

Resilience, Leadership, and Crisis Competence: Lessons from People Living with HIV During the COVID-19 Pandemic

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BACKGROUND

The COVID-19 pandemic disrupted HIV care across the globe, presenting unprecedented challenges to people living with HIV (PLWH). While much research has described the pandemic disruptions to HIV care services, the strategies employed by PLWH to cope with these challenges remains understudied. Recognizing PLWH's active management of their health, this study examined sources of resilience and crisis competence among PLWH in the USA during the COVID pandemic. By highlighting their adaptive strategies and leadership, we aim to reframe PLWH not solely as vulnerable populations but as agents of strength, insight, and self-determination.

OBJECTIVE

Our goal was to inform the design of future care engagement initiatives to strengthen crisis resilience in HIV care.

METHOD

We conducted in-depth interviews with 40 participants (22 men, 10 women, 8 transgender/gender diverse; aged between 23 and 64 years) in New York City during the fall of 2023. The interviews examined the lived experiences of PLWH during the pandemic, focusing on their coping mechanisms, adaptation to evolving pandemic-related challenges to care engagement, and perspectives on the resources they considered necessary to navigate the healthcare system during the pandemic and beyond.

KEY FINDINGS	EXAMPLE QUOTES
<p>Self-advocacy Proactive resource-seeking and self-advocacy, involving collaboration with multiple stakeholders across social agencies and their personal networks, enabled many PLWH to effectively manage their care needs and maintain the standard of care they desired</p>	<p><i>I became a pain in the butt, to be honest with you. And I literally had to call, I called the doctor's office. ... I called the doctor's office, left the message. I left her maybe like two emails. And then I also reached out to my caseworker, which works alongside with her as well..</i> [Participant 1]</p> <p><i>Getting medications was one of the very difficult issues. From my pharmacist, they'd be out, I would have to borrow some from somebody else. So, we all kind of borrowed from one another. One pharmacy would have it, the other one wouldn't, but I have a network of friends that we relied on one another to make sure we all had our medications.</i> [Participant 22]</p>
<p>Community leadership Participants' prior and ongoing community engagement and leadership roles had fostered resilience, enabling them to navigate COVID mitigation efforts like lockdowns and manage their own care while also providing support to others in the HIV community.</p>	<p><i>I try to be a peer leader. So that way I can help my people stay connected. If people don't want to use their name, if Code Name Ketchup needs his medication dropped off up under the bridge on 21st, guess what? I'ma come right here and I'ma drop it off to you.</i> [Participant 18]</p> <p><i>I've never let it make me out to be a victim. ... I'm the referrer. I have someone said you have a lot of information. Because you have to remember I've been HIV positive since 1985. So, I've been, you know how long, that's like 38 years ... I have a whole lot of good resources that I'm willing to pass on to people if I run into them.</i> [Participant 5]</p>
<p>Patient involvement Participants advocated for greater involvement of patients in decisions about their health care and the design of healthcare systems overall.</p>	<p><i>I believe that healthcare providers would benefit from taking a more active interest in their patients' concerns about the healthcare system, not just about their own personal health, but the system in general. Through honest and open discussion about where the patient feels like their services might be lacking.</i> [Participant 35]</p> <p><i>I think throughout the years, I've been very open and honest about how my care is. And if I disagree with something, I'm allowed to say, Hey, I don't know why are we doing this?</i> [Participant 22]</p>

DISCUSSION AND IMPLICATIONS

- This study reframes PLWH not as passive recipients of care but as resilient actors with valuable crisis leadership capabilities
- PLWH leverage the knowledge cultivated through years of managing their HIV to overcome pandemic-related care challenges.
- To build a more resilient healthcare delivery system for PLWH, clinical practice should work with community programs and peer-led interventions in a collaborative manner.
- It is important for PLWH to be acknowledged as leaders within their communities. Future research on HIV care engagement should avoid defining this population solely by their vulnerabilities but recognize their resilience, strengths, and leadership qualities as resources in maintaining engagement in care.

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