

Legislating Immigrants' Health Inequities and Injustices? An Institutional Ethnography of the social organization of HIV Healthcare, Treatment and Un/detectability for African, Caribbean and Black Immigrants Living with HIV in Canada

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Background

The advancement of HIV infection into a chronic condition that is manageable through HIV healthcare and treatment has transformed the landscape of HIV response and health outcomes for people living with HIV (PLHIV). Current best and optimal practices in HIV health care that are considered to optimize the health of PLHIV and prevents onward HIV transmission is timely HIV testing, use of antiretroviral therapy (ART) and engagement and retention of people infected and diagnosed with HIV in HIV healthcare services [1]. The primary goal of HIV healthcare and treatment is the achievement of viral suppression or undetectable viral load. A person who has less than 200 copies of HIV per milliliter of blood is classified as having achieved viral suppression or an undetectable viral load. Previous studies indicate that suppression of viral load to undetectable levels has several beneficial health outcomes, including enhanced physical functioning, reduced infections, improved quality of life, and reduced HIV-related mortality [2]. Findings that timely access and adherence to ART can suppress viral load and reduce HIV transmission have led to prioritizing HIV healthcare and treatment as a key strategy for HIV management and prevention.

The concept of undetectability has radically changed people's understanding of HIV risks and revolutionized HIV response strategies. In Canada, HIV viral load is presently being used in legal processes associated with alleged HIV non-disclosure to set the threshold of HIV transmission risks and make court decisions. Most recently, undetectability of HIV viral load found its way into the criminal justice system when the federal and provincial government of Ontario declared that there will be no criminal prosecutions for alleged HIV non-disclosure where "an individual has a suppressed viral load for six months". In July 2016, the Prevention Access Campaign, a collective of clinicians, researchers, community and HIV organizations, launched the social media campaign U=U (undetectable=Untransmittable) [3]. The U=U campaign aimed to highlight the significance of HIV treatment and prevention and reduce HIV-related stigma. According to the U=U campaign, if a person living with HIV is consistently on treatment and maintains an undetectable viral load, that person is less likely to pass on HIV to sexual partners.

The uptake of the concept of undetectability in biomedical and legal approaches in managing the HIV epidemic is devoid of HIV-positive individuals' material conditions and the practicalities of socio-political context that shape their efforts and experiences of achieving and maintaining undetectable HIV viral load. Although access to healthcare and treatment has been universally framed as a right, "there are numerous economic, social, structural, and legal barriers that intersect in someone's life and may make it difficult or impossible to reach an undetectable viral load." [4]. In Canada, the provision and delivery of healthcare and treatment in Canada involve a complex healthcare system that interface with various legal regimes, policies and institutional practices, which make navigating the healthcare system to access HIV healthcare and treatment complex and unjust.

Knowledge Gap

Several studies have been done on healthcare and treatment access for refugees and immigrants with precarious status in Canada [5-8]. Few studies have been conducted to explore access to mental healthcare, treatment and support services for immigrants, refugees and non-status people living with HIV in Canada [9, 10]. One of the few studies that have explored HIV healthcare and treatment for immigrant, refugees and non-status people living with HIV in Toronto was done 13 years ago. The Committee for Accessible AIDS Treatment in Toronto conducted community-based research to examine how legislation, regulation and policy shape access to services for immigrants, refugees and non-status HIV-positive individuals in Ontario [11]. Since this report was published, there has been little research on this area. While attempts have been made to capture healthcare access experiences of refugees and immigrants in general, the experiences of ACB immigrants living with HIV are unique and troubling considering the precarious nature of their day-to-day actualities as persons with precarious immigration status and living with HIV. However, there has been no study focusing on access to HIV healthcare and treatment access and un/detectability for ACB immigrants living with HIV Toronto and very little research on this topic has been done in Canada. No attention has been paid to legislation, policies and institutionalized practices that coordinate inequitable and unjust access to HIV healthcare and treatment and “achieving” and/or maintaining undetectable viral load by ACB immigrants living with HIV. Such a gap in knowledge is problematic especially in this era where the concept of undetectability has become a key component of HIV healthcare and treatment as well as the criminal law on HIV non-disclosure. Undetectability need to be examined beyond biomedical practices of HIV healthcare and treatment that has is common in scientific literature. It is difficult to argue that achieving undetectability is definitive, when ACB immigrants who are precariously positioned face barriers and challenges accessing timely and routine HIV healthcare and treatment, adhering to HIV treatment, and achieving and/or maintaining undetectable HIV viral load. The broader HIV research communities and practitioners acknowledge that ACB immigrants experience an interface of challenges and tensions living with HIV and accessing healthcare in Canada [12-14]. Such linear way of thinking detracts from the way in which HIV healthcare, treatment and undetectability is experienced and negotiated in the everyday social work, and the work that people must do to achieve undetectability. I propose that research on undetectability has a great deal to gain by moving beyond linear thinking and focusing on how healthcare, treatment and “un/detectability” is negotiated in the everyday social world.

Method of Inquiry

Using institutional ethnography, a critical research approach to inquiry, this doctoral research intends to demonstrate that what is less considered in the biomedical discourses and practices of undetectability are issues concerning how HIV healthcare and treatment are accessed and delivered through structured professional work practices and routines governed by legislations and policies. Institutional ethnography sees the everyday experiences in the world we live in as intricately organized, coordinated and shaped by complex social relations and institutional forces which often are invisible to individuals who are locally positioned (Smith, 2005). Developed by Dorothy Smith (1987), IE emerged as a critical feminist approach to understanding the social organization of knowledge. Based on Smith's understanding of the social organization of knowledge [15], the everyday individuals' lives and experiences are sites of an interface between individuals and a vast interlocking web of institutional relations, discourses, and work processes. Within IE, the term ‘institution’ draws our attention to complexes of coordinated social relations that accomplish a particular institutional function, such as healthcare [16]. IE holds promises for understanding the ways institutional relations infiltrate and shape the daily lives of individuals. IE studies typically begin with exploring the everyday life experiences, activities and perspectives of a group of people concerning their engagement with a particular institutional complex and connecting them back to social relations that shape their activities and coordinate their doings within this institutional complex. In IE, the gaze is turned from individuals to textually mediated relations in which individuals’ experiences are situated to reveal how ruling relations are regulated and coordinated by activated texts [15]. An institutional inquiry also includes an analysis and understanding of “work” which refers to anything that people do that has intent and requires time, effort, and skill [17]. In this study, the notion of work is the experiential pathway to understanding what people living with HIV, healthcare providers, administrators and policymakers do in the institutional complex of healthcare. Institutional ethnography has been used in healthcare research to explore individuals’ experiences at different levels of the healthcare systems [18, 19]. It has also been used to understand how policy and institutional governance and accountability processes shape health and social outcomes. Namaste used IE to document the experiences of transsexual who were trying to access health and social services in Ontario [20]. Laura Bisailon work on “immigration medicine” employed the social organization of knowledge

approach and IE to investigate the social organization of mandatory HIV testing policy and medical inadmissibility law in the Canadian immigration system [21, 22].

Study Objective

Informed by these sets of understanding, this study is concerned with the tensions and disjunctures between the day-to-day material conditions of ACB immigrants living with HIV and the interface of social policies, legislations and institutional practices that structure, organize and coordinate access to HIV healthcare and treatment and achieving and/or maintaining undetectable HIV viral load. The study aims to explore and critique the organization of the Canadian healthcare system, with particular emphasis on the inequitable and unjust social organization of HIV healthcare and treatment for ACB immigrants living with HIV. More specifically, I purpose to make visible how multiple social relations and institutional practices related to the institutional complex of healthcare interface to constrain access to HIV healthcare and treatment and achieving/maintaining undetectable HIV viral load for ACB immigrants living with HIV. I will critically examine the practices associated with accessing HIV healthcare and treatment and achieving and/or maintaining un/detectability as crossing various institutional boundaries (healthcare, immigration and welfare). This will help provide a nuanced understanding of the disconnections and disjunctures that exists between what ACB immigrants living with HIV need to achieve and/or maintain undetectable HIV viral load and the institutional legislation, policies and practices which act to objectify, organize and regulate what they do to access HIV healthcare and treatment. The findings from this study will demonstrate the manner in which health and healthcare inequities and injustices experienced by ACB immigrants living with HIV are formalized through policies that regulate healthcare access in Canada.

The above objectives will be achieved through the following core research question: How do social relations related to the institutional complex of healthcare and treatment coordinate inequitable and unjust access to HIV healthcare and treatment and work practices related to “achieving” and/or maintaining undetectable HIV viral load for ACB immigrants with HIV in Toronto? There are a number of specific questions that might be posted about the everyday world of ACB immigrants living HIV working to access HIV healthcare and treatment and achieve and/or maintain undetectable HIV viral load to address this core question. 1) How do ACB immigrants with HIV go about accessing HIV healthcare and treatment and achieving and/or maintaining undetectable HIV viral load in Toronto, (2) Within the institutional complex of healthcare, what legislations, social policies and institutional practices exist to coordinate and regulate access to HIV healthcare and treatment and, (3) How do the legislations, social policies and institutional practices constrain the health work that is done by ACB immigrants living with HIV to access HIV healthcare and treatment and achieve and/or maintain undetectable HIV viral load?.

Method:

Research problematic: I arrived at the above questions after establishing a clear research problematic from preliminary interviews. From the beginning of my doctoral research journey, I struggled with establishing a clear problematic for my doctoral research. Initially, I set out to investigate empirically how the criminal case law on HIV non-disclosure shapes ACB immigrants' experiences' of accessing HIV healthcare and treatment. However, the emergence of the concept of undetectable viral load and its application in criminal law on HIV non-disclosure triggered new concerns. To arrive at a clear problematic, I first conducted 5 semi-structured interviews with 5 ACB immigrant living with HIV. I discovered a disjuncture between biomedical practices of HIV healthcare, treatment and undetectability and the actualities of ACB immigrant living with HIV. For Smith, disjunctures point to the social relations underpinning the coordination of people's actual work in real-life settings. On one hand are the social relations and institutional practices that regulate, organize and coordinate delivery of HIV healthcare and treatment, and on the other, what it means to access HIV healthcare and treatment and to achieve and/or maintain undetectable HIV viral load as an ACB immigrant in Canada. The inequities created by precarious immigration status and conditions of immigrants intersect with immigration, welfare and healthcare policies to coordinate inequitable access to HIV healthcare and treatment and achieving and/or maintaining undetectable HIV viral load. This has become the problematic (Campbell & Gregor, 2002) of my study.

Interviews with ACB participants: I will conduct further interviews with 15 ACB immigrants living with HIV, primary with those experiencing precarity as a result of immigration status -refugee claimants, non-status, international student, those with temporary visas, expired visas, or on sponsorship. Through these interviews, I will capture the work that ACB immigrants do to access HIV healthcare and treatment and achieve and/or maintain undetectable HIV viral load and locate the tensions and struggles in their day-to-day HIV healthcare work. I will focus on the work of accessing HIV health and treatment which includes linkage to HIV specialist or family doctors, booking and making clinical visits, accessing prescriptions and drugs, and adherence to treatment and medication. A detailed description of the everyday routinized work practices involved in accessing and providing HIV healthcare and treatment will reveal

how readily and routinely ACB immigrants can access HIV healthcare and treatment and have their HIV healthcare needs addressed.

Interview with healthcare professionals: Once I have articulated the HIV healthcare work of ACB immigrants, I will conduct one-on-one interviews with n=15 healthcare professionals (HIV specialists, family doctors, nurses, clinical social workers, administrators, clinic pharmacists and policymakers) involved in the provision of HIV healthcare and treatment to ACB immigrants with HIV in an institutional healthcare setting such as hospitals, HIV clinics and community health centers. I will inquire about their daily routine work of providing HIV healthcare and treatment, about the work processes surrounding a new immigrant or an existing immigrant patient, about the document they handle in the course of their work, and about policies and legislative documents, practices and processes that organize, regulate and/or constrain their work of providing HIV health care and treatment to ACB immigrants with HIV.

Textual analysis: Drawing on the experiences and knowledge that ACB participants and healthcare professionals have, I will pay attention to texts that mediate and link work processes beyond the local settings of ACB participants to coordinate the work of healthcare professionals providing HIV healthcare and treatment. Thus, as I comprehensively capture the “work” that ACB immigrants do to access healthcare and treatment and to achieve and/or maintain undetectable HIV viral load, and document institutional tasks and processes undertaken by healthcare professionals to address the HIV health needs of HIV-positive individuals; I will explicate the ways textually mediated relations such as legislations and social policies related to healthcare and treatment, and interlocking web of institutional practices coagulate to govern, organize and coordinate the delivery of HIV healthcare. I will examine how legislation, social policies and institutional practices infiltrate actual people’s local settings to constrain the work of accessing and providing HIV healthcare and treatment and achieving and/or maintaining undetectable HIV viral load.

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