

The Meaning of “Community” and “Peers” from the Perspective of Those Affected by HIV

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Background

Community-based researchers typically define “community” and “peer” as those affected by an issue (e.g., HIV). We asked people living with HIV and those at-risk how they define the terms “community” and “peer.”

Methods

60 individuals participated in 10 focus groups.

Participants were chosen from a self-selected pool of individuals (N=1,011) who completed a previous survey on factors influencing HIV research participation. They represent populations most affected by the HIV epidemic in Ontario, based on gender, race, sexual orientation and HIV exposure category.

- Separate focus groups were held for HIV-positive and HIV-negative participants, as well as for different ethno-racial groups (White; African, Caribbean and Black; other racialized; and Indigenous).
- Focus groups were conducted at local sites (e.g., ASOs, libraries) in three Ontario cities.
- Participants discussed the meaning of “community” and “peer” and community and peer involvement in research.

With permission, focus groups were audiotaped and transcribed. Transcripts were then coded by pairs of peer research associates and study investigators and thematically summarized.

Results and Discussion

Community perspectives on the meaning of “community” and “peer” were multifaceted.

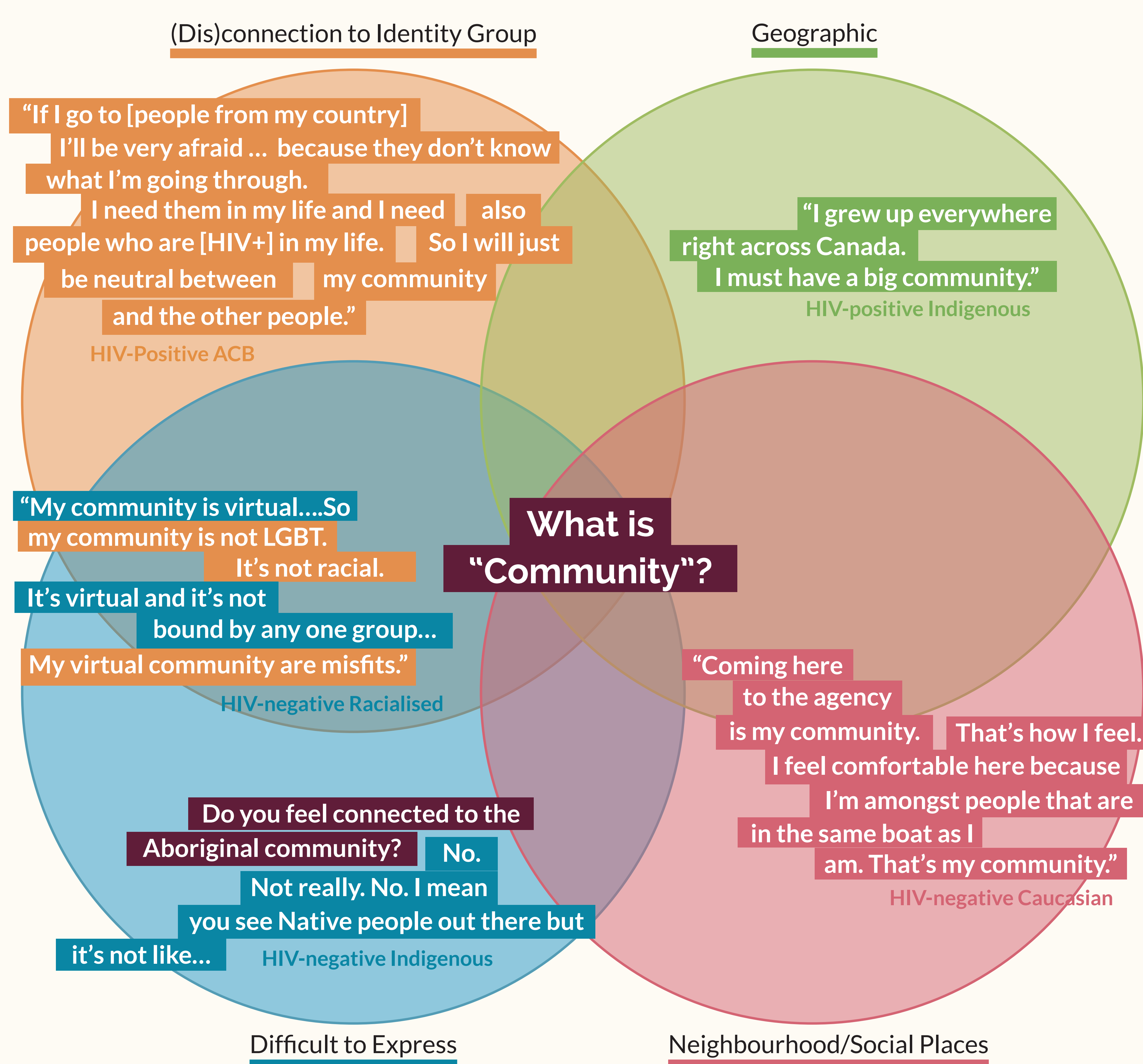
“Community” was a fluid concept, with many different layers, and was perceived differently across groups. Some groups had difficulty expressing any sense of what a “community” was, others described it as:

- a geographic entity (e.g., town) or place of origin (e.g., reserve)
- a neighbourhood or place where they socialized
- a sense of (dis)connection to a multi-layered identity group (e.g., “gay world,” “Black community”)
- a virtual or online community

“Communities” were viewed as complex and emanating from intersecting networks – defined by a sense of belonging (or disconnection) and/or inclusion (or stigmatization).

A “peer” was understood as someone with similar life experiences or attributes (including age, gender, sexual orientation and experience of HIV), but could also be someone that a person felt respect for, who had a shared understanding of the world. Peer was also understood as someone who provided acceptance and a sense of safety.

Not surprisingly, community perspectives on the meaning of “community” and “peer” in research were more complex than the research-based definition of those affected by an issue.



Facilitators and Barriers to HIV-Related Health Research

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