

ORIGINAL ARTICLES

**THE INFLUENCE OF HIV/AIDS ON COMMUNITY-BASED
REHABILITATION IN DAR ES SALAAM, TANZANIA**

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ABSTRACT

Community-Based Rehabilitation (CBR) is the method of choice for delivering services for people living with disabilities in many countries. HIV/AIDS is changing the daily lives of many women by adding to their responsibilities. How realistically can such women participate actively in community development activities like CBR? This paper examines the impact of HIV/AIDS on CBR in Dar es Salaam, Tanzania. Observational sessions and individual interviews were conducted with caregivers of children with disabilities, CBR workers and managers over a three month period. Among the findings was a significant decrease in CBR activities in families affected by HIV/AIDS. This change in family priorities was due to better knowledge of acute diseases and increased stigma of HIV/AIDS in comparison to disability. Older CBR workers were more likely to incorporate elements of HIV/AIDS care with CBR, while younger CBR workers were more likely to avoid HIV/AIDS support. The ability of CBR workers to adapt their working habits to an environment with high HIV/AIDS prevalence is linked to their sense of skill competence and their knowledge/beliefs about risk of infection. Further integration of CBR work with general health development initiatives may improve this situation.

INTRODUCTION

Community-Based Rehabilitation (CBR) is the method of choice for delivering services for people living with disabilities in many African countries. However, these countries are currently facing the major crisis of HIV/AIDS. While the international scientific community has started to look at the impact that HIV/AIDS represents for many areas of development (e.g. education, health care, economy), little has yet been done to explore its impact on the

field of rehabilitation. This paper examines the impact of HIV/AIDS on CBR in Dar es Salaam, Tanzania.

LITERATURE REVIEW

Disability in Tanzania

The necessary programs for people living with disabilities in Tanzania include prevention, treatment of impairments, rehabilitation approaches and referral components. It is estimated, however, that less than 5% of disabled people in Tanzania receive rehabilitation services (1). These services have been organized and maintained mainly through internationally funded initiatives and Non Governmental Organizations (NGO). The country has adopted CBR as a national strategy to target disability issues, but few concrete actions have been taken because of a lack of specific programs and trained staff (1).

The initial concept of CBR has evolved over the years from a focus on restoring function to a holistic approach, considering the environmental factors that influence disability (2). Through a community development approach, people create partnerships and contribute to the creation of a more inclusive environment for those with disabilities (3).

Many internationally initiated CBR projects in developing countries have failed to be self-sustaining (4). The main challenges in CBR implementation and long-term survival are: a rapid turnover of volunteers (or workers); difficulties in the mobilization of local resources; lack of technical and professional support; lack of ownership of the projects by the communities where they are implemented (often secondary to a “top-down” implementation (5)); and poor participation of the local authorities (6).

Poverty, particularly in Africa, also constitutes a considerable barrier to community participation in CBR. Resources are scarce everywhere and it is understandable that people are concerned about their own needs and may not be disposed “to meet the needs of the minority group such as disabled persons” (7).

HIV/AIDS

The HIV/AIDS epidemic is taking dramatic proportions in sub-Saharan Africa. The situation there is particularly disturbing, with more than 10% of the adult population infected by the

virus in 12 countries (8). The number of people living with HIV/AIDS in Tanzania was estimated at 1,500,000 at the end of 2001; of these, most were adults, constituting 7.8% of the adult (15-49 years old) population (9).

While most of the research effort on HIV/AIDS is directed towards medically related aspects, such as prevention and treatment, there are some reports on the economic effect of the disease and on the social consequences of the epidemic (10, 11). The impact of HIV/AIDS on the education system, reflected by the loss of teachers and students, is already the subject of some investigation (12). However, the consequences of the HIV/AIDS epidemic on community based rehabilitation programs are not well documented, although in that context, these two issues represent many commonalities due to psychological, gender, and poverty factors.

In a study about HIV/AIDS related stigma in Uganda, the association of the disease with sinful behaviors, or the transgressions of cultural taboos, were common (13). In particular, beliefs about witchcraft and curses were important contributors to the stigmatization of people affected by AIDS and their family members.

The HIV/AIDS epidemic has a particularly important impact on women due to the added workload of sick family members (14). Women in Africa are traditionally the main family caregivers and are responsible for most of the household chores and related activities (fetching firewood and water, cooking, gardening). They have to take care of more children (due to the high number of orphans), care for sick people in advanced stages of AIDS, take more responsibilities for earning income, while often being themselves infected by the virus. This pattern is also true in Community Based Rehabilitation programs where more women volunteer than men (15, 16). HIV/AIDS is changing the daily lives of many women by adding to their responsibilities. How realistically can such women participate actively in community development activities like CBR?

METHODOLOGY

Setting

The study was conducted within the “Comprehensive Community-Based Rehabilitation, Tanzania (CCBRT)” organisation. CCBRT started its activities in 1994 as a small CBR

project, but then began operating a disability hospital, offering both hospital and mobile clinic services.

The CBR program was managed by a coordinator, reporting to the director and was assisted in his work by two supervising physiotherapists. Together, the coordinator and physiotherapists oversaw the work of 14 Community Rehabilitation Workers (CRW) workers, dealt with issues surrounding daily management of CBR work, such as working schedules and leaves, and oriented the development of the program.

CCBRT subsequently started an HIV/AIDS initiative, recognising the urgency of taking action to contend with the epidemic's impact. The initiative offered a wide range of services to people living with HIV/AIDS including: voluntary counselling and testing; medical counselling and treatment; home based care; legal aid; community based orphans program; and a school education program. These services were provided only to people living in Dar es Salaam.

Study sample

The study participants were both men and women currently active in providing or receiving CBR services. Particular attention was given to involving as many men as women in the study. However, very few men took part in the study because the CRWs and family caregivers of persons with disabilities were mostly women (4 men, 19 women).

The people interviewed in the families were all women and the main caregivers of a disabled child. These were the mothers or grandmothers of disabled children and were in direct contact with the CBR project. The CRWs were all currently working in the CBR program and had been involved for between 1 and 8 years. The managers in the study were the persons in charge of supervising the work of the CRWs, providing training, and developing the program. Two managers were in direct contact with the families, through field supervision of the CRWs.

Data Collection

Ten organised observational sessions took place in the first month of the study. The daily activities of CBR workers, their use of time, and the perceived direct and indirect impact of

HIV/AIDS on the CBR program, were the focus of the observations.

Individual interviews were then conducted with all study participants to get a deeper understanding and descriptions of their experiences. Individual interviews consisted of open-ended, non-leading questions and lasted between 30 and 45 minutes.

Data Analysis

The data consisted of interview transcripts, observation notes and fieldnotes. A content analysis process was used to identify the main ideas, recurring themes and relationships between concepts which were then used to create an explanation of the HIV/AIDS - CBR phenomenon (17).

RESULTS

The environment of HIV/AIDS in Dar es Salaam

As in most African urban cities, people come to Dar es Salaam in search of employment, as a way of getting out of the poverty and difficult living conditions in the villages. However, poverty and poor living conditions are important problems in Dar es Salaam, and, in many situations, social support is non-existent. A typical story includes the following:

Bibi¹ Samuel is sitting on the floor of her little house. It is very small and has 2 beds and a cooking area. She is the main provider of the family: her husband is not around: he is not assisting the family in any way. Bibi Samuel has had 4 children. One of them died some years ago. The husband of her daughter also died and left her daughter and grandson alone with no resources; they had to come back and live with her. Her grandson Samuel, 8 years old, is disabled. He can't stand, sit or walk. She has to feed, dress and clean him every day. His mother had to leave the house and go away to work and try to earn some money, so Bibi Samuel is the one responsible for the care of Samuel.

A few months ago, the sister of Bibi Samuel came to live with her. She was sick with AIDS and had nowhere else to go. Bibi Samuel felt she had the

¹ Grandmother (a pseudonym is used)

responsibility to take care of her sister. It was difficult for her to find the time to do all the required activities in the day. The CBR worker, Maria, came to visit Bibi Samuel every week to advise her on what to do with Samuel. At the same time, Maria noticed her sister who was sick and talked about the HIV/AIDS home-based care program. She arranged for the HIV/AIDS workers to come and give her advice and support. But still, it was not possible to do the exercises with Samuel the way it was before. Bibi Samuel had to care for people at home, work for money, and after her sister died, she had to organize and pay for the funeral...

Coping in families with disabilities and HIV/AIDS

The daily roles and responsibilities of women are changing. In addition to caring for people with disabilities, the caregivers have to pursue their regular home activities and earn money to meet added living costs. When the caregiver is affected by HIV/AIDS, these other responsibilities can be difficult to meet. The support the families receive from the CBR program takes many forms including: receiving information; getting access to services (for disability and AIDS); and getting direct support in the form of money or food.

Care-giving Roles

Tasks related to rehabilitation of a disabled child are seen as distinct responsibilities of the women in the household. These responsibilities include being available for meeting with the CRWs when they visited and providing regular skill training for the child. The latter aspect of care seemed to be often neglected by the caregivers due to caring for a sick person in the home. One mother explained why she was not able to do exercises consistently with her disabled child:

After having his meals I do his exercises. You can see that his body is now not stretching because it's been a long time since I did exercises with him. I had no time to do exercises for him, because I was the only one to take care of my dying son.

Another important parental role for women is to take care of orphans. This is frequently the case when the caregiver is a grandmother. HIV/AIDS, in addition to disability, has led some families to make difficult decisions about whom they should prioritize in the family. It has also brought an added financial burden, lack of space, and lack of food. Overall, because there are more responsibilities and more tasks to do in a day, caregivers have less time for the care and rehabilitation of the child with a disability. When the caregiver of the child is also sick with AIDS, the situation is even more difficult:

Mama Lydia is sitting on the floor of her small room. It is about 9 feet square and there is 1 bed, 2 kerosene stoves, a few chairs, a bed and some dishes. She lives there alone with her child. The child is about 2 years old and has cerebral palsy. (...) While we are talking, the mother is preparing a meal for her disabled daughter. She only has water and flour. She pours a little bit of flour in boiling water, and then adds a pinch of salt because she doesn't have enough money to buy sugar. That is the only food she has to feed her daughter. Lydia is crying and coughing a lot (...). The mother explains that she is completely abandoned, not only by her husband, but also by her own family. When I ask why it is like that, she says it is maybe because she has a "bad life" is not married and has a child on her own. When she started to be very sick last July, she went back to her mother's home to get some assistance. When she realized she was not getting any help, she came back alone with her child to her little room in Dar es Salaam (...). She went for HIV testing² last week, and she is very scared of the result. She says she is thinking of taking poison to kill herself if the result is positive (...). When I ask her if she has a question or something to add, she says: "If I continue to be sick like that, and because I am so alone, without support or help, what will happen with my child?"

Excerpt from fieldnotes, November 8th 2002.

² The result of the test was found to be positive

Urgency and Knowledge of HIV/AIDS

Most caregivers who have to choose between providing care to a person living with AIDS or a child with a disability, consider AIDS as a more serious problem and give more care and attention to that person. Caregivers have the perception that the child with a disability has a condition that is not “changing” and that the disability will still be much the same, even if they neglect the exercises. However, the person with AIDS requires more care, because of the sudden onset of opportunistic diseases that are considered serious and life threatening:

And in most cases, I was taking more care of that patient³ than the disabled child because I was thinking that the sick one was more serious than the disabled.

Caregivers' level of knowledge also contributed to setting priorities. They generally seemed to have a better understanding of what should be done with someone who is sick, as compared to someone with a disability. They will bring the person with AIDS to see a doctor or a traditional healer, and buy the required medicine if they can afford it. In contrast, they have less knowledge about the need for making the disabled child more independent, investing in special equipment, or arranging corrective surgery.

Stigma of HIV/AIDS

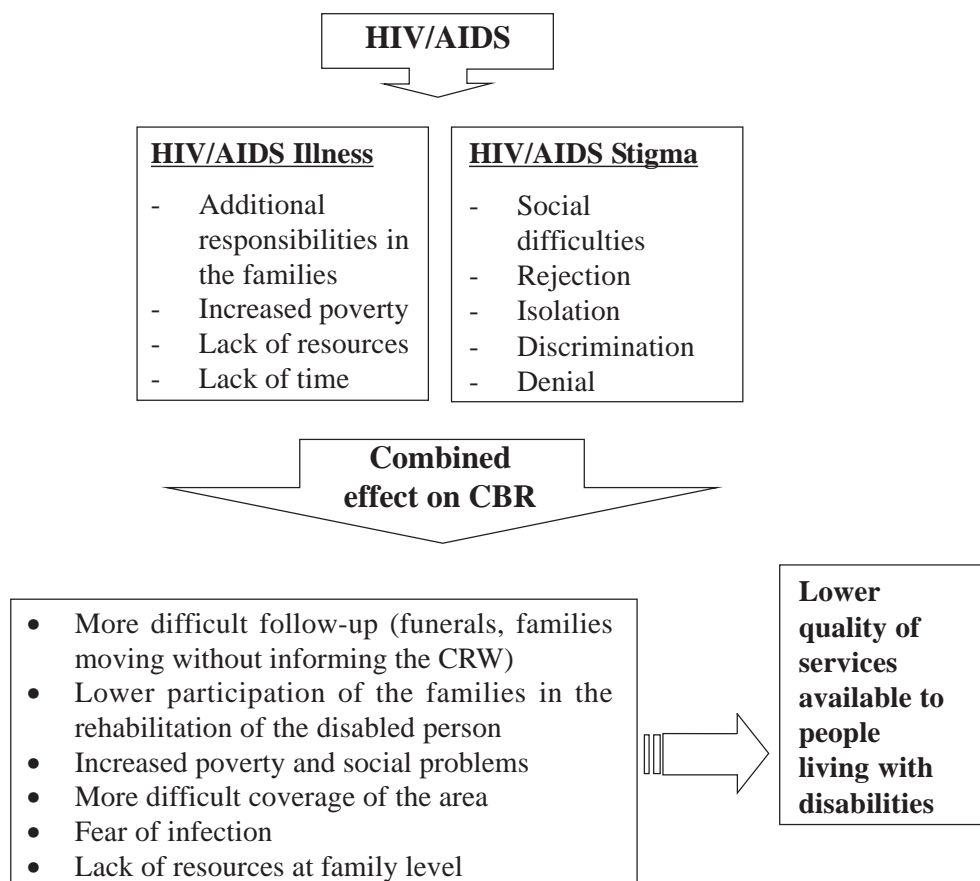
To be able to respond effectively to the issues that AIDS brings into CBR work, the problematic of AIDS in the community needs to be recognised. However, there is still resistance to talk about HIV/AIDS and to acknowledging its presence in Tanzania. People fear discrimination if they are known to be affected in any way by HIV/AIDS.

Sickness from AIDS-related illnesses is usually not confirmed by HIV testing, so it is easy for people to attribute their sickness to causes other than AIDS and to avoid talking about it. When HIV status is known, family members are scared to reveal it because of the stigma associated with the disease, and the negative social consequences and discrimination it may bring to them or their families. Thus, AIDS is known to be in communities, but most people prefer to believe it is not affecting them directly. Families do not tell the CRWs that they

³ Referring to the person living with AIDS

have fewer resources and more difficulties in caring for their disabled child because of being sick with AIDS, or of having an added burden of caring for more people (orphans or a sick relative). The CRWs do not report their field difficulties or having come across a person living with AIDS to the CBR coordinator because they are not sure if it is their responsibility or they simply choose to ignore it. Consequently, the CBR management is not fully aware of the HIV/AIDS realities in the community and is not able to take appropriate measures to assist and support their workers. A model for understanding the effects of HIV/AIDS illness and stigma is illustrated in Figure 1.

Figure 1. The effect of HIV/AIDS and stigma on CBR



Process of health-decision making

To better understand the implications for CBR, it is essential to understand the distinction people make between disability and HIV/AIDS. This understanding can be applied to the decision-making process when it comes to the allocation of limited family resources.

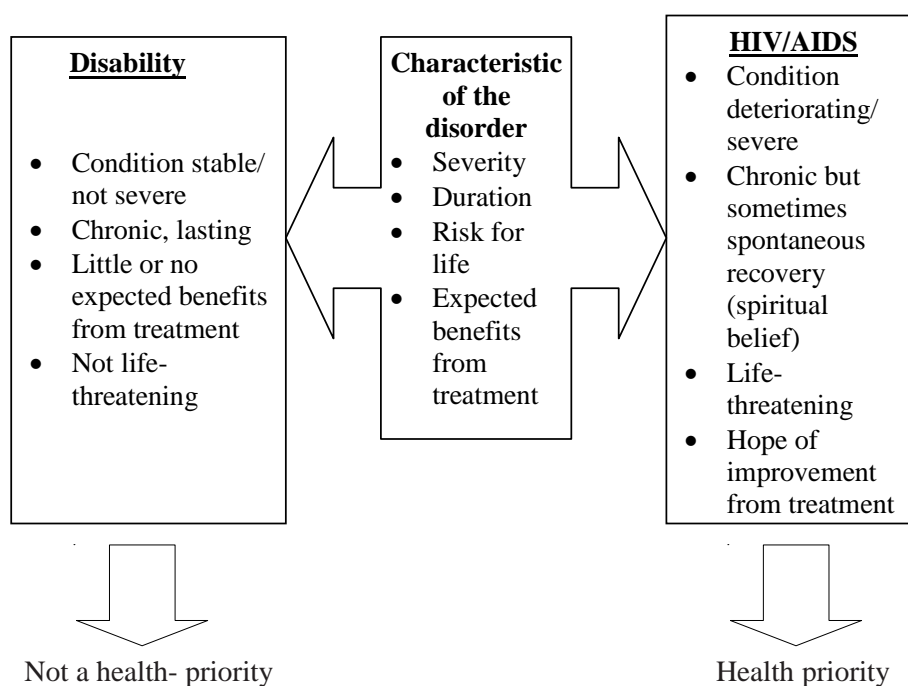
Caregivers of disabled children and CRWs often refer to disability as something that does not change much over time and is not life threatening. Unlike other health-related conditions, disability does not mean rapid deterioration, even without specialized care and intervention. Disability is perceived as a chronic condition, but not an emergency, and a disabled person can remain unattended for some time without consequences. Families who receive attention from the CBR program have the impression that the changes in the life of their disabled child were minor and even imperceptible to the layperson, despite the fact that families had provided the child with special care and attention for a prolonged period of time. Their overall impression is that disability does not change much with or without treatment. Families do not know what to expect from on-going rehabilitation services and have little expectation of seeing improvements. In comparison to other acute health conditions (that might involve recovery), the slow progress of the rehabilitation process discourages the caregiver and eventually diminishes the efforts she makes in trying to make the disabled child more independent. Collaboration of the caregivers with the CRWs on rehabilitation goals becomes increasingly difficult, but in the context of AIDS, the caregiver is already drained because of other responsibilities. Some families continue to request CBR services because of the expectation of other tangible benefits, other than rehabilitation and advice for their disabled child.

The perception of health problems due to HIV/AIDS is quite different than the perception of disability. Usually people do not refer to the health problems as AIDS itself, because of the strong stigma associated with the disease, or because they just do not suspect AIDS. Instead, they notice an ongoing, recurring illness in a family member. The condition is very often acute, judged severe and life threatening by the family, and requires help and support from traditional healers or modern medicine, or both, according to the beliefs associated with the specific symptoms. Families hope that the situation will improve, that things will come back to normal, and that the illness can be cured. Even though people know that AIDS and the severe opportunistic conditions that come with it can all lead to death, they still

believe that there is a possibility to improve and recover. This belief is strongly linked to their knowledge of health and the tendency to attribute a supernatural origin to diseases. Thus, there is always a possibility for improvement from a life-threatening condition, which justifies the provision of special care.

Other studies have shown that health-seeking behaviours in developing countries are influenced by several factors including: the characteristics of the people; their perception and the characteristics of the disorder; and the characteristics of the health services available (18). When comparing Dar es Salaam families' reactions to disability and to HIV/AIDS, the main difference appears to lie in the nature of the condition and the expectation for improvement or deterioration. If there are some expected benefits from treatment, action is more likely to be taken. Thus, in most families, more time and resources are devoted to medical treatment of AIDS, leaving the disabled child with comparatively less attention. These decision-making processes are illustrated in Figure 2.

Figure 2. Decision-making at family level: Disability vs. HIV/AIDS



Community Rehabilitation Workers and CBR work

Maria starts her day at 8h00 every morning. She has planned to visit about 6 families in her day. The first visit is to Mama Lydia⁴. It is a very difficult situation and she knows that she will probably not be able to do anything with the disabled child because there will be other more important problems. Last week, Maria found Mama Lydia very sick in her bed. The child was on the floor crying alone and nobody was there to help. The neighbours are not assisting her. Only once, they went to tell the mother of Mama Lydia that her daughter was sick, but the mother never came. So last week, Maria had to use her own money to buy some medicines for Mama Lydia. She then reported the situation to the CBR office, because she felt that more help was needed.*

So this morning when she reaches the house of Mama Lydia, she finds her a little bit better, trying to cook some porridge for her daughter. But still, she is very weak and the child is crying and has not yet eaten. The child is also coughing and Maria thinks he is also sick. She knows the mother has been tested for HIV and even if the result is not yet known, she suspects it will be positive. Maria is worried that maybe she will get herself infected if she touches the child or the mother, but she has no choice, she can't just avoid the child because it would make the mother feel bad. She will try to come another time this week to check on her, as asked by the CBR office. More help will maybe be offered.

*Excerpt from fieldnotes and interview with *Maria (name changed)*

Community rehabilitation workers in Dar es Salaam are learning to work in a changing environment. It is becoming increasingly difficult for the CRWs to concentrate their efforts exclusively on disability issues. More and more people are sick, or die, because of AIDS and this affects them and the families with whom they work. A CRW explains:

⁴ Mama Lydia's name has been changed

CBR deals with rehabilitating disabled children, but you find that the issue of HIV has come into CBR work. The changes we experience are that we find ourselves doing one, two or three jobs at one time. We visit families where there is a disabled child and at the same time, someone suffering from AIDS.

Commonly, the CRWs find children who are not receiving basic care, such as being dressed, fed, and cleaned. Before the CRWs can start doing rehabilitation interventions, they may have to provide such basic care-giving. This takes the attention of the CRWs away from the original purpose of their visit, and reduces the time spent on giving advice to the families on rehabilitation for the child. When the family financial situation is critical, a supervisor (physiotherapist) is sent to evaluate the condition of the family and decide if financial assistance should be offered.

CRWs are asked about the availability of antiretroviral drugs and the treatment of opportunistic diseases. Some CRWs educate people about the means of transmission of HIV and how to prevent infection. However, the level of knowledge about the services available outside the CBR program vary widely among the CRWs. Most CRWs think that people living with AIDS need assistance from other organizations such as the home-based care HIV/AIDS program of CCBRT. However, some CRWs are fully involved in providing care for people living with AIDS. They consider it as a responsibility and part of their regular work:

And also, it has changed because if I hear somebody is HIV positive, even if there is no disabled person there, I will have to go there and see the problem, and help the family and let them know what to do. The changes are there because I see both of them as disabled, so where there is an HIV patient, I have also to give services. I don't see it as a problem because I feel that I am helping people who are disabled. The HIV person is also disabled because he can never recover from his condition.

Overall, most CRWs believe they can make some intervention because of their training and because of the disabling effect of AIDS. One CRW provides an interesting example of how she could use her rehabilitation skills and knowledge for assisting a person living with AIDS who was having some problems swallowing:

Sometimes when he was drinking water he was vomiting, so I directed him to drink little by little and he doesn't vomit anymore.

Differences between CRWs in addressing HIV/AIDS issues is related to their different levels of knowledge about both HIV/AIDS and disability, and their perception about their own vulnerability to the virus. The CRWs in the younger age group which is most affected by HIV/AIDS seem more resistant to get involved, in comparison to older staff.

Due to the increasing prevalence of HIV/AIDS in Dar es Salaam, it is common that CBR work is disturbed by AIDS-related funerals. When this happens, CRWs have to attend the funeral for a short time before they can go to the next family:

You have to participate in the funeral activities. You are not supposed to go away and take the child to do exercises. Even if you don't stay for so long, you have to present yourself to the family and tell them that you are supporting them with the problem, and then you can tell them that you are going.

CRW Concerns about HIV/AIDS

A main limitation in CBR work is worry and concern about the possibility of contracting HIV. All of the CRWs have strong concerns about these risks and they perceive their work as a potential way of becoming infected. Fear of infection affects CBR work by bringing excessive worries and stress to the CRWs and by making them adopt strategies to avoid infection risks, which ultimately results in neglect of children who they judge to be at high risk.

Working in an environment with a high prevalence of HIV/AIDS makes many CRWs "very unhappy" with their work. They are constantly looking for signs of infection, such as skin rashes. They are also conscious of open sores on children's skin and feel very worried about continuing their work without protection:

Our health is threatened by this AIDS problem. You go to a family without any protective instruments and you do not know whether the child you are giving services to has been infected or not. But from the way you see her you would say the child is infected.

I had to do the exercises to the child but when the rashes were giving out fluid I stopped doing the exercises because there are no gloves.

Some CRWs express concerns about the possibility of transmitting the infection to their own family through their clothes:

So when I touch the child with those rashes and my dirty clothes I can transmit the rashes from that child to others at my home.

Other CRWs were also unsure of their own HIV status and were worried about the possibility of transmitting the infection to disabled children:

When I'm doing my work, I'm not sure whether I, myself, I'm HIV positive or the one I am doing exercises with is HIV positive. I don't know if this family I am dealing with has HIV problems. I don't know.

Most CRWs deplore the fact that they could not wear surgical gloves, and sometimes could not easily wash their hands after touching the children:

A major problem is that for example they say that you should put on gloves when you want to give service to an HIV patient. You can treat a swelling with your bare hands and sometimes you may have cut yourself on the process of cooking or you can touch a child with rashes.

However, CRWs report that it would make the families feel uncomfortable if they were to start wearing gloves or washing their hands. At the same time, they are not provided with gloves by the CBR program. Therefore, some CRWs have adopted strategies to avoid being in close contact with some of the children when they suspect HIV/AIDS in the family. They sometimes avoid doing any type of handling of these children or avoid seeing them altogether:

We try to avoid such things like hugging the children in one way or another by giving the children some presents for example you go there with balloons, so you give the children the balloon before they hug you.

The fear of contracting HIV through CBR work is a common worry. Similarly, a study among physiotherapists in South Africa showed that their relative lack of knowledge had made the physiotherapists overly conscious of the risks of infecting themselves through their work (19).

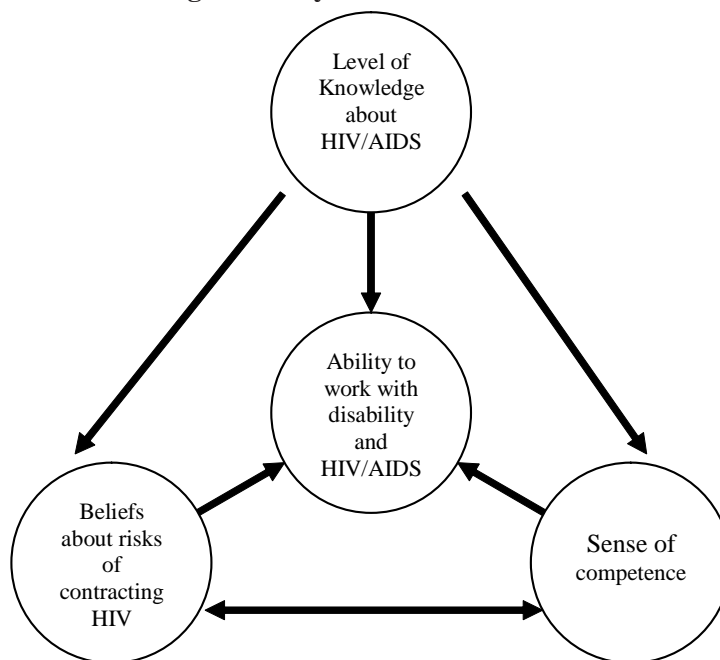
Roles of CRWs' sense of capacity, knowledge and perceived risk

A model for CRW ability to work in AIDS-affected communities is illustrated in Figure 3. CRW attitudes towards HIV/AIDS are quite variable although denial is a major reason. Some CRWs are well informed about the condition but others know very little. This finding is consistent with a study among hospital-based workers in Uganda which found that important gaps in workers' knowledge about HIV/AIDS had a direct effect on their services, and resulted in reduced quality of care offered to patients who were potentially HIV positive. Fear of contagion, and concern about treating AIDS patients were reported by both nurses and doctors. Misperceptions of the risks of infection were common (20).

This finding is also consistent with observations made by Rugalema (21) indicating that the level of awareness about HIV/AIDS was high in various countries of sub-Saharan Africa but the level of infection was not going down, suggesting that acknowledging the existence of HIV/AIDS does not mean knowing what to do about it.

The older, more experienced CRWs are more likely to talk about HIV/AIDS during their CBR work, and to be more involved in providing some type of AIDS intervention, than the younger, less experienced CRWs. Older CRWs seem to be more confident in their skills and to be better able to adapt these to serve people living with AIDS. In some studies the level of knowledge about HIV/AIDS among health-care workers has been related to age, although other studies have found that attitudes towards people living with AIDS was not linked to age (22, 20).

Figure 3. Factors influencing the ability of CRWs to work in AIDS-affected communities



The ability of CRWs to adapt their working habits to an environment with high HIV/AIDS prevalence is linked to a sense of competence in their skills and beliefs about their risk of infection. The latter belief is directly influenced by their HIV/AIDS knowledge base. The experienced CRWs have more years of practice and feel more confident about knowing what to do when confronted with HIV/AIDS during their work. They may also feel less at risk of HIV infection in general, as they are older.

This model reinforces the need for better training and the importance of informing CRWs about HIV/AIDS to increase their sense of confidence in working with people that are susceptible of being infected with HIV/AIDS.

DISCUSSION

The roles of CBR in the context of HIV/AIDS

It is evident that even though no clear policy has been made by CBR programs to take concrete action in the field of HIV/AIDS, there is already something being done. The question

is not if CBR programs should get involved in HIV/AIDS action, but rather how CBR programs can be better used and how that action should be targeted. At the local level, lack of clear direction causes confusion for both family members and CRWs. Lack of direction also leads to a wide variety of responses, that are not necessarily appropriate, because of variability in CRW skills, HIV/AIDS knowledge base and understanding of useful CBR roles. It is unrealistic to think that community-based work can ignore the difficulties that people are facing in AIDS, and simply concentrate on working on disability goals. Without facilitating the involvement of the family to the degree possible, by meeting immediate needs, little will be accomplished with the disabled child.

The WHO international classification of functioning (23) suggests that the environment can act as a facilitator, or as a barrier, to participation of persons with disabilities. Rehabilitation is intended to create an environment favourable for the person living with a disability. In the context of HIV/AIDS, however, the environment is not favourable to the rehabilitation and the inclusion of people with disabilities. Therefore, it becomes important to concentrate some efforts towards allowing caregivers to meet other needs so they have the time and resources to give to the disabled person. But how exactly this can be done within the existing structures of CBR is debatable.

One obvious way of addressing the issue of HIV/AIDS is through a referral process to appropriate resources for HIV/AIDS. Referral systems are already an integral part of CBR and CRWs are already referring people for issues that relate to their disabilities. However, referral is a complex process and does not always provide the needed support to people who require it. Referral rates in most community based health projects are known to be relatively low (24). These low referral rates are due to social, demographic and economic barriers and can also be related to the knowledge and attitudes of staff, as well as to the level of knowledge and past experiences of the referred individual (24). Referral rates can be improved by providing referral training and ensuring that referral sites are appropriate.

Another way to address more immediate HIV concerns is to offer services at the lowest possible level and avoid referral to specialized personnel. CRWs could be involved in providing some basic care to people with AIDS during their home visits. HIV/AIDS home-based care workers could train CRWs in basic care techniques. Training CRWs to be more skilled at identifying HIV/AIDS concerns and referring families to the appropriate resources

would be a great improvement. Because of the stigma in acknowledging HIV/AIDS, people usually resist going to services outside the home unnecessarily and it may be easier to provide these services in the home setting.

There is undeniably a growing role for rehabilitation workers in HIV/AIDS (25). However, CRWs need their concerns to be addressed through general training on HIV/AIDS (means of transmission, ways to protect themselves), and on how it may affect them in their work. This includes identifying the rehabilitation needs of people living with AIDS and the potential roles of the CRWs in assistance (26). People living with AIDS have activity limitations in relation to their conditions and can benefit from rehabilitation advice. Information about available HIV/AIDS services could also be made accessible to the families as part of CRW intervention. Training CRWs in working with other community projects that address HIV/AIDS is essential.

Finally, there is a need to offer support to CRWs in the form of psychological and health care services. These services could offer HIV testing and counselling. This would be a good way to start alleviating the stress that CRWs are going through in their work and lives.

Future research aiming at better describing the complex reality of CBR evolving in an environment with a high HIV/AIDS prevalence could target the following issues:

- The attitudes about disability and the reasons motivating the families to get involved in CBR
- The beliefs associated with HIV/AIDS as compared to those associated with disabilities; and the influence these beliefs have on health-decision making
- The expected outcome of rehabilitation and the perceptions about the importance of rehabilitation for families of people living with disabilities
- The similarities and differences in stigma due to disability and HIV/AIDS

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