

The Sepo Study Report

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The purpose of this report is to share findings from the Sepo Study and to facilitate discussions with collaborators and stakeholders about the experiences of people with disabilities who are HIV-positive.

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Disability and HIV/AIDS Trust (DHAT)
Health Economics and HIV/AIDS Research Division (HEARD)
International Centre for Disability and Rehabilitation (ICDR)

Research Objective

The objective of the Sepo Study was to conduct a pilot study that explored the experiences and perceptions of stakeholders (i.e. *people with disabilities who are HIV-positive and key informants*) regarding health equity issues related to HIV care for people with disabilities (PWD) who are HIV-positive.

In particular, this project provided us with the opportunity to:

1. Explore the feasibility of conducting this kind of study in Zambia (e.g., how to obtain ethics review in South Africa and Zambia, identifying the most appropriate protocols for participant recruitment, data storage and other procedures).
2. Acquire preliminary data to support the development of a larger operating grant for an expanded project in this area.
3. Develop working relationships among the investigators and community partners in Canada and Southern Africa in a way that is respectful and mutually beneficial.

Study Implementation

- Ethics approval was received from three universities - University of Zambia, University of Toronto in Canada and University of KwaZulu-Natal in South Africa.
- The study was implemented in two phases:
 - In phase 1, interviews were conducted with PWDs in Lusaka, Zambia who are HIV-positive.
 - In phase 2, interviews were conducted with additional PWDs who are HIV-positive and also with key informants from among AIDS Service Organizations (ASO), Disabled People's Organizations (DPO), health care providers and health policy makers.
 - This report includes data from both phases.
- A Zambia-based fieldwork team was hired that included a project coordinator, 7 fieldworkers (4 men, 3 women including individuals with disabilities, sign language interpreters and trained HIV counselors) and 2 transcriptionists/translators.
- The study was conducted in three local languages - Nyanja, Bemba and English.
- Data collection was conducted from August 2010 to June 2011 .

Descriptive Analysis

- All investigators participated in a collaborative data analysis process including developing a coding framework based on clustered concepts that were jointly identified in phase 1.
- All transcripts were coded by two members of the research team using a coding worksheet. Completed worksheets were inputted into a data organization software programme called NVIVO.
- The research team was then divided into pairs and the coded categories (or 'nodes') were distributed amongst the team to be analyzed descriptively (i.e., concise descriptions were written for each, and examples of quotes were included).
- A '*November 2010 Descriptive Analysis Report*' was developed based on phase 1 analysis.

- For this current report, phase 2 interviews with people with disabilities who are HIV+ were analyzed with consideration to the following questions and then findings from the phase 1 report were reviewed and integrated:
 - 1) *What are the main issues raised in the data?*
 - 2) *What do these data tell us (if anything) about the intersectionality of HIV and disability?*
 - 3) *What key actions (if any) are suggested in these data (e.g., policy, education, practice, advocacy, research, other) by the participants themselves? in your opinion?*
 - 4) *What specific ideas strike you (if any) for more in-depth analysis in the future?*
- A descriptive summary of the feedback from key informant interviews was also developed based on a collaborative review and with consideration to the following question: *What are the key informant's biggest messages about what needs to happen to better the situation for PWD who are HIV+.* These findings are also incorporated in this report.

Participant Characteristics

Table 1 - Participant Characteristics

PWDs Living with HIV (Aug 6, 2010 to June 1, 2011)	Age Range	29 - 61
	Sex	9 men, 12 women
	Type of Disability	Hearing 3 Mobility 12 Visual 4 Intellectual 2 (1 mobility also)
	Disability preceded HIV+	15/21
	Key Informants (Feb 3 - March 23, 2011)	Number
	Organizations represented	Organizations in Zambia that included AIDS service organizations, disabled persons' organizations, HIV health care providers and health policy makers

Disability-related Stigma associated with HIV Experience

- Participants described frequent and ongoing experiences of stigmatization and discrimination from family, friends, health care providers, and others seeking HIV care and treatment.
- Despite having both HIV and a disability, participants primarily described the stigma as linked to their disabilities.
- People whose disabilities were longstanding described heightened experiences of disability-related stigma upon acquiring HIV (e.g., people with visible disabilities described being stared at in queues for ART). Others described feelings of shame and blame at the added burden they had “created” by becoming HIV+.
- There appeared to be both externalized and internalized forms of stigma and discrimination.
- Participants indicated that they internalized the negative attitudes encountered from many sources.
- PWD spoke of feeling “sidelined” by community members and being viewed as less than human, which translated into feelings of vulnerability and isolation. This was frequently reported as a reason for delaying or not seeking HIV treatment. *“Don’t they realize we’re human?!”, “Are we not citizens?”*
- There were many instances where negative attitudes of community members were encountered by participants. These were attitudes expressed verbally (e.g., negative comments overheard or made directly to them by community members) or non-verbally (e.g. stares/looks that made them feel uncomfortable). A frequent negative attitude encountered was that able-bodied persons saw PWD as being asexual (or that they should not be sexual), and thus it was considered ‘shameful’ for PWD to have HIV as this was ‘evidence’ that they had had sex.

"We the disabled have not received citizenship, because the life that we lead is hard, yes. It is very tough. They don't realize that we have children. We need to take them to school. No, them what they've put in place, the law that is strong that 'you must stop begging'. Now you have children, what are they going to eat? They don't consider that we eat? We are also humans like them."

"The way they'll look at you, the way they'll comment on you. You'll be discouraged even to access those medicines from the health centres".

For Consideration and Discussion

1. What are possible interventions to address disability-related stigma and counteract the negative stories of PWD who become HIV+?
2. How does HIV status shine a light on pre-existing disability-related stigma?

Experiences of Stigma from Health Care Providers (HCPs)

- Participants frequently described negative encounters with health care providers at various stages along the HIV prevention/care continuum based on their stigmatizing attitudes. Some interactions appeared to be linked to beliefs about PWD being asexual.
- This could be enacted through direct comments (e.g., whereby HCPs expressed surprise at seeing PWDs arrive for testing because of assumptions regarding asexuality) or behaviour (e.g. being forced to stand for long periods to await treatment, being seen last or passed over, lack of accommodation for persons with mobility impairments).
- HCPs were largely portrayed as having the same attitudes towards PWD as the rest of the community.
- The stigmatizing attitudes recounted in the interviews appeared pervasive and can be assumed to have direct health implications (e.g., delay in being tested).
- Both participants and other key informants recounted stories where PWD would rather not seek life-prolonging treatment than face this hostility. If the stigma is so great that it is preferable to “die quietly at home” (according to a KI interview) rather than seek treatment, this is a major health equity issue.
- Several key informants who worked in the disability sector advocated a shift from a charity model of disability to a rights-based approach to disability to address these concerns.

"... the doctor was surprised at me. He had laughed at me saying, "Um, can you also have HIV?" I then answered him that, "Doctor, I'm human. I also have the same feelings that you have. It's only that the legs are the ones that differentiate us". So the doctor said ok, go to that room ... Even there in the room, they laughed. They didn't treat me to say this person is also human, she can have, no. Until at last they tested me...But I had told them that a lot of disabled people come to the hospitals. You discourage us ... that's not how it's supposed to be. A disease that an able-bodied person can have, even me I can have it."

For Consideration and Discussion

1. **What are the implications of disability-related stigma among health care provider for HIV prevention, testing, care, treatment and support for PWD?**

HIV Testing and Counseling Experiences

- Circumstances around HIV testing were different depending on whether participants were: (1) people with disabilities acquired many years earlier or (2) people who had recently acquired disabilities through illnesses. For this second group, it was often the interaction with the health care system while addressing that illness (e.g., TB, stroke, vision problems) that precipitated getting an HIV test.
- Communication was identified as a barrier to access for people with visual or hearing impairments and the physical environment of clinics and health facilities (e.g., stairs) was a barrier for those with a physical disability.
- Some participants described people with disabilities delaying accessing HIV testing or treatment due to fears and experiences of stigmatization. Getting an HIV test was seen as evidence of being sexually active (as is pregnancy) which some participants described as being perceived as shameful for people with disabilities.
- Several participants mentioned that they encountered people (medical professionals and others) who did not recognize that people with disabilities could get HIV.

"At first they couldn't tell me straight that I was HIV/AIDS. And I knew at last to say maybe they don't want to tell me straight just because I'm disabled. And I thought of saying maybe it's not easy for them to tell me that I was HIV/AIDS because, uh, of my disability. But the first instance, when I was just about to...to deliver [my baby], that's when they told me and they gave me that drug [PMTCT]"

"Um, it wasn't easy [going for HIV testing], because a lot of people were staring at me just there on the queue. Others were passing comments. Honestly, I didn't find it easy."

For Consideration and Discussion

1. What might be the impact of these concerns on health outcomes (e.g., adherence to treatment)?

Experiences of being on HIV Treatment

- Most of our participants were able to access ART but described multiple challenges.
- A key challenge was transportation to the clinic to get ART. One respondent described being carried by a neighbor; another mentioned having no one to push his/her wheelchair, the wheelchair being too fragile to manage the long distance to the clinic, and delays in getting there by bus.
- An issue named by almost every respondent was the lengthy waiting time to access the medications and that few, if any, accommodations were made for people with disabilities.
- Several PWDs and key informants mentioned that lack of food interfered with their treatment regimen, e.g., they did not take medications while lacking food because of the side effects, or that not having food made them too weak to go access their treatment.
- As mentioned previously, participants with visible impairments frequently described experiences of stigma that occurred when they accessed treatment (e.g., being stared at while in the queue).
- Several respondents mentioned that separate centers should be available for people with disabilities where stigma would be minimized and accommodations would be made (e.g. chairs, shorter wait times). In contrast, key informants supported mainstreaming individuals with disability into HIV/AIDS programmes and policies.

"... at the moment I have a problem because of transport. ...so now when you are late [to pick up your ART], they'll tell you to come on another day. If it's today that they've told you to come on Saturday, you go today on Saturday, they tell you that no, you are late, you're late, you should come on Monday. Again on Monday, if you are slightly late, again they'll tell you that you should come on Wednesday ... And if you go late five times ... they tell you to go back, you are not serious. Even when you explain to them that no, transport is difficult for me, for instance in the rain season, meandering in the floods, it's difficult for me, but them they don't understand. So me they stopped giving me my file, it got lost."

"... whenever I take my medication, when I don't take enough food, I experience a lot of problems"

For Consideration and Discussion

1. Most of the PWDs who participated in the Sepo Study were on ART despite the challenges they identified related to getting on and staying on ART. Is this reflective only of our sample - i.e. we ended up attracting people to this study who were more likely to be on treatment - or is it that PWDs are accessing testing and treatment perhaps due to emphasis on universal access to ART?
2. How do negative and stigmatizing incidents experienced by PWDs while in the ART 'queue' influence treatment access and adherence?

Sexuality and Intimacy

- Many participants described how their HIV diagnosis had a negative impact on sexuality, intimacy and relationships with their partners, family and friends.
- Most respondents report a decrease in amount of sexual intimacy since diagnosis. Some of them report that they have initiated the change themselves (e.g., abstaining, “avoiding men”, being “less promiscuous”, asking for condom use) and some of them report that their partner had initiated the decrease (e.g., partners leaving them, no longer intimate).
- HIV diagnosis appeared to influence the status and nature of relationships including with their spouse/partner (e.g., no longer intimate, lack of support, discord), and there was variable disclosure and acceptance among family and friends.
- One participant identified a perceived belief within the disability community itself that individuals who are disabled cannot be infected with HIV and a need to increase awareness.
- Participants spoke at length about family members’ attitudes upon learning that the PWD had become HIV positive. Negative comments from families were characterized as particularly ‘hurtful’ and difficult to receive. For at least one participant, disclosure of HIV status resulted in marital breakdown. Some participants would only disclose their HIV status to family, and only to family members that they thought should know or would be supportive (e.g., children, extended family that they relied upon for support).

"AIDS could be for every person, either disabled or abled"

"Life has changed in terms of having sexual intercourse because, why I've said so, the way I used to interact with maybe other ladies, now, this time I've stopped since I know my sta-, since I know that I'm sick. And I was told by the health workers how to go about it. I shouldn't behave like somebody who doesn't know his status."

For Consideration and Discussion

1. What are the implications of disability and/or HIV status on traditional gender roles and inequities?

Intersectionality of HIV and Disability

- Participants described their experiences of the intersection of both HIV and disability in ways that varied among participants, e.g., depending on their disability/impairment, and over time.
- Having a disability and HIV was described as a double burden or "carrying two things".
- The respondents report situations where disability, HIV, poverty, food security, housing and other social determinants of health were intimately interlinked.
- However, one theme involved the difference in experience between people with longstanding disabilities for whom their HIV diagnosis was often an added burden/challenge, and that they are not managing as well now that they also are HIV+. Conversely, people whose disabilities had occurred in the same time frame as their HIV diagnoses often described their disabilities as restricting their engagement in society.
- A number of participants reflected on HIV as making things "difficult" or "tough". People described feeling weak, tired and/or "powerless". Several women explained that they were "strong" PWD but HIV has made them weak and they now find it "difficult to manage".

"Life, it's become difficult. The way I used to be long ago, but I was disabled before having this disease. I was very strong. I was managing to do anything. Now since becoming HIV positive, things have become tough for me, even medicine. When I take medication, I need to rest ... I'm not managing like I used to manage way back..."

"...to be a sole provider of the family now, things happen like this. It's very difficult for one to continue whatever I was doing because I used to be an entrepreneur, yes. So now when I stopped seeing, I say things ended just there. It was instant, yes. It was instant".

For Consideration and Discussion

1. How might the experiences and needs be different for PWD who are HIV+ who have had their disability for a long time vs those whose disabilities and HIV diagnosis coincided?
2. Which of the issues in this report are:
 - a. Experienced only by people with disabilities who are HIV+
 - b. Experienced differently by people with disabilities who are HIV+
 - c. Universal?

Work

- People with longstanding disabilities often described the added burden of HIV as manifesting as malaise, pain, tiredness, or other side effects that limited their ability to make a living in the ways that they used to.
- People with a new HIV diagnosis and a concomitant disability also described a direct impact on their ability to work. Either way, income was directly affected, which seriously compromised access to basic needs. Participants' discussions about solutions were dominated by how to make a living.
- A number of participants indicated that their primary source of money was begging.
- Most participants want to be able to support themselves and be self-sufficient but felt the opportunities or supports to do this are not available.

"What is needed more especially is food. Mealie meal and money for food because I don't have any business. I can't go to town to order since I'm blind now. I used to sell second-hand clothes"

Priority of Needs

- Over and above the need to find work and the experience of HIV and disability, the following three concerns were consistently raised as the participants' greatest priorities:
 - Hunger, food security, nutrition
 - Housing and shelter
 - Education for their children (and occasionally for themselves)

Losses

- Over and above their loss of financial security, participants also described a range of other losses that were part of their experiences.
- Other losses included: the status and nature of relationships among family and friends and within the community, hope for the future, their role within their household and family, identity, and feelings of shame and blame related to their HIV status.

"...the disease and the disability have stopped me from progressing."

For Consideration and Discussion

1. **Participants proved themselves to be extremely resourceful given the difficult circumstances they face. What can be learned from this resourcefulness and resilience?**

Sources of Material Support

- Participants described great challenges in meeting basic needs, with their financial support primarily coming from specific family members or through their own resourcefulness which often included begging.
- It was conspicuous that extremely limited reference was made to any programmes or services offered by the government, NGOs or community-based organizations, with the important exception of ART clinics.
- Furthermore, some participants perceived that the government provided less support to (and “cared less about”) disabled people than able-bodied people, and also noted that begging, a primary source of income for some, is against the law.
- The perceived role of NGOs is one of service provision rather than transforming power relations that may have result in inequity.

"You know, the government need to support us in every way, especially for us [the disabled] who are HIV/AIDS. And for those maybe who are not HIV/AIDS. Yes maybe because of poverty that has made us, many of our disabled people, uh, to engage themselves with men so that they give them money and at the end of the day you find yourself with HIV/AIDS."

"I don't , I receive no care, or rather support, apart from my medicines. The medicine that I get from [removed clinic name], is, that's all. I don't receive any care or any support from anybody."

For Consideration and Discussion

1. Why might there have been so little discussion of services available from government, NGOs or CBOs, i.e., is it that the services do not exist, that PWD are excluded or unaware of them, or other reasons?

- A number of the women in our sample had children and were the primary caregivers for those children. Burden of care and concern for children was consistently expressed by the female PWD participants.
- Key issues raised by women in this study were experiences of exploitation often linked to their disability status and their need for money and food, and the abandonment by men following their HIV diagnosis.
- The differential impact of HIV infection and disability on sexual partnerships and relationships was expressed along gender lines among almost all participants.

"I'm thinking that, 'Yeah! Maybe this man will give me more money, let me just agree', not knowing he is bringing me diseases."

"You just abstain then if you are doing other things, ok what causes me not to abstain is the way I live. Maybe I'm poor, I need to eat, I need to pay rentals, you see? Then me I don't have that money, there will come maybe another man, he'll propose to me. I'll accept just because he'll give me that money, I pay. Now if I'm working or doing business, I can abstain, taking care of myself, and my life can be prolonged."

For Consideration and Discussion

1. What are the unique challenges that women face who have a disability and HIV?
2. What are the various levels at which responses might be proposed, e.g., individual, community-level, policy changes?

Priority Actions

1. Anti-stigma interventions to address disability-related stigma and discrimination that was highlighted because of participants' HIV experiences. These interventions could target certain audiences, such as:
 - a. Health care workers providing HIV prevention, care, treatment and support services (e.g., a disability-related anti-stigma toolkit)
 - b. HIV policy-making or direction-setting organizations (e.g., awareness-raising activities regarding inclusion of PWDs in leadership on HIV)
2. Policies and programs to address the basic food, shelter, education and income-generation needs of people with disabilities who are HIV+, with attention to the unique needs of women and men.
3. The PWD in our sample who are on ART (i.e., the majority) need (a) nutrition, and (b) care and support to address the side effects of the drugs.

For Consideration and Discussion

1. Do you agree that these are the priorities? What actions should be taken to address these issues?
2. What additional priorities and actions should be considered?
3. To what extent are our findings different, or the same, as the issues identified and advocated by disability community leaders (e.g. mainstreaming disability into HIV service delivery, inaccessible services, HIV NSPs)?
4. What are the interesting and/or important ideas that you would like to know more about?

Knowledge Translation and Exchange Activities

Completed:

- *Canadian HIV/AIDS Research Conference, Toronto, Canada (April 16, 2011):*
 - Poster: Inspiration, Hope and Silence: Canadian Reflections on Zambian Fieldworker Involvement in International HIV Research
 - Poster: Intersectionality of HIV and Disability in Zambia: Results from the Sepo Study
 - Poster: Wrestling with our Imperialist Do-Gooder Legacy: Coming into Critical HIV Research in a Zambia-Canada Partnership as a New Researcher
- *World Congress of Physical Therapy, Amsterdam, Netherlands (June 22, 2011):*
 - Poster: Opportunities for Physiotherapists to Advance Practice, Policy and Research with People with Disabilities who are HIV-Positive
- *Ontario HIV Treatment Network, Toronto, Canada (November 15, 2011):*
 - Oral Presentation: Making a Living: Livelihood experiences of people with disabilities who are HIV+ in Lusaka, Zambia
- *Global Health Conference, Montreal, Canada (November 15, 2011):*
 - Poster: "Are we not human?!": The need for anti-stigma interventions for people living with HIV and disability in Zambia
 - Oral Presentation: Operationalizing qualitative research fieldwork in a resource-poor setting: Lessons learned for effective, efficient and ethical research procedures
- *International Conference on AIDS and STIs in Africa (ICASA), Addis Ababa, Ethiopia (December 4-8, 2011):*
 - Poster: "Are we not human?!": Results of the 'Sepo Study' Examining the Experiences of People with Disabilities who are HIV+ in Lusaka, Zambia
- *Masters Dissertation (December, 2011):*
 - "Disabling Sexualities: Exploring the impact of the intersection of HIV, disability and gender on the sexualities of women and men in Lusaka, Zambia", Institute of Development Studies, University of Sussex, Brighton, UK

Planned:

- *Canadian Association of Occupational Therapists (CAOT) Conference, Quebec City, Canada (June 6-9, 2012)*
 - Oral Presentation: "Examining the experiences of people with disabilities who are HIV+"
- Various manuscripts are under development for submission to peer-reviewed journals for review in 2012.
- A meeting grant has been submitted to the Canadian Institutes of Health Research for funding to support a meeting to develop a strategy and multi-sectoral research team to create a collaborative, international research grant proposal for developing, piloting and testing an anti-stigma intervention for HIV and disability in Zambia.
- Additional knowledge translation activities related to advocacy, education and policy are being explored with Southern African study collaborators, DHAT and HEARD.

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