginning, I just put it into my subconscious mind. It would come up maybe if I saw a red ribbon...or when somebody talked about AIDS. But it was like it wasn't happening to me, as if I had never tested, as if that was not my blood.

“And then I got pregnant. At 16 weeks, I went to see a gynaecologist, and he tested me, with my consent. I pretended this was the first time I'd been tested. My husband also got tested, and his results came back before mine and they were negative. When my results were positive, I just said, “How can this be? I thought I would also be negative because he was negative.”

Thembi's husband has stuck by her, but she has never been able to tell him the full story of her personal battle with HIV. She hints that it might have been the result of a needle-stick injury during her work at the hospital among HIV-positive babies, though she does not herself believe that that was how she got infected. “Ninety per cent of the time I was practising unsafe sex,” she says.

What did Thembi feel when she was treating patients on the wards, nursing people she thought might be HIV-positive or who had AIDS? “It was painful!” she says. “I didn't know what to do. Just to see a mirror image of you at the end of it all...And it makes you wonder, ‘How long am I going to live?’ But you can't talk about it; you can't tell these people! I was always in a kind of ‘mid-depressive’ mood, if there is a term like that. I'd make a point of going to work, but I would meet these challenges all the time; I would try to cope, but it was painful.

“What was painful too was to see the attitude that other people displayed on the ward—the prejudice and the stigma related to a person being HIV-positive. I would go to the toilet and cry and then come back and work. There was lots of uncertainty among nurses because nobody knew much about this disease. That aggravated the stigma and the attitude towards patients who were HIV-positive. People were not sure how to behave—whether to touch this patient, or not; whether to put on a mask when they were cleaning this patient, or not.”

Seeing how some of them treated patients who were HIV-positive, did Thembi feel guilt at hiding her own HIV status from her colleagues? “It was not guilt as such. But I felt more comfortable with me not telling them, because I knew the attitude.” How did she finally break out of the silence? “When I took the test when I was pregnant, my doctor said to me, ‘I can give you this number; please phone this woman and go and see her’. So, in that state of crying and shock and anger, I had to call a counsellor to book an appointment. I said to her, ‘Please help me explain to my husband that this is the situation’. I would say that I attribute everything that has happened to me since then to that lady, because she was able to manage the situation. She was able to explain to him why he is negative and I am positive.”

Thembi eventually felt she needed to get away from the stresses of working on the hospital wards, so she applied for a job in a community health clinic. Her employers were aware of her HIV status, but she still did not tell any of her colleagues. After working for some time in child health, she was informed by the clinic management that she might be called upon to work with TB clients. “That didn't go down well with me,” she recalls. “I was afraid I might get TB. I think that's when I started to get late to work, going off sick now and then.

“There was a volunteer at the clinic who was doing HIV/AIDS counselling at the time—a beautiful young girl,” she continues. “I called her to my consulting room, and I said, ‘I am not a patient, I am working at this clinic, and I am HIV-positive’. So, the first person I disclosed to, other than the doctor, the counsellor and my husband, was a person who was not a professional. It was just a volunteer coming to the clinic.”

Thembi met a young man who was also HIV-positive, and he persuaded her to come to meetings of the support group for which he worked. “When I was at the meeting, I would see that almost all of them were my clients at the clinic, and so I couldn't disclose and say, ‘I

am HIV-positive' around them. But there was a time when there was a psychologist at one of these meetings, and we were separated into groups to share our experiences and our feelings. I thought to myself, 'These people are suffering more than me, so why am I quiet about my own situation?' So I started to tell my story from there. Then, I disclosed to a larger group in the next meeting."

Thembi resigned from the clinic in 2000 to work full time for the National Association of People Living with HIV/AIDS (NAPWA), in South Africa's Eastern Cape region. "That's when I started opening up a lot to my colleagues. But I found that they were shocked. Some couldn't face me the first day I disclosed at a public gathering. And I said to myself, in the end, they are going to accept me and use me the way they are supposed to use me. Because one objective of me coming out was to help other nurses who are afraid to come out.

"I think that, as nurses, we always feel that the disease only happens to the patient! And I think nurses find it hard to accept that they are HIV-positive when they think back to how they have treated others with the infection."

Thembi was hugely relieved when she started to disclose her HIV status and to tell a number of people she trusted. "I cannot even describe it," she says. "I knew I was over my fears; I knew that even if I got sick I would know who was going to be on my side. It has empowered me, coming out. It has given me a chance to offer my experiences to the next person, and say, "This is what you can choose if you want to. If you don't want to, you can keep quiet. But I believe the choice is yours."

## The lessons of experience

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***There's a lot of suffering out there and we nurses are very much needed. So just get started and things will happen...***

— Beatrice Chola

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Nurses and midwives in Southern Africa face unprecedented challenges. They must carry on delivering care to the best of their ability while HIV/AIDS gradually overwhelms the health services for which they work—crowding hospital wards, devouring the lion's share of resources, crippling budgets and picking off their friends and colleagues. At every turn, the epidemic challenges their strength and commitment to their profession. But, as these brief profiles show, many are meeting this challenge with courage, resourcefulness and tremendous determination. How do they do it? What inspires them? And how do they keep going? This section looks at the lessons of experience and highlights those that should be of help to others working on the front line of the HIV/AIDS epidemic and wondering how to do their best for their patients. There are lessons here, too, for managers, programme donors and others about what is needed to support and enhance the work of nurses and midwives.

### ■ **Nursing practice is where care and prevention meet.**

At one time, prevention and care were seen as exclusive activities making competing demands on HIV/AIDS budgets. But, today, it is recognized that both are necessary for an effective response to the epidemic, and that one without the other limits the chances of success. Ideally, care and prevention should go hand in hand. Nowhere is this more relevant than in nursing practice. Indeed, nursing is, in many ways, an embodiment of this principle, and there are numerous examples in these stories of nurses carrying out activities that combine prevention and care as a matter of course. Counselling is one obvious example. So, too, is teaching family members at the bedside how to care for their sick relative while protecting themselves. And midwives working in programmes for the prevention of mother-to-child transmission of HIV are involved in both care and prevention activities at the same time. Where prevention is not an integral part of their caring role, nurses and midwives should be aware of the opportunities their involvement with families and communities gives them to encourage prevention, such as through the distribution of information materials and condoms, and should take advantage of them.

### ■ **Education and specialist training in HIV/AIDS is hugely empowering to nurses and midwives, and is often the catalyst for taking personal action.**

It was very apparent from the many interviews with nurses and midwives that lack of knowledge about HIV/AIDS is a root cause of fears about safety in the workplace, demoralization, loss of commitment, and a decline in the quality of patient care. It was also apparent that attending workshops and training programmes on HIV/AIDS is often the stimulus for individuals to get involved in action to combat the epidemic, within or outside their regular work. However, opportunities for improving knowledge and skills are scarce, and nurses and midwives feel they are overlooked by information, education and communication campaigns that address the general public. Health service managers and policy-makers need to look at this problem and

to recognize the pressing need of nurses and midwives for specialist information on HIV/AIDS and regular upgrading of their professional skills. Evidence suggests that counselling skills are particularly important in improving patient care and motivating nurses to go beyond the call of duty in helping PLWHA.

■ **Nurses can provide the leadership to stimulate, guide and focus community action.**

Communities very often have the ideas and the energy to meet their own needs but what they require is someone with leadership qualities to stimulate, guide and focus their actions. Nurses should recognize that, with their specialist knowledge and skills and their professional status, they have much to offer in this respect.

■ **Starting small and growing gradually from the bottom up is the best way to build something that will last.**

Sustainability is a big issue for all HIV/AIDS programmes. Experience shows that enlisting the support and commitment of the community is a vital prerequisite, but something that cannot be rushed—especially given the stigma and prejudice that surround HIV/AIDS. Gaining support requires painstaking effort, talking to community leaders, demonstrating competence and building trust. Thus, the soundest policy when starting a programme is to lay the foundations and build on these gradually, rather than to go to the community with a master plan already mapped out. It is also important to remain flexible, so that changes can be made to working practices, if necessary.

■ **Networking and adding on to what already exists makes better sense than creating new structures.**

Anyone wishing to get involved in HIV/AIDS activities in the community should establish what is already being done by others and what opportunities there are for networking, partnerships and the sharing of resources. Not only does this avoid unnecessary duplication of effort and maximize the impact of scarce resources, but it also helps to foster a spirit of cooperation rather than jealousy and rivalry, which are a very real problem in some places.

■ **Communities have ideas and skills that nurses should learn to respect and harness.**

In many places, there is not a strong tradition of working with communities, and health-care workers have a tendency not to recognize or respect the wisdom of those without professional qualifications. Experience shows, however, that there is a wealth of wisdom and initiative within communities, and professionals who work with lay people should strive to keep an open mind and capitalize on these natural assets.

■ **It is important to make the procedures and paperwork of community-based HIV/AIDS programmes as simple as possible to avoid excluding volunteers with little education and confidence but something to offer.**

The fight against HIV/AIDS requires the energy and commitment of as many people as possible. Nobody can afford to be excluded unnecessarily, and HIV/AIDS programmes should ensure that their rules of recruitment for volunteers and systems of operation are as simple and attractive as possible. Furthermore, when working



with people with varying levels of education, such programmes should try to avoid hierarchies and to make everyone feel equally valued for what they can contribute. Hierarchical structures are often inefficient since they tend to undermine the confidence and effectiveness of those at the bottom. The principle of simplicity should apply to all aspects of a programme. Nurses should ask themselves constantly how they can make it easier for their clients to access the services they offer, whether it be obtaining their drugs for TB, taking an HIV test, attending a clinic or hospital for treatment, or getting someone to visit them at home in an emergency.

■ **HIV/AIDS programmes should nurture relationships with donors.**

The commitment and long-term support of donors for a project or programme is immensely valuable. It helps to relieve the anxieties of insecurity that plague most programmes, and allows for time and effort to be spent where most needed. It is important, therefore, that programme managers nurture trust by always being transparent, and by being open and honest with donors about what is involved in trying to achieve the programme's objectives. Regular communication is also important, since it is often difficult for donors working out of efficient offices in the developed world to remain aware of the myriad frustrations and unanticipated set-backs of work in the field. It is a wise policy not to put all the eggs in one basket, and to seek the support of a number of donors.

■ **Nurses working for HIV/AIDS programmes should focus their efforts on transferring skills and building the capacity of the family and community, rather than doing everything themselves.**

The primary responsibility of nurses working in community-based HIV/AIDS programmes is to pass on their professional skills to others, rather than to do the hands-on caring for PLWHA themselves. Not only is this necessary to extend the coverage of the programme, but it helps to avoid families and communities becoming dependent on the professional staff, and it encourages sustainability. If and when the funds run out and a programme ends, ordinary people will still have their skills. Furthermore, by drawing as many people as possible into the care of PLWHA, nurses help to loosen the grip of stigma and prejudice on communities.

■ **Nurses should beware of creating unrealistic expectations in those they work with in HIV/AIDS programmes, such as community volunteers, and family caregivers.**

In places where there is high unemployment, people are sometimes motivated to volunteer in the hope that work with a formal programme will be a gateway to paid employment or bring them opportunities to earn money in due course. Unrealistic expectations can quickly undermine the morale and effectiveness of programme volunteers and it is therefore important that new recruits into any position be given a proper understanding of what their work involves and what the organization has to offer. It is also important for the credibility and good standing of the programme within the community that family caregivers have a realistic view of the assistance and support they can expect.

- **There is a lot nurses can do even without resources: showing concern and compassion towards lonely, isolated people is worthwhile even if they cannot carry out their nursing duties.**

Working in conditions where there are shortages of everything—from protective gear, medicines and staff, to laboratory facilities and transport—calls for ingenuity and imagination. There are many examples in the profiles of how people get around such obstacles. They use ordinary household rubber gloves, plastic shopping bags, or even incontinence sheets as protection against infection when nursing patients; midwives frequently ask pregnant women to bring their own gloves when they come to hospital for delivery; and nurses on crowded wards enlist the help of relatives whom they train at the bedside to help care for their patients. But where there is nothing practical that can be done, nurses can still perform a worthwhile service just by showing that they are concerned and are prepared to visit and listen to a person. In addition, there is nearly always advice they can give on diet and other aspects of positive living.

- **The death of a patient is not the end; life goes on for the rest of the family.**

Generally speaking, HIV/AIDS affects far more people than the individual with the infection. In households where someone is sick or dies of AIDS, there are often vulnerable children, and destitute husbands, wives or other relatives who give up work to care for the patient. And there is anxiety about the future. Nurses, especially those working in home-based care, should try not to dwell on the death of someone they have cared for or to see it as the end of their involvement: they still have valuable work to do in helping family members cope with their loss.

- **HIV/AIDS programmes should beware of creating bills they cannot pay.**

Too often, donors are prepared to give money for capital assets but not for running costs or overheads. It is important, therefore, when buying equipment or constructing buildings, that careful consideration be given to running and maintenance costs and to what can be afforded. Those operating programmes should ask themselves, for example, whether it is necessary to put electricity into a new community or day-care centre for which they have funding, or whether they can afford the petrol and spare parts for a vehicle. Donors, too, should recognize the problem, and be more prepared to build in something for overheads, such as salaries, utility bills, and running costs, to their funding schemes.

- **Stigma and prejudice are a psychological burden to those who harbour such negative attitudes as well as to those at whom they are directed.**

Negative attitudes are particularly demoralizing for front-line health workers whose job it is to care for people who may be HIV-infected, and such attitudes inevitably undermine their quality of service. Inadequate knowledge and lack of protection in the workplace help to foster such attitudes, and these need addressing as a matter of urgency. But there is also a need for open and honest discussion. Nursing managers should remain alert to the personal struggles of their staff and give them the opportunity and a safe and nonjudgemental environment in which to explore their feelings. The same applies to those supervising community volunteers and caregivers.

■ **People with HIV should be encouraged and helped to share their diagnosis with significant people in their lives.**

The silence imposed by stigma on people who are infected with HIV has many ill effects. It leads to loneliness and isolation, increases mental strain, and undermines health and sometimes even the will to live. It also inhibits HIV-positive people from taking the necessary steps to protect others from infection, such as practising safe sex. While the rules of confidentiality should be strictly observed, health personnel should do what they can to encourage infected people to share their diagnosis and seek the support of someone significant in their lives.

■ **Departments of health and managers of health institutions need to review their policies governing the care and support of nurses and midwives.**

Many health institutions lack specific policies or guidelines on the protection of nurses and midwives in the workplace, or on the care and support of those who are HIV-infected. Where such policies do exist, they are often poorly developed and/or staff members are unaware of them. Research indicates that fear of occupational exposure to HIV is widespread among nurses and midwives and is a root cause of low morale and poor-quality patient care. Furthermore, lack of official concern and support for those who are HIV-positive is a powerful disincentive to getting tested, or to living openly and positively with the virus. Those responsible for nurses and midwives need, therefore, to review their policies and practices as a matter of urgency. They need to ensure that all necessary measures are taken to protect the health of staff in the workplace, and to give them job security, care and support if they are infected. Post-exposure prophylaxis should be offered as a matter of course to those whose work has put them at risk of contracting HIV—as, for example, in the case of needle-stick injury. Support groups for nurses and midwives should be set up in all health institutions. Measures also need to be taken to protect the psychological and emotional health of front-line workers with programmes to relieve stress and avoid burnout. This issue has been looked at in depth in *Caring for carers: Managing stress in those who care for people with HIV and AIDS*, a Best Practice Collection report available from UNAIDS.

## Afterword

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Nurses and midwives are at the very heart of efforts to control HIV/AIDS. They represent the majority of the health providers within the region of Southern Africa and elsewhere, and are well educated in theory and practice. It is a tragedy, therefore, that the crisis currently facing nurses and midwives in Southern Africa—a crisis of working conditions, of public confidence and of morale—should be allowed to continue, for it undermines the efforts and effectiveness of some of the most important players in the field. It is a waste of potential that Southern Africa, bowed by the worst HIV/AIDS epidemic in the world, cannot afford. As nurses and midwives leave in droves for the promise of better lives elsewhere, urgent action is required to resolve the situation.

Nurses are among the champions of the health system. As this brief report makes clear, there is among those who remain at home a wealth of initiative, energy and commitment. In order to tap this resource, governments need to give the professions of nursing and midwifery a listening ear. Then they need to jointly reassess their priorities, to make fundamental improvements in the working conditions of nurses and midwives, and to give to these vital front-line workers the personal and professional support they deserve.

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## Recommended further reading

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# Annex 1. Strategic objectives and strategies of SADC AIDS Network of Nurses and Midwives (SANNAM)

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***The overall goal of the SADC AIDS Network of Nurses and Midwives is to improve the quality of HIV/AIDS nursing and midwifery care in the SADC region.***

**Objective 1.** Expand the nursing and midwifery response to HIV/AIDS in the region.

- Advocate an increase in quantity and quality of care available to people living with HIV/AIDS and their families.
- Work for the greater involvement of people living with HIV/AIDS in communities and institutions, including HIV-positive nurses and midwives.
- Speak out as leaders in civil society about stigma and discrimination, especially in health-care settings, and develop strategies to eliminate these practices.
- Ensure that HIV/AIDS content is integrated into the training curricula of all nurses and midwives.

**Objective 2.** Provide support and reduce the impact of HIV/AIDS on nurses and midwives, both professionally and personally.

- Lobby for better protective equipment for nurses and midwives to ensure the practice of universal precautions, as well as access to post-exposure procedures and prophylaxis.
- Train nurses and midwives to adhere to universal precautions, and to avail of post-exposure prophylaxis, when necessary.
- Ensure safe and flexible working conditions regarding tuberculosis transmission, including for HIV-positive health professionals.
- Identify mechanisms for nurses and midwives to obtain voluntary and confidential counselling and testing and follow-up care, as necessary and appropriate.
- Conduct research on: a) stress management and caring for caregivers; and b) the impact of HIV/AIDS on the professional and personal lives of nurses and midwives, and develop and implement strategies to manage and mitigate the impact.

**Objective 3.** Develop a strong, well coordinated network of national, regional and international partners to strengthen the response of National Nursing Associations (NNAs) to the HIV/AIDS pandemic.

- Build the capacity of NNAs to disseminate HIV/AIDS information, and train and provide support to nurses.

- Review national HIV/AIDS strategic plans and policies, and advocate better nursing care, and also support and supplies for caregivers, as well as NNA membership on national AIDS councils and commissions.
- Develop twinning relationships between NNAs to fast-track best practices related to HIV/AIDS.
- Strengthen the NNA secretariats and expand partners in order to improve collaboration for more impact on HIV/AIDS and to mobilize resources.
- Develop and implement standard procedures at the SANNAM Secretariat to improve communication with all partners.

**Objective 4.** Make visible the contributions of nurses and midwives towards HIV/AIDS prevention, care and support.

- Document and publish best practices by nursing and midwifery champions in their work with HIV/AIDS.
- Update and promote the SANNAM website regularly.
- Present research and information about HIV/AIDS-related nursing care and support to caregivers at conferences and meetings.
- Write about, and publish information on, the work of nurses and midwives, institutions and the NNAs on HIV/AIDS.

**Objective 5.** Promote investment towards the retention of nurses in accordance with the impact of the HIV/AIDS pandemic on the profession.

- Conduct a survey to establish the relationship between recruitment and retention of nurses and HIV/AIDS.
- Develop strategies to lessen the negative impact of the HIV/AIDS epidemic on nurses and midwives and the profession.



## Annex 2. SANNAM member association contact information

Nursing association	Address	Tel. number	Fax. number	E-mail address
1. Angola Nursing Association	1201 Luanda R. da Samba No. 13 Angola	+244 92607447	+244 2 338053	
2. Nurses Association of Botswana (NAB)	PO Box 126 Gaborone Botswana	+267 353 840	+267 353 840	nab@global.bw
3. Réseau Infirmiers Généralistes Accoucheuses Congo (RIGIAC-SIDA)	Bongolo No. 12 Yolo Nord C/Kalamu Democratic Republic of Congo			Rigiacy_rdc@yahoo.fr
4. Lesotho Nurses Association (LNA)	PO Box 473 Maseru Lesotho	+266 31322 700	+266 31322 700	
5. National Association of Nurses of Malawi (NANM)	PO Box 30361 Lilongwe Malawi	+265 1 772 044	+265 773 932	
6. Nursing Association Mauritius	159 Royal Road Beau Bassin Mauritius	+230 464 5850	+230 464 5850	Nur.ass@intnet.mu
7. Associação Nacional dos Enfermeiros de Moçambique (ANEMO)	PO Box 8 Maputo Mozambique	+2581 320828	+2581 320828	
8. Namibia Nursing Association (NNA)	PO Box 3390 Oshakati Namibia	+264 65 231 383	+265 65 231 383	
9. Nurses Association of the Republic of the Seychelles (NARS)	PO Box 52 Victoria, Mahé Seychelles	+248 388 000	+248 373 236	dp@moh.gov.sc
10. Democratic Nursing Organisation of South Africa (DENOSA)	PO Box 1280 Pretoria 0001 South Africa	+27 12 343 2315	+27 12 344 0750	info@denosa.org.za
11. Swaziland Nursing Association (SNA)	PO Box 2031 Manzini Swaziland	+268 505 8070	+268 505 8070	ar18@iafrica.sz
12. Tanzania Registered Nurses Association (TARENA)	PO Box 4357 Dar es Salaam Tanzania	+255 27 266 44308	+255 27 266 44308	jmkaupunda@yahoo.co.uk
13. Zambia Nurses Association (ZNA)	PO Box 50375 Lusaka Zambia	+260 1225 135	+260 1225 135	znana@zamnet.zm
14. Zimbabwe Nursing Association (ZINA)	PO Box 2610 Harare Zimbabwe	+263 4 700.479	+263 4 700 479	zimmurse@mweb.co.zw

The Joint United Nations Programme on HIV/AIDS (UNAIDS) brings together eight UN agencies in a common effort to fight the epidemic: the United Nations Children's Fund (UNICEF), the United Nations Development Programme (UNDP), the United Nations Population Fund (UNFPA), the United Nations International Drug Control Programme (UNDCP), the International Labour Organization (ILO), the United Nations Educational, Scientific and Cultural Organization (UNESCO), the World Health Organization (WHO), and the World Bank.

UNAIDS, as a cosponsored programme, unites the responses to the epidemic of its eight cosponsoring organizations and supplements these efforts with special initiatives. Its purpose is to lead and assist an expansion of the international response to HIV/AIDS on all fronts. UNAIDS works with a broad range of partners—governmental and nongovernmental, business, scientific and lay—to share knowledge, skills and best practices across boundaries.

Produced with environment-friendly materials

## BEST • PRACTICE • COLLECTION

### The UNAIDS Best Practice Collection

- is a series of information materials from UNAIDS that promote learning, share experience and empower people and partners (people living with HIV/AIDS, affected communities, civil society, governments, the private sector and international organizations) engaged in an expanded response to the HIV/AIDS epidemic and its impact;
- provides a voice to those working to combat the epidemic and mitigate its effects;
- provides information about what has worked in specific settings, for the benefit of others facing similar challenges;
- fills a gap in key policy and programmatic areas by providing technical and strategic guidance as well as state-of-the-art knowledge on prevention, care and impact-alleviation in multiple settings;
- aims at stimulating new initiatives in the interest of scaling up the country-level response to the HIV/AIDS epidemic; and
- is a UNAIDS interagency effort in partnership with other organizations and parties.

Find out more about the Best Practice Collection and other UNAIDS publications from [www.unaids.org](http://www.unaids.org). Readers are encouraged to send their comments and suggestions to the UNAIDS Secretariat in care of the Best Practice Manager, UNAIDS, 20 avenue Appia, 1211 Geneva 27, Switzerland.

#### **Where there's a will there's a way**

##### **Nursing and midwifery champions in HIV/AIDS care in Southern Africa**

HIV/AIDS needs champions—and nurses and midwives need recognition—for providing care and support to people living with HIV/AIDS, their families and communities.

This publication describes nursing and midwifery champions in HIV/AIDS care in Southern Africa, who, with singular commitment and resourcefulness, are delivering good-quality care in spite of innumerable obstacles and constraints. They carry a heavy burden, and they know the meaning of the expression, “where there's a will there's a way”.

UNAIDS and the SADC AIDS Network of Nurses and Midwives (SANNAM) celebrate just a few of the many thousands of champions who are on the front lines of care and treatment, many times feeling the sadness, shame and anger of having so little to offer. In describing the work of a few, the intention is to pay tribute to all who are doing a caring, committed job in the face of great odds, and to share the valuable lessons they have learned from experience.

In addition to being of value to nurses and midwives, this report is also aimed at all those with an interest in improving the quality of care and support of people living with HIV/AIDS—especially those responsible for training, managing and supervising nursing and midwifery staff, and policy-makers within health-care services.



Joint United Nations Programme on HIV/AIDS

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