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# We Are (a Measurable) Family: Affect and Audit in a Toronto HIV/AIDS Service Organisation

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**Abstract:** To celebrate its 30th anniversary, a Toronto HIV/AIDS service organisation (HASO) held an event called “Family of HIV” at its annual general meeting in 2017. A drag queen’s performance of the popular gay anthem “We Are Family” and a statement of “love” for the organisation from two clients followed regular annual meeting items like the auditor’s report and election of board directors. These actions created a complex affective and bureaucratic arrangement for an organisation formed through grassroots activism by and for a historically marginalised group (gay men infected with HIV), but that now serves a diverse group of HIV-positive people and is funded through state and private sectors, and is thus enmeshed in a set of obligations and responsibilities to various scales of stakeholders, including local, provincial and national health and welfare agencies. This article argues that the performance of family at the annual meeting privileges a particular affective arrangement of relationships between full-time staff, clients and volunteers that, not coincidentally, occurs in a bureaucratic culture emphasising data as a measurement of value and efficiency. This results in a closely surveilled form of family produced through dense personal and bureaucratic entanglements of regulation, alienation, care, conflict and anxiety.

**Keywords:** HIV/AIDS, affect, audit cultures, Canada, non-governmental organisations

**Résumé :** Pour célébrer son 30e anniversaire, une organisation de services aux personnes atteintes du VIH/sida à Toronto a organisé un événement intitulé « *Family of HIV* » (Famille du VIH) lors de son assemblée générale annuelle de 2017. L’interprétation par une drag-queen de l’hymne populaire gai « We Are Family » et une déclaration « d’amour » faite par deux clients à l’organisation ont été suivies des points habituels de l’ordre du jour de l’assemblée annuelle, telles que la lecture du rapport du vérificateur et l’élection des membres du conseil d’administration. Ces actions ont créé un agencement affectif et bureaucratique complexe au sein d’une organisation formée à travers le militantisme par et pour un groupe historiquement marginalisé (les hommes gais infectés par le VIH), mais qui dessert aujourd’hui un groupe diversifié de personnes séropositives et qui est financée par les secteurs public et privé, s’inscrivant ainsi dans un ensemble d’obligations et de responsabilités à différentes échelles envers divers intervenants, notamment les organismes locaux, provinciaux et nationaux de santé et de bien-être. Dans cet article, je soutiens que la performance d’une famille à l’assemblée annuelle privilégie un agencement affectif particulier de relations entre le personnel à temps

plein, les clients et les bénévoles, ce qui se produit naturellement dans une culture bureaucratique qui met l’accent sur les données comme mesure de valeur et d’efficacité. Il en résulte une forme de famille étroitement surveillée produite à travers un enchevêtrement dense, personnel et bureaucratique de réglementation, d’aliénation, de soins, de conflits et d’anxiété.

**Mots-clés :** VIH/sida, affects, cultures de l’audit, Canada, organisations non gouvernementales

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To celebrate its 30th anniversary in 2017, the planning committee of a Toronto organisation that supports people living with HIV/AIDS (PHAs) developed a campaign called “Family of HIV.” The campaign was inaugurated at the annual general meeting, held in one of the larger rooms of the suite of offices where the organisation is located in the downtown core. The room was festooned with balloons, posters from past campaigns and fundraising events, and photos of smiling clients, staff and volunteers. The organisation’s annual report, distributed at this meeting, contained the following brief explanation of “family of HIV”:

In the 1980s, gay men living with AIDS needed desperate support, the kind you can only get from family. But because they were gay and had AIDS, most no longer had a traditional family they could turn to, so they turned to each other . . . From turning to each other they created a family out of HIV, they created [this organisation] – a home away from home, a family away from family . . . gay men living with AIDS made [this organisation] a safe and welcoming space for everyone. Everyone living with and affected by HIV/AIDS was welcome to become part of the family of HIV. And like a family, [this organisation] provided a safe place to be themselves and to receive fundamental support and unconditional love.<sup>1</sup>

Similar to Kath Weston’s groundbreaking ethnography on kinship in San Francisco’s gay and lesbian communities in the late 1980s, this passage conveys overlapping realms of biological and symbolic kinship

in recounting the history of HIV/AIDS in Toronto: gay men living with AIDS, often rejected by their biological families, consciously created their own kinship networks from a mix of friends, partners and ex-lovers, and these relationships were often framed in terms of heteronormative biological or “blood” relations (Weston 1991). However, while Weston notes that HIV/AIDS was a discourse utilised in the mainstream media as yet another way to discriminate against gay men in the late 1980s and early 1990s, this PHA organisation’s annual report highlights HIV/AIDS as a conduit through which families or family-like relations can be created, chosen and/or formalised, in this case, through membership in a non-profit HIV/AIDS support organisation (HASO).

Yet the annual meeting was not just a celebration of the “family of HIV”: it was also a business meeting, where the first hour was dedicated to administrative items like the executive director’s report; the auditor’s report; summaries of client numbers and engagement with various programs; funding and fundraising goals; and the election of new board members. Following a brief break, the 30th anniversary celebration began with a drag queen’s lip-synched performance of Sister Sledge’s classic gay anthem “We Are Family,” followed by two pre-selected clients who spoke briefly about their “journeys with HIV” (the emcee’s words), and how much this organisation meant to them. One of them, a recently arrived refugee from a Caribbean country, repeatedly mentioned how much he loved the staff and how the organisation was a “home away from home,” echoing the annual report’s statements and sentiments about family.

In my volunteer training at this organisation, familial affects expected in relations between staff, volunteer and client relations were oft-communicated. I was told by various staff members that a top priority for all workers in this organisation was to foster a safe, welcoming space of inclusivity, so that everyone experienced “affirmation, joy and inspiration” (these terms could be found in one of the five directives outlined in the organisation’s strategic plan). I was also told that for many clients this organisation had become their one and only family. However, in subsequent volunteering sessions, where I encountered staff in their daily work environment and met other volunteers and new clients through my volunteer role as an intake worker (where I would obtain information such as proof of HIV status and home address, ask a series of questions about immediate needs and priorities, and then create an online file with that information), a more

complex range of relationships and sentiments emerged, complicating the loving family framework.

In this article, I consider the annual meeting’s juxtaposition of a slightly revised version of Weston’s “families we choose” as a way to represent the affective ethos of an HIV/AIDS service organisation alongside its attendant administrative and bureaucratic duties, which include budget reports and discussions about funding from municipal, provincial and federal governments as well as numerous corporate and private donors. I argue that the annual general meeting’s business agenda items, followed by a rendition of “We Are Family” and a statement of “love” from two clients, perform a complex affective arrangement produced in part through the bureaucratised operations of a social service organisation formed over 30 years ago through grassroots activism by and for a historically marginalised group (gay men infected with HIV) but that is now well established and funded through the state and private sectors, and thus enmeshed in a set of obligations and responsibilities to various scales of stakeholders, including (but not limited to) the local, provincial and national health and welfare apparatus. I argue that the way in which family is articulated in the annual report and performed at the annual meeting privileges a particular affective arrangement of relationships between full-time staff, clients and volunteers that emphasises certain sentiments (love, affection, empathy, support) while obscuring others (anxiety, frustration, estrangement, isolation), and that is produced through dense personal, bureaucratic and temporal entanglements of care, regulation, memory and hope.

Additionally, while family may be the primary metaphor through which relationships between staff, clients and volunteers in this HASO are conceptualised for an annual report and meeting, clients’ identities and actions are also carefully measured, analysed and evaluated through the ongoing collection and recording of particular pieces of information, resulting in a formation of family produced in and through metrics and data and thus deeply enmeshed in an audit culture reflecting state health and welfare agencies’ increasing surveillance through demands for measurable outcomes and maximised efficiency to justify ongoing provision of funds (Greenspan 2018). Therefore, an additional argument of this paper is that the gradual enmeshment of Toronto HASOs in increasingly metrics-driven models of efficacy in the Canadian state’s health and welfare bureaucracies creates alienating and depersonalising affects that in turn produce an aspirational desire among some HASO staff, volunteers and clients to

rekindle intimate bonds produced through memories of the intensities of past crises, with differing effects for differentially positioned clients. In developing these arguments, this paper contributes to a growing body of anthropological research on HIV/AIDS examining metrics and effects of evidentiary regimes (Sangaramoorthy and Benton 2012) by focusing on the mutual centrality and productivity of affect and audit in HIV/AIDS service organisations at a particular historical moment in which state funding and general public interest in HIV/AIDS are waning.

This article is based on 18 months of fieldwork conducted in 2017–18, primarily in two well-established Toronto HIV/AIDS service organisations that provide a variety of services pertaining to HIV prevention, education and/or various forms of practical, therapeutic and financial support for PHAs residing in Toronto. I participated in these organisations as a researcher/volunteer.<sup>2</sup> Both organisations have well-organised, long-standing volunteer programs – current and former clients of these HASOs, interested members of the public and interning students from local colleges and universities are welcome to enroll in the mandatory volunteer training programs and are then able to choose the specific service/program to volunteer in, based on availability. I was particularly interested in volunteering in HASOs that provide practical, psychosocial and/or therapeutic support to PHAs, and I wanted to learn about the organisation and delivery of these services, as well as the clientele and their experiences of these HASOs. After my training, I requested to volunteer as an intake interviewer at one of the organisations, conducting initial interviews with new clients in order to find out more about their situation and most pressing needs. I was also assigned to a service desk in the main lobby of the organisation, where I would perform some basic service duties, help clients navigate the services of the organisation and/or link them to the appropriate staff member for assistance.

As will be outlined in more detail below, my arguments were developed through meetings with new clients at intake interviews, conversations with fellow volunteers and staff, and interactions with ongoing clients at the front desk of one HASO. My positionality as a gay-identified older white male with Canadian citizenship who had also been a client in these organisations facilitated my entry as a volunteer – I represent a common demographic of PHAs in Toronto, so my volunteer presence was not “outstanding” in any way and made for relatively straightforward interactions with staff and some clients with similar backgrounds. On the other hand, many of

my intake interviews and service desk interactions were with new clients of different ethno-racial, age, gender and/or migratory status backgrounds, and often (but not always) resulted in more formal conversations, where someone like me may have been perceived to be an official representative of the state or public health apparatus, in which case personal information and/or opinions may have been withheld or edited. Furthermore, in some cases, mutual comprehension may have been limited due to linguistic and/or sociocultural differences.

## HIV/AIDS, Affect, and Audit Cultures

Anthropological research on HIV/AIDS has made important interventions into hegemonic biomedical and epidemiological frameworks, demonstrating how the specificities and contingencies of transnational forces, structural violence, political economy, and asymmetric power relations of race, class, gender and sexuality shape the conditions of HIV risk and vulnerability (Butt 2005; Comaroff 2007; Farmer 2006 [1992], 2001 [1991], 2003; Herdt 1987; Jolivet 2016; MacQueen 1994; McGrath et al. 2014; O’Daniel 2016; Patton 1990, 2002; Singer et al. 1990; Smith 2014; Sobo 1999; Treichler 1999; Wardlow 2008; Yingling 1997). That is, “people are differentially exposed to HIV on the basis of their social locations in ways that mirror exposure and vulnerability to damaging structures of inequality, requiring approaches that account for the epidemic’s intersectional inequalities” (Watkins-Hayes 2014, 433). Anthropological research has also queried how responses to HIV/AIDS engender new forms of life (subjectivities, affects and conduct) as well as potentially constituting new communities, activisms, institutions and publics (for example, Benton 2015; Boellstorff 2009, 2011; Lorway 2017a; Pigg 2001). Nguyen identifies the important development of “therapeutic citizenship,” the network of state and non-governmental organisations involved in the definition and maintenance of healthy populations as moral and ethical projects that develop techniques to control, manage and assess bodies (2010; see also Nguyen et al. 2011, and Whyte’s [2014] discussion of “clientship”). The concept of therapeutic citizenship helps to elucidate the ways in which some HIV-positive (HIV+) people are named, normalised and “responsibilised” as acceptable citizens through public health models in the age of treatment, while others are vilified and/or deemed not worthy of outreach, treatment and support (Biehl 2007; Colvin et al. 2010; Igonya and Moyer 2013). However, questions pertaining to therapeutic citizenship as a “normalising model” for HIV+ people in Canada and its relevance to differentially defined HIV+ populations and other possible forms of therapeutic and socio-political

(dis)engagement between HIV+ people, HASOs and the state do not appear to be a central focus of existing HIV research in the Canadian context.

With a shift from survival to long-term living with the virus, more anthropological research in the age of treatment has focused on life projects of those on treatment, including the desire to have children and return to work (Hirsch et al. 2009; Seeley 2014; Smith and Mbakwem 2010), issues of dignity and privacy (Moyer 2012; Seeley 2014), the use of alternative therapies (Kalofonos 2010), shifts in family-based care arrangements (de Klerk 2011), and sexual activities (Moyer 2015). In addition, some anthropologists are now focusing on how time and temporal frameworks mediate and conjure notions of difference, health and the self in different sociocultural contexts (Benton, Sangaramoorthy, and Kalofonos 2017). However, Mykhalovskiy and Rosengarten (2009) observed an overall decrease in theoretical and critical social inquiry into HIV/AIDS as the pandemic entered its third decade, and I would argue not much has changed as we enter its fourth decade when we examine research on HIV/AIDS in Canada: while historians have foregrounded the centrality of grassroots activism to the formation of successful treatment and support networks for PHAs (McCaskell 2012), the lack of sustained anthropological and related critical social research into the organisation and transformation of Canadian HASOs and state health agencies over the past 30 years, changing relationships between Canadian HASOs and increasingly diverse HIV-positive communities, changing political-economic contexts of HIV/AIDS funding and support in Canada, and the ways in which diverse HIV+ Canadian populations experience and interpret new knowledge and discourses of HIV/AIDS prevention, transmission and treatment are resulting in forms of knowledge that continue to emanate primarily (and problematically) from clinical, epidemiological and positivist science perspectives (see Gagnon 2018, Guta et al. 2017 and Hindmarch, Lorway 2017a and Orsini as exemplary exceptions to this trend).

In contributing toward a resuscitation of theorising HIV/AIDS in the age of treatment, I argue that recent anthropological research from the fields of “affective labour” and “audit cultures” may produce important insights into the social, political and economic organisation of the HIV/AIDS pandemic as it enters its fourth decade. Andrea Muehlebach applies the term “affective labour” to her exploration of debates around forms of governmentality and subjectivation associated with the rise of neoliberalism in Italy in the early 2000s, where public systems of social security were being substituted with voluntary forms of collective caretaking. She notes

that the rise of voluntarism in certain sectors of the Italian population was perceived to be an act of compassion, magnanimity and good citizenship in response to the dismantling of the social welfare state, yet it was simultaneously the very product of neoliberal reforms and strengthened through the promotion of intimate good feelings (2011, 60–62; see also 2012). I argue that the “family of HIV” metaphor simultaneously privileges similar assemblages of intimate good feelings attached to a Toronto HIV/AIDS service organisation and obfuscates the paid and unpaid work of staff and volunteers, tensions around stagnant or decreasing funding, and the sometimes conflicting relationships between diverse HIV+ communities in the Greater Toronto Area.

Muehlebach also notes that voluntary associations in Italy are overseen by national and regional agencies that are invested in “huge amounts of statistical reporting:” the production of graphs, numbers and typologies of volunteering shapes the ways in which citizens understand themselves and are understood by public authorities, and reflects neoliberal governance through pairing the state’s commitment to privatisation, devolution, and empowerment of citizens with retrenchment of state power through new regulatory mechanisms (2011, 66). Muehlebach’s observations on the increased use of data in “the technocracy of virtue” are similar to Ruckenstein and Schull’s arguments about the “datafication of health,” that is, the conversion of qualitative aspects of life into quantified data in a wide array of everyday life domains, from corporate marketing to epidemiology and public health, and the ways in which data come to permeate and exert power on all manner of forms of life (2017, 262–263). Strathern (2000) notes a similar tendency in the higher education sector, where increased assessment procedures and measurements of quality and efficiency appear to be “helping people help themselves,” but produce new forms of self-surveillance, accountability and monitoring that in turn contribute to new forms of value, productivity and social worth.

This anthropological focus on the social dimensions of professionalisation, datafication and quantitative measurements of quality and efficiency is a focus on what has been referred to as “audit culture.” Shore describes audit culture as a condition in which the techniques and values of accountancy (routine systems of financial management designed to verify budgets and ensure that organisations comply with administrative norms and regulations) have become a central organising principle in the governance and management of human conduct:

The spread of audit reveals a great deal about the ways in which processes of “neoliberalization” are

reorganizing patterns of life in advanced industrial societies. Through it we can also glimpse something of much deeper historical significance: a process that is remodelling our public sector institutions, refashioning working environments, and transforming our sense of our selves. (2008, 279–280)

A number of researchers have argued that datafication and audit cultures are increasingly important conceptual frameworks for understanding how global responses to HIV/AIDS are organised (Benton 2012; Biruk 2018; Lorway 2017b; Sangaramoorthy 2012; Sangaramoorthy and Benton 2012). Cain et al. (2014) and Greenspan (2018) delineate some of the tensions produced through the gradual professionalisation of the HIV/AIDS sector in Canada over the past 30 years, particularly in relation to HIV+ clients' sense of declining involvement, and the increasing reliance by the state health sector on data to monitor and evaluate HASOs in relation to funding decisions. This paper supports Greenspan, Cain et al.'s findings, but emphasises the ways in which audit cultures produce particular arrangements of affective relations between variously positioned individuals in the HASO sector.

### **HIV/AIDS and HASOs in Toronto**

In Toronto, over 20,000 people have been diagnosed with HIV in Toronto since 1985. The AIDS Committee of Toronto (ACT) estimates that about 10,000 Torontonians are currently living with HIV (ACT 2018). Men continue to contract HIV at significantly higher rates than women, and of the males diagnosed with HIV in Toronto in 2013, 79 percent were men who have sex with men (MSM) (City of Toronto 2015). Additional populations that continue to face a higher burden of HIV infection include injecting drug users, Indigenous persons, “African, Caribbean and Black” communities, and persons who come from areas of the world where HIV infection is more common (City of Toronto 2015; Government of Canada 2016). However, over the almost 40-year lifespan of this pandemic, the meaning and impact of an HIV/AIDS diagnosis for someone living in Toronto have changed profoundly. What was formerly classified as a “terminal” disease has changed in status to “chronic and manageable,” predicated on radical transformations in biomedical interventions stemming from a combination of improved pharmaceutical treatments, massive expansion of state and global health apparatuses specifically targeting HIV, more accurate epidemiological profiling, and the relatively new framing of HIV as a disease that could be eradicated in the near future (Moyer 2015).

An additional key factor animating this generational shift from “crisis” to “normalisation” in the response to

and treatment of people living with HIV/AIDS in Canada has been a gradual shift away from lesbian, gay, bisexual, transgender and queer (LGBTQ) activism located within a predominantly secular socio-political context driving the response to HIV/AIDS (McCaskell 2012; Lorway 2017a). LGBTQ activism in Canada led to the establishment of multiple grassroots HIV/AIDS service organisations in the 1980s and early 1990s catering to the diverse needs and requirements of specific groups defined around HIV status, sexual orientation, ethno-racial identity and/or gender. However, as many HASOs have become more established, some (but not all) have been increasingly professionalised with full-time staff who have specialised training in the fields of social work, psychology and/or public health. This professionalisation is partly in response to these organisations' increased reliance on state funding since the 1990s, and increased demands for research, monitoring and evaluation of programs in order to ensure funding (Greenspan 2018).

Thus, in the age of treatment, many (but by no means all) newly diagnosed HIV+ residents in Toronto are potentially able to access medical, social and psychological support and lead lives uncompromised by severe illness and the threat of imminent death. Recent biomedical research findings (for example, an HIV+ person with an undetectable viral load cannot transmit the virus to another person through sex; Public Health Agency of Canada 2017) contribute to the popular perception that HIV+ people are now able to lead “near normal” lives with less fear and uncertainty about their own health status and its impact on others, with less stigma attached to an HIV+ status. However, while there is no doubt that this era of “normalisation” of HIV is cause for optimism among many HIV+ people and their allies, ongoing challenges for differentially positioned PHAs remain under-reported in mainstream HIV/AIDS coverage. For example, the ongoing criminalisation of PHAs in Canada for non-disclosure to sexual partners (that is, the possibility of receiving a charge of sexual assault that could lead to imprisonment) increases stigma and discrimination against PHAs, spreads misinformation about HIV and undermines public health initiatives (Hastings, Kazatchkine, and Mykhalovskiy 2017). A second challenge arises from “vulnerable” population classifications in HIV research such as “men who have sex with men,” which may gloss over significant intersectional desires, relationships, and inequalities related to ethno-racial, class, age, sexual and gender identifications (Boellstorff 2011; Gosine 2013). A third challenge in the Toronto area is the diversity of HIV-positive and vulnerable populations, as noted above (AIDS Committee of Toronto 2018; City of Toronto 2015), which has created programming

challenges for some of the larger and more established HASOs as they attempt to address the substantially different needs of these groups. Finally, HASOs in Toronto (and throughout Canada) are facing increasing financial pressures in the face of declining public interest and private donor funding, as well as stagnant or decreasing funding from government agencies (Easton 2016; more on this below). Thus, in the context of an increasingly audited environment accompanied by the devaluation of HIV as a pressing issue in mainstream media and increased funding precarity, how do HASOs in Toronto (re)organise their staffing, programs, outreach and support for a diverse set of people living with HIV who may face complex, interrelated physical, psychological, social and/or economic challenges?

### Service/Surveillance

In one of my first volunteer training sessions as an intake worker at a downtown Toronto HASO that provides practical support and therapeutic services to HIV+ people, Georgio, a full-time staff member, outlined what needed to be done prior to the intake interview, where a new client would be given an overview of this organisation's services and asked a series of questions in order to determine their most urgent issues or needs. Pre-interview preparation included ensuring that a total of 15 forms, brochures and folders were assembled and ready to be either filled in by the new client and/or me (the interviewer) or handed over to the new client at the end of the interview. Seeing my eyes widen as he produced the stack of material, Georgio reassured me, saying, "I know, it's a lot to take in, but you'll get used to it." He informed me that the most important documents were the two intake forms that I would have to fill out based on the interview and then upload into the Ontario Community-Based AIDS Service and Evaluation (OCASE) system, an online client records management tool currently used by most AIDS service organisations in Ontario.<sup>3</sup> Georgio emphasised that certain questions were of critical importance. I was required to ask the client to produce documentary proof of their residency in the Greater Toronto Area and documentary proof of their HIV status – without this evidence the organisation could not provide services. I would also need to check off certain boxes pertaining to the new client's identity – that is, gender; sexual orientation; ethnic origin (which included categories like "Aboriginal," "African," "Caribbean," "Middle Eastern," "South Asian," "White Eastern European" and "White Western European"); immigration status (citizen, permanent resident, visa holder, refugee claimant); employment and income status (are they receiving social or disability assistance, are they in

debt); number of children; housing status; relationship status; medication access (if they had drug coverage and a family/HIV physician); and disclosure status (if they had disclosed their HIV status to others).

Tony, a volunteer whom I shadowed during intake interviews, told me that he found some of this required information intrusive and not appropriate for a first interview, and that some interviewees were reluctant to divulge personal and sensitive information to a relative stranger in an environment they were unfamiliar with. He also found asking a stranger certain questions to be difficult – for example, he often did not ask about the person's sexual orientation or gender identity but surmised it from observations and/or information revealed in other questions (for example, he would ask the new client if they had a partner, and then listen carefully to hear if the partner's gender was revealed in answers to other questions). Another volunteer, Hernando, told me how he didn't like to ask new clients about their ethno-racial identity. "It's usually pretty obvious," he said, but then he remembered how in one intake interview he had assumed the client was from an African country because he was black and had an accent. When he asked what language the client spoke, they responded French, as they were from Haiti, which Hernando was not expecting. However, some volunteers, like Tony, recognised that despite the discomfort in extracting this information, much of it was necessary for record keeping: "They [the HASO] need this information when they are submitting reports to funders." Georgio, the full-time staff member, reminded me during another training session how important it was to accurately fill out the criteria on the intake interview forms: "Everything needs to be recorded – even handing out a bottle of vitamins [to a new client] – so that when auditors come there are accounts of where items have gone, and what services [were] provided." Detailed client service files on OCASE would provide the data that would help to justify the value of existing programs and thus the need to maintain or obtain funding from various local, provincial and federal funding agencies.

Georgio and other full-time staff in the organisation were aware that funding was an increasing problem for them, as the Public Health Agency of Canada, a major funding body, had recently shifted their HIV/AIDS strategy to focus more on "prevention," which disadvantaged organisations and programs for PHAs (Easton 2016). Since he had started working at this HASO, Georgio had noticed that there were increasing measurement and evaluation demands from state agencies in order to guarantee ongoing funding – for example, Georgio said he was now required to ask clients if they were

remembering to take their meds and to record their responses, which could then be provided as proof of adherence, which in turn would be used as proof of the effectiveness of treatment programs as a form of prevention of HIV transmission.<sup>4</sup> However, Georgio didn't think this line of questioning should be a priority of this HASO:

People talk about how this is a safe and supportive space, where they can come and not feel judged or stigmatized, and not worry about HIV-related issues; or they are focused on other issues that are not directly tied to HIV like income, housing, [and] food: Questions like "Have you remembered to take your meds?" will remind people of the burden of their status.

However, other staff had no problem with data collecting: Another staff member, Javier, was adamant in his support of the data amassed in the OCASE files. Pointing at a poster on his office wall filled with statistics about HIV in Canada, he said, "We are sitting on a gold mine of data, but we have only just begun to use it to our advantage. We should use it, combined with qualitative data, to prove to them we deserve more funding."

Similar to the bureaucratisation of the higher education sector, reliant upon the production of new and more data as a way to audit evolving categories of efficiency, quality and productivity (Spooner 2014; Strathern 2000), it appears that Canadian HASOs and their clients are being placed under increasing surveillance and assessment through an audit culture formulated partially in response to shifting priorities around HIV/AIDS treatment and prevention, funding cuts, and a general retreat by the federal government in prioritising HIV/AIDS as a significant health issue. In March 2018, the Canadian HIV/AIDS Legal Network (CHALN) published a report documenting the Canadian federal government's ongoing underspending in funding the HIV response since 2004:

In most subsequent years, the Public Health Agency of Canada's own data confirm that in the 12 years since the Federal Initiative was launched, more than \$104 million dollars in funds committed to the federal HIV strategy has been lost . . . Given the substantial loss, through steady erosion of federal funds ostensibly committed to the HIV response, it is unacceptable that numerous services and organizations across the country will be forced to close or discontinue programs in a matter of months despite the clear need that exists. (CHALN 2018)

In this context of stagnant or decreased HIV/AIDS funding, staff and volunteers at a number of Toronto HASOs face increasing pressure to collect data that produce

"measurables" that confirm "efficiencies" or "productive outcomes" of all activities and programming. As one director at another HASO told me, "This is fine for programs like food banks or condom distribution, where numbers tell a fairly straightforward story, but what about counselling services, art therapy or peer support groups? How does one define and measure outcomes of these activities?" Another staff member spoke of developing different strategies to measure success, such as using pre- and post-counselling questionnaires to confirm behavioural changes via participants' answers to statements such as, for example, "I was anxious about my HIV status and disclosing to new sexual partners before the group therapy sessions but now I am less anxious" or "I now have tools and strategies to manage HIV related stress" – but he acknowledged that these measures do not necessarily reflect the intended objectives or goals of numerous activities and are put in place primarily to meet funding agencies' criteria and obtain/retain funding. A director of another Toronto HASO noted that as evaluation is being ramped up, staff at her agency have learned to write things in reports and applications like "By the end of the year people in this support group will have increased their capacity to better communicate their health concerns." "[This HASO] is not a research organisation," she said, and the increased requirements around data collecting and measurement are "total bullshit . . . but you figure ways around it."

In addition to these data collection processes placing an additional burden on staff and volunteers to secure or maintain funding, as Tony the volunteer noted, we should also be asking about the impact of these questions and information gathering practices on clients and client-staff relations. As noted above, some volunteers felt that asking questions about sexual orientation, ethno-racial identity, disclosure of HIV status and/or sources of income was problematic as these questions could have a discomfiting effect on new clients. According to full-time staff member Javier, about half the new clients coming to this HASO are newly arrived immigrants or refugees, some of whom have just learned they are HIV positive due to required immigration/refugee medical tests, creating additional emotional burdens and pressures in an initial interview, where the forced intimacy of intake questions posed by a relative stranger in an unfamiliar environment may invoke anxiety or fear. This assumption of the intrusiveness of certain intake interview questions would lead some volunteers to skip those questions and provide answers based on inferences or observations that may or may not be accurate.

Thus, the intake interview, its attendant questions and documents, and the uploading of information

to an OCASE file form a very particular ritual of family-making. While the “family of HIV” metaphor may help render sensible feelings of relief, non-judgment, support and *communitas* (a sense of sharing and intimacy among persons who experience liminality as a group) generated in and through social relations within the HASO, all of which may be of profound importance to an HIV+ person, the process of joining this family is simultaneously formed through the extraction of specific pieces of personal information defined through particular arrangements of identities and statuses (viral, income, relationship, racial/ethnic, sexual, gender). If all people affiliated with this HASO are encouraged to envision themselves through the metaphor of family, then we must acknowledge that this is not only a family defined through affective ties of love and caring, but it is also one in which each member is carefully screened to ensure that minimal criteria are met (HIV and city residency status) in order to belong and extensive personal data are recorded on a computer file in order for the member to be identified and tracked, with almost every subsequent HASO interaction recorded and uploaded to the member’s OCASE file. When all activities, from receiving vitamins or a massage to participating in a support group, are recorded in order to justify services provided (and state funding to support those services), we see the formation of a highly surveilled and measurable family.

### **HIV as (a Dysfunctional) Family**

In addition to the underlying auditive dynamic of the “family of HIV” metaphor, another unspoken yet central issue pertaining to social relationships in this HASO is the increasing diversity of HIV-positive clients. As noted by Javier above, the client base of this organisation has diversified significantly since its founding in the 1980s, reflecting changes in the demographic profile of HIV-positive people in the Greater Toronto Area. While I was not able to obtain data on specific demographics of this organisation’s client base,<sup>5</sup> staff and volunteers who had been affiliated with the organisation for many years often commented on changes in who has been accessing the organisation’s services. Richard, a gay-identified white man in his early 60s, who has been an “on again, off again” client of the HASO for over 30 years and was involved in the development and organisation of the 30th-anniversary theme and festivities, said that among his friends (whom I assumed to be other white, gay-identified, older HIV-positive men), there had been remarks on how “over the past decade there’s been a big change – a shift in complexion of who’s coming through the door.” Some of his friends were now making comments like “Who are all these women and black

people?” Richard said that the increasing diversity of HIV-positive clients in Toronto was a touchy subject, with some of his friends feeling that there were now HIV/AIDS service organisations for “everyone else” (referring to HIV/AIDS organisations serving ethno-racially defined populations such as “South Asian” and “Black”) but there wasn’t really an organisation focusing on “us” (again, I inferred this to be older, gay, white HIV-positive men). Richard said that some of his friends also felt like they couldn’t say anything: “If they complain, then they’ll get shut down.” Javier, the full-time staff member at this HASO, corroborated this observation: When he first joined the organisation in the early 2000s, he observed significant tensions between the “old guard” and newer members, who were often refugees, immigrants (with or without legal status) or Indigenous. Javier noted that these tensions were not found only in this organisation and that in the early to mid-2000s, there were discussions and debates across the province around (lack of) support, services and representation for increasingly diverse HIV+ populations. Javier and Richard both noted that staff and clients at this HASO recognised the importance of starting dialogues between these different client groups. Richard was involved in some of these meetings and said that his conversations with Lucette, a client originally from a central African country, allowed him to better understand African women’s experiences with HIV and Lucette to better understand gay men’s perspectives. Richard and Lucette recognised the need for both sides to meet and get to know each other in order to better understand their similarities and differences. While Richard felt that there were still tensions between the groups (some of the African women were still homophobic and some of the gay men were still racist), increasingly they recognised what they had in common. Cathy, another full-time staff member, outlined how a network of HASOs had developed a leadership training program for HIV-positive clients so that they would be “empowered to take up leadership positions in this organisation and beyond.” The leadership training program brought together a range of clients, who started listening to each other:

This is where white gay men started to listen to African women. They [the men] heard about genocide in their [the women’s] countries and what they had been through. The African women heard about the “genocide” of gay men in North America – and it was a genocide, as early in the epidemic a generation was wiped out because nobody cared and the government’s approach was “we can let them die.” Both experienced genocide and trauma, and this brought



them together, and both realised they lacked the social determinants of health.

Richard also noted commonalities between the two groups in dealing with HIV stigma in their respective (African and gay) communities and their shared difficulties with local and provincial health and welfare bureaucracies. According to Richard, it was partially from these meetings and training sessions that the “family of HIV” phrase developed, in order to acknowledge the shared respect and mutual support between these diverse client populations, staff and volunteers. However, Richard ended our conversation by saying that he still wondered if “the people who started this organisation are getting left behind.”

## Conclusion

While data may produce statistics about HIV+ people that help to illuminate affiliations between HIV risk, status and structural determinants of health based on race, nationality, gender, sexual orientation, age, citizenship and/or income status, these statistics do not reveal much about the relational dynamics of said categories in everyday encounters in HASOs, or the ways in which these categories may overlap in multiple ways for some clients and not for others. Similarly, the Family of HIV campaign conveyed that the HASO was a “safe and welcoming space” full of love and support, highlighting a particular nexus of positive affects between staff, volunteers and clients, but simultaneously omitted any reference to past and ongoing frictions between different categories of clients. In some ways the “family of HIV” metaphor was an apt choice for this HASO, intentionally reflecting and resuscitating Weston’s observations of lesbians and gay men’s “families we choose” in the 1980s and early 1990s – that is, their intentional resignification of hegemonic Euro-American biogenetic kinship terminologies (Weston 1991; see also [Schneider 1980](#)). However, familial bonds were now articulated through claims to a shared substance (HIV) that created relations between a much more diverse group of people than just gay men. The tensions within and between the various clientele of this HASO produced another dimension of affective familial bonds – discordance, hierarchy, (in)visibility, favouritism and resentment – which received much less attention in official presentations and performances.

Anthropological research on transnational care workers and “care work” (childcare, eldercare and house cleaning) has highlighted how that sector’s affective aspects, such as intimacy, personalism, and fictive kin relationships, extract “surplus emotional labor” (Hochschild 2003 [1983]) mostly from racialised women workers, who,

in turn, often justify their caregiving labour through expressions of sentiment and kin obligation ([Glaser 2017](#)). These observations can be extended to certain forms of care for HIV-positive people in which the paid and unpaid work of a non-profit HASO’s staff and volunteers is defined primarily through familial caregiving sentiments, creating a grey zone of care where the lines between labours of love and institutionally compensated work are blurred ([Wool and Messenger 2012](#)).

While I do not want in any way to discount the effective and profound assistance provided through this HASO – I witnessed tears of relief when some new clients realised that this organisation would help them find shelter or get registered for the provincial drug plan, or would just listen non-judgmentally and empathetically – it is nevertheless important to think through the effects of the institutionalisation of emotional and material support for PHAs: Many long-term Canadian HASOs supporting PHAs have gradually shifted from informal, ad hoc networks of support in the 1980s to professional organisations deeply enmeshed in the bureaucratic health and welfare apparatus of various levels of the state today ([Hindmarch, Orsini, and Gagnon 2018](#); [Lorway 2017a](#); [Mykhalovskiy and Rosengarten 2009](#)). Individuals coming in through the door of this HASO today must be counted, categorised and analysed, and their ongoing interactions with the HASO must be tracked and recorded, from the receipt of a vitamin bottle to the achievement of a new level of confidence in a peer support group. Thus, while unconditional love, support and mutual respect may be central affective nodes through which a past gay “family” is partially remembered and an aspirational new “family of HIV” is performed at an annual meeting, we would do well to heed “love’s labour’s lost” (taking Shakespeare’s play into a rather different context) that is, to think about how love is now organised through the roles, responsibilities and obligations of mostly full-time professional workers embedded in the audit culture of the health and welfare apparatus of the Canadian state.

While I have not conducted a systematic search of all Toronto HIV/AIDS service organisations’ histories, I have yet to come across any mention of the HIV virus as a generator of affective kinship ties in past annual reports or publicity materials. Much research on the first two decades of the pandemic discussed the devastating impact of HIV/AIDS on consanguineal or affinal families (for example, [Ankrah 1993](#)) around the world: HIV was depicted as a homewrecker, an unwanted destructive agent, threatening the cohesion or existence of existing nuclear or extended family units. However, in the “age of treatment,” strategies for HIV treatment, prevention

and education have undergone significant shifts in content and moral suasion, producing new ways of thinking and feeling about the relationship between the virus, bodies, illness and sociality, such that at the present moment, in some locations, the virus has become a benign, productive symbol of intimate kinship.

However, this fictive kinship has emerged, perhaps not so coincidentally, alongside pressures to produce data demonstrating efficacies of service and measurables of “success:” the gradual professionalisation and institutionalisation of HASOs in Canada, along with the increased importance of audit cultures in numerous state sectors like health and education, inadvertently produce the family metaphor as a simultaneously nostalgic and aspirational counterweight to the estranging effects of datafication inherent in neoliberal bureaucratic systems. “Family” becomes a safe-word conveying a nostalgic image of valued, popular affective relations that is simultaneously recognisable, translatable and appealing to a diverse array of clients as well as funding agencies and the wider public. Meanwhile, discussions with volunteers, staff and clients reveal that some volunteers are uncomfortable asking certain intake survey questions, and some clients feel that their needs (based on their age, race, gender, sexual orientation, citizenship and/or income status) are receiving less attention due to the increased diversity of clientele and attendant issues in an environment of shrinking funding for HASOs, revealing new and ongoing tensions linked to the demands of a diverse population of PHAs and the bureaucratisation and professionalisation of these agencies.

From toxic to benign, destructive to productive, fearful to loving – these representational shifts of HIV are at once moral and political in their effects. While I am not convinced that I have witnessed “armed love” as described by Miriam Ticktin (2011) in her analysis of humanitarian work around immigration and gender violence in France, in which a harmful moral discourse premised around the gendered and racialised suffering victim of the global South circulates among workers in humanitarian organisations, the Toronto HASO that I volunteered with is nevertheless part of a dispersed network through which a politics of care is produced, such that a set of regulated discourses and practices, grounded on a moral imperative to relieve suffering, come together through a diverse set of actors. Following Ticktin, I argue that the institutionalisation of support for PHAs through audit cultures results in regimes of care that may ultimately work to displace possibilities for larger forms of collective change generated through remembrance of and critical engagement with past and present political actions of HIV/AIDS activists, as well

as contemporary forms of activism generated in other sectors (that is, movements responding to labour, gender, migration or racial inequities) for those most disenfranchised through neoliberal reforms and audit cultures. In the age of treatment, we must pay close attention to the differential affective, social, political and economic dimensions of new biomedical, epidemiological and other evidence/data-based models of treatment and care, their enmeshment in larger apparatuses of the state, and their impact on differentially positioned PHAs.

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## Notes

- 1 The image beside this paragraph was a drawing of a tree with green leaves, red fruit and a black trunk and roots, but no explanatory link between text and image was provided. I interpreted the tree as the HIV/AIDS service organisation, which provided protection and sustenance to PHAs (the fruit, obviously), and the roots as the many networks of people living with HIV who contributed to the organisation’s existence.
- 2 In both organisations, I informed volunteer coordinators and program facilitators that I was also a researcher working on a project examining how PHAs and HASOs are navigating the increasing diversity of PHA populations in the Toronto area, the effects of stagnant or reduced funding on HASOs, and the impact of new biomedical knowledge about HIV medications and HIV prevention. The central role of voluntarism in Toronto HASOs, its relationship to stagnating or decreasing levels of public sector funding and private donations, and its impact on HASO organisational cultures, service delivery and HIV-positive clients indicate another realm of transformation and change in the sociocultural

and political-economic worlds of HIV that merits further research. For more on voluntarism, citizenship and neoliberalism, see (Muehlebach 2012).

- 3 OCASE is a “monitoring and evaluation tool” funded by the AIDS Bureau of the Ontario Ministry of Health and Long-Term Care and managed through the Ontario HIV/AIDS Treatment Network (Greenspan 2018, 156). Every agency that uses OCASE must record its client information and the services it has delivered in an agency-specific, confidential database. Only authorised individuals from each agency can access the recorded information.
- 4 This claim could be based on the now widely accepted medical fact that if an HIV-positive person has an undetectable viral load based on adherence to antiretroviral therapy medications, then they cannot transmit the virus to another person.
- 5 An ironic point, given my argument about the increased surveillance and measurement of HIV-positive clients. The organisation’s annual report notes that in 2016–17, over 2,669 clients accessed its service, but no classifications based on gender, sexual orientation, race/ethnicity, age or income status are provided.

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