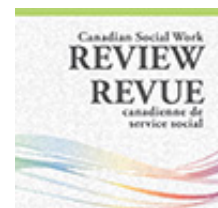


## Canadian Social Work Review Revue canadienne de service social



### ***“Trust Me, It’s Different”*: Experiences of Peer Case Management of Women Living with HIV in Ontario, Canada**

Saara Greene, Allyson Ion, Gladys Kwaramba, Mary Mwalwanda, Janet Caswell, Esther Guzha and Adriana Carvalhal

Volume 32, Number 1-2, 2015

URI: <https://id.erudit.org/iderudit/1034144ar>

DOI: <https://doi.org/10.7202/1034144ar>

[See table of contents](#)

#### Publisher(s)

Canadian Association for Social Work Education / Association canadienne pour la formation en travail social (CASWE-ACFTS)

#### ISSN

2369-5757 (digital)

[Explore this journal](#)

#### Cite this article

Greene, S., Ion, A., Kwaramba, G., Mwalwanda, M., Caswell, J., Guzha, E. & Carvalhal, A. (2015). *“Trust Me, It’s Different”*: Experiences of Peer Case Management of Women Living with HIV in Ontario, Canada. *Canadian Social Work Review / Revue canadienne de service social*, 32(1-2), 73–93.  
<https://doi.org/10.7202/1034144ar>

#### Article abstract

In response to the dearth of research for delivering women-centred support to women living with HIV, the Women’s HIV Empowerment Through Life Tools for Health (wHEALTH) intervention was developed. This project was grounded in a community-based research framework and aimed to respond to barriers of women living with HIV in accessing appropriate and meaningful social supports. Participants described the benefits of the peer case management intervention including support, mentorship, flexibility in which the intervention was delivered, and the notion of “moving forward” in one’s journey with HIV. Through education, awareness, and advocacy, peer case managers are important partners in addressing HIV-related stigma, and ensuring a multi-level approach to providing care and support to women living with HIV.

# **“TRUST ME, IT’S DIFFERENT”: EXPERIENCES OF PEER CASE MANAGEMENT OF WOMEN LIVING WITH HIV IN ONTARIO, CANADA**

*Saara Greene  
Allyson Ion  
Gladys Kwaramba  
Mary Mwakwanda  
Janet Caswell  
Esther Guzha  
Adriana Carvalhal*

**Abstract:** In response to the dearth of research for delivering women-centred support to women living with HIV, the Women’s HIV Empowerment Through Life Tools for Health (wHEALTH) intervention was developed. This project was grounded in a community-based research framework and aimed to respond to barriers of women living with HIV in accessing appropriate and meaningful social supports. Participants described the benefits of the peer case management intervention including support, mentorship, flexibility in which the intervention was delivered, and the notion of “moving forward” in one’s journey with HIV.

---

*Saara Greene is associate professor and Allyson Ion is a PhD student and research assistant in the School of Social Work at McMaster University. Gladys Kwaramba is a research associate who has contributed to multiple community-based research projects focused on HIV and women’s health issues across Ontario and Canada. Mary Mwakwanda is a peer case manager with the wHEALTH team, who assisted with the revision of the Peer Case Management Manual and organized the delivery of knowledge translation and exchange events in the community. Esther Guzha is completing her BA in Sociology at York University and is a women’s HIV support worker in Toronto. Janet Caswell is a social service provider and expert in Case Management from Ontario. Adriana Carvalhal is assistant professor in the Department of Psychiatry at the University of Toronto and a psychiatrist at St. Michael’s Hospital in Toronto.*

**Canadian Social Work Review, Volume 32, Number 1 (2015) / Revue canadienne de service social, volume 32, numéro 1 (2015)**  
Printed in Canada / Imprimé au Canada

Through education, awareness, and advocacy, peer case managers are important partners in addressing HIV-related stigma, and ensuring a multi-level approach to providing care and support to women living with HIV.

**Keywords:** Peer support, HIV, women, social support

**Abrégé :** L'intervention wHEALTH a vu le jour pour pallier le peu de recherches sur la façon d'offrir un soutien adapté aux femmes séropositives. Elle s'est inscrite dans un cadre de recherche communautaire et visait à aplanir les difficultés qu'éprouvent les femmes séropositives à accéder à des initiatives de soutien sociales pertinentes et utiles. Les participantes ont décrit les avantages de la prise en charge de cas par des pairs, y compris le soutien et l'encadrement dont elles ont bénéficié ainsi que la souplesse avec laquelle l'intervention a été offerte, et elles ont abordé l'idée « d'aller de l'avant » dans la vie avec le VIH. En misant sur la formation et la sensibilisation, les gestionnaires de cas sont d'importants partenaires pour combattre la stigmatisation liée au VIH et pour assurer une approche multiniveau dans la prestation de soins et le soutien aux femmes séropositives.

**Mots clés :** Soutien par les pairs, VIH, femmes, soutien social

## Introduction

### *Women Living with HIV (WLWH) in Canada*

*THE NUMBER OF WLWH* in Canada continues to increase dramatically; 26 % of all positive tests in 2008 were among females, and women accounted for the majority (58 %) of all positive test reports among young adults aged 15 to 19 years (PHAC, 2009). HIV in women most often occurs vis-à-vis heterosexual contact and injection drug use. At the same time, acquisition of HIV is connected to social determinants of health including housing, mental health, and exposure to violence (Kilbourne, Herndon, Andersen, Wenzel, & Gelberg, 2002; Wenzel, Tucker, Elliot, & Hambarsoomians, 2007). Coupling a lower socioeconomic status with risk factors for HIV often results in barriers to accessing adequate health and social services (Parish, Burry, & Pabst, 2003). Through advances in treatment, HIV has evolved into a chronic illness (Scandlyn, 2000). Medical management, social challenges, and unpredictable periods of wellness and illness positions HIV as an episodic disability that is influenced by living strategies and personal attributes, alleviated by practical, emotional, and social supports, and exacerbated by HIV-related stigma (O'Brien, Bayoumi, Strike, Young, & Davis, 2008).

Poverty, lack of affordable housing, racism, stigma, and discrimination all contribute to the progression and management of HIV (CAAN, 2005; PHAC, 2009). Encouraging WLWH to access relevant health and social services has been challenging and has not resulted in the provision of women-specific services. Many women face barriers to accessing services including limited transportation, caregiving responsibilities, employment,

drug coverage, housing instability, immigration, HIV stigma, and relationships with multiple providers in multiple locations (Logie, James, Tharao, & Loutfy, 2013; Melchoir et al., 2001; Wood & Tobias, 2004). Furthermore, women and men differ in HIV progression and treatment responses, which are compounded by social and behavioural factors and comorbid health conditions (Loutfy et al., 2013). As HIV services were not originally created by or for women, it appears their unique issues have not been considered in program design and implementation, thereby limiting services that would specifically address their needs (Selbin & Del Monte, 1998). Although tailored services that respond to women's unique needs are critical in improving health outcomes, the notion of women-specific HIV/AIDS services remains poorly conceptualized in the literature (Carter et al., 2013).

### *Case Management Models*

Care has shifted from the hospital to the community for people living with HIV (PLWH) (London, LeBlanc, & Aneshensel, 1998), and offering comprehensive services to PLWH in community settings has proven effective (Browne, Roberts, & Byrne, 2001). Case management is one model to offer community-based HIV care; it is a client-centred approach that assists clients in navigating health and social systems, thus empowering both the client and supports that manage their needs (Moxley, 1989). Case management activities include advocacy, counseling, service referrals, and resource allocation (Albrecht & Peters, 1997) and are coordinated according to the client's needs to ensure positive and sustainable outcomes, particularly for those who have not benefited from traditional care models (Austin & McLelland, 1994). Research has demonstrated the social and economic importance of implementing community-based case management programs for PLWH with multi-faceted physical and mental health challenges (Husbands et al., 2007). For WLWH, case management is important to ensure access to social support and medical services as it connects women and their families with food, clothing, and shelter, thereby improving stability (Parish et al., 2003). Furthermore, having access to a trustworthy, non-judgmental case manager, who provides consistent support, is of particular importance to women (Passey, Sheldrake, Leitch, & Gilmore, 2007).

### *Peer-Based Approaches*

Conventional case management may not always be effective for hard-to-reach populations and those living in resource-limited communities (Albrecht & Peters, 1997). Peers enhance case management by modeling hope and understanding community culture; peer case management (PCM) focuses on mutual, reinforcing efforts of both the client and the peer case manager.

Peer case management has been shown to improve the client's mental health, social functioning, and vitality in other chronic illnesses (Helgeson, Cohen, Schultz, & Yasko, 1999); it improves coping skills, reduces isolation, and improves the client's confidence when speaking with physicians (Campbell, Phaneuf, & Deane, 2004). Peer interventions in HIV may alleviate demands on healthcare systems while offering social and practical supports vis-à-vis assistance with daily living (Heckman, Somlai, Sikkema, Kelly, & Franzoi, 1997). These interventions have been promoted by international bodies (Simoni, Nelson, Franks, Yard, & Lehavot, 2011; U.S. President's Emergency Plan for AIDS Relief, 2009), however the potential uniqueness of a women-centred approach in HIV-specific peer interventions is missing from the literature (Boyd et al., 2005).

Most peer-support HIV research has involved HIV-negative Caucasian, heterosexual women and gay men who volunteer to provide social support (Cassel & Ouellette, 1995; Marino, Simoni, & Silverstein, 2007). Although peer support research has increased in many areas (Hilfinger-Messias, Moneyham, Vyavaharkar, Murdaugh, & Phillips, 2009; Simoni, Nelson, Franks, Yard, & Lehavot, 2011), more in-depth, theoretical, and contextualized knowledge of peer support is needed (Simoni, Franks, Lehavot, & Yard, 2011), particularly for WLWH who represent a range of cultures and social locations.

Research has recently responded with more rigorous evaluations of peer interventions (Maticka-Tyndale & Barnett, 2010; Simoni, Nelson, Franks, Yard, & Lehavot, 2011; Webel, Okonsky, Trompeta, & Holzemer, 2010). However, diversity in methodology, outcomes, and reporting have limited generalizability from published studies (Simoni, Nelson, Franks, Yard, & Lehavot, 2011) making consensus regarding efficacy a formidable challenge. Researchers posit that we can have some confidence in peer interventions but require more rigorous research to demonstrate an effect (Simoni, Nelson, Franks, Yard, & Lehavot, 2011). Limited research, however, has examined why peer support may be a unique form of social support for WLWH who represent diverse social circumstances.

## Overview of wHEALTH

The Women's HIV Empowerment Through Life Tools for Health (wHEALTH) study was imagined in the early 2000s when service providers and WLWH across Ontario, Canada recognized the importance of peers when it came to clients receiving support. Research and best practices on how to best deliver support to WLWH were also limited, highlighting the need for an effective model.

### *Our Community-Based Research Approach*

wHEALTH is a community-based research study, which collaboratively involved a team of interested stakeholders including Voices of Positive

Women, community leaders, and researchers in all aspects of the research process. Community-based research has a broad goal to strengthen communities by putting their issues at the centre of the research while acknowledging the influence of multiple sources of knowledge on practice and policy changes (Marchand, 2001). The wHEALTH team worked together to establish guiding principles and solve logistical issues to ensure the research reflected the community's vision of social change (Israel, Schultz, Parker, & Becker, 1998).

### *The wHEALTH Intervention*

The goal of wHEALTH was to evaluate PCM for WLWH in the Greater Toronto, Hamilton, and surrounding areas. The PCM model was grounded in women-centred and strengths-based social work practice, and was based on the belief that individuals possess abilities and inner resources that allow them to effectively cope with the challenges of living (Weick, 1983; Weick & Pope, 1988). Strengths-based case management combines a focus on client strengths and self-direction with three other principles: (1) promoting the use of informal helping networks, (2) offering assertive community involvement by case managers, and (3) emphasizing the relationship between client and case manager (Brun & Rapp, 2001). The wHEALTH team also defined four core values to theoretically and philosophically ground the development and implementation of the intervention, as well as the ongoing work of the research team, including: (1) Operating from an anti-oppressive framework; (2) Harm reduction; (3) Women-centred and inclusiveness; and (4) Sex positive.

Finally, the wHEALTH intervention was delivered by WLWH; together the client and peer case manager assessed and prioritized issues and strengths related to daily living; housing; financial supports; social supports and relationships; vocation, employment and education; leisure and meaningful activities, etc. The philosophy behind, and steps to deliver, the wHEALTH peer case management intervention have been summarized in a manual (Carvalho, Caswell, Ion, Kwaramba, & Mwalwanda, 2010).

### **Methods**

From June 2008 to August 2010, WLWH who were 18-years or older were recruited through Voices of Positive Women; other HIV/AIDS service organizations (ASOs) located in Toronto, Hamilton and surrounding areas; and a regional outpatient clinic where women receive HIV care. Recruitment flyers were posted and distributed at ASOs and the outpatient HIV clinic and individuals were directed to the Research Coordinator. Women were also proactively told about the study by their clinician and were connected to the Research Coordinator as they attended routine appointments at the outpatient HIV clinic.

Participants were randomized to receive either: (1) peer case

management (PCM): 12 bi-weekly, one-hour, individual sessions with a trained peer delivered over six months; or (2) support from existing community-based programs: participants would establish or maintain a connection with their local ASO, in particular Voices of Positive Women, and engage in health promotion activities, group sessions, meetings with community-based support workers, etc. for a total of 12 contacts (also referred to as standard care). All participants completed surveys at baseline, end of intervention (six months) and three months post-intervention (nine months) assessing socio-demographic characteristics, quality of life, depression, social support, coping, and satisfaction. The quantitative data is beyond the scope of this paper.

A decision was made by Voices of Positive Women to close the organization in August 2010 after an independent organizational review, which affected our ability to compare wHEALTH to standard care. Following preliminary data analysis, and considering our ethical responsibility to ensure women had access to peer support, our team decided to assign women recruited from August 2010 to April 2011 to peer case management.

In line with our community-based research approach, WLWH who were interested in delivering PCM were invited to apply and hired. The part-time employment opportunity was promoted at ASOs and the outpatient HIV clinic. Qualified applicants had demonstrable knowledge and experience with case management and/or peer support, as well as knowledge of community resources through personal and/or professional experiences in employment and/or volunteer capacities. Applicants also had to demonstrate strong self-directed and problem-solving skills as they would be working independently with participants. Seven women applied and were interviewed and five were hired and trained. Peer case managers completed seven days of training to strengthen their understanding of wHEALTH. All team members developed the content and facilitated a component of the training. Peer case managers worked between three and 10 hours per week, depending on the number of clients and project activities.

Matching peer case managers with participants was based on the city of enrolment (Toronto vs. Hamilton) and availability (e.g. daytime vs. evenings/weekend sessions). Sessions were held in a space where both women felt comfortable (e.g. HIV clinic, coffee shop, park bench, walking trail). The study received approval from the McMaster University Research Ethics Board, and all participants provided written, informed consent.

### *Qualitative Data Collection*

The qualitative component of the study focused on understanding women's experiences with PCM. From April 2009 to July 2010, the first 17 PCM participants were invited to participate in a semi-structured interview. Interview participants were selected consecutively as they completed



50 % of their 12 PCM sessions from the overall participant pool. Although interview participants represented 14 % of women enrolled in wHEALTH, and 21 % of participants in PCM, interview recruitment ended after 17 interviews due to saturation of emerging themes. Semi-structured interviews conducted by the Research Coordinator were organized around an interview guide while enabling flexibility in participant engagement (Fontana & Frey, 2000). All interviews were recorded and transcribed verbatim, and underwent thematic analysis. Three team members identified the pattern of experience within each transcript, identified data that related to a specific pattern amongst the transcripts, and coded the patterns into sub-themes “bringing together components or fragments of ideas or experiences” (Leininger, 1985, p. 60). Thematic analysis was followed by reflexive debriefing, where themes were discussed amongst multiple members of the research team (Creswell & Miller, 2000).

## Findings

### *Participants*

A total of 121 WLWH consented to participate in wHEALTH; 84 were randomized (43 participants worked with peer case managers, the remaining 41 received standard care). After the closure of Voices of Positive Women, an additional 37 women were recruited and assigned to peer case managers. T-test and chi-square tests were conducted to assess differences between the PCM and standard care groups for continuous and categorical demographic variables, respectively. There were no significant differences between PCM ( $n = 80$ ; includes 17 interview participants) and standard care ( $n = 41$ ) study groups with regard to age, place of origin, ethnicity, immigration status, time spent in Canada, first language, and site of enrolment.

The median age of interview participants was 47, ranging from 27 to 52 years of age. Most women ( $n = 10$ ) were Canadian-born; five originated from an African country and two were from a Caribbean country. Ten women identified as Caucasian and seven identified as Black. The majority were Canadian citizens ( $n = 12$ ) followed by refugee claimants ( $n = 5$ ). One participant identified as a Trans woman. Many women had graduated from, or completed some, college or university ( $n = 11$ ), however, six were on long-term disability. Almost half ( $n = 8$ ) had used the services of an ASO; three were new users within one year, while five had accessed ASOs for more than a year; nine women had never accessed support from an ASO. Demographic characteristics of interview participants were similar to the demographic characteristics of the overall study cohort. Interviews with PCM participants highlighted three broad themes including: barriers to accessing support, the benefits of PCM, and how women interpret the term “peer” in PCM.



## 1. Barriers to Accessing Support

### a) Limited Women-Specific Programming

*I didn't know what was there for me ... so I just figured OK, I have to try to go through this on my own because there is nothing for us.*

Eight women had sought HIV support through ASOs prior to participating in wHEALTH, whereas nine had never reached out to community-based HIV services. All participants did not see themselves reflected in community-based services and shared the perspective there was a lack of women-specific programming, support, and web-based resources. As one participant shared: “*Getting help as a woman ... there wasn't much. It seemed to be all geared to men, but, unfortunately, women and children get it too.*” This woman was interested in receiving emotional support and her ASO was not helpful in meeting this need. PCM participants echoed WLWH in the Midwestern U.S., citing a lack of resources and support groups specifically directed towards women's issues, as well as discomfort in discussing sexual, emotional, and biological issues unique to women in mixed-sex groups (Peterson, 2010). Nine participants resided in a mid-sized city, with one ASO serving a large geographical region with a population of almost one-million people and one HIV clinic. This highlights the limited number of services dedicated to PLWH and the perception of insufficient support services due to HIV not being a salient, public issue (Peterson, 2010).

The lack of available women-specific services resulted in challenges in accessing HIV support. Participants said they were uncomfortable going to ASOs because they were women and required women-specific programs. As one woman stated:

*I want the [local ASO] to be something that it's not and how dare I? That's arrogant in a way, but I think that it's a little bit sad that I don't feel comfortable going there ... As an ASO I thought it would be a place where I could go to get all the information I want ... I haven't been welcomed there, and I'm not sure I can change that.*

This woman's experience highlights her perceived lack of power to change this gap in service.

In some regions, discomfort in accessing ASOs had overarching consequences for women, including barriers to medical care. For example, in some cases the only way to obtain a referral to see an HIV specialist was through a local ASO. However, because of the lack of services available to women in the ASO, and their subsequent choice not to visit the ASO, participants experienced barriers to accessing medical care. As one woman articulated:

*One of the deterrents that I had too was that when I was looking for a doctor, the doctor that was in [city] would not take anybody unless you belong to [local ASO]. And then when you look on the internet to see about [local ASO], to see what they have for women ... it's all men's groups.*

Barriers to accessing support was linked to gender; participants did not believe that ASOs aligned with their unique needs and experiences, which resulted in their feeling excluded.

Challenges to accessing services were exacerbated for a Trans participant who shared her experience of being treated like “a medical discovery” by service providers. As a result, she felt excluded from her ASO citing a lack of sensitivity to her needs as someone who identified as a Trans woman. Peer case management participants did not see themselves, or their specific needs reflected in ASO services, which resulted in their discomfort, isolation, and disconnection from a community (Lichtenstein, Laska, & Clair, 2002; Peterson, 2010) as well as a feeling of lack of power to change gaps in services.

#### *b) Stigma and Disclosure*

Participants also identified HIV-related stigma as a barrier to accessing community-based support. Many wHEALTH participants had not disclosed their HIV status to anyone beyond their health care team, as one woman reflected: “*Like the stigma is, I'm sorry, it is so big; it is so, so, so big and that's why I won't disclose.*”

HIV-stigma and fear of disclosure continue to create barriers for WLWH to access HIV-specific support (Kako & Dubrosky, 2013; Sandelowski, Lambe, & Barroso, 2004) and can result in avoidance of critical health services (Turan, Miller, Bukusi, Sande, & Cohen, 2008). Disclosure to friends, family, and health-care providers has been associated with marginalization, isolation, and social exclusion (Loutfy et al. 2012; Venable, Carey, Blair, & Littlewood, 2006). Fear of HIV-related stigma and related consequences resulted in participants choosing not to disclose their HIV status, often resulting in women traversing “two groups” of relationships in their lives:

*I sort of have two groups of people in my life. It's those that know and those that don't, and so a part of me really feels torn up inside because, um, the people that are closest to me, my oldest, closest friends, my family, do not know about my diagnosis ... that's really hard because I want so desperately to reach out to them but at the same time, I sort of feel as if I'm sparing them of, you know, a terrible situation, embarrassment, shame, and all of that stuff that goes, you know, surrounds being positive.*

This sentiment echoes Peterson (2010) where WLWH expressed concern with the burden they may place on their families through disclosure, both to provide support and to cope with stigma. This also highlights how fear of disclosure and HIV-related stigma creates consequences and barriers to accessing both HIV and non-HIV social and medical supports.

Women's concerns about HIV-related stigma were also present in the context of receiving support in other settings, where being offered support did not guarantee respecting their privacy and confidentiality. For example, when women's programming was offered, it was commonly delivered in a support group with several people, which increased women's anxiety about HIV disclosure and the potential for HIV-related stigma:

*I've done those group things when I was in a shelter ... I really don't like sharing with other people ... I think in my situation, and being infected you know, basically in my little world it's only me that knows.*

This woman's experience in a shelter confirmed her fear of HIV-related stigma and criticism of the lack of appropriate support for WLWH.

Interestingly and perhaps surprisingly, this same anxiety was expressed in support settings with other WLWH: *"I do want sessions, but I don't want to disclose, so I am quite honestly terrified of walking into a room where I know somebody."* Fear of HIV-related stigma and discrimination transcended both ASOs and broader community services, and this was the experience of participants regardless of their social location (e.g. age, ethnicity, geographic region where they reside, or rural vs. urban community). This highlights the intersection of gender, HIV and stigma, which culminate to complicate the lives of WLWH across Ontario in accessing and receiving HIV and non-HIV support services (Jacobs & Kane, 2010). The intersectional model of HIV stigma, where HIV stigma is layered on a foundation of marginalized social identities and inequities related to sexism, racism and homo/transphobia, is well documented in the literature (Logie & al., 2011; Loutfy et al., 2012; Parker & Aggleton, 2003). Taken together, these intersecting axes of marginalization created particular challenges for PCM participants to have their support needs met, and left them feeling disconnected and powerless to shift this gap in services.

## **2. Benefits of PCM**

### *a) Individual Support*

Because fear of HIV stigma was a pressing concern, participants articulated a need for a support model that allowed them to not have to disclose their HIV status to anyone besides the person providing the support. Our response to this reality was to provide support where WLWH could meet

one-on-one with other WLWH. The results were positive for participants; individual support neutralized the trepidation previously experienced in group settings or when reaching out to community organizations: *"I've been diagnosed almost 16 years and this was my first time, so for me, my very first meeting with [PCM] that day, like I was on air!"* Until participating in PCM, only this woman's HIV specialist was aware of her HIV status. After meeting with a peer and opening up dialogue about HIV, this woman felt a sense of relief. Similar responses have been documented in research throughout the world, whereby positive disclosure beliefs are associated with lower perceived stigma, higher self-esteem, and fewer depressive symptoms (Kako & Dubrosky, 2013; Patel et al., 2012).

Receiving support from another WLWH was also important because participants felt they would not be judged based on HIV: *"I prefer the one-on-one meeting because I just feel like I can be more myself and say what I really want from the heart and not have to be worried about being judged."* This woman's experience highlights the meaningful and intimate connection that can be achieved through one-on-one peer support (Marino & al., 2007). Women indicated talking with other WLWH, whom they believed understood what they were dealing with, was valuable:

*You know exactly what it's like to be on all these meds; you know exactly how it feels, the pain, the nausea, the depression sometimes, you know ... if somebody's not HIV, they get an idea, they get a sense, but not 100% ... It really doesn't sink in, they're not there, you know, they're not the person living with it ... trust me, it's different.*

For many participants, experiences through PCM were often the first time they received safe and accessible HIV support without fear of disclosure and stigma.

Finally, PCM catalyzed motivation for some participants to access additional supports thereby decreasing social isolation:

*I think meeting other people who are case managers and who are also HIV-positive, who are willing to help you in any problem that you may encounter, is better and so motivating because I for one, I'm coming from Africa; HIV in Africa is actually a death sentence. Once you are diagnosed with HIV you see yourself dead in two weeks, you actually just get wasted because of being alone, you don't have anyone to talk to; it's just you and your HIV.*

For many women, PCM was critical in supporting them through a period in their lives when an HIV diagnosis went beyond fears of stigma to include fears about death and being alone. Having access to PCM was a safe alternative to other forms of support as it created an opportunity and motivation to talk about the meaning of the diagnosis and possibilities for the future.

### b) Mentorship

Peer case management enabled WLWH to not only access safe, confidential, and non-judgmental support, but to also think about their own journeys living with HIV and, from witnessing the longevity and successes of a peer, realize that many things were possible:

*Just the idea of talking to someone who is going through what I'm going through; just knowing that if I cry somebody knows the pain that I'm going through. That has been really, really good for me ... if you're not going through what I'm going through, you really don't know what I'm going through ... it's been the best part [of PCM].*

Consequently, peers became mentors and an inspiration for how participants could move forward in their lives:

*Seeing [PCM], the longevity ... she's been HIV-positive for 18 years ... her life has gone on and she's, you know, doing well ... that's great. I mean to me, it's a good mentor because of like I said, I have a career and still function and I don't want to give it up and she's showing me that I don't have to give it up.*

Some women sought advice and/or living strategies from their peer who had dealt with similar circumstances, which was viewed as mentorship:

*I have very positive results about my worker because she is my mentor; I call her my mentor and I believe she, she is there to give me the best so, and uh, she does this without prejudice ... Most of the times, uh, my mentor was dealing with the issues I have for the day, how I'm feeling, how my work is affecting me, how my life is affecting me, how my son is affecting me, how my health is affecting me. So, all those things, she used to deal with them accordingly and she used to be very good at addressing them.*

Mentorship in PCM enabled many participants to experience a sense of normalcy in their lives, coupled with hope for the future.

### c) Place and Space

Peer case management enabled WLWH to receive professional and confidential support in informal settings like coffee shops, parks, libraries, living rooms, and public spaces. As one woman asserted: *"It's not against the law, you know, to be in an enjoyable space when you are participating."*

The combination of social informality with client-centred professionalism was also appreciated: *"It's the idea of hanging out with someone ... for my case I have never had the opportunity to do that."* Peer case management recognized and valued the knowledge and skills of the peers and

acknowledged that their personal, lived, and professional experiences would shape how support was delivered, accessed, and experienced by clients, as one woman described: “[She] was very professional and um, very confidential, so, she didn’t reveal a whole lot about herself initially and allowed me to, so she allowed me to take charge.” Women framed it as their right to access formal, professional and confidential support in an informal and often public setting, which made PCM more meaningful and fulfilling.

#### *d) Connecting Women to Services*

Peer case management reduced barriers to women accessing support by increasing awareness of and connection to services. One woman, who was familiar with ASOs in Toronto, found it confusing to know where to go for services:

*I would have never known about those things ... and getting me in touch with the right people at least I know, who I need to call to get into those programs, or those services ... It takes a load off your mind because then you don’t have to sit on the computer and try to look up all the information yourself, I mean she’s really great in that.*

Peer case management enhanced this woman’s understanding of program eligibility and connected her with the “right” people; obtaining accurate and trustworthy information was a relief for this woman and this enabled her to focus on other aspects of her life.

Through communication and partnership, peers drew from relevant community resources to resolve clients’ unique needs, resulting in connectedness and improved quality of life:

*[I] managed to meet lawyers through her ... people who could help me with some funds immediately ... people with ... health care and stuff like that. I managed to get connected to [culturally specific ASOs]... I’m really connected.*

For some women, feeling connected went beyond accessing services to a sense of connectedness to the larger HIV community:

*I’m getting more connected to the HIV community because now I know I belong to them. I’m willing to tell them like even if we are positive, let’s stop looking down on each other; let’s help each other because if we have some information that I think is useful to you, let me share it with you ... I think yeah, I’m connected to my HIV people.*

An important aspect of supporting WLWH is to understand how it feels to be part of a highly stigmatized group, what it means to feel a sense of belonging, and to receive and provide support from someone with a shared experience.

*e) Moving Forward*

Participants were asked of any noticed changes after participating in peer case management sessions and responded positively, describing feelings of hope, empowerment, and transformation: *"I feel that you have brought me out of the cage, so I really feel free now ... I have learned to stand my ground. I have learned to advocate for myself."*

Many women described peer case management as a mechanism to break the chains of silence, guilt, and shame; they felt they were "being loosened from the bondage that is ... binding you." This was often framed as achieving a sense of normalcy where HIV was no longer the focus in their lives and attention was shifted to the future:

*I used to feel more sorry for myself ... some days you get up and you know having a bad day especially with medication, everything you want to blame on the medication or sickness ... Talking to [peer case manager] ... some weeks I don't even remember that I'm HIV ... you just feel like there's ... so much things to live for, so much to do I'm like you can do whatever you want to do, so you just forget about that and try to move on.*

Many women felt acceptance and comfort following their experiences with peer case management, realizing they could self-determine their lives and futures.

### **3. Complicating the Term "Peer" in Peer Case Management**

While all participants agreed meeting with another WLWH was a positive experience, there was disagreement about the meaning of the term "peer." Some women agreed: *"It doesn't matter where you come from, you both have the same thing,"* while others thought other factors, not only HIV, were important to consider when meeting with a peer. Fifteen participants preferred to meet with a PLWH for any kind of HIV-related support. Two participants were indifferent to their peer case managers' HIV status, believing having HIV was not imperative to providing support as long as there was a motivation to assist PLWH and knowledge of HIV resources. Twelve participants preferred to meet with a woman for support, believing they could more openly communicate with a woman compared to a man; participants felt they could relate with women regarding biological and medical issues, mothering and caregiving responsibilities, and establishing a work-life balance as a woman and mother. The remaining five participants did not feel shared gender was imperative to create a supportive, meaningful relationship with another PLWH.

Other common threads of class, race, parenting, etc. determined the nature of connection and partnership in PCM. Moreover, women could not always be connected to relevant community services through PCM. For example, the Trans participant expressed connectedness to the Trans



community as crucial to her mental well-being and a strong desire to meet with a Transgender peer case manager. Reactions were mixed regarding shared ethnicity. Nine participants did not require a peer from a similar cultural background; it was more about getting to know each other as WLWH: “*I guess as long as the chemistry is right and we feel comfortable and I feel comfortable talking to her then, I don’t think it has any relevance.*”

Conversely, five participants preferred a peer from a similar cultural background as they felt it would help to build a connection and draw them closer:

*I know she’s lived in Africa and even though it was a different part of Africa where I come from, but our culture is kinda the same, we have similarities, so she really understands some of my background ... how can you help someone if you don’t know their background?*

Three participants were adamant they preferred a peer from a different culture:

*Maybe it is the cultural thing ... my family doesn’t know it, if I talk to somebody in my culture I’ll just feel like “Oh my gosh” somehow it will kind of go back to my family ... I’m more comfortable with somebody who doesn’t know my family or doesn’t know my culture.*

Meeting with a peer from a different culture raises concerns of confidentiality, disclosure, stigma, and perceived judgment. These mixed reactions highlight the complexity of defining “peer” in the HIV community, especially when offering peer support to WLWH. When developing a peer case management program, one must consider what constitutes “peer identity” and consider it may not always be HIV-status alone that results in a “good match.” Peer case management must include flexibility and responsiveness that is dependent on the needs of the communities involved.

## Discussion

This paper highlights the wHEALTH PCM model as an innovative way to provide meaningful support to WLWH in Ontario. wHEALTH participants highlighted barriers to accessing HIV supports including HIV-related stigma and their dissatisfaction in relation to limited women-specific HIV services. Women’s historical experiences of accessing support, coupled with sub-optimal, women-specific, HIV services resulted in social isolation and exclusion of supports for WLWH. By providing tailored programming for women that responds to their unique issues and concerns, support services for WLWH can be reimagined across Canada (Carter et al., 2013); delivering women-centred HIV/AIDS services is also an opportunity to integrate multidisciplinary services to meet the diverse needs of

WLWH while facilitating meaningful access to culturally sensitive care (Carter et al., 2013).

Peer case management participants highlighted the need for one-on-one support, citing past negative experiences with support groups and/or fear of attending a group where, by virtue of being for WLWH, necessitated HIV disclosure. Women consistently discussed fear of HIV-related stigma, resulting in a desire to keep their HIV status a secret even amongst other WLWH. Consequently, without the promise of confidentiality, many women are prevented from accessing HIV support. Furthermore, even when HIV-specific supports exist, service models that meet the needs of WLWH, who are unprepared to discuss the topic of HIV with anyone beyond their HIV specialist, are lacking.

Through wHEALTH, women not connected to ASOs were able to receive safe, social support. Numerous benefits of PCM were described including individual support, mentorship, effectively connecting women to services, flexibility in place and space where sessions occurred, and “moving forward.” A key success of PCM was the witnessing of a mentor’s life—also a woman living with HIV—which renewed optimism amongst participants about their own futures.

Having women decide when and where support sessions occurred increased accessibility through PCM. Walking into an identifiable ASO was in and of itself enough to prevent some women from accessing support, particularly for women who had not yet come to terms with their HIV status. Peer case management created an interesting dynamic where intimate, private support could be received in a public and accessible location. Peer case management did not have to be available to women in a particular setting; flexibility to offer PCM anywhere opened the door for women to access HIV-related support on their terms while avoiding the fear associated with walking through the doors of an “AIDS” organization. For many women, this normalized their HIV status.

Finally, participants highlighted how the defining of a “peer” is complicated; only recently has research explored the mutual process of peer support (Hilfinger-Messias et al., 2009; Marino et al., 2007). People living with HIV are not a homogenous community; a peer’s ethnicity, for example, may take precedence over HIV status. While some participants were open to meeting with a woman living with HIV regardless of her background, other women valued shared sociocultural characteristics because of the possibility of a shared understanding of HIV. Sometimes defining “peer” intersected with a fear of HIV disclosure within a community, highlighting how the concept of “peer” must be carefully considered in a support program.

*Implications for Practice: Addressing HIV-Related Stigma and Decreasing Barriers to Support Through PCM*

HIV-related stigma was a particularly salient theme that complicated women's access to HIV supports in wHEALTH. Stereotypes associated with HIV have remained unchanged over time and internalization of these stereotypes results in women being blamed for HIV transmission and feeling stigmatized (Kako & Dubrosky, 2013; Lekas, Siegel, & Schrimshaw, 2006; Loutfy et al., 2012). HIV-related stigma seeps into other areas of women's lives including parenting (Greene et al., 2015; Sandelowski & Barroso, 2003) and when accessing shelter and housing supports (Greene et al., 2010). Finally, HIV-related stigma is further exacerbated for racialized women in Canada (Logie, James, Tharao, & Loutfy, 2013; Loutfy et al., 2012), suggesting that stigmatization is a societal process that reflects power along existing race and gender hierarchies (Parker & Aggleton, 2003). Peer case management is an opportunity to address factors that result in barriers to health and social care for WLWH while addressing HIV-related stigma. At the micro-level, PCM provides individualized support that is holistic and responsive to women's unique needs; she sets the agenda, as well as short and long-term goals through a mutual partnership with a peer mentor. From a meso-level, through peer support, women equip themselves with knowledge and confidence to navigate care landscapes in their region, streamlining the process to accessing services and receiving support. Through disclosure and sharing with another woman living with HIV, women gain confidence and self-esteem to challenge notions about HIV stereotypes and HIV-related stigma (Kako & Dubrosky, 2013; Patel et al., 2012). Peer case management can strengthen and mobilize communities of WLWH across Ontario to challenge sexism, racism, and HIV-related stigma and to shift how support is provided to WLWH at a macro-level. By acting as outreach workers, skills trainers and advocates, peer case managers are important agents of social change who transcend micro, meso, and macro levels and help to address personal and societal issues that affect all WLWH (Albrecht & Peters, 1997).

HIV/AIDS service organizations, HIV clinical services, and program administrators play an important role in shifting the care landscape for WLWH. HIV-specific services must integrate policies and practices that are women-centred (Carter et al., 2013); this is especially important for ASOs that may be the only HIV service available. As participants highlighted, WLWH may not seek support from an ASO if they do not see their unique needs reflected in programs. HIV/AIDS service organizations can help to strengthen social support networks for WLWH (Peterson, 2010) through the provision of women-centred peer support and by considering the unique concerns women may have regarding privacy, disclosure, and appropriate peer matching. Strengthening peer support networks does not lie with ASOs alone; ASOs can join forces with HIV clinics, testing

centres, public health departments, and other community services that serve women to collaboratively deliver a regional PCM program. In this way, WLWH will have various avenues through which they can access support while respecting their privacy concerns.

## REFERENCES

- Albrecht, G., & Peters, K. (1997). Peer intervention in case management practice. *Journal of Case Management*, 6(2), 43-50.
- Austin, C., & McLelland, R. (1994). Case management in human services: Reflections on public policy. *Journal of Case Management*, 6, 119-128.
- Boyd, M. R., Moneyham, L., Murdaugh, C., Philips, K. D., Tavakoli, A., Jackwon, K., Jackson, N., Vyavaharkar, M. (2005). A peer-based substance abuse intervention for HIV+ rural women: A pilot study. *Archives of Psychiatric Nursing*, 19(1), 10-17.
- Browne, G., Roberts, J., & Byrne, C. (2001). The costs and effects of addressing the needs of vulnerable populations: Results of 10 years of research. *Canadian Journal of Nursing Research*, 33, 65-76.
- Brun, C., & Rapp, R. (2001). Strengths-based case management: Individual's perspectives on strengths and the case manager relationship. *Social Work*, 46(3), 278-288.
- Campbell, H., Phaneuf, M., & Deane, K. (2004). Cancer peer support programs - do they work? *Patient Education and Counseling*, 55(1), 3-15.
- Canadian Aboriginal AIDS Network (CAAN). (2005). *Aboriginal women living with HIV/AIDS: Care, treatment and support issues*. Retrieved from <http://pubs.cpha.ca/PDF/P43/24582.pdf>.
- Carter, A. J., Bourgeois, S., O'Brien, N., Abelsohn, K., Tharao, W., Greene, . . . Loutfy, M. R., on behalf of the CHIWOS Research Team. (2013). Women-specific HIV/AIDS services: Identifying and defining the components of holistic service delivery for women living with HIV/AIDS. *Journal of the International AIDS Society*, 16, 17433.
- Carvalho, A., Caswell, J., Ion, A., Kwaramba, G., & Mwalwanda, M. (2010). Strengths-based case management: A manual for HIV-positive women working as peer case managers. Unpublished.
- Cassel, J. B., & Ouellette, S. (1995). A Typology of AIDS Volunteers. *AIDS Education and Prevention*, 7, 80-90.
- Creswell, J. W., & Miller, D. L. (2000). Determining validity in qualitative inquiry. *Theory into Practice*, 39(3), 124-130.
- Fontana, A. & Frey, J. H. (2000). Chapter 24: The interview: From structured questions to negotiated text. In Y. S. Lincoln & N. K. Denzin, (Eds), *Handbook of Qualitative Research*, (2nd ed., pp. 645-672). Thousand Oaks, CA: Sage Publications.
- Greene, S., Tucker, R., Rourke, S. B., Monette, L., Koornstra, J., Sobota, M., . . . Watson, J. (2010). "Under My Umbrella": The housing experiences of HIV positive parents who live with and care for their children in Ontario. *Arch Womens Ment Health*, 13, 223-232.

- Greene, S., Ion, A., Elston, D., Kwaramba, G., Smith, S., Loutfy, M. (2015). (M)othering with HIV: Resisting and Reconstructing Experiences of Health and Social Surveillance. In B. Hogeveen & J. Minaker (Eds.), *Criminalized Mothers, Criminalizing Motherhood* (pp.231-263). Toronto, ON: Demeter Press.
- Heckman, T., Somlai, A., Sikkema, K., Kelly, J., & Franzoi, S. (1997). Psychosocial predictors of life satisfaction among persons living with HIV infection and AIDS. *Journal of Association of Nurses in AIDS Care*, 8(5), 21-30.
- Helgeson, V., Cohen, S., Schultz, R., & Yasko, J. (1999). Education and peers discussion group interventions and adjustment to breast cancer. *Archives General Psychiatry*, 56, 340-347.
- Hilfinger-Messias, D. K., Moneyham, L., Vyavaharkar, M., Murdaugh, C., Phillips, K. D. (2009). Embodied work: Insider perspectives on the work of HIV/AIDS peer counselors. *Health Care for Women International*, 30, 570-592.
- Husbands, W., Browne, G., Caswell, J., Buck, K., Braybrook, D., Roberts, J., Gafni, A., Taylor, A. (2007). Case management community care for people living with HIV/AIDS (PLHAs). *AIDS Care*, 19(8), 1065-1072.
- Israel, B., Schultz, A., Parker, E., & Becker, A. (1998). Review of community-based reasearch: Assessing partnership approaches to improve public health. *Annual Review of Public Health*, 19, 173-202.
- Jacobs, R. J., & Kane, M. N. (2010). HIV-related stigma in midlife and older women. *Social Work in Health Care*, 49, 68-89.
- Kako, P. M., & Dubrosky, R. (2013). "You comfort yourself and believe in yourself": Exploring lived experiences of stigma in HIV-positive Kenyan women. *Issues in Mental Health Nursing*, 34, 150-157.
- Kilbourne, A., Herndon, B., Andersen, R., Wenzel, S., & Gelberg, L. (2002). Psychiatric symptoms, health services, and HIV risk factors among homeless women. *Journal of Health Care for the Poor and Underserved*, 13(1), 49-65.
- Leininger, M. M. (1985). Ethnography and ethnonursing: Models and modes of qualitative data analysis. In M. M. Leininger (Ed.), *Qualitative research methods in nursing* (pp. 33-72). Orlando, FL: Grune & Stratton.
- Lekas, H., Siegel, K., & Schrimshaw, E. (2006). Continuities and discontinuities in the experiences of felt and enacted stigma among women with HIV/AIDS. *Qualitative Health Research*, 16(9), 1165-1190.
- Lichtenstein, B., Laska, M. K., & Clair, J. M. (2002). Chronic sorrow in the HIV-positive patient: Issues of race, gender, and social support. *AIDS Patient Care & STDs*, 16, 27-38.
- Logie, C., James, L., Tharao, W., & Loufty, M. (2011). HIV, gender, race, sexual orientation, and sex work: A qualitative study of intersectional stigma experienced by HIV-positive women in Ontario, Canada. *PLoS Med* 8(11): e1001124. doi:10.1371/journal.pmed.1001124.
- Logie, C., James, L., Tharao, W., Loutfy, M. (2013). Associations between HIV-related stigma, racial discrimination, gender discrimination, and depression among HIV-positive African, Caribbean, and Black Women in Ontario, Canada. *AIDS Patient Care & STDs*, 27(2), 114-122.
- London, A., LeBlanc, A., & Aneshensel, C. (1998). The integration of informal care, case management and community-based services for person with HIV/AIDS. *AIDS Care*, 10, 481-503.

- Loutfy, M. R., Logie, C. H., Zhang, Y., Blitz, S. L., Margolese, S. L., Tharao, W. E., . . . Raboud, J. M. (2012). Gender and ethnicity differences in HIV-related stigma experienced by people living with HIV in Ontario, Canada. *PLoS ONE*, 1(12): e48168. doi:10.1371/journal.pone.0048168
- Loutfy, M. R., Sherr, L., Sonnenberg-Schwan, U., Walmsley, S. L., Johnson, M., d'Arminio Monforte, A., on behalf of Women for Positive Action. (2013). Caring for women living with HIV: Gaps in the evidence. *Journal of the International AIDS Society*, 16, 18509.
- Marchand, R. (2001). *Gay men building local knowledge: community-based research in HIV prevention & health promotion*. Retrieved from <http://cbrc.net/sites/default/files/Gay%20Men%20Build%20Knowledge.pdf>.
- Marino, P., Simoni, J. M., Silverstein, L. B. (2007). Peer support to promote medication adherence among people living with HIV/AIDS: The benefit to peers. *Social Work in Health Care*, 45(1), 67-80.
- Maticka-Tyndale, E., & Barnett, J. P. (2010). Peer-led interventions to reduce HIV risk of youth: A review. *Evaluation and Program Planning*, 33(2), 98-112.
- Melchoir, L. A., Huba, G. L., Gallagher, T., Jean-Louis, E., McDonald, S. S., Smereck, G. A., et al. (2001). Unmet needs in groups of traditionally underserved individuals with HIV/AIDS: Empirical models. *Home Health Care Services Quarterly*, 19(1-2), 29-51.
- Moxley, D. (1989). *The practice of case management*. Newbury Park, CA: Sage Publications.
- O'Brien, K. K., Bayoumi, A. M., Strike, C., Young, N. L., Davis, A. M. (2008). Exploring disability from the perspective of adults living with HIV/AIDS: Development of a conceptual framework. *Health Qual Life Outcomes*, 6, 76. doi:10.1186/1477-7525-6-76.
- Parish, M., Burry, C., & Pabst, M. (2003). Providing comprehensive case management to urban women with HIV/AIDS and their families. *Affilia*, 18(3), 13-24.
- Parker, R., & Aggleton, P. (2003). HIV and AIDS-related stigma and discrimination: A conceptual framework and implications for action. *Social Science & Medicine*, 57(1), 13-24.
- Passey, M., Sheldrake, M., Leitch, K., & Gilmore, V. (2007). Impact of case management on rural women's quality of life and substance use. *Rural and Remote Health*, 7(710).
- Patel, R., Ratner, J., Gore-Felton, C., Kadzirange, G., Woelk, G., Katzenstein, D. (2012). HIV disclosure patterns, predictors, and psychosocial correlates among HIV positive women in Zimbabwe. *AIDS Care*, 24(3), 358-368.
- Peterson, J. L. (2010). The challenges of seeking and receiving support for women living with HIV. *Health Communication*, 25, 470-479.
- Public Health Agency of Canada (PHAC). (2009). *HIV and AIDS in Canada: Surveillance Report to December 31, 2008*. Retrieved from <http://www.phac-aspc.gc.ca/aids-sida/publication/survreport/2008/dec/index-eng.php>.
- Sandelowski, M., & Barroso, J. (2003). Motherhood in the context of maternal HIV infection. *Research in Nursing & Health*, 26, 470-482.
- Sandelowski, M., Lambe, C., & Barroso, J. (2004). Stigma in HIV positive women. *Journal of Nursing Scholarship*, 36(2), 122-128.

- Scandlyn, J. (2000). When AIDS became a chronic disease. *The Western Journal of Medicine*, 172, 130-133.
- Selbin, J., & Del Monte, M. (1998). Waiting room of their own: The family care network as a model for providing gender-specific legal services to women with HIB. *Duke Journal of Gender, Law & Policy*, 5, 103-132.
- Simoni, J. M., Franks, J. C., Lehavot, K., Yard, S. S. (2011). Peer interventions to promote health: conceptual considerations. *American Journal of Orthopsychiatry*, 81(3), 351-359.
- Simoni, J. M., Nelson, K. M., Franks, J. C., Yard, S. S., Lehavot, K. (2011). Are peer interventions for HIV efficacious? A systematic review. *AIDS Behavior*, 15, 1589-1595.
- Turan, J. M., Miller, S., Bukusi, E. A., Sande, J., & Cohen, C. R. (2008). HIV/AIDS and maternity care in Kenya: How fears of stigma and discrimination affect uptake and provision of labor and delivery services. *AIDS Care*, 20(8), 938-945. doi: 10.1080/09540120701767224
- U.S. President's Emergency Plan for AIDS Relief (PEPFAR). (2009). Prevention of sexual transmission for people engaged in high risk activity. Washington, D.C.
- Vanable, P. A., Carey, M. P., Blair, D. C., Littlewood, R. A. (2006). Impact of HIV-related stigma on health behaviors and psychological adjustment among HIV-positive men and women. *AIDS Behavior*, 10, 473-482.
- Webel, A. R., Okonsky, J., Trompeta, J., Holzemer, W. L. (2010). A systematic review of the effectiveness of peer-based interventions on health-related behaviors in adults. *American Journal of Public Health*, 100(2), 247-253.
- Weick, A. (1983). A growth-task model of human development. *Social Casework*, 64, 131-137.
- Weick, A., & Pope, L. (1988). Knowing what's best: A new look at self-determination. *Social Casework*, 69, 10-16.
- Wenzel, S., Tucker, J., Elliot, M., & Hambarsoomians, K. (2007). Sexual risk among impoverished women: Understanding the role of housing status. *AIDS and Behavior*, 11(Suppl 2), 9-20.
- Wood, S. A., & Tobias, C. (2004). Barriers to care and unmet needs for HIV-positive women caring for children: Perceptions of women and providers. *Journal of HIV/AIDS & Social Services*, 3(2), 47-65.