

community
VOICES

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international

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Who we are

ActionAid International's vision is a world without poverty in which every person can exercise their right to a life of dignity. We currently work with nine million people in 40 countries across Africa, Asia, Latin America and the Caribbean to obtain this goal.

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To protect the identities of the people and communities who have taken part in producing 'Voices', the images we have used are for illustrative purposes only and do not depict any person or persons who are HIV positive.

Introduction

ActionAid International is campaigning to ensure the right and access to HIV and AIDS related care for poor and marginalised people, especially women and children.

Care in relation to HIV and AIDS has become an increasingly urgent focus of political attention. But what exactly is meant by "care"? What are people currently receiving? What are their aspirations and dreams? In the face of limited resources, where do they want their governments to place priority?

In the first half of 2004, ActionAid International interviewed a range of HIV-positive people, their families and communities in Bangladesh, India, Kenya, Malawi, Nepal, Nigeria and Vietnam about care. In the following pages, they speak about their hopes, their priorities and the barriers they face in attaining their right to care.

We asked: **If there were no shortage of money and you could have your dreams come true, what would your perfect HIV and AIDS health care look like?**

Over and over again, whether in Africa or Asia, high or low prevalence countries, people stressed the importance of local, affordable, stigma-free care. Some of the elements most frequently mentioned were:

- ARVs and essential drugs available locally and cheaply.
- Sufficient counselling and testing services, based in the community.
- Nutritional support/food supplements.
- Vocational skills training/job opportunities/small business loans/micro-credit.

"A place free from stigma and discrimination, with well equipped medical personnel and stock of drugs."

Edward A Ogenyi, positive man, Nyanya, Abuja, Nigeria

Poor workers and children must be guaranteed access to HIV/AIDS related care when it is needed.



Mark Phillips/ActionAid UK

These same items above recurred frequently in answer to the question: **Given the shortage of government funds, what are your top priorities for health care and other care to tackle HIV and AIDS?** In addition, the following were commonly cited:

- Sufficient trained health workers.
- Provision of condoms.
- Access to HIV information.

"It was during my antenatal clinic in 2001 that I knew my HIV status. It was my first pregnancy. Nobody told me the precaution to take in pregnancy so that I can protect the health of my baby. When I delivered, I went to state house clinic and they told me they cannot give me ARV because I was breastfeeding, instead of telling me to stop breastfeeding so as to protect the life of my baby. Later, a doctor friend advised me to stop breastfeeding and I did. But it was too late. I lost my baby when she was 8 months old."

31-year-old positive woman, Nigeria

- Transport.
- Housing.
- Tackle discrimination & loneliness.

"Discrimination should not be there – we must not allow the infected to be alone."

13-year-old boy, Bangalore, India, who lost his mother to AIDS 10 months earlier and is now living with his elderly grandparents

- Support for families.
- Help with children's education.

"I would like to see my children finish school. All my children have written memory books and are well aware of the HIV status of their parents."

Christina Chimbe, Nkhotakota, Malawi, whose husband Charles is also positive.



Trained healthcare workers like these can provide access to HIV and AIDS information.

Dave Clark/ActionAid UK

Apart from care, what do you think are the most important things that must be done to sort out the HIV and AIDS problem?

A wide range of answers came out, with responsibility from individual level up to national and international level. In addition to the aspects already listed above, the following were the main categories of response:

- **Behavioural/cultural change**
e.g. abstinence, fidelity, use of condoms, avoidance of blood transfusions or sharing of sharp instruments, change of harmful cultural practices such as wife inheritance.
"We should unveil issues that lead to people failing to abstain, being faithful, and using a condom. Then develop ways of addressing these underlying factors that cause these inconsistencies in behaviour."
Group of women of mixed ages, Kasungu village, Central Region, Malawi
- **Intensified HIV awareness campaigns**
e.g. education through all media, communication with rural areas, improvement in literacy levels.
- **Involvement and empowerment of positive people**
e.g. openness about HIV status, positive living, reduction of stigma and discrimination, equal rights for positive people in the workplace, involvement of positive people as counsellors and peer educators.
"People still believe it is only people who are bed-ridden that have AIDS. So the people who are infected and are healthy should take a lead in the campaign."
William Okara, Community Health Worker, Got Agulu, Usigu, Kenya
- **Alleviation of poverty**
e.g. economic empowerment of women, financial independence for youth.
- **Research**
e.g. find a vaccine – and a cure.

It must be noted that the communities, and even some positive people themselves, also reflected prevailing stigma and discrimination in their responses. Some suggestions were punitive and marginalising, e.g. to make testing compulsory; to outlaw bar workers; and so on.

Key lessons about care

A number of clear and consistent lessons emerged during the consultation.



Care should be available to all members of communities, even the poorest.



People in rural areas should have equal access to care.

Lisa Taylor/ActionAid UK

Mark Phillips/ActionAid UK

Care must be affordable to the poorest.

"I don't know much about these drugs, but what I know is that they are expensive and not affordable to a poor person like myself."

Bequiet Meke, Salabeni village, Nchalo, Malawi

"The medicine itself is very expensive, and from the moment it is used must be continuous, so the simplest person can't afford."

Charo M Langai, Ziwa-la-Ngombe, Mombasa, Kenya

"In 2000, my husband got ART which cost 4,000 rupees per month. He developed resistance and needed a different combination which cost 8,000 rupees and towards the end went up to 30,000 rupees a month. He could not afford this so he stopped taking them. Everybody should get medicine and not die like my husband."

33-year-old positive woman, Bangalore, India, whose husband died in December 2003

Care must be delivered close to the users and available throughout all geographical areas within a country.

"My priority would be to have painkillers available locally within walking distance."

Judith Khofi, Sekeni II village, Nchalo, Malawi, who looked after her brother and sister-in-law (both HIV-positive) until their deaths

"Build a hospital that is accessible to us, that is not expensive and with friendly doctors and nurses."

Group of young men, Nassarawa, Nigeria

Women and girls bare the brunt of the HIV and AIDS pandemic.

Liba Taylor/ActionAid UK



Gideon Mendel/Corbis/ActionAid UK

Counselling like this should be carried out with a respect for people's privacy.



Liba Taylor/ActionAid UK

Care must be non discriminatory and available to all.

Care must be confidential and respect people's privacy.

"I did not expect that people who should protect us can talk bad things about us."

Patrick Kalirani, Namichimba, Malawi, whose positive status was disclosed in church by a nurse

"Although there is VCT at the health centre, the issue of confidentiality is still a problem. That is why a mobile VCT centre can be a solution."

Alex Mito, Urima village, Kenya

Care must be non-discriminatory and accountable. It must be a legal right.

"When your family member gets AIDS the hospital sends you home. Nurses at the hospital ignore you when they learn you have AIDS."

Group of women of mixed ages, Kithimu village, Kenya

"My children haven't been tested as the health worker just assumed that they are already infected. When I asked for HIV test for the children the health worker just asked me, 'Since you know that you are HIV-positive, do you think your children can be negative?'"

Edith Ndindi, Minama, Malawi

"The ARVs that come to the centre are not given to those of us who have come out to declare our status, but to those 'BIG' men who bribe their way through and we are left to suffer and scout round for the drugs."

Mr Ali, Makurdi, Benue State, Nigeria

Quality of care should be defined by minimum acceptable standards.

"The government health centre is about 9 km away. It is poorly staffed and most of the time doesn't have drugs in stock."

Group of women from four villages around Nyambi, Malawi

"There was stock-out for two months last year and because I could not afford to buy ARV on my own, all the opportunistic infections came back. The government is trying, but what will 10,000 people being given ARV amount to out of four million who are living with AIDS? Does it mean others should go and die or what?"

Zainab Haruna, positive woman, Nigeria

Nutrition advice and support are crucial components of care.

"At times I feel weak. Even an egg has to be divided. Any other nutritious food we cannot even imagine to have."

35-year-old positive woman with four children, Dhaka, Bangladesh

"Most of us who are infected sometimes are too sick to fend for ourselves. If you are not eating your condition becomes worse and worse."

Patric Odhiambo Aigo, positive man, Got Ramogi, Usigu, Kenya

"The nutrition regime [in the rehabilitation centres] should be drastically improved to maintain health, especially for HIV-positive trainees. Lack of nutrition will result in a decrease in their physical resistance making it easy to catch opportunistic diseases and death will surely come."

Group of mothers of drug users detained in reform centres for up to five years, Go Vap district, Ho Chi Minh City, Vietnam

06 Community voices **ActionAid International**



Food security is vital to any care and treatment programme.



Women should be included in the planning and implementation of HIV and AIDS related healthcare.

Failure to tackle the issues of poverty and food security will undermine any care and treatment programme.

“Without a job I cannot pay the rent. If I cannot pay rent, relatives will not give us shelter, they won't even give us food. I am in a very difficult situation.”

38-year-old positive man, Bangalore, India

“Instead of giving us food directly we should be supported to begin income-generating activities so as to help us support ourselves and our children better. If we are given food daily, we will die the day that food supply will be stopped.”

Raphael Achucha, positive man, Got Ramogi, Usigu, Kenya

Any HIV-related care policy will fail to meet needs unless it has a strong gender analysis and commitment to gender equity.

“The position I hold in the society being a woman hinders every move I want to take. My husband despite knowing about his illness married me. If I had known condom would save me then at least I would try that. The society in which I live has confined me with barbed wire.”

Jhumoor, positive woman, Dhaka, Bangladesh

“You know the pain of an infected woman; if she is poor, you can't imagine her suffering.”

Babita Rana, positive woman, Rauthhat, Nepal

“Involve men more in the campaign against AIDS. Men are very difficult. If a couple comes for testing most men always want to use the wives' results. They want the wives to be tested and take the result of the wife to be what his result is. A way should be found to handle the men.”

Douglas Malowa, Uhwaya village, Nurse in Charge, Got Agulu Health Centre, Kenya

Positive people, including women, must be included in the planning, implementation and evaluation of HIV and AIDS-related health care policy and programming.

“The stakeholders in the field of HIV/AIDS should deal directly with PLWHA, because it is only who wears the shoe that knows where it pinches.”

Zainab Haruna, positive woman, Nigeria

“There are very few health care centres that provide care and support to PLWHA. Now I have made up my mind to be bold enough and fight against stigma and discrimination. I am working as one of the activists and helping other infected women like me.”

26-year-old positive woman, Kathmandu, Nepal

The special needs of women and children must be addressed in all care programmes.



Jenny Mathews/Network/ActionAid UK

Conclusion

For those most severely affected by the epidemic, care in relation to HIV and AIDS goes far beyond the traditional remit of the health sector to include many non-medical issues. Thus, alongside treatment involving ARVs and the provision of medicines to deal with opportunistic infections, care also includes aspects of prevention; voluntary counselling and testing; nutrition; palliative care; and support to families and the wider community, including psycho-social support and building self-esteem. Vitally, care must also be set in the context of poverty eradication.

“Medicines will be an important aspect – but along with that one needs a lot of love and affection, counselling, assurance, good nutrition. There should not be any discrimination. When all these are there, a person who is affected by HIV/AIDS can lead a normal life.”

33-year-old positive woman, Bangalore, India

The impact of proper care and treatment is unmistakable.

“Some of us take the ARV drugs for over one year now and it helps us a lot. With the ARV all the symptoms of HIV virus in us disappeared. And we have been managing the virus without stress. We were all looking tiny but now we look very big and fat. We carry out our normal daily job like any other persons.”

Mixed group of men and women, Karu, Abuja, Nigeria

HIV-positive people, their families and communities are raising their voices to fight for the right to care in its widest sense. It is time for these voices to be heard.

Abbreviations

AIDS – acquired immune deficiency syndrome

ART – antiretroviral therapy

ARV – antiretroviral

HIV – human immunodeficiency virus

PLWHA – person living with HIV/AIDS

VCT – voluntary counselling and testing

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