Mitigating the Impact of HIV & AIDS on People with Disabilities through Equitable Information Dissemination

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Abstract
The study sought to investigate equity and access to HIV & AIDS information dissemination to people with disabilities. Information dissemination was viewed as the strongest strategy of mitigating the impact of the HIV & AIDS pandemic. The impetus of the study stems from the apparent absence of literature and media images that incorporate the HIV & AIDS information needs of people with disability especially the deaf and the blind. WHO 1998, global survey on disability and HIV & AIDS showed that people with disabilities have an equal or greater exposure to all risk factors for HIV infection. The qualitative study used four focus group discussions’ (FGD) strategy to obtain data from four samples of young people with the following disabilities, deaf, blind, mental retardation and physical disability. The findings indicated the HIV & AIDS information in the media is inconsistent with the information needs of people with disabilities especially those who are blind and deaf. Deaf young people receive incorrect information from the media. On the other hand blind people too do not access critical information on HIV & AIDS. While people with disabilities are equally exposed to HIV & AIDS, they do not receive the requisite information to reduce and mitigate the impact of the scourge. There is therefore a need to make available HIV & AIDS information in modalities that are compatible with the information acquisition dispositions of people with disabilities.

Introduction
The study focused on the equitable dissemination of HIV & AIDS information in order to impact positively on reproductive health for young people with visual and hearing impairment. According to Emasu (2004:1) “…many deaf people are ignorant about AIDS because their family, especially their parents, think they are not sexually active.” The sexuality of people with disability is often overlooked to such an extent that relevant information is not availed to them. Going by the findings of the WHO 1998 Global study on Disability and HIV & AIDS, people with disabilities have an equal or greater exposure to all risk factors of the scourge. Unfortunately there are no specific HIV & AIDS programmes for people with disabilities, (Emasu 2004). It is therefore pertinent that in the context of youth reproductive health education, young people with disabilities be accorded access to the requisite HIV & AIDS information. Information through awareness programmes was found to be the most potent measure for the prevention of HIV infection. Access to critical information such as HIV & AIDS knowledge should be viewed as a right to all including people with disabilities.

According to Mukuta, Director of the National Association of Societies for the Care of the Handicapped (NASCOH), more than 1.2 million people in Zimbabwe were disabled, of which 300,000 were HIV positive. The instructions for the use of condoms had never been distributed in Braille for people with visual impairments nor in sign language for those with hearing impairment. Contrary to the popular belief that people with disabilities had no sex lives and therefore were not at risk of contracting HIV, Mukuta and Choruma (2006) asserted that most of them were sexually active. However, in many cases, people with disabilities did not have access to sufficient sex education to protect themselves against HIV and other sexually transmitted illnesses (STIs).
Efforts to reach out to disabled persons in terms of knowledge and skills for HIV & AIDS prevention have been minimal. Two projects targeted at people with disabilities included the two videotapes for deaf persons and the Braille Red Ribbon project for people with visual disability. The two tapes - ‘An HIV/AIDS Sign Language Vocabulary’ and ‘Dancing with Death’ attempt to package information in a way that appeals to the needs of people with disabilities. The other initiative was the ‘Braille Red Ribbon Project’ which uses the Braille alphabet as an innovating tool to prevent and give information about HIV/AIDS to people with visual disabilities (Poblete, Bonanno, Carballo, 2004). Its aim is to produce preventive materials about HIV/AIDS printed in Braille Alphabet and recorded in audio tapes, and to develop peer counsellors who propagate the information, with a multiplier effect, among blind and low vision people in the field of HIV/AIDS. While the two initiatives are appreciated, a lot more needs to be done in order to have an all-inclusive HIV & AIDS prevention strategy that promotes youth reproductive health among people with disabilities.

Lack of access to appropriate information about HIV/AIDS control measures was the biggest problem for people with disabilities in society. Firstly, existing HIV/AIDS intervention initiatives did not take into consideration vulnerable social groups such as people with disabilities (PWD). Secondly, there were inequitable HIV & AIDS information dissemination strategies between persons with disabilities compared to people without disabilities in society. And thirdly, fewer disabled persons in proportion to people without disability, had access to HIV/AIDS information. Therefore inadequate and lack of HIV & AIDS information, awareness and skills specifically directed to PWD impacted negatively on national initiatives to combat the epidemic. Lack of targeted HIV & AIDS information dissemination negatively affected prevention and reproductive health of PWDs. This study sought to identify HIV & AIDS intervention information needs of PWDs in an effort to come up with prevention and reproductive health mitigation strategies. Equitable HIV & AIDS intervention information dissemination was viewed as the strongest mitigation strategy against the impact of the pandemic. The impetus of the study stems from the apparent absence of literature and media images that incorporate HIV & AIDS information needs of PWD. WHO (1998), Global Survey on Disability and HIV & AIDS established that PWD have an equal chance or greater exposure to all risk factors for HIV and other STI infection. The problem statement for this study was ‘What are the HIV & AIDS intervention information needs of PWDs that positively impact HIV prevention and reproductive health.’ In order to fully explore the problem, a number of research questions were formulated as follows:

- What do young people with disabilities know about HIV & AIDS?
- What should young people with disabilities know about HIV & AIDS intervention?
- What are the preferred HIV & AIDS intervention information modalities for people with disabilities?
- How do socio-cultural aspects of life impact on HIV & AIDS prevention and reproductive health among PWDs?

**Method**

The study utilises the qualitative research paradigm using the focus group discussions (FGDs) participatory research design. It was envisaged that critical and very personal information relating to sexuality, stigma and disability would be revealed if the affected social group had an opportunity to tell its own story. Within the humanistic perspective, an individual’s subjective self is a function of self-interpretation. Meanings would therefore be constructed from the individuals with disability self-report as revealed within the context of focus group discussions (FGDs).

An initial convenient sample of thirteen (13) young people with disabilities (deaf, blind, physically disabled and the mentally retarded) formed the focus groups. Their distribution according to type of disability was: 4 were visually impaired, 4 were hearing impaired, 2 were physically disabled while 3 were mentally retarded. Of the 13 young people with disabilities, 6 were students at University, 2 were at a vocational training centre, 4 were on permanent professional employment, 2 were self-employed and 2 were unemployed.
The instrument of the study was a FGD guide made up of the following research questions:

- What do you know about HIV & AIDS?
- How would you like to get (access) HIV & AIDS prevention information?
- How does your culture affect the spread of HIV & AIDS in your society?

The study took the form of a workshop in which participants were firstly, given three explorative talks on the following topics:

- The status of HIV & AIDS in Zimbabwe
- How HIV & AIDS impacts on reproductive health

The brief presentations were done by experts (nurses, social scientists and educationist in a lively manner using communication modalities compatible with the information acquisition dispositions of the different types of disabilities such as audible voice, charts, overhead slides and sign language. Secondly in disability specific groups the participants discussed the research questions and prepared a report for the plenary session. Each of the four groups had a facilitator from among the research team who explained the questions and clarified the meaning of the participants’ responses. Lastly there was a plenary session for groups report backs. The groups selected their own person from among themselves to present their answers to the research questions. During this session members of the research team posed further questions to clarify issues reported on. The participants’ reports were recorded and reconstructed into themes in order to come up with meaning and answers to the research questions. The information was validated with other groups of PWDs at a national training workshop for disability advocacy through a plenary discussion.

Findings

The study findings were divided into four themes which were HIV & AIDS intervention information needs of PWD, preferred communication modalities, socio-cultural aspects that impacts negatively on HIV prevention and reproductive health and misconceptions on sexuality of people with disabilities. The four themes form the basis of the mitigation and intervention strategies for people with disabilities.

HIV & AIDS Intervention information needs for PWD

Responding to the question, “What should young people know about HIV & AIDS” all the groups agreed firstly that they should know signs and symptoms of AIDS and how it is spread. Secondly they were interested in ways to prevent themselves from contracting HIV. Thirdly the participant in all the groups wanted to know how they could live longer after contracting HIV.

The study established that PWD have the same HIV & AIDS information needs as people without disabilities. However they do not access the information in the same manner as the rest of society. PWD were exposed to HIV & AIDS risk factors due to lack of requisite information. People with disabilities especially the deaf and blind had wrong understanding of media HIV & AIDS information due to incompatibility between information presentation and their receptive modalities. For example a young girl with visual impairment said that;

- If I want to buy a condom I have to ask another person to identify it for me but that person then thinks that I want to have sex and exploits this exposure. We need Braille labels on condoms so that I do not have to ask anyone to assist me in identifying and purchasing it. I need my privacy like anyone else.

Participants with hearing impairment said that from media images they understood that big fat people and businessmen do not have AIDS. The situation suggests that people with hearing impairment did not get the same HIV & AIDS prevention information from the media as other people.

Preferred HIV & AIDS intervention information communication modalities

The participants differed according to disabilities type on the preferred information dissemination modalities. Young people with hearing impairment required the information to be conveyed through sign language. Media images should be also accompanied by sign language in order to convey meaning to people with hearing

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impairment. Sign language was so emphasized that the participants requested the abolition of O’level English pass as a pre-requisite for advancement in training because English was considered a third or fourth language by people with hearing impairment and therefore could not be given a prominent status ahead of sign language. For people with hearing impairment sign language required to be given the status that English is given for hearing persons because it is their language of school instruction and a media for communication in all aspects of their lives. The participants with hearing impairment also would like to see sign language interpreters at all levels where they required services. Participants with visual impairment preferred HIV & AIDS information conveyed in Braille alphabet or sound. They preferred radio programmes as they conveyed to them a complete image as opposed to television whose visual images they could not see.

On the other hand participants with physical disability and those with mental retardation said that they preferred to get HIV & AIDS information from aunts, uncles and grandparents. This group also said they preferred to hear testimonies of HIV & AIDS patients particularly from those who were also disabled. Other people with disabilities would put the message across in simple language and example they would understand. For example, a young man with mental retardation, referring to the advert on Zimbabwe television, showing use of an umbrella to shield one from rain to infer condom use as protection from HIV infection, said that he understood it to imply that he should always have an umbrella when going out. The young man got the real inference of the advert many years later when somebody explained to him that it was all about using a condom to protect oneself from HIV infection.

PWDs said that they could access the same HIV & AIDS intervention information if it was given in appropriate formats commensurate with their information reception dispositions and intellectual capacity. The study found out that people with hearing impairment (deaf) do not comprehend figurative speech, instead they follow the literal meaning of the words. For example if we say a person has kicked the bucket implying that they have died, a deaf person visualizes a person literally kicking a bucket as if kicking a bucket. Therefore it is imperative to use ‘light’ English in HIV & AIDS information pamphlets /booklets and avoid phrases such as ‘point of no return' or 'hit the nail on the head'. Therefore, when communicating HIV & AIDS information to deaf persons one should avoid figurative speech, euphemisms, proverbs etc. Media images on HIV & AIDS intervention information were found to be fraught with figurative speech.

Socio-cultural aspects that impact on HIV & AIDS prevention & reproductive health

The study found that parents and guardians of PWD treated them as if they were asexual, but on the contrary, PWDs confirmed that they were sexually active. All participant groups sighted the prevalence of abuse because of lack of appropriate sex education because society believed that PWDs were not sexually active.

Both the participant with visual impairment and those who are physically disabled agreed that they are abused because they are usually left alone at home and that very little attention was given to them. PWDs were more often susceptible to sexual abuse due to myths and wrong cultural beliefs and perceptions. However, the young PWDs said that abuse was on their part a result of lack of exposure, lack of love and lack of self-esteem such that they overly responded to any person who showed them attention and kindness or affection.

PWDs reported that lack of self-esteem on their part resulted in them being sexually abused.

The PWD especially the visually impaired, the hearing impaired and the physically disabled reported that poverty was a factor that exposed them to sexual abuse by people mostly known to them. The people with physical disabilities reported that they were discriminated at employment hence they sell themselves for money which exposes them to HIV infection.

The respondents in all the four disability groups agreed that ‘if you talk about sex you are labeled a prostitute.’ The problem is that they are not allowed to discuss sex matters nor does anybody teach them about these issues thus, there exists
a culture of silence surrounding the sexuality of people with disabilities. Also, in wife inheritance (nhaka) PWDs do not make a choice but the choice was made for them. In line with the same perceptions marriages were more often arranged for PWDs instead of allowing them to make their own choices.

Culturally PWDs were treated as if they were minors, that is, they were treated as if they had no individual rights. This is exemplified by people who talk to the PWD’s helper instead of directly to him/her.

The United Nations declaration on Commitment on HIV & AIDS affirmed that “Stigma, silence, discrimination and denial as well as lack of confidentiality undermines prevention care and treatment efforts and increase the impact of the epidemic on individuals, families, communities and nations.” Much of the stigma faced by PWDs was built on existing prejudices related to race, gender, socioeconomic status, culture and disability (UN 2001).

Mitigation strategies for reducing the impact of HIV & AIDS on PWDs reproductive health

In order to mitigate the impact of HIV and AIDS among PWDs, focus should be on prevention and reproductive health. The participants suggested information dissemination in modalities compatible with the information reception modalities of each disability type. For example, the deaf said they would prefer information conveyed through sign language while the blind preferred Braille alphabet labels and information in Braille and or audio tapes. All groups concurred that they preferred to have aunts, uncles and grandfathers to give them information on HIV and AIDS as well as on sexuality and growing up. The deaf in particular said they would benefit from drama that would include sign language for all information presented in sound. All groups said that they would benefit from drama where PWDs were included. The deaf requested to get access to HIV counsellors who could use sign language proficiently while the blind requested for HIV & AIDS literature in Braille or audio tapes. All groups felt that Voluntary Counselling and Testing Centres (VCTC) should be made accessible to people with disabilities and that testimonies of PWD should be included in all media messages.

In a survey by Choruma (2006.15) PWDs recommended the following strategies to mitigate the impact of HIV & AIDS:

Establish an integral approach in providing health care services that are accessible, affordable, accountable applicable and most importantly responsive to the needs of PWDs:

- Ensure that PWDs have access to appropriate and adequate communication systems and information in the health sector. This includes that information is produced in other formats
- Ensure that heath care personnel curriculum includes disability issues
- National Aids co-coordinating body should ensure the development of responses that are specific to the needs of PWDs
- Raise awareness on the reproductive rights of PWDS and eliminate myths and beliefs about HIV & AIDS cure
- Provide structure for reporting sexual abuse on PWDs etc. (Choruma, 2006. 15-16).

Discussion

The study revealed that PWDs were inadvertently denied access to HIV & AIDS information thereby rendering them more vulnerable to the scourge. This finding is consistent with Groce (2004) and Banda (2005) who assert that HIV and AIDS presents a significant threat to PWDs throughout the world because of lack of information. PWDs themselves perceive themselves to be vulnerable and at risk hence they registered the need to access the same requisite HIV & AIDS intervention information as the rest of society.

The challenge is for societies to have HIV & AIDS interventionist strategies that includes and embraces communication needs of PWD.

According to Groce, the HIV & AIDS crisis cannot be effectively eradicated without the participation of PWD. Groce’s assertion was consistent with the findings of this study that PWDs would like to be involved in deciding the best information dissemination modalities compatible with the nature of their disabilities. For instance the use of sign language and the Braille alphabet was cited as critical in HIV& AIDS information dissemination for people with hearing impairment and people with visual impairment respectively.
The issue of culturally based myths and beliefs about disability negatively affect equitable access to HIV & AIDS information for both PWDs and the rest of society. Cultural practices such as perceiving PWDs as perpetual children and as asexual human beings exposed them to continued abuse, unwarranted confinement and lowered self-esteem (Chakuchichi et al, 2006). Choruma (2006.15) argues that, “the sexuality of PWDs is poorly understood and often not recognized or discussed by society and family members, and therefore PWDs were not commonly regarded as a community that is vulnerable to HIV or affected by AIDS.” It is therefore pertinent that societies accept that PWDs are at increased risk of HIV & AIDS exposure because of unchanging cultural practices. It can be argued that negative perceptions and practices in society about PWDs can be changed if PWDs are accorded equal participation in HIV & AIDS mainstream intervention initiatives through the provision of sign language interpreters, brailled information and inclusion in community and national workshops. Education was considered to be both a prevention strategy and a concrete response to the HIV & AIDS problem. Through Information-Education-Communication (IEC) strategies, HIV & AIDS awareness of basic facts and intervention information are disseminated to society (Southern Africa Regional Universities Association– SARUA 2008). According to SARUA (2008), IEC strategies could include:

- Mass campaigns, messaging, advertising, distribution of pamphlets and other resources such as DVDs, posters, etc
- Routine information presentation about HIV/AIDS policies, programmes, stigma, discrimination etc.
- Peer education programmes, which help to mobilize one person at a time or in groups

These strategies were quite ideal for PWDs and as such they should have been included in all programmes while taking care of their information receptive modalities of PWDs.

Conclusion
The purpose of the study was to establish HIV & Information needs of PWD in an effort to mitigate its impact on prevention and reproductive health. Focused groups strategy was used to gather information from young people with disabilities. While literature viewed HIV & AIDS within the socio-economic context, people with disabilities expressed concern on the lack of information presented in modalities suitable to their information acquisition dispositions. Also PWDs preferred to interact with people who respected their individuality. PWD expressed the need to have HIV & AIDS intervention strategies in their control. Certainly inclusion of HIV & AIDS intervention information needs of PWD was critically important in all national initiatives to combat the pandemic. People with disabilities were aware of cultural practices that expose them to sexual abuse and putting them at the risk of contracting HIV & AIDS. Access to appropriate HIV & AIDS information, access to counselling services including VCT centres and to media information that they identify with, form the basis of mitigation on the impact of the pandemic on young PWD reproductive health.

The study suggested that HIV & AIDS international, national and community initiatives should take on board PWDs as integral minority group of society who should access the same services as the rest of society.

The sexuality of PWD should be explored to remove myths, cultural beliefs and general negative perceptions that make them more vulnerable to abuse.
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