
Home Based Care

Same Epidemic, New Vision

Mary Crewe

Early on in the HIV/AIDS epidemic in South Africa, we were often reminded as latecomers to the epidemic, we had a time lag which could be used to our advantage. We would be able to stem the seemingly relentless pace with which the epidemic was spreading. We failed in that - for reasons which are well known - apathy, lack of understanding, lack of co-operation between groups and lack of political will.

Today, we are aware that we have to find innovative ways to care for people with AIDS. We are aware that in other countries, home based care programmes have been launched with varying success, in areas differing greatly in terms of resources and rates of infection. Yet again, we are unprepared. We remain ignorant of how such programmes were developed, implemented and sustained. We are at an early stage of prevention programmes development, and much remains at the level of talk. Very little is happening in terms of concrete action or indeed preparation for action. It seems as if we are determined to do nothing while we still have a little bit of time on our side. We seem satisfied to wait until we are faced with people needing care from families and communities, who are largely unprepared for the reality of this epidemic and the rigours of care.

Where Did We Go Wrong?

In part, this is a result of the failure of our education campaigns. Fourteen years on, we are still dealing with people who do not understand the epidemic, its routes of transmission and methods of prevention. We are still faced with large scale denial and a refusal by influential people to add HIV/AIDS to the political agenda. We still wait for a comprehensive and coordinated strategy to deal with HIV/AIDS in South Africa.

When we should be well into the establishment of care facilities, and training of care givers, we are still debating ways in which to get people to come to terms with the epidemic. We are now faced with moving into phase II of this epidemic, while phase I has barely shown any progress or success.

This lack of success in education and prevention programmes should not be a reason to hold back on the provision of home based care training modules, and facilities. From now on, such modules should be an integral part of all AIDS education and prevention campaigns. We cannot afford to make the same mistakes about care, as we did with education.

It is well known that as the HIV epidemic spreads, the majority of people with HIV and AIDS will not be cared for in hospitals or clinics, because of the nature of the illness and the lack of resources to cope with the numbers who will, at one time or another, require treatment and nursing. From this recognition has emerged the emphasis, world wide, on the provision of home based care services as an integral part of AIDS campaigns.

Is Home Based Care Viable?

From the evaluations done by the WHO of a number of home based care programmes, the benefits of home based care may include reduction in pressure on hospital beds, allowing other programmes to continue and develop; strengthening of family support for a person with HIV; reintegration of the patient into the community; preventative education taking place within the immediate family, the extended family and in the wider community; and the reduction of costs.



With the current housing crisis how feasible is it to care for people with AIDS in the home? Photo: Ismail Vawda

While the WHO guidelines on the provision of home based care (see appendix) are concise, moving from abstract recommendations to action can be very difficult. As housing is one of the most serious problems facing disadvantaged people with HIV illness, what is meant by home based care must be decided. For many people finding somewhere to live can be an almost insurmountable problem, and for those with HIV infection these problems are magnified many times. People who are ill often have difficulty in keeping up their income to pay for accommodation, and people with AIDS suffer discrimination, rejection and harassment. It is practically very difficult to provide any sort of care for someone who has no where to live or for whom the only accommodation is over crowded or unsanitary or when the person is regarded as a burden by the rest of the family.

This situation has led many to suggest that we should not talk about home based care, but rather community based care. Although this debate is useful in highlighting the problems of inadequate housing and the lack of community commitment to understanding the epidemic, in the end one will be addressing both home based and community based care. The debates should, therefore, not deflect us from this. There has to be an overlap and connection between the two, and both services need the support of each other.

The Community's Role

The community needs to recognise that collectively, there are ways of dealing with needs arising from the epidemic. One is to get accommodation for people who do not have care at home, and to ensure that such accommodation and treatment offered is as close to a home environment as possible. Another is to organise the collection, storing, hiring or loaning of equipment, which families are likely to need when they have to get involved in home care. Communities should arrange the collection of bed linen, blankets, clothes, soap and cleaning materials, candles and lamps, towels, buckets and food so that they can become a resource centre for the families. This would go some way to resolving problems such as finding medical help for persistent diarrhoea and weight loss; problems in eating, skin problems, bed sores, chest pains; tuberculosis and a variety of other medical conditions; and the problem of material assistance to buy or acquire nutritious food, blankets, soap and basic medications such as soothing cremes.

Through the development of such community projects and services, much of the stress on home care could be alleviated. Likewise in very poor communities, such as squatter areas, it could ensure that the care of people was



**Home based care needs to be linked with comprehensive
PHC programmes. Photo: Ismail Vawda**

a community issue, that available equipment could be shared and that the very real problems of dealing with diarrhoea etc in communities with limited access to water and heating could be addressed through the community structures. Most current information on home based care assumes that certain basic services are available and that there will be adequate support from the health services. This is clearly not the case for many people in South Africa. We need to develop methods of home care in resource deprived areas which, as far as possible, do not compromise the care and comfort of the patient. In areas with inadequate water, sanitation and heating some of the most basic suggestions and advice for the care of people with AIDS will be very difficult to follow. We must find alternatives so that people offering care do not get demoralised when they cannot make the provision which is currently recommended.

In addition to material support, communities can be expected to help with the other needs of affected families such as emotional and spiritual support to cope with disease, impending death and fears of leaving dependents; advice on infection control; removing the fear of discrimination and rejection; financial and material assistance; relief from the extra work load of washing sheets, blankets, clothing and from the nursing of the patient, running the household; emotional and spiritual support.

Team Work

Home care teams, such as have been developed in Zimbabwe, Zambia, Uganda, Zambia and Kenya can operate in conjunction with hospitals, clinics, outpatient services and hospices. The objectives of such teams are to visit people with HIV infection in their homes to assess their physical, psychological, social and spiritual needs and to provide for these needs where possible; to do counselling and education within families and communities, providing personal support and promoting sustained behaviour change through community counselling; to assess the educational impact of AIDS management on people with HIV/AIDS and their families.

Home based care programmes and teams will need to be incorporated into the existing and planned programmes of primary health care (PHC). Planners seeking to establish home based care programmes should utilise existing methods of PHC delivery by utilising primary health care workers such as clinic based nurses and community workers. If such PHC workers are to be effective, they will need to acquire new skills through new programmes of training and be supervised by those responsible for operating the home based care services. Another challenge for health planners in the provision of home based and community care concerns the need for a multi-sectoral approach to the disease. The social consequences of AIDS cannot be adequately addressed through the conventional health care programmes. Alliances need to be formed between the health structures, community based and social welfare organisations, women and youth groups to ensure that the social and spiritual needs of AIDS patients and their families are not neglected.

Clinical and Social Advantages of Home Based Care

AIDS provides us with a unique challenge and opportunity to establish home based care programmes and community programmes which directly involve affected communities. This should lead to a strengthening of PHC. It is crucial that the provision of home and community care be recognised and supported by the national AIDS programme and becomes part of a national strategy. Resources will need to be fought for and diverted from the Department of Health, in order that socially based organisations can meet needs, obtain facilities, pay workers and provide support for volunteers.

Through the development of programmes, we can begin to challenge the conventional roles of members in the household. We can challenge the assumption that women must necessarily take on most of the care. We can train

World Health Organisation (1991): Home Based Care

"a programme that, through regular visits, offers health care services to support the care process in the home environment of the person with HIV infection. Home visits may be the only service provided, or they may be part of an integrated programme which offers the patient and her/his family services in the home, hospital and community.

Home care can mean the provision of holistic care at home including:

- medical and nursing care;
- training of the care giver in the home;
- counselling and social support;
- spiritual or pastoral support;
- material, financial and practical support; and
- referrals.

Consequently it should provide:

- training for family members to cope with the needs of the patient;
- psychosocial, spiritual, practical, financial and material support for the care givers and dependents; and
- the possibility of planning for the future with respect to orphans and other dependents.

Home care:

- allows patients to die at home in familiar surroundings;
- promotes support for the entire family, not just the patient;
- avoids the problem of transporting dead bodies;
- enables the family to understand AIDS better, which has important implications for prevention, and for coping with further AIDS cases in the family;
- promotes community awareness of AIDS prevention, and encourages supportive attitudes within the community;
- identifies families where there will be orphans and other dependents left behind, and facilitates the planning of future support; and
- frees hospital beds and reduces the cost to the health services."

volunteers who will both administer to the needs of the families, but also challenge the traditions and conventions that ultimately hinder AIDS work. We can also use AIDS to give new meaning to the terms community action and community structures.

Mary Crewe is the manager of the Community ATICC, Johannesburg