

HIV “In My Day”: Reflecting Back, Looking Forward – Early Findings From An Oral History of the First Decade of Vancouver’s HIV/AIDS Epidemic

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Background

- In the mid-1980s, the AIDS epidemic rapidly accelerated within Vancouver’s gay communities, bringing unprecedented sickness, death, and loss
- Faced by a socially conservative provincial government, many gay men and their allies mobilized to care for persons with AIDS (PWAs), lobby for increased government support, and demonstrate against a government who did little to confront the epidemic in its early years
- Thus far, early community responses to Vancouver’s HIV/AIDS epidemic have received little scholarly attention

Methods

- Between July and December 2017, our community-based research project conducted 20 oral history interviews with gay men born before 1970 and diagnosed with HIV/AIDS before 1996 (i.e., long-term survivors, N=16), and with caregivers who served extensive emotional support roles in the context of Vancouver’s early HIV epidemic (N=4)
- Interviewees were asked about their recollection of the first decade of the local AIDS epidemic and how their experiences were impacted by factors such as HIV/AIDS stigma, homophobia, and racism. Additionally, we asked participants to share their perspectives on Vancouver’s broader community mobilization and grassroots response
- The open-ended storytelling that accompanies oral history allows participants to share and narrate their experiences with more authority
- Interviews were video recorded, transcribed verbatim by team members, and subjected to thematic analysis

Results

Community cohesion and alienation were both expressed

The epidemic brought some participants into a closer relationship with Vancouver’s gay communities, but this was not universal. Indeed, for other participants, the epidemic contributed to alienation from gay communities.

“[Before HIV/AIDS] I wasn’t conscious of being part of the gay community. I was conscious of being gay. My sense of becoming part of a community arose out of my response to... HIV and the community’s response to HIV... They happened together. I responded and the community responded, and that brought me into a sense of community.”

“I wasn’t comfortable with the gay world back then – not at all... I didn’t find there was really a place for me in the early-eighties, so I felt really uncomfortable with that and when the AIDS thing came out that really just freaked me out and I ran away from the gay world... I never really found there was a place for me.”

Community resilience and trauma were often in tension

Many participants suggested that the epidemic ultimately strengthened gay communities, while others emphasized legacies of trauma.

“Even though there are positive outcomes to the HIV crisis... I don’t see it in any way as a positive thing... I often think of resilience as, you spring back like a foam cushion. The cushion is not damaged by the fact that it has been crushed. I don’t see human resilience in the same way. I see resilience as you respond in the best way you can. And sometimes we respond successfully, and sometimes we don’t. But there’s always a cost”

Participants’ responses to the epidemic varied immensely

While a small number of our participants engaged in direct-action AIDS activism, the majority engaged in other forms of community mobilization, such as caregiving and health advocacy, both within and outside of AIDS service organizations.

*“The thing about **ACT UP** was it was probably **successful in mobilizing the community**, of creating a culture of resistance and, you know, struggling... It raised our own self-confidence as a community. I think that was really important, because we were – because we had been through so much in that decade, so much that was so harmful and so negative. So, it’s like teaching us if you struggle, you can win”*

“I drove back and forth between Seattle like I was going into downtown or something, you know – like, I had to go down all the time to go to look after him. So, work here, drive down here, be with him, come back... It was quite a difficult time”

*“I started on all those awful drugs [laughs] and had some awful, awful side effects. And then ended up taking some other **trial drugs** too... I just kept thinking in my mind, ‘Take it. They’ll get something out of it that may not help me, but sooner or later, down the road, **it’s gotta help someone**,’ right?”*

Intersectionality differentiated participants’ experiences

While participants generally had shared experiences as gay men, their experiences diverged immensely along the lines of race and HIV status.

*“**Being a darker-skinned person within the gay community was a second-class citizen**... So, personally, as far as my journey [with HIV], it was a combination of things... Within my community I felt like a second-class citizen because I was gay, and then within the gay community, where I would feel that I should – I’m part of this community but yet I was – there was one aspect of me that was not mainstream within the gay community... [T]here is **white privilege within the community**.”*

*“it was **segregation**: ‘If you’re positive, do not approach me.’ There was lot of negativity surrounding it, and **when I became positive**, that sort of transferred it into... **this feeling that I was toxic**. That was probably the hardest thing to get over. The deep feeling that you’re toxic and you don’t want people touching you, and you don’t want to express yourself sexually or affectionately. It was tough.”*

Discussion

- While the impact of direct-action AIDS activism on the social and political course of the epidemic is undeniable, narratives that exclusively emphasize activism may marginalize a myriad of other essential community responses and obscure the intricate ways in which these responses fit together.
- It is crucial that our historical understanding of the AIDS epidemic accounts for the variability and complexity of gay men’s identities and lived experiences, rather than imposing a cohesive but non-representative narrative.
- Our participants’ personal responses to the epidemic often occurred outside of organizational or institutional frameworks, especially within the context of caregiving. If we want to capture individuals’ experiences of the epidemic, we also need to look beyond activist and AIDS service organizations.
- Similarly, the legacies of the epidemic on Vancouver’s gay communities are complex. While it is important to emphasize community resiliency and togetherness, we must also account for experiences of alienation and trauma that continue to resonate within communities today.

The authors have no conflicts of interest to disclose.
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