IDENTIFYING PATHWAYS FOR ORGANIZATIONAL INTEGRATION OF DISCLOSURE INTERVENTIONS FOR WOMEN LIVING WITH HIV

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A. Barry[1], W. Tharao[1], M. Muchenje[1], F. Ongoiba[2], G. Walker[3], M. Owino[4], M. Jose[5], N. Stein[6], R. Cameron[7], S. Ryan[8], V. Pierre-Pierre[9].

[1]Women's Health in Women's Hands CHC, Toronto ON, Canada. [2]Africans in Partnership Against AIDS, Toronto ON, Canada. [3]Positive Living Niagara, St. Catherines ON, Canada.
[4]Committee for Accessible AIDS Treatment, Toronto ON, Canada. [5]Toronto People With AIDS Foundation, Toronto ON, Canada. [6]Teresa Group, Toronto ON, Canada.
[7]AIDS Committee of Cambridge Kitchener Waterloo and Area (ACCKWA), Kitchener ON, Canada. [8]Black CAP, Toronto ON, Canada. [9]African and Caribbean Council on HIV/AIDS in Ontario (ACCHO), Toronto ON, Canada.

Introduction

Disclosure is linked to reductions in HIV transmission, adherence to medical regimens, access to support services, improved mental health status, and effective adaptation to living with HIV. Yet, it remains a significant challenge for people living with HIV and their service providers. A group of service providers and women living with HIV (WLWH) in Toronto, Canada developed and pilot tested an HIV-positive status disclosure intervention to provide a systemic way to support individuals through the process. To support uptake of the intervention, our study investigated issues affecting organizational disclosure processes and mechanism for integration of interventions within organizational infrastructures.

Methodology:

- In 2012/13, an in-depth literature review was conducted to identify existing guidelines on intervention integration and facilitators/inhibitors of organizational adoption of HIV disclosure interventions.

- 4 focus groups (N=28) were held with organizational management, peers/volunteers who have disclosed, support workers, and HIV-positive women who have not disclosed.

- Participants were recruited through AIDS Service Organizations (ASOs) and community health centres in Toronto. Discussions were recorded and transcribed verbatim, and the data was analyzed thematically using N-Vivo 10

Findings:

Focus group findings revealed 7 themes as facilitators or inhibitors of disclosure within organizations:

I) Provision and need for training at multiple levels

- Lack of uniformed policies/approaches about disclosure can lead to misinformation, miscommunication and conflicting approaches in supporting individuals in their disclosure journeys.

- Providing training to staff and volunteers can facilitate effective implementation of HIV disclosure support within organizations.

SPG Participant 6:
"…I feel that…everything has become so convoluted in regards to the duty to disclose because - that's why I said people feel like a personal duty to disclose, and that personal duty is their ethics, their morals, and their values, right? And that's where I think everything's become confused…I do believe that we have, you know, good training…however, like everyone said, there needs to be a way to break down the legal jargon as well because I don't understand half of the trainings that I've been to…and I can't then t- transfer that knowledge…"

II) The need to support the 'support giver'

- Service providers, particularly those who identified as Persons with HIV/AIDS (PHAs) expressed a significant burden in doing what they felt would be best for their clients versus respecting their clients' decisions.

- With shifting HIV non-disclosure laws/policies service providers struggle with issues pertaining to ambiguity around record keeping, sharing of information, and directing/supporting their clients' disclosure needs.

SPG Participant 7:
"I am a PHA and a service provider… And I know that there are these challenges of disclosure. I understand the issues behind why people don't disclose and the same time as being a-service provider, trying to tell someone to disclose when you look at criminalization of HIV and disclosure-- I also understand where they're coming from, but you also are scared that in the end you feel guilty if something happens to them."

III) Influences of organizational infrastructure and support programs

- Creating secure spaces for dialogue and developing diverse and culturally inclusive programs were shown to be great ways to support disclosure processes within organizations.

MG Participant 4:
…you have to be working within a context of trust, right, to be able to work with the person around the issue of disclosure, which might take a couple of years or two to actually – for them to feel comfortable doing it.…the more support you have – even if you never discussed disclosure you might help someone disclose just by giving them a lot of support in other ways…"

IV) The impact of organizational frameworks/policies & the consequences of professionalization, segmentation and specialization of services

- AIDS Service Organizations often have to prove to funders that they are filling a void in the communities they serve, which leads to the quantification of services.

- Service providers in regulated professions expressed facing challenges around adhering to their professional code of conduct versus the need to build trusting relationships with their clients.

MG Participant 5:
"…But that in some ways these frameworks are, are nuance, right? They're nuanced to a bigger service delivery model. Um, what we do try to do… you know, we're not, we're not an emotional support agency, so we don't necessarily create time to sit and connect to see where you're at. We're very much transactional, right? Uh, which is wonderful because we get lots of stuff out the door, but are we meeting people with everything that we need? And we only know that sometimes when they stop us…"

V) Positions/roles that influence disclosure processes within organizations

- Issues around building trust, developing ongoing relationships, ensuring safe spaces and power dynamics between service providers and clients all play a large role in disclosure processes within organizations.

- PHAs and peers were considered key facilitators of organizational disclosure processes, and participants reported that they were more likely to disclose their HIV-positive status to PHA service providers than those who were not.

PSG Participant 9:
"The only time I have disclosed is if the person I am talking to, comes out and discloses to me first. So that way, that person has shown me by disclosing to me that he or she is trustworthy."

VI) The effect of peoples' historical engagement with systems

- The ways in which African Caribbean and Black (ACB) populations access services is significantly determined by previous personal experiences of stigma and discrimination.

- Institutional distrust is also a rooted in past history of colonization, segregation, racism, etc.,

Respondent 1:
"When we look at ACB population, their engagement with systems is usually very – they question systems a lot and it's based on our historical engagement with – particularly with the issues around colonization. So when you think about, um, um, multiple dimensions of stigma, it's not only about HIV stigma…There's also issues around, um, uh, racism, and homophobia, and transphobia all intersecting together and impacting how people engage in the different dynamics in which they enter."

VII) The significance of counselling and mental health services in supporting disclosure processes

- Most participants agree that providing counselling services would be essential in supporting disclosure processes.

- Some participants however, felt that counselling would be ineffective for ACB women living with HIV.

- The main arguments against counselling were its cultural irrelevance to ACB populations, lack of diversity in the field, and culturally competent counsellors.

ACB Participant 2:
"Counselling always works…A lot of counselling because you're preparing to disclose whatever, and even though you do either, you need counselling afterwards and that's worked."

PSG Participant 9:
"I just want to say, in terms of what is being shared about counselling… I've been to a counsellor and honestly I've found it a waste of time…To them it's like "Just come out and tell them, you'll find it liberating". It's not that easy, there is always other cultural barriers, religious barriers and it's really difficult to find a counsellor who can understand all that barriers…"

Conclusion:

Disclosure is an effective HIV prevention and support strategy and when managed properly, it can be beneficial for both the person disclosing and the person being disclosed to. These benefits can be realized only when effective interventions to support disclosure are integrated into services offered to support WLWH. Our study highlights the significance of strengthening organizational infrastructures to support integration of HIV disclosure interventions as part of their overall service delivery.