Women's Health Issues 25-4 (2015) 410–419

WOMEN'S
HEALTH ISSUES
www.whijournal.com

Original article

Examining the Health Care Experiences of Women Living with Human Immunodeficiency Virus (HIV) and Perceived HIV-Related Stigma

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Article history: Received 8 March 2014; Received in revised form 17 March 2015; Accepted 23 March 2015

ABSTRACT

Introduction: The increased incidence of human immunodeficiency virus (HIV) in women, particularly marginalized women, prompted research to examine women's health service experiences at a local outpatient clinic.
Methods: A qualitative case study using semistructured interviews examined facilitators and barriers to health care services. Seventeen women living with HIV who accessed care at an outpatient HIV clinic in central west Ontario were interviewed. Thematic analysis was used to code health care experiences perceived as HIV-related stigma.
Results: Women perceived HIV-related stigma when health care providers lacked basic HIV knowledge and failed to uphold the ethical principles of patient–provider relationships, resulting in women's disengagement from health care.
Conclusions: We propose a community-based participatory research framework to reform health care educational curriculum toward a culture of health care safety that is inclusive of people living with HIV.

Human Immunodeficiency Virus Infection in Canada: Current Context

Advances in the medical management of human immunodeficiency virus (HIV) including access to combination antiretroviral therapy and improved treatment options have resulted in increased life expectancy for people living with HIV across Canada and North America. From 1996 to 2005, as mortality rates fell from 16% to 10%, life expectancy rose from 36% to 49% (The Antiretroviral Therapy Cohort Collaboration, 2008). Currently in Canada, treatment outcomes have improved dramatically and, for many, HIV is managed as a chronic health condition (Scandlyn, 2000; Thompson, Aberg, Cahn, Montaner, 2010). The intersection of complex medical management of HIV with enduring social challenges experienced by people living with HIV including access to social support and HIV-related stigma, however, positions HIV as an episodic disability (O'Brien, Bayoumi, Strike, Young, & Davis, 2008) that is characterized by unpredictable periods of wellness and illness spanning physical, mental, emotional, and social life domains. As an episodic disability, HIV is influenced by living strategies and personal attributes, alleviated by practical, emotional, and social supports, and exacerbated by HIV-related stigma (O'Brien, Davis, Strike, Young, & Bayoumi, 2009).

Women Living with HIV in Canada

The epidemiology of HIV in Canada has also evolved over time; the number of positive HIV tests reported in women has steadily increased across Canada since the beginning of the HIV epidemic. Before 1999, females represented 11.7% of all positive HIV test reports. By 2006, this figure had increased to 27.8% increasing across almost all age categories (Public Health Agency of Canada [PHAC], 2010a). In 2010, 26% of all new HIV infections occurred in women (PHAC, 2010a), more than 80% in women between the ages of 25 and 44 and primarily through heterosexual contact (71%; PHAC, 2010a). The feminization of the HIV epidemic has largely been driven by key differences in biological and social realities between men and women around the world

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This study was funded by the Gender and Health Education Initiative at McMaster University.

The authors have no financial conflicts of interest to disclose.

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http://dx.doi.org/10.1016/j.whi.2015.03.012

(Carter et al., 2013; Hankin, 2008). Increased rates of HIV in women have necessitated a reconceptualization of the structural and social determinants of HIV. Sandelowski, Lambe, and Barroso (2004) suggest that the changing epidemiology of HIV is related to women's gender-linked vulnerability that often remains hidden within the context of incarceration, systematic rape and torture in conflict zones, sex trafficking, street involvement, polyaddiction, mental illness, intimate partner violence, and poverty (MacGillivray & Yudin, 2012; Teti, Bowleg, & Lloyd, 2010).

Furthermore, in Canada, racialized women, who experience multiple and intersecting oppression based on their gender/racial/ethnic background (Canadian Research Institute for the Advancement of Women, 2002; Ontario Advisory Committee on HIV/AIDS, 2002) are overrepresented in new infections. In 2011, the HIV infection rate was 3.5 times greater among Aboriginal people in Canada characterized by more diagnoses in younger Aboriginal women (PHAC, 2011). Canadian surveillance data suggest that injection drug use is a particularly important risk factor for HIV among Aboriginal people and accounts for more HIV infections among Aboriginal women than Aboriginal men (PHAC, 2010b, 2010c). Women from HIV-endemic countries (i.e., where the prevalence of HIV is 1% or greater) are also overrepresented in new HIV infections in Canada (PHAC, 2010a). The infection rate among individuals from HIV-endemic countries was estimated to be at least 12.6 times higher than other Canadians in 2005 (PHAC, 2009): "determinants of health, including stigma, racism, income, unemployment, lack of access to culturally appropriate health services and loss of support from extended families in home countries for those who recently moved to Canada, contribute to this population's vulnerability to HIV/AIDS." As such, HIV risk is increasingly understood as linked to social determinants of health, that is, social conditions that influence health status and lifespan of individuals and populations (Raphael, 2006), rather than individual risk behaviors (Parker & Aggleton, 2003; Raphael, 2004). In the context of HIV, gender, race, culture, HIV stigma, and discrimination intersect as important determinants of health (Ontario Advisory Committee on HIV/AIDS, 2002).

Health Care as a Human Right and Enduring HIV-Related Stigma

At the intersection of the social determinants of health and the medical management of HIV, which optimally includes holistic HIV and primary care (Krentz, Dean, & Gill, 2006; O'Brien et al., 2008), is the right for all Ontarians, including people living with HIV, to access equitable health care (Ontario Patient Bill of Rights). All residents of Ontario and Canada have the right to receive "all necessary health care services in a health care system that is accessible, universal, comprehensive," receive care "with courtesy and respect" and "in a manner that recognizes individual dignity and privacy" (cite Bill 22, pg. 2) (Legislative Assembly of Ontario, 2003). This provincial legislation applies human rights principles to the context of patient care with a particular emphasis on the interactions between patients and providers (Cohen & Ezer, 2013). Furthermore, this provincial law, passed in a context of frameworks promoting international human rights law, highlights government responsibility to support equitable health care and equitable access to health care services especially for vulnerable and marginalized populations in society, in particular people living with HIV (Cohen & Ezer, 2013; UN Committee on Economic, Social and Cultural Rights, 2000).

Despite legislation to respect the right of accessibility and access to health care without discrimination, women living with HIV continue to experience challenges and barriers to receiving care. At a critical time when people living with HIV are increasingly accessing health services for episodic or chronic health conditions, women with HIV can experience multiple barriers to accessing care, including lack of transportation, care giving responsibilities, employment, drug coverage, housing instability, immigration, HIV disclosure, stigma, and discrimination (Buka, 2002; Marx, Katz, Park, & Gurley, 1997; Melchoir et al., 2001; Wood, Tobias & Mccree, 2004). Women living with HIV experience gender inequality or social marginalization, including HIV-related stigma. Notwithstanding improvements in longevity and quality of life in the era of combination antiretroviral therapy, women with HIV may experience greater health disparities, which may impact HIV health status and disease outcomes (Krentz et al., 2006; OHTN Rapid Response Service, 2010; The Antiretroviral Therapy Cohort Collaboration, 2008). Women living with HIV in Ontario are less likely to be on combination antiretroviral therapy and have undetectable plasma HIV viral loads, and are more likely to experience HIV symptom burden, compared with men with HIV (Bayoumi et al., 2010; Krentz et al., 2006). Women, particularly those who use drugs and racialized women, are overrepresented in hospitalizations and emergency department visits (Krentz et al., 2006). Women living with HIV are less likely to have medical benefits, but are more likely to have caregiving responsibilities, resulting in financial challenges associated with health disparities (Kates & Carbaugh, 2006).

HIV-Related Stigma and Discrimination

When considering the various health disparities and challenges women may face when accessing and receiving health and social care, the impact of HIV-related stigma as a determinant of health cannot be ignored. Goffman (1963) defined stigma as a "mark," aspect of the self and "attribute that is deeply discrediting" (p. 3) and socially devalued. Furthermore, Link and Phelan (2001) conceptualize stigma as a social process where labeling, stereotyping, separation, status loss, and discrimination coexist with power dynamics. Parker and Aggleton (2003) also conceptualize stigma as a social process that operates at the intersection of culture, power, and difference. Regardless of the conceptualization of stigma, we agree with Earnshaw and Chaudoir (2009) that HIV-related stigma can prompt a cascade of deleterious outcomes for people living with HIV. The intersectional model of HIV-related stigma operating at the intersection of culture, power, and difference is supported by a plethora of research, which highlights the layering of HIV stigma on a foundation of marginalized social identities and inequities related to sexism, racism, and homo/transphobia (Land & Linsk, 2013; Logie, James, Tharao, & Loutfy, 2011; Loutfy et al., 2012; Parker & Aggleton, 2002; Voisin, Bird, Shi Shiu, & Kreiger, 2012). For example, differences have been shown between Caucasian and non-Caucasian people with HIV regarding HIV stigma, whereby people of color living with HIV are more likely to report feeling stigmatized because of their HIV status (Emlet, 2007; Land & Linsk, 2013).

How does HIV stigma play out in the lives of women? Women are not only more vulnerable to HIV infection, they are also more likely to be stigmatized or blamed for its transmission resulting in greater stigma toward women living with HIV (Lekas, Siegel & Schrimshaw, 2006; Long, 2009a, 2009b). HIV-related stigma and fear of disclosure continue to create barriers for women with HIV