

CHAPTER 14

HIV/AIDS and Community Based Rehabilitation (CBR)

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SUMMARY

The AIDS epidemic across sub-Saharan Africa, is affecting all strata of society. This chapter examines the factors that make people with disabilities (PWDs) vulnerable to the HIV/AIDS epidemic. The social issues that lead to discrimination of PWDs are the very concerns that make them vulnerable to HIV/AIDS. These factors are inter-related and exacerbate each other. Poverty, low self esteem, lack of information, family up-bringing and negative attitudes are some of the reasons given by PWDs, their carers and service providers (including community based rehabilitation (CBR) workers), that make disabled people vulnerable to HIV infection. The role of CBR is discussed here as a contact point or door between PWDs and the various services and activities, that address HIV/AIDS. CBR should also ensure that interventions in HIV/AIDS are presented to PWDs in an accessible and acceptable form. Programmes implementing CBR should be careful not to divert from their primary objectives and concentrate on HIV/AIDS related activities, even when the interventions are targeting PWDS.

INTRODUCTION

In the last two decades the HIV epidemic has swept across sub-Saharan Africa with an increasingly destructive force. According to UNAIDS and WHO, the epidemic has so far claimed over 14 million men, women and children south of the Sahara (UNAIDS, WHO 2000). Gains made in life expectancy are being wiped out in many countries. The recent increase in adult deaths in East Central and Southern African countries can be attributed to HIV/AIDS infection. For example, in Zimbabwe, adult mortality among men nearly tripled between 1988 and 1994 (Commonwealth Regional Health Community Secretariat for East, Central and Southern Africa, 1999). Approximately, 4 million new HIV infections occurred in the region during 2000 (Centre for Disease Control, 2001), but despite the rising prevalence in most of the sub-Saharan countries, Uganda in the mid-nineties, registered declining prevalence (Centre for Disease Control, 2001). HIV prevalence in pregnant women declined in five sentinel sites by an average of 6% between 1991 and 1995 (MOH, Uganda 1996). The overall decline in adult HIV prevalence has decreased from 14% in 1990, to 8% in 2000 (Centre for Disease Control, 2001), while in Masaka, Uganda, HIV prevalence among females aged 20-24 years, has decreased from 20.9% to 13.8%, from 1989-1997 (Kamali et al. 2000). This drop is attributed to mainly, declining incidence and partly due to AIDS related mortality. Change in sexual behavior, a result of openness that has characterised Uganda's national response, has mostly contributed to the declining trend. Transmission of HIV/AIDS in sub-Saharan Africa is mainly heterosexual, followed by mother-to-child transmission. In many African countries, blood transfusion remains an important root of transmission.

AIDS in Africa, has left a trail of socio-economic upheavals characterised by reduced income at family level, orphans and strain on health services. Traditional coping mechanisms to combat disasters have been stretched to breaking point. Every fibre of life has been affected by this epidemic.

Sub-Saharan Africa has responded to the epidemic through National Control Programmes. These programmes have focused on the following strategies:

- Promotion of behaviour change
- Condom promotion
- Minimise risk of HIV transmission through safe blood transfusion
- Early detection and treatment of sexually transmitted diseases
- Community based management of AIDS and TB
- Special focus on priority groups such as sex workers, adolescents, truck drivers etc.

International agencies, non-government organisations (NGOs) and western governments have all rallied to help governments and civil society, respond to the epidemic. Communities and family members are moving from a judgmental attitude, to one of support to the sick and orphaned. This phenomenal response to the epidemic will bring about a turn around, as already evidenced by the experience in Uganda.

PWDS, HIV

Although a lot is known about how the epidemic has affected special interest or vulnerable groups, little is known about its impact on people with disabilities. Do impairments protect them or make them more vulnerable to HIV? Are PWDs benefiting from, or contributing to the massive community, national and international response to the epidemic? A major concern of PWDs, is that the strong and rapidly expanding fight against HIV/AIDS excludes them.

CBR has been discussed at length, in earlier chapters of this book. It is a strategy that has been adopted by most African countries, as the most appropriate means to facilitate the inclusion of PWDs in the community and within national development. CBR in all its forms and colours has been in Africa longer than the AIDS epidemic, although they both experienced rapid expansion over the last two decades. How has CBR responded to the epidemic? What is the impact of the epidemic on CBR and PWDs? Does CBR have a role in fighting the epidemic?

This chapter will try to respond to the above questions. The voices of men and women with disabilities, parents of children with disabilities, CBR practitioners and ‘professionals’ across Africa were heard through a mini workshop on HIV/AIDS and CBR in Kampala, Uganda in 2001. The group grappled with the above issues concerning the HIV/AIDS epidemic and came up with a way forward through CBR in Africa.

VULNERABILITY OF PWDS TO HIV/AIDS

The complex interplay between disabled and non-disabled people over the past century has made a commendable shift in power from the latter to the former, especially at the apex of society. Negative attitudes and discrimination, however, continue to play a decisive role in shaping the lives of PWDs at all levels of social strata. Many decisions and therefore outcomes of disabled people’s lives are a result of the social environment in which their disability was born and bred.

Various social, mental and physical barriers limit participation by PWDs in their own, as well as community development. As a result of these barriers, one would assume that PWDs are protected from HIV, a disease that is often associated with interaction and participation. On the contrary, the opposite is true. Factors that hinder participation and integration of PWDs make them more vulnerable to HIV/AIDS. These same issues on the other hand, hinder access to services for the prevention and treatment of HIV/AIDS. Impairments biologically do not make PWDs vulnerable to HIV/AIDS. Societal response to the impairment is what makes PWDs an easy target for the HIV infection. The major factors that contribute to the vulnerability of PWDs to HIV, are discussed below.

The Family

The label of disability is often, but not always, attached in the home. The response to the impairment by family members plays an important role in shaping the life of the disabled person.

Overprotection by the family, was identified as an important factor in exposure to HIV infection. The overprotected child is not exposed to sexual challenges. This limited exposure results in an adolescent who is

not empowered to handle his/her own sexuality and the external sexual demands made on them. Children with disabilities often miss out on sex education, whether this includes traditional initiation ceremonies or the more modern skills for life training. Parents view their disabled adolescent as a perpetual child who does not require sex related education and must be protected from the advances of the opposite sex. Many women with disabilities (WWDs) have complained that they do not receive the same information that is given to other women. For example, when preparing for marriage, the deaf women in Uganda have taken it upon themselves to counsel deaf girls on married life because the aunt who traditionally should play this role, often neglects this or finds communication difficult. The lack of sex education and life skills render PWDs vulnerable to HIV infection.

In Africa, many PWDs continue to live with their parents even as adults. Accessibility or the lack of it, was cited as a major reason for continued stay at home. This is reported to limit the romantic exposure of PWDs. There is less privacy at home and if one does go out, the parents monitor the whole event. When PWDs get an opportunity to meet, they want to make the most of it, especially sexually. This is one reason given for the promiscuity that PWDs have observed among themselves. It was observed that HIV tends to spread among members of a disabled persons organisation (DPO) because of 'in house sharing of partners'.

'We stick to ourselves and mess our selves more'

Angela Balaba- WWD

The other side of the coin in the family includes the abused children and youth with disabilities. A study in the Kibwezi CBR programme in Kenya (AMREF, 2000), found that sexual abusers are usually family members. This is also often the case with non-disabled children. The disabled child and youth are less likely to report abuse than other children, especially if they have been raised to believe that they are inferior to other members of the family. Others such as the mentally handicapped, may not be able to comprehend they are being abused. Some ask why they are removed from an incestuous relationship.

Although parents and carers are concerned about the sexual abuse or rape of their children, their primary concern is not the danger of getting HIV, but unwanted pregnancies in the case of girls. Many girls with disabilities from all cultures across the continent, are on contraceptives without their knowledge.

Low self-esteem is another reason that leads PWDs to have multiple partners, thus increasing exposure to HIV. Low esteem, PWDs noted, starts in the home. Low self esteem also leads to easier coercion into sexual encounters and one is less likely to report abuse. Having a lover tested for HIV before any sexual relations is difficult for women, and especially women who are already marginalised in so many other ways.

Access to Information

The HIV/AIDS epidemic has created a worldwide response with massive production of information in many languages, using multi media channels for delivery. This information blitz has not reached people with disabilities in Africa. The blind, deaf and mentally handicapped persons have especially been left out. In Uganda, deaf-to-deaf life skills education has already started to try and address the information gap. In Namibia and Kenya, work has begun to provide deaf children with information on AIDS and how to avoid it. These efforts are however, a drop in the ocean considering the size of the problem. PWDs need information designed and packaged to meet their needs. Parents of children with disabilities, need information on bringing up their child so that they can ably prepare their special child for future challenges. CBR workers need information on how to address the HIV/AIDS issue in their work. Programmes for sexually transmitted disease should include CBR programmes among their target audience.

Poverty

Poverty is a factor that is closely interlaced with the HIV/AIDS epidemic. Poverty fans the epidemic and is also the fruit of the epidemic (Cohen, 2002). Poverty related factors can affect household and community coping strategies in dealing with HIV/AIDS, and in turn the experience

of HIV/AIDS can reduce the ability of individuals to be economically productive. Disability and poverty too, have a symbiotic relationship especially in the developing countries (DFID, 2000). PWDs may experience limited opportunities for participation in education and employment, leading to increased vulnerability to poverty. The downward spiral of poverty and disability will not be dwelt upon, in this chapter.

Both men and women with disabilities are driven by poverty to use sex, as a means to meet their economic needs. Poverty also limits the choice for safe sex and for safe partners. Disabled street women in Kampala have multiple partners and do not use the condom. One lady outside the main market said, *“I have been involved with several men on the street, but I have never used a condom. The men who have sex with me do not want to use a condom”* (Ruhweza, 2001).

Sexually transmitted infections (STI) increase the opportunity for HIV invasion of the body. When effective STI treatment programmes are compromised, opportunities for HIV prevention are lost (Grosskurth et al. 1999). Many disabled people who become infected with STI cannot afford treatment. Others do not know where to go for treatment, while some fear ridicule from health workers for getting STI. The presence of untreated STIs increases the vulnerability of PWDs to HIV infection.

Low Social Status of PWDs

In Sub Saharan Africa, the AIDS epidemic has been followed closely by an increase in sexual abuse of children and other sections of society, who are felt to be free of HIV, such as older persons. PWDs are among those who are assumed to be free of the virus because of the discrimination they suffer. This has increased the vulnerability of men, women and children with disabilities, to sexual abuse, rape and HIV infection. Low self esteem, communication difficulties and the low value of PWDs make redress of abuse difficult.

In agrarian societies, survival depends on physical capabilities. Women are married because they are a source of labour. Disabled women are

therefore, viewed as liabilities and have less opportunity for marriage. In addition, beauty in the African context is largely physical. Beauty of the soul rarely comes into play when choosing a spouse. The low social status of women makes WWDs less likely than men with disabilities, to find a spouse.

In Africa the ability to have children increases acceptability. In addition, children are a source of security for the future. A 34-year-old woman said, *“I want to have another child, so that I can be assured of help in my old age.”*

The difficulty in finding a partner, coupled with the need to have children makes WWDs especially vulnerable to HIV. Many WWDs are single parents during the day and married at night. Men are ashamed of WWDs as spouses, so the men visit these partners with disabilities only at night, or abandon the WWDs once conception has taken place. All these factors reduce the bargaining power of WWDs for safe sex or safe partners.

‘We are normal human beings who also need love and sex’

The assumption by society that PWDs are asexual, contributes to the vulnerability of disabled people to HIV infection. It bars information on sexuality, HIV/AIDS and its prevention from reaching PWDs. Access to health services is limited due to the negative attitude of health workers. PWDs are thought to be free of HIV and end up targets of abuse, or coercion into unwanted sex.

PWDs, like other people, have sexual needs, but do not have a strong negotiating position and consequently can end up practising unsafe sex. Parents of mentally handicapped adolescents have often raised concern over inappropriate sexual advances made by disabled children to the opposite sex. Normal sex hormones in a disabling environment make PWDs vulnerable to HIV infection.

AIDS CAUSES DISABILITY

It is estimated that 1/3 of people with AIDS develop a disability(s), an area which is receiving growing interest (Harworth & Turton, 1993). With access to anti-retroviral drugs and chronicity of AIDS, it is likely

that rehabilitation programmes will not only have to deal with disabled people with HIV/AIDS, but also with people who have been disabled by AIDS.

ORPHANED CHILDREN WITH DISABILITIES

Africa has 92% of the estimated 13 million children who have been orphaned worldwide by AIDS (UNICEF, 1999; UNICEF, 2002). It is estimated that 4-5% of these orphans have disabilities (UNICEF 1999, UNICEF 2002). Unlike other orphans, relatives are reluctant to take on children with disabilities (CWDs) in their families. Sick mothers therefore, worry more about their child with disability and try to prepare them to be self-reliant. This is often not possible.

THE ROLE OF CBR IN HIV/AIDS PREVENTION AND CONTROL

CBR programmes in sub-Saharan Africa do not directly address the issue of HIV/AIDS in their programmes, yet, the epidemic affects all people in Africa and especially PWDs who are more vulnerable to the infection. By enhancing the profile and value of PWDs, CBR does, in a round about way, address the epidemic.

CBR has an important role to play in the prevention and management of HIV/AIDS and should participate in all programmes that are aimed at addressing the epidemic. HIV/AIDS interventions should also include CBR, among the strategies.

The holistic approach to disability is one of the hallmarks of CBR. Unfortunately, most interventions through CBR in Africa, omit the sexuality of PWDs and the factors that affect this aspect of life. As CBR improves activity and participation, it is important to ensure that integration is accompanied by social skills that protect PWDs from sexual exploitation and exposure to HIV.

The primary role of CBR is therefore, dealing with the roots that make PWDs vulnerable to HIV. The families of adults and children with disabilities must be helped to raise PWDs who are confident and able to

refuse unsafe sex. Families need to recognise that children with disabilities will one day be adults with sexual desires, which they will have to learn to deal with. CBR should therefore be a vehicle of information to PWDs and their families, on sex and the HIV epidemic.

More difficult, but just as important, is the need for CBR to address the need for communities to protect PWDs from sexual exploitation. There is a need to awaken social consciousness to the plight of WWDs. Some of the more vulnerable disability groups such as the blind, deaf and mentally handicapped persons need special attention. Although CBR should spearhead the protection of PWDs, care needs to be taken to avoid hindering the opportunities to have children.

CBR should be a point of entry for PWDs to access HIV prevention programmes. For example, CBR should challenge HIV projects to provide information packaged for different disability groups. The dissemination of this material can be done either by DPOs, or the HIV prevention organisation, with the CBR programme playing a contact or facilitatory role.

Many communities in Africa have responded to epidemics with community initiatives that take care of the sick with HIV. The CBR programme needs to ensure that PWDs who have AIDS, have access to the services provided by community based AIDS support organisations.

Where disabled orphans are concerned, the CBR workers need to ensure acceptability and integration of these children in their new homes.

DPOs, together with CBR programmes should network with district, regional and National HIV organisations (government and NGOs), to ensure that PWDs and their families access and participate in HIV prevention and treatment interventions.

CBR needs to work with research programmes to identify information gaps that PWDs have about the epidemic. Socio-cultural issues that surround disability and HIV/AIDS need to be studied and interventions planned. The role of CBR may not be in conducting the actual research, but to bring the disability issue to the attention of researchers in HIV.

CONCLUSION

The issues that limit participation of PWDs are the very factors that make them vulnerable to HIV infection. If CBR is to remain relevant to this population group, their families and the communities in Africa, CBR must address HIV. Strategies to ensure that available interventions reach PWDs and their families need to be formulated. CBR must take care that the programme continues to focus on promoting participation of PWDs in community development. Direct interventions concerning HIV/AIDS health promotion to PWDs, should as often as possible, be done by other organisations. The role of CBR is merely to open the door for PWDs and their families, to access these interventions. In opening the door, CBR will have to build networks that are wider than the traditional liaisons with disability related organisations.

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