

The Sepo II Study: Living Life on ART

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“I am not thinking about HIV. No, I’m thinking about how I am living. Since I have life, I think about how I will live in the future.”

50 year old man on
ART 1 year

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What was the purpose of the Sepo II Study?

Access to antiretroviral therapy (ART) has had a profound impact on the experiences of people living with HIV. For many, ART has transformed HIV into a chronic illness with ups and downs. As such, people are likely to have new needs related to **living with HIV**. But what are these needs and what are the implications for HIV policy, programs and service delivery?

The Sepo II Study¹ explored the experiences of women and men living with HIV and on ART in Lusaka, Zambia in order to better understand their hopes and challenges over time. **The goal of the Sepo II Study is to inform the evolution of policy and care to better address the long-term management of HIV as a chronic condition.**

This study used two frameworks² from the world of rehabilitation science to focus on not only medical issues related to HIV, but also life-related challenges. By “rehabilitation”, we mean activities that address or prevent impairments, activity limitations or social participation restrictions. Rehabilitation is concerned with physical well-being as well as mental and spiritual dimensions of health. This approach also focused on changes that occur over time to better understand the ups and downs of living with HIV.

The Sepo II Study is part of a broader program of research and advocacy to advance the field of **rehabilitation in the context of HIV** in sub-Saharan Africa. The Sepo II Study contributes to this movement by providing deeper understanding of the needs of people on ART who are living with HIV as a chronic illness.

¹ The Sepo I Study was conducted in 2010–12 and explored health equity issues for people with disabilities who are living with HIV in Lusaka, Zambia. For Sepo I Study findings, please see: <http://www.physicaltherapy.utoronto.ca/research/icdr-lab/sepo-1>

² The 2 frameworks were:

- The World Health Organization’s International Classification of Functioning, Disability and Health, (ICF). Geneva: The World Health Organization; 2001.

- The Episodic Disability Framework:

O’Brien KK, Bayoumi AM, Strike C, Young NL, Davis AM. Exploring disability from the perspective of adults living with HIV/AIDS: development of a conceptual framework. Health Qual Life Outcomes. 2008;6:76.

O’Brien KK, Davis AM, Strike C, Young NL, Bayoumi AM. Putting episodic disability into context: a qualitative study exploring factors that influence disability experienced by adults living with HIV/AIDS. J Int AIDS Soc. 2009; 12 (1):5.

Who participated in this study?*			
	Chawama Level 1 Hospital (n=28)	Lusaka Trust Hospital (n=7)	Overall (n=35)
Age	21-56 years (average 40.3)	36-54 years (average 42.9)	21-56 years (average 40.8)
Sex	15 women, 13 men	3 women, 4 men	18 women, 17 men
Time on Treatment	1-13 years average: 5.3	3-12 years average: 8.1	1-13 years average: 5.9

* at time of first interview

How was the study conducted?

Thirty-five adults (18 years and older) living with HIV and on ART for at least 6 months participated in this study from December 17, 2012 to April 17, 2015. They were recruited from 2 sites in Lusaka:

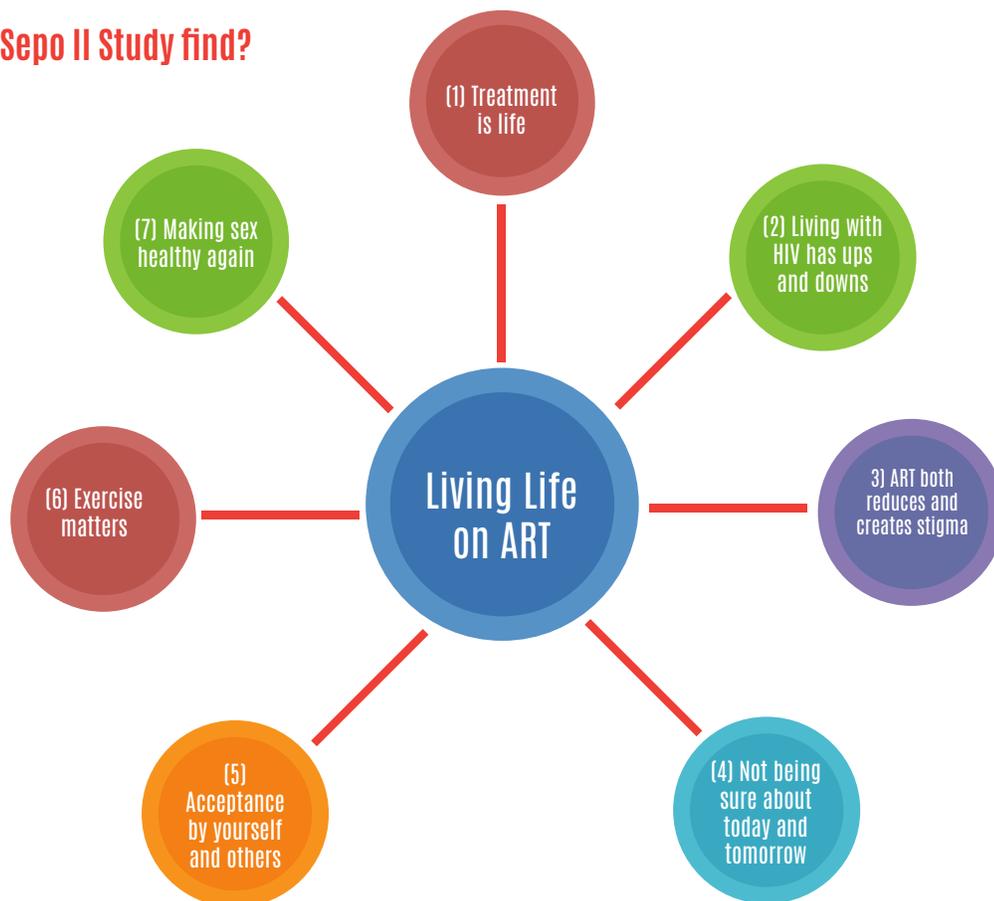
- Chawama Level I Hospital (28 participants)
- Lusaka Trust Hospital (7 participants).

One-on-one interviews were conducted with each participant on 3 occasions about 6 months apart. Thirty-one participants completed all 3 interviews. In the interviews, participants were asked to share their experiences of living with HIV and ART related to their body's functioning, day-to-day activities, and their relationships at home, at work and in their communities. Interviews were conducted in English, Bemba or Nyanja.

Data were analyzed after each interview and longitudinally (over time) using a collaborative analysis process.³ Participants and health staff provided input on these findings prior to dissemination.

Ethical clearance for this study was received from four review boards in Zambia, Canada, and South Africa, and from the Ministry of Health in Zambia.

What did the Sepo II Study find?



(1) Treatment is life

Context: Health services for HIV in Zambia have focused on HIV testing, starting treatment and ART adherence. This approach has successfully facilitated widespread access to ART. However, there has been little attention to the health and social supports needed for living with HIV as a chronic and episodic condition.⁴⁻⁶

Sepo II Finding: Participants spoke enthusiastically about how they are living their lives with HIV, which has been made possible by ART. They are committed to taking ART because it has improved health and enabled social participation. However, barriers remain in accessing care and support including:

- **not knowing where to get help to address concerns** (e.g., worries about the future, healthy sexuality)
- **supports or services that are unavailable** (e.g., counseling on how to live with HIV)
- **inability to afford care** (e.g., getting an x-ray, non-ART medication)
- **time and effort required to access care** (e.g., long queues, time from work)

“When you come to the clinic, they say the old ones should just get medicine and go. You will not see the doctor.”

44 year old man on
ART 8 years

“When you’re HIV-positive, it doesn’t mean that you cannot have a future. Me, I’ll still continue being productive until such a time when God takes me.”

41 year old woman on
ART 3 years

“It is not every day, but in chapters. Sometimes today you wake up and feel weird, tomorrow you wake up better, the other day you feel weird.”

25 year old woman on
ART 2 years

“Sometimes you’ll feel like you have numbness or are drowsy. Sometimes you’ll feel like you are dizzy. It keeps on changing.”

51 year old woman on
ART 6 years

(2) Living with HIV has ups and downs

Context: HIV care and research in Zambia have focused largely on clinical markers and diagnoses, with less attention to the impact of HIV and ART on people’s daily lives. Furthermore, little attention has been paid to the experience over time of living with HIV.

Sepo II Finding: Participants described ups and downs in their health, well-being and function over the course of a day, week or month. These changes can be called “episodic disability”² and they relate to:

Impairments

(i.e., challenges related to body structure or function) that improved, worsened or stopped over time.

- All participants experienced at least one impairment (physical, psychological or sensory), now or in the past, and often experienced many at the same time.
- Experiences were highly diverse in terms of which impairments they had, how many, or severity.
- Common impairments included numbness, tingling or burning in feet and/or legs; memory issues; vision problems; pain; fatigue; and body composition.

³ Flicker S, Nixon SA. The DEPICT model for participatory qualitative health promotion research analysis piloted in Canada, Zambia and South Africa. Health Promotion International. 2015;30(3):616-624, DOI:10.1093/heapro/dat093. <http://www.ncbi.nlm.nih.gov/pubmed/24418997>

⁴ Hanass-Hancock J, Myezwa H, Carpenter B. Disability and living with HIV: Baseline from a cohort of people on long term ART in South Africa. 2015. PLoS One. DOI: 10.1371/journal.pone.0143963

⁵ Hanass-Hancock J, Myezwa H, Nixon S, Gibbs A. “When I was no longer able to see and walk, that is when I was affected most”: Experiences of disability in people living with HIV in South Africa. Disability and Rehabilitation, Jul 25, 2015; 1-11.

⁶ Deeks SG, Lewin SR, Havlir DV. The end of AIDS: HIV infection as a chronic disease. The Lancet, 2015; 382(9903): 1525-1533.

"I can do everything. Farming I still do, sweeping I sweep, chores I still do, running I run, washing I wash, thinking I still think properly, eating ... everything I do."

43 year old woman on ART 6 years

"This business of having to get permission before leaving work... [It's difficult] when your appointment comes and you need to go."

41 year old woman on ART 6 years

Activity limitations

(i.e., challenges related to doing daily tasks) that vary by individual and often improve after initiation of ART.

- Participants generally reported that they managed most daily activities very well, including self-care, walking, sweeping, gardening, lifting, and caring for others.
- Exceptions were the three participants who experienced a stroke either before or during the study, who were challenged to manage daily tasks.

Participation restrictions

(i.e., challenges for a person in her/his community or society) in roles related to work, intimate relationships, parenting, friendships and church.

- HIV has an impact on work. Getting time off for clinic appointments often compromised disclosure. Taking time away from work meant lost wages which affected basic needs.
- With regard to relationships, HIV could both worsen and improve relationships with partners, friends and within the community (e.g., at church). On one hand, fear of HIV disclosure could lead to secrecy about personal and health challenges. On the other hand, some participants gained support and encouragement by sharing their experiences.
- Being on ART allowed many participants to be a parent to their children. Ensuring their children's well-being was a key motivation for adhering to treatment.

(3) ART both reduces and creates stigma

Context: It was originally thought that widespread access to ART would eliminate stigma.

Sepo II Findings: Despite ART, stigma persists and affects the lives of people living with HIV.

- Almost every participant spoke often about stigma even though no interview questions asked directly about this topic.
- Participants spoke of discrimination related to changes in their level of function, day to day activities and relationships.
- Participants explained how being on ART can both reduce and also create stigma because of continued associations with death and sickness, lack of productivity and uncertainty.
- As such, participants described how stigma continues to impact participation in their community, work and family roles.
- Most participants remained cautious about disclosure and described only partial disclosure of their HIV-status.

"When they just know that you're on ARVs, they will make sure that they start talking. You will not have peace."

24 year old woman on ART 2 years

"I manage to live where people are talking about me because I'm better than I was when I wasn't taking medicine. I even look better than those who say I'm sick ...so that strengthens me."

41 year old woman on ART 6 years

(4) Not being sure about today and tomorrow

Context: Uncertainty has emerged as a common experience for adults living with HIV in other contexts (e.g. Canada),²⁷ but little is known about this issue for people in resource-limited settings like Zambia.

Sepo II Findings: Participants shared significant worries about meeting basic needs (e.g., food, shelter), providing for the well-being and education of their children (now and in the future), finding and maintaining work, and future availability of ART (cost and supply).

- These uncertainties focus on basic needs and access to medicine more than has been found in higher income settings.

"It's difficult to manage to find food, even educating children... I am failing to buy them everything that is required for them to go to school... even food at home is not sufficient."

51 year old man on ART 2 years

"I do not feel good because I think to myself, 'One day I will go to the clinic and they will tell me there is no medicine now.' What will we do because they say you cannot stop this medicine."

42 year old woman on ART 7 years

"I have accepted. It's part of me, it's part of my life now."

40 year old woman on ART 2 years

"...the first medication is acceptance. When you accept your situation, this medication will just add on."

41 year old woman on ART 12 years

"If I don't accept myself, who is going to accept me? No one."

23 year old man on ART 4 years

(5) Acceptance by yourself and others

Context: There has been little research on acceptance of one's HIV status as people are living longer on ART in resource-limited settings like Zambia.

Sepo II Findings:

Participants spoke frequently about striving for acceptance by themselves and by others.

- Participants explained how accepting their HIV status encouraged them to seek care, treatment and support.
- This included accepting lifelong ART and its challenges, such as side effects, the daily regimen, collecting medication, and stigma.
- They described 'accepting' as contributing to their physical and emotional well-being.

Participants also spoke of acceptance (or not) by others at the household and community level (e.g., neighbours and at church).

- They described experiences of wanting to be accepted after disclosing their HIV status, or keeping their HIV status secret to remain accepted.
- In some cases, being on ART strengthened acceptance because of improved health and productivity, or being a source of information and support for others living with HIV.

“Without exercises, I think I wouldn’t be the way that I am.”

51 year old man on ART
7 years

“Now I just do exercises. That is what helps me because when I sit for a long time, the legs become numb. So... you walk around a bit and stretch them... then you feel better.”

25 year old woman
on ART 2 years

(6) Exercise matters!

Context: Exercise has been demonstrated to improve health, well-being and functioning in adults living with HIV.⁸⁻¹¹

Sepo II Findings: Many participants described exercise and physical activity as strategies for improving health and maintaining well-being.

- This included stretching, walking, running, going to a gym, or receiving physical therapy.
- However, participants also described barriers to staying physically active.

(7) Making sex healthy again

Context: For people living with HIV, sex is often discussed as something dangerous or harmful. Rarely is sex framed as healthy, normal or pleasurable.

Sepo II Finding: Many participants described ongoing and diverse challenges related to what it means to live with HIV as sexual beings.

- Challenges included feelings of guilt associated with having sex, concerns about body image and sexual performance, navigating new or existing intimate relationships, discussing HIV testing and disclosure with partners, and fear of rejection.
- Participants also discussed challenges related to family planning as they look to their future.

“My sex life hasn’t been so good after my illness. I am not as active as I used to be so sometimes I think maybe it is because of the medicine.”

51 year old man on
ART 12 years

What are the most important messages from the Sepo II Study?

Sepo II findings point to shortcomings in the current model of HIV care that focuses primarily on initiating and adhering to ART. These health services are necessary but not sufficient for meeting the *new needs of people living longer as a result of ART*.

HIV policy and programs also need to address the health- and life-related impacts of *living longer* with HIV such as counseling for issues beyond VCT and adherence, and rehabilitation to promote function and quality of life.

Overall, findings from the Sepo II Study promote an evolution of the HIV care continuum to embrace a long-term approach to living well with HIV.

7 Solomon P, O'Brien K, Wilkins S, Gervais N. Aging with HIV and disability : The role of uncertainty. *AIDS Care : Psychological and Socio-Medical Aspects of AIDS/ HIV*. 2014 ; 26(2). Available from : <http://www.tandfonline.com/doi/abs/10.1080/09540121.2013.811209>

8 Mutimura E, Stewart A, Crowther NJ, Yarasheski KE, Cade WT. The effects of exercise training on quality of life in HAART-treated HIV-positive Rwandan subjects with body fat redistribution. *Qual Lif Res*. 2008 Apr; 17(3): 377-385. Available from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3167195/>

9 Mutimura E, Crowther NJ, Cade TW, Yarasheski KE, Stewart A. Exercise training reduces central adiposity and improves metabolic indices in HAART-treated HIV-positive subjects in Rwanda: A randomized controlled trial. *AIDS Res Hum Retroviruses*. 2008 Jan; 24(1):15-23. Available from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3936606/>

10 O'Brien KK, Nixon SA, Tynan AM, Glazier R. Aerobic exercise interventions for adults living with HIV/AIDS. *Cochrane Database of Systematic Reviews* 2010, Issue 8. Art. No.: CD001796. DOI: 10.1002/14651858.CD001796.pub3

11 O'Brien K, Nixon S, Glazier R, Tynan, AM. Progressive resistive exercise interventions for adults living with HIV/AIDS. *The Cochrane Database of Systematic Reviews*. 2004, Issue 4. Art. No.: CD004248.pub2. DOI: 10.1002/14651858.CD004248.pub2.

12 www.hivandrehab.ca

Recommendations for people living with HIV and HIV advocates:

1. Spread the news that many people living with HIV lead full, happy and productive lives:

It is important to know that in Zambia and around the world, many people on ART are living long and fulfilling lives. They are having families, finding work, and looking forward to their futures. People living with HIV can advocate for greater understanding in their communities that one can live well with HIV.

2. Ensure churches, schools, workplaces and other influential institutions advocate the long-term benefits of ART:

HIV advocates can help influential institutions in the community educate themselves and each other about the value of long-term treatment.

3. Consider the benefits of reframing HIV as a chronic, episodic illness:

Many people living with HIV around the world have found it reassuring to learn that others are experiencing HIV as a chronic, episodic illness with ups and downs that may occur through the day, week or year. The Sepo II Study shows that this experience is also shared in Zambia. Thinking about HIV as a chronic, episodic illness may help advocates imagine services that better respond to the needs of living long-term with HIV.

4. Get moving:

Incorporating exercise and physical activity into one's day can improve the well-being of people living with HIV who are medically stable.

Recommendations for health care providers, educators and policy-makers:

5. Expand or create programs to address the long-term needs of people living with HIV:

HIV clinical practice, education and policy needs to evolve to better support people living longer with HIV in all aspects of their lives, including body function, daily activities and social participation. Examples include:

- counseling for issues beyond ART adherence such as family planning or ongoing HIV disclosure
- rehabilitation services, and support for greater exercise and physical activity
- expanded HIV curricula for health workers

6. Incorporate rehabilitation into the HIV care continuum:

Rehabilitation is a field that addresses challenges in function, daily activities and social participation. Incorporating rehabilitation into HIV care helps broaden the focus to the life and health-related impacts of living day-to-day with HIV.¹² A new online, open-access resource is available at ssa.hivandrehab.ca to educate health workers on rehabilitation for adults and children living with HIV in Sub-Saharan Africa.

7. Ramp up efforts to address HIV-related stigma:

ART alone will not eliminate stigma. In fact, ART has created new forms of stigma. A broader approach to mitigating stigma is urgently needed. HIV disclosure continues to be limited and partial despite improved access to ART. People living with HIV and their families need support navigating complex disclosure decisions.

8. Address food security and employment as crucial determinants of health:

Nutrition and paid work remain urgent priorities for people living longer with HIV and their families. Sepo II findings call for not only expanded health services but also programs to address these broader determinants of health.

Recommendations for researchers:

9. Investigate strategies for addressing HIV as a chronic, episodic illness in low-resource settings like Zambia:

This includes rehabilitation interventions to prevent or mitigate the negative impact of HIV on people's bodies and lives as they grow up and grow older with HIV. This research is also needed for people living longer with HIV in rural settings.

10. Investigate the needs of women and men aging with HIV in low-resource settings like Zambia:

Research in high-income countries has focused on the needs of people over 50 years old who are living with HIV. One-third of Sepo II participants were 50 or older to begin capturing unique experiences. Further research on HIV and aging is needed for resource-limited settings.

11. Investigate strategies to mitigate the diverse and destructive forms of stigma in the era of ART:

Stigma emerged as one of the most significant themes in this study despite no interview questions explicitly addressing this topic. Strategies to mitigate stigma are urgently needed.

“All I can say is that living with HIV, it has made me stronger and it has helped me to stand on my own. I see life in a different way, in a different picture, you know? It’s bright, the future is bright and I hope for the best now.”

40 year old woman
on ART 2 years

Acknowledgements

- We thank the women and men who courageously shared their personal stories with us so that we can better understand the experiences of living with HIV on ART in Lusaka, Zambia.
- We also acknowledge our generous collaborators at the Lusaka Trust Hospital and the Chawama Level 1 Hospital.
- Graphic Design by Anthony Zaza, Digiprint, Lusaka, Zambia
- This work was supported by the Canadian Institutes of Health Research (Ref: #114907).

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December 2015



Zambart

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