

An Exploration on the Challenges Faced by People with Disabilities in HIV and AIDS Prevention, Care, Support and Treatment in Chipinge West Constituency in Zimbabwe

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ABSTRACT

This study is coming against the background of general challenges faced by people with disabilities that have been reported at global, regional and national levels. Not much has been reported on the challenges faced by people with disabilities (PWDs) in the rural communities in HIV and AIDS prevention, care, support and treatment. The study therefore sought to explore these challenges and to answer the research question, a descriptive survey research design was used. The target population were people with disabilities and a sample of 30 PWDs and 5 key informants was chosen using the purposive sampling technique. Questionnaires and interviews helped in exploring the challenges faced by PWDs. Some of the challenges identified were that PWDs in the rural community do not have knowledge about the HIV and AIDS epidemic, they are not participating in HIV and AIDS related projects and programmes and they are having difficulties in accessing health services. Basing on these findings, the researchers recommended an empowerment of PWDs, their participation in HIV and AIDS related programmes and a comprehensive accessibility in health services.

Keywords: People with Disabilities, HIV and AIDS, Treatment, Care, Prevention and Support.

INTRODUCTION

HIV and AIDS have affected an increasing number of people with disabilities in rural communities of Zimbabwe. People with disabilities, like any other person require information on HIV and AIDS as well as access to programmes, services and resources. Existing HIV/AIDS prevention, care, treatment and support programmes generally fail to meet the specific needs of people with disability. These include access to reading material, lack of availability of the reading material that is friendly to their plight and lack of access to reach health facilities. There are also negative perceptions and attitudes from the health personnel to the disabled who seek preventative, curative care and treatment to HIV/AIDS. These are some of the challenges of people with disabilities that have been unravelled elsewhere. However, using Chipinge West Constituency as a case study, this study sought to investigate the challenges faced by people with disabilities in the rural communities in seeking treatment, care and preventive support in as much as the HIV and AIDS epidemic is concerned.

BACKGROUND

Generally, a health person can be described as a person who is in a state of complete physical, mental and social well-being or is in the absence of a disease. Chireshe et al (2010) and Choruma (2006) are of the opinion that to reach a state of complete physical, mental and social well-being, an individual or group of people must be able to identify and realise aspirations, satisfy needs and change or cope with the environment. To this end, some have suggested that health is a resource for everyday life, not as an objective of living. To emphasize this perception, Umeasiegu et al, (2011) claim that the Ottawa Charter emphasized that the fundamental conditions and resources for health include education, social justice and equity. What it shows is that a holistic approach to health promotion including disability is imperative and it should look at all forms of discrimination in society so that development is inclusive of an important sector of the population, in this case people with disabilities who have the potential to be affected or infected with HIV and AIDS.

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Chijokwe Sithinyiwe & Mutanana Ngonidzashu “An Exploration on the Challenges Faced by People with Disabilities in HIV and AIDS Prevention, Care, Support and Treatment in Chipinge West Constituency in Zimbabwe”

On the contrary, it would seem people with disabilities in rural communities are often excluded from HIV/AIDS health education, prevention, care and support services under the wrong misconceptions that they are not sexually active. As such societal expectations and perceptions on the sexuality and sexual activities of the people with physical challenges are negative and when they try to seek prevention and treatment they are shunned.

Some have suggested that the physical infrastructure in rural communities also hinders those who are physically challenged to access health facilities. It would also appear the health facilities and the HIV and AIDS service policies do not reflect disability-inclusive practices and access rights. For some, economically, those who are physically challenged face many problems including but not confined to lack of capital to travel to and from the hospital facilities as well as to buy food to meet their increased nutritional needs as a result of HIV infection.

People who are living with disability, in particular those infected and affected with HIV need to be seriously considered when it comes to health matters. A person with a disability is an umbrella term which covers people with impairments, activity limitations and participation restrictions. Impairment can be described as a problem in body function or structure while an activity limitation is a difficulty encountered by an individual in executing a task or action and participation restriction is a problem experienced by an individual in involvement in life situations.

People with disabilities living with HIV can be healthy despite their primary disabilities. However, there is a growing relationship between HIV and AIDS and disability. Disability is an emerging issue which is a cause for concern as persons with disabilities are at risk of exposure to the HIV epidemic. Disability includes deafness and blindness. It also includes other impairments such as albinism or epilepsy. Chireshe et al (2010) claims that there is a growing understanding that people living with HIV and AIDS are at risk of becoming disabled on a permanent or episodic basis as a result of their condition. It is also important to note that despite the growing relationship between HIV and AIDS and disability, people with disabilities have not received sufficient attention within the national responses to the HIV and AIDS programmes in developing countries. It would also appear the existing HIV/AIDS prevention, treatment, care and support programmes generally fail to meet the specific needs of the disabled.

According to Groce (2003) exclusion and segregation of people living with disabilities that are infected and affected by the HIV and AIDS epidemic has never been viewed as discrimination until recently in many African states. Chireshe et al (2010) also claims that in India disability has also been based on the assumption that the problems faced by people with disabilities such as inaccessibility to public health information was an inevitable consequence of their condition. It was only recently that it was recognised that the inferior social and economic status of people with disabilities could be as a result of prejudice and society towards such people.

Sightsavers International, (2010) an organisation which fights for the rights of people with disabilities concurs that disabled people experience disproportionately high rates of poverty. The organisation says that this is mainly because aid is less likely to reach women and girls and those with disability in particular because they are less likely to compete in situation of scarcity including in the fight against HIV and AIDS. The UN Enable (2011) also adds that women and girls with disabilities are vulnerable to sexual assault or abuse.

There also seems to be a meeting of minds with the UN-Enable report (2011) which states that around the World, children with disabilities form a large proportion of children and persons with disabilities who are not enrolled in schools. This results in their exclusion from vital sexual and reproductive health education that is often provided in school settings. As a result of low literacy levels, the majority of people who are living with disabilities have not yet understood that they have the right to health education like able-bodied people.

From this background, it can be seen that people with disability who affected and infected with the HIV and AIDS epidemic face a number of challenges. This range from prevention, care, support to treatment because of their condition.

ABOUT THE STUDY

HIV/AIDS is affecting increasing numbers of people with disabilities in rural communities of Zimbabwe. Chipinge West is an example of one such area where people with disability who are affected and infected with the HIV and AIDS have been known to be suffering. These people face

Chijokwe Sithinyiwe & Mutanana Ngonidzashe “An Exploration on the Challenges Faced by People with Disabilities in HIV and AIDS Prevention, Care, Support and Treatment in Chipinge West Constituency in Zimbabwe”

numerous problems in HIV/AIDS prevention, care, support and treatment. The study therefore sought to unravel the challenges and reveal the extent of the nature and effects of the difficulties.

METHODOLOGY

Research Setting

Chipinge West Constituency is found in Manicaland Province of Zimbabwe. It is located along the Save Valley. The constituency has mainly a peasantry background with most of the people making a living through agricultural production and supplementing their income through working in farming communities. The community is also made up of people from different backgrounds and cultures, with refugees from countries such as Rwanda, Democratic Republic of Congo and Angola. In Chipinge West Constituency there are a number of physically people who include the visually impaired, the physically handicapped, the albinos, the deaf and dumb just to name but a few.

Research Methods, Research Design and Data Collection

Leeds (1980) states that a research design refers to a plan, structure and strategy of investigation so conceived as to obtain answers to research questions and objectives. It is therefore a programme for guiding the research in collecting, analysing and interpreting data and information. In this case, the researchers adopted a descriptive survey design. Hancock (1998) posits that a survey is one of the most frequently used research design which is popular with first time researchers. Though the researchers were not first timers, they adopted descriptive method because it is suitable for describing opinions, attitudes and feelings and enabled conclusions to be drawn from among the people with disability. It was flexible, versatile and investigated phenomena in their natural settings hence more realistic. The researchers also utilised a mixed research approach paradigm described by Tashakkori and Teddlie (2003) as one that involves mixing qualitative and quantitative research methods. The two can compensate each other's weakness and complement each other's strength.

This survey also allowed the use of questionnaires and interviews as instruments for collecting data. Muchengetwa (2000) posits that the descriptive survey allows the researcher to question individuals by asking them to complete questionnaires and to conduct face to face interviews to collect data. This method gives the researcher more control over the research process and allows the collection of large amounts of data from a sizeable population and thus the researcher felt that the method could establish the nature of the existing conditions and the problems that the people with disabilities face in their day to day living. By using the survey design the researcher collected a lot of data on opinions, attitudes and feelings of the people with disabilities.

The target population in this study included the handicapped, the albinos, the blind and the guardians of the deaf and dump in order to get the correct information. The researchers used purposive sampling method to come up with the number of individuals to be used in the research and this method of sampling will reduce the level of bias in choosing the number of participants from each group. A sample of 30 participants from among people with disability and 5 key informants were used in data collection.

Study Limitations

The study suffered from methodological limitations particularly in the sample size. The study focused on only one rural constituency. However, the number of respondents for the study was large enough to ensure a representative distribution of the population and to be considered representative of groups of people to whom results will be generalized or transferred.

Data Analysis

Logical content analysis of data was used. As such, the content of data was simplified. Data or research findings were presented into graphs, tables and charts to simplify the findings and for easy analysis as well as evaluation.

FINDINGS AND DISCUSSION

Figure 5.1 above shows that the majority of the participants (50%) were physically handicapped. The other participants were albinos, visually impaired and deaf and dump. The United Nations Convention on the rights of people with disabilities has defined people with disabilities as those who have long term physical, mental, intellectual or sensory impairment which in interaction with various barriers may hinder their full participation in society on equal basis (United Nations Enable, 2006). Those who are physically handicapped, deaf and dump, visually impaired and albinos are covered in the United

Chijokwe Sithinyiwe & Mutanana Ngonidzashé “An Exploration on the Challenges Faced by People with Disabilities in HIV and AIDS Prevention, Care, Support and Treatment in Chipinge West Constituency in Zimbabwe”

Nations Convention of the rights of people with disabilities definition. According to the United Nations Enable (ibid) the world organisation has estimated that there are at least 650 million people with disabilities worldwide.

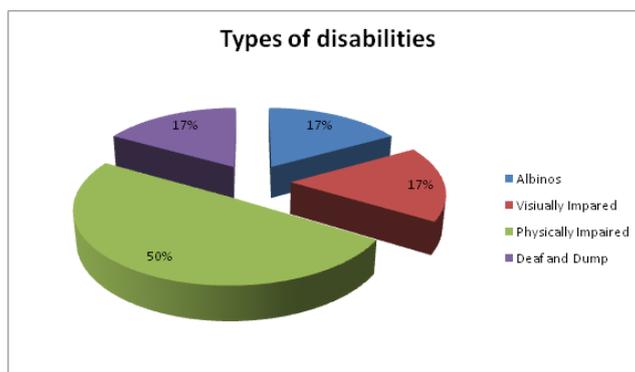


Fig1. Types of disabilities identified (N=30)

Source: Study Results in Chipinge West Constituency in 2015

People with disabilities (PWD) are exposed to the HIV and AIDS epidemic, contrary to the perception by many people that they are not. Most studies conducted in African countries have revealed that people with disabilities are aware of the HIV and AIDS epidemic. For instance, Banda (2005) discovered that most people living with disability perceive themselves as particularly vulnerable to contracting HIV. Giros (2004) also found that people with disabilities are fully aware of the consequences of the HIV and AIDS epidemic. In another study, Mulindwa (2003) observed that 55% of people with disabilities in Uganda perceived themselves as at risk of contracting HIV. Ngazi (2004) in Zimbabwe showed that 75% of participants perceived themselves to be at risk of HIV infection. In Kenya a study among the deaf indicated that 80% also perceived themselves to be at risk. Similarly, Phillander (2006) in South Africa discovered that 93% of the people who are blind indicated that they could be at risk of contracting HIV. What it shows is that people with disabilities need treatment, care, prevention and support on HIV and AIDS issues.

Table5.1. Responses on whether participants have been involved in a sexual encounter (N=30)

Participants	Involvement in sexual activity	Percentage (%)
Male	12	40
Female	18	60

Source: Study Results in Chipinge West Constituency in 2015

Table 5.1 above shows that all the participants have engaged in a sexual activity at some point in their life. What it shows is that people with disabilities are sexually active like any other person. According to Groce (2004) a global survey by the World Bank and Yale University on HIV and AIDS effectively disproved the myth that persons with disabilities are not likely to be sexually active and therefore not at significant risk of HIV infection. Shisana et al. (2008) and Touko et al. (2010) discovered that HIV and AIDS represented a significant threat to persons with disabilities, with prevalence comparable to—and in some places possibly higher than—rates found in the overall population. This is contrary to the misconception that people with disabilities are asexual and therefore should not be involved in campaigns and sex and reproductive education. However, six of the participants had sexual encounters out of sexual abuse and exploitation. A key informant claimed that many of these people are exploited because it is believed that if you have sexual intercourse with a girl who is still virgin it helps to treat AIDS. Similarly, Yousafzai et al’s, (2004) in a study in Swaziland observed that sexual abuse and exploitation was believed to be higher among the disabled women than their non-disabled peers because the disabled are perceived to be free from the HIV virus.

Table5.2. Responses on whether participants have knowledge about HIV and AIDS (N=30)

Respondents	Number of Participants	Percentage (%)
Have enough knowledge	06	20
Slightly knowledgeable	08	27
No knowledge	16	53

Source: Study Results in Chipinge West Constituency in 2015.

Chijokwe Sithinyiwe & Mutanana Ngonidzashe “An Exploration on the Challenges Faced by People with Disabilities in HIV and AIDS Prevention, Care, Support and Treatment in Chipinge West Constituency in Zimbabwe”

Table 5.2 above shows that the majority of people with disabilities (53%) have no knowledge about HIV and AIDS. This was supported by a key informant who has observed that the majority of people with a disability in the rural community are not well equipped with knowledge about HIV and AIDS. What it shows is that these people are being deprived of the necessary information to prevent themselves from the HIV and AIDS epidemic. Similarly, Wazakili et al (2006) observed that people who have disabilities have limited factual HIV knowledge and that their choices about sexual behaviour are not informed by what they know but actually by the context in which they live. Consequently, they want to conform to what others are doing in the community and to be part of the community. Nduta et al (2010) also observed that inspite of the growing number of PWD, little is known about HIV and AIDS. Cambridge (1997) attribute this lack of knowledge to literacy rates of PWDs which he claims are exceptionally low and estimates that the adult literacy rate is only 3% globally. Communication of information and messages about HIV and AIDS becomes difficult.

Participation in HIV and AIDS Awareness and Programming.

Key informants interviewed disclosed that people with disability are not participating in HIV and AIDS awareness programmes. They are excluded from activities such as training and other development projects. As a result awareness of HIV and AIDS among the people with disability is low and HIV and AIDS programs are inaccessible as a result of exclusion. There is lack of representation of the people with disabilities in programming as members, office bearers and leaders in HIV and AIDS programming. This is supported by several researchers such as Shisana et al. (2008), Hanass-Hancock, Strode, and Grant (2011), Chireshe, Rutondoki, and Ojwang (2010) and Yousafzai (2005) who have reported clearly that persons with disabilities are not included in HIV outreach efforts, national HIV strategic plans, or HIV-related services, and are not being reached by the general HIV prevention campaigns. Nduta et al (2010) argue that most organisations working in the area of HIV have not included PWDs in their programmes, or do not know how to do this while disability targeted organisations rarely have HIV on their agenda, or do not know how to develop HIV and AIDS programmes and projects. Collins et al (2001) believes that the consequence is that sex education programmes for those with disability become rare. To support Collins (ibid) observation, UNICEF (1999) claim that there are no general campaigns about HIV and AIDS that focus on the needs of PWDs or include disabled populations and there few rehabilitation services, especially in rural areas with an estimate of only 3% of PWD getting access to the rehabilitation services they need. What it shows is that PWD disability need to part of the programmes and projects about HIV and AIDS programmes. This does not only bring a sense of ownership about the programmes, but it also enhances responsibility among PWDs.

Table5.3. Responses on whether participants are having access to health service (N=30).

Respondents	Accessibility to Health Services.	Lack of accessibility
Albinos	03	02
Visually impaired	00	05
Physically Handicapped.	05	10
Deaf and Dump	00	05
Total (%)	27	73

Source: Study Results in Chipinge West Constituency in 2015

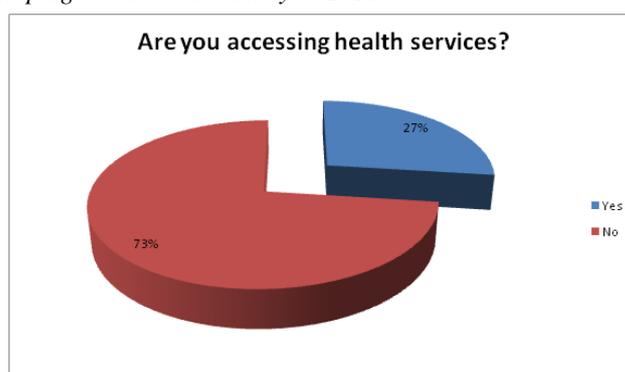


Fig5.2 Responses on whether participants are having access to health services(N=30)

Source: Study Results in Chipinge West Constituency in 2015

Chijokwe Sithinyiwe & Mutanana Ngonidzasho “An Exploration on the Challenges Faced by People with Disabilities in HIV and AIDS Prevention, Care, Support and Treatment in Chipinge West Constituency in Zimbabwe”

Table 5.4 and figure 5.2 above show that health services particularly on HIV and AIDS are not accessible to PWD in the district. Findings revealed that only 23 % are having access to health services. The majority indicated that they had difficulties in accessing health care services. A key informant noted that HIV and AIDS treatment initiation was conducted at large Clinics or Hospitals such as Chipinge District hospital, Birchenough Bridge hospital, Mount Selinda hospital and Saint Peters hospital at Checheche Growth point. Distance becomes a barrier in accessing care and support among the disabled as these health centres are far away from PWDs. Another key informant explained that some PWDs lacked the financial resources to go to the hospitals and as a result they fail to access the services. Those who are closer to the health services expressed dissatisfaction with the services offered by health care personnel. Some have negative perceptions towards people with a disability. Consequently, some have to think twice before they go for HIV health service. They therefore fail to access the facilities due to negative attitude, perceptions and feelings towards the disabled in HIV and AIDS related issues. Nduta et al (2010) explain that the majority of the existing HIV Testing and Counselling (HTC) services are physically inaccessible, do not offer counselling using sign language. Information Education Communication (IEC) materials on HIV and AIDS are not available in Braille for the visually impaired, complex and vague messages do not reach those with intellectual impairments. Nduta et al (ibid) also argue that the physically handicapped people often depend on their sexual partners to put on condoms. According to UNFPA (2003), people with disabilities are not aware of their reproductive health rights and the existing sexual and reproductive health (SRH) services are often inaccessible to them. This exposes PWD to the HIV and AIDS epidemic.

The Extent of the Difficulties amongst the Physically Challenged.

Findings revealed that PWDs are having difficulties food security and lack of proper nutritional requirements and management. The majority claimed that they felt hungry after taking drugs and the drugs they take make them feel uncomfortable especially when take them without food. Consequently, some skip drugs putting them at the risk of drug resistance and complications. Some said due to poor nutrition they suffered from side effects due to the antiretroviral drugs that they take without proper nutrition. Watson (1994) claims that food cannot cure AIDS nor does it treat the virus, but can certainly improve the fitness and the quality of life of people living with HIV and AIDS. Yousafzi and Edwards (2004) claim that in many places across sub-Saharan Africa, where these factors are pervasive, a person who has a disability and who is HIV-positive often experiences double discrimination and perhaps triple if the person is female. Rohleder (2009) identify factors that increase the vulnerability of persons with disabilities to HIV as poverty, lack of education, lack of sex education, lack of knowledge about HIV and safe sex practices, sexual abuse, substance abuse, poor access to health services, and stigma and discrimination.

CONCLUSION

Based on these findings, the researchers concluded that;

- Persons with disabilities are sexuality active contrary to the belief by many people that they are not.
- Persons with disabilities are not knowledgeable about HIV and AIDS related issues.
- People with disabilities are not participating in programmes and projects related to HIV and AIDS issues.
- People with disabilities are failing to have access to health services because of distance, poor communication and negative attitude from service providers.
- People with disabilities are facing challenges of food insecurity which affect them when they are taking their drugs.

RECOMMENDATIONS

Based on these conclusions, the researchers recommended that,

- There is need to empower the people with disabilities. To achieve empowerment of the disability, both the disabled and the able-bodied need to be allies and partners in the reform.

Chijokwe Sithinyiwe & Mutanana Ngonidzashé “An Exploration on the Challenges Faced by People with Disabilities in HIV and AIDS Prevention, Care, Support and Treatment in Chipinge West Constituency in Zimbabwe”

- The people involved in HIV and AIDS programs need to ensure that people with disabilities are able to and participate in information and training sessions.
- There is need for comprehensive accessibility to health care by the disabled.
- There is need for people with disabilities to feel that they are part of the family and community even when they are disabled and this can start with family members or at family level. This can be done through the show of love, security, encouragement, confidence, motivation and thus the development of self-esteem.

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Chijokwe Sithinyiwe & Mutanana Ngonidzashe “An Exploration on the Challenges Faced by People with Disabilities in HIV and AIDS Prevention, Care, Support and Treatment in Chipinge West Constituency in Zimbabwe”

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