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Literature Review

Barriers to HIV and AIDS Prevention, Treatment, and Care among People Living with Disabilities in Tanzania: A Cross-Sectional Study

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Abstract

Background: People living with disability in the context of a generalised HIV/AIDS epidemic potentially shoulder multiple burdens of disability, poverty, stigma and discrimination. This is obvious when a person is both disabled and HIV positive. Despite the fact that they are at equal or increased risk for HIV infection, more often, their specific needs regarding HIV/AIDS prevention, treatment, care and support services are not well aligned with existing HIV/AIDS policies and programmes.

Objectives: The objectives of this study among others were to determine the important factors affecting disabled people's access to HIV/AIDS information, counselling, testing, treatment care and support services, and to assess whether the design, content and format of HIV/ AIDS IEC materials are accessible, friendly and communicate the required messages to the disabled for behaviour change, prevention, treatment, care and support services in order to inform programming for HIV and AIDS interventions which are currently not user-friendly to the special needs of people living with disabilities.

Methodology: This study employed cross sectional design whereby qualitative and quantitative methods of data collection and analysis were used. In qualitative methods of data collection, key informant interviews were used as a principal technique whereas structured questionnaire with close-ended questions was the key technique for quantitative data collection. Analysis of quantitative data was done using STATA® statistical software. Thematic content analysis was used for qualitative data analysis.

Results: The major findings of this study are summarised as follows: The physically disabled people constitute the highest (43%) of the studied population. In addition 79.9% indicated that main reason of perceiving themselves to be at the same or higher (compared to non-disabled peers) level of risk of HIV infection is because they are sexually active, contrary to the popular misconception by community members that disabled people are not sexually active. The level of stigma and discrimination against disabled people is still high in the communities. In this study, 49.4% of the interviewed participants believed/thought that they stigmatised and discriminated because of either being disabled or being HIV+. Related to this, 39% of the interviewed participants said that they have ever experienced stigma and discrimination either in the communities they live or when they were seeking health care at health facilities. Moreover, majority (90%) of the blind, 77.5% of the mentally challenged, 60.4% of the dumb and 58.8% of the physically challenged) of the disabled people considered that the existing IEC materials are not user-friendly (in terms of format and content) to the needs of different types of disabled people.

Conclusion: The descriptive findings from quantitative and qualitative data permit two major conclusions regarding barriers which affect disabled people from accessing HIV/AIDS services. Firstly, access and utilisation of HIV/AIDS services among disabled people is mainly affected by high levels of stigma and discrimination by community members and health care workers. Secondly, unfriendliness of the existing IEC intervention aggravates the marginalisation of disabled people from accessing HIV/AIDS prevention messages and information about treatment, care and support services related.

Background

A hallmark of the HIV/AIDS epidemic has been its impact on vulnerable populations. Surprisingly, one of the world's most vulnerable populations - individuals who live with a permanent physical, sensory (deafness, blindness), intellectual, or mental health disability - had been almost entirely overlooked despite the fact that they are at equal or at increased risk of exposure to all known risk factors for HIV and AIDS [1,2]. Although people living with disabilities in Tanzania are considered a vulnerable group in almost all national HIV policy documents and programmes HIV initiatives have rarely targeted the country's four million or so disabled individuals, nor taken into account their unique circumstances and needs. This negligence or rather indifference might partly be explained by lack of comprehensive data to support effective programming for the needs of disabled people. Thus, the aim of this paper isto attempt and bridge the evidence gaps on the barriers to HIV/AIDS prevention, treatment and care among people living with disabilities and recommend for optimal interventions for future directions in the fight against HIV/AIDS. In achieving the above thispaper attempts tospecifically addressthe following: Firstly; to determine the important

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factors affecting disabled people's access to HIV/AIDS information, on counselling, testing, treatment, care and support services and secondly to assess disabled people's awareness, Knowledge Attitude and Perceptions of the implementation of the existing HIV/AIDS interventions on prevention, treatment, care and support services in their communities.

There is no single definition of disability. The World Health Organization defines it as a "physical, sensory, intellectual, or mental health impairment that has significant and long-lasting effects on the individual's daily life and activities" [1]. Tanzania's National Disability Policy (2004) defines it as "the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical, mental or social factors" [6]. Disability is defined in this paper is in accordance with the latter and therefore includes people with albinism and intellectual/mental impairment.

It is commonly assumed that individuals with disability are at low risk of HIV infection. Disabled people are often incorrectly believed to be sexually inactive, unlikely to use drugs or alcohol, and at less risk of violence or rape than their non-disabled peers. However, since the last few years, there has been a growing body of literature which indicates that these assumptions are far from true [3]. Note that, many of the published evidence on the interplay between HIV/AIDS and disability point to a consensus that many of the established risk factors for HIV/AIDS - poverty, illiteracy, stigma, and marginalization - are identical to those for disability [2,4].

Related to the above observations, individuals with disabilities are considered more at risk of HIV - Infection mainly because of social exclusion factors such as being deprived of information, education and communication, and in particular the women and children who are exposed to sexual exploitation due to society's likening of disability with less essential, desperate and fruitless people. It is not inevitable for many to assume that persons with physical and sensory (deafness, blindness), or intellectual disabilities are not at high risk of HIV infection. Unfortunately, there are wrong perceptions that disabled people are not sexually active, unlikely to use drugs or alcohol, and at less risk of violence or rape than their non-disabled peers [1-4]. Research and programming for this population lag behind compared to what is available for the general population.

A series of Tanzania Demographic and Health Surveys (For example [3] have been done, but little or virtually none of these reports has documented on the burden of HIV/AIDS among disabled people in relation to their specific needs. This may perhaps be due to the wrong perceptions and probably misconceptions about disabled people's exposure to HIV/AIDS risk factors. The literature further indicate that because of limited access to HIV/AIDS interventions, it is obvious that disabled people shoulder 'four burdens' namely: (1) Living with HIV/AIDS; (2) Facing HIV/AIDS-related stigma and discrimination; (3) Living with disability; (4) Facing disability-related stigma and discrimination [1-3]. There is an obvious evidence gap in many countries hit by the disease (including Tanzania) on how to break the barriers that disabled people face in accessing and utilising HIV/AIDS interventions as they equally face the same level (or more) of risk factors of being infected and affected by HIV and AIDS.

The exact number of persons with disabilities in sub-Saharan Africa infected with HIV is unknown, but it is presumed that prevalence rates among this group are high. According to the World Health Organization (WHO), it is estimated that a total of 600 million individuals are currently living with a disability of one form or the other. Of this total, approximately eighty percent of people with disabilities are living in the developing countries [1-3]. Most persons with disabilities are considered to be the poorest citizens in most if not all of the communities where they reside [1-5].

Recent estimates in Tanzania indicate that about four million people were living with a disability by the year 2008, half of whom were children [3]. This figure includes all types of disabilities, such as the visually impaired (the blind) people and the deaf. In Tanzania, little is known about how disabled people access (or face access barriers to) HIV/AIDS prevention, treatment, care and support services interventions. In addition, reaching them with education and healthcare services is a challenge as resources are scarce. They often need special services for information and other interventions. In other words, very few of them have access to basic services or even know the existing resources. Anecdotal evidence regarding IEC materials for behaviour change communication indicates that they have not been friendly to the specific needs of disabled people. For example, the content, format and positioning of these IEC materials have been questioned on whether they equally cater for specific needs of all groups of disabled people as the case it is for their non-disabled peers.

There are several reasons to justify that people living with disabilities are at a high risk of HIV/AIDS infection and thus logical to find evidence which will inform HIV/AIDS programmatic decision making. These reasons can be summarised as follows:-

Limited access to HIV/AIDS information

People with disabilities are widely shut out of formal education: an estimated 98 per cent of the world's disabled children are not in school and 97 per cent of people living with a disability are illiterate. In addition, information, including HIV information, is rarely circulated in an accessible format (e.g. Braille, using simplified pictorial formats) for this vulnerable groups [1].

Stigma and discrimination

Parents, caregivers and health workers often assume people with disabilities do not have sex, or disapprove of them being sexually active. This can result in caregivers refusing to escort them to health service centres; health workers turning them away; or them being missed during HIV outreach work as some of the community members with grave misconceptions about people with disabilities tend to hide them in their households [2].

Limited access to health services

The often health workers' negative attitudes (perceived or real) towards people with disabilities, are frequently seen as a barrier to accessing health services among this vulnerable group: for example, service providers may lack knowledge of the special needs of people with disabilities, or may have stigmatizing attitudes towards them. They may also consider them to be a low priority for their care, attention or treatment. This may further marginalise them from not only accessing HIV/AIDS services but also from accessing and utilising other non-HIV/AIDS support services.

Increased incidence of sexual abuse among the disabled people

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People who live with a disability are up to three times more likely to be victims of physical and sexual abuse. They are often perceived as easy targets, unable to fight off, recognise, or report their perpetrators [2]. Women and girls who are intellectually challenged and those in special schools and care facilities are particularly at a higher risk. Since people with disabilities are widely thought to be sexually inactive, they have become victims of the 'cleansing myth' of 'virgin rape' (i.e. the notion that you can pass your own HIV infection on if you sleep with a virgin) [2]. Groce and Trasi (2004) found evidence of the virgin rape practice in two thirds of the countries studied for the Global HIV/AIDS and disability survey [2]. Dependency, isolation and the general environment of discrimination also mean that people with disabilities are less likely to report abuse or seek (or gain) legal recourse [1-2].

Disabled people are equally affected by HIV/AIDS as their non-disabled peers

Having a child with a disability makes one more vulnerable to infection [3-4]. For example, test results compiled in Tanzania's disability hospital in 2001/2 showed that mothers with a disabled child were twice more likely to be infected with HIV than non-disabled pregnant mothers [3]. Giving birth to a child with a disability makes an individual to be more likely to be abandoned by a husband or wife, move rapidly through a series of relationships, or engage in transactional or paid sex in order to survive. In turn, having a parent who is HIV positive is likely to reduce the quality of one's care: a vicious cycle of disability and HIV/ AIDS [3-6].

Surveys, not surprisingly, reveal that people with disabilities have less knowledge about HIV than other people. Part of the world survey provided data indicating that deaf participants are more likely to believe in incorrect modes of transmission ($p < 0.05$), like kissing, hugging, touching or sharing dishes [2,7]. The two studies quoted above were conducted in Nigeria and Swaziland used comparison groups. Otteet al, whose research included a comparison group, reveal similar data about blind adolescents in Nigeria. The study found that blind adolescents are prone to believing in wrong modes of transmission and prevention ($p = 0.001$). However, the same study found no significant differences for questions related to HIV treatment [8].

Wazakili et al (no comparison group) make similar claims about young people with physical disabilities. Their study reveals that the participants have limited factual HIV knowledge and that their choices about sexual behaviour are not informed by what they know. The authors emphasize that the sexual behaviour of adolescents with disabilities is particularly influenced by their living contexts [9-10]. Looking at disability more broadly, Munthali's study in Malawi (no comparison group) yields similar results and states that "knowledge about HIV is basic". Thirty-six percent of the respondents stated that HIV is AIDS, and 42.5% said that they could tell if someone has AIDS "by just looking" [11].

In spite of popular misconceptions, people with disabilities are in fact sexually active. Focusing on adults with disability, studieshad revealed that 76% in Malawi had been sexually active while in Cameroon 80% were sexually active and in Kenya 89% were sexually active [7,11-13].

Pregnancy rates also indicate sexual activity and as several studieshad shown that 77% of the participating women had been pregnant [7,11-13]. Although such comprehensive data are not readily available in the Tanzanian context, they clearly indicate that disabled people are at a similar or at least higher risk of HIV/AIDS transmission and thus the existing interventions need to be more focused and pragmatic to cater for specific needs of disabled people and increase their access to prevention, treatment, care and support services.

There is a growing movement to address the need for increased collaboration in programming between those who advocate for the rights of people with disabilities.and those involved in HIV education, prevention, care and treatment [7]. Organizations dedicated to advocating for the rights of People with disabilities are beginning to develop and implement programmes in order to effectively educate People with disabilities on HIV treatment and prevention techniques. Many of the people with disabilities have been excluded from conventional HIV programming, despite having similar or increased rates of exposure to HIV risk factors [1-2]. Unfortunately, the vast majority of HIV and AIDS programmes lack the training, resources and the commitment necessary to accommodate the special needs of People with Disabilities. However, numerous studies are being conducted to examine this gap, and explain what measures must be taken to provide the necessary accommodations [11-13]. The findings presented in this paper is one among such efforts. While many organizations advocating for therights of People with disabilities are actively implementing HIV programming in their curriculum, there is an urgent need for existing HIV/AIDS organizations to follow suit and modify their programming to better integrate the special needs of people living with disabilities. Evidence from this study will thus contribute to HIV/AIDS organisations which will help them to refocus their programming techniques so much that the needs for People with disabilities are effectively integrated in their plans and day to day operations of implementing HIV/AIDS programmes which seem to downplay the special needs of the disabled. The paper is outlined as follows. The following section describes the methodological approaches used to execute the study. This is followed by the results section before presenting the discussions of the key findings, methodological and policy implications and the discussion of strengths and weakness of the study. The conclusion and optional recommendations are presented at the end.

Methodology

Study design

In order to collect data needed to address our research questions and objectives, a cross sectional study design using qualitative and quantitative data collection methods was employed. The study data collection and analysis was conducted between December 2012 and February 2013. The study relied on both in-depth information (through interviews and informal discussions) from representatives of disabled organisations (at regional, district and community levels) and structured and semi-structured interviews with a sample of disabled people. Key informants at community level (village leaders, religious leaders, health facility in-charges) were consulted through interviews and discussions.

Sampling strategy and sample size

Since the main focus of this study was on understanding the plight of disabled people in accessing and utilising HIV/AIDS services, the study employed a purposeful sampling strategy in order to ensure that all study participants are truly disabled (this is only for disabled people who were involved in the questionnaire survey). Key informants at all levels (regional, district and community/village levels) were strategically selected, based on their knowledge and experiences in dealing with PWDs in relation to HIV/AIDS prevention, treatment, care and support. At the regional level, a Regional Social Welfare Officer (RSWO), Regional Medical Officer (RMO), and three (3) representatives of disabled organisation(s) at the regional level (or from the regional umbrella organisation of the disabled people) were considered as key informants at this level. At the district level on the other hand a District Social Welfare Officer (DSWO), the District Medical Officer (DMO), District AIDS Coordinator (DAC) and three representatives from different disabled organisations or from the district umbrella organisations of the disabled people were involved as key informants. In each village/community, in-charge of the health facility in that community was considered as a key informant. In addition two (2) religious leaders (one Moslem and another Christian) and village/community health worker were consulted as key informant at this level (village). Social welfare officers at the ward level were also involved in in-depth interviews.

Regarding which communities/villages to include in each study districts, the research team consulted with the district authorities and leaders of disabled organisations and strategically deicided on this. Thus selection of study communities depended on the context of each particular district so much that, communities/villages which were known to have no disabled persons were not included in the sample.

In case a participant was not legally or ethically competent to respond to the questions (for example the mentally or intellectually challenged individuals), their care takers were enrolled as proxies. Selection of study sites followed a multistage sampling strategy. From the ministry of Health and Social Welfare (MoHSW)'s eight (8) zones, 3 zones were randomly selected and from each zone, three (3) regions were randomly selected. In each region, one district (1) was randomly selected to make up a total of three (3) districts which were included in the study.

To estimate a sample size in a single cross-sectional survey like this one, two numbers were considered importantnamely: a) estimate of the expected proportion (p) of disabled people and b) desired level of absolute precision The determination of the sample size of disabled people to be involved in a questionnaire survey was restricted by the following parameters: 80% power and 95% confidence interval which allows for a relatively small error when making inferences of the study findings. In the calculation of the sample size, we assumed that our study sites had a slightly higher (10.5%) proportion of disabled people than the national average of about 8%. The prevalence was set at that range because the existing data on the proportion of people living with disability is based on a survey done in 2008 and thus many changes might have occurred with time lapse. In this case the sample size of the disabled that was included in the study was expected to be around~ 240 from all selected districts {meaning that, in each district about ~eighty (80) people with disability were involved in the study}. Three districts were selected from three regions namely: Kongwa district (from Dodoma region), Muheza district (from Tanga region) and Moshi urban district (from Kilimanjaro region). However, the researchers were required to conduct some interviews at the regional and district headquarters because most of the organisations dealing with disabilities were headquartered at district and regional headquarters. Thus the data collected reflect both urban and rural pictures. In consultation with village and hamlet leaders, only households where there was/were a disabled Person(s) were purposely selected and were asked to consent in order to participate for the study.

Data Collection Methods and Techniques

Quantitative data

Structured questionnaire with close and open ended questions were used. Information collected included socioeconomic, cultural, demographic, rural/urban backgrounds and the perceived important barriers that might potentially hinder or help adisabled person or some of his/her relatives or friends to access HIV/AIDS services such as prevention, treatment, care and support. These same factors were analysed against the socioeconomic, cultural, demographic and rural or urban background of all respondents.

Qualitative data (in-depth interviews)

At the beginning of interviews, a broad question capturing the study's research questions and objectives was asked to each informant. This was followed by questions which sought clarifications on specific issues on disability and HIV/AIDS in relation to prevention, treatment, care and support services with a focus on people living with disability. An interview guide with open-ended questions was used for this purpose. New issues relevant for the study especially in relation to the interplay between HIV/AIDS and disability were added to the interview guide and were further explored in the subsequent interviews. All the interviews were conducted face to face and in Swahili, which is the official language in Tanzania. In total, 23 key informants were interviewed. Initially it was planned to involve 46 key informants at all levels (regional, district, health facility and community levels). However, after reaching saturation stage, the remaining interviews were terminated.

All the information collected through interviews was tape-recorded. The main topics in all interview sessions at the district and regional levels focused on district/regional officials' practical knowledge and experiences on handling programming and policy matters related to ensuring that people with disability secure equal access (as their non-disabled peers) to HIV/AIDS services without facing any barriers. Particularly, the officials at regional and district level were inquired to unleash their opinions regarding best ways to effectively integrate specific issues as captured by the national disability policies within the existing multi-sectoral HIV/AIDS response as pioneered by the Tanzania Commission for HIV/AIDS (TACAIDS).

At the community level, informants were asked to share their experiences regarding the barriers faced by their disabled community members in their attempt to seek HIV/AIDS services. Specifically, the situation of health facilities and the communities within which disabled people live was discussed to see if they are friendly and effective enough to cater for disabled peoples' special needs for HIV/AIDS prevention, treatment, care and support services.

Data Analysis

(a) Quantitative data analysis

Quantitative data was double entered into a computer database using EpiData (3.1)® software in order to reduce errors induced during data entry. After data entry, two datasets were compared in order to identify and fix errors by matching the correct data as written in the questionnaire. Responses from questionnaire survey were coded before being entered into a computer. Data quality checking process was undertaken and thereafter the database was exported to STATA® statistical software for analysis.Simple descriptive analysis was undertaken and frequencies and proportions were produced.

(b) Qualitative data analysis

All information collected through in-depth interviews was subjected to thematic content analysis. The process of analysing data was iterative and was concurrently done with data collection. The recorded data was transcribed and translated verbatim. The transcribed notes were combined with notes that were hand-written during data collection. Initial familiarization with the data was done at this stage. The research team used multiple-coding which involved the cross-checking of coding strategies and interpretation of data by different researchers. Three researchers were involved in this process. Multiple coding was done to create coding categories which were capable of reflecting the content of the data and concepts used by the informants rather than the questions or concepts predetermined in the interview guide. The coding categories extracted from the transcripts were used to systematically analyse commonalities and apparent contradictions which were reflected in the data by focusing on issues which were repeatedly mentioned or strongly emphasized by the informants. All these processes of analysing data were supported by the use of Atlas T.i™ special software for qualitative data analysis.

(c) Ethical considerations

This study was non-intrusive. However, ethics clearance was requested from the Medical Research Coordinating Committee (MRCC) of the National Institute for Medical Research (NIMR) prior to actual data collection. Informed consent was sought from the study informants and participants after having explained the aims of the study and assuring them that their participation is voluntary and no personal identifiers will be made available to anyone outside the research team. Consent from study participants (for example the mentally challenged) was sought through the involvement of their parents (if they were under 18 years) and care takers and parents. The same process of consenting was used for those with multiple disabilities. For physically disabled people who were not blind, deaf or mentally challenged, consent was sought directly from themselves after explaining the aims/objectives of the study. Regional and district authorities were requested by the research team to provide permission for the study to be conducted in their areas of jurisdiction. Community leaders were consulted as gate keepers (to give permission), before the study was conducted within their communities.

Results

This paper presents results from two strands namely: the quantitative strand and the qualitative strand. We first present the quantitative part which will be followed by the qualitative part. Note that results from both quantitative and qualitative methods should be viewed as complementing each other rather than contradicting. That is, the strentghs of one is further strengthened by the other and the weaknesses of the results from one strand are off-set by the other additively.

Quantitative Results

Socioeconomic and demographic characteristics of study participants

This study involved 240 participants whereby women constituted 48.3% (n=116) while men were 51.7% (n=124). Regarding respondents' marital status, about fifty seven per cent of the respondents were single, 56.67%, (n=136). In addition, 32.92% (n=79), 4.58% (n=11) were widowed and 5.83% (n=14) were divorced respectively. The high proportion of disabled people who were single might partially be explained by the negative perceptions by community members towards people with disabilities, thus giving them limited opportunities to be accepted for marriage. The mean age of the participants was 34.2 years (ranging from 25 years to 55 years). Some of the socioeconomic attributes of the study participants are presented the following Table below. (Table 1).

Types of disabilities studied

There are various types of disabilities with different levels of magnitude in terms of the health impacts they bring to the victims. For the purpose of this study, the following table summarises the findings. (Table 2).

Awareness about HIV/AIDS Programmes

In addition to other interests, this study also sought to understand if disabled people are aware of any HIV/AIDS interventions/programmes existing in their communities, and if there are programmes whichfocus on the specific needs of the disabled people. In this regard, only 20% of the interviewed respondents conceded that they are aware of the existing HIV/AIDS programmes in their communities. In addition only 11.25% indicated that they are aware of HIV/AIDS programmes which focus specificallyon the needs of disabled people in their communities.

Table 1: The highest level of education among the disabled people by gender (N=240).

Level of education	Gender	
	Men %	Women%
No formal education	50 (n=29)	50(n=29)
Completed Primary Education	57.78(n=78)	42.22(n=57)
Secondary education (O-level)	33.33(n=10)	66.67(n=20)
Secondary education(A-level)	0(n=0)	100(5)
Some college/diploma education	100 (n=1)	0(n=0)
University Education	54.55 (n=6)	45.45 (n=5)*

*some might have struggled from form four, get some certificates/diploma and finally upgrade to university.

Table 2: Percentage of people with different types of disabilities.

Type of disability	Percentage (% N=240)
Physically Impaired	43%(n=104)
Deaf	10%.83(n=26)
Blind/visually impaired	26.67%(64)
Mentally/intellectually challenged	5.83%(n=14)
People with Albinism	11.25%(n=27)
The Dumb	2.08%(n=5)

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Table 3: Main source of HIV/AIDS information (N=240).

Source	YES	NO
Radio	70.42% (n=169)	29.58 (n=71)
Television	24.17% (n=58)	75.83% (n=182)
Newspapers	22.92% (n= 55)	77.08% (n=185)
Church/Mosque	39.17% (n=94)	60.83% (n=146)
Health facilities	18.33% (n=44)	81.67% (n=196)
Village meetings	20% (n=48)	80% (n=192)

Table 4: The content of information frequently delivered from different sources.

Content	YES	NO
Safe sex	47.50% (n=114)	52.50% (n=)
STIs	45.42% (n=109)	54.58% (n=131)
Drug abuse/misuse	17.50% (n=42)	82.50% (n=198)

Main sources of HIV/AIDS information about prevention, treatment, care and support services among people with different types disabilities

Table 3 below indicates the main sources of information about HIV/AIDS prevention, treatment and support services among people with disabilities.

Furthermore respondents were asked whether the information from these sources was presented in a user-friendly manner (responsive) to the needs of disabled people. In this, only 17.92% of the respondents agreed that the information was presented in a friendly manner (in terms of format and content) to the needs of the disabled people. In addition, respondents were asked to appraise the type of information relayed from the mentioned main sources. Table 4 below synthesises perceptions of respondents regarding the content of information provided.

HIV/AIDS risk perceptions among people living with disabilities

Unlike the popular misconceptions among community members about disabled people and their risk of being infected with HIV, these findings confirms that the disabled people are well aware of their risks of equally being infected like their fellow non-disabled peers.

Table 5: Why do you consider yourself to be at the same risk level of HIV/AIDS infection as the non-disabled people? (N=174).

Reason for the perception(s)	YES	NO
I am sexually active	79.89% (n=139)	20.11% (n=35)
I m in the same risk of being raped or abused	15.52% (n=27)	84.48% (n=147)
I am in the same risk of drug abuse or misuse	0.57% (n=1)	99.43% (n=173)
I am in the same risk of exposure malpractices in medical procedure	29.89% (n=52)	70.11% (n=122)
I may lack correct and sufficient information about HIV infection	50.57% (n=88)	49.43% (n=86)
I may not have access to HIV prevention programmes	51.72% (n=90)	49.28% (n=84)
My family members may not let me participate in the HIV/AIDS programmes	9.20% (n=16)	90.80% (n=158)
Prevention programme strategies are not in the language and format which I can easily understood	18.39% (32)	81.61% (n=142)

Table 6: Risk perceptions among disabled people relative to non-disabled people (N=240).

Risk perception	YES	NO	Don't know
I consider myself to be at a higher risk of infection than non-disabled peers	62.08% (n=149)	32.92% (79)	5.00% (n=12)
I consider other disabled people to be at a higher risk	68.75% (n=165)	14.58% (n=35)	16.67% (n=40)

This confirms that disabled people are sexually active and are exposed to other risks of HIV infection contrary to the community members misconceptions about disabled people sexual behaviour in particular and sexuality in general. Finding from this study indicate that 72.08% (n=173) of the interviewed respondents said that they are in the same risk level of HIV infection astheir other non-disabled peers. Among them, 24.17% (n=58) did not consider themselves to be at the same risk level as non-disabled people while 3.75% (n=9) did not know their risk level in comparison with people who are not disabled. The following Table 5 summarises the reasons associated with their risk perceptions

Interestingly and in addition to the above findings, the majority (62.08% n=149) of the interviewed people conceded that they are at a higher risk of HIV infection than their non-disabled peer. Table 6 below summarises these findings:

Access to HIV/AIDS prevention messages, treatment, care and support services and friendliness of IEC materials.

The content and format of IEC materials were consistently complained of by the interviewed participants in this study. Different types of disabled people have quite varied needs in relation to their general health and particularly, in relation to HIV/AIDS needs. The following table (Table 7) summarises the respondents' perceptions on accessing HIV prevention messages and the extent to which the Information, Education and Communication (IEC) materials are friendly and responsive to the needs of disabled people.

Table 7: Disabled peoples' perceptions about friendliness of IEC materials for HIV prevention, treatment, care and support services.

Perception(s)	YES	NO	Don't know
I consider the existing IEC materials for HIV/AIDS prevention, treatment care and support services to be friendly and sensitive to the needs of physically challenged people	27.08% (n=65)	58.75% (n=141)	14.17% (n=34)
I consider the existing IEC materials for HIV/AIDS prevention, treatment care and support services to be friendly and sensitive to the needs of mentally/intellectually challenged people	6.67%(n=16)	77.50% (n=186)	15.83% (n=38)
I consider the existing IEC materials for HIV/AIDS prevention, treatment care and support services to be friendly and sensitive to the needs of the blind/visually impaired	9.17% (n=22)	90.42% (n=217)	0.42% (n=1)
I consider the existing IEC materials for HIV/AIDS prevention, treatment care and support services to be friendly and sensitive to the needs of the Deaf	25.42% (n=61)	51.50% (n=138)	17.08% (n=41)
I consider the existing IEC materials for HIV/AIDS prevention, treatment care and support services to be friendly and sensitive to the needs of the Albinos	43.33% (n=104)	32.92% (n=79)	23.75% (n=57)
I consider the existing IEC materials for HIV/AIDS prevention, treatment care and support services to be friendly and sensitive to the needs of the Dumb	21.25% (n=51)	60.42% (n=145)	18.33% (n=44)

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Table 8: Perceived stigma and discrimination against people living with disabilities in relation to access to HIV/AIDS prevention, treatment, and care and support services.

Perception(s)	YES	NO	Don't know
Do you think/believe that a disabled person can be stigmatised and discriminated by his/her being HIV+ status and by being disabled?	49.37% n=118	33.05% (n=79)	17.45% (n=42)
Have you ever experienced sigma/discrimination in the community or when seeking health care at the health facility?	39.58% (n=95)	57.50% (n=138)	2.92% (n=7)
Do you know any person with disability who had experienced stigma and discrimination in the community or when seeking care?	42.08% (n=101)	46.67% (n=112)	11.25% (n=27)

Stigma and discrimination and the experienced difficulties in accessing and understanding HIV/AIDS prevention messages, treatment and support services among people living with disabilities.

Findings in this study profile the dreadful situation of the existing stigma and discrimination against people with disability. In addition, people who happen to simultaneously live with disability and HIV perceive themselves to face a double burden of stigma and discrimination namely; one that is associated with their disability and the other one associated with their HIV status especially when health workers and community members are aware that some disabled person(s) are HIV+. The following table (Table 8) highlights the magnitude of stigma of stigma and discrimination as perceived by the interviewed disabled people and their implications for difficulties they face in accessing health care services particularly HIV prevention, treatment, care and support services.

In addition, this study sought to know what are the reasons which lead to disabled peoples' perception of being discriminated. The majority (88.54%) perceived that stigma and discrimination against them was because of their being disabled. In addition 2.08% perceived that their HIV+ status was the main reason for their being stigmatised and discriminated against. Additionally, 4.17% considered that their being disabled and HIV+ at a go was the main reason of their being stigmatised and discriminated.

Qualitative Findings

This section presents qualitative findings with the aim to confirm, coimpliment and consolidate what has been done in the quantitative part of the results section. Note that the qualitative information analysed and presented in this sections come from more or less the same key questions as used to capture quantitative data and thus it is an attempt to triangulate the findings methodologically and from different participants and different context texts. In this way, we attempt to enrich the interpretation of our findings to allow for a broader and a more comprehensive conclusions of issues covered in the analyses pertaining to barriers to HIV/AIDS prevention, treatment and care among the disabled people in a resource constrained setting, like Tanzania.

HIV counselling and testing among disabled people

HIV/AIDS counselling is one of the key entry points to utilisation of other important services related to HIV and AIDS. In this regard, majority of key informants in the study sites indicated that people living with different types of disabilities always go to the nearby health facilities for HIV/AIDS counselling and testing. There was however a consensus among informants that relative to the general population and the number of disabled people in the community, it happens most often that people with disability come for counselling in small numbers. It was further clarified that, among those few who attend for counselling and testing, it is because of the influence of friends in the communities they leave and health workers' advice especially when they attend health facilities for treatment of other diseases such as Malaria. Long distances to health facilities was mentioned to be one of important factors for disabled people's access to HIV/AIDS services. This finding confirms what was presented in the quantitative findings section

….“ Distance to health facilities and income poverty are among the key factors which hinder disabled people's access to health services, including those related to HIV and AIDS. In some cases however, it is due to disabled peoples' hesitance to seek HI/AIDS counselling and testing services. They hesitate to get tested as they are scared of getting positive results. In fact it is not only the positive results which scare them but also the stigma and discrimination tendencies which are still entrenched in the communities where they live" (Key informant, district level)

Care, treatment and support services among disabled people

It was of interest to understand health workers' and other informants' experiences on treatment, care and support services for the disabled people. It was confirmed by the majority of key informants at health facilities that treatment for disabled is available and given to the disabled people much the same way and following the same standard operating procedures similar to those applied to their non-disabled peers. Almost all district health managers had the view that HIV/AIDS treatment, care and support services to the disabled people are delivered through the cooperation of different stakeholders from the district down to the community levels.

Availability and user friendliness of HIV/AIDS Information, Education and Communication (IEC) materials

Majority of interviewed key informants conceded that HIV/AIDS information, education and communication materials are available in different places such as schools, health facilities and community halls.This is in line with what is reported earlier in the quantitative analyses. However they unanimously conceded that the available IEC materials are not friendly to some categories of people with disabilities. During the interviews with key informants, it was learnt that there are virtually no IEC materials (except the audio materials through radio) particularly those which are suitable for the blind. Equally, informants were deeply concerned about the difficulties that the deaf experience in accessing preventive and treatment messages presented in audio or visualised formats.

"I think HIV/AIDS programme managers and other stakeholders should consider the special needs of the disabled people and the barriers that they face in their quest to access HIV/AIDS information in order to put them as an equal peers with other non-disabled, when it comes to accessing information about prevention, treatment and other support services associated with the disease..”(Key informant, Regional level)

Regarding the level of awareness of HIV/AIDS among disabled people, key informants described the level of knowledge among all categories of disabled people as 'very high'.

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"…Not just disabled people but all members of this community are aware about the presence and dangers of the disease. The problem which is looming around our communities is the way the contents of HIV/AIDS messages are packaged and presented. In fact their presentation is not fairly done to the extent that the costs incurred to design, produce and distribute them, are far higher than the expected outcome" (Key Informants, district level).

Disabled peoples' utilisation of HIV/AIDS, treatment, care and support services

Majority of informants at the district and community levels conceded that disabled people are well aware about the HIV/AIDS scourge. However, community attitudes and misconception about disabled peoples' participation in sexual activities, stigma and discrimination, negatively influence disabled peoples' utilisation of health services particularly those related to HIV and AIDS

HIV Risk perception among disabled people

It was confirmed by majority of informants at all levels that to date, almost everyone (disabled and non-disabled) in the communities are aware that (s) he can be in the same risk level of the HIV infection. It was further conceded that people disabled peoples' risk of HIV-infection is always underestimated due to community misconception about their vulnerability. The following quote concretises this observation and thus confirms what we observed in the quantitative analyses of the data presented in this paper:

.. Most often people with disabilities are misperceived especially when community members consider them as free from all kinds of risks to HIV infection. In fact, they are more at risk because of their limited access to information, education and health care services. In addition their vulnerability to poverty further marginalises them from accessing different HIV/AIDS services" (Key informant, district level).

Stigma and discrimination against people with disabilities

Majority of key informants at all levels conceded that stigma and discrimination against people with disability and who are HIV+ is still visible in the communities. The following quote clearly illustrates this contention,

"..It is unfortunate that after so many years of implementing interventions which addresses issues related to HIV/AIDS and disability, stigma and discrimination is still an important factor which negatively affect efforts which are geared to increasing access and utilisation of health services (including HIV/AIDS services) among disabled people" (Key informant, district level).

Discussion

This study attempted to shed light on how the disabled people are left out in the many HIV/AIDS interventions which are currently ongoing in the country. It has revealed quite a number of issues affecting people with disabilities which were previously taken for granted or are simply misconceived and thus given low priority in HIV/AIDS policies and programmes. The following sections are devoted to discussing these issues.

Awareness about HIV/AIDS programmes

Findings from this study indicate a discouraging picture that a small proportion (20%) of interviewed participants was aware of the existing HIV/AIDS programmes in the communities they live. An even smaller proportion (11.3%) admitted that they were aware of the HIV/AIDS programmes in their communities. This finding implies that, the existing IEC materials for HIV/AIDS services have not been effective enough to reach the disabled population as required. In addition, low levels of education among the disabled people could also partially explain why there is low proportion of disabled who are aware of HIV/AIDS programme within their communities [13-17].

Perceived risk of HIV infection among disabled people

Majority (62%) perceived themselves to be at a higher risk of infection than non disabled peers. In addition, about 68% of the interviewed participants perceived their fellow disabled people to be at a higher risk of being infected by HIV. The main reason given by interviewed respondents on why they perceive themselves to be at a higher or same risk with non-disabled peers was that they are 'sexually active' (79.9%). This finding refutes a popular misconception among many community members that disabled people are at a lower risk of HIV infection than the non-disabled peers. This is so concluded because disabled people are incorrectly perceived to be sexually inactive[1,2,7,13-15]. In addition, this finding indicates that knowledge about HIV/AIDS is not very low to conceive preventive messages delivered by HIV/AIDS programmes. The problem might be due limited HIV/AIDS programme infrastructures which impede disabled people to access and utilise health (HIV/AIDS) services such as counselling and testing among disabled (38%) people who consider themselves as 'not at a higher risk' of HIV infection.

Stigma and discrimination: a barrier to utilisation of HI/ADS services among disabled people

This study confirms that the magnitude of the stigma and discrimination against people living with disability is not insignificant (about 40%). It is even bigger when a disabled person is also living with HIV/AIDS, culminating to what can be termed as 'double burden of stigma and discrimination'. The study has found that 39.6% of the interviewed respondents had had experienced some kind of stigma and discrimination in the community where they live or when seeking care. In addition 42% confirmed that they know of a person who had experienced stigma and discrimination in the communities that they live or when seeking care. More intriguing is the finding that 49.4% of the interviewed respondents believed that a person can be stigmatised and discriminated against because of being both disabled and HIV positive. These findings emphasise the need by policy and programme managers to go back to the drawing board and review the existing strategies foe dealing with stigma and discrimination facing people living with disabilities and HI/AIDS. Several reports emphasise the need for HIV/AIDS programme managers to design disabled –specific interventions in order to take on board the specific needs of disabled people in all HIV/AIDS interventions [1,2,4,7,11-13,14-19].

(User) - Unfriendliness of IEC materials: a barrier for disabled people to access HIV/AIDS prevention messages, treatment, care and support services

Information, Educational and communication materials are essential tool for all people to be knowledgeable about HIV and AIDS and its interplay with disability. This study has indicated

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the inadequacies that are inherent in the existing IEC materials, is one of the main factors which aggravates the marginalisation of disabled people from accessing HIV/AIDS prevention messages, information concerning treatment, care and support services. Accordingly, 90.42% of the interviewed participants considered that the existing IEC materials are not (user) friendly to the special needs of blind or visually impaired people. Similarly, 60.42 % and 77.5% of respondents considered that the existing IEC materials are not friendly to the specific needs of the dumb and mentally challenged people respectively.

The above findings indicate that a relatively large proportion of disabled people might be left out in many HIV/AIDS interventions which use IEC materials as a tool for delivering HIV/AIDS prevention messages, information about treatment, care and support services. The Word Health Organization and Groceet al, have indicated that this situation is exacerbated by extreme poverty and lower levels of education among marginalised people a phenomenon which further marginalises disabled people from the mainstream programmes or interventions which address HIV/AIDS issues for the general [1,2,14-18].

Strengths and limitations of the study

This study is one of the few attempts in Tanzania to analyse barriers to accessing HIV/AIDS services among the disabled people. It has revealed how stigma and discrimination contributes to marginalisation of disabled people in accessing and utilising HIV/AIDS services. It has shown that, there is a great potential for designing affirmative policy interventions which provide for more inclusive and affirmative actions in ensuring that disabled people are taken on board in all HIV/AIDS interventions while at the same time taking cognizance of their special needs. In addition and in terms of methodology, a hybrid approach was used in this study by combining qualitative and quantitative methods which had enriched the study findings. However, this study is limited by its small sample size which hampers the generalizability of its findings. This could not be avoided given the resource constraints.

Conclusion

The descriptive findings from quantitative and qualitative data permit two major conclusions regarding barriers which affect disabled people from accessing HIV/AIDS services. Firstly, access and utilisation of HIV/AIDS services among disabled people is mainly affected by high levels of stigma and discrimination by community members and health workers. Similarly, unfriendliness of the existing IEC intervention aggravates the marginalisation of disabled people from accessing HIV/AIDS prevention messages and information about treatment, care and support services related.

Recommendations

- There is a need for stakeholders to integrate disability issues into HIV/AIDS programmes/interventions. The shared experience of stigma and discrimination of people living with HIV/AIDS and people living with disability provides a strong foundation for stakeholders' collaboration

- Advocacy and awareness campaigns to community members need to be strengthened in order to enhance their understanding of the effects of stigma and discrimination against people living with disabilities and HIV/AIDS.

- In order to get optimal IEC materials, policy makers, programme managers researchers and community members need to mobilise resources and put their efforts together to review the existing IEC materials in order to make them more inclusive and user friendly and thus cater for the special needs of the disabled people.

- Policy makers, HIV and AIDS programme implementers need to ensure that the existing interventions are more focused and pragmatic to cater for specific needs of disabled people and increase their access to prevention, treatment, care and support services for people living with disabilities. This can be achieved by conducting a comprehensive disabled needs' assessment (related to HIV and AIDS services) in order design disabled peoples' focused HI/AIDS programmes and thus take appropriate affirmative actions geared towards doing away with their marginalisation in accessing and utilisation of HIV/AIDS services

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Authors' Contribution

Michael AMunga conceived the idea and led all the processes of study design, preparation of research tools, data collection, and analysis. MAM had the responsibility of preparing the first drafts of this paper. Gilbert MNdyetabula had participated in all processes of study design, research tools development, data collection and analysis; and had commented on all drafts of this paper. All authors read and approved the final manuscript.

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