

**HIV/AIDS and Development:
The Chikankata Experience**

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Acronyms used the text

AIDS	Acquired immune-deficiency Syndrome
CPT	Care and Prevention Team
HBC	Home Based Care
MoH	Ministry of Health
HIV	Human Immunodeficiency Virus
NACP	National AIDS Control Programme
STI	Sexually Transmitted Infection
UNAIDS	United Nations joint Programme on HIV/AIDS
PLWHA	People Living With HIV/AIDS

Introduction

HIV/AIDS is one of the most pressing health problems confronting the world. Africa especially is experiencing the impact of the disease and its multiple affects. HIV/AIDS has exposed the gaps in public health care systems. Some of those gaps existed prior to the early 1980s, others emerged under pressures to reform national economies and social services in the 1980s and 1990s. With HIV/AIDS itself, the international response to create national AIDS control programs, along guidelines laid out by the World Health Organization (WHO), did little to meet the needs of communities attempting to deal with the impact of AIDS. In response to this fast growing epidemic that even permeated the strictest traditional values, many non-governmental organizations (NGOs), community-based organizations and religious organizations joined the effort to try and mitigate the impact of HIV/AIDS and foster prevention.

In Zambia, the Chikankata Health Services, run by the Salvation Army, has developed a response that is community based. This paper discusses the work of the Chikankata Health Services AIDS Programme to foster a community empowering response that is appropriate, affordable, applicable and sustainable to the people it serves. The response has evolved over time and after other approaches were tried. In large part, the Chikankata approach reflects the basic principles long advocated for effective community development: consultation, facilitation, and building on communities' own needs, ideas and multiple resources.

The hospital at Chikankata and other health facilities across Zambia are unable to cope with the demands for services of people infected and affected by HIV/AIDS. While hospital facilities are failing to provide quality care especially due to reduced funding, communities have responded in unique ways to develop and run care, support, and prevention assistance. At least from the early 1990s, community spokespersons and NGOs have argued for national and international programs to support a continuum of prevention and care, this being the only way to achieve advances in both (Campbell, 1994; Osborne). These care programs provide anything from toothpaste, to food, clothing, and shelter. The capacity of the neighborhood is still a big strength in care and prevention of HIV/AIDS. The Chikankata experiences reinforce the community development concept of linkages between families, communities, and social services, such as hospitals and other health care institutions. The approach seems to be the only developmental way that allows families to continue with daily chores and life when a family member is ill and in need of care, as other community members feel for and are involved in the whole care process. The community gets engaged in the care process and this affects behavior and attitudes that lead to prevention.

Zambia's situation

The first HIV/AIDS cases were reported in 1984. At that time the Zambian people did not respond in a helpful way. The response was characterized by scorn, blame, denial and witch hunting. This was basically so because of lack of information about the disease at that time, how HIV was transmitted, and what kind of condition/disease it was etc. This period of stigma and blame continued until in 1987 when the former President of Zambia (Dr. Kenneth Kaunda) made an announcement that his son had died from HIV. This announcement was significant in the sense that Zambians could now discuss the disease more openly than before. However, the pandemic continued to grow during the 1990s, although there are wide variations within provinces. Some surveillance sites in mid-2000 recorded prevalence rates of 25 to 30 percent, although the national rate is estimated at over 19 percent. In 2000, some evidence suggested that behavior change among young people contributed to a decline in HIV prevalence.

Zambia has been hit by the epidemic at a time when the economy has been at low ebb. HIV/AIDS coincided with nearly three decades of economic problems, including low prices for copper, the country's major export, erratic production of food supplies, major layoffs by public and private employers, and a substantial international debt that diverts Zambia foreign exchange earnings to lenders rather than productive imports. Efforts to correct these problems, including with guidance from international lenders, have yielded only limited results. Today, most of Zambia's people have less economic security than twenty years ago.

AIDS adds another downward pressure on both household and national economic conditions. The Ministry of Health (MoH) asserts that the majority of people dying of AIDS are of working age, many breadwinners for their families. A case study carried on Chilanga Cement in Lusaka Province reveals that as a result of HIV infection the man-hours lost due to hospital and funeral attendance is alarming. In 1992/3 Chilanga Cement lost 13,380 employee hours due to sickness and funeral attendance. The number of lost hours doubled in the following year, while 1994/5 saw 43,370 hours lost as a result of sickness and funerals (MoH HIV/AIDS in Zambia, 1999:46).

Generally firms in Zambia have witnessed increased costs for health care, burial fees and recruitment and training. In order to mitigate the negative impact of HIV/AIDS on firms and companies, The Bank of Zambia, Standard Chartered Bank, and many other formal sector businesses in Zambia have responded to HIV/AIDS through in-house prevention programs, corporate matching grants to employee contributions for care, and advocacy through the Business Coalition on HIV/AIDS (Deborah Boswell, 1999: Evaluation Report of the AIDS Management and Training Services Project).

More specifically to Southern Province, where Chikankata is located, is the impact of HIV/AIDS on the local economy and household well-being. Deaths of both young women and men means that less land is cultivated and fewer crops produced and harvested. In turn, this affects incomes and food supplies. Small and medium sized farms that grow maize have difficulty ploughing as much land as in the past. Combined with high fertilizer and transport costs (both outcomes of economic reforms over the last two decades of the 20th century), less maize and other crops are being produced. A 1997 study of rural households in neighboring Monze District found that it was common for women who devoted a lot of time to caring for a family member sick from AIDS to "abandon their planting or harvest because all their time went into care giving" (Waller; Foster, 1996). Low income households not only reduce maize production, but "sell off livestock and other assets in order to pay for traditional and modern medical treatment, transports, and funeral expenses" (Waller; Foster 1996).

The situation of women, including their economic insecurity and high levels of illiteracy increases their risk to HIV infection and compromises the quality of care of those who are sick. It must be emphasized that the care process in this part of the world is mainly underpinned on women (Macwan'gi, Sichone and Kamanga, 1994). This is especially the case in rural Zambia, including the catchment area of Chikankata Health Services, where women are expected to provide care for sick relatives and children, contribute substantially to food production, and supplement household income through market sales and, if necessary, on neighboring farms.

Chikankata Health Services, HIV/AIDS Program

It was against this background of rising HIV/AIDS rates, economic crises, rural vulnerability and need that Chikankata responded. From the beginning, Chikankata approached HIV/AIDS within the context of the national framework of health care: "provide Zambians with equity of access to cost effective, quality health care as close to the family as possible" (MoH/CBOH). In addition, prior interventions in the Chikankata Health Services catchment area had shown a community capacity to cope with difficult problems.

Chikankata is in Mazabuka District, some 125 kilometers from Lusaka, the nation's capital, and 60 kilometers from the district center, Mazabuka. The Salvation Army has had a mission at Chikankata for about sixty years, providing health, education and training services. Like other mission-based health facilities in Zambia, Chikankata operates with grants from the central government and external donations. The hospital serves some 100,000 people, supported by local health centers.

The origin of the HIV/AIDS program was triggered by the diagnosis of a skin condition, *Kaposi Sarcoma*, in a patient in 1986. By the end of that year, 37 more cases of HIV/AIDS had been diagnosed and admitted to the hospital wards. It was clear that a sustainable intervention was needed to help stem the further spread of HIV in the catchment area. If nothing was done, the hospital was going to be overwhelmed by HIV/AIDS and disrupt other hospital functions. In March 1987, an HIV/AIDS Care and Prevention department with minimal number of staff was formed.

At that time an international NGO offered funding to build a hospice that would exclusively care for AIDS patients. The idea to build a hospice was debated by the hospital staff and community members and finally rejected. Lessons from the care of persons with leprosy, which was also a disease that went with stigma and isolation like HIV/AIDS, convinced people that isolation was not appropriate. Also, it was felt that the numbers of patients who would require care would soon overwhelm a hospice. A convincing reason was not offered to care for a small number of people on an indefinite basis while ignoring other cases in need of care. Alternatively, it was felt that existing systems of caring for the sick in the community provided an alternative and it was argued that it was more appropriate and cost effective (Barnett and Blaikie, 1994). Williams summed up the situation surrounding the decision: "The hospice did not take into account the inherent strength of Zambian society, particularly the extended family support network. For generations, Zambian families have cared for their sick at home." (G. Williams, 1990:7)

After careful consideration and consultation, it was agreed that the best way to care for those people living with HIV/AIDS (PLWHA) would be a system that involved the family, neighborhood, community and hospital as key players. This meant that patients were to be cared for in their own home setting. An approach to home based care was formed on three assumptions:

- In rural Zambia, the family is the effective means of supporting PLWHA and of assisting the hospital in the provision of health care and psychological support.
- That as the incidence of HIV infection continued to increase rapidly, decentralization of care would be key to affording those PLWHA with medical, nursing, spiritual, social and psychological support.
- That taking care into the community and neighborhood had in itself an educational effect on both family and community members and therefore contributed to behavior change and prevention of HIV transmission in the long run.

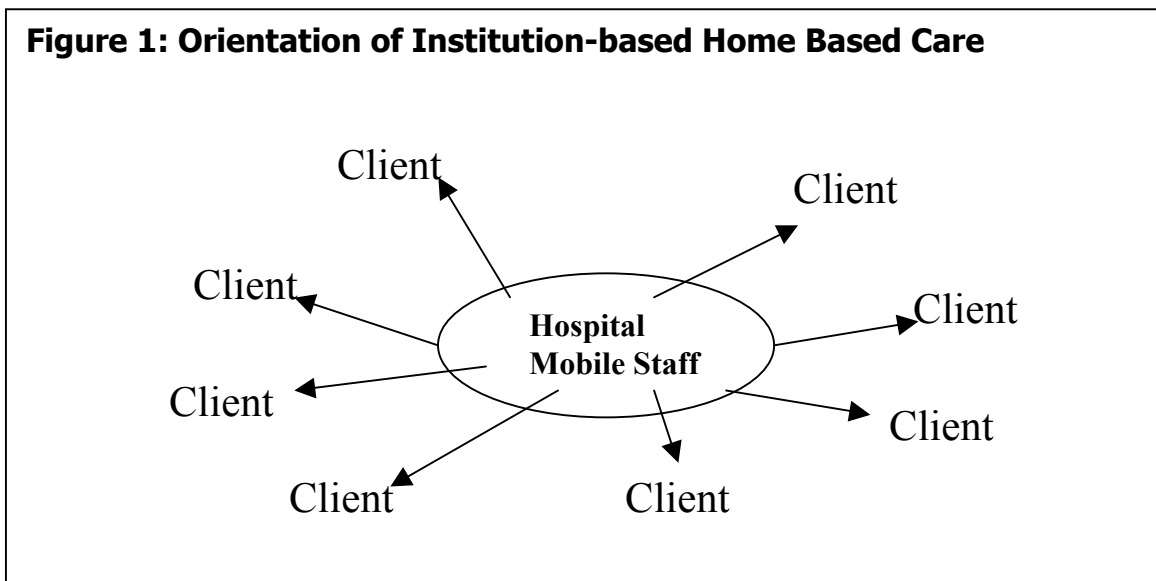
A special ward at the hospital was set up to care for terminally ill PLWHA. The ward also offered a way to improve the organization of patient care as well as help to refine counseling approaches (I. Campbell & G. Williams, 1990:25). On this ward, close relatives were encouraged to participate in the care of their family members. Relatives and close friends learnt practical skills in nursing care with the anticipation that once clients were discharged to their homes caring and support skills would be available through family and community members. PLWHA were themselves given training to allow them to have an active role in providing care to others living with HIV/AIDS. Through this active engagement in care, misconceptions about HIV/AIDS were discussed and clarified, for example that HIV is transmitted through touching or hugging. The active engagement in care manifested itself in love, compassion and *the act of being with*, and rekindled patients' spirits. This resulted in patients living longer. The ward became a big resource in training community members in nursing rudiments for PLWHA.

The Home Based Care

Interaction with communities assumed that family members were available, strong and capable of sharing responsibility. Communities also felt that regular visits from the hospital would supplement the care that they were providing in the home setting. Finally, it was noted that caring for PLWHA at home was economical because it did not cause unnecessary disruptions to family economic life.

In 1987 Chikankata medical and health education staff formed a small mobile team to visit clients and provide medical, nursing, psychological, and spiritual care. Part of this team would visit five to eight clients per day. These visits (three per week) to AIDS patients were within a radius of twenty to thirty kilometers from the hospital. In addition to offering care to patients, the mobile teams conducted contact tracing to reduce chances of the infection being transmitted further and to provide counseling and education within families and communities, to provide personal support and promote sustained

behavior change through community counseling. Home based care (HBC) also provided opportunities for educating family members about HIV/AIDS, and misconceptions about the disease were also clarified. The structure of the home based care approach is illustrated in Figure 1.



The home based care approach of the late 1980s had mixed results. Some of the strengths/achievements of the HBC for the health facility and patients included:

- The reduction in pressure on hospital beds allowed attention to other health care issues.
- Family support for the person with HIV infection was strengthened during the course of illness and also for the person’s dependents after death.
- Costs were reduced especially that most of the expenses did not have a direct benefit to patient care

As an outreach effort to inform and engage the community, the home based care initiative also achieved several positive results. For example:

- Preventive education took place within the immediate family, the extended family, and outwards into the wider community, thereby reducing the stigma associated with the disease and helping families and communities to “recognise the reality of HIV/AIDS, analyse its effects on life... and take action to prevent its spread... and to improve the quality of life of PLWHA...” (Working towards AIDS competent districts in Uganda; Facilitators Manual, October 2001:5 Uganda AIDS Council published in Uganda)
- The patient was not excluded from the community.
- Information on HIV/AIDS was shared widely with community members, thereby clarifying misconceptions about the disease and promoting behavior change.

Local responses to the disease begun to emerge. For example, ritual cleansing of widows—a cultural tradition of sex between a widow and an in-law who assumed responsibility for providing for her and her children following the death of the husband. A process of community counseling (facilitation) to explore problems and identify solutions enabled people to recognize cleansing as one way that HIV was transmitted. Attitudes of young people changed, as is reflected in a song in which they acknowledged the problems of HIV/AIDS and their resolve to adopt positive behaviors.

If we do not believe that it is possible ... who will
 If we do not trust in showing love ... who will
 If we do not try learn from mistakes ... who will
 If we do not change the tides ... who will
 If we do not say what is important ... who will
 If we do not succeed to have ideas for a better future ... who will

If we do not believe anymore it is possible ... who will
If we do not come with a plan ... who will
If we do not endure that there is a future for the children of tomorrow ... who will.

Problems with Institution-based Home Based Care

Over a period of about three years, however, it became apparent that sustaining home-based care from the hospital had several limitations. Mobile care teams were expensive, involving increasing costs for vehicles and fuel, drugs, and personnel as the client load increased. The cost of running HBC was not commensurate to the time and actual care given to clients. In 1990 alone, the AIDS Programme traveled 38,760 kilometers to carry out 998 visits to 292 patients and traced 107 contacts for HIV infected patients (I. Campbell & G. Williams, 1990:17)

Contrary to what was intended, the outreach care team approach encouraged dependency on outside donors and community dependency on the health institution. We observed that at times clients had been totally neglected by immediate families, denied a clean environment and food because the client "ceased" to belong to the family and had become hospital client. Communities at times, also, abdicated their responsibilities toward patients. Access to good food and care became more scarce as the illness progressed. Burnout and the drop-out of volunteers increased due to the large number of clients. Due to accumulated grief, communities were exhibiting forms of "grief fatigue".

It was felt by Chikankata staff and community volunteers that while HBC helped in a number of ways, it also had gaps that needed filling to make the model more responsive to the needs of communities and clients. At best, it was concluded, institutions can only do home visits and not home based care.

The Care and Prevention Team

A change in approach to HIV/AIDS care and prevention emerged from changes in the underlying concept. A process of dialogue and facilitation with communities emerged. The process recognized that "community" is build and sustained as people "transcend their individual difference so as to work together toward their common goal." All community members are acknowledged as "thinking creative people with the capacity for action." Communities have problem-solving skills to identify issues and their causes and often have some of the basic resources to apply practical solutions to those problems (Mutonyi, Community Development).

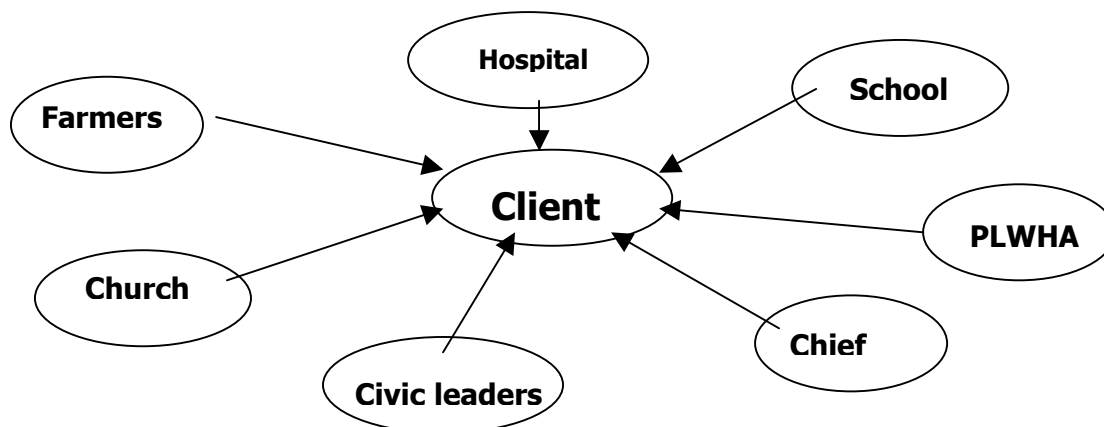
A new approach was needed to meet the challenges brought about by HIV/AIDS, such as an increased number of deaths, eroded extended family support systems, an increased number of AIDS patients with no practical means of support and, to an extent, prevailing attitudes that hindered adequate care and support. By the mid-1990s many families had been destabilized by HIV/AIDS, leaving no one to provide care. It was apparent that new ways of working and revitalizing care and coping mechanisms within households and neighborhoods had to be found.

Chikankata staff realized the risks involved: a slower pace of action than if they themselves led responses; the building of mutual commitment; the confirmation that a base of community care existed and could be mobilized; and the potential for HIV/AIDS prevention and care to lose its focus if subsumed under broader issues of concern to communities.

The new initiative was to draw communities into active engagement in care, build community capacity through training of community members, and widen the overall response to HIV/AIDS. Through this process the understanding of resource also widened to include money, time, materials, human skills, equipment (in village set up this could include ox driven carts to bring patients to hospital), methods – the way that communities come up with ways of responding to stressing situations. Yet, some of the first meetings with communities to discuss the approach met with resistance. Government and the hospital, not community members, were said to be responsible for care of sick people. Subsequent meetings began to bring changes: an acknowledgement that HIV/AIDS was a major problem; that ideas existed to begin to deal with care and prevention; that resources—organizations, time, equipment, and skills—could be applied to aspects of the problem.

Through discussions with community members, it was mutually realized that the hospital/institution is just one of the many support pillars available to the community. Communities were encouraged (and facilitation was provided) to identify other support pillars that could be relied on to provide care and support to people living with HIV/AIDS. Eventually, a network of support mechanisms was identified by and for community members, as illustrated in Figure 2.

Figure 2: Pillars of Support for People and Families living with HIV/AIDS



Each pillar provides its own comparative advantages to render support and care. In many instances, other support pillars were identified and involved, such as government authorities. The network of community support had to receive and coordinate resources, human and material. Most of that was handled within communities as existing and new leaders emerged. Chikankata provided training and support for community counselors, and helped to coordinate activities and mitigate the stress on any one pillar of support. One of the trainers for the volunteers described the system as follows:

Communities have recognized that the hospital will still play a role in the care network but not at a level it used to in the past. What these communities are calling care and prevention teams that will surround a patient with pillars of care. The essence of this is that if one pillar of support is over stretched (like the extended family system has adversely been affected), patients will know that there are other pillars to provide them with care and support (Siame, 1995).

Putting Community Development into Practice

People living with HIV/AIDS, their family members and people in the surrounding community all took part in identifying the particular needs of sick individuals. Needs ranged from the basics of food and water, to transportation, medicine and psychosocial counseling and spiritual guidance. Often, individual and family needs were very extensive. It was necessary to explore these in-depth, recognize which ones could be handled locally, and to prioritize them.

Needs identification was followed by the identification of the people or groups of people best qualified to provide the services. In most cases, the people or groups of people identified include businessmen, teachers, farmers, medical staff, the family, friends, school children, individual rich people, church members, professionals in specific areas, and government organs and NGOs. Again, people or groups are matched to meet specific needs, although the most important criteria is having a sympathetic heart to the patient and the problem or task at hand.

Taken together, the service providers formed what is called a Care and Prevention Team (CPT). All the providers know who else is providing what kind of assistance. It is possible to have many CPTs within one locality and small CPTs can link to form a bigger CPT, creating a network of caregivers who have a specific contribution to make to the patient, problem or task.

As teams were being formed, up to twenty people could be involved in identifying needs, resources, and actions. Because money was usually in short supply, the team approach stressed the wealth of other resources that existed locally. At these initial meetings an animator or influential person who could spearhead linking up all these community cadres into a strong CPT was nominated. A

management structure to guide and coordinate the team was outlined. In some instances, an individual with skills to manage community projects was selected and in other cases, a management committee was developed.

Although care and support for PLWHA was at the center of the team approach, the CPTs sought ways to allow the development issues to be discussed and to reach other community members. Consider training CPT members in community development principles and project management.

The CPTs are essential parts of a broader approach to HIV/AIDS and development. Their role is to facilitate the identification of pillars of support and to include in the process groups of people who have the ability to offer support but who have, in most cases, been ignored in most HIV/AIDS development responses. The emphasis and priority in CPT formation is the identification of community individuals and groups of people who from their own resources can provide for needs of patients voluntarily.

By early 2001, there over 23 Care and Prevention Teams in the catchment area surrounding Chikankata. In addition, the concept and practice has been shared through training seminars with many organizations within Zambia, elsewhere in Africa, and in countries on other continents. There is living testimony of the Care and Prevention Teams in Embu and Molo districts in Kenya, in Kwazulu/Natal Province of South Africa, in Mbarara and Kampala, Uganda, and in several other southern Africa countries. In addition, Chikankata provides technical assistance and training in its approaches for application by other organizations.

The Value of a Community Development Approach to HIV/AIDS

In the context of the growing impact of HIV/AIDS on households and communities, the CPT strategy offers direct support from within communities, not from an imposed short-term project. While Chikankata Health Services offers funding, training, and medical care, its role is recognized as but one pillar among many that exists to aid PLWHA and their families. Chikankata has made a conscious decision not to be at the center of the program. The decentralization of home care is possible to the extent that community members are willing and able to provide sustainable support to those infected and affected by HIV/AIDS. This is possible if institutions are willing to delegate and work with communities (International AIDS Alliance, 2000).

Sustained care systems within the community can function even in the absence of hospital personnel. Unlike Chikankata's initial experience with mobile hospital teams contributing to home-based care, with the CPT community members take more active roles so that in the absence of hospital staff clients continue to receive care. Hospital personnel would visit once per month but communities do it more often than hospital teams that do not reside in those areas. In this way neglect of clients is minimized.

Community resource mobilization is central to fostering meaningful community participation in development. While communities may be poor in terms of money, they have other resources that could be used to care for PLWHA. For instance, communities may have cows that can provide milk for clients, gardens from which vegetables can be supplied, ox-carts that can provide transport to hospital when a client needs hospital attention, to mention but a few examples of viable community resources. This mobilization is only possible when communities come together and identify problems and solutions like is happening with the CPT. This arrangement negates the status of communities being passive recipients of outside help and prescriptions. We have also noted that once recognition of community resources is ignored, community capacity and initiative is crippled. With this meaningful participation, an environment is created were communities would freely make decisions in terms of resources mobilization with the hospital working as a partner and not donor. This is especially important as communities identify other issues of central concern to their well being, including hunger, a lack of clean water and firewood, and livestock diseases.

Care and Prevention Teams provide a forum for linking up of all those providing care and support and networking of trained community cadres, influential people as well as people of sex, age, race and religion. The teams are mechanisms for organizing, advocating, and mobilizing to address a variety of issues.

Some Successes of CPTs

As an evolving process, the Care and Prevention Team approach is constantly subject to change. Successes, too, evolve, over time, not always evident at first, but emerging as communities work to solve problems. Among the “successes” that have been noted are:

- The CPT approach fosters and encourages communities to provide care and talk about HIV/AIDS. Through the CPTs, community members arrange meetings where they talk about HIV/AIDS prevention and care. Also, through community counseling HIV/AIDS as an epidemic and how it is affecting communities/individuals is discussed without condemnation or accusations against others.
- Communities that do not have a CPT are requesting those with CPTs to help them initiate CPTs in their areas. This is happening among communities. Successful CPTs are therefore positive triggers for community development.
- The stigma of surrounding HIV/AIDS and other chronic illnesses, such as TB and epilepsy is diminished. Communities have looked at HIV/AIDS as one of a number of chronic illnesses that can benefit from social support systems. This inclusiveness in looking at care has helped diminish the stigma associated with HIV/AIDS.
- The cost in time and transport for PLWHA and their families is reduced. Also, family members are freed to attend to other activities, thereby sustaining the household economic well-being.
- The number of carers per client has more than doubled since the end of the mobile team approach. The number of carers per client has increased from 5 per client in 1992 to 12 by the end of 1997.
- Community dependence on hospital resources has reduced, as communities first look to what they can provide before seeking outside help. New relationships have dawned on hospital teams and communities such as working as partners and not supervisors/donors. From the health providers side, this new way of working has broadened our professional perspectives. For example as an AIDS Programme we looked at HIV/AIDS while communities looked at people with chronic illnesses, we looked at helping orphans but communities sought to help all children in need.

The issue of children orphaned by HIV/AIDS is one of concern to many communities. For example, five communities within the Chikankata area have a combined population of 18,791. As of December 2001 these communities had a total of 4,677 orphans. Of this number, 1,806 were registered as orphans or vulnerable children. Some of the orphans have come from relatives who died after taking in the children themselves. Communities have mobilized themselves to provide shelter, education, health, food, and other needs for orphaned children and other children in need.

These successes stimulate new thinking and new questions. For example:

- How can communities identify triggers for development? Also understanding what is it that propels communities to excel and go forward?
- How do we help change mentality of communities from ‘crippling dependence’ to ‘liberating partnership’ in development? What do communities have and how can they use what they have to go forward?
- How do we facilitate the creation of an enabling environment that builds the capacity and fosters working as teams?

Conclusion

Communities have capacity to respond to HIV/AIDS in spite of the overwhelming number of HIV/AIDS infections at present. Externally supported programs are needed that seek to alleviate the suffering of the orphans, vulnerable children, and PLWHA. However, what should not be ignored is the inherent capacity to care that exists in the neighborhood and communities. Care programs should seek to create a presence of “being present with” clients to bring about hope, healing and wholeness. This arises from a respect for and appreciation of the internal strengths and skills of communities to identify and address a variety of problems. As seen from the Chikankata situation, it is this active engagement in care manifested in oneness with communities that has motivated communities to embrace concepts of care and prevention with passion. The community counseling process allows

for openness, flexibility and respect for comparative advantages. The structure of the care and prevention teams is a unique tool with which to foster care and prevention and development in the context of AIDS prevention.

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