

HIV care and support services for African Caribbean and Black women living with HIV: A qualitative study of women’s and service providers’ perspectives

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BACKGROUND

African Caribbean and Black (ACB) women in Manitoba are over-represented in HIV infections relative to other racial groups. Evidence from published literature suggests a number of social and structural factors as leading contributors that increase vulnerability and poor health outcomes among ACB women. To enhance health of HIV-positive ACB women in Manitoba, research focusing on HIV care services and associated support networks for these women is crucial.

AIM

- To explore from the perspectives of HIV-positive ACB women and care providers, knowledge, attitudes, feelings, interpersonal experiences related to HIV care and support services, as well as use and perceptions of these services.
- To develop recommendations for future improvement and learning based on health care supports for HIV-positive ACB women in Winnipeg

METHODOLOGY

Theoretical perspectives: Qualitative study, informed by critical race theory and feminist methodological research design.

Methods: In-depth semi-structured interviews.

Interviews: Face to face and telephone interviews with HIV-positive ACB women and service providers.

Interview for ACB women conducted in two sessions, while service providers had only a session of interview.

Who We Heard From

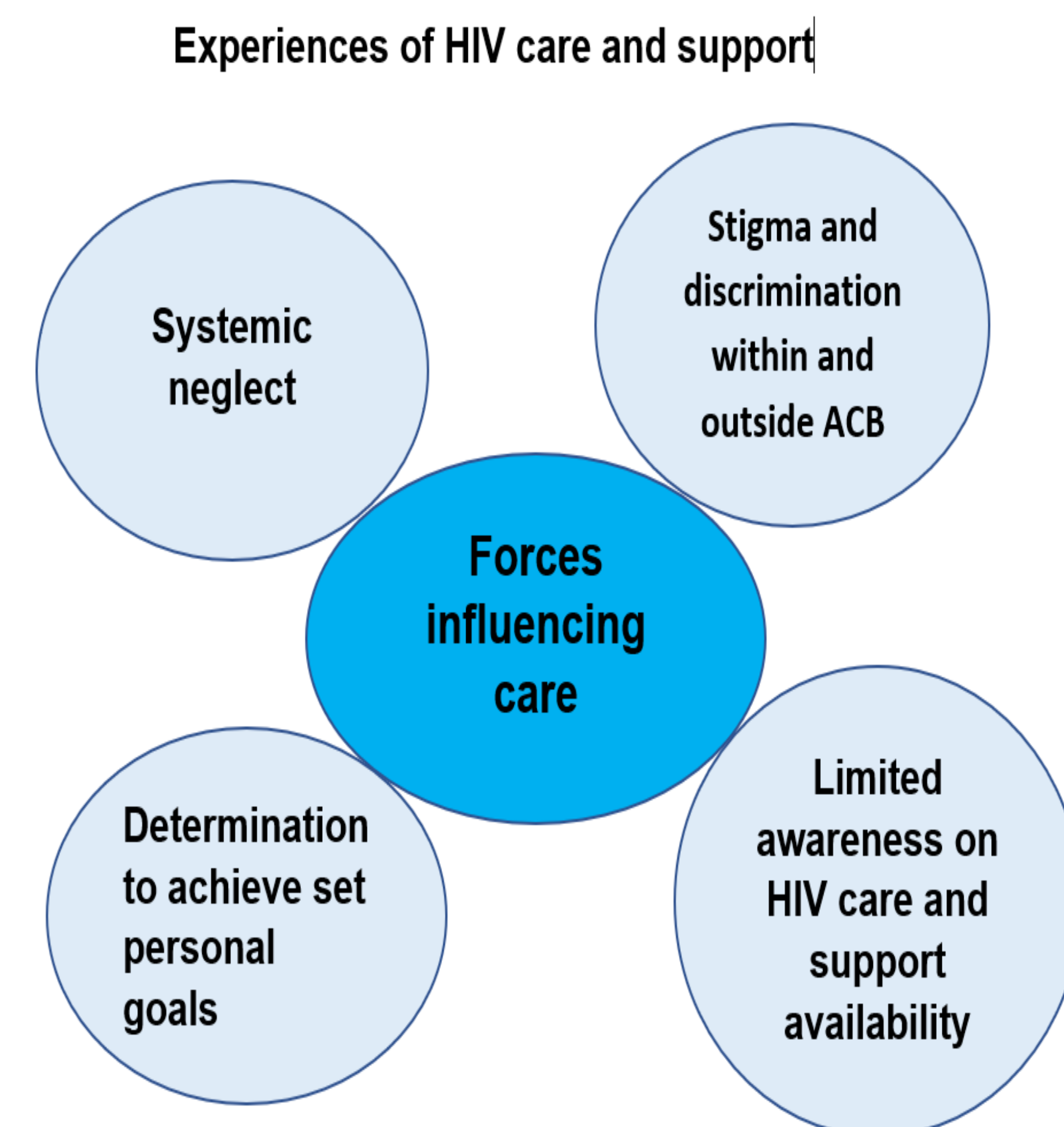
10 ACB women with HIV

- Self-identified as female
- Aged between 25 and 54 years old.
- 4 married, 3 single, 3 separated, 1 divorced
- 3 full-time employed, 2 part-time employed, 4 unemployed and 1 on maternity leave
- 4 had higher than secondary school education, 4 below high school and 2 high school graduates.

12 Services providers

- Aged between 38 and 59 years
- 8 African/Black, 3 White and 1 Biracial
- 8 female, 4 male
- 9 married, 1 separated and 2 partnered
- 10 full-time employed, 2 part-time employed
- All had higher than secondary school education

RESULTS



Stigma and Discrimination Within & Outside ACB

“You know, stigma, I don’t want that one to happen to me. That’s why I don’t look for any, group (HIV support group) No, I don’t. I just don’t want to go anywhere. I stay in my place. I just go to my hospital get my pills, done. Like nobody knows my status. I know it by myself only. I didn’t know that sickness one week ago, or one month ago that I need people to talk to me. I knew over 18 years ago. I’m very strong” (45-year-old, ACB HIV woman)

“Yeah, my place where I’m working in the hospital, true, it’s very challenging. They do not even believe anybody can attain that HIV. They think that HIV is only for stubborn people. They don’t discuss nicely and discriminate. All because a patient is HIV like me. Now, I think by myself, omg! me too I’m the same with this person, what about if they know about me, how it will be?” (41-year-old, ACB HIV, woman).

“So, with Black people they talk, when they know you or they see you, they simply go straight and gossip. So, with them, I get scared, but I’ve never met them. No, I’ve never met anybody from my place, or who is staying near downtown or next to my apartment. So, I am not scared going there (clinic x). I’m just okay.” (45-year-old, ACB HIV woman)

“I would say, stigma is huge from all directions from community, from service providers. Some people think that they are preventing by stigmatizing the person but that is still stigma, that’s not prevention” (38-year-old, African, man, care staff)

Systemic Neglect

“Obviously, the way the programs are set up is geared towards English speaking people. It’s English speaker friendly, more so than people like me, who are ethnic minority. And so, the whole program is set up, even from the cultural, it’s centered on the culture and understanding of the West and is generalized. And so, for me being an ethnic minority, coming in with a different language, having to deal with the lack of safety. Doesn’t feel like a safe space, because there’s different people coming in to interpret for me. It doesn’t feel safe because, also it’s not geared with my cultural understanding in mind. So, it feels like, injustice in the system and I do not feel I fit in, taken care of and seen as well as it should be. I do not find it safe space for me to participate. And because of that no longer wants to partake in the program.” (50-year-old ACB HIV woman)

“Yes, we are very under-looked community because concerning opportunities we are like, even if you’re a Canadian citizen, you are like a second-class citizen. You don’t get the opportunity as easily. You don’t get any information; you are almost like you are kept in a dark” (36-year-old ACB HIV woman)

“I think that clinic x offer some really great programs. But I don’t think that there’s necessarily anything here that speaks directly to that population of people (ACB community). I feel most things are generalized and meant to welcome everybody. I don’t really know the word like, it’s not for them. I think it would be important for clinic x and, and anywhere really, to just offer specific and direct programming, specifically for that community, the same as they do for Indigenous folks, to learn some of their customs and their culture, because you don’t find that here. I don’t anyways, maybe I’m looking in the wrong places. But, you know, essentially, I know nothing of the African culture” (53-year-old, Bi-racial, woman, care staff)

Limited awareness on HIV care and support availability

“Honestly speaking, I don’t get involved a lot in clinic x care programs, anything, I don’t know any other HIV support other than seeing a doctor. And then they tell me when they need to see me. And then I make an appointment when I need to see them. When I had babies, they gave me free formula. That is, probably through HIV support, but I don’t have any information about what they do, how the support is, where it is. I don’t know” ((36-year-old ACB HIV woman)

As an adult going to school, there’s no, enough information. There’s no enough information online, there is no actual offices that you could go and be like, this is an immigrant, where should I start my life. This is from my experience. I was very confused of where to go to, whom to talk to when I arrived. If I didn’t know internet, if I didn’t have a support person, I would have lost, I wouldn’t have gotten my medication on time because sometimes you need to keep up with taking medication” (36-year-old ACB HIV woman)

Determination to achieve set personal goals

For most HIV-positive ACB women, staying healthy, supporting selves and families are key personal goals. Therefore, despite facing barriers, these women often tend to connect to HIV treatment and care.

“So, when it comes to my care for instance, I don’t play with that even back home, no matter how busy I am, I can make out time to attend my clinics. And if I can’t make my clinics, I communicate to my doctors to reschedule. If it comes to my care here, I don’t trade those appointments for anything else. And if I can’t make it on a certain day or time, I am always free to reschedule and I will always take into cognizance, the importance of making sure I didn’t push it later than I shouldn’t” (44-year-old, ACB HIV woman)

“These are people who immigrate, not just because, they are sick, they have other goals. They come to Canada with a goal to better their lives and the lives of their families and their children. And the thing is that HIV is not going to stop them. In terms of outreach work support, 99% of people I know who immigrate from Africa, they would use it first, they would use the resources that they need once they land in Manitoba. And then they will definitely adhere to treatment. To be honest with you, they don’t kid with treatment. So, my experience with the African community is very successful. For the great majority of them, within six months, they become undetectable, and they live healthy lives, productive lives” (49-year-old, African, man, care staff).

CONCLUSION

For ACB women living with HIV, a major concern remain stigma and discrimination which they encounter as they navigate life on a daily basis, including facing systemic and structural issues. As implications, ACB women remain less likely to talk freely and honestly about HIV and socialize within ACB community. To better support HIV-positive ACB women in Winnipeg, it remains crucial to consider the various and intersecting needs of these women.

REFERENCES

Crotty, M. (1998). Introduction: The research process. The foundations of social research: Meaning and perspective in the research process, 1-17