REVIEW PAPER

Challenges in accessing HIV and AIDS services for persons with disabilities: a review of a study carried out among persons with disabilities living with HIV and AIDS in Uganda

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Abstract

This review reported experiences in accessing human immunodeficiency virus (HIV)/acquired immune deficiency syndrome (AIDS) services of persons with disabilities living with HIV and AIDS in sub-Saharan Africa, Uganda. The purpose was to explore the barriers faced by persons with disabilities living with HIV, which hinder their ability to access HIV services and managing the disease. This study revealed the real-life experiences of persons with disabilities living with HIV to raise awareness among the program implementers and policy-makers about the barriers faced by them in accessing HIV services.

Focus group discussions (FGDs) were conducted in 3 countries, including Ghana, Uganda, and Zambia, with a total of 76 individuals with disabilities living with HIV/AIDS interviewed. In Uganda, there were 28 persons interviewed, and out of the 28 respondents, 1 had hearing impairment, 14 had visual impairment, 12 had physical impairment, and 1 had both physical and visual impairments. Out of 14 participants from Ghana, 4 had hearing impairment, 1 had visual impairment, and 9 were physically impaired. Zambia had a total of 34 respondents with disabilities interviewed living with HIV/AIDS, and out of the 34 respondents, 8 had hearing impairment, 9 visual, and 17 were physically impaired. Study activities were conducted in capital cities of Ghana, i.e., Accra, Uganda, i.e., Kampala, and Zambia, i.e., Lusaka as well as one peri-urban/rural site for each country, i.e., Amasaman in Ghana, Jinja in Uganda, and Solwezi in Zambia. In each country, semi-structured interviews were conducted to obtain information about barriers and facilitators to access HIV services for persons with disabilities. Sign interpreters were employed for FGDs with hearing-impaired individuals, and before each discussion, data collector along with a sign interpreter for deaf participants sought informed consent from potential participants in private, and obtained a signature or fingerprint. Interviews were recorded, transcribed, and translated.

Persons with disabilities living with HIV/AIDS encountered a wide variety of challenges in accessing HIV services. Delays in testing for HIV were common, with most patients postponing testing until they became severely ill. Reasons for delayed testing included challenges in reaching health facilities, lack of information about HIV and testing, and HIV- and disability-related stigma. Barriers to HIV services, such as care and treatment, at health facilities included lack of disability-friendly educational materials and sign interpreters, providers and other patients' stigmatizing approach, lack of skills to provide tailored services to those with disabilities living with HIV, and physically inaccessible infrastructure, all of which were extremely difficult for persons with disabilities to initiate and adhere to HIV treatment. Challenges were similar across the three countries. Favorable experiences in accessing HIV services were reported in Uganda and Zambia, where disability-tailored services were offered by non-governmental organizations and government facilities (Uganda only).

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Article history:
Received: 16.05.2022
Revised: 05.10.2022
Accepted: 06.10.2022
Available online: 05.05.2025

International Journal of HIV-Related Problems
HIV & AIDS Review

The challenges in accessing HIV and AIDS services for persons with disabilities are significant, and have major implications for HIV treatment. Deliberate efforts for necessary changes at every level should be implemented to ensure that individuals with disabilities have access to HIV services. It is crucial to improve the access to HIV and AIDS services among patients with disabilities as well as to enforce the implementation of policies to include these persons at all levels.

HIV AIDS Rev 2025; 24, 2: 94-99
DOI: https://doi.org/10.5114/hivar/155194

Key words: disabilities, access, services, HIV and AIDS, Uganda.

Introduction

Article 1 of the United Nations Convention on the Rights of Persons with Disabilities states that: "Persons with disabilities include those who have long-term physical, mental, intellectual, or sensory impairments, which in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others" [1]. This definition does not explicitly refer to human immunodeficiency virus (HIV) or acquired immune deficiency syndrome (AIDS) in the definition of disability. However, statements are required to recognize that persons living with HIV (asymptomatic or symptomatic) have impairments which, in interaction with the environment, result in stigma, discrimination, and other barriers to fully participate in a society, can fall under the protection of the Convention. Globally, it is estimated that over 650 million people or 10% of the world's population have disabilities. The relationship between HIV and disability has not received proper attention, although persons with disabilities are found among all key populations at higher risk of exposure to HIV. People living with HIV may develop impairments as the disease progresses, and may be considered having a disability when social, economic, political, or other barriers hinder their full and effective participation in a society on equal basis with others. Laws of different countries have been established at the national legal level to advocate for the rights of people with disabilities (PWDs), as indicated below:

- The 1996 Children's Statute for early assessment of disabilities among children to achieve early treatment, rehabilitation, and education.
  - Zambia: Persons with Disabilities Act, 1996.
  - Ghana: Persons with Disability Act, 2006.
- The Parliamentary Elections Statute of 1996 established five positions in the parliament, of which one must be a woman and the use of sign language for the deaf in parliament recognized (International Labor Organization – ILO) 2004: 6; Republic of Uganda 2006).
- The 1997 Local Government Act that established representation of PWDs at all local government levels for both males and females.
- The 1997 Uganda Communication Act for the development of techniques and technologies to ensure communication services for PWDs, and the 1997 Universal Primary Education Act that demands families to give children with disabilities (CWDs) priority at enrolment.
- The 1998 UNISE Act: The establishment of the Uganda National Institute of Education (UNISE) for special teachers' training for CWDs.
- Others include special allocation of university scholarships for persons with disabilities through affirmative action and the right to assets, including land [2-4].

Statement and purpose

Accessibility and utilization of HIV and AIDS services is still a big challenge for individuals with disabilities across sub-Saharan Africa, including Uganda. Globally, it is estimated that persons with disabilities represent approximately 10% of the world's population, with 80% living in low- and middle-income countries. Further evidence indicates that PWDs are at the same or elevated risk of contracting HIV due to various vulnerabilities they face, including poverty, lack of education, lack of sex education, lack of knowledge about HIV and safe sex practices, sexual violence, substance abuse, poor access to health services, and stigma and discrimination [5]. A systematic review by De Beaudrap *et al.* [6] found that persons with disabilities are not at lower risk of HIV infection compared with general population. This was evidenced by stigma from the community, discrimination in accessibility of services, and lack of trained personnel at facilities to provide disability-friendly services, among others.

The current study, therefore, presented an opportunity to explore the challenges faced by persons with disabilities in accessing HIV and AIDS services in Uganda [5].

Material and methods

A total of 28 HIV/AIDS-positive individuals with disabilities, aged 18 years or older, were participating in the study. Out of 28 subjects, 1 had hearing impairment, 14 had visual impairment, 12 had physical impairment, and 1 had both physical and visual impairments. Participants were recruited through a convenience sampling of disability partner organizations (DPOs) and peer referrals. Designated DPO staff recruited candidates in private and confidential manner, providing information about the study, including eligibility criteria. DPO staff instructed interested candidates to attend a focus group discussion (FGD) at specified time and place, where they were screened and consented. Participants were also asked to invite potentially interested and eligible peers with disabilities to contact DPO staff. The study was conducted in three countries, including Ghana, Uganda, and Zambia, representing settings of different stages of the HIV epidemic as well as the degree, to which the needs of persons with disabilities are recognized in the National Strategic Plan for HIV and AIDS. In order to explore factors affecting access and utilizing HIV services, FGDs were conducted among persons with disabilities living with HIV [5, 7]. Study activities were performed in capital cities (Accra, Kampala, and Lusaka), and one peri-urban or rural site (Amasaman, Jinja, and Solwezi) in each country. Respondents were interviewed at different intervals. Assistants waited in another room to maintain confidentiality of participants during FGD. Semi-structured interviews were conducted to elicit information about barriers and facilitators to access HIV services by persons with disabilities [5]. Sign interpreters were employed for FGDs with hearing-impaired persons, and before each FGD, data collector along with a sign interpreter for deaf participants, sought informed consent of each potential participant in private, and obtained signature or fingerprint. Interviews were recorded, transcribed, and translated. The study was approved by the Ethical Review Boards of the Population Council, University of Zambia, the Ghana Health Services, the AIDS Support Organization-Uganda, and the Uganda National Council for Science and Technology. FGDs transcripts were imported into ATLAS.ti version 5.2. Research team reviewed transcripts and conducted analysis using a framework analysis approach [5], which is appropriate to describe and interpret what is happening in a specific setting to provide recommendations, as opposed to generating theory to be tested. Codes were developed using key domains outlined during research design and data analysis. Three researchers reviewed the transcripts and added codes based on emergent themes. Themes were assessed and compared to determine how often the same concept emerged across the countries and types of disabilities. Analysts double-coded 30% of the transcripts for quality insurance.

Results

Persons with disabilities living with HIV and AIDS encountered a wide variety of challenges in accessing HIV services, such as delays in HIV testing (which were common), with most of them postponing testing until became severely ill. Reasons for delayed testing included challenges in reaching health facilities, lack of information about HIV/AIDS and testing, and disability-related stigma. While barriers to HIV-related services (with care and treatment) at health facilities were lack of disability-friendly educational materials and sign language interpreters, providers and other patients' stigmatizing approach, lack of skills to provide tailored services to persons with disabilities living with HIV, and physically inaccessible infrastructure, all of which were extremely difficult for persons with disabilities to initiate and adhere to HIV treatment. Moreover, females encountered greater challenges regarding accessibility as compared with their male counterparts.

Facility-based HIV services

Consistently, among persons with disabilities, reaching the clinic was a huge barrier to accessing facility-based HIV services, specifically physical access to HIV facilities [7]. Across all types of impairments, most persons with disabilities emphasized the lack of accessible physical infrastructure, such as good roads, sidewalks and ramps deficiency, inability to use public transport as well as the social and emotional trauma of being mocked by other riders or drivers, and having to pay extra for their crutch or wheelchair on a bus. Some of them had to travel with an assistant to help them, but admitted that this brings additional complications due to difficulty of finding a person prepared to devote their time and be publicly seen with a HIV-infected individual as well as the additional transport costs required. A male Ugandan, aged 38 with visual impairment reported:

"We, the blind, we have a challenge – most of our guides do not want to guide us to the areas where the services are offered, simply because they fear the community associating them with HIV and AIDS" [5].

Facility-level barriers – within the clinic

While being at a health facility, participants reported varying experiences on how services address their impairment's specific needs [5]. In all three countries, many subjects indicated that, although they had not been directly refused services because of their disability, the challenges they encountered at health facilities (most often at government facilities) were so numerous and discouraging that they often ended up forgoing HIV treatment or seeking services elsewhere (e.g., at private facilities or from traditional healers). Disability-specific inaccessibility to health facilities, which were mentioned often in all countries, included lack of sign language interpreters and Braille or large-print materials, inaccessible toilets, and lack of ramps and wide doors for wheelchairs [5].

In Uganda, a number of participants reported several ways, in which healthcare facilities and providers recognized and addressed their needs. The respondents indicated that some health facilities were beginning to respond to their needs by improving infrastructure and making accessible information available. Many participants mentioned improved accessibility to some government facilities, such as construction of ramps, and availability of printed HIV-related information resources in large font and pictures [8].

The lack of skills and sensitivity among healthcare providers, regardless of impairment type, was another key obstacle to accessibility of quality HIV and AIDS social services. Most persons with disabilities felt that they were missing out on critical information about how to take care of themselves living with HIV, e.g., taking medications correctly. Deaf participants reported that it was difficult to receive counseling and instructions for taking and adhering to medications. Facilities lack informational materials in accessible format, and several persons with disabilities revealed their desire for information on living positively.

Persons with disabilities commonly reported that healthcare providers, while anticipating communication challenges, frequently give priority to people without disabilities, leading to extended waiting times and consequently, medication' stock-outs by the end of the day [5].

Economic barriers

Most persons with disabilities equally indicated facing excessive economic challenges due to costs associated with traveling to clinics, clinical services, and food to support the increased nutritional needs of people on antiretroviral therapy (ART) [8]. The challenge persons with disabilities experienced was while being poor and on ART, the medicines require them to eat nutritious food; therefore, many of them become reluctant and not taking their medicines, simply because they do not have the money to buy food to accompany the drugs, which results in not taking them at regular basis, as prescribed by doctors. Challenges associated with limited financial resources were especially hard for persons with disabilities, as most of them were unemployed, less educated, and lived in poverty as compared with those without disabilities [8].

Stigma related to HIV and disabilities

Persons with disabilities reported experiencing multiple dimensions of stigma from various sources, resulting in social isolation and being cut off from sources of critical information and services [5]. Briefly, the dual stigma of HIV and disability as well as the internalized stigma, such as feeling ashamed because of disability and HIV status, discourage people from HIV testing due to fear of judgment from others and concern about who will take care of them. The overlapping stigmas were shown the paramount underlying reason for late HIV diagnosis, sub-optimal attendance at health clinics to obtain ART services, and lack of family and community supports. Stigmatizing attitudes were threatening in the community as well as at health facilities. Most individuals with disabilities revealed that they experienced stigmatizing attitudes from other patients and even healthcare providers when accessing HIV/AIDS services [8].

Discussion

The barriers discussed in this paper reflect findings from other studies on persons with disabilities in sub-Saharan Africa. However, the current study emphasizes the struggles faced specifically by persons with disabilities living with HIV in accessing HIV testing as well as obtaining HIV care and treatment services, which may ultimately negatively influence HIV treatment outcomes.

From the reviews of the studies conducted on HIV/AIDS, the findings revealed multiple sources of stigma among persons with disabilities, including those living with HIV, which have equally been reported elsewhere [5]. Through the various voices of persons with disabilities living with HIV, this study highlights specific challenges and facilitators for persons with disabilities living with HIV in accessing HIV services [8]. PWDs encounter enormous challenges in accessing HIV testing as well as continued care and treatment services. These barriers exist at many levels right, including individual (e.g., lack of accessible HIV information), psycho-social (e.g., stigma), economic (e.g., poverty), and health systems (e.g., provider attitudes and skills, inaccessible physical infrastructure) [5]. While some of the barriers are similar to these experienced by HIV-positive patients without disabilities (e.g., HIV-related stigma, long waiting time at health facility), these barriers are amplified for persons with disabilities, with some of the challenges being similar in Uganda and Zambia. Favorable experiences in accessing HIV services were reported in Uganda and Zambia, where disability-tailored services are offered by non-governmental organizations and government facilities (Uganda only) [5, 7].

The barriers highlighted and discussed in the study reflect findings from other studies on persons with disabilities in sub-Saharan Africa. However, the present study emphasizes the struggles faced specifically by persons with disabilities living with HIV in accessing HIV testing as well as obtaining HIV care and treatment services, which may ultimately have a negative impact on HIV treatment outcomes. It was found that the double burden of being HIV-positive with a disability and the associated stigma, lead to delays in accessing essential services, such as HIV testing, due to fear of obtaining positive result and its potential consequences. In addition, many of them postponed HIV diagnosis until severely ill, and upon diagnosis, they did not want to seek care and treatment due to various challenges faced while reaching facilities as well as within the facilities. The challenges at the point of care highlighted in this study included lack of sensitivity and skills among healthcare workers for this population and lack of accessible infrastructure, which significantly inhibited persons with disabilities living with HIV from obtaining the services they needed, including information on correct medication usage, adherence, and how to live positively [5, 7].

The need of accessibility of services to the disabled persons as well as sensitive and compassionate health workers for providing services to this population are extremely vital. In addition, programs need to reach out to persons with disabilities for testing and treatment initiation. For example, testing and ART can be provided through disability organizations or even at home by home-based services, as shown by programs developed in Zambia and Uganda [5]. Such interventions are part of a compendium of best practices in HIV programs for persons with disabilities. Furthermore, interventions should not only be targeted at improving services and infrastructure, such as provision of sign interpreters and accessible materials or delivery of outreach services, but must also address stigma reduction and gender equity within the larger community to reduce stigma associated with HIV and disability as well as the harmful gender norms, which impede the access of women with disabilities to healthcare services.

Despite challenges highlighted in accessing HIV services, the study found favorable experiences emerging from Uganda and Zambia, resulting from actions initiated by NGOs, disability organizations, and supportive national policies. Although the progress may be relatively slow, Zambia and Uganda in particular, serve as examples in supporting and implementing policies and programs to provide tailored HIV services for persons with disabilities living with HIV [7].

Suggestions and recommendations

There is a need for accessible facilities to persons with disabilities as well as sensitive and understanding healthcare workers for providing services to persons with disabilities without discrimination. Furthermore, programs must reach out to persons with disabilities for testing and treatment initiation. For example, testing and ART can be provided through disability organizations or at home, for instance, the National Union of Disabled Persons in Uganda (NUDIPU). Such interventions are part of a compendium of best practices in HIV programs for PWDs. In addition, interventions should not only be targeted at improving services and infrastructure, such as the provision of sign interpreters and accessible materials or delivery of outreach services, but programs must address stigma reduction and gender equity within the larger community, to reduce stigma associated with HIV and disability as well as the harmful gender norms, which impede the access of women with disabilities to healthcare services. The laws and policies protecting and promoting the rights of persons with disabilities should be strengthened and enforced at both national and local levels, as in the case of Uganda, where there is a number of policies promoting the systematic inclusion of persons with disabilities in the national HIV planning efforts, such as the Persons with Disabilities Act, 2006, and other very useful legal frameworks [8]. These should be reinforced through, for instance, ensuring more slots given to persons with disabilities in parliament for effective representation and voicing issues affecting persons with disabilities.

There is need to change both individual and community attitudes, and perceptions towards PWDs, especially that persons with disabilities face dual stigma, and sometimes they are ignored and not attended to. This can be addressed through continuous sensitization of individuals and communities on the rights of persons with disabilities and their self-respect as they have like every other human being.

Limitations

Although the selection of participants according to different impairments enabled capturing a range of experiences, the study sample was small, and may not be representative of persons with disabilities living with HIV in Uganda, Ghana, and Zambia [5]. Furthermore, the sample comprised persons with disabilities, who were linked in some way to disability organizations, and many had basic schooling. Therefore, the sample may be more resourced than other populations with disabilities. This could potentially bias the results to obtain more favorable reports, as those not linked to services may likely experience and report negative experiences to a greater degree than was shown in the current study. However, the participants reported not only their own experiences as persons with disabilities living with HIV, but also about others in similar circumstances. In addition, the use of FGDs as opposed to in-depth interviews could bias the findings as the sample consisted of subjects who were comfortable with openly discussing their experiences as an HIV-positive persons.

Conclusions

The challenges to the accessibility of HIV/AIDS services among persons with disabilities have major implications for HIV treatment outcomes of PWDs living with HIV as well as for reaching the UNAIDS 90-90-90 HIV treatment targets in Uganda and the globe [5, 7]. There should be a deliberate effort to plan the needed changes in Uganda at both the national and local levels, to ensure persons with disabilities have access to HIV services, including the provision of accessible services, infrastructure, availing professionals trained in the use of sign language and other services, which are friendly and understanding to persons with disabilities. Additionally, the formation of support groups for persons with disabilities, change of attitude and harmful practices around those persons, HIV and gender norms within the community and health facilities, outreach and home-based interventions, are all needed to mitigate accessibility barriers.

Disclosures

1. Institutional review board statement: Not applicable.
2. Assistance with the article: None.
3. Financial support and sponsorship: None.
4. Conflicts of interest: None.

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