"People try and label me as someone I'm not": The social ecology of Indigenous people living with HIV, stigma, and discrimination in Manitoba, Canada

Roberta L. Woodgate[a,*], Melanie Zurba[a], Pauline Tennent[a], Carla Cochrane[b], Mike Payne[c], Javier Mignone[d]

[a] College of Nursing, Rady Faculty of Health Sciences, University of Manitoba, 89 Curry Place, Winnipeg, Manitoba R3T 2N2, Canada
[b] Assembly of Manitoba Chiefs, 200-275 Portage Ave, Winnipeg, Manitoba R3B 2B3, Canada
[c] Nine Circles Community Health Centre, 705 Broadway, Winnipeg, Manitoba R3G 0X2, Canada
[d] Deptartment of Community Health Sciences, Max Rady College of Medicine, Rady Faculty of Health Sciences, University of Manitoba, 307 Human Ecology Building, 35 Chancellor's Circle, Winnipeg, Manitoba R3T 2N2, Canada

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ABSTRACT

Indigenous peoples (First Nations, Inuit, and Métis) are currently overrepresented in the HIV epidemic in Canada and are infected at a younger age than those who are not Indigenous. This article presents our findings on the stigma and discrimination (as well as related themes such as disclosure) experienced by Indigenous people who contracted HIV in their youth and live in urban and non-urban settings in Manitoba, Canada. The findings were derived from a qualitative study that sought to understand the experiences and needs of Indigenous people living with HIV (including AIDS). We situate such experiences within a social ecological framework towards developing a better structural understanding of the impacts of stigma and discrimination on the lives of Indigenous people who are HIV positive. Stigma and discrimination caused barriers for Indigenous people living with HIV through inhibiting their ease of access to supports including family, peers, community, and long- and short-term health services. Creative forms of outreach and education that are culturally appropriate and/or rooted in culture were considered to be possibly impactful ways of reducing stigma and discrimination at the community level. Learning from communities who are successfully managing stigma also showed promise for developing new programming.

1. Introduction

Stigma is a socially constructed negative stereotype, attitude, or belief that is used to produce or justify social difference and when that stigma is acted upon, it can result in discrimination, or the unfair treatment resulting from prejudice (Canadian HIV/AIDS Legal Network, 2004). HIV-related stigma and discrimination can come in many forms for people living with HIV, and interacts and intersects with other social determinants of health and forms of pre-existing stigma (Woodgate et al., 2017a; Parker and Aggleton, 2003; Poteat et al., 2013). The general effects of stigma and discrimination on the prevention and treatment of HIV are fairly well known (Parker and Aggleton, 2003; Poteat et al., 2013). For example, it is well established that stigma can act as a barrier to education and preventative measures (e.g., condom use) as well as obtaining treatment and health information following infection (Saewyc et al., 2014; Brent, 2016). Stigma can be a strong factor in psychological distress and diminished wellbeing due to increased social pressures and the creation of disconnects within the community (Adams et al., 2016; Miller et al., 2016). Many of the effects of stigma and discrimination are dependent on socio-economic, cultural, and geographic contexts (Nunn et al., 2014; Parker et al., 2016). Additionally, the highly social and critical developmental stage that is adolescence and young adulthood can add complexity to the stigma and discrimination that comes with being diagnosed with HIV as a young person.

Indigenous peoples (First Nations, Inuit, and Métis) are currently overrepresented in the HIV epidemic in Canada and are infected at a younger age than those who are not Indigenous (Public Health Agency of Canada, 2014a, 2014b). The higher prevalence of HIV infections among Indigenous people in Canada has been associated with the

transgenerational effects of racial policies and colonization (Bingham et al., 2014). The Residential School System and the "Sixties Scoop" in Canada have resulted in trauma that continues to affect Indigenous peoples. The Residential School System in Canada, beginning in the 1870s and ending in 1996, were "government funded, church-run schools" that "were set up to eliminate parental involvement in the intellectual, cultural, and spiritual development of Aboriginal children" (Truth and Reconciliation Commission of Canada, 2016). The "Sixties Scoop" refers to the "mass removal of Aboriginal children from their families into the child welfare system" (Hanson, 2016). It is a term coined by Patrick Johnson in the 1983 report Native Children and the Child Welfare System, and is named as such because the removal was particularly pronounced in the 1960s. Children were typically adopted by white middle-class Canadians (Hanson, 2016). Many also argue that the workings of the current child welfare system are grounded in discriminatory policies and are a continuation of past systems that sought to eradicate Indigenous culture in Canada (Tait et al., 2013; McKenzie et al., 2016). The effects of such colonial systems have been strongly connected to issues with mental health and high-risk behaviours including binge drinking, injection drug use, and unprotected sexual encounters, and has been attributed to the increased prevalence of HIV within Indigenous communities (Prentice, 2004; Bingham et al., 2014). For Indigenous peoples, colonial discourse and perceptions (e.g., being part of a marginalized group) means that stigma and discrimination is often amplified, and can be variable within different social environments (Lavoie et al., 2010; Saewyc et al., 2014).

This article presents our findings on the stigma and discrimination (as well as related themes such as disclosure) experienced by Indigenous people who contracted HIV in their youth (i.e. 15–29 years of age) within their various settings in Manitoba, Canada. We adopt a lens that sees HIV-related stigma and discrimination as interrelated and confounded by intersecting layers of pre-existing stigma and discrimination related to factors such as gender, sexuality, race and ethnicity, and social class. The findings were derived from a qualitative study that sought to understand the experiences and needs of Indigenous people living with HIV (including AIDS) who were diagnosed in their youth. Specifically, we situate such experiences within a social ecological framework towards developing a better structural understanding of the impacts of stigma and discrimination on the lives of Indigenous people living with HIV. Unless otherwise indicated as the Indigenous community, we use the term community to refer to other communities that participants identified with.

2. Conceptual framework

Social ecology has evolved into a transdisciplinary field that merges diverse theoretical perspectives and methodologies towards solving complex real-world problems, such as those related to the various social factors affecting health and wellbeing (McLaren and Hawe, 2005; Ungar, 2012). Social-ecological frameworks are particularly useful for understanding how confounding social factors, such as stigma and discrimination, affect the lives and systems of care around individuals (Kohrt, 2013; Newman and Fantus, 2015). Such frameworks have roots in Bronfenbrenner's ecological theory of human development (1979, 1986, 1995), which describes the way in which human development is created through interactions with interconnected environmental contexts. Bronfenbrenner's social-ecological model places environmental contexts into different levels reflecting the size, proximity and ability for interaction, and level of formality of the environmental context or setting. Each environmental context or layer has the ability to facilitate or impede the development of the individual.

Bronfenbrenner's social-ecological model is a nested system with the individual at the centre and subsequently surrounded by the microsystem, mesosystem, exosystem, and macrosystem (Fig. 1). Each system provides a structure for explaining the social world around and affecting the individual. At the 'individual' level, while socially

constructed, stigma and discrimination exist as internalized structures based on misconceptions about the self, affecting a person's wellbeing, and often resulting unfair self-treatment (Yebei et al., 2008; Mittal et al., 2012). The 'microsystem' is the immediate setting in which the developing person is situated. Interacting factors that are typical to the microsystem are the individual's family, home, peer group, and school (Eamon, 2001; Campbell et al., 2009). The next level, the 'mesosystem' includes the interactions among two or more microsystems. Links between microsystems can be numerous, and as Eamon (2001) explains, such linkages can provide much of the context for socio-emotional development. An example of a mesosystem would be the relationships between the person's peer group and family. The layer beyond the mesosystem is the 'exosystem,' which contains two or more settings; however, only one interacts with the individual. Exosystems are typically organizations, and in the context of health research includes health services, such as hospitals and clinics (Campbell et al., 2009). Such systems are typically influenced by bureaucratic systems that an individual (i.e., patient/client) seldom has access to. The part of the system that interacts with the individual is generally facilitated through service providers. The outer layer of the social-ecological system, the 'macrosystem' encompasses the broader societal and cultural norms and socio-economic influences on development. Examples of factors within the macrosystem include policy domains, as well as lifestyle, customs, and knowledge systems and cultural beliefs (Eamon, 2001; McLaren and Hawe, 2005). Bronfenbrenner (1995) referred to the macrosystem as the "blueprint" for social structures.

3. Methods

3.1. Methodological approach

In order to study the lived experiences of Indigenous people who contracted HIV in their youth we used a phenomenology approach. This approach facilitates description of an individual's lived experiences in social worlds with a view of influencing social change, places the individual's perspectives at the centre of analysis, and ensures that the research works with the individual rather than on them (van Manen, 1990). The approach aligns with research that has shown a deeper appreciation for marginalized and vulnerable people's perspectives in research (Charmaz, 2008; Woodgate et al., 2017b). The research was also guided by a participatory research approach which sustained the full and active participation of the community being researched, involved seeking and respecting the knowledge and expertise of community members (i.e., collaborators, Indigenous people living with HIV, their support persons, health and social care service providers, a 62 years old Indigenous man who had been living with HIV for 12 years, and the Assembly of Manitoba Chiefs) from the very beginning of the project, and supporting personnel throughout the entire research process (Bennett, 2004; CIHR, 2007).

3.2. Recruitment and participants

This study was conducted in Winnipeg (population: over 718,000), Manitoba (population: 1.282 million), in mid-Western Canada. The 2011 Canadian National Household Survey (NHS) found that that approximately 5.9% of Winnipeg's population self-identify as First Nations and 6.3% self-identify as Métis (Statistics Canada, 2011). There are 63 First Nations reservations in Manitoba, which have over 130,000 registered members. In 2015, Winnipeg had 70 new HIV infections. 23% of these infections were among the First Nation, Inuit, and Métis population (Manitoba Health, 2016). Several strategies were used towards recruiting participants. Both purposeful and snowball sampling techniques were used. Invitation letters were distributed via a designated intermediary to potential participants who utilized HIV services and programming at three of the study's collaborators including: Nine Circles Community Health Centre, a community based, non-profit