The Benefits and Costs of Empowerment: Impact on access to support and self-care when PHAs become service providers

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PHA Empowerment and Engagement: Benefits, Challenges and Costs
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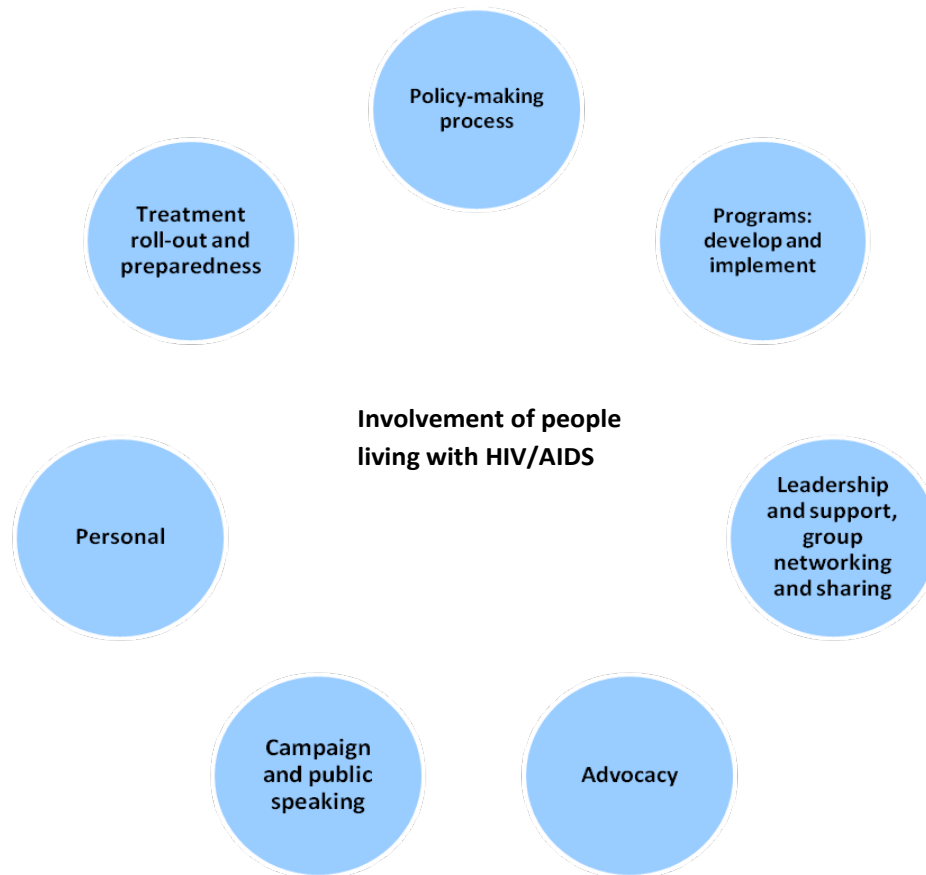OHTN 2013
RESEARCH
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CHANGING THE COURSE OF THE
HIV PREVENTION, ENGAGEMENT AND
TREATMENT CASCADE

Acknowledgement

- **Research Team:**
- Alan Li, Maureen Owino (Committee for Accessible AIDS Treatment)
- Joshua Wales, Charlie Guiang (St. Michael's Hospital)
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- Josephine P.H. Wong (Ryerson University)
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- &
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Background

Greater and more meaningful involvement of people living with HIV/AIDS

Policy-making process

Treatment roll-out and preparedness

Programs: develop and implement

Involvement of people living with HIV/AIDS

Personal

Leadership and support, group networking and sharing

Campaign and public speaking

Advocacy

Background

Challenges/barriers to access to mental health services for PHA service providers

- Isolation from previous peer social support
- Decreased access to previously used mental health services.
- Poses significant risk to occupational health

Research Questions

- 1. What are the changed needs of PHAs resulting from these transitions from client/service user to staff/service provider?

- 2. What are the barriers or challenges to accessing care and services, as well as the beneficial effect associated with this transition, if any, on access to care;

- 3. What are potential strategies and solutions to address a gap in services or support;

- 4. Are there differences in the experiences and/or needs of racialized versus non-racialized PHAs.
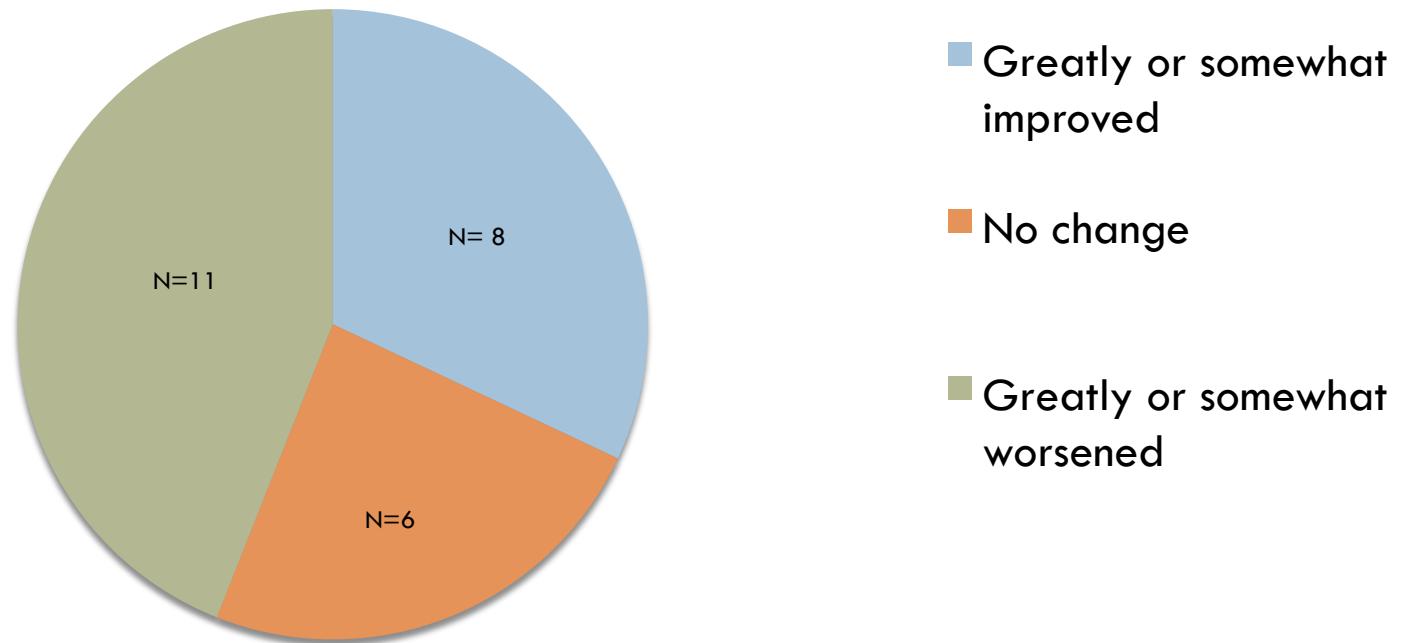
Methodology

- Community based participatory action research.

- Recruitment: 27 PHA service providers at ASOs in GTA

- Focus Groups
  - Racialized, non-racialized and ethnically heterogeneous

- Individual Interviews

- Demographic Surveys

Demographics

- N = 27
- Age: 28-35
- Gender (self-identified): M- 9   F- 18
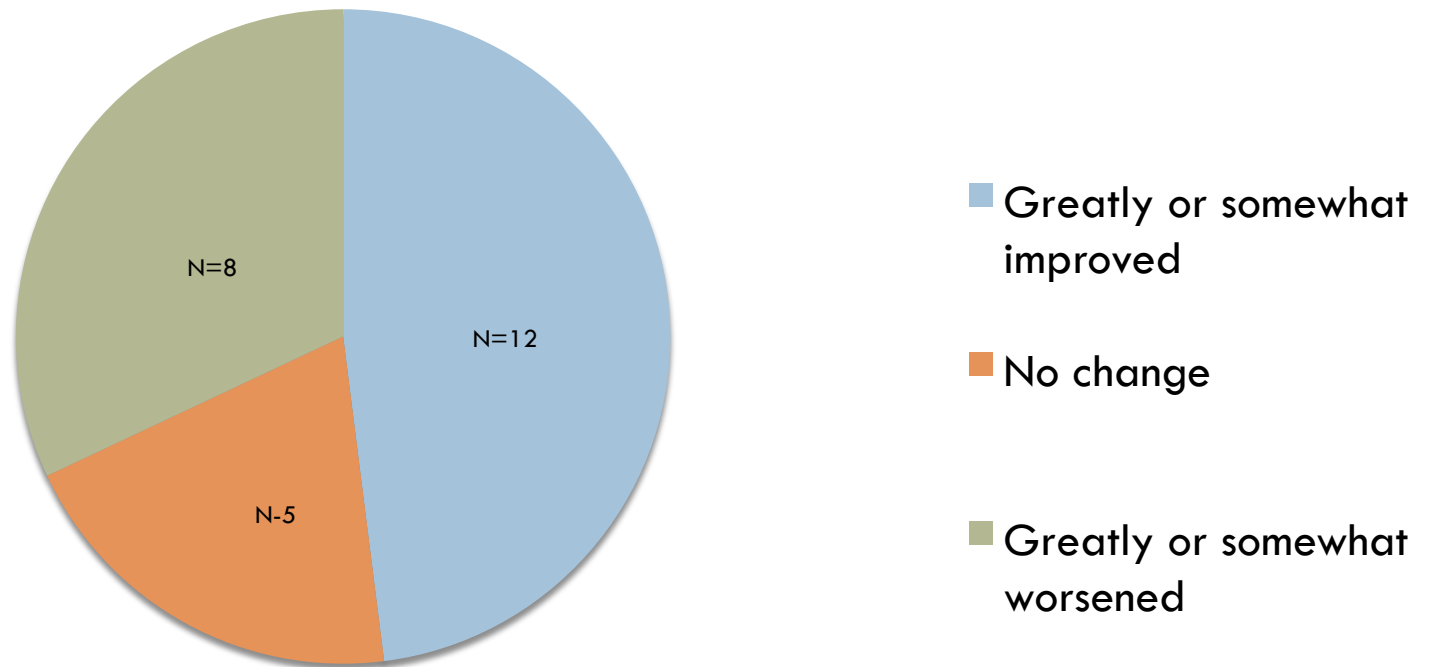- Ethnoracial identity:
  - Racialized: 15
  - Non-racialized: 12

Results

Effect of Transition on Access to Mental Health Care and Social Support

Legend:
- Greatly or somewhat improved (N= 8)
- No change (N=6)
- Greatly or somewhat worsened (N=11)

Results

Effect of Transition on Mental Health Status

- Greatly or somewhat improved
- No change
- Greatly or somewhat worsened

N=12

N=8

N-5

Results

- Main themes
  - Barriers to access
    - Confidentiality
    - Stigma
    - Boundaries
  - Facilitators of access
    - New networks of colleagues and peers
    - Supportive work environment

Barriers to Access

□ Confidentiality

"**Accessing mental health services in general is embarrassing, and for me it feels even more so in the workplace, because of my colleagues and peers…** (I) don't necessarily want them to know how dark some of my days have been in the past. I don't want to be perceived as a weakness in the workplace. "

Barriers to Access

□ Confidentiality

"When you become a service provider, **wherever you go, you will always be wearing that hat of service provider.** So I can't go, lets say to the women's skills building and do whatever I want. So I will always be seen as (name), that works at (ethnospecific ASO) **and they may come back and report it to my boss.**"

Barriers to Access

□ Stigma

"I felt now that I was employed fulltime, that even if I wasn't making a lot of money, I felt really guilty about wanting to go and access them for the medical funds, or any of those support things, even though I could use them…..
I would be very embarrassed to go to my colleagues for HIV support."

Barriers to Access

☐ Stigma

"I would go to the food bank for me…. And I showed up for my meeting the following Saturday, and I hear, **"Oh my god, I hear that you were at the food bank… Aren't they paying you enough at the office**, what are you doing?"

Barriers to Access

- Boundaries

> I cannot have access to counseling, because not the counselors are my colleagues. I cannot be part of a support group because the support group are my clients…
>
> I had a breakdown… I couldn't access the counselors at my organization, because all the people that I knew were also my colleagues."

Barriers to Access

☐ Boundaries

"I would feel great reluctance of entering into a peer support, or formal peer support network, say a support group, where there were clients or potential clients…

You want to be careful around boundaries and personalizing stuff."

Facilitators of Access

□ New Peer Support

"It was more of a peer support with people in similar positions, with similar insight into, so more of that social **support that comes from debriefing rather than counseling.**"

Facilitators of Access

□ Supportive Work Environment

"This has been a very challenging year for me in terms of health, like I'm exhausted, my work, I used my sick hours many times over from work, **and I can take as much as I want as long as its legitimate.** I have to say, that's a very big positive for me."

Facilitators of Access

☐ Supportive Work Environment

"I'm very lucky that **I was very supported by my colleagues when I changed from being a client to being a colleague…** I guess because our agency is very small, so we are like once big family

Conclusions

- Significant isolation, lack of access to services, and decreases in mental health associated with transition to PHA service provider

- Implications for plans for effective implementation of GIPA/MIPA

- Implications for care provision and occupational health:
  - Important to ensure access to mental health services, referrals to other resources/sources of care.
  - Improve workplace orientation & training on GIPA/MIPA

Conclusions

- Policy Implications:
  - Systemic support for PHA service provider peer network
  - Improve ASO human resource policies & practices
- Next Steps:
  - National Think Tank on Supporting PHAs in service provision roles (CIHR-REACH)
  - Intervention study to evaluate current CAAT/ABRPO supporting PHA employment training module