

Sepo III: Promising Practices that Improve the Functioning, Disability and Health of Children and Young People Living with HIV as a Chronic Illness in Zambia.

Sepo III Study Backgrounder

What is Sepo III?

Sepo III is a study that aimed to identify and showcase 'promising practices' (e.g. policies, programs, services, community initiatives, or other innovations) providing support for young people (0-24 years of age) living with HIV.

Who participated in the Study?

Seven case studies were selected from 4 districts 3 provinces (Southern, Western and Lusaka) in Zambia. The seven sites included: 1 youth led organization, 2 hospitals (1 in a rural setting), 1 government ministry and 1 University student centered organization, 1 community based NGO and 1 initiative supporting key populations. A total of about 166 people participated in the study; either as service providers or clients/patrons.

Why was the study conducted?

Sepo III is a sequel to the Sepo II study (2011-2014) that investigated experiences of living one's life with HIV. In the December 2015 policy dialogue on the Sepo II results, the Zambian Minister of Health at that time, declared, "*It's not enough to dish out tablets; you need to go into the life of the person*", and called for further research to identify and mobilize solutions. Sepo III takes up this call by exploring how young people (0-24 years of age) living with HIV as a chronic illness are supported in Zambia, in order to inform other programs across the country and internationally.

What was the design of the study?

A case study design was used in this study. Seven sites were recruited and in-depth interviews, focus group discussions and observations of service providers,

clients and community spaces were conducted at each site over a period of at least two weeks. Researchers also reviewed relevant documents and policies when available.

What were the study objectives?

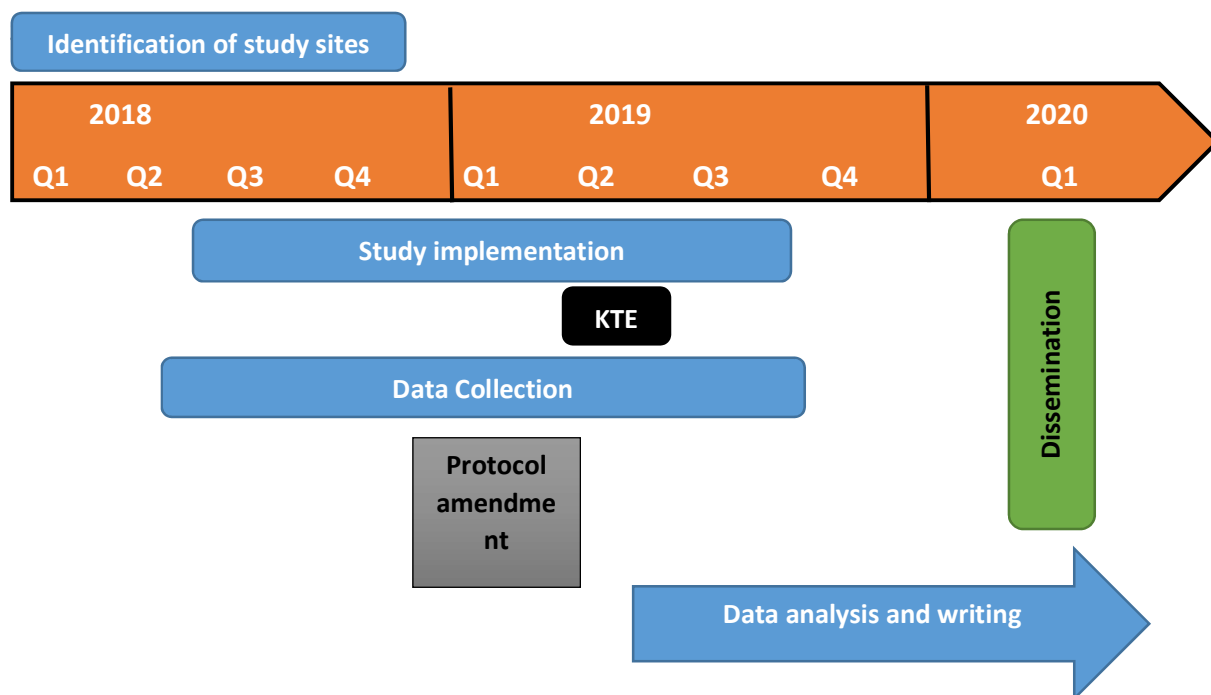
Study objectives were to:

- Identify diverse promising practices providing support for young people (0 – 24 years) living with HIV as a chronic illness
- Explore and develop an understanding of each promising practice using a self-management framework
- Provide opportunities to share information and practices among the study sites and others stakeholders

How did Sepo III differ from other case studies of its kind?

We sought to identify cases that reflected a range of promising practices that support children and youth (0-24) living with HIV in terms of those served (e.g. by age), the nature of services provided, and region and urban/rural contexts. This study allowed an in-depth understanding of these varied practices and programs that might strengthen the support for children and youth growing up and living with HIV.

What was the study timeline?



Main finding: Self-management reminds us that we need to consider the whole lives of young people, including their physical, psychological and social relationships – and not just treatment.

What is self-management:

- “Self-management” is an approach that has proven useful with people living with chronic disease. It focuses on supporting people to management their symptoms and treatment, and also the psychological, physical and lifestyle changes that accompany chronic disease.
- Swendeman et al (2009) developed a model for self-management in the context of HIV, which we used to inform the Sepo III Study. This model includes the following domains:

Physical health	Psychological health	Social relationships
Understanding illness and wellness	Self-efficacy and empowerment	Collaborative relationships with healthcare providers
Health promoting behaviours	Cognitive skills	Social support
Treatment adherence	Reducing negative emotional states	Disclosure and stigma management
Self-monitoring of physical status	Managing identity skills	Positive social and family relationships
Accessing appropriate treatment and services		
Preventing transmission		

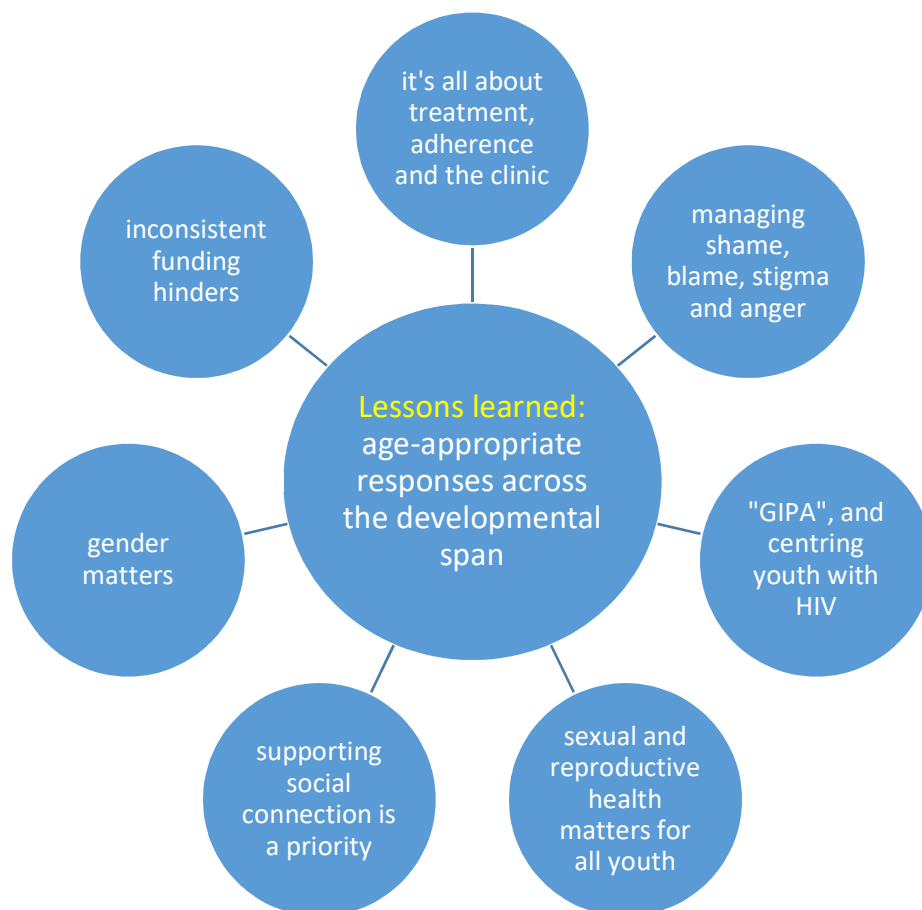
We asked participants: **What are the skills that children, adolescents and young adults need in order to manage as they live with HIV as a chronic illness?**

Participants’ responses reflected the range of domains in the self-management framework, including:

- I need future perspective

- Communication and critical thinking skills about what to say and what not to say
- Peer support so you don't feel like you are here alone
- Capacity building on the facts about HIV
- But not limiting knowledge to just HIV, also knowing the facts of life
- Parental guidance and support
- Knowing my rights
- Academic needs and athletics
- Having a sense of belonging
- Inspiration from those who have already disclosed

Lessons learned:



Who were part of the Sepo III study team?

The project is co-led by *Dr. Virginia Bond*, Director-Senior social scientist, Zambart, and *Dr. Stephanie Nixon*, Director, International Centre for Disability and Rehabilitation, University of Toronto in collaboration with co-investigators, *Prof. Margaret Maimbolwa*, Senior Lecturer, University of Zambia;; *Dr. Anitha Menon*, Senior Lecturer, University of Zambia; *Dr. Jill Hanass-Hancock*, South Africa Medical Research Council; and, *Dr. Patricia Solomon*, Associate Dean of Rehabilitation, McMaster University. The grant was also supported by the following collaborators: *Ms. Katongo Silwizya*, Zambian National AIDS Council; *Dr. Clara Mbwili-Muleya*, *Ms. Irene Muzyamba*, *Ms. Pelina Phiri*, *Dr. Andrew Silumesi*, *Dr. Francis Lyawali*, Ministry of Health, Zambia; *Ms. Tammy Yates*, realize (formerly known as the Canadian Working Group on HIV and Rehabilitation), Canada.

Who were the funders?

This work was funded by the Canadian Institutes of Health Research (CIHR) and the Canadian Foundation for AIDS Research (CANFAR).



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