

Factors Associated with Willingness to Participate in End-of-Life Cure Research: Perspectives from People Living with HIV



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Background

HIV cure-related research focuses on HIV persistence in body reservoirs.

Participants thus have to **donate tissues** (blood, genital secretions, rectal swabs, etc.).

Some tissues must be collected **post-mortem**.

Participants will thus need to be approached at end-of-life (EoL)

Canadian HIV Cure Enterprise (CanCURE) prepared a protocol for an HIV biobank, modelled after the *Last Gift Study* (UC San Diego). However, EoL research raises **ethical challenges**:

- protecting participant autonomy
- avoiding exploitation & fostering altruism
- maintaining a favourable benefits & risks balance
- safeguarding against vulnerability
- ensuring acceptance of family, loved ones & community



Dube K, et al. 2018 Ethical considerations for HIV cure-related research at the end of life. *BMC Med Ethics*.

Objective

To understand ***determinants of participation and preferences*** to ensure acceptability and a positive experience for people living with HIV (PLHIV) and their close or family circle.

Methods

Participatory and patient-oriented research principles:

2 community members were consulted on EoL HIV cure-related research; Furthermore, the CanCURE community advisory board (CAB) revised all research instruments

Mixed-method research design

Participants: people living with HIV aged ≥ 65 years or be diagnosed with a terminal illness



Results



Surveys

All participants (n=50)

- 1) sociodemographic characteristics
- 2) quality of life and experience of health
- 3) willingness to partake in...
 - ... EoL HIV cure-related research
 - ... HIV biobanking,
 - ... a postmortem research autopsy

In-depth interviews

Subset of participants (n=16)

- 1) relative to EoL HIV cure-related research, HIV biobanking, and research autopsies...
 - ...motivation and barriers,
 - ... perceived risks and benefits
- 2) perspective on life and mortality (participants' and their family's and social circles')

To increase comfort, acceptability, and accessibility participants will decide **with whom** and the **context** in which they answer surveys and interviews

Conclusion

We hope that this participatory and patient-centered study will provide a better understanding of people living with HIV's perspectives, in association to their social context.

This understanding will be considered when designing ethical and meaningful patient-centered interventions to approach, include, and interact with participants in the CanCURE HIV Autopsy Biobank and other EoL HIV cure studies.

It will also provide guidance for interventions respectful of participants' values, and their family and social circles', while emphasizing their autonomy and benefits and minimizing risks.

REB approval was obtained April 19, 2020. Data collection will be conducted in Summer 2020. Surveys and interviews will be conducted by phone or videoconferencing, to respect Covid-19 and social distancing regulations.

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