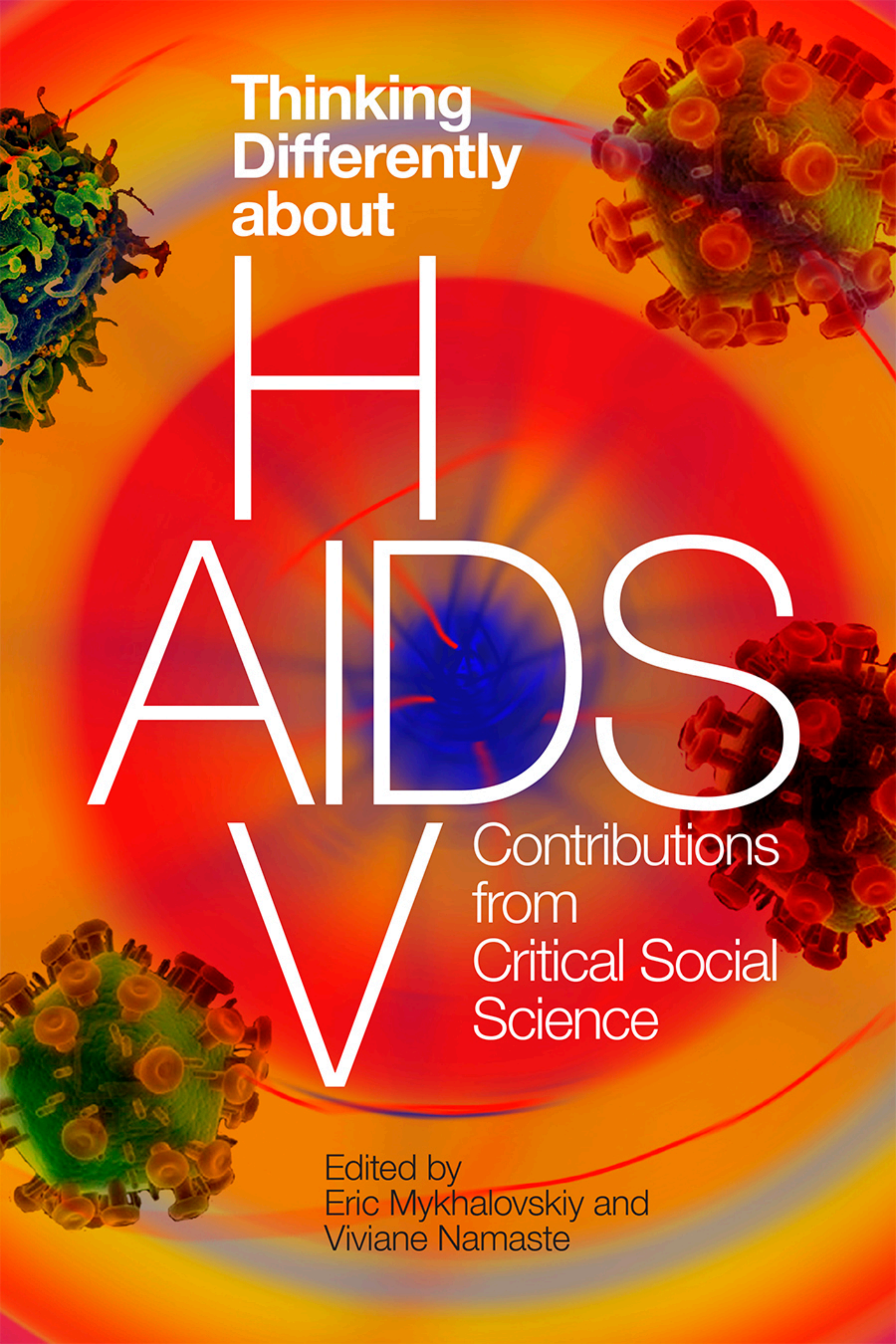

Thinking Differently about
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Contributions from Critical Social Science

Edited by
Eric Mykhalovskiy and
Viviane Namaste

Thinking
Differently about
HIV/AIDS

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We dedicate this book to
George W. Smith (1935–94),
whose intellectual and political influences
flow throughout its pages.

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Thinking
Differently about
HIV/AIDS

Introduction

Knowing and Responding to HIV/AIDS Differently

Eric Mykhalovskiy and Viviane Namaste

This anthology raises questions about knowledge and HIV/AIDS: what we know, how we know it, and the relationship between knowledge and action. The book invites us to consider why questions of knowledge matter in our response to the HIV/AIDS epidemic, including the knowledge used to justify funding decisions, to develop policy, to inform community education, and to organize the delivery of health services. Contributors to this collection argue that if we wish to respond to the HIV/AIDS epidemic in all of its complexity, deep reflection on knowledge is required.

As we sit down to write this introduction, two recent news stories bring these questions about knowledge to the forefront and point to the complex landscape of the HIV/AIDS epidemic addressed by this book. The first story, from a British online newspaper, heralds a "breakthrough treatment" that it claims may have resulted in the first British man to be cured of HIV (England 2016). While the article quotes scientists who urge caution in interpreting early study results, it nevertheless recapitulates tales of faith in the capacity of biomedicine to resolve the epidemic. Such tales received a big boost in the mid-1990s with the development of antiretroviral treatments that, when taken in combination, successfully suppress HIV in the bodies of people living with the virus. The news article extends such tales by invoking the possibility of a cure. A number of current clinical trials, including the study referred to in this article, aim to cure HIV by destroying all HIV-infected cells in people living with HIV, including "dormant cells that evade current therapy" (England 2016).

The second story, published in the Canadian daily the *Globe and Mail,* offers a rather different narrative about HIV. It focuses on the efforts of a group of front-line physicians to have the government of Saskatchewan declare a public health state of emergency in response to the dramatic increase in people newly diagnosed with HIV in the province (Picard 2016). The story does not tell a promissory tale of a soon-to-be cured disease but, rather, resurfaces discourses of a dangerous, out-of-control infection that is to be publicly feared. It notes how provincial neglect and enduring stigma have resulted in widespread HIV transmission among the province's most disadvantaged people – members of its Indigenous communities. Rather than heralding a cure, the physicians in André Picard's article issue a "*cri de coeur* for action" in the face of a public health crisis.

Of course, these news stories are representations that strategically frame the response to HIV in particular ways, a point that Denielle Elliott makes in her contribution to this collection. Here, we juxtapose the two news accounts to help put into relief the complexities and tensions that mark HIV/AIDS in the present moment. Juxtaposing them tells us about more than the differences in HIV/AIDS's narration. It invites us to examine the stratified and uneven nature of biomedical intervention into the epidemic as well as the inequality, settler colonialism, and institutional inaction that, among other structural relations, continue to drive HIV transmission in Canada.

In Canada and other developed countries, advances in biomedical science and treatment have transformed what used to be regarded as a death sentence into a chronic manageable condition. People living with HIV/AIDS who have access to effective treatment can now expect to live long and healthy lives (Antiretroviral Therapy Cohort Collaboration 2008; Samji et al. 2013). Treatments have also transformed the landscape of HIV/AIDS prevention. The combined results of research conducted since the early 2000s has led to the conclusion that people living with HIV who are on treatment and have been virally supressed for at least six months cannot transmit HIV to their sexual partners (Barré-Sinoussi et al. 2018; Cohen et al. 2016; Loutfy et al. 2014; Rodger et al. 2016). This has encouraged the development of what is called biomedical HIV prevention (Imrie et al. 2007) as well as a global movement committed to popularizing the message that people living with HIV who are on effective treatment cannot sexually transmit HIV.[1]

One approach to biomedical prevention, discussed by Adrian Guta and Stuart Murray in this volume, encourages widespread HIV testing and near immediate treatment initiation for people newly diagnosed with HIV, not only to improve their health but also to reduce their likelihood of transmitting HIV. Another approach, explored by Chris Sanders, Jill Owczarzak, and Andrew Petroll in this volume, called HIV pre-exposure prophylaxis (PrEP), involves HIV-negative people taking antiretroviral treatment to reduce their risk of becoming HIV-infected should they become exposed to the virus. Recently, widespread testing, rapid treatment, and PrEP have been cited as the source of dramatic declines in new HIV diagnoses among gay and bisexual men in the United Kingdom (Nwokolo 2017), the United States (Maslin Nir 2017), and Australia (Grulich et al. 2018).

At the same time that these important developments have occurred in the biomedical prevention of HIV transmission, HIV infection remains a serious public health problem. To take Canada as an example, of the roughly 65,000 people living with HIV in the country, some 21 percent do not know they are HIV positive (Public Health Agency of Canada 2015). New HIV infections are fundamentally patterned by structural relations of inequality. For instance, the prevalence of HIV in Canadian federal and provincial prisons is roughly ten times greater than in the Canadian population (Canadian Treatment Information Exchange 2017), and HIV incidence is 131 times higher among gay and bisexual men than among other men, fifty-nine times higher among people who inject drugs than among those who do not, and almost three times higher among Indigenous than non-Indigenous people (Challacombe 2017).

The forms of inequality associated with HIV are manifold. In Canada, for example, HIV remains closely tied to poverty and housing insecurity. A recent Ontario study of over 600 people living with HIV found that 87 percent of participants were unable to meet basic food, clothing, and housing needs; 50 percent experienced housing instability; and 30 percent were at risk of losing their home (Rourke et al. 2015). Recent years have also seen a wave of unprecedented HIV criminalization, for which Canada and the United States serve as hot spots (Hastings, Kazatchkine, and Mykhalovskiy 2017; Hoppe 2017). As Colin Hastings notes in this volume, at precisely the time that HIV has become increasingly difficult to transmit, people living with HIV are facing the threat of harsh criminal punishment, at times facing aggravated sexual assault charges even when they pose a negligible risk of transmitting HIV to their sex partners. Such overuse of the criminal law contributes to the ongoing stigmatization of HIV. After almost three decades of HIV education and prevention, a 2012 study of public attitudes reported sobering findings about HIV stigma in Canada: 15 percent of survey participants felt "afraid of people living with HIV," 48 percent "would feel uncomfortable using a restaurant drinking glass once used by a person living with HIV/AIDS," and 51 percent would be "uncomfortable if a close family member or friend dated someone living with HIV" (EKOS Research Associates 2012, x, 47, 82). The persistence of such HIV-related stigma complicates any suggestion that biomedical advancements have somehow normalized HIV (Moyer and Hardon 2014).

We live in a peculiar moment of the growing biomedicalization of the response to HIV (Clarke et al. 2010), in which narratives promising a cure are coincident with widespread HIV criminalization, structural inequality, HIV stigma, and rising infection rates among socially marginalized people, which, altogether, make HIV an ongoing health and public health crisis. The contributors to this volume have faced the challenge of making sense of the many tensions and complexities associated with the Janus-faced nature of the contemporary HIV/AIDS epidemic. This has required them to recognize how biomedical treatments have improved the lives of people living with HIV who have access to them, while also acknowledging that processes of inequality, stigma, racialization, and the social dynamics of new infections mean that HIV is about so much more than treatments. It has also involved recognizing that biomedical developments are themselves suffused with social, political, and cultural relations and occasion new forms of self-governance, stratification, and inequality that are worthy of social science scrutiny.

For the first time, this volume brings together the work of Canadian social scientists – primarily sociologists but also scholars from anthropology, social work, interdisciplinary public health sciences, and elsewhere – who specialize in HIV/AIDS research.[2] Some contributors focus their chapters on the role that particular traditions of critical social inquiry can make to research on HIV/AIDS. Others present examples of empirical research that they have conducted on HIV that draw on critical approaches to social science inquiry. All of the contributors write about HIV in the North American context, with a primary emphasis on Canada. While they address a range of issues, concerns about biomedical and public health interventions in the epidemic, the forms of expertise they rely on, and their effects on varied communities of people living with HIV are a preoccupation for many of the volume's contributors. The contributors to this volume engage with theoretical and methodological work from a range of authors including Michel Foucault, Dorothy Smith, Didier Fassin, Bent Flyvbjerg, Bruno Latour, and Linda Tuhiwai Smith, to name a few, and cover a range of topics including biomedical prevention, HIV criminalization, HIV disclosure, front-line community work, public health emergencies, and epidemiological ways of knowing. Overall, the volume suggests how using a critical social science perspective can help us to better understand and intervene in the relations that produce and respond to the HIV/AIDS epidemic.

Why This Book?

We brought together this edited collection because we feel that critical social science inquiry of HIV can make important contributions to scholarship and to the response to the epidemic. We were driven by a set of interrelated concerns about the biomedicalization of HIV, the changing political context of the response to HIV/AIDS, and the closure of institutional and discursive spaces that encourage critical social science work on HIV/AIDS. In some circles, the success of biomedical treatments has promoted a kind of complacency about the HIV/AIDS epidemic and its social dimensions. It has promoted a way of thinking about treatments as purely biomedical phenomena that have no social character. This way of thinking places great faith in the capacity of biomedicine to "treat our way out" of the epidemic, a position critiqued by a number of scholars within and beyond the health sciences (Auerbach and Hoppe 2015; Bassett and Brudney 2014, 200; Nguyen et al. 2010). It also misrecognizes the fundamentally social character of biomedical developments and turns attention away from large-scale structural relations that continue to drive the epidemic. Taking a cue from decades of scholarship in science and technology studies that firmly position biomedical innovation within the scope of social science inquiry, the various chapters of this book that address biomedical treatments offer an important counterpoint to conventional biomedicalizing viewpoints.

At the time of writing, the Canadian state has yet to renew its commitment to properly fund a response to the HIV/AIDS epidemic (Hindmarch, Orsini, and Gagnon 2018). Federal funding for frontline HIV/AIDS organizations has remained stagnant since 2008. In 2016, some 30 percent of organizations funded through the Public Health Agency of Canada faced the prospect of immediate closure when their funding was eliminated by the agency (Minsky 2016). More broadly, proposed cuts to US funding of global HIV treatment and prevention efforts have prompted widespread concerns, including those expressed at the 2017 Paris International AIDS Society Conference, about the very future of the global fight against HIV (Alcorn 2017). Given the volatile and precarious presence of HIV within current state policy priorities, a collection that directs critical attention to established approaches for managing HIV is both timely and relevant.

Over the course of three decades of conducting HIV/AIDS research, we have noticed a waning appreciation of the significance of critical social science research for addressing HIV-related issues. We suggest that undervaluing social science research on HIV is coincident with the consolidation of what has been described as an HIV/AIDS industry (Nguyen 2005; Patton 2002). By HIV industry, we have in mind a complex assemblage of state, civil society, and corporate actors and the forms of biomedical, pharmaceutical, behavioural, epidemiological, and related forms of expertise, discourse, policy, and technology that they draw on to know and respond to HIV/AIDS as a governable problem. The HIV/AIDS industry privileges biomedical responses to the epidemic, nominally relies on evidence-based decision making and its associated hierarchy of statistical and epidemiological knowledge, and encourages front-line responses to HIV that produce demonstrable measurable outcomes and that transfer the responsibility for addressing HIV to private citizens. These relations generate a demand for narrowly applied forms of research that treat HIV/AIDS as something to be addressed within the established terms of state, managerial, pharmaceutical, and biomedical discourses and technologies. The resulting agenda for research gives little value or significance to the styles of social science research that critique oppressive relations, attend to problems of inequity and injustice, locate HIV/AIDS in its social, economic, and political context, and emphasize remedial responses that connect biological, social, and cultural processes.

We imagine this collection as a space that encourages and emphasizes precisely these styles of analysis and substantive concerns. We intend it to intervene in the institutional and discursive closure of critical social science HIV/AIDS research. This closure manifests itself in HIV/AIDS conferences with social science tracks that have remarkably little, if any, theoretically informed social science content; so-called interdisciplinary HIV/AIDS journals that publish a steady fare of epidemiological, health sciences, and behavioural research to the relative exclusion of critical social science inquiry; and extramural funding opportunities that make securing the resources required to conduct critical social science inquiry of HIV incredibly difficult.

Of these limits, funding practices are perhaps most familiar to Canadian readers. Numerous scholars have argued that the policy change resulting in the transfer of health research from the Social Sciences and Humanities Research Council to the Canadian Institutes of Health Research (CIHR) has had a detrimental effect on critical social science health research. They have critiqued the CIHR's conception of interdisciplinarity (Albert and Laberge 2017; Whitfield and Reid 2004) and its policing of the boundaries of acceptable health research (Albert 2014) and have called into question the capacity and commitment of the CIHR to value the contributions of critical social science research on health (Graham et al. 2011).

Our own participation in external funding for HIV research raises similar concerns. In our experience, the mandates of the CIHR emphasize applied research that is produced through large teams of researchers and that relies primarily on positivist quantitative research methods. Funding applications that support established policy and program directions and that promise clear measurable outcomes related to HIV services are privileged. Many of the funding opportunities of the Ontario HIV Treatment Network (OHTN) are organized by the imperatives of implementation science, which seek to systematically apply scientific knowledge in the design, implementation, and evaluation of public health programs (Aral and Blanchard 2012; Glasgow, Eckstein, and Elzarrad 2013).[3] Implementation science relies heavily on epidemiology, mathematical modelling, and evaluation research. What results from such funding opportunities is research formulated within established HIV/AIDS policy and program directions that designs and tests interventions or that evaluates their implementation, scale-up, and delivery.

While we recognize the value of HIV/AIDS research supported by the CIHR, the OHTN, and similar funders, we are concerned with how established funding relations for HIV research limit and corrode critical social science research on HIV/AIDS. The current funding and research infrastructure perceives research as a product, the results of which can be operationalized and known in a calculable way. It offers little space for work that is driven by theory rather than by a discrete set of outcomes, that centres the voices and experiences of those most affected by HIV, that calls into question the epistemological assumptions of program science, that commits to small-scale case studies over the goals of generalizability or scale-up, that eschews the values of efficiency, or that critiques rather than supports existing structures that govern the HIV/AIDS epidemic.

In creating a space for research that works against the grain of the established HIV/AIDS research apparatus, we have been inspired by a rich tradition of critical social science research on HIV/AIDS. In the very early years of the epidemic, social scientists emphasized the need to respond to the social, cultural, and political dimensions of HIV/AIDS. The body of work they produced destabilized assumptions about the neutrality of scientific and biomedical knowledge about HIV/AIDS and highlighted the socially constructed nature of the disease (Epstein 1996; Fee and Fox 1988; Martin 1994). It foregrounded the experiences of people living with, and affected by, HIV in analyses of risk, illness, sexuality, and identity formation (Adam 1996; Aggleton, Davies, and Hart 1990, 1995) and criticized the limitations of state, public health, scientific, and pharmaceutical industry responses to HIV (Oppenheimer 1988; Patton 1990, 1996; G.W. Smith 1990). Led by humanities scholars, the early literature on HIV/AIDS also examined the ways in which representations – in the mass media, in government discourse and policy, and in the work of community-based organizations – shaped both what was known about the epidemic and the actions made possible by that knowledge (Crimp 1988; Patton 1990; Watney 1988).

The contributions to this edited volume have all been inspired by the early tradition of critical social science research on HIV and have been freed, relatively speaking, from the constraints of current funding imperatives. Collectively, they are an example of what is possible when critical social science research is not overwhelmed by evidence-based decision making, implementation science, neoliberal policy imperatives, or narrow conceptions of applied research. While early scholarship in the field was deeply influenced by the humanities, as editors we have made the decision to develop a volume centrally concerned with a social science response to HIV/AIDS. This decision should not be interpreted to suggest that humanities scholarship and interdisciplinary perspectives are not important for the study of HIV/AIDS. Rather, it simply indicates our wish to situate the volume within a framework of social scientific theories, methods, and practices.

Many contributors to this volume are emerging scholars. The collection thus showcases the research of a new generation of social scientists dedicated to critical social science inquiry about HIV. If emerging scholars have faced an institutional context in which they have needed to insert themselves into a managerial logic in the mainstream HIV/AIDS industry, this book has created a space for them to connect with critical traditions of HIV social science, to address different questions, and to think and write differently about their contributions.

What Do We Mean by Critical Social Science Research?

We orient to the term critical social science research as a placeholder that groups together diverse styles of theoretico-empirical inquiry that diverge from approaches to research supported by relations of governance and ruling. Critical social science research calls into question the processes, limitations, and effects of practices that govern people's lives and seeks to contribute to contemporary struggles against social injustice, inequality, human suffering, and oppression. Using any concept that designates a mode of scholarly practice invites a host of questions about the specificity and range of its referent. To be clear, we reject any effort to equate critical social science with any particular tradition of social inquiry, whether it be Marxist, feminist, postcolonial, decolonizing, Indigenous, anti-racist, or poststructuralist. We also avoid the use of "straw-man" versions of critical scholarship to suggest that critical work in the social sciences has largely run its course (Latour 2005). We wish critical social science research to operate as a generous and relatively open concept that names a range of analytic styles and approaches, including those that have been promoted by social scientists calling for public sociology (Burawoy 2004, 2005; Hanemaayer and Schneider 2014), engaged anthropology (Beck and Maida 2013; Fassin 2017; Low and Murray 2010; Mullins 2011), and activist scholarship (Frampton et al. 2006; Hale 2008; G. Smith 1990).

We recognize that because of the dominance of highly applied forms of research in the HIV field, the term "critical" sometimes gets used by social scientists to distinguish themselves and their work from what becomes framed as less politically sophisticated or expressly progressive forms of inquiry. At its worst, this type of engagement can take the form of smug self-assurance, whereby "critical" is invoked as an emblematic status without much reflection on what precisely makes one critical and what might be good about practising critical scholarship. To discourage this orientation to the term, we have asked contributors to this volume to draw on traditions of theory and research that they understand to offer a critical view of the social practices and arrangements they write about and to suggest how this is so. This has resulted in chapters that are informed by a variety of traditions often associated with critical social inquiry, such as Dorothy Smith's approach to investigating ruling relations (Daniel Grace; Colin Hastings), studies in governmentality (Adrian Guta and Stuart Murray), critical ethnography (Denielle Elliott), Indigenous methodologies (Randy Jackson) and Flyvbjerg's approach to phronetic social science (Chris Sanders, Jill Owczarzak, and Andrew Petroll). It has also resulted in chapters on approaches that have a less stable relationship to critical social science research such as actor-network theory (Martin French) and conversational analysis (Jeffrey Aguinaldo).

In shaping this collection, we have encouraged the contributors to inhabit an analytic space that negotiates between negative critique and principled normative claims-making about the objects of their inquiry. By negative critique, we have in mind a style of analysis that takes delight in identifying what is missing, absent, wrong-headed, or otherwise problematic about contemporary responses to the HIV/AIDS epidemic. Negative critics stand at some distance from efforts to intervene in the epidemic and repeatedly recite what is wrong with those efforts, without demonstrating any serious obligation or sense of responsibility to participate in efforts to make things work differently. It is a shallow form of critique that we discourage.

At the same time, we have seen a reluctance on the part of some scholars to engage in normative claims-making or to contribute concrete suggestions for improving the HIV/AIDS response. In an important statement on critical social science research, Andrew Sayer (2009) diagnoses this problem by referring to a historical divide between science and ethics in modernist thought. He argues that this divide continues to hinder the ability of critical social scientists to articulate a conception of the good. For Sayer, the result is the displacement of a robust critique of social practices in favour of more "timid" forms that seek only to unsettle current arrangements or encourage greater reflexivity on the part of scholars. We suspect that we find more value in reflexivity and analytic unsettling than does Sayer. Still, we have felt the need to explicitly encourage contributors to delve into normative questions about the social practices they have researched. Critiques of scientific rationalism, essentialism, progress, and other master narratives were extremely important for tempering and calling into question the hidden standpoints, biases, and lacunae of early critical social science projects. However, in our experience, some of the ways such critiques have been taught appear to have helped produce scholars who, while adept at calling into question the limitations of others' perspectives, are far less able or willing to articulate their own position on matters of the day.

Of course, the very collocation "social science" invokes a variety of different disciplines, including, but not limited to, sociology, political science, geography, and anthropology. While the contributors to this volume draw on a number of related social science traditions, sociology remains a common reference point for many of them. This is not to say that all contributors strictly limit themselves to sociological theories and methods. Rather, it is to underline that their engagement with the idea of critical social science takes place, in large part, in dialogue with debates in sociology. The iterative process in which the book chapters were created, outlined in more detail below, has invited contributors to engage with sociological reflections on the concept and practice of "the critical."[4]

Building on Organizational and Discursive Interventions

The approach to critical social science research that we have encouraged in this volume builds on earlier national and international efforts to articulate and express a critical social science perspective on health and on HIV/AIDS. In Canadian scholarship, an important watershed moment was the development of a critical social science in health perspective in the mid-1990s by Joan Eakin, David Coburn, Blake Poland, Ann Robertson, and other social scientists working out of the Department of Behavioural Science at the University of Toronto. They describe a critical social science perspective as a reflexive stance that poses questions about power relations, contradictions, and the dialectical relationship between individual action and structural forces in all areas of the research process (Eakin et al. 1996). They further argue that its value lies in exposing the political dimensions of authoritative research in ways that make it possible to envision alternative realities and ways of knowing that challenge the status quo. The collaborative work of Eakin and colleagues draws on a critical social science perspective to critique the displacement of health promotion by emerging population health frameworks (Robertson 1998). They critique population health for its mistrust of social theory and over-commitment to empiricist quantitative epidemiology and enlist the political economy tradition to express an alternative perspective that emphasizes how the social determinants of health of groups of people are structured by advanced industrial capitalism (Poland et al. 1998).

The designation of a critical social science perspective in health promotion and population health research by the University of Toronto group offered social scientists working on HIV in Canada an important example of the value of putting a name to scholarly work that questions and articulates alternatives to established approaches to researching health phenomena. In 2008, a group of Ontario social scientists came together to make a similar move with respect to research on HIV. With support from the OHTN, they met to share experiences and concerns about funding and work conditions faced by social scientists conducting HIV research. A report summarizing the proceedings and making recommendations for change coined the term critical social science research on HIV and expressed a shared conception of its key features (Mykhalovskiy and Cain 2008). This edited volume is a response to one of the key recommendations made by the report – to create opportunities for publishing scholarly work on HIV that emphasizes critical approaches to social science research. The orientation to critical social science that we have encouraged is partly informed by the approach taken by this report. We have been particularly influenced by its emphasis on producing research for progressive social transformation and on reflexively exploring how the experiences of researchers and research participants are shaped by broad social, political, cultural, and economic forces.

Two more recent interventions in the form of meetings and meeting reports have further informed the development of this edited volume. In the first of these, a group comprising researchers, people living with HIV, health and social service providers, and activists met in Montreal in 2012 to participate in a one-day meeting entitled New Directions for Critical Perspectives on HIV and AIDS, which was organized by Marilou Gagnon and colleagues (2013). The purpose of the meeting was to reinvigorate critical social science and humanities research on HIV by encouraging new networks among participants and by sharing emerging research and its relationship to intervention, policy, and research trends. New Directions for Critical Perspectives on HIV and AIDS was an important meeting that signalled a growing interest in critical perspectives on the part of a new generation of emerging HIV researchers in Canada, a number of whom were invited to contribute to this collection.

The second meeting was entitled "Beyond Failure: Thinking Critically about HIV Prevention, Research, and Services" and was held in Montreal in the spring of 2013.[5] The meeting, which brought together many of the participants in this volume as well as scholars, researchers, and front-line workers in HIV/AIDS, sought to provide an occasion for deep reflection on the very notion and idea of failure. The current orientation of research funding in HIV/AIDS, in particular, requires researchers to claim that their work will positively impact the HIV/AIDS industry and ultimately reduce new HIV infections in Canada. While such a goal can have tremendous benefit, it precludes deep analysis of what has not worked at the level of research, policy, and programming. The idea behind this symposium, then, was to provide an occasion for sustained engagement with moments of failure in the HIV/AIDS industry in order to think about failure as being productive for learning and future action.

Finally, this volume has been inspired by the vision of critical, theoretically informed social science scholarship promoted by the international organization, the Association for Social Sciences and Humanities in HIV (ASSHH). ASSHH was created in 2011 by a group of social scientists in response to the ongoing marginalization of social science and humanities research by the International AIDS Society and its conference programs. During its six-year existence, ASSHH supported and promoted critically informed and theoretically engaged social science and humanities research on HIV at the global level. It realized this commitment by organizing the first global HIV conferences committed to social sciences and humanities research in 2011 (Durban), 2013 (Paris), and 2015 (Stellenbosch). ASSHH conferences were attended by hundreds of social science and humanities scholars from around the world and generated an unprecedented interest in critical social science research on HIV at the global level. The networks of scholars that were formed through ASSHH, and the ongoing research that its members are producing, form important scholarly contexts for the contributions in this collection.[6]

To help build a coherent collection, the contributors to this book participated in two meetings. At our first meeting, held in Montreal in 2015, participants shared emerging understandings of critical social science and collectively explored what connects and distinguishes us as social scientists, including our substantive areas of interest, theoretical influences, and methodological and political commitments. At the second meeting, held in Toronto in 2016, contributors presented draft chapters that were pre-circulated to participants. With a view to realizing a collective vision for the collection, participants received feedback on their chapters and discussed the relationship between the individual trajectories of their analyses and arguments as well as the methodological and epistemological foci of their work.

Structure of the Book

Our edited volume is divided into two sections: “Critical Dispositions” and “Empirical Case Studies.” We use the term critical dispositions to name theoretical perspectives, methodological approaches, and traditions of inquiry that can be enlisted in critical social science research on HIV/AIDS. The first section of the book addresses five such dispositions: studies in governmentality, actor-network theory, institutional ethnography (IE), conversational analysis, and Indigenous methodologies. As we have already noted, this list includes perspectives that are at some distance from the established traditions of critical social science research as well as perspectives more typically associated with such work. Contributors to this section describe how a given tradition of research formulates versions of critical inquiry and constructs problem spaces for investigation. They outline the questions that animate the fields they examine and introduce readers to relevant concepts, terminologies, and concerns of the dispositions they take up. Contributors also explore the possibilities, limitations, and challenges associated with making use of a given critical disposition in HIV/AIDS research, often by discussing particular empirical research topics. Finally, contributors to this section make arguments about how particular traditions of inquiry can move social science research on HIV/AIDS in novel empirical and analytical directions. Overall, the chapters in this section foreground questions about the relevance, impact, and limits of different frameworks for understanding the HIV/AIDS epidemic and, thus, for engaging with it in practical terms. We encourage readers to approach these chapters as an opportunity to learn more about particular theoretical traditions of critical social science inquiry and what they can offer to critical research on HIV/AIDS. The chapters in this section are not simple applications of a given critical disposition to an empirical site. Instead, they are occasions for considering different kinds of knowledge frameworks for making sense of HIV/AIDS more broadly.

Adrian Guta and Stuart Murray introduce readers to Michel Foucault's work and to studies in governmentality. They review Foucault's various discussions of governmentality and explore how social scientists have used the concept to problematize the relationship between power and knowledge in health care and in the HIV sphere. Drawing on a "critical analytics of governmentality," and its particular concern for the organization of governance at the level of the population, they turn their attention to the widespread and zealous implementation of treatment as prevention (TasP) and its associated monitoring technology, the HIV care cascade. They interrogate the conditions of possibility for the uptake of TasP. They also call attention to a host of potential power effects associated with the forms of biomedical, virological, public health, and epidemiological knowledge being produced by the unprecedented monitoring of people through the stages of the HIV cascade. Overall, they demonstrate how a governmentality perspective can direct researchers to critically examine the power-knowledge relations through which the HIV/AIDS epidemic is governed and rethink our assumptions about what is needed to effectively intervene.

Martin French's chapter explores the critical potentialities of a perspective with an ambiguous relationship to critical social science: actor-network theory (ANT). In his discussion of ANT, French reflects on how the question of technology has been addressed in critical social scientific accounts of HIV/AIDS. He identifies a tendency in these accounts to underplay important technical details, favouring instead modes of analysis that foreground social-structural factors. While critical social science accounts have made important contributions by illuminating the broader social context of technologies, more remains to be said about the assemblage of technical artifacts that helps to materialize and govern HIV in bodies and populations. To make this argument, French provides an introductory discussion of ANT, a framework that devotes empirical attention to the way material realities are constructed, to the role of non-humans (thereby decentring human actors), and to the contingencies of enactment that yield unanticipated, or controversial, sites of inquiry. Using the example of a mobile phone application designed in the United States to help users manage their pill consumption regimes – Every Dose, Every Day (E2D2) – French also considers both what ANT can bring to the critical social science table and its limitations as a critical social science strategy. Taking us into a realm of theoretical inquiry that would not "normally" be associated with critical studies on HIV/AIDS, he invites us to suspend our taken-for-granted ideas of what counts, *a priori,* as critical inquiry.

Daniel Grace's chapter focuses on an approach to sociological inquiry that has received considerable attention in Canadian social science research on HIV – Dorothy Smith's approach to studies in the social organization of knowledge and IE. Grace takes the novel step of basing his discussion on interviews he conducted with social scientists who have used IE in their research on HIV. He offers a discussion of the particular approach IE offers for the critical investigation of "ruling relations" and traces the strong links between IE and Canadian HIV/AIDS activism. He also reviews HIV research based on IE with a particular emphasis on critical studies of the social organization of access to HIV treatment and social and health services. Grace encourages us to think about IE not in isolation but, rather, in dialogue with other traditions of critical inquiry. He makes a plea for scholars not to oppose IE, *a priori,* against more applied forms of health research. Instead, he suggests that IE can help rearticulate and recalibrate some of the ways in which more mainstream public health research is conceptualized and operationalized.

Jeffrey Aguinaldo provides another example of a tradition of inquiry not typically associated with critical social science or with the study of HIV – conversational analysis (CA). In his chapter, Aguinaldo provides an overview of key features of CA, including its careful attention to the content of talk and how it is delivered in naturally occurring interaction. He also reviews debates about the potential for CA to contribute to scholarship that is explicitly political and raises important questions about our assumptions about the relationship between critical social science and the analytic and methodological approaches used to realize its goals. As a scholar with an interest in critical social science on HIV/AIDS, Aguinaldo argues that CA's commitment to political neutrality does not negate its potential contribution to critical social science research. To support his argument, he produces a discussion of HIV stigma based on a CA analysis of HIV-positive disclosures. Aguinaldo cautions us not to ignore the micrological in research on HIV/AIDS and encourages us to question our assumptions about the content, theories, and methods of critical social science.

Finally, Randy Jackson's chapter offers important insights about the relationship between Indigenous knowing and critical social science research on HIV. Drawing on his experiences as an Indigenous scholar on a range of HIV research projects, he produces a reflexive narrative about how he continues to negotiate tensions at the interface of colonialism, Western science, critical social science, Indigenous world views, and decolonizing methods. Jackson describes his move from community-based participatory research methods to ways of creating knowledge that more actively integrate Indigenous perspectives by incorporating Indigenous traditions of storytelling and traditional teachings about the medicine wheel into his research process. Through a strong critique of the Western objectification of Indigenous people and the appropriation of Indigenous knowledge, Jackson underscores the need to produce knowledge differently. One provisional response he explores is the use of two-eyed seeing to weave Indigenous and Western approaches while avoiding "the pull towards sole use of Western theoretical foundations" (Jackson, in this volume).

The second section of this collection, "Empirical Case Studies," offers readers examples of original critical social science research on HIV/AIDS written from different theoretical and methodological traditions across a range of empirical sites. The chapters explore issues at the forefront of contemporary debates about HIV/AIDS, including HIV prevention and syndemics, treatment optimism, HIV PrEP, community-based HIV work, HIV criminalization, public health emergencies, and the epidemiological construction of HIV. Collectively, they direct attention to forms of biomedical, public health, and policy knowledge that limit our ability to respond to the medical, social, and political challenges posed by HIV/AIDS and that aggravate or sustain relations of inequality, discrimination, and marginalization. In their respective chapters, authors report on their empirical findings and suggest how their research offers a critical analysis of the topics under study. Rather than simply finding fault with current arrangements, they demonstrate how critical social science perspectives can contribute to better meeting the needs of people living with, and affected by, HIV/AIDS. As case studies, these chapters engage with theoretical and methodological debates in writing that emphasizes the authors' original empirical contributions to research on HIV/AIDS. Rather than posing questions about the strengths, limits, and possibilities of a given critical disposition for HIV/AIDS research – the focus of the first section of this book – the chapters in this section apply particular theoretical and methodological perspectives to a given empirical site.

In his chapter on HIV prevention for gay and bisexual men, Barry Adam forcefully addresses the question of how critical social science can contribute to efforts to prevent HIV transmission. Adam takes issue with how "social" interventions, focused on individual risks and behaviour change as well as the growing emphasis on biomedical prevention, bypass broader structural relations that drive vulnerability to HIV. Adam invites us to consider how research that fails to consider structural issues discourages critical scrutiny of agenda and policy setting by powerful actors in the pharmaceutical, health services, and public health sectors. In an effort to move past the "biomedical individualism" and epidemiological reductionism characteristic of the mainstream HIV-prevention landscape, Adam turns to the concept of syndemics. He draws on American and Canadian literatures, as well as his own research on men newly diagnosed with HIV, to produce what he describes as an "experience-near" view of how syndemics shape gay and bisexual men's sexual and risk practices. Adam's analysis shows how a critical social science perspective can ground the psychosocial problems that are a characteristic focus of syndemics research in their broader cultural, political, and socio-economic contexts. He demonstrates how interventions from critical social science can help to refocus what it means to do applied HIV-prevention research.

Mark Gaspar offers a fine-grained empirically based critique of HIV prevention that echoes the concerns raised by Adam. Gaspar considers the focal point of his critique to be the epidemiological concept of treatment optimism. Treatment optimism has been used to suggest that gay men who believe in the prevention benefits of antiretroviral treatment are more likely to engage in sexual risk-taking. Gaspar offers an internal critique of the discourse of treatment optimism and a discussion of its foundational presence in HIV prevention, despite a slim evidentiary base. Like Adam, Gaspar's research demonstrates how a critical social science perspective can fundamentally reorient our understanding of what constitutes a sound empirical basis for HIV-prevention strategies. Using IE and other conceptual resources, he questions the relevance of treatment optimism and calls into question its reliance on narrow behavioural and psychosocial measures of gay men who engage in unprotected anal intercourse. Drawing on his interview research with young HIV-negative gay men, he offers a counter-perspective that offers a deeper and more complex understanding of how gay men make sense of biomedical innovations and respond to them through their sexual practices.

Chris Sanders, Jill Owczarzak, and Andrew Petroll extend the critical social science discussion of biomedical prevention through a focus on PrEP. Drawing on Bent Flyvbjerg's (2001) phronetic case-study approach, they examine the organization and delivery of PrEP services at an inner-city US health clinic. Their chapter raises important questions about the population-level use of antiretroviral medications as a biomedical technology for HIV prevention among a group of clinic users who are primarily young African American gay and bisexual men. The authors document how this prevention work is conceptualized and operationalized. But, more than simply telling us about how prevention is currently organized biomedically, they raise fundamental questions about the allure of the pharmaceuticalization of HIV prevention, given the complex and tense historical relationship between biomedical experimentation and service delivery and processes of racialization. Drawing on their research insights, they consider whether the use of pharmaceutical drugs as a solution to high rates of HIV in some inner-city US communities might, in fact, obscure some of the structural factors that explain how and why racialized people living in these communities become HIV positive.

In recent years, HIV criminalization has emerged as one of the most significant political issues facing the global HIV/AIDS movement. Canada is routinely identified as a world leader in prosecuting people living with HIV for not disclosing their HIV status to their sexual partners. Colin Hastings's chapter offers an analysis of how some community-based HIV/AIDS organizations in the Toronto area respond to HIV criminalization. He stages a comparative consideration of the relative merits of IE and studies in governmentality for exploring community-based responses to HIV criminalization. Hastings argues that, while studies in governmentality attend primarily to the reasoning and techniques of community-based responses, IE requires the social scientist to map how community organizers' interventions are coordinated by, and hooked into, broader social relations such as the criminal law. Hastings's chapter extends IE's characteristic critique of objectifying managerial discourses to the site of community work. He further suggests how IE can provide social scientists with the basis for reflexive, critical dialogue with community organizers. In doing so, he exemplifies a form of social science inquiry that can facilitate critical reflection not only among scholars but also among community organizers.

Finally, Denielle Elliott's chapter extends this volume's critical discussion of HIV, epidemiological knowledge, and public health through an analysis focused on the declaration of a public health emergency in Vancouver's Downtown Eastside in 1997. Drawing inspiration from the critical ethnographies of Didier Fassin and other medical anthropologists, Elliott examines the framing of public health emergency as "discursive practice and political action" (Elliott, in this volume). She traces connections between risk-factor epidemiology, study results about deaths related to heroin overdoses and HIV, the mainstream media's representation of such research evidence, and the public and professional understandings of the Downtown Eastside as a diseased and drug-addicted space. Elliott examines how the declaration enlisted a host of biomedical technologies for governing the poor and fuelled a disconnect between representations of the Downtown Eastside and the lived realities of its community members. A particular concern she raises is the foreclosure of clinical care for Indigenous women and men living in the Downtown Eastside who have become overcoded as drug-using people living with HIV. At a time of growing concern about dramatic increases in opioid-related deaths, Elliott's chapter offers an important cautionary note about the knowledge politics and unintended consequences of declaring public health emergencies.

Conclusion

This volume intervenes in what we know about HIV/AIDS. It reinvigorates a tradition of critical social science research, the significance of which has been challenged by the forms of research, policy, funding, pharmaceutical technologies, biomedicalized HIV prevention, and other contributing relations that organize mainstream responses to the epidemic. This book does not offer a monolithic account of what constitutes critical social science research on HIV/AIDS. While we have encouraged contributors to navigate analytic tensions associated with negative critique and normative claims-making, we have not tightly policed the boundaries of critical scholarship. We understand critical social science research on HIV/AIDS to be an open terrain. In our view, it encompasses a range of theoretico-empirical social science inquiries that challenges authoritative epidemiological and behavioural science ways of knowing, critiques established approaches to managing the HIV/AIDS epidemic, and creates knowledge that aims to help end the forms of inequality, oppression, and stigmatization that drive the epidemic.

To produce this anthology, we brought together a group of Canadian social scientists and invited them to contemplate and write about what makes their work critical. We asked them to demonstrate what is useful about reflecting on the "critical" in critical social science research, what it means for their approaches to investigating their substantive areas, and how it can contribute to the types of interventions into the epidemic that can be imagined. Their responses, organized in terms of critical dispositions and empirical case studies, traverse a range of theoretical perspectives, methodological approaches, and substantive areas of inquiry. We prepared this volume with different audiences in mind. Most obviously, we hope it speaks to social scientists in Canada and beyond who do research on HIV, including those who are well versed in critical approaches to inquiry and those for whom the book's contents may pose a novel enticement. We also hope social scientists who study health and health care, but do not specialize in HIV research, may find the book of interest. The discursive and institutional constraints on critical, theoretically informed inquiry identified in this book are not unique to the field of HIV. As such, the critical response this book makes to those constraints may be of interest to non-specialists. Of course, it is also the case that many of the issues explored in the volume – the nature of critical social science inquiry, the similarities and distinctions between different traditions of critical social science research, how those traditions shape particular objects of knowledge, and the connection between research and social transformation, for example – are of potential interest to any social scientist with a critical imagination.

We also hope this collection will speak to our colleagues in public health, the community sector, and other areas of direct response to the HIV/AIDS epidemic. This book seeks to change mainstream ways of thinking about, researching, and responding to HIV. Public health scholars and community-based researchers may find the volume useful for considering how to engage social science inquiry when carrying out research that traverses theoretical and applied relevancies. They will also find a unique invitation to consider how reflecting on the critical is relevant for public health and clinical practice. Readers who are located in the community-based HIV/AIDS services sector might read the chapters in this book in a spirit of discovery and learning. Critical social science research questions taken-for-granted ways of knowing, and, therefore, of acting, in relation to the HIV/AIDS epidemic. This anthology invites community workers to think about different ways of organizing services, articulating policy, and mobilizing communities. This book's primary interlocutors are social scientists. However, epidemiologists, implementation scientists, community workers, and research managers might use the book to consider how we all create knowledge about HIV/AIDS and what forms of intervention and engagement can be opened up when we begin to create knowledge differently.

In no sense is this book the final word on critical social science and HIV/AIDS. It does not include all possible versions of critical social science research, nor does it address all topics of interest or all of the affected communities. In setting out to create this anthology, we did not privilege certain theoretical and political perspectives that are currently popular in the HIV sector such as intersectionality and the politics of identity. We did not begin with the *a priori* assumption that an anthology devoted to critical social science research on HIV must address questions that relate to specific communities or identities such as racialized people, immigrants, or trans women. While not denying the importance of attending to those questions, as we have stated, our approach was to encourage contributors to consider what the critical in critical social science research means in their work. The Canadian community of social scientists invested in the concept and practice of critical social science is not boundless. Among those included in this volume, we find more research attention paid to gay and bisexual men than to other communities. We look forward to critical and other responses to this collection and, of course, to the novel and unanticipated work in this area that this volume might stimulate.

Our volume includes a short conclusion. Rather than reiterating the arguments of individual chapters, we use the conclusion to reflect on how this volume offers a new knowledge response to HIV/AIDS. We invite reflection on what robust engagement with critical social science can offer to our collective response to the epidemic. In the conclusion, we also take the opportunity to inquire where the field of critical social science research on HIV/AIDS needs to go.

We hope this book helps to reinforce a specifically critical orientation to social science research on the HIV/AIDS epidemic. We hope that the empirical case studies and discussions of critical dispositions that it offers contribute to a collective dialogue about the nature of critical social science engagement with HIV/AIDS and the spaces of understanding, complexity, and intervention it promises. Most of all, we hope this collection encourages researchers and scholars to think deeply and carefully about how we produce knowledge about HIV/AIDS and why doing so matters for the responses to the epidemic that are proposed. Critical social science is deeply implicated in the history of scholarship on HIV/AIDS. This volume seeks to extend that tradition and to ensure that our current response to the HIV/AIDS epidemic includes a robust consideration of critical social science traditions.

Notes

1 The Undetectable = Untransmittable (U=U) campaign is a global effort to transform how people understand and respond to HIV/AIDS. U=U is a health equity initiative that seeks to improve the lives of people living with HIV/AIDS, end HIV-related fear and stigma, and advance efforts to stop the HIV epidemic (https://www.preventionaccess.org/).

2 The contributors to the volume also include a humanist, Stuart Murray, and two Americans, Jill Owczarzak and Andrew Petroll.

3 For an indication of the Ontario HIV Treatment Network's commitment to implementation science in its funding see http://www.ohtn.on.ca/research-and-funding/reach-2-0/.

4 Key authors here included Boltanski 2011; Eakin et al. 1996; Fay 1987; Flyvbjerg 2001; Sayer 1997, 2009; and D.E. Smith 1987, 1999.

5 Beyond Failure: Thinking Critically about HIV Prevention, Research, and Services, http://beyondfailure.org/.

6 The papers presented at the conferences of the Association for Social Sciences and Humanities in HIV and the broader scholarly and interdisciplinary dialogues stimulated by the meetings have resulted in a wide range of critical social science publications on HIV. A small sample includes work on HIV criminalization (Dodds et al. 2015; Hoppe 2014, 2017; Race 2012; Rosengarten 2016); HIV disclosure (Kilty and Orsini 2017); online dating and gay men's sexual cultures (Race 2015); pre-exposure prophylaxis and gay men's sexuality (Dowsett 2017); failure and HIV research (Kingori and Sariola 2015); biomedical HIV prevention (Keogh and Dodds 2015; Persson 2015; Race 2016); behavioural surveillance (Holt 2013); epistemic communities and HIV risk reduction (Holt 2014); and HIV and pharmaceutical citizenship (Persson 2016).

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PART 1

Critical Dispositions

1

On the Possibility of Being Governed Otherwise

Exploring Foucault's Legacy for Critical Social Science Studies in the Field of HIV/AIDS

Adrian Guta and Stuart J. Murray

The prominent French intellectual Michel Foucault died in 1984 from AIDS-related complications, leaving strict instructions for "no posthumous publications" to be produced from his archives (McLemee 2015). Despite Foucault's final appeal, in the decades since his death few scholars have been as "productive"; there have been significant contributions in the form of previously unpublished lectures, interviews, and public talks (see, for example, Foucault 2013, 2014c). Each new publication has been followed by attempts to make sense, again, of Foucault's legacy and how this work might be applied in new and emerging fields of research (see, for example, Davidson 1997; Faubion 2014; Prado 2011). In this chapter, we attempt to situate Foucault's legacy for critical social science studies in the field of HIV/AIDS. As two scholars working in different interdisciplines – one with training in social work and public health, the other in ethical and rhetorical studies – we approach Foucault's work with distinct interests but with a shared sense of its continued importance and critical value. Previously, our respective interests have converged in work related to advancements in HIV care, treatment, and prevention (Guta, Murray, and Gagnon 2016; Guta, Murray, and McClelland 2011) and in community engagement in HIV/AIDS research (Guta et al. 2014, 2016). Together, we reflect the relationship between the humanities and critical social sciences that Foucault's work has inspired. In many respects, Foucault's legacy has yet to be written because it is ongoing; scholars continue to respond to his work, much of it published posthumously, and they do so from within rapidly evolving socio-political contexts, in relation to new technologies and the emergent subjectivities that they inculcate. For example, what many earlier commentators perceived as hyperbole in Foucault's writings about governance, regulation, discipline, and surveillance now strikes us in many ways as prescient, if not prophetic. Our overview of Foucault's legacy, then, is both specific and necessarily incomplete; it points the way to further Foucauldian studies on HIV/AIDS and on the many intersecting responses to the epidemic – ethical, social, cultural, political, medical, pharmacological, and legal, to name just a few.

In the study of HIV/AIDS, Foucault's analytic techniques have been adapted by scholars working in the medical humanities and social and health sciences to examine how HIV has been understood by diverse actors along the spectrum from prevention to treatment and care (Elbe 2005; Ingram 2010; Mykhalovskiy, McCoy, and Bresalier 2004; Nguyen 2009). In this chapter, we explore Foucault's (2000) extended historical examination of how power has been exercised by the state through various techniques, strategies, and institutions and its broad effects on individuals and populations. We start with an overview of governmentality (or "the conduct of conduct") and consider how this analytic concept has been taken up by proponents and critics alike, with attention to its ambiguous relationship to advancing a critical politics of freedom. We then explore how key scholars working in the social sciences have used governmentality to analyze HIV-related practices, policies, guidelines, and interventions since the emergence of the epidemic. Here, governmentality has been successfully used across disciplines and applied to different contexts to raise challenging questions about power and knowledge in the global HIV/AIDS response. Next, we offer an example of governmentality studies in action by exploring the recent shift in clinical and public health practice toward adopting the logic of HIV "treatment as prevention" (TasP). TasP is a seductively simple intervention that is understood to advance treatment for people living with HIV and to create shared benefits for society. As we will elaborate, governmentality invites us to understand problems and their solutions to health issues by thinking beyond the scripts, tools, and evidence offered by biomedicine and public health. Specifically, we will take on what has been termed the HIV "cascade of care" as an important articulation of TasP to read multiple intersecting forms of discipline, control, resistance, and subjectivation (*assujettissement*). Here, a Foucauldian analysis is useful for critically interrogating both the emergence of a field of knowledge, its framing and focus, and its implication for public health interventions, clinical guidelines, and the everyday lived realities of people living with HIV/AIDS. The chapter ends with a reflection on Foucault's (2001) use of the ancient Greek concept of *parrhesia* (free speech) and its critical political importance given the implicit (and sometimes explicit) constraints on dissent within the current HIV/AIDS response.

Foucault and the Critical Tradition

Drawing on the Kantian tradition, and inspired by Friedrich Nietzsche, Foucault (2007a, 46–47) described critique as "the movement by which the subject gives himself [*sic*] the right to question truth on its effects of power and question power on its discourses of truth." Critique, then, is an act of "insubordination" and "desubjugation" (*désassujettissement*), the method by which the subject enacts a critical distance from those norms by which that subject is formed as socially recognizable and intelligible, to him- or herself as well as to others (see Daniel Grace in this volume for how others locate their work within a critical tradition). Specifically, the critical endeavour is a normative commitment to understand the subject's position within the nexus of governmentality, power/knowledge, and ethics (see Butler 2002). Elsewhere, Foucault (2010, 21) elaborated on his position and situated himself within a critical tradition, saying:

> It seems to me that the philosophical choice confronting us today is the following. We have to opt either for a critical philosophy which appears as an analytical philosophy of truth in general, or for a critical thought which takes the form of an ontology of ourselves, of present reality. It is this latter form of philosophy which, from Hegel to the Frankfurt school, passing through Nietzsche, Max Weber and so on, has founded a form of reflection to which of course, I link myself insofar as I can.

Foucault is most associated with the poststructuralist tradition, which, although comprising different theories, is united in its interest to challenge dominant hierarchies, ideologies, and epistemologies – systems of meaning that make sense of social practices, subjectivities, and perceived truths (Agger 1991; Newman 2005). According to Joan Scott (2001, 255), poststructuralism is an anti-foundationalist approach that attends to language and meaning making: “A starting point for understanding how social relations are conceived, and therefore – because understanding how they are conceived means understanding how they work – how institutions are organized, how relations of production are experienced, and how collective identity is established.” Poststructuralist critiques diversely demonstrate how those structures that govern our social worlds are themselves products of cultural beliefs and practices; in other words, these structures are contingent, socially and historically situated, and provisional rather than foundational. Despite – or, indeed, by virtue of – this critical impetus, Foucault explicitly refused to propose a “better” way of structuring the systems and processes he critiqued for fear that his recommendations would result in new systems of domination. Nevertheless, Foucault actively participated in political resistance movements and publicly advocated for labour, mental health, and prison reform (Cooper and Blair 2002). Foucault’s work therefore has important implications for advancing social change while also helping us to better understand the conditions of possibility for that change (Schaff 2002; Sinnerbrink, Deranty, and Smith 2005).

As we have noted earlier, our engagement with Foucault is interdisciplinary and open to a plurality of interpretations of his work. Our approach to the critique used in this chapter, as it aligns with Foucault's, will make some readers uncomfortable because of its lack of specificity. For Foucault (2000, 456), "a critique does not consist in saying that things aren't good the way they are. It consists in seeing on just what type of assumptions, of familiar notions, of established and unexamined ways of thinking the accepted practices are based ... To do criticism is to make harder those acts which are now too easy." Such an attitude to critique is premised on an "ethic of discomfort," through which Foucault (2007a, 144) encouraged others to "never consent to be completely comfortable with your own certainties ... [and] remember that, in order to give them an indispensable mobility, one must see far, but also close-up and right around oneself." This leads us to see actions and interventions by the state and its institutions, especially those promoted as neutral or benevolent, as potentially dangerous and requiring "hyper-pessimistic activism" to prevent them from becoming technologies of domination (Foucault 1997, 256).

Foucault on Governmentality

Foucault's (1994) self-described theoretical "tool box" offers a range of techniques for problematizing the relationship between power and knowledge in historical and contemporary social relations, institutions, and systems. Foucault is especially well known for his seminal writings about madness (1965), medicine (1973), discipline (1977), and sexuality (1978). More recently, his posthumous publications, including a series of lectures delivered at the Collège de France between 1970 and 1984, have offered new insights and "tools" for the critical scholar. The Collège de France lectures explored issues ranging from the history of penology and psychiatry to the role of truth-telling in the formation of the modern subject and forms of ethical resistance. They have been credited with filling important gaps in Foucault's published monographs and have instigated much discussion and debate.[1] Most relevant to the discussion in this chapter are Foucault's (2007b, 108) reflections during the 1977–78 lecture series entitled *Security, Territory, Population,* in which he describes "governmentality" as follows:

> The ensemble formed by institutions, procedures, analyses and reflections, calculations, and tactics that allow the exercise of this very specific, albeit very complex, power that has the population as its target, political economy as its major form of knowledge, and apparatuses of security as its essential technical instrument.

This particular lecture on governmentality has been significant because it was one of the earliest to be translated into English (Foucault 1991). However, before describing how governmentality has been taken up in the social and health sciences, and in HIV specifically, we will give a brief overview of the evolution of "governmentality" in Foucault's writings and lectures. In the 1978–79 lectures titled *The Birth of Biopolitics,* Foucault (2008) elaborated on his earlier definition and traced the relationship between the emergence of (neo)liberal political theory (as taken up in Germany and the United States), the emergence of population(s) as "massified" bodies in need of regulation, and the invention of *homo oeconomicus* (the autonomous, rational, and entrepreneurial subject), who is compelled to maximize his or her productive potential as "human capital." During the 1979–80 lecture series entitled *On the Government of the Living,* Foucault (2014a, 13) turned his attention to the relationship between the subject and "government by the truth," claiming that "the art of government and, let's say, the game of truth are not independent of each other and that one cannot govern without, in one way or another, entering into the game of truth." Foucault was highlighting the role of truth claims within modernist projects of governance where the use of scientific evidence supposedly connotes neutrality and objectivity outside the bounds of power and strategy – where the evidence, we are told, "speaks for itself." Earlier in his career, Foucault (1973) had discussed how individual professions such as medicine gain power through their relationship to formally sanctioned knowledge, which determines what can be known and seen within the body. In the current period, we extend this to the growth of evidence-based medicine (Holmes et al. 2006) and evidence-based policy development (Marston and Watts 2003), which have been critiqued for ignoring power.

Although Foucault's 1980–81 lecture series *Subjectivité et vérité* (2014b) has not yet been translated into English, he delivered several lectures during this period that have been translated and that return to the relationships between the subject, truth, and governance (Foucault 2014c, 2015). During a series of lectures delivered at the Catholic University of Louvain concerning the function of avowal in justice, Foucault (2014c, 240) articulated a definition of governmentality firmly rooted in material conditions:

> Society can be governed, a group can be governed, a community can be governed, a family can be governed, someone can be governed. And when I say "govern someone," it is simply in the sense of determining their conduct on the basis of strategies, using a certain number of tactics … it is governmentality in its broadest sense, understood as the set of relations of power and techniques that allow these power relations to be exercised – this is what I have tried to study. How have we governed the mad? How did we pose the problem of governing the sick? And once again, I put forward "government" in quotation marks, giving it once a vast and rich meaning – how did we govern the sick; what was done with them; what status did we give them; where did we put them, in what system of treatment, or surveillance, of caretaking, of philanthropy; in what economic field was care brought to the sick … I think that all of this should be explored.

In the 1981–82 lectures titled *The Hermeneutics of the Subject,* Foucault (2005, 252) turned to questions of ethics and historical modes of governing the self and others. Here, he frames his wider project in the following way:

> In the type of analysis I have been trying to advance for some time you can see that power relations, governmentality, the government of the self and of others, and the relationship of self to self constitute a chain, a thread, and I think it is around these notions that we should be able to connect together the question of politics and the question of ethics.

Central to this understanding of ethics is the notion of *parrhesia,* which Foucault borrows from antiquity and translates as "frankness" or "free speech" and a "principle of how one should conduct oneself verbally with the other in the practice of spiritual direction" (164). This interest continues in the 1982–83 lectures titled *The Government of Self and Others,* in which Foucault (2011b, 69) offered a "history of the discourse of governmentality," arguing that, "with *parrésia* [*sic*] we have a notion which is situated at the meeting point of the obligation to speak the truth, procedures and techniques of governmentality, and the constitution of the relationship to self." In these lectures Foucault spoke less of governmentality and, instead, focused on how subjects emerge within verbal or rhetorical relations of governmentality, saying, "in posing the question of the government of self and others, I would like to try to see how truth-telling (*dire-vrai*), the obligation and possibility of telling the truth in procedures of government can show how the individual is constituted as subject in the relationship to self and the relationship to others" (42). In his final 1983–84 lectures titled *The Courage of Truth,* Foucault (2011a, 8) examined the way courageous forms of truth-telling associated with *parrhesia* were articulated by the Cynics and, eventually, in the Christian tradition's fixation on "truth." The significance of Foucault's particular approach to the analysis of power is difficult to measure, except to say that it has now influenced several generations of scholars across diverse fields and has even spawned what has been termed "governmentality studies."

Governmentality Studies

In the decades since his death, Foucault's work has had considerable impact in the humanities and social sciences (Lloyd and Thacker 1997), with highly influential applications to the social study of health (Bunton and Petersen 2002). Beyond health, Foucault's work has been taken up by political scientists, sociologists, psychologists, geographers, and anthropologists. Scholars working in diverse traditions have used Foucault's ideas to advance critical perspectives concerning social issues and have turned inward to examine the logic of their own disciplines and the kinds of evidence they produce. This particular style of engagement with Foucault's work may be attributed in part to sociologist Nikolas Rose and anthropologist Paul Rabinow who made Foucault's writings widely available to an anglophone readership (Foucault 2003a). Of significance has been governmentality, as advanced by Rose (1999, 2007), Peter Miller (2008), and Mitchell Dean (2010a) who, along with others, have taken up Foucault's early interest in neoliberal forms of governance, the emergence of *homo oeconomicus,* and technologies for the administration of life. Most influentially perhaps, Miller and Rose (2008) collaborated on *Governing the Present: Administering Economic, Social and Personal Life* and extended Foucault's historical discussion of governmentality to the contemporary neoliberal divestment of social care and the emergence of new subjectivities and organizing based on risk, responsibility, commodification, and community. In the Canadian context, Foucault's work on governmentality and beyond has been mobilized by sociologists and criminologists (O'Malley, Weir, and Shearing 1997; Rose and Valverde 1998; Weir 2006). Through what has been termed "governmentality studies" (Binkley 2007), Foucauldian interpretations have been further advanced in studies of medicine (Waring 2007), nursing (Holmes and Gastaldo 2002), public health (Petersen and Bunton 1997), criminology (Garland 1997), education (Peters 2002), social work (Pollack 2010), international development (Larner and Walters 2004), and countless other fields.

Together, these works offer a critical intervention into dominant discourses that "naturalize" and "normalize" the medical, social, and material conditions of people's lives and that help to make visible other ways of thinking and experiencing reality than are usually offered in official discourses. They invite readers to ask questions about how the subject is imagined within various systems, what rules are in place to encourage acceptable conduct, and to what ends. When focused on practitioners (for example, social workers), this scholarship challenges them to think about their practices and how they themselves are implicated in relations of governance, simultaneously governing the poor and sick while themselves being governed through organizational rules and policies (Chambon 1999). Furthermore, these studies ask readers to think across the home, school, hospital, prison, and other socio-institutional and cultural settings in order to identify relationships between different sites and strategies for governing populations and regulating the conduct of conduct.

Governmentality and Critical HIV Studies

To apply Foucault's (2011b, 3) terms, HIV constitutes a "focal point of experience" "in which forms of a possible knowledge (*savoir*), normative frameworks of behavior for individuals, and potential modes of existence for possible subjects are linked together." As such, scholars from a range of disciplines, but working in a critical social science tradition, have used aspects of Foucault's "tool box" to examine aspects of the global HIV/AIDS response from micro-forms of power operating in sexual negotiations, for instance, to macro-national public health responses or the distribution of international aid (Guta, Murray, and Gagnon 2016). This literature is too vast to explore here, and does not necessarily engage with governmentality explicitly, but Foucault's influence is pervasive. Notwithstanding, we wish to make a distinction between social sciences and critical social sciences in the HIV/AIDS sector – for example, we would differentiate between, on the one hand, the social scientific project of studying why people living with HIV/AIDS fail to be adherent to medication (or what is needed to improve their adherence) and, on the other hand, the critical question of how and why – under what conditions – adherence has become a matter of concern, how programs and interventions promote adherence, and how these are implemented and policed as well as how they might discourage, sideline, or defund other responses and with what social and material effects. In other words, a critical social science approach studies the conditions of possibility for the uptake of a particular response and how it often silently works to conduct the conducts, the comportment, and the thoughts and affects of those subject to these powers. Governmentality, then, becomes a useful critical lens through which to view and advance such questions.

One of the earliest discussions of governmentality in relation to AIDS was offered in Simon Watney's (1987, 86) seminal critique of the ways "AIDS is increasingly being used to underwrite a widespread ambition to erase the distinction between 'the public' and 'the private,'" wherein he identified the relationship between politics, health, and education as an emergent battleground. In the 1990s, discussions of governmentality emerged in relation to the racialized dimensions of HIV (Worth 1995), the legal implications of HIV transmission (Donovan 1995), and how discourses on risk and responsibility govern affected groups (Kinsman 1996). In the 2000s, governmentality studies in HIV/AIDS grew considerably to include examinations of HIV as a site of knowledge production (Brown 2000), the emergence of HIV subjectivities (Adam et al. 2005; Bartos and McDonald 2000), the governance of "risk" groups (Geary 2007; Keogh 2008), HIV-testing programs (Gagnon and Holmes 2008), and the securitization of HIV/AIDS as a global threat (Elbe 2009). This work has evolved throughout the 2010s with further discussions on governing people living with HIV/AIDS (Sangaramoorthy 2012), gendering the epidemic (Guta et al. 2016), securitization (Ingram 2011), biomedical and surveillance technologies (Gagnon and Guta 2012), evolving and conflicting subjectivities (Rangel and Adam 2014), the role of civil society in research (Knutsson 2014), and HIV criminalization (French 2015). Individually, these studies have challenged formal responses to the management of HIV by public health, medicine, and criminal law. They challenge dominant discourses that inform how those at risk, those affected, and those who care for them should conduct themselves.

Collectively, these studies have mapped the evolution of the HIV/AIDS response across the decades and have interrogated each new articulation of messaging that tells people how to protect, care, and "empower" themselves and others to do the same. These discourses are enacted in public health interventions that have medical, social, and material effects, including, for example, discourses that determine increasingly specific ways of being such as the ideal viral load that a person living with HIV should have (see our discussion below). An analytics of governmentality enables the critical study of power and of the ways that knowledge is created and deployed in the ostensibly neutral and evidence-based epidemiological responses to HIV. Governmentality invites us to disarticulate the assumptions, subtexts, and "unintended" consequences of these discourses, which oftentimes further marginalize those who "fail" to be governed appropriately. Marginalized perspectives are what Foucault (2003b, 7) termed "subjugated knowledges" that have been dismissed and disqualified because they are below "the required level of erudition or scientificity" (see Randy Jackson in this volume for a discussion of Indigenous ways of knowing). These include the counter-discourses of the unrepentant slut, the disorganized and non-compliant AIDS patient, the viral outlaw, and also the radical nurse who refuses to document his or her patients' pharmacological and sexual transgressions. Although bringing such perspectives to the forefront is not necessarily critical on its own, when combined with the goal of challenging hegemonic political and medical truths, it becomes possible to imagine other forms of conduct rooted in different ways of knowing and being. For some, Foucault's reluctance to prescribe alternatives makes his work uncritical and even complicit in projects of oppressive governance, but we reject this as a misreading that overlooks Foucault's many explicit calls for resistance to acts of domination.

However, one salient criticism is that, unlike a biomedical response, a Foucauldian perspective does not directly improve the material conditions of those living with and at risk for HIV. That is, a critical analysis of the ways in which care providers and people living with HIV/AIDS are governed through medical and public health knowledge and interventions is said to do little to improve conditions for either. Indeed, those "in charge" are unlikely to ever read such critical work, and it is dismissed with "authority." For example, concerns about the ethics of public health research and practice are absolved with assurances that informed consent was obtained (as if that were the limit of ethics) (see, for example, the critique offered by Michael Vonn [2012] about the blurred lines between research and practice in Vancouver's HIV "seek-and-treat" strategy). What has been more challenging, even distressing, is to see how analyses of governmentality can at times produce an embodied and visceral response from those whose well-intentioned practices come into question (including those with lived experience). Governmentality is as useful for analyzing top-down approaches as it is for understanding supposedly grassroots responses. For example, interrogating long-held beliefs about the importance of community engagement and the greater involvement of people living with HIV/AIDS (GIPA) may not be well received by those who see themselves as activists. Nevertheless, a critical study might demonstrate, for example, the ways that GIPA has been quietly coopted by the vested interests of biomedicine and Big Pharma, which then operate as yet another means by which to "conduct the conduct" of people living with HIV/AIDS in ways that effectively thwart activism and dissent (McClelland, Guta, and Greenspan 2018).

Applying Governmentality to the HIV "Cascade"

The global HIV/AIDS response has been undergoing a radical transformation in the past few years with the integration of HIV treatment and prevention programming (Mykhalovskiy 2010). While this might not seem significant on its own, it has come with new biomedical diagnostic and surveillance technologies, medical guidelines, legal statutes, and new ways of thinking about HIV (Guta, Murray, and Gagnon 2016). At the programmatic and policy level, the US Centers for Disease Control and Prevention (CDC) (2011, 6) has advanced a "High-Impact HIV Prevention" approach, which involves "using combinations of scientifically proven, cost-effective, and scalable interventions targeted to the right populations in the right geographic areas." This approach is based on TasP, which promotes the scale-up of HIV testing and early treatment initiation (regardless of current health and treatment readiness) as a strategy to improve individual health outcomes for people living with HIV/AIDS and, simultaneously, to reduce the number of new infections at the population level (Granich et al. 2010; Montaner 2011). TasP requires high rates of HIV testing and diagnosis, unrestricted access to antiretroviral therapy (ART), and strict medication adherence leading to low individual viral loads (Kalichman 2013). TasP received wide praise and was even named the scientific "breakthrough of the year" by the journal *Science* in 2011 (Cohen 2011). However, concerns have been raised about what this means for the HIV/AIDS sector.

An early critique was offered by Cindy Patton (2011, 263), who raised concerns about the implications of this policy shift and warned that TasP "programs require testing and mandatory treatment on a scale seen only in dictatorships." Elsewhere, the physician and anthropologist Vinh-Kim Nguyen and colleagues (2011, 292) have described TasP as a re-medicalizing of the epidemic by moving away from recognizing, and responding to, the social determinants of health, warning that

> in the rush to paradigm shift, game-change, rollout and scale-up yet a new set of acronyms and standardized interventions, local epidemiological, political, and socio-historical context is once again being ignored, surely only to resurface later as "culture" once much-heralded interventions fail to deliver. Holding out for a magic bullet – unlikely to ever come – diminishes interest

> in the hard, messy work required to enable social change and address the social inequalities and structural violence that drive this epidemic.

What has concerned some, including ourselves, is that these "high-impact" approaches entail more than just "opportunities" for testing and treatment. The goal of achieving an "undetectable viral load" is now promoted through public health campaigns that zealously distinguish between the virally suppressed and the virally unsuppressed, and one's viral load is no longer something only documented in an individual's medical chart.

In most US jurisdictions, viral load is now reportable to public health and is used to map "viral hot spots" and concentrations of people living with HIV/AIDS (Gagnon and Guta 2012). As we write, similar proposals for viral load reporting are being put forward by public health authorities in Ontario. The United States and Canada are widely recognized as leading the way, internationally, in criminalizing HIV non-disclosure. In Canada, viral load has become a determining factor in criminal law's regulation of HIV non-disclosure (Mykhalovskiy 2016; see also, in this volume, Colin Hastings and Jeffrey Aguinaldo for discussions about aspects of disclosure and Martin French for a discussion about viral load and HIV criminalization). Collectively, this has created a situation in which traditional HIV stakeholders are responding to legal and medical advancements in ways that may unintentionally "govern" people living with HIV/AIDS in ways not previously imaginable (Mykhalovskiy 2010, 2016). Moving well beyond discourses of responsibilization in "safe" sex, the conduct of people living with HIV/AIDS is now being orchestrated through new biomedical forms of knowledge, particularly where knowledge about viral states comes to stand as a metaphor for their entire being. This type of knowledge is being used to understand people living with HIV/AIDS in multiple ways (their relationship to treatment, their sexual conduct, their legal standing, and so on) and thus becomes a technology through which to govern them.

Canadian proponents of TasP have used statistical modelling to support the "cost effectiveness" of early treatment initiation in the province of British Columbia, citing direct medical cost savings of $900 million over thirty years (Johnston et al. 2010). However, such models do not consider the impacts of early treatment initiation on individuals (Haire and Kaldor 2013) and the collective impacts of TasP-related programming on different communities affected by HIV, including those that may have a precarious or troubled relationship with the medical system (for example, Indigenous peoples, people who use drugs). Nevertheless, the province was persuaded by the potential cost savings and agreed to fund what was called the "Seek and Treat for Optimal Prevention of HIV/AIDS" (STOP HIV/AIDS) pilot program, which sought to "expand HIV testing, treatment, care and support to reduce HIV transmission and improve the quality of life of people living with HIV/AIDS in British Columbia" (Johnston 2013, 7). Deemed a success, the pilot program was scaled up to the entire province and has become the standard of care. Now the matter has turned from questions over whether this program works to monitoring where it is working.

In response, a new logic and discourse has emerged in the form of what has been termed the "HIV care cascade" (also referred to as the "HIV care continuum"), which seeks to measure the numbers of individuals, and related laboratory values, along various stages of care, ranging from HIV infected but undiagnosed, to diagnosed and linked to HIV care, retained in HIV care, on highly active antiretroviral therapy (HAART) if indicated, adherent to HAART, and virologically suppressed (Nosyk et al. 2014). This model has been adopted by the Joint United Nations Programme on HIV/AIDS (2014) and entitled "90/90/90," with the goal of implementing these targets globally by 2020. As the name "90/90/90" suggests, this is an aspirational model in which 90 percent of people living with HIV/AIDS are diagnosed, 90 percent are on antiretroviral therapy, and 90 percent are virally suppressed. These targets are conservatively described as "ambitious," considering how few people currently move along the trajectory as intended. For example, data from the United States suggest current figures are closer to 80/50/19 (Gray et al. 2014; Hull, Wu, and Montaner 2012; Mugavero et al. 2013). The decreasing numbers at each stage pose a significant threat to achieving the benefits of TasP. Thus, the original focus of making treatment widely available shifted to ensuring those on treatment remained adherent, and this shift necessitated new ways of describing an individual's relationship to care at any given time.

The researchers behind the Vancouver STOP HIV/AIDS program are leading the study of the HIV cascade of care through the comprehensive, linked, and longitudinal data of people living with HIV/AIDS uniquely available in the province of British Columbia (Hull, Wu, and Montaner 2012; Lourenço et al. 2014; Nosyk et al. 2014). The cascade is simply the quantification of the number of people living with HIV/AIDS in a city, region, country, or globally who have been tested and diagnosed, provided with treatment, achieved an undetectable viral load, and remain engaged in care over the long term. The cascade extends monitoring and surveillance beyond those in care to those who have been "lost to care," helps identify points of attrition, and establishes targets for future intervention. Mark Hull, Zunyou Wu, and Julio Montaner (2012, 585) were early to point out the cascade's importance in ensuring the success of TasP:

> At present, despite significant improvements in offering cART [combination antiretroviral therapy] to individuals in care in the North American setting, the overall proportion of individuals receiving therapy is low due to high proportions of undiagnosed individuals and incomplete retention of individuals aware of their status. Strategies to maximize engagement at each step of the care pathway will serve to improve the proportion of individuals receiving cART, diminish community viral load and ultimately contribute to decreasing HIV incidence. Optimizing the engagement of care cascade represents a critical step to maximize the individual and societal impact of cART and therefore deliver on the promise of HIV Treatment as Prevention.

Lillian Lourenço and colleagues (2014, 2) explain that the cascade "has been proposed as a comprehensive monitoring tool to identify attrition, or 'leakage' points, along the 'HIV continuum of care,' and … has become a focal point in the monitoring and evaluation of TasP initiatives worldwide." In order to identify these "leakages," calls have been made to collect even more public health and medical data (for example, testing, viral loads) at each stage of the cascade and from "the facility to global levels" (Kilmarx and Mutasa-Apollo 2013), where these data are linked "in population-based cohorts and data linkage … to complement clinical cohorts for 'broad' longitudinal cascade analyses" (Haber et al. 2016). The introduction of the cascade has resulted in new lines of research about key "risk" groups (for example, gay men, sex workers) in diverse settings, which positions them along the prescribed stages of the cascade using new measurements and monitoring techniques, and from which policy and practice recommendations for evidence-based interventions are made (Mugavero et al. 2013). Importantly, health care systems have not necessarily changed in contexts where cascade data are being collected to improve access to testing, treatment, or care, but the surveillance mechanisms themselves certainly have. Overall, this research is overwhelmingly biomedical and epidemiological, with a focus on improving treatment-related outcomes and retention in care (see Barry Adam as well as Mark Gaspar in this volume for a discussion of how gay men are responding to evidence-based medicine and public health logic) and improving and integrating surveillance mechanisms to enable robust global monitoring (Granich et al. 2017).

There has been little (critical) social science research about how care providers engage people living with HIV/AIDS at each stage of the cascade; however, what patients and providers think can – and obviously does – lead to treatment failure and withdrawal from care. Bertrand Lebouché and colleagues (2013) interviewed care providers about early ART initiation and found greater heterogeneity and uncertainty among clinicians who wanted to weigh the risks and benefits for their individual patients. Asha Persson (2014) interviewed care providers about TasP for serodiscordant couples and identified similar tensions. Christy Newman and colleagues (2015) have collected the perspectives of people living with HIV/AIDS who are reluctant to initiate treatment and cite ongoing concerns about toxicity and wanting to wait for "the right time." More recently, Sara Paparini and Tim Rhodes (2016, 2–3) provided a critical reading of the cascade literature informed by the concepts of therapeutic and biological citizenship (biocitizenship). They draw on both public health and qualitative and ethnographic approaches to identify key limitations in the cascade construct:

> First, the narrow focus on viral load progression (from detectable to undetectable) detracts attention from the broader aspects of HIV as a health and social condition, and not only a virus ... Second, viral suppression is not a "goal" that needs to be reached, but rather a "state" that must be maintained over time via ongoing systemic care provision coupled with continuous patient re-engagement ... Third, by delineating the accomplishment of viral suppression as and for public health control, the cascade distinguishes success and failure, of services and patients alike, in stark biomedical terms.

Paparini and Rhodes (2016, 5) offer an important starting point for exploring and synthesizing the literature, focusing on what they see as three main themes: patient engagement, therapies and politics, and biosociality and responsibility. Importantly, they identify the ways people living with HIV/AIDS understand HIV-related knowledge and interventions (drawing more on the embodied and relational forms of knowledge and help seeking), the politicized nature of access to health care, and how people living with HIV/AIDS come to understand themselves and others through the virus and treatment. They have laid the groundwork to start thinking about the cascade through a critical analytics of governmentality.

In these next few paragraphs, we offer our own reading of the cascade through the lens of governmentality. We aim to create a space for a critical counter-narrative about the cascade that identifies areas of potential concern and future analysis. Rather than point "blame" at a single target, governmentality invites us to explore how the range of actors and stakeholders inside and outside the cascade (from the "at risk" to the suppressed/unsuppressed, those who care for them, and those who make decisions on their behalf on the global stage) are implicated in this shift, how they benefit, and the myriad implications for research, treatment, and care. First, governmentality invites us to think about the forms of knowledge (biomedical, epidemiological, economic) and evidence (statistical modelling of longitudinal cohort data, cost-benefit analyses, and quality-adjusted life years) discussed earlier that have necessitated the cascade as a way of seeing and responding to HIV. In contrast to claims that quantification is a neutral activity, it is integral to maintaining the social bureaucratic machinery of the modern state and serves to govern through numbers (Hacking 1991). Reducing people to the cost of their medications and their viral loads to justify improving care, after having ignored more humanistic and rights-based appeals for universal access for decades, has not been questioned and, instead, has been received simply as welcome news.

Ayo Wahlberg and Nikolas Rose (2015, 85) have written about what they call the governmentalization of living, in which the "epidemiological gaze has crystallized" and "shifted focus from biological processes and events of life (disease and death) to social processes and events of living (disability and health), from morbid death to morbid living." This means that the cascade is being used to make the illness trajectories of people living with HIV "objects of political concern [that are] made knowable, calculable and thereby amenable to various strategies of intervention" (62). We do not mean to suggest that this is new (indeed, an entire volume could be dedicated to the different ways HIV has been quantified and measured over the decades) but, rather, that the current articulation should always be interrogated for its governing effects. The appeal of the cascade has created new lines of research across the health sciences (systematic and meta-analyses are available to help readers identify the most rigorous), which are being used by international organizations such as the World Health Organization and UNAIDS to develop policy and programs at the international and state level (see, for example, the revised treatment guidelines from the World Health Organization [2015]). Such guidelines serve as a kind of international governmentality shaping the practice of actors globally (Dean 2010b). On its own, this is not – and we use Foucault's own language here – "bad." But it may be dangerous. The history of AIDS is marked by countless examples of programming and interventions that were applied in diverse settings regardless of health systems and social issues, only to fail. Next, we explore the "trickle-down effect" for a range of stakeholders.

Governmentality invites us to think about being governed and how groups and individuals might uniquely come to understand their role and purpose. We have been interested for some time in the ways the current articulation of the AIDS response is working to govern both care providers and people living with HIV/AIDS through the imposition of biomedical truths and how these are being taken up and practised (Guta, Murray, and Gagnon 2016). As we see it, both health care providers and people living with HIV/AIDS are being governed through the logic of the cascade and related evidence and interventions; care providers will recommend treatment and "patients" will take it. Consider, for example, the gay man who receives a positive HIV test result and who is encouraged to initiate treatment immediately, in compliance with new prescribing guidelines. Ideally, he will initiate treatment and remain engaged in care for the long term. He may further come to identify with being adherent and achieving an undetectable viral load, which he might choose to display publicly on a t-shirt (one example reads "UNDETECTABLE, UNDENIABLE, UNDESTROYABLE, UNDETERRABLE, UNDEFEATABLE") and to post on his gay dating profile to advise others of his status. This individual is not only being governed through the logic of the cascade but also governing himself and others who may come to see this as desirable and aspirational.

Alternatively, the testing moment might lead that person to be expelled from the country, or his detectable viral load may raise questions by his clinical team about his level of adherence and commitment to his own care, and he may not be able to describe himself as "undetectable" in online fora. Perhaps his care team, comprising an infectious disease specialist, a nurse, and a social worker, come to view him differently, and this affects the care they provide. Perhaps some prospective partners may find him less desirable and wonder if he does not "care" about his health. In its most recent articulation, the cascade has been expanded to include prevention and now covers people who are HIV negative but deemed to be "at risk" for HIV infection (Hargreaves et al. 2016). In this case, those who test positive should be linked to HIV treatment, while those who test negative should be linked to HIV pre-exposure prophylaxis (PrEP) to prevent HIV; both groups will be supported through a range of programs to be adherent and remain engaged in care (see Chris Sanders, Jill Owczarzak, and Andrew Petroll in this volume for a discussion of PrEP). What started by measuring the number of people living with HIV/AIDS, including the number of those who are tested, accessing care, suppressed, and engaged in care, has now expanded to include a growing number of interventions, contingencies, and directives designed to enable socially marginalized people to conduct themselves in the right direction for their health and for the public's health too. Now, the testing moment (whether positive or negative) leads to new relationships with a medical provider. Again, this is not necessarily a "bad" thing, and it may very well meet important material needs, but, in drawing on the history of HIV, we anticipate new forms of resistance emerging in opposition to the inducement to lead an evidence-based healthy life. What if large numbers of people refuse treatment? How will this be addressed and by whom? What if people who newly test HIV positive opt not to disclose their status? What responsibilities do medical professionals, public health authorities, and community-based AIDS workers have to ensure that people test, remain compliant with their medication, and disclose their HIV status?

Analyzed in this way, the cascade loses its seeming neutrality. The emphasis on viral suppression (as evidenced through the militaristic strategy of mapping viral "hot spots" for targeted intervention) becomes highly problematic in terms of protecting the rights of people living with HIV/AIDS to make choices about their health when they might be at odds with desired clinical outcomes and public health policies. Returning to Foucault's original definition of governmentality as the relationship between the population, political economy, and security, the logic of the cascade offers a possible convergence between the goals of maximizing the health of the population and the current political economic rationality espoused through neoliberalism and austerity. New dividing practices are being used to mark the adherent from the non-adherent, resulting in previously stigmatized groups becoming understood as potentially responsible for undermining the potential cost savings of scaled-up treatment and improvements to public health (the poor care outcomes of people living with HIV/AIDS and addictions have been deemed especially concerning [Lesko et al. 2016]). Our concern is that the convergence of these new forms of surveillance constitutes an apparatus of capture that invites problematic forms of intervention into the lives of socially marginalized people (gay men, injection drug users, sex workers, and so on), all the while sidestepping the critical social, political, and economic determinants that drive the HIV epidemic.

Conclusion: Resisting Governmentalization

Governmentality invites the tracing of such developments, as they have happened, are happening, and may continue to happen, to map how actors and systems are governed, and to identify points of contact and conflict between enacted and prescribed forms of conduct, in order to understand and, at times, to challenge those forms of power that operate as direct and indirect regulation and normalization. For example, this approach might critically explore the reasons that prisons are seen as "good" places to test and initiate treatment as part of the cascade (Iroh, Mayo, and Nijhawan 2015) or how racialized and criminalized bodies can now be mapped according to their viral loads and in proximity to others deemed to be "at risk."[2] A governmentality analysis invites us to think about the operations of power, whether they be in the form of a welcomed increase in access to testing and treatment or of more objectionable practices such as the criminalization of HIV non-disclosure. Beyond identifying and documenting, governmentality studies trace new relationships between the micro and the macro, the local and the distant, as well as past, present, and imagined futures, often in ways that may be objectionable to those who promise easy biomedical solutions to global pandemics with catchphrases such as "90/90/90." Experience has taught us that such analyses are often marginalized. In recent years, we have heard those who question the logic of TasP likened to AIDS denialists – as if questioning a top-down approach, which requires everyone living with HIV to achieve certain goals regardless of their ability and desires, was synonymous with governmental propaganda used to deny people access to treatment.

In his final works, Foucault went to considerable lengths to explore truth-telling within modes of governance, with a focus on ethical resistance – the desubjugation (*désasujettissement*) of the subject. Foucault (2007a, 45) described critique as the process of resisting governance or "the art of not being governed quite so much," with particular attention to those figures of authority that dispense truth. In this chapter, we have described the evolution of governmentality as a theoretical stance and analytic framework to map forms of control and to understand how they operate on the lived and social body, on individuals and communities (or "populations"), and within global systems. Our stance echoes Geneviève Rail, Stuart Murray, and Dave Holmes's (2010, 219) invitation to employ *parrhesia* "to disrupt the epistemological status quo and to unpack the play of power in health research." We have questioned the logic of TasP, as have others, and extended this to its most recent articulation in the cascade of care.

Many might ask who could possibly take issue with the goal of increasing access to testing and treatment. We do not dismiss the reality that many people in Canada and globally do not have access to testing and treatment. We do take issue with how TasP is operationalized and with what effects. Our concern is that an entire system is being created based on the logics of control rather than of care and that, while some will surely benefit (and profit), others may find themselves further marginalized and excluded. We do not claim that our critique is a *parrhesiastic* act in the historical sense. Our lives are certainly not in jeopardy in writing these words, although it is fair to say that many people's lives are directly affected by current articulations of health care and treatment. Rather, we feel an obligation to respond to diminishing opportunities for "counter-conduct" in an HIV/AIDS sector that increasingly promotes a singular response (Adam 2011; Patton 2011). At the beginning of this chapter, we called for the importance of an ethic of discomfort and the need for hyper-pessimistic activism, which we have attempted to demonstrate throughout our analysis of TasP and the cascade, which has moved in a short time from radical to mainstream care and overshot opportunities for debate. Thus, we have extended governmentality to consider both how we are being governed as scholars and how our critique might, with care, be mobilized across systems of control beyond the scope of what we have written here.

Notes

1 The Columbia Center for Contemporary Critical Thought and the Society of Fellows in the Humanities at Columbia University presented Foucault 13/13, a public lecture series in which David Armitage, Rosi Braidotti, Judith Butler, Veena Das, François Ewald, Didier Fassin, James Faubion, Nancy Fraser, Frédéric Gros, Daniele Lorenzini, Nancy Luxon, Achille Mbembe, Judith Revel, Pierre Rosanvallon, Ann Stoler, and Linda Zerilli engaged with the lecture series and explored their ongoing relevance.

2 See AIDSvu, http://aidsvu.org/map/.

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2

Tracking Treatment Adherence

Should Critical Social Scientific Accounts of HIV Theorize Non-Human Actants?

Martin French

The human immunodeficiency virus (HIV) is a cagey actor. Since it is nothing that can be seen with the naked eye, the only way it appears for human perception is by participating in a complex actor network. Prominent in this network – in addition to countless viral particles – are HIV tests, sexual health clinics, bodily fluids, test subjects, nurses, counsellors, laboratories, and myriad forms of inscription associated with making an HIV diagnosis. Also prominent are scientific discourses (for example, virology, immunology, epidemiology, pharmacology) that describe the structure and function of HIV and its behaviours in bodies and populations and in response to various treatments. And let us not forget government policies, which attempt to chart the courses of state intervention contra the HIV epidemic; the mass media, which commonly portray moralizing tropes about HIV risk; and social scientific scholarship, which stakes out a range of positions on the broader meaning and significance of HIV. These, along with a host of other actors, help to materialize HIV and to render the virus visible and amenable to human intervention.

For those living with an HIV diagnosis, the expansive actor network dedicated to rendering the virus visible communicates a number of imperatives. As Kane Race (2001, 177) notes, “the imperative to remain ‘undetectable’ assumes the always-present possibility of detecting HIV; that is, it induces a process of constant monitoring and vigilance around the presence of the Other (the virus) at the level of the individual." This constant vigilance makes HIV "visible in different ways, through different techniques, and in different concentrations." For example, Race argues that, whereas HIV antibody tests "distributed and individuated the experience of HIV, the presence of viral load testing allows the epidemic to be imagined as an aggregate of individuals with viruses capable of being managed by these individuals, 'in partnership' with doctors" (179). What Race is emphasizing, with reference to the heterogeneous experiences of gay men, is that the work of making HIV visible – of managing it – helps to constitute and entrench power relations. Those living with a HIV diagnosis must partner with medical expertise and authority. They must enter regimes of surveillance and biomedical management that encourage them to begin taking drugs, often before they have had any significant, embodied experience of symptoms.[1] And as Adrian Guta, Stuart Murray, and Marilou Gagnon (2016, 98) note, within these regimes of surveillance, management, and biomedical authority, responsibility for maintaining viral suppression is morally coded, such that "the unsuppressed subject may become relegated to the margins – in effect, a failed neoliberal subject who has rejected the invitation to be 'better.'"

All of this amounts to significant institutional, social, and cultural pressure for certain social groups (for example, those living with, and at risk of, HIV) to begin taking antiretroviral medicines. This pressure provokes a range of questions: for instance, how to render HIV as a visible phenomenon in people's everyday lives; how best to help people integrate new pill-taking regimes into their daily routines and ensure adherence; how to help people understand the protective action of these drugs when they may feel no symptoms associated with their serostatus diagnosis or when they may not even have a diagnosis; and how, in short, to materialize the positive effects of the drugs alongside whatever negative side effects they may cause medicine consumers to feel (see, for instance, Gagnon and Holmes 2016)?

This chapter presents actor-network theory (ANT) as a prism for critically engaging such questions. Perhaps because of ANT scholars' tendency to dwell on empirical description, ANT might not be the first tool kit that jumps to mind when considering what theoretical resources would be helpful for staging a critical, social-scientific analysis of HIV medicines. Nevertheless, this chapter argues that ANT is a critical disposition, which is particularly useful for troubling notions of individual agency and responsibility that underpin contemporary approaches to HIV prevention and treatment. It first considers how critical social science has heretofore theorized technology. It then introduces ANT as a promising tool kit for conceptualizing HIV-prevention and treatment regimes. It also considers some criticisms of ANT, especially the charge that ANT provides primarily apolitical accounts. Then, in order to highlight what ANT approaches might contribute to the critical social science of HIV, it offers a brief, illustrative analysis of Every Dose, Every Day (E2D2). E2D2 is the name of a mobile phone application (or app), supported by the US Centers for Disease Control and Prevention (CDC) and designed to assist "people living with HIV with dose, refill, and medical appointment reminders" (Centers for Disease Control and Prevention 2017). This chapter considers how E2D2 can be critically theorized from the perspective of ANT.

My approach in this chapter is more explication than application. I concentrate on the description of how ANT can work as a critical disposition – and I also discuss some of the potential pitfalls of working within this disposition – in order to emphasize for critical-thinking scholars and advocates the importance and value of attending to socio-material and socio-technical details. Following Race (2015, 254), I think it is difficult to understand the ways that technical objects mediate sociability "without getting specific about the affordances, formats, design features and uses" of these objects. As I shall argue, scholars and advocates who are equipped with a critical analysis of socio-technical arrangements can find ways to productively intervene in the politics of supposedly technical decisions that govern those identified as living with, or at risk of, HIV.

Critical Social Scientific Accounts of Medical Technology

Critical social scientists have long held a less-than-sanguine view about modern medical technologies. In *Medical Nemesis,* for example, Ivan Illich (1975, 3) famously argued that the "medical establishment" had "become a major threat to health." For Illich, a large part of this threat stemmed from misplaced faith in medical technology and professional expertise. "Awe-inspiring medical technology," he wrote, "has combined with egalitarian rhetoric to create the impression that contemporary medicine is highly effective" (22). To question the assumed efficacy of modern medical interventions, Illich drew from several earlier studies that had argued that advances in medicine were not primarily responsible for reductions in morbidity and mortality (for example, Cochrane 1971; Dubos 1959). This critique of the efficacy of medical technology, and of medical interventions more generally, turned a skeptical gaze on claims (and interests) of technological proponents, including the medical diagnostic and therapeutic industries and the medical profession.

Continuing in this skeptical vein, critical social scientific accounts have provided a range of important critiques of the ambivalent roles played by medical technology in responses to HIV and AIDS. João Biehl, Denise Coutinho, and Ana Luzia Outeiro (2001, 119), for example, develop a critique of the way that HIV-testing technology articulates together with epidemiological expertise to engender what they call "technoneurosis." Here, the "testing apparatus" is said to play "a determinant role in the production of a socially visible imaginary AIDS and of neurotic incorporations" (119). They develop a strong critique of the organization of counselling and testing services in northern Brazil, arguing that it has been set up to serve clients whose "practices are in fact 'minimally risky'" (104).

Biehl, Coutinho, and Outeiro (2001) provide a nuanced account of testing technology, consistently situating it within a complex web of social relations and, thereby, resisting the common-sense tendency to treat technical objects as Kantian things in themselves.

Practices associated with HIV-testing technology, they argue, must be placed "in historical, political, economic and cross-cultural perspective" (89). To achieve this perspective, the authors describe testing experiences of service users, while also weaving into this description a consideration of several broader factors. These broader factors include the service users' low-risk sexual practices, uncertainties, and ambiguities in the HIV testing and diagnosis process, the formal logic of the HIV-testing apparatus, the increasing use of HIV tests in Brazil, the patenting of (and expenditure of public monies on) HIV tests, and the development of centres for HIV testing and counselling in Brazil. In this way, the authors raise critical, social-scientific questions about how the HIV epidemic is socially and epistemically (re)configured and with what consequences for those living with, or at risk of, HIV. Indeed, the critical analysis developed by Biehl, Coutinho, and Outeiro locates testing technology within a broader "technoscientific ethos of governance" (120). The authors want to understand how it is appropriated and internalized in complex and unanticipated ways by test users. And they want to locate these diverse appropriations within an emergent governmentality that enables "new inscription patterns of social and sexual domination, and the client's addictive self-tooling" (120). The authors thus raise key questions about the role of HIV-testing technology as part of a broader governance apparatus.

Curious Quietness: What about Technical

Biehl, Coutinho, and Outeiro's (2001) critique clearly rests on a sophisticated understanding, which goes beyond the simplistic description of technology as a thing in itself. Nevertheless, they tend to talk about technical artifacts as adjuncts to the more important social and structurally mediated relations that take shape in the problem spaces that they analyze. They focus, for instance, on the unconscious processes that "become the new material and medium through which contemporary technoscientific mechanisms of governance are made up" and on "the ways human affects are engendered by these processes" (94). This is an important line of inquiry, but, in bringing it into the foreground, important technical aspects of the HIV test (such as how it is made to work in the diagnostic process) are largely left out of the picture.[2] Such details have long been dismissed as being beyond the scope of critical social scientific inquiry and thus represent an as yet relatively untouched area of research and reflection. Additionally, Biehl, Coutinho, and Outeiro do not go so far as to attribute agent-like capacities to technology. As the next section will discuss, this is the fraught terrain into which ANT approaches dare to tread. In venturing into this terrain, ANT approaches offer a novel way to think about the power of non-human actors to shape, enable, or constrain thought and action. In so doing, they also raise some difficult questions for critical social scientists, which have to do with what should be the object of critique.

It is curious, for instance, that in spite of excellent work engaging various dimensions of technology in the prevention and treatment of HIV infection, communications technology has tended not to be featured very prominently. As a barometer of this relative neglect of communications technology, it is noteworthy that (at the time of writing) a query of the EBSCO Academic Search Complete database for the terms "communication technology" and "HIV" yields only thirty-two results. Adding the term "critical" to this search returns only five results. Meanwhile, a search for the terms "technology" and "HIV" yields over 6,000 results. Can (and should) the use of an ANT-informed approach that foregrounds communications technology rectify this situation? In other words, is it (or why is it) important to highlight communications technology in critical social scientific accounts of HIV? In the next section, I provide an introductory description of ANT before returning to these questions.

An Introduction to ANT

Setting aside the question of whether critical social science has, as a result of its epistemological and ontological commitments, actively discouraged and marginalized the discussion of the role of communications technology in regulating HIV – a provocative question that does not, in any event, admit a straightforward answer – I want to turn now to a consideration of ANT. I would also like to acknowledge some criticisms, which have pointed to certain limitations of ANT approaches. This will set up a subsequent effort to analytically tinker with the E2D2 app using the ANT tool kit.

On the Difficulty of Being an ANT

> STUDENT: "I can't imagine one single topic to which ANT would apply!"
> PROFESSOR: "Beautiful, you are so right, that's exactly what I think."
> STUDENT: "That was not meant as a compliment"
> PROFESSOR: "But I take it as a true one! An application of anything is as rare as a good text of social science." (Latour 2005, 156)

Running through the middle of Bruno Latour's (2005) book, *Reassembling the Social* – which ostensibly provides an introduction to ANT – is a bizarre chapter that stages a fictional dialogue between a student and a professor. The dialogue begins when the student drops in on the professor's office hours and confesses to having difficulty applying ANT to a case study. The professor immediately responds: "No wonder! It isn't applicable to anything" (141). Confusion of the "Who's on First" variety ensues; channelling Abbott and Costello, Latour's staged dialogue would probably make Socrates weep. The student appears to leave the dialogue somewhat less enlightened:

> PROFESSOR: "Why come to me then? Why try to use ANT?"
> STUDENT: "For the last half hour, I have to confess, I've been wondering the same thing." (156)

Nevertheless, for all of the (staged) miscommunication, the dialogue does hammer home an underlying axiom: there is no such thing as ANT – in the singular – and no sense in which it can be simply applied to any given empirical case.

At least, this is one way of reading Latour's dialogue, along with his various articulations of ANT. Many a critical theorist has erred, Latour suggests, by seeking to explain reality through the application of crude concepts to whatever situation is under scrutiny. Yet these concepts, along with the notion that they could be somehow applied to a situation without also simultaneously changing that situation, obscure as much as they reveal. For instance, Latour argues that it has become commonplace in sociology

> to posit the existence of a specific sort of phenomenon variously called "society," "social order," "social practice," "social dimension," or "social structure." For the last century during which social theories have been elaborated, it has been important to distinguish this domain of reality from other domains such as economics, geography, biology, psychology, law, science, and politics ... Once this domain had been defined, no matter how vaguely, it could then be used to shed some light on specifically social phenomena – the social could explain the social – and to provide a certain type of explanation for what the other domains could not account for – an appeal to "social factors" could explain the "social aspects" of non-social phenomena. (Latour 2005, 3)

These concepts – social order, social structure, and so on – have interfered, in Latour's view, with sociologists' capacity to take seriously the complex, messy, empirical materiality of the real world.

A key problem for Latour has been a tendency in critical theory to fixate on supposedly purely theoretical points while simultaneously neglecting the empirical work of describing the actual substance that theories are meant to explain. This is a tendency that does not simply neglect the empirical; it neglects the "sociotechnical imbroglios" of what Latour (1993, 7), borrowing from Donna Haraway (1991), calls "nature-culture." The upshot has been "a certain form of critical spirit" that has

> sent us down the wrong path, encouraging us to fight the wrong enemies and, worst of all, to be considered as friends by the

> wrong sort of allies ... The question was never to get *away* from facts but *closer* to them, not fighting empiricism but, on the contrary, renewing empiricism. (Latour 2004, 231; emphasis in original)

To address this problem, Latour (2005, 9) has argued strongly for an empiricism that is, tongue-in-cheek, very ant-like, "myopic, workaholic, trail-sniffing." From this perspective, ANT is about steadfastly eschewing the classic attempt to apply theory in order to explain reality and, instead, adopting a tightly focused, descriptive orientation devoted to enumerating the nodes and vertices in the unruly network of material-semiotic relations that actually make up reality.

Okay, but What Is ANT?! A Few (among Many) Characteristics

Latour does a wonderful job of writing colourful prose about how not to do ANT. To those searching for a beginner's guide to ANT, however, Latour's *Reassembling the Social* is probably not the best place to start. Other introductions to ANT are decidedly less cryptic (though not necessarily less playful). John Law (2009, 141), for instance, describes ANT as a "disparate family of material-semiotic tools, sensibilities, and methods of analysis," which have been devised by an array of humanities and social scientific scholars of science and technology over, roughly, the past forty years.[3] Law presents several characteristics of ANT, including a commitment to a relational ontology that treats "everything in the social and natural worlds as a continuously generated effect of the webs of relations within which they are located" (141). Yet, with this description, Law also offers several caveats. First, Law notes that ANT has been articulated primarily in relation to specific case studies and that it makes most sense when it is understood as something that is embedded and "extended in empirical practice" (141). Second, because of its sensitivity to "the messy practices of relationality and materiality of the world," ANT tends to be skeptical about "the large-scale claims common in social theory" (142). This skepticism should be extended to, and rule out, large-scale claims about ANT. Third, ANT is less a coherent body of research and more "a diaspora that overlaps with other intellectual traditions" (142).

With these qualifications in view, Law offers a review of select studies that illustrate some key characteristics of ANT. Rather than reproducing Law's review, let me simply identify a few characteristics that will be useful for my subsequent consideration of the E2D2 app. This will be necessarily selective and undertaken in the spirit of approaching ANT as a tool kit for analysis, where it is understood that the conceptual tools are themselves mutable, changeable, and rendered according to the actor networks in which they are instantiated.

Constructionism, but Not Social Constructionism …

A definitive period in the history of ANT, circa the 1990s, has come to be known as the "science wars." As Ullica Segerstråle (2000, 2) notes, the science wars are best described as a strong critique "by a relatively small minority of 'proscience activists' against a particular school" of thought known as the sociology of scientific knowledge. At bottom, they can be characterized as an argument over realist epistemologies, typically assumed to underpin scientific knowledge production, and social constructivist epistemologies articulated within the sociology of knowledge, which emphasizes the socially mediated nature of scientifically observed phenomena. Segerstråle states that, around the mid-1970s, "traditional sociology and history of science had given way to new research programs promoting the idea that science was 'socially constructed,' or suggesting that science was on a par with other knowledge systems, such as Azande witchcraft" (3). Within these research programs, scientific facts were viewed as socially constructed. The definitions of social construction varied, as did the way that scholars described the term's epistemological implications.

ANT initially appeared to ally with social constructivists. However, ANT authors, such as Latour, would later come to "ditch" the idea that science was socially constructed (Latour and Woolgar 1986). This had to do with a tendency in some social constructivist scholarship to disavow any reality outside of that which is mediated by human sociality, a position that Latour and other ANT scholars criticized. A key implication of ANT's disavowal of social constructionism was, therefore, a decentring of human meaning making (Hird 2009, 16). As Latour (2005, 91–92) argues, "'constructivism' should not be confused with 'social constructivism' ... For any construction to take place non-human entities have to play the major role." From this perspective, human meaning making does not encapsulate, nor exhaust, all of reality. Moreover, in articulating a constructivist (but not social constructivist) epistemology, ANT innovatively pushed through the impasse, which seemed to characterize the science wars, between social constructivist and realist epistemologies. In place of these unsatisfactory alternatives, it proposes a realist constructionism. The upshot of this, for critical social scientific accounts of HIV is that one can take seriously the "how was it built" and "how does it work" questions in a way that does not necessarily reduce them to epiphenomena of symbolic exchange.

A Flat Ontology: Decentring the Human

Another characteristic of ANT that has been particularly appealing, and not uncontroversial, has been its embrace of posthumanism. Bound up with its realist constructionism and consequent decentring of the human has been a doggedly empirical effort to document actors within their networks. Latour (2013, 31) argues that "a network is not only a technological arrangement such as, for example, a network for rail transport, water supply, sewers, or cell phones." It may also be conceptualized as a process, signified by the concept of the actor network. What is an actor network? Think of a human, any individual human, whom liberal philosophy has endowed with rationality and autonomy. ANT undercuts assumptions about the liberal rational actor by locating that individual human within a network. When that human acts, it is not by the grace of free will (whatever that means) alone; it is by enrolling allies – other nodes in the network – toward the end of action. This may seem rather abstract, but by situating actors within networks, ANT causes analytic attention to focus on how agency, far from residing within any singular node, may be actually distributed across a network of human and non-human actors.

To use a simple example, if a person marks a piece of paper with a pencil, it would be conventional to assume that the person chose to act, to mark the paper with a tool, and then did so. ANT would present a different interpretation of this event: a person chose to act, but only within the conditions of possibility permitted by networked connections between person, pencil, and paper. Agency on this ANT-informed interpretation may be viewed as being distributed across the network, with the human actor and non-human actants (pencil and paper, not to mention desk, chair, pencil sharpener, lamp, electricity, paper supply company, paper mill, trees, semiotics, and myriad other actors, actants, and actor networks) all coming together to make the mark. For critical social scientific accounts of HIV, this perspective forces a rethinking, for instance, of treatment adherence, which has largely been conceptualized as a matter of individual responsibility. It would point, for example, to all of the heterogenous agents involved in accomplishing, or interrupting, pill consumption.

Performativity, Practice, and Enactment

How do ANT scholars operationalize this rather abstract-sounding realist-constructionist epistemology-flat ontology? Frequently, the strategy has been radically empiricist. Take, for instance, Annemarie Mol's (2002) *The Body Multiple: Ontology in Medical Practice*. Written like a concrete poem, this book exemplifies what ANT can do with a focus on the performative and enacted nature of everyday life.[4] With ethnographic observations across the top of each page, and theoretical argumentation running in two columns, like supporting pillars, across the bottom of each page, the book understands objects as things manipulated in practice. This has the effect, Mol contends, of multiplying reality: "The body, the patient, the disease, the doctor, the technician, the technology: all of these are more than one. More than singular" (5).[5] The focus on performativity, practice, and enactment hews closely to the method of myopic empiricism and has enabled ANT scholars to discover novel realities within even ostensibly well-studied actor-networks, such as laboratories. For critical social scientific accounts of HIV, this perspective can be leveraged to understand how social arrangements that might seem favourable for given actors can change, and become unfavourable, depending on how these arrangements are enacted. Seemingly helpful devices may not always, as I will argue, perform in helpful ways, and the ANT emphasis on performativity, practice, and enactment helps to illustrate this potentiality.

Critiques of ANT

As Law (2009) observes, ANT has been criticized from a variety of perspectives. He groups these criticisms into three strands: 1) ANT studies attend primarily to the powerful and are sometimes very functionalist; 2) ANT studies have failed to recognize their own role "as an intellectual technology of Othering" (149); and 3) ANT studies have not been very aware of their own politics and the political agendas of their own stories. Each of these strands of critique would seem to suggest a diminished capacity for ANT to be used as a critical social scientific tool. In this section, I want to briefly delve into the question of ANT's lack of awareness of its own politics.

What sort of awareness does, or can, ANT have of its own politics? ANT has been said to favour description over explanation; however, does the endeavour to be descriptive not severely blunt ANT's critical edge? In seeking to provide descriptions of the world, is ANT not failing to ask why the world is so? Haraway (1997), drawing on the work of Paul Edwards (1994), shows how this descriptive orientation of ANT may lead to a failure of reflexivity. She argues that ANT has sometimes ended up "importing unexamined psychologistic assumptions" when it comes to theorizing how knowledge is produced (Haraway 1997, 128). These assumptions have, for instance, "deep roots in behaviourism and artificial intelligence research" and "provide impoverished representations of cognitive and social processes for humans and nonhumans alike" (128).

A preliminary response to this important critique is that the importing of unexamined assumptions is a possibility in all works of social theory, not just in ANT. At issue here is a lack of reflexivity and not, I would contend, any intrinsic weakness in the ANT tool kit. What is required is to be aware of the fact that the necessary work of description can be read as atheoretical and, therefore, acritical. Given this awareness, ANTs critical edge can be sharpened by seeking to be explicitly reflexive about the politics of its accounts and, as Latour argues, by deploying critique at the right moment, which is to say once analysts have a solid working understanding of how actor networks operate. Latour (2005, 251) writes:

> ANT has been accused of two symmetric and contradictory sins: the first is that it extends politics everywhere, including the inner sanctum of science and technology; the second is that it is so indifferent to inequalities and power struggles that it offers no critical leverage – being content only to connive with those in power.

In Latour's view, these criticisms should cancel each other out. Summing up his response to both positions, he asserts that the problem has been to equate critique with critical distance. To be too close to one's objects of research, this line of argument contends, is to compromise one's ability to think and write critically. In response to this, Latour argues that "critical proximity, not critical distance, is what we should aim for" (253).

In addition to arguing that ANT can be (and must be) reflexive and provide accounts of its own politics, ANT scholars have also asserted that their approach often involves moving political contestation into an ontological register. Mol uses the phrase ontological politics to capture the work that ANT does in this register.[6] Ontology, she writes, commonly "defines what belongs to the real, the conditions of possibility we live with. If the term 'ontology' is combined with that of 'politics' then this suggests that the conditions of possibility are not given" (Mol 1999, 74–75). Engaging in ontological politics can involve reworking perceptions of reality so as to open up new conditions of possibility for critical thinking. Let me attempt to demonstrate this in the next section.

Performing ANT: Act One of an ANT-Informed Analysis of E2D2

A number of scholars who have developed critical social scientific accounts of HIV and AIDS have incorporated, more or less explicitly, insights from ANT. Steven Epstein's (1996) classic book *Impure Science,* for instance, is influenced by the attention that ANT has accorded to the work of enrolling allies to build scientific credibility. His study demonstrates how scientific discourse constructed certainty around the hypothesis that HIV was the cause of AIDS and how AIDS activists allied in various ways with scientific experts while also undergoing, themselves, a "process of 'expertification'" (13). Performing the important, ANT-inspired work of showing how scientific knowledge is constructed and mobilized, Epstein shed light on the ensemble of social actors and sometimes conflicting social interests that assert knowledge about HIV and AIDS.

Race's research similarly illustrates how ANT can be used to open up new lines of critical inquiry. In a number of works, Race (for example, 2003, 2007) has theorized affective climates, which characterize the broader environment of knowledge/power that configures technologically mediated subjectivities. Affect, Race (2009, 121–22) notes, refers "not just to the structures of feeling arising from participation in specific social and cultural practices or historical conditions, but [also] to the accumulation and cultivation of specific capacities – powers to move and be moved." The concept of an affective climate draws from ANT in the sense that it

> presumes nothing about the nature of humans or their psychological states. Rather, it directs attention to the concrete specificities of the technical media through which bodies come into contact with, and apprehend, one another. Bodies are impacted by specific structures of entanglement through which certain

> capacities, forces and powers of acting are made available. (Race 2010, 9)

By foregrounding the networked entanglements that link bodies and objects together in the course of everyday life, this conceptualization enables a consideration of what Race calls “the changing contours and interactional conditions of HIV-positive experience” (9). In Race’s hands, the ANT tool kit thus brings to light the sometimes elusive, yet always fundamental, capillary action of power that identifies, sorts, and regulates bodies and populations according to their ostensible serostatus.[7]

Working in this vein, I would like to sketch in the reminder of this chapter the opening act of an ANT-informed critical social scientific account of the role of communications technology in the regulation of HIV. To do so, I will focus on the E2D2 app, suggesting some lines of research that ANT might open up in this substantive area as well as some potential limitations this tool kit might have. Owing to space constraints, I cannot provide a fully worked-up ANT account of E2D2. This would require, in my view, a much deeper engagement with the app and its extended actor network, including users, app developers, the CDC, discourses of HIV prevention and treatment, not to mention drugs, mobile devices, and communication networks. It would also require sustained attention to the way E2D2 operates *in situ,* in its relation with users, and according to the rhythms of their everyday lives. Because this chapter is more about exploring ANT as a critical disposition, I can only stage the first act of a longer play here. Nevertheless, my hope is that what follows will whet the critical “app”etite and help to grow the assemblage of analyses to come.

What, then, does the opening act of this analysis look like? To get things started, I want to make three moves. These will exemplify the three characteristics of ANT, which I have highlighted above: constructionism, a flat ontology, and performativity/practice/enactment. To keep these analytic moves confined to the small stage we have in the space remaining, I will not look at the app in its entirety. Instead, following a brief overview of how the app is meant to work, I will concentrate on its Terms and Conditions, the legal contract that ostensibly governs the use of the app. I am particularly interested in how the app performs individual autonomy and responsibility, while also promising strong privacy protection. These performances are part of a larger network of practices that we can theorize in terms of neoliberal governmentality. I want to use ANT, therefore, to think about these self-governing performances and the ways they connect with – or, better, collide with – other governing practices mediated by the criminal justice system.

How Was the App Constructed? How Is It Supposed to Work?

By asking basic "how" questions, ANT approaches enable critical analysts to open up the black boxes that hide complex realities. By opening black boxes, it may be possible to see the political implications of what are often regarded as apolitical, technical decisions. How, then, was E2D2 constructed and how is it supposed to work? In 2013, with funding from the CDC's Division of HIV/AIDS Prevention, the Boston-based John Snow Research and Training Institute (JSI), partnered with Mad*Pow, a Boston-based design agency, to produce the E2D2 app. The app was embedded within a larger project that involved creating "a web-based program to inform clinical providers and community partners about five HIV medication adherence strategies that were recently designated [by the CDC] as effective" (John Snow, Inc. 2017). According to Mad*Pow, the app was meant to go "beyond typical reminder apps, offering a variety of features that provide the support and motivation necessary to foster adherence" (Mad*Pow 2017). This included what Mad*Pow described as "seeing the Big (Data) Picture":

> While prompting patients to log each dose is important, it is only the first step in building adherence competency. Each time a patient logs a dose, this data is used to create a visualization of adherence over a given week, month, or year, thus revealing a bigger picture of progress. (Mad*Pow 2017)

Mad*Pow is aware of the potential privacy concerns this type of "big data" visualization of medicine consumption could raise. "Privacy," according to their discussion of the app, "is paramount":

> To comply with strict privacy requirements, all patient data is entered by the patient and stored on the device. In addition, password protection and customizable reminders mean users won't unintentionally share their medical information with prying eyes (a key concern of our user test group). (Mad*Pow 2017)

This manufacturer description is in line with how the E2D2 app is described on the CDC's *High Impact Prevention* website (Centers for Disease Control and Prevention 2017). This site, while bearing the imprimatur of the CDC, was developed by JSI and Mad*Pow. Among other things, it notes that users may use the app to "log reasons for missing a dose." This function is presented as something that could be "useful in discussing adherence challenges" with medical providers. As these descriptions indicate, the E2D2 app is designed to help users undertake a complicated treatment regimen. It stores useful, if highly sensitive, information that users can access on an as-needed basis – for example, when discussing adherence challenges with medical providers.

The Apple App Store describes E2D2 as a "new, free, easy-to-use app created by the Centres for Disease Control and Prevention (CDC) for people living with HIV":

> The app allows you to set up medication reminders easily, and keep track of your appointments, laboratory results, and refills. The app also provides motivational tips to help you stick to your regimen. This app is simple and secure. It will keep any information you enter confidential and stored only on your phone. (Apple 2017)

To emphasize user privacy, the Apple App Store description asserts: "Your privacy is important to us. No data entered will be stored externally or used for any other purpose other than your own personal use" (Apple 2017).[8] Already we can see a large and extended actor network beneath and behind the app interface. Nodes in this network include not only the CDC (which is described as the app developer in the Apple App Store materials) but also the much less visible companies that procured CDC funding to build the app. In addition, by asking how the app was built, we can see that the network extended to consultations with a user test group (presumably people living with HIV/AIDS, who might benefit from using the app, although this is not specified in the publicly available materials). By asking about how the app is supposed to work, we can see that the actor network extends to health providers, who track patients' CD4 counts, as well as non-human actants, such as viral load tests, privacy requirements, hand-held devices that are capable of storing data and turning that data into statistics that can be graphed, and so on. The interconnected material reality of this assemblage of actors and actants makes the app a real construction. It was built by, and works because of, a multiplicity that is both material and symbolic, which is what ANT, following Haraway (1997), would describe as a material-semiotic multiplicity.

A Flat Ontology: Actor Networks and Decentring the Human

What else is in the E2D2 actor network, and how does thinking of E2D2 as part of a larger material-semiotic multiplicity have the effect of decentring the human actor? I downloaded the app on an Apple iPhone in order to be able to access its Terms and Conditions. These kinds of electronic documents, which preface virtually every mobile phone application along with most other software applications and which must be traversed by clicking "I agree" before the application can be accessed and used, are notorious for being difficult to understand. Research suggests that they are only rarely read by users (for example, Acquisti, Brandimarte, and Loewenstein 2015). In the following discussion, I want to consider what the Terms and Conditions say and what it would mean to think of them as a non-human actant.

On downloading E2D2, users are taken through a brief tutorial, which highlights different functions of the app, including a database of antiretroviral medicines that allows users to select their medication and enter their prescription details, as well as functions that track pill consumption, laboratory reports, appointments, and prescription refill timelines. Following this introductory tutorial, users are brought to the Terms and Conditions screen. Clicking "I Decline" brings up a dialogue box, which asks: "Are you sure you want to quit the application? NO/YES." This is noteworthy – though not unusual for Terms and Conditions agreements – because users are forced to either consent to all of the application's terms and conditions or to "quit" using the app. There is no middle ground. The only way into the app is to click "I Agree." Below are a couple of excerpts of the lengthy statement that users must agree with.

> CDC IS NOT RESPONSIBLE FOR CONFIDENTIALITY OR ANY INFORMATION SHARED BY THE OWNER OR USER OF THE DEVICE WITH OTHER PARTIES. CDC IS NOT RESPONSIBLE FOR INFORMATION SHARED WITH THIRD PARTIES THROUGH LOSS OR THEFT OF THE DEVICE. (Every Dose, Every Day 2016; all caps in original)

The Terms and Conditions also state:

> WHILE USING THE APPLICATION, CERTAIN GENERAL DATA ANALYTICS ON THE USAGE OF THE E2D2 APP MAY BE GATHERED AND STORED AUTOMATICALLY ABOUT THE USAGE OF THE APP. (Every Dose, Every Day 2016; all caps in original)

Although the Terms and Conditions document also subsequently assures readers (at least those who have scrolled down to read this passage) that the app does not collect any personally identifiable information, it is unclear what is meant in the above quotation by "certain general data analytics."[9] How easily, for example, could this de-identified information be re-identified? The Terms and Conditions do not permit an answer to this question, though there have been studies on the increasing ease of re-identification in de-identified data (for example, McGraw 2010).

In addition to reading the Terms and Conditions to understand their description of the data collection processes enabled by E2D2, an ANT-informed analysis might ask about the work that the document does as an actant. On the surface, we must acknowledge that the majority of app users are probably not reading – or, if they are reading, probably not entirely understanding – E2D2's Terms and Conditions. This would be consistent with research that has found that, when mobile health apps do have privacy policies, they tend to be "mostly incomprehensible, out-of-scope, and lacking transparency" (Sunyaev et al. 2015, e31). It would also square with the more general finding that "only a minority of subjects read policies with any frequency" (Jensen, Potts, and Jensen 2005). In what sense, then, is the Terms and Conditions document an actant if E2D2 users are simply ignoring it? To answer this question, we must note that the document can only be ignored up to a point. It forces users to click "I agree" prior to allowing them to use the app. By forcing even this minimal interaction, E2D2's Terms and Conditions, when read through the analytic prism of ANT, is an electronic document that acts. It acts in such a way that compels users to perform their individual autonomy. For those who do not read the document, it asks users to take on faith that their use of the app will help (and not harm) them. In an awkward manner of speaking, it forces non-reading users to assent to choose to take personal responsibility for any potential harms that might arise from using the app.

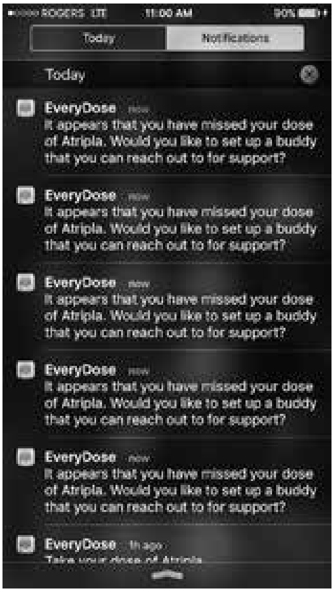
Additionally, for the minority of users who actually read the Terms and Conditions, we may say that the document is likely to act in a different way. For instance, if users read the document's statements promising that "E2D2 collects no personal information about you" in conjunction with similarly strong privacy statements on the CDC website, at the Apple App Store, and at the Google Play app store, they may feel reassured about disclosing their pill-consuming habits.

Hence, another way this document may work as an actant is by providing assurance to users about the privacy of their data. It may work to legitimate a culture of self-tracking and disclosure about the details of one's pill consumption. Drawing from Deborah Lupton (2016, 68), we could theorize this as "a practice of self-hood that conforms to cultural expectations concerning self-awareness, reflection and taking responsibility for managing oneself" – a practice, in other words, that "represents the apotheosis of the neoliberal entrepreneurial citizen ideal."

From an ANT perspective, theorizing E2D2's Terms and Conditions document as an actant means according it similar ontological status to that of other actors (for example, the human lawyers that write up impenetrable end-user license agreements, the human application developers who collect and monitor "certain general data analytics," the human users who download and use the application) in the actor network. ANT's flat ontology requires a decentring of the analytic focus on humans – who tend to be front and centre in standard critical social science accounts – and a re-centring of the analytic gaze on networks of humans and other actors. This is an ontology that does not merely transform the role of humans in the analytic picture; it also transforms the role of objects. It transforms E2D2, for example, from a pedestrian and uninteresting tool that humans command into a serious player that may work with – or against – humans and other actants in the larger actor network that produces and consumes antiretroviral medicines.

Performativity, Practice, and Enactment

In the space remaining, I can only gesture toward an account of performativity, practice, and enactment. Accordingly, I will briefly outline a site that desperately needs this type of analysis. Consider the following question: how could E2D2 be said to work against human users and other non-human actors? To answer this question, I want to first imagine how E2D2 might work against treatment adherence regimes. Working with E2D2 on an iPhone, I entered details for an Atripla prescription and set a dose reminder



EveryDose now
It appears that you have missed your dose of Atripla. Would you like to set up a buddy that you can reach out to for support?

EveryDose now
It appears that you have missed your dose of Atripla. Would you like to set up a buddy that you can reach out to for support?

EveryDose now
It appears that you have missed your dose of Atripla. Would you like to set up a buddy that you can reach out to for support?

EveryDose now
It appears that you have missed your dose of Atripla. Would you like to set up a buddy that you can reach out to for support?

EveryDose now
It appears that you have missed your dose of Atripla. Would you like to set up a buddy that you can reach out to for support?

EveryDose 1h ago
Take your dose of Atripla

Figure 1 Screen grab of notifications from the E2D2 application on home screen

at 10:00 a.m. each day. Every day at 10:00 a.m. on the button, the iPhone sends the following reminder: “Take your dose of Atripla.” I can enter the app and hit the “I took it!” button, registering my consumption of Atripla. However, for some reason – let us call it a glitch – the iPhone sends another notification at 11:00 a.m. each day stating: “It appears that you have missed your dose of Atripla” (see Figure 1). This is in spite of the fact that I have already registered taking my dose. Perhaps the version of the app I downloaded was corrupted; perhaps the iPhone is not set up in a way that is compatible with the app. Whatever the reason, the point is that, although I am only meant to take one dose of Atripla per day, the app gives me two reminders an hour apart to take Atripla. At 11:00 a.m., I am wondering: “Did I really take my pill, or just imagine taking it.” It is not hard to see how E2D2 could work, in this instance, against a treatment adherence regime.

Let us push the situation illustrated in Figure 1 a bit further and consider the potential negative effects of a phone registering that a user has missed a dose of Atripla. In Canada, where I am writing this article, a countless number of people have been placed under criminal investigation for allegedly not disclosing their HIV serostatus to their sex partners. As Colin Hastings astutely observes in this volume, criminal investigation for anything related to HIV has the effect of organizing the lives of people living with HIV/AIDS according to the logics of the criminal justice system. According to the latest published data in Canada, there have been at least 184 so-called non-disclosure cases where persons have been charged, prosecuted, and, in many circumstances, convicted of a criminal offence (Hastings, Kazatchkine, and Mykhalovskiy 2017, 2; Mykhalovskiy 2015, 373). As Eric Mykhalovskiy and Glenn Betteridge (2012, 33; emphasis in original) note, these cases have "focused on HIV non-disclosure and the *risk* of transmitting HIV infection rather than on the actual transmission of the virus." As a consequence, the current legal situation requires persons living with HIV to disclose their serostatus to their sex partners unless "(i) the accused's viral load at the time of sexual relations was low, *and* (ii) condom protection was used."[10]

This requirement effectively transforms information about viral load and medicine adherence into potential evidence that could be used in a criminal trial. A number of cases in Canada have considered whether a person's viral load was undetectable, suggesting that the problematic fetishization of "undetectability," to quote Mark Gaspar in this volume, is now becoming increasingly entrenched in Canadian law. There is a sense in which E2D2 could be an ally of a person in such circumstances; it could be used to demonstrate adherence and, therefore, to suggest a low viral load. However, we can also imagine the obverse situation. E2D2 registers missed doses (in my case, even when I have indicated that a dose was taken). This type of information could be very dangerous for an app user in a criminal trial setting in a country, it should be noted, that has an outrageously high conviction rate for charges related to non-disclosure of HIV status (for example, Mykhalovskiy and Betteridge 2012).

Conclusion

The subtitle of this chapter raises the following question: should critical social scientific accounts of HIV theorize non-human actants? I would like to frame my concluding remarks as a response to this question. Obviously, having written a chapter on how ANT approaches can be used to theorize communications technology, I feel that it has both merit and utility. But are ANT approaches, in the idiom of this volume, really "critical dispositions" (see Eric Mykhalovskiy and Viviane Namaste in this volume)? What are the strengths and limitations of the approach I have just outlined and, in specific terms, what are the implications of concentrating analytic attention on non-human actants?

Let me begin with the limitations. To indicate these, it will be helpful to undertake a self-positioning exercise. I write from a position of class and identity privilege. I am a white, male university professor of unknown serostatus. To the extent that this subject position has conditioned my selection of ANT as a worthy analytic tool and critical disposition, one might raise questions about how my "ANT advocacy" reproduces the interests of those in my privileged social class. Moreover, it must be said that my ANT advocacy is, to borrow from Namaste (2005, xi), "bound within much broader social and economic relations of imperialism." I think the surfacing of positionality is paramount to any critical project – in the absence of this, it is all too easy to assume that one's analysis speaks to some universal human experience. It is all too easy to ignore, in the absence of reflexivity, the material differences that shape the diversity of experiences. Indeed, it is true that ANT scholars have tended to favour descriptive, empirical approaches to research. There is a tendency in descriptive approaches, furthermore, to furnish just-so accounts of the world, to naturalize inequalities, and thereby, wittingly or not, to support the status quo. These are potential limitations that plague all critical scholarship but that, because of ANT's descriptive orientation, may be particularly recalcitrant.

Then again, undertaking an ANT-informed analysis with an awareness of these limitations may allow scholars, however socially positioned, to open up new possibilities for critical social science and social justice. ANT approaches may tend toward the descriptive, but they also push politics into the ontological register. This is a radical move that, I would argue, militates against just-so accounts of the world by striving, in the words of Latour (2005, 253), for critical proximity instead of critical distance. This is particularly important when forms of inequality, which are deeply sedimented into systems of governance, may be reproduced and amplified by the extended array of the often-invisible actants with which humans co-exist.

In conclusion, I think that there is an important role for ANT in critical social scientific scholarship and advocacy on HIV. Nevertheless, because it decentres humans – and, by extension, those in human societies most affected by HIV – ANT probably ought to play a supporting role rather than a starring role. In this chapter, I set out to consider how a rather pedestrian mobile phone application might be critically theorized through the prism of ANT. I began by noting that critical social scientific approaches have tended to turn a skeptical gaze on medical technologies while simultaneously relegating the details and materiality of technology to the analytic margins. I then introduced ANT as a promising tool kit for conceptualizing the role of non-human actants, such as apps, in HIV treatment (and prevention) regimes. I also considered some criticisms of ANT and addressed the question of ANT's politics. In order to highlight what an ANT-informed approach could contribute to the critical social science of HIV, I offered a brief, illustrative analysis of E2D2 using some tools from the ANT tool kit. With Jeffrey Aguinaldo, who also provides a chapter in this volume, my aim has been to show the utility for critical social science of a tool kit that some have called acritical. In using ANT, analysts have to be aware of its baggage. But, if performed reflexively, an ANT-informed analysis can illuminate important issues, including the way that public health strategies of (self-)governance may interlock with other stigmatizing and punitive forms of governance, including those mediated by the criminal justice system and HIV criminalization.

Notes

1 During the 1990s, it was recognized that highly active antiretroviral therapy (HAART) could significantly reduce progression to symptoms associated with AIDS. A debate ensued over when people should start treatment, and many came to believe that it was crucial to "hit HIV" with HAART "early and hard" (Ho 1995, 333). Today, it is argued that "individuals have a considerably lower risk of developing AIDS and other serious illness if they start taking antiretroviral drugs sooner when their CD4+ [cluster of differentiation 4] T-cell count – a key measure of immune system health – is higher, instead of waiting until the CD4+ cell count drops" (National Institutes of Health 2015). In addition, studies of HIV pre-exposure prophylaxis (PrEP) – the use of antiretroviral therapy by people who are HIV negative – demonstrate that they protect HIV-negative people from acquiring HIV (for example, Grant et al. 2010). Importantly, for the arguments that will be developed in this chapter, as Chris Sanders, Jill Owczarzak, and Andrew Petroll note in this volume, the use of PrEP may be accompanied by intensive forms of monitoring that go beyond the thresholds established for those deemed at highest risk of acquiring HIV: "Rather than relying solely on a quarterly HIV baseline test in order to receive a prescription renewal, the UHC youth clinic [where they conducted their research] requires a monthly HIV rapid test in addition to the quarterly serology tests."

2 Of course, no article can do everything, and some domains of the testing process have to be left out of the discussion in order to do justice to other domains. And, it must be said, even though Biehl, Coutinho, and Outeiro (2001) did not centre technical artifacts, they did provide a description of HIV-testing technology as well as an extensive reference list to point readers toward work dealing with new (at the time) "ultrasensitive" enzyme immunoassay techniques and screening methods using polymerase chain reaction.

3 Law (2009) argues that one of the best ways to get to know actor-network theory (ANT) is to read any number of its seminal case studies. A bibliography may be found at the "ANT Resource," *Centre for Science Studies,* http://www.lancaster.ac.uk/fass/centres/css/ant/ant-a.htm.

4 Mol (2002), in the context of her study of atherosclerosis, centres the analysis of practice. She favours the concept of enactment over performativity: "The performance metaphor has some inappropriate connotations … It may be taken to suggest that there is a backstage, where the real reality is hiding … I don't want those associations to interfere with what I want to do here: to shift from an epistemological to a praxiographic inquiry into reality. So I need a word that doesn't suggest too much. A word with not

too much of an academic history. The English language has a nice one in store: *enact*. It is possible to say that in practices objects are *enacted*" (31–33; emphasis in original).

5 Law (2009, 151; emphasis in original) argues that the focus on enactment and performativity pushes ANT beyond constructionism: "We are no longer dealing with *construction,* social or otherwise: there is no stable prime mover, social or individual, to construct anything, no builder, no puppeteer ... Rather we are dealing with *enactment* or *performance*. In this heterogeneous world everything plays its part, relationally. The shift is easily misunderstood, but it is crucial. The metaphor of construction – and social construction – will no longer serve."

6 This idea resonates with the recent work of Brian Massumi (2015, vii) on ontopower. Whereas many ANT scholars would claim to be doggedly empirical and would therefore eschew the speculative techniques of philosophers (however, see Latour 2013), Massumi blends speculation and pragmatism. His approach is thus very different than what one would typically find in the ANT repertoire. Nevertheless, his work on ontopower shares with ANT approaches the goal of exploring how diagrams of power and action are operationalized. As Massumi (2015, viii) says, ontopower is a "positive power" that brings phenomena "into being"; the goal of his work on ontopower is, therefore, to "explore how this operationalization works." ANT scholars share this goal.

7 The list of scholars using ANT insights to critically theorize HIV is not long. Nevertheless, see especially, among others, Chen 2015; Dijstelbloem 2014; Holt 2013; Rosengarten 2004.

8 The same description appears, verbatim, in the Google Play app store.

9 However, if users link out to the more general Centers for Disease Control and Prevention's privacy policy (http://www.cdc.gov/other/privacy.html), further details about the type of aggregate data collected are provided. This privacy policy is actually much clearer, and more robust, than the statements about privacy made in Every Dose, Every Day's Terms and Conditions. But, as I will explore in the next sub-section, it does not go far enough.

10 *R. v Mabior,* 2012 SCC 47, para. 94.

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3

Institutional Ethnography as a Critical Research Strategy

Access, Engagement, and Implications for HIV/AIDS Research

Daniel Grace

> *Starting from local, particular settings in the everyday world, the work of the activist ethnographer is to extend his or her member's knowledge to grasp how a ruling régime works with a view to transforming it.*
>
> *– G.W. Smith, "Political Activist as Ethnographer," 629*

Critical thought, argues Loïc Wacquant (2004, 97; emphasis in original), "is that which gives us the means to *think the world* as it is and *as it could be.*" As a method of inquiry, institutional ethnography (IE) provides an analytic tool box to help researchers and activists map social relations and explicate how individuals are governed. IE, at its heart, is about working toward a more equitable society (Campbell and Gregor 2002) and is analytically concerned with exploring the ways in which power is exerted in practices of ruling. Developed by Canadian Marxist feminist scholar Dorothy Smith (1987, 2001, 2005, 2006), this alternative sociology provides a research strategy that allows for an understanding of the socially organized nature of everyday life. IE is committed to discovery and is a highly empirically driven form of social research that draws principally from primary interview, observational, and text-based data sources. This approach to critical social science focuses on the material actualities of people's lives in order to help develop analytic descriptions of ruling practices.

For the institutional ethnographer, starting investigations with "objective" social or political theories, or notions of a "pristine" Archimedean point, are rejected in favour of beginning with the experiences, events, and concerns of people in the everyday world (G. Smith 1990, 631). IE departs from many other forms of (critical) social scientific writing that often begin inquiries "from a standpoint in a text-mediated discourse or organization" (D. Smith 1999, 4) and may "lift phenomena out of time and place, constituting them as discursive entities in the peculiar timelessness of established sociological discourse" (7). That said, IE does offer a number of conceptual tools to guide researchers in their mapping of social organization. For example, the concept of "ruling relations" in institutional ethnography "directs attention to the distinctive trans-local forms of social organization and social relations mediated by texts of all kinds (print, film, television, computer, and so on) that have emerged and become dominant in the last two hundred years" (D. Smith 2005, 227).[1]

In their discussion of how this tradition developed, Marie Campbell and Francis Gregor (2002, 14) explain:

> Dorothy Smith's work in the sociology of knowledge is the product of her struggle against the hegemony of this scholarship. Beyond debates about positivism, Smith's research was affected by her developing feminist consciousness and her involvement in the women's movement of the 1970s (for example, Smith 1977). Smith was one of the feminist scholars of that time who had come to see that women were not adequately represented by the forms of knowledge that claimed to be speaking about them. Feminists recognized that the research being conducted within their disciplines failed themselves and other women – Smith and others proposed new ways of knowing. Smith's *Everyday World as Problematic: A Feminist Sociology* (1987) put institutional ethnography into the scholarly discourse.

As William Carroll (2010, 15) describes, Smith's approach to critical inquiry draws from feminist traditions (for example, second-wave feminism and consciousness raising), Marxism (for example, "the Marx of *The German Ideology*"), and ethnomethodology, resulting in the "pull[ing] together of three radical approaches."[2] Kevin Walby (2007, 1010) explains that "IE draws influence from Marx and his conception of political economy as arising from the activities of actual people but also from ethnomethodology, in that the institutional ethnographer is interested in people and how they know and do in their specific situations."

Many traditions of ethnography and qualitative inquiry, including symbolic interactionism, are concerned with the investigation of lived experience. However, it is important to note that the institutional ethnographer is not interested in accounting for individual experience or meaning making per se but, rather, in the analytic mapping of organizational process and social relations. Furthermore, while IE is a sociology focused on mapping the everyday, it is not a sociology of everything. Frequently, institutional ethnographies focus on the "text-mediated" nature of everyday life and seek to reveal how ruling relations are organized or enabled by the production, widespread circulation, and activation of texts. To ground their investigations in people's actual activities, institutional ethnographers have adopted a generous understanding of "work" as that which involves a combination of intention, effort, and a degree of acquired skill or competence (McCoy 2006; D. Smith 1987). Liza McCoy (2006, 110–11) highlights that focusing on work in this way directs "analytic attention to the practical activities of everyday life in a way that begins to make visible how those activities gear into, are called out by, shape and are shaped by, extended translocal relations of large-scale coordination." In short, while IE is not unique because of its interest in drawing on lived experience, it represents a distinct sociological tradition for mapping social relations and thinking critically about the actualities of everyday life.

Since recently beginning to teach IE in graduate seminars and supervising students applying this strategy in the context of

HIV/AIDS and public health research, I have become interested in reflecting on how Canadian scholars have engaged in this tradition, including the form of critical social science critique they see IE furthering and the new frontiers and possibilities they imagine for its use in HIV research. My interest in this inquiry has also been shaped by my own experiences, as a graduate student and early career professor, conducting IE research on the transnational coordination of HIV-related state laws (Grace 2013a, 2013b, 2015) and the work of local government in legislating for public health (Grace et al. 2014; Grace, Egan, and Lock 2016).[3] This volume on critical social science perspectives on HIV/AIDS presented a unique opportunity to engage in dialogue with other social scientists – many of whom are involved as contributors to this collection – who have applied IE in their HIV/AIDS research in Canada.

In the sections that follow, extended excerpts are presented from interviews conducted via written response with seven Canadian social scientists who have applied IE in the context of their academic and activist work at varied career stages. I asked these researchers a series of questions that focused on trying to understand how they have used IE in their HIV/AIDS research, what this research strategy has helped them to uncover, what theoretical or methodological limitations or challenges they have encountered, and any reflections they have on how IE has been, or could be, combined with other critical research traditions in the social sciences. Based on the responses received, and my own review of the literature and experience with this research strategy, I have organized this chapter to highlight some of the most interesting and important foci, tensions, and new directions I see in Canadian HIV/AIDS institutional ethnographic research.[4] This review connects IE to a critical tradition in social science research that "question[s] the detachment that has in the positivist tradition tended to produce social science that reinforces status quo arrangements and understandings" (Carroll 2004, 1).

First, as a way of extending the discussion of IE at the opening of this chapter, I draw on the reflections of social scientists to highlight the form of critique offered by IE. Second, I review some of the diverse forms of IE scholarship conducted in Canada, using the accounts of those interviewed. I focus on the centrality of access-related questions across much of this work as well as the continued significance of George Smith to the HIV research and activism in this tradition. Third, I reflect on two key areas that social scientists have discussed related to the current and future uses of IE as research theory and practice. I explore the relationship of IE to principles of engagement and community-based research (CBR) that have been increasingly mainstreamed in the Canadian HIV/AIDS research landscape. Next, I discuss the tensions and possibilities of engaging with social theory, including governmentality and Foucauldian perspectives, in IE research. To conclude the chapter, I offer some final thoughts on new directions and possibilities for HIV research that may be informed by IE.

IE as Alternative Sociology: The Form of Critique Offered

IE is, at its foundation, a deeply political project. As Campbell and Gregor (2002, 103) state: "Its politics are built into its mode of inquiry. It requires taking sides." Researchers working in this tradition are committed to not making people the objects of research. Instead, IE researchers make ruling relations the object of study. They try to put into view the relations of power that shape, direct, and, indeed, limit our lives. As Dorothy Smith (1999, 8) explains, the goal of beginning in the standpoint of people's everyday lives is "not to explain people's behaviour but to be able to explain to them/ourselves the socially organized powers in which their/our lives are embedded and to which their/our activities contribute." In reflecting on the form of critique they see IE offering, the researchers I interviewed elaborated on Smith's argument, providing insight into some of the essential features of this research strategy. Their responses help to provide a useful overview of the commitments of this tradition and the ways in which it has been formed as an alternative sociology.

In drawing on their own research experience, Viviane Namaste and Liza McCoy both discussed the ontological grounding of IE:

> One of the most obvious critiques made by IE is about the need to move beyond an objectivist sociology. The commitment to documenting, understanding and explaining how experiences are shaped does, at some fundamental level, challenge a traditional social scientific investment in "neutrality." Building on this, one of the ways IE does this, of course, is by valuing the everyday experiences of people – a move which can (but not always) displace the sociologist as expert. Aside from these broad questions about the role of the sociologist, IE seeks to provide a way to struggle with the dichotomy between structure and agency. The framework's influences from Marxist, ethnomethodological and phenomenological traditions offers students, teachers, and social theorists an occasion to think about how to develop a framework that makes sense of the relations between structure and individual actors. In this regard, IE provides a wonderful pedagogical opportunity for grappling with one of the most vexing problems of social theory itself.[5] (Namaste)

IE's response to the so-called structure-agency dilemma is to reject concepts, such as structure, that posit a superordinate level of ontology beyond the activities of people in real time and place. Namaste's comments underscore that the ontology of institutional ethnographers is focused on actualities (D. Smith 2005, 223). Agency, in this critical tradition, is not given to concepts. In reflecting on the analytic goal of this sociology for people, Liza McCoy explained:

> Institutional ethnographic studies do, nonetheless, often start by learning how people live and make sense of what happens in their lives, and some description of everyday doings and experience is therefore a pertinent feature of many institutional ethnographic studies. But that this is not the ultimate analytic goal. That goal is to investigate and describe the determinants of the described experience, to "map" some aspects of the extended relations of rule in which the doings occur.

McCoy's use of the metaphor of mapping highlights another important analytic component to much IE research. Dorothy Smith (2005, 226) describes the indexical nature of maps and how, in the IE sense, the idea of mapping is analogous: "Institutional Ethnography's project of mapping institutions always refers back to an actuality that those who are active in it know (the way the phrase *you are here* works on a map)."

In my own HIV and public health research, I have found mapping to be an important component of IE research, using maps as a tool to assemble "different work knowledges" as well as "account of the texts coordinating work processes in institutional settings" (D. Smith 2005, 226; for examples, see Grace 2013a; Grace, Egan, and Lock 2016). For example, in past IE research in West and Central Africa, I explicated how harmful legislative environments that now criminalize HIV transmission were created through a transnational process of "model law" standardization funded by the US Agency for International Development (USAID). By considering the complex work process at play, I mapped the ways in which model laws were shaped ideologically and have come to be used in the everyday world, acting as a powerful regulatory text with a set of specific social relations of use (Grace 2015). I drew analytic attention to the ways in which so-called best practice policy standardizations have led to an onslaught of highly problematic laws that have criminalized HIV non-disclosure (Grace 2013a, 2015). Mapping takes multiple, interrelated forms in this IE – a way to think about specific text-mediated activities of policy standardization (for example, how a model law is used to make state laws; see Grace 2013b, 79), a metaphor helping to account for complex work processes across time and space, and even a way to visualize the policy landscape in West and Central Africa that went from a "policy desert" prior to 2004 with no HIV-specific laws to a region where thirteen of eighteen targeted countries had HIV specific laws by 2010 (Grace 2013b, 79–80).

IE offers at its core, as Colin Hastings puts it in this volume, "a profound critique of the ontology of traditional sociology by starting with people and taking ruling relations as its object of analysis."

Again, people are not the objects here. IE's materialist conception of the social world is linked with the broader political commitment of its sociological project. That is, institutional ethnographers want to surface the experiences of people that are objectified or ignored by ruling discourses. Their projects seek to expose relations of power that shape our worlds while preserving the doings of active subjects. To exemplify what this form of social research strategy can help to make visible in the field of HIV/AIDS, we will turn to consider some of the experiences that the researchers interviewed for this collection have had with HIV/AIDS research conducted in an IE tradition.

Access and the Social Relations of HIV

IE HIV research in Canada has focused on creating knowledge to understand and improve the lives of people living with HIV/AIDS. Drawing on the standpoint of people's everyday lives, IE has been used in diverse forms of HIV/AIDS scholarship in and beyond the Canadian context. For example, in his highly influential application of IE (which he called political activist ethnography) George Smith (1990, 632) demonstrated that the medical treatment being made available in Ontario in the late 1980s was organized ideologically according to the idea of "AIDS as a fatal disease":

> Palliative rather than aggressive "accelerated care" was the order of the day. The provincial health department, for example, basically allocated funds for hospice care and for psycho-social support for the dying. While most local doctors also followed regimens of palliative rather than accelerated care, PLWAs [people living with HIV/AIDS] in Toronto knew through personal contacts and "underground" networking with their counterparts in the United States that people with AIDS could live longer. Contrary to the official prognosis of the politico-administrative regime in charge of managing the epidemic, they believed that AIDS was no longer a necessarily fatal illness in the short run.

> These kinds of ruptures of consciousness are located in the social relations which produce them. This is where my research began; not in the objective domain of sociological theory, but with everyday events in people's lives. These kinds of problems of knowing – of being told one thing, but in fact knowing otherwise on the basis of personal experience – provided a starting point for the research that then went on to explicate how a regime works. Essentially, it called for an investigation of ideological practice extending beyond the scope of local settings. (G. Smith 1990, 632)

George Smith's IE research, which was produced through his activism, offered an empirically grounded account of the Canadian state's failure to establish an institutional infrastructure for delivering experimental medical treatments to people living with HIV/AIDS. Findings from his ethnography were used to direct the activities of AIDS ACTION NOW!, a Toronto-based AIDS activist group, to redress these system failures (G. Smith 1990, 1995; see D. Smith 2005, 150; 2006, 33).[6]

Many institutional ethnographies have continued to focus analytic attention on how access is institutionally coordinated for people living with HIV/AIDS. IE studies have explored access to medical treatment as well as broader health and social services for people living with HIV/AIDS (for example, Bresalier et al. 2002; McCoy 2006; Mykhalovskiy and McCoy 2002; Mykhalovskiy, McCoy, and Bresalier 2004; Mykhalovskiy and Smith 1994; Smith, Mykhalovskiy, and Weatherbee 2006). For example, building on the scholarship of George Smith (1990, 1995), McCoy (2005, 2006, 2009) examined the experiences of HIV-positive women and men, with a particular emphasis on the work of people living with HIV/AIDS who were socially and economically marginalized. Her ethnographic investigation was conducted in collaboration with other researchers and focused on the nature and social organization of people's "health-work" at a time when new antiretroviral medications were becoming available to people living with HIV/AIDS in Canada in the late 1990s.

McCoy explored the extended institutional and professional relations that shape the doctor-patient relationship (and ways to improve the relationship) as well as the health-related work of obtaining appropriate health care services, accessing HIV treatment information, making decisions regarding treatment, and managing pill taking. Focusing on a different set of relations, other IE HIV research has explored the challenges of counselling provided by AIDS service organizations. Here, analytic attention has been directed at how the delivery of social services are negatively shaped by social relations that foster heterosexism (O'Neill 2002; see Smith and Smith 1998).

Outside of the Canadian context, recent institutional ethnographies have been conducted that examine responses to HIV and AIDS within (Muñoz-Laboy et al. 2011; Murray et al. 2011) and across (Grace 2013a, 2015) countries. For example, Miguel Muñoz-Laboy and colleagues (2011, 973) examined the role of institutionalized religion on the political and cultural responses to HIV and AIDS in Brazil, arguing that "religious responses are not monolithic and that institutional ethnography may be the most effective way for public health researchers to explore the influence of religion on national responses to the AIDS epidemic." As noted above, my own research has offered a transnational analysis of the rapid standardization of HIV/AIDS laws across West and Central Africa (Grace 2013a, 2015).

In their discussions of their own IE experiences, many of the researchers I interviewed noted how George Smith (1990) informed their own research as a colleague and/or as a textual source of inspiration. Eric Mykhalovskiy explained that his use of IE has frequently involved collaboration with both community-based AIDS service organizations (ASOs) or AIDS activists and other academics based in universities:

> Some of the early research I did with George Smith looked at how social services were institutionally organized and where the problems were in how their organization intersected with the way people living with HIV/AIDS went about their day-to-day

> lives. The study grew out of the horrible experiences people living with HIV/AIDS were having getting income assistance, home care and other social services and used the metaphor of "hooking up" to focus on access as an institutionally organized phenomenon. In late 1990s I partnered with a group of researchers and community workers to do a study about the institutional organization of the healthwork of people living with HIV/AIDS in the context of the emergence of new antiretroviral therapy.

Liza McCoy, a university-based academic, who has experience doing HIV/AIDS IE research in collaboration with Mykhalovskiy, noted the work of accessing research funds. She elaborated on the notion of "healthwork" referenced above:

> I joined a team of community- and university-based researchers who were trying to get funding for a research project. We got funding ... We interviewed people living with HIV/AIDS individually and in focus groups. Our analytic focus was on the work that people do to look after their health as this takes shape within institutional relations of, in particular, health care and treatment information.

The concept of "healthwork," noted by both McCoy and Mykhalovskiy, is a key analytic contribution of this Canadian IE scholarship, and it continues to inspire IE research outside of the HIV field (Roddick, Smith, and Grace 2016). The notion of healthwork developed within IE reorients the notion of illness work developed within the symbolic interactionist tradition (Corbin and Strauss 1985). Rather than focusing attention on the meanings people create and attach to illness or to the identity or biographical work they do when faced with a chronic illness diagnosis, healthwork commits analytic attention to how the activities that people do to maintain their health are organized by, and gear into, a complex of discursive and institutional relations both within and beyond biomedicine and the formal health care system (Mykhalovskiy

2008). Namaste (2000) also connected her experience with IE to the work done by George Smith and Eric Mykhalovskiy. Namaste explained how her first use of IE was in the context of documenting the experiences of transsexuals who were trying to access health and social services in Ontario, followed by subsequent work examining the needs of transsexuals in Quebec related to HIV/AIDS:

> I was not trained in IE in any formal scholarly sense, and during the 1990s was doing doctoral work in a francophone intellectual tradition at the Université du Québec à Montréal. That said, after reading the report [*Getting "Hooked Up"*], by George Smith and Eric Mykhalovskiy [Mykhalovskiy and Smith 1994], I felt that this framework was well suited to the work I needed to do. Their report showed the work that HIV-positive people need to do to access health and social services. It also demonstrated, for me, a particular kind of social inquiry that went beyond mere description and beyond an objectivist sociology. So I used that framework to help inspire the kinds of questions I would ask and the disjunctures in accessing care that I sought to document and explain.

A number of the researchers I interviewed used IE in the context of their HIV/AIDS doctoral or postdoctoral research. For example, Laura Bisaillon's (2013) doctoral work in this tradition explored the practice of "immigration medicine" in the context of HIV/AIDS. Like others, Colin Hastings also noted the significance of the foundational scholarship of George Smith in his current doctoral research and explained that he was "hooked on IE" after his first exposure to George Smith's (1990) "Political Activist as Ethnographer."[7] Hastings's IE research in this volume maps the social relations of HIV disclosure in order to contribute to critical social science on HIV while informing activist responses to authorities that work to shape the conduct of people living with HIV/AIDS.

Finally, Heather Picotte explained how she used IE in her HIV doctoral research on "food security" that focused on the health-work of people living with HIV/AIDS in British Columbia. She spoke about how, in her work at an ASO, she found clients often had trouble getting access to nutritional food and that "IE allowed me (or forced me, actually) to look at food security as work, and to examine the kinds of activities that go into that work." Picotte elucidated the "reciprocal" relationship between her access-focused IE research and frontline work:

> When I had finished the research, I returned to the same ASO in a slightly different capacity as an outreach/harm reduction worker ... so much of what I learned in my job helped me understand the complex work that people carried out in order to be healthier and more food secure. This included things like accessing the care of a family physician or the HIV specialist, applying for disability benefits through the provincial government, and even reading grocery store flyers to get the best deals on food. When I returned to the ASO a couple of years later, I found I was better able to help people navigate the health and welfare system because, during my research, I had gained a very in-depth understanding of how a variety of institutions worked in my region. In particular, I knew more about the texts that clients needed to negotiate in their everyday lives in order to accomplish certain goals related to wellbeing.

Researchers discussed the necessity of working across bureaucracies when conducting institutional ethnographic research in the field of HIV/AIDS. For example, Namaste explained how her work has frequently examined the ways in which people become "caught between institutions. For example, how lack of access to healthcare prevents a transsexual from changing their identity papers."[8] Namaste emphasized the importance of understanding how different institutions relate or are dis/connected with one another. Picotte also explained the necessity of not focusing exclusively on a particular health, educational, or social service – a common approach in much IE research – in order to understand how food security access work for people living with HIV/AIDS is shaped by a range of institutional practices.

It is worth underscoring that the notion of institution has a specific meaning in institutional ethnographic research. Dorothy Smith (2005, 225) explains that "institutional" and "institutions" are used in IE research:

> To identify complexes embedded in *ruling relations* that are organized around a distinctive function, such as education, health care, and so on. The terms identify the intersection and coordination of more than one relational mode of ruling. State agencies are tied up with professional forms of organization, and both are interpreted by relations of discourse, including the institutional discourses that are systematically developed to provide categories and concepts expressing the relationship of local courses of action to the institutional function.

Yet, even if one is aware of the importance of examining processes across bureaucracies in one's HIV research, institutional access – along with other access challenges – remains a barrier that many IE researchers have experienced in conducting their HIV research work. In fact, just as access has been a key focus of IE research in the area of health care and HIV/AIDS, it has been a key challenge faced by IE scholars in doing their research and includes such problems as access to research funds, to institutional field sites, to relevant texts, and to research participants willing to speak openly about their experiences and healthwork. One important development in the institutional organization of health research in Canada, which has provided a point of entry for IE health research, is the growing funding emphasis placed on CBR. I will now turn to a discussion of the relationship between IE and CBR strategies.

IE, Engagement, and Community-Based Research

CBR has been celebrated, even lionized, within many HIV research circles and appears to be increasingly mainstreamed in Canadian HIV research and training contexts.[9] An interesting tension shared by CBR and IE research is "unlearning" traditional ways of conducting HIV research. For example, just as HIV CBR principles demand researchers reflect critically on how data are collected, analyzed, and used, IE has its roots in a critical unlearning of conventional sociological research approaches and ways of knowing. That said, while much IE is aligned with broad principles of CBR, such as using knowledge for positive change in people's everyday lives, in my reading, most CBR in the Canadian HIV research context takes neither an IE nor a critical social science perspective.

Of course, this is not surprising; the mainstreaming of CBR across research domains allows the label to be applied to both large-scale epidemiological or socio-behavioural quantitative studies as well as small, critical ethnographic works, some of which are conducted in an institutional ethnographic tradition. For an example of the latter, Namaste drew on her experience of doing IE research on bisexuals in the context of CBR:

> I am fascinated by how a particular object of knowledge comes into being, and what that means for how we understand a particular issue. In the field of public health and HIV/AIDS, this matters a great deal: the objects that are identified as "appropriate" for study then become the matter for programmes and services, as well as evaluation and future research. My research in this field, working with a community-based advisory committee, sought to document and understand how bisexuals are virtually absent in HIV/AIDS research. Much of this methodology invoked the IE principle of reading against the grain, and not taking the scientific literature of a field at face value. Through textual analysis of policy documents, as well as readings of the methodological criteria used to define sexual orientations in research, we examined how bisexuals were made to disappear … The framework of IE is useful because, rather than simply accepting the populations identified in mainstream public health research as a given, the approach asks us to suspend the implicit

> assumptions of what we know, how we know, and the categories we use to know.

As Namaste's comments help us to recognize, some CBR research that is not informed by critical approaches such as IE may allow for the uncritical adoption of categories and assumptions in mainstream public health research.

A number of the researchers I interviewed talked about how the history of the engagement of IE with activist pursuits raises important questions for community-based research. Hastings commented:

> I think it's important to keep in mind that IE's particular intervention into how we investigate the social is doing more than just revealing ruling relations. Institutional ethnography is also posing a significant methodological critique about where research findings can end up – that is, that research can produce knowledge that doesn't merely cycle back into theoretical texts but that can also produce knowledge that is useful to activists. There is, of course, a strong legacy of institutional ethnographers in the field of HIV starting their inquiry in the everyday experiences of people living with HIV/AIDS, developing an understanding of how people's lives are socially organized, and then most importantly, using that work to inform interventions. In addition to this legacy of IE in HIV research, CBR frameworks and GIPA/MIPA (the greater and meaningful involvement of people living with HIV/AIDS) principles have become central to the HIV/AIDS research field in Canada. It has been suggested that the fundamental question underlying the development of CBR in the field of HIV/AIDS is not about the content of knowledge, but rather, what knowledge is for ... I think both IE and CBR equip critical social science researchers in the field of HIV to do research differently and to model ways to keep people visible at every stage of the research process.

Here, Hastings is connecting shared aims of CBR and IE to the pioneering community-based researchers Terry Trussler and Rick

Marchand (2005, 45; emphasis in original), who emphasized that CBR in the HIV field has developed by focusing on "not about what knowledge is or is not but about what knowledge is *for*." IE is deeply concerned with the social practice of objectified forms of knowledge (G. Smith 1990). What counts as knowledge is central for institutional ethnographers, and any combination of IE with CBR requires a commitment to questions of knowledge production, ontological commitment, and what knowledge is for.

Extending Hastings's insights above regarding IE and CBR, Mykhalovskiy offered comments on how the forms of critique offered by IE relate to activist and community commitments:

> A lot of the health sciences associated with HIV are individualizing. IE sits among those approaches to social research that counter the focus on the individual. I think what makes IE a good "fit" with community activism and organizing around HIV is that it is concerned with people, including people living with HIV/AIDS, and what their day-to-day lives, concerns and experiences are – so it connects with a focus of community work to understand and honour the experiences of people. But it offers a different take on those experiences by focusing on their social organization or how they are geared or hooked into forms of knowledge, processes of standardization, ruling practices, and so on that shape and limit people's experiences and that create problems for them. IE's concern with "how things work" or "how things are put together" offers a critical form of knowledge, a way of knowing and challenging what shapes our present that I think is useful for activists and community organizations. Its particular emphasis on how expert forms of knowledge, science, and managerial ways of knowing can objectify and discount people's everyday practical knowledge and experiences of the world offers a kind of critique that can resonate with community and activist politics.

The potential relationships between CBR strategies and IE is an interesting area of potential further development in the Canadian context (Mykhalovskiy and McCoy 2002). For example, just as IE can productively “displace the sociologist as expert,” as Namaste reflected, so too can CBR research strategies, which appear increasingly common in the Canadian HIV/AIDS research landscape, albeit in varied incarnations. In addition to disrupting assumptions about who is the knowledgeable actor and how people are engaged in the research process, both IE and CBR place emphasis on the purpose of generating knowledge. The allied purpose across much IE and CBR HIV/AIDS research in the Canadian context relates to the quotations from George Smith (1990, 629) and Loïc Wacquant (2004, 97) at the beginning of this chapter: generating knowledge of ruling systems with a view toward transformation. That said, conducting IE in ways that are consistent with CBR principles is not a straightforward process and will likely not always be desirable or appropriate.[10] Just as the combination of IE with CBR traditions is not without its challenges, the combination of IE with other theoretical perspectives and critical research strategies raises important questions for researchers.

Combining IE with Other Critical Research Traditions

Critical social scientists have a range of perspectives and traditions they can choose from when formulating their research; this collection serves as a compelling illustration of this theoretical buffet in the HIV research field. However, how a given researcher or group of researchers relates to, and engages in, those perspectives is an open question. Some follow a tradition quite closely, being more comfortable, or possibly professionally socialized, to adhere to a given perspective in a close or even orthodox fashion. Others may either combine and/or select certain aspects of a given approach to follow. This use of theory, of course, raises a number of questions regarding the essential features of a given perspective and the principles and potential pitfalls of the theoretical combination.

Given the commitments of IE as a materialist sociology, the question of combining this critical research strategy with other perspectives is particularly interesting. In my experience, IE is primarily taught as a research strategy – as methodology – to understand how the world is put together as it is. In seminars, conferences, and dissertation defences, I have seen first-hand the tensions and disagreements that can arise when someone who claims to use IE is being perceived as not researching, speaking, and/or writing like an institutional ethnographer. In some, but certainly not all, cases, the selective use of IE principles and/or the combination of IE with other theoretical perspectives has been the main source of disagreement. Researchers were asked to reflect on how IE has been, or could be, combined with other critical research or theoretical traditions in the social sciences. Mykhalovskiy articulated both the challenge and necessity of social scientists reflexively engaging in social theory:

> I think it is important for people who use institutional ethnography in their work or who identify as institutional ethnographers to be conversant with a range of theoretical and research perspectives in the social sciences and to draw on them when they are helpful. The question of how to productively engage with other critical research traditions while holding to the epistemological and ontological commitments of IE is a challenging one. But, in the end, I do think it is possible to engage with contemporary social theory without transforming IE into a project of theory making or without subverting its emphasis on an empirical critique of ruling relations. There are concepts used in other intellectual projects that can be useful for IE and that can assist with the work of exploring how a ruling is actually put together. They can be used in ways that do not produce the mode of theorizing that IE objects to.

Mykhalovskiy highlighted one example of this in his use of the concept of the "medico-legal borderland" in his research on the criminalization of HIV non-disclosure. It is interesting to consider how his account attends to potential concerns on the part of institutional ethnographers about using objectifying theoretical concepts:

> I introduced the concept of the medico-legal borderland to social science research on HIV criminalization [Mykhalovskiy 2011]. It comes from American sociologists Timmermans and Gabe [2003] who used it in ways that some IE scholars might find objectionable. They created or adapted the concept as a way to encourage more dialogue between criminology and medical sociology, by suggesting that scholars attend to sites of intersection between the medical and criminal justice systems including, for example, the creation of medico-legal categories of people such as the criminally insane. I can't speak to how others have subsequently used the concept in their work on HIV criminalization. What I have tried to do is use the concept in ways that can actually assist thinking about how HIV criminalization is put together. I haven't used the concept to lift analysis out of the realm of people's coordinated activities or to create or contribute to some kind of theory about the medico-legal borderland. Instead, I've used it as a kind of conceptual prompt, that encourages me to be mindful of empirical sites where the ruling practices of public health and criminal justice system are both operative and to help empirically explore the many ways those practices work, overlap or are differentiated.

Bisaillon also offered critical comment on the importance of theoretical engagement in the pursuit of IE:

> A central learning that I take away from my first reading of Smith and subsequent opportunity of receiving training from her is to practise curiosity and intellectual diversity. I understand this to involve reading widely and from as diverse a range of materials, traditions and forms as is possible. Doing so nourishes the quality of our experiences, sharpens our analytic abilities, and challenges our assumptions, which all stand to benefit our research. And yet, from my experience in academic institutional ethnography milieus, I am led to concur with Kevin Walby's [2007, 1010] observation that "most institutional ethnographers draw almost exclusively from [Dorothy Smith] for theoretical

> guidance." On the one hand, this seems to me to be an economical or reasonable choice if made, for example, within the parameters of a doctoral project. On the other hand, I believe that human curiosity is likely to lead many of us to want to blend, experiment, and reach in the direction of syncretic forms of research practice. And so, I am suggesting that too narrow a commitment to any single approach, whether IE or another strategy, dangerously limits us as thinkers and researchers. Importantly, for the purposes of knowledge production, too narrow an insistence on a single approach constrains what we can find out about the social problems and processes we are grappling to understand ... Where we draw from and experiment with approaches that share a common genealogy and/or ontological and epistemological commitment with IE, I suggest that we position ourselves to valuably push beyond the contours of what has come before.

Adding to these reflections, Bisaillon spoke to the importance of engaging with social theory and what she learned from Dorothy Smith in an IE training course: "If you want to know about Marx, you need to read Marx, Smith told students. Reading historical texts and source materials is important because our engagement gives us the opportunity to interpret for ourselves."

The most common critical research tradition discussed by researchers interviewed was the field of governmentality and Foucauldian perspectives. For example, Hastings's work in this collection looks at the relationship between IE, biological citizenship, and Foucauldian scholarship. In reflecting on Foucauldian traditions and IE, Hastings noted:

> I think intriguing and important conversations happen when we place critical social scientific research into conversation with IE and its insistence on starting with the grounded fullness of people's embodied, everyday lives. I think combining IE and other research traditions prompts us to think carefully about how effectively critical social science keeps the presence of embodied subjects as knowers in view.

McCoy highlighted the tension of engaging in studies of governmentality and other social theory traditions while remaining true to the core commitments of IE:

> One of the principles of institutional ethnography is to keep people and their activities at the forefront of analytic description. In her writing, Smith has always been sharply critical of analytic accounts that give agency to theoretical objects. Michael Billig [1994, 2011], writing recently on language in the social sciences, is similarly critical of what he calls "depopulated" accounts in which noun-heavy language makes it nearly impossible to refer back to anything people might be doing. Two of the critical research traditions that interest people who are also interested in institutional ethnography are actor-network theory and studies of governmentality. I have learned much from both of those analytic projects. But I try to take those ideas/visibilities/challenges into the institutional ethnographic project without adopting elements of their conceptual language that work against the kind of analytic description I strive for.

Given the popularity of Michel Foucault in the social sciences and HIV/AIDS research, and mutual interests in power relations, texts, and strategies of governance, it is perhaps not surprising that the field of governmentality and Foucauldian perspectives was discussed by multiple researchers as a theoretical tradition that could be potentially used in concert with IE (see Adrian Guta and Stuart Murray in this volume). Like Mykhalovskiy's interview reflections discussed above, I share the belief that being knowledgeable about critical social theory and making use of it strategically within one's IE work is possible "without transforming IE into a project of theory making or without subverting its emphasis on an empirical critique of ruling relations." While I am mindful of McCoy's concerns about not reifying theoretical objects in one's institutional ethnographic writing, I think it is possible to critically deploy the conceptual language of critical social theory while remaining true to the roots and ontological commitments of this tradition. Current work that seeks to build on critical social theory, Foucauldian traditions, and IE (see Mark Gaspar as well as Colin Hastings in this volume) represents an exciting theoretical trajectory in the ongoing development of this scholarly tradition.

IE and Future HIV/AIDS Research in Canada

As Campbell and Gregor (2005, 14) have argued, "the potential for the marriage of scholarly research and political engagement remains a motivation for successive generations of students working in institutional ethnography." The commitment to scholar activism when using IE in the field of HIV/AIDS has continued in the activities of many Canadian academics, as highlighted in the work of scholars I interviewed to prepare this chapter. At present, this strategy for social research continues to be drawn on in varied HIV/AIDS research projects that range from small studies conducted by graduate students to relatively large programs of research completed by multidisciplinary teams. The perspectives from social scientists drawn on in this chapter provide insight into how researchers continue to focus on access challenges, building on the legacy of HIV/AIDS institutional ethnographic work in Canada. The possibilities for engagement in both CBR approaches and other theoretical traditions when conducting IE were reviewed.

The current HIV research funding climate in Canada poses challenges not simply to IE research but also to diverse traditions of critical social science scholarship that do not fit neatly within an applied tradition. That said, some IE scholarship has the possibility of being framed in a way that is consistent (or certainly not antithetical) with applied research, such as research that aims to understand health systems and bureaucratic practices for the purposes of improving health care processes or service access. Some institutional ethnographic research may also be framed as being consistent with the objectives and principles of CBR that have been mainstreamed within Canadian Institutes of Health Research funding calls. I argue that in some cases IE may be better equipped to do CBR than positivist social science research traditions that are labelled CBR but do not have meaningful, sustained engagement with people in the everyday world.

Some institutional complexes, such as the criminal justice system, may remain a somewhat "closed shop" to those who seek the kinds of rich, empirical data IE demands. From my research work experience to date, I have come to recognize that, at times, it may be strategic to use IE (or key principles of IE) alongside other research traditions especially in the context of large, biomedically focused multidisciplinary research studies that are common in much HIV/AIDS research (Grace et al. 2015). Such marriages across research traditions may be challenging for multiple reasons, including how the institutions in which some researchers work (for example, hospitals, universities) frequently become objects of critical inquiry.

Current interest in using quantitative research techniques in the context of IE – a topic of discussion at the recent Society for the Study of Social Problems IE meetings – may also help open up possibilities for IE being conducted as part of multi-method research teams largely situated within the quantitatively driven public health sciences. I continue to experiment with these possibilities in my own mixed methods public health research (Grace et al. 2014). However, quantitative methods may not be useful in much IE inquiry, and it is also worth considering if and when seeking large state funding for IE research is the appropriate course of action – a point much debated in activist-oriented research in and beyond the HIV research sector.

A number of the researchers interviewed provided reflections on the state of institutional ethnographic research in the area of HIV/AIDS in Canada. I will conclude this chapter with their call for continued critical engagement with IE. One example focuses on suggestions for IE research in a particular substantive area: biomedical prevention.[11] In light of IE's unique capacity to ethnographically explore large-scale forms of social organization, Mykhalovskiy called for new directions in this area of research:

> We need more of it. I think scholars interested in biomedical prevention might make use of IE to try to get at some of the

> institutional and discursive relations through which a novel (preventative) use of biomedical therapy is coming into being. Most of the studies of biomedical prevention that I've read are conceptually organized by concerns about "roll out" or "uptake" and so contribute to a kind of managerial project of promoting its use. I think IE can offer an alternative to that type of research by linking people's varied experiences of PrEP [pre-exposure prophylaxis] or PEP [post-exposure prophylaxis] or TasP [treatment as prevention] to the complex of processes through which new preventative uses of what has until recently been a clinical treatment are being tested, known, promoted, funded and so on.

I am currently engaged in PrEP research – conducting qualitative research with people who have accessed PrEP – and have found the tool box of IE to be analytically helpful as I consider how to come to understand the healthwork of people trying to gain and maintain PrEP access (Grace et al. 2018). Beyond access and "roll-out" questions, mapping the governing processes related to PrEP in the lives of gay men are central to this work. While research on PrEP is different from foundational IE scholarship reviewed at the outset of this chapter (G. Smith 1988, 1990), I am also interested in how current research and activism in this field may help to address system failures. Like Mykhalovskiy, Namaste also saw promise in further IE research in the HIV/AIDS field in Canada:

> I look forward to future iterations of IE, with regard to HIV/AIDS and beyond. That said, I would encourage students and practitioners to take up the IE challenge of always, at some level, engaging in a research process that is disruptive. IE emerged out of an interest and commitment to documenting and explaining the disjunctures of life, and is [profoundly] unsettling in this regard. As it develops, it would be useful, I think, to remember this general approach: IE is best used not as a simple recipe, but as a lever into how we understand and the limits of what and how we know. I would encourage students of IE in particular, then, to move beyond a simple case study or application of the

> framework. I would encourage them to begin to explore more broadly not simply what IE can offer a substantive area (for example, Aboriginal women and HIV), but rather how IE orients us to knowledge differently, and why that matters for our current and future knowledge work in the HIV/AIDS epidemic.

The continued interest in this tradition by scholars, including a growing number of graduate students who become quickly "hooked," make me optimistic about the sustained and expanded use of this critical social science research strategy. The institutional ethnographer, as critic, is able to "see that our world is marked by extreme inequalities and injustices, and that our knowledge of ourselves and our world is caught up in those very practices and structures of inequity and domination" (Carroll 2004, 2). The IE critic also recognizes, as is evident in this chapter, that their social science research is part of an ethical-political project of positive social transformation (Carroll 2004). IE research in the field of HIV/AIDS is, and must remain, deeply political. While much has been done in this field, the potential for IE to contribute to a critical social science on HIV is only beginning. IE, of course, does not offer a methodological silver bullet for all HIV social research. However, IE's focus on drawing on lived experience and everyday actualities to elucidate social relations and institutional processes – with a view toward positive social change – offers significant opportunities for expanded application in the field of HIV research.

Notes

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1 Dorothy Smith (2005, 227) continues this explanation of ruling relations: "They are objectified forms of consciousness and organization, constituted externally to people and places, creating and relying on textually based realities."

2 For a thoughtful interview on the history of Dorothy Smith's work, including reflections on her reading of Karl Marx and her experience with her doctoral supervisor Erving Goffman, see Carroll 2010.

3 I was mentored in institutional ethnography (IE) through the supervision of experts in this field – namely, Dorothy Smith, Bill Carroll, and Eric Mykhalovskiy. I have also had the opportunity to discuss the critical foundations, challenges, and new possibilities of this alternative sociology with many colleagues over the last eight years through casual discussions, formal mentorship opportunities, and organized spaces for critical dialogue such as the annual Society for the Study of Social Problems conference.

4 It is important to note that many fantastic introductory resources to IE exist for researchers new to this tradition (e.g., Campbell and Gregor 2002; D. Smith 2005). My hope is that this account will complement these resources.

5 The quotations from researchers throughout this chapter are taken from interviews with scholars working in the field.

6 As the AIDS Activist History Project, https://aidsactivisthistory.ca/, puts it: "AIDS activists changed the world. They organized, strategized, and put their bodies on the line. They worked for change in Canada, and worked to extend the lives of people living with HIV/AIDS."

7 This work of G.W. Smith has been undeniably influential within and beyond IE circles, inspiring researchers and activists (see, e.g., Frampton et al. 2006).

8 Namaste was referring to the Quebec context in the 1990s and noted that this has recently changed legally in Quebec.

9 For example, in my own graduate training, I, along with others contributing to this critical social science collection, have had opportunities to benefit from training/funding programs in community-based research (CBR) / community-based participatory research (CBPR), including Universities without Walls (UWW) (Worthington et al. 2014). Programs such as UWW place emphasis on commitments to CBR/CBPR (Israel et al. 2003); Ownership, Control, Access and Possession Principles for research with Aboriginal Peoples (Schnarch 2004); and the Greater Involvement of People Living with HIV/AIDS (McClelland and De Pauw 2010; Worthington et al. 2014, 188).

10 Researchers have also highlighted the negative implications and governing practices of some CBR research in the field of HIV/AIDS in Canada (Guta et al. 2014).

11 This volume presents a series of chapters that engage in critical social science to complicate and contextualize the everyday actualities of implementing biomedical HIV-prevention strategies, including a critical case study of prescribing pre-exposure prophylaxis to "at risk" adolescents in the United States (Chris Sanders, Jill Owczarzak, and Andrew Petroll in this volume). For an overview of biomedical HIV-prevention interventions, see "Highly Effective HIV Prevention Strategies," *HIV in Canada: A Primer for Service Providers,* https://www.catie.ca/en/hiv-canada/4/4-2A.

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4

Conversation Analysis and Critical Social Science

The Interactional Organization of HIV-Positive Disclosures

Jeffrey P. Aguinaldo

THIS CHAPTER DEMONSTRATES THE utility of conversation analysis (CA) for critical social science in the field of HIV/AIDS. I first examine the key features of CA, the tensions that arise between CA and critical social science, and the possibilities of CA for critical social science on HIV/AIDS. I then demonstrate the utility of CA for critical social science through an analysis of interactional disclosures of HIV status. I conclude the chapter with a discussion of issues that arise for those who wish to pursue CA for critical social science on HIV/AIDS.

CA is the method *par excellence* for the study of talk-in-interaction. It is defined by its commitment to develop a cumulative body of empirical findings on the competencies people use to participate in intelligible conversation. One feature of CA is its use of extremely detailed transcripts in conjunction with corresponding audio or video recordings of interactions. Jeffersonian transcription notation commonly used by conversation analysts represents the minute details of talk, including in-breaths, exhales, pauses, cut-offs, overlaps among speakers, and intonation (see Atkinson and Heritage 1984). Unlike other qualitative analytic methods, CA attends not only to the content of what people say but also to how it is delivered in interaction. A second feature of CA is its analytic assumption that talk is action-oriented. People do things (such as compliment, accuse, challenge, request, offer) through talk, and CA's analytic goal is to discover the practices through which those actions are accomplished. As CA has shown, participants draw meaning from, and exploit, the minutia of talk to discern and effect action in interaction. A third feature of CA is its preference for the analysis of naturally occurring interactions. In relying on naturally occurring rather than researcher-driven data, such as those gathered by interviews and focus groups, CA has been able to identify the organizational features of talk-in-interaction: turn-taking (Sacks, Schegloff, and Jefferson 1974), repair (Schegloff, Jefferson, and Sacks 1977), sequence organization (Schegloff 2007), person reference (Sacks and Schegloff 1979), action formation (Schegloff 1996), and preference organization (Pomerantz 1984).

It should be apparent by now that CA is not, in the first instance, a critical enterprise. There is a tendency for scholars to gravitate toward particular modes of inquiry to do critical social science. A survey of the current volume reveals a set of theoretical and methodological frameworks, including Foucauldian analysis (Adrian Guta and Stuart Murray), decolonialism (Randy Jackson), and critical or institutional ethnography (Denielle Elliott, Colin Hastings, Daniel Grace), which are attractive to critical scholars because these frameworks presume from the start, the operation of power that an analysis must expose. By contrast, Emanuel Schegloff (1997), one of CA's progenitors, warned against analyses of interaction that presume, in advance, asymmetries of power between or among speakers to explain what is happening in interaction. Those who hope to benefit from the methodology of CA should bracket their own theoretical and political commitments in order to privilege participants' orientations as they are displayed in interaction. These orientations, not the concerns of the academic analyst, are what constitute the socio-interactional reality. For analysts to rely on explanations external to the interaction is said to commit a form of "theoretical imperialism," which simply prioritizes the analyst's understandings over those of the participants (167).

In response, some scholars argue that CA is fundamentally incompatible with critical social science (for example, Billig 1999; Wetherell 1998). Others complain that CA "has had very little to say about gender, and next to nothing about sexuality, 'race,' class, and the normalising of dominance and oppression" (McIlvenny 2002, 24). Indeed, even a cursory review of classic CA collected editions (for example, Atkinson and Heritage 1984), handbooks (for example, Sidnell and Stivers 2013), and instructional texts (for example, Hutchby and Wooffitt 1998; Sidnell 2010; ten Have 1999) would lead one to conclude that CA holds no intrinsic commitment to critical inquiry and that practitioners of CA need not necessarily engage in socio-political critique in order to do good rigorous CA. However, as someone who is committed to the aims of critical social science both within and beyond the field of HIV/AIDS and who draws on the analytic insights of CA, I argue that an analytic method's apolitical commitments do not necessarily negate its utility for critical social science.

The relationship between a critical social science perspective and the analytic method used to achieve the goals of such a perspective is not so straightforward. Noted epidemiologist Nancy Krieger (1994, 889) is critical of the assumptions on which her discipline is based and observes the "incomplete and biased slant of epidemiologic theories reliant on a biomedical and individualistic world-view." However, this has not compelled her to reject epidemiology but to use it strategically in order to document inequalities in health and experiences of discrimination (for example, Krieger 2014). Feminist methodologists acknowledge the utility of positivist empiricism for critiquing the sexism of mainstream health research as "bad science" and for developing and asserting their own egalitarian "good science" (Wilkinson 2004). Similarly, research used to compel the removal of homosexuality from the *Diagnostic and Statistical Manual of Mental Disorders* was based not on social constructionist or Foucauldian analyses of homosexuality but on traditional experimental psychology that "proved" the normalcy of homosexuals (cited in Bayer 1987). My point here is not to endorse epidemiology, positivist empiricism, or experimental psychology uncritically but, instead, to advise that it is a mistake to overlook any one analytic framework as a potential tool for critical work simply because that framework is not critical in its intent or by its design.

Uses of so-called value-neutral methods for critical purposes are evident in a number of influential anthologies on the social and cultural aspects of HIV/AIDS (for example, Aggleton, Davies, and Hart 1990, 1993; Aggleton, Hart, and Davies 1991). These anthologies include scholarship that utilizes longitudinal cohort studies (Abrams et al. 1990), survey data (Currie 1990), and program evaluation (Gatter 1993). Such methods do not mandate a critical analysis but are nevertheless used toward that goal. Scholarship of this sort suggests that critical politics can be achieved not by rigid selection of theory or method but from a commitment to pursue critical politics and capitalizing on whatever tools are available to achieve those goals (although see Randy Jackson in this volume for a more ambivalent perspective on Western methodologies).

CA offers critical social science a rigorous analytic method that identifies the specific practices through which interaction is accomplished. Technical aspects of interaction such as turn-taking and sequence organization might seem far removed from issues such as HIV/AIDS. However, as Don Zimmerman (2005, 445) suggests, “such issues can have very ordinary affairs as a foundation, sustained by routine and largely unnoticed practices that are a part of interactional organization. Perhaps big issues have a humble home hidden in plain sight, in the ordinary workings of social life.” More recently, some have used CA to articulate the mundane operation of racism (Whitehead 2015), sexism (Weatherall 2015), heterosexism, and heteronormativity (Kitzinger 2005; Land and Kitzinger 2005) as these are produced and resisted in interactions. For these scholars, it is in and through interaction that inequality and oppression are enabled and realized at a micro level.

Schegloff (1998, 415–16) offers one programmatic articulation of the intersection between CA and critical social science, which we might then extend to critical work on HIV/AIDS. It begins by

> addressing what the parties to the interaction understand themselves to be doing in it, what sort of interaction they show themselves to be collaboratively constructing. Each utterance could then be understood by reference to its place in that enterprise. And then attention might be turned (if there was continuing interest in doing so) to issues of cultural constructions, ideological formations ... Those analyses would not themselves be conversation-analytic, because they would be grounded in, and answerable to, concerns extrinsic to the interaction (unless of course it were possible to show the parties themselves oriented to these terms of analysis). But they would be addressed to utterances, to discourse, interpreted by serious reference to what they seriously were for their speakers and recipients.

This approach starts from CA's mandate to privilege participants' orientations, but it then departs from that mandate by interrogating those orientations. Put another way, CA identifies the specific practices that produce socio-interactional realities, and critical social science evaluates those realities for their social and political import. Of course, the terms by which "import" is weighed and assessed must be clearly articulated by those whose concerns are now imposed on (and may not be shared by) participants in the interaction. For Zimmerman (2005, 445), "an understanding of language and interaction affords purchase on how typical, recurrent, obdurate social configurations are produced, often as a by-product rather than as a conscious aim of mundane, everyday practices."

There are, then, at least two possibilities for the intersection of CA and critical social science on HIV/AIDS. One possibility would explore the ways that HIV risks are negotiated through talk or other means (such as gesture or gaze) in interaction. Such a project coincides with Mark Gaspar's work in this volume that documents the contingencies that inform sexual decision making among gay men. CA could potentially contribute meaningfully to Gaspar's research by understanding how viral load or other sexual health information might be tacitly sought out, conveyed, assumed, or foreclosed *in situ* that might then inform interactants' sexual risk behaviours. In CA terms, this research would ask: how is HIV made relevant in interaction? Another possibility, one that will be explored in this chapter, is to identify the everyday practices that collectively constitute the normative social world and the ways that world might exclude and marginalize people living with HIV/AIDS. This approach starts from the assumption that an HIV-positive status is not only a biological or medical condition but also a social identity that, like any other "spoiled identity," forms the basis for stigma and discrimination (Goffman 1963). For critical scholars, CA can be used as a tool to denaturalize the taken-for-granted social world and to envision "another world as possible" (Sayer 2009, 772).

My own interests in this area stem from my critical social science commitment to expose not only the full range of social oppressions but also the array of practices that facilitate those oppressions. HIV activists have campaigned against the most egregious forms of HIV-related stigma and discrimination through macro-level interventions, such as social media campaigns (for example, HIVstigma.com and HIVequals.org) and international public policy (for example, UNAIDS 2014). Such interventions seek to subvert stigmatizing assumptions about HIV and, in effect, normalize people living with HIV/AIDS. Despite these interventions, I am acutely aware of the persistence of a normative social world that sustains HIV-related stigma and discrimination. CA is uniquely fitted to articulate how that world is produced in and through interaction. In the next section, I demonstrate the utility of CA for the analysis of the ways a normative social world materializes through disclosures of HIV.

HIV-Positive Disclosures

People living with HIV/AIDS treat disclosures of their status as profoundly meaningful events. HIV-positive mothers disclose to their children in order to educate them about HIV or to prepare them for potential health concerns that might arise if the mother's health deteriorates (Schrimshaw and Siegel 2002), and HIV-positive gay men disclose to their sexual partners out of a sense of morality (Klitzman 1999). The stress of disclosure compels people living with HIV/AIDS to plan timing, target selection, and method of disclosure (Catona, Greene, and Magsamen-Conrad 2015; Cusick 1999; Klitzman 1999) in order to manage anticipated negative responses from those to whom they disclose (Greene and Faulkner 2002; Kalichman et al. 2003). Research suggests that disclosure of one's HIV-positive status reflects the integration of HIV with one's sense of identity (Baumgartner and David 2009), resulting in improved psychological "release" from the shame of HIV (Paxton 2002). For many, disclosure of HIV in interaction is perhaps one key site where a stance toward HIV is displayed and consolidated by participants in that interaction. According to Tewksbury and McGaughey (1998, 221), HIV disclosure "is the event that most clearly and substantively alters the way others (e.g., family members, friends, coworkers, employers) perceive, define, and interact with the individual."

The vast majority of research on HIV disclosures is based on data gleaned from surveys or semi-structured interviews in which research participants share recollections of their HIV disclosures. There are very few studies that use actual instances of HIV disclosures as the primary source of data. For example, in a recent anthology on disclosures in health and illness (Davis and Manderson 2014), research on HIV disclosures (Davis and Flowers 2014; Root 2014; Squire 2014) relied exclusively on retrospective accounts. Although qualitative interviews are a powerful method for gathering participants' perspectives, the analysis of actual instances of HIV disclosures can identify social processes that participants may not report during a qualitative interview.

To date, I have collected nine interactional instances of HIV status disclosures. These disclosures come from a variety of sources including doctor-patient interactions and talk show interviews. The interactional disclosures of HIV analyzed for this chapter were taken from two reality television shows on HIV/AIDS. These interactions were transcribed (see Appendix A for transcription notation), and I have indicated on the transcripts where production edits may have been made. Although conversation analysts urge caution when using interactions from reality television shows as data because these shows are often edited in ways that might call into question the integrity of the interaction (Sidnell 2010), we should nevertheless "allow ourselves to notice (and be inspired by) candidate phenomena however way they come to our attention" (Kitzinger 2008, 185). I thus submit these candidate instances and analyses of them as a proposal for continuing research on the interactional organization of disclosures of HIV.

Extract 1 is taken from MTV's *I'm Positive*. This television special documents the struggles of three twenty-something HIV-positive youths. Kelly, a twenty-five-year-old women living in Santa Monica, California, who tested positive for HIV at the age of twenty-three, had called her ex-boyfriend Dan whom she has not seen for some time to arrange a meeting because she has "so much to tell." After greeting Dan at his gym, Kelly jumps on a nearby trampoline as Dan watches on for an unknown length of time. Extract 1 begins when Kelly dismounts the trampoline and sits down to talk with Dan.

Extract 1

01 KELLY: a'right. uHHhhh
02 ((cut))
03 DAN: so what is::: (0.2) <°this.°>
04 KELLY: wha:t- u::m yeahhhh. I 'av u:mh gone through alott'uv: changes.
05 hhh u::mhh .hhh I have HIV. HHh .hhhh
06 (0.3)
07 KELLY: [hhhh
08 DAN: [seriously?
09 KELLY: seriously.
10 (0.4)
11 DAN: HH [hhh ((his eyes lower and shift to his right then left))
12 KELLY: [↑yeah:: u:mhh
13 DAN: I don't really know what to say tuh that. uhHHuh
14 KELLY: I know. (0.3)/(.hhh) u:::m hh
15 (.)

16 DAN: when. er: ho:w.
17 (0.3)
18 KELLY: my ex:. (0.2) u:[:m]
19 DAN: [wo]oh:::.
20 KELLY: yeah hhh .hhh
21 DAN: do you still talk to him?=
22 KELLY: =no.
23 (0.2)
24 KELLY: like I: I'm fine now. .hhh yihknow I'm on:: I'm on medication::,
25 I:m:: undetectable,
26 (0.2)
27 [a::nd
28 DAN: [what does that mean.
29 KELLY: undetectable mea:ns that (.) thuh: virus: is: suppressed to thuh
30 point where you: almos:t can't detect it in:: my blood. an: [duh]
31 DAN: [can]
32 it get worse than that?
33 KELLY: .hhh if I don't take my medicine_ if I'm not under: proper
34 medical supervision. (.) it ca:n get worse than that.
35 (0.2)
36 but um in this day and age wi:th medication the way it is, (.)
37 u:m: I'm gonna live until my seventies. I can have a totally
38 normal li:fe,
39 DAN: °tha[t's good.°
40 KELLY: [I can have kids an:: an [not
41 DAN: [really?
42 KELLY: ↑yeah
43 (.)
44 yeah.
45 DAN: ↑o::h. ↑wow.
46 ((cut))
47 KELLY: I- I was waiting to tell you in person. yihknow,
48 DAN: thank you.
49 KELLY: you mean a lot to me.
50 ((cut))
51 but yeah.

52 DAN: that's [crazy.
53 KELLY: [that's what's goin' ↑on.
54 ((cut))

In this brief extract, Kelly's disclosure of her HIV-positive status occurs (on line 5) after some intervening activity that delays her disclosure.

Like *I'm Positive,* MTV's *Me, Myself and HIV,* from which Extract 2 is taken, follows the lives of young people who are HIV positive. Paul, a twenty-one-year-old disc jockey and aspiring hip-hop artist living in Lusaka, Zambia, is out for lunch with Carol, his not-yet girlfriend. After lunch is served and part way through their meal, Carol solicits news from Paul (line 2), and Paul eventually discloses his HIV-positive status, likely to determine the possibilities for a more serious relationship with her.

Extract 2

01 ((cut))
02 CAROL: you look like you want to say something
03 (1.2)
04 PAUL: yeah. I'll say it.
05 (1.2)
06 CAROL: what's that,
07 ((cut))
08 CAROL: you're mak'in me nervous. just ta:lk.
09 (1.5)
10 ((cut))
11 PAUL: one guy I know.
12 CAROL: mhmm
13 PAUL: he's got big drea::ms, (0.6) he knows he's gonna ma:ke i:t, that
14 kinda thing, (0.2) but he's HIV positi↓:ve('n) he keeps thinking
15 abou:t (1.2) hav'in a wife, (0.3) would you date such a man.
16 ((cut))
17 CAROL: ↑yeah. what's wrong with that.
18 (0.3)

19 PAUL: like really.
20 (0.4)
21 CAROL: hmmm?
22 PAUL: like really.
23 (0.2)
24 [you mean that.
25 CAROL: [((nods))
26 (0.5)
27 PAUL: uhn nHuh .HHh (.) wo:::w.
28 ((cut))
29 PAUL: can I tell you a little more about that guy.
30 (0.4)
31 CAROL: shaw.
32 (0.4)
33 PAUL: are you sure.
34 CAROL: mhmm
35 (2.2)
36 PAUL: I'm that guy.
37 (11.0)
38 CAROL: yuh (0.3) yuh mean it?
39 (1.0)
40 PAUL: yeah. like I'm not joking like (0.2) seriously. I'm thet guy.
41 ((cut))
42 CAROL: there's one thing about HIV. it only has people's body, (0.3)
43 but it doesn't have their minds, (0.7) and feelings, (0.5) and
44 their heart.
45 (0.4)
46 PAUL: wow.
47 (1.5)
48 I guess what you're: try'in to tell me is um: (0.3) it's alright
49 with you,
50 (0.2)
51 CAROL: °°yes°° ((nods))
52 PAUL: like seriously?
53 CAROL: °°mhmm°° ((nods))
54 (0.3)

55 PAUL: like you mean it?
56 CAROL: mhmm ((nods))
57 PAUL: mhh Hhhhh
58 ((cut))

Paul's disclosure is reminiscent of what HIV scholars call "incremental disclosures," which involve revealing one's HIV-positive status in stages so as to gauge the reactions of recipients (Catona, Greene, and Magsamen-Conrad 2015). Paul discloses ("I'm that guy," line 36) after Carol registers her response (line 17) to his initial inquiry about dating "one guy I know" (line 11) who is HIV positive (line 14).

There is considerable CA literature on the interactional organization of sharing information. New information can be offered in such a way as to share some event-in-the-world without treating it as the focal action of the talk. To say to a host of a party, at which you just arrived, that a mutual friend, "Ryan, wanted to come but he had a death in the family and so wasn't able to make it" conveys information of the death in Ryan's family. However, the focal action of the turn is not to announce this death as news but, rather, to explain or excuse Ryan's absence from the party. Of course, the death in Ryan's family could be "extracted out" and responded to as news, thereby shifting the trajectory of the conversation toward the death in Ryan's family and perhaps the emotional aftermath as a result of it. But the information of that death is, in a sense, buried in its presentation and obviates any requirement for uptake (see Terasaki 2004). By contrast, news announcements are designed to be responded to (as newsworthy) and make relevant a receipt and assessment of the information. The delivery of news is the focal action of news announcements. They sometimes follow pre-announcements ("guess what?") or news inquiries ("what's new?"), which prepares for news to be told. Of course, what I have described here is an oversimplification of what Douglas Maynard (2003) calls a news delivery sequence, which can be expanded by consecutive newsmarks, elaborations, and the like or curtailed altogether by claims that one already knows what will be told.

A first observation, then, is that Kelly and Paul's disclosures are not simply conveying information about their HIV status. They are designed specifically to announce their HIV status as news. In Extract 1, Kelly's announcement of her HIV status is occasioned by Dan's inquiry ("so what is this," line 3) and is received as news via Dan's newsmark ("seriously?" line 8). Dan's final assessment ("that's crazy," line 52) after a series of elaborations accepts the news and proposes to bring the news delivery to a close, which Kelly ratifies (line 53). In Extract 2, Paul's disclosure is prepared for by the pre-announcement: "can I tell you more about that guy" (line 29), which builds on his initial telling of an HIV-positive "guy I know" (line 11). Like Dan, Carol marks Paul's disclosure as news (line 38) and provides a positive spin to the news (lines 42–44), which Paul takes as an assessment ("I guess what you're trying to tell me is it's alright with you," lines 48–49). That Kelly and Paul are doing news announcements and that Dan and Carol jointly participate in the production of those announcements rely not on an assumption of one's positive HIV status as inherently newsworthy but on the interactional organization of their disclosure. However, to leave the analysis at that would gloss over important details of the talk that suggest the news is of a particular sort.

From a CA perspective, the valence of news announcements does not rely on the inherent goodness or badness of the news reported. After all, announcements of pregnancies can be either good or bad news, as can deaths in the family. The valence of news announcements depends not only on the choice of words used to characterize the news but also on prosody and sequential placement of that announcement. Pre-announcements, such as "I have some great news to tell you," provide clues to recipients about the (good) news to come and serve as a resource to determine the appropriate response (for example, "how wonderful!"). Good news is often marked by high pitch or fast talk, laughter particles, and smiles (or smiley voice), all of which convey enjoyment, eagerness, or excitement (Freese and Maynard 1998). Good news is immediately volunteered and forthrightly delivered. At times, good news may be interactionally delayed, but the valence of the news (as good) is often "leaked out" to heighten anticipation (Maynard 2003). By contrast, bad news is characteristically delayed and may require multiple requests or "go-ahead" signals for the news to be told. Bad news is often delivered with low intonation and slowed speech, which conveys reluctance to tell (Freese and Maynard 1998). As Maynard (2003) notes, bad news is sometimes forecasted (for example, "something happened to Ryan today") and is often followed by "good news exits" in the form of remedy announcements, bright-side sequences, and optimistic projections before new interactional business can be initiated (Maynard 2003).

A second observation, then, is that Kelly and Paul's disclosures of HIV are produced as bad news. For example, neither Kelly nor Paul reveal their status straightforwardly and, instead, delay their telling. Kelly's news is delayed in two respects. First, while Kelly's disclosure in Extract 1 occurs relatively early in the transcript, her disclosure is delayed by intervening activity (with the trampoline) for an unspecified amount of time, and Dan's observable conduct displays an understanding of Kelly's news as having been delayed. His inquiry (on line 3), which elicits the news for which he had been summoned to receive, is marked with a so-preface. According to Galina Bolden (2008), the discourse marker "so" (for example, "so what's up?") is commonly used to preface utterances that introduce the (first) official business that prompted the interaction but was delayed by substantial expansion or interruption of the opening sequences of the interaction (see Schegloff 1986). While "so's" are not obligatory for such "moves to first topic," they nevertheless flag to recipients that some pending official business is now being introduced into the conversation. Thus, in Extract 1, Dan's so-prefaced inquiry serves to initiate the telling of Kelly's news that he understands to have been derailed. Second, rather than immediately deliver her news in response to Dan's inquiry, Kelly relegates her news to the last turn construction unit of a multi-unit turn (lines 4–5) (Sacks, Schegloff, and Jefferson 1974). Kelly begins, but then abandons, what could be a response to Dan's prior turn as a straightforward question (for example, "what [this is, is ...]"). But where Kelly could conceivably have delivered her news, she instead delays (with "um, yeah") and then forecasts the news ("I have gone through a lot of changes," line 4). Only then, and with some hesitation, does she finally announce her news ("I have HIV," line 5).

In Extract 2, Paul delays what Carol (and we) later learns to be his disclosure of HIV. At the beginning of the extract, Carol attempts to solicit any newsworthy items from Paul ("you look like you want to say something," line 2). But rather than deliver his news, Paul defers his disclosure, resulting in a 1.2 second pause (line 3) and, with an agreement token ("yeah," line 4), he simply confirms that he does, in fact, have something to say. Again, Paul declines to deliver his news at this point and, instead, offers a compliance token ("I'll say it," line 4) that both orients to the now relevantly missing thing-to-be-said and yet forestalls its delivery. In the absence of the pending thing-to-be-said, which results in another 1.2 seconds of silence (line 5), Carol pursues (line 6), thereby providing yet another interactional slot for Paul to share his news. The recording is cut, and we are brought back to one further attempt (on line 8) by Carol to pursue what Paul has to share. However, by now, Paul's displayed reluctance in the face of Carol's repeated solicitations begins to hint at the thing-to-be-said. Although it is equivocal to Carol that what Paul is about to tell is bad news, Carol nevertheless orients to the gravity conveyed through Paul's delivery ("you're making me nervous," line 8) before pursuing with a reassuring "just talk" (line 8).

In sum, HIV disclosures as news announcements can convey a stance toward HIV. Clearly, Kelly and Paul do not disclose their HIV status in a matter-of-fact way nor do Kelly and Paul rush to disclose their status in a display of exuberance to share their good fortune. Instead, the bearers of the news produce their disclosures as the telling of bad news by characteristically "shrouding" their news with delays and forecasts (Maynard 2003). In doing so, news bearers convey a reluctance to tell. In the face of Kelly and Paul's less than forthrightness, Dan and Carol must extract the news with (sometimes repeated) solicitations.

One final observation, then, is that Dan and Carol orient to the news bearers' announcement of their HIV-positive status as bad news. Neither recipient responds to Kelly and Paul's HIV disclosure with "oh," which would have displayed simply that they have been informed by the news (Heritage 1984) or with "wonderful," which would have displayed an understanding that good news had been delivered. Of course, at the same time, neither recipient explicitly registers the news as bad (for example, "I'm so sorry to hear that"). However, Dan and Carol align with the news announcement as bad news by collaboratively moving toward "good news exits" (Maynard 2003). For example, in Extract 1, Dan declines to provide an assessment to the announcement (line 11, 13). Instead, he seeks elaboration ("how?" line 16), perhaps to determine a more fitted response, and Kelly discloses by whom she was infected ("my ex," line 18) to which Dan assesses with a sympathetic "wooh" (line 19). Kelly receipts his expression of sympathy (line 20) and further shares that she no longer has any involvement with her ex (line 22). But where the conversation could have descended into troubles talk (Jefferson 1988), Kelly instead initiates optimistic projections that effectively mitigate reception of her news as bad. She describes the improved state of her health ("I'm fine now," line 24; "I'm undetectable," line 25) and her access to medication (line 24). Although recognizing the possibility that her health might deteriorate (lines 33–34), Kelly reports a favourable prognosis ("I'm gonna live until my seventies. I can have a totally normal life," line 37–38; "I can have kids," line 40). Thus, Kelly goes to considerable lengths to buffer the news of her HIV status with optimism. While Dan encourages Kelly's elaborations (lines 16, 19, 21, 28, 31–32) and eventually aligns with her optimism (lines 39), his alignment is nevertheless based on the presumption that having HIV is bad news, which can nevertheless be overcome.

In Extract 2, it is the news recipient, Carol, who consoles Paul for the news he has shared. After marking Paul's announcement as news (line 38), Carol ratifies the valence of that news (as bad) through her optimistic characterization (line 42–44). In it, she relegates the impact of HIV only to "people's body" (line 42) and not to their "minds and feelings and their heart" (line 43–44). Her response offers a proverbial "silver lining" that provides a positive spin to the bad news Paul shared. Thus, Carol aligns with Paul's stance of his HIV-positive status as bad news by offering consolation that his news is not so bad.

Of course, much more can be said about Excerpts 1 and 2. However, given editorial constraints, I limit my analysis to the claims that Kelly and Paul produce their HIV disclosures, and Dan and Carol orient to these disclosures, as bad news. The valence of Kelly and Paul's disclosure of their HIV status is not based on the presumption that a HIV-positive status is intrinsically bad or on any explicit negative reception of the disclosure. Rather, it is the interactional organization of these disclosures that makes recognizable Kelly and Paul's actions as delivering bad news and, equally, Dan and Carol's orientation to the news as bad.

Implications for Critical Social Science on HIV/AIDS: Reproducing and Resisting a Normative Social World

Whereas the foregoing analysis identified how participants orient to disclosures of HIV, a critical social science demands an interrogation of those orientations. In these interactions, participants produce a normative world. While that world may change from interaction to interaction – and moment by moment – what the normative world is in these interactions at these particular moments for these participants is constituted by the participants' taken-for-granted assumptions and shared understandings displayed in their interaction. In that world, an HIV-positive status is treated as newsworthy and requiring disclosure. Kelly and Paul do not simply share the news of their HIV-positive status. Instead, they manage the delivery and reception of their disclosure. In Extract 1, Kelly's favourable prognosis (line 37–38) functions to neutralize any implications of her HIV status. And, yet, by suggesting that her news needed to be told in person (line 47), Kelly underscores the seriousness of her news. In Extract 2, Paul painstakingly prepares for his disclosure of HIV by first eliciting Carol to pursue his news announcement and, second, by ascertaining Carol's response to dating "one guy" who is HIV positive. Thus, Kelly and Paul's HIV-positive status is not one that might be presumed from the start. An HIV-negative status is treated as the default and normative way to be, and the interactional work of the participants in Extracts 1 and 2 suggests that an HIV-positive status constitutes a breach of that normative world.

It should be stated here that Kelly and Paul's willingness to share their lives openly for a reality television show suggests they do not live clandestine lives veiled in secrecy and shame. If asked in a qualitative interview, both Kelly and Paul would likely report that they hold "positive attitudes" toward their HIV and that their disclosures otherwise "went well." But, regardless of whatever attitudes they may hold or how they may feel about their disclosures, Kelly and Paul nevertheless produce their disclosures as bad news. Bearers of the news do not anticipate positive responses to their HIV-positive status and recipients treat the news as misfortune. Kelly acknowledges (line 14) Dan's apparent inability to formulate an assessment of her news. Paul's expressions of surprise and disbelief (lines 19, 22, 27, 46, 55) to Carol's displays of acceptance and reassurance suggest that those displays were unexpected, thereby re-inscribing negative responses to HIV-positive disclosures as the default norm.

Throughout the extracts, the participants reproduce at the most mundane levels of interaction the foundational assumptions that reinforce broader societal responses to HIV. Because an HIV-positive status is bad news, concerted efforts should be taken to prevent people from becoming HIV positive. Equally, however, such a stance enables HIV-related stigma and, by extension, the criminalization of HIV non-disclosure. HIV would not need to be prevented, nor would it be stigmatized and criminalized if being or becoming HIV was anything other than bad news. Of course, HIV-related stigma and criminalization are not solely determined by social interaction. However, interaction is one everyday social process that privileges and reinforces particular kinds of social relations. Put another way, HIV-related stigma and criminalization persist not only because of malice or prejudice but also because negative inferences about HIV are embedded in the very of fabric of social interaction.

However, to conclude the chapter here would fail to address concretely the very real problems that HIV-positive people face. According to Judy Auerbach, critical social science perspectives "have been helpful in describing the dynamics of HIV epidemics, but not in informing specific responses to them" (quoted in Mykhalovskiy and Rosengarten 2009, 286). For some, then, critical social science must demonstrate its utility for pragmatic interventions that address the realities of HIV/AIDS. Thus, having utilized CA in the preceding discussion to identify how negative inferences about HIV proliferate through interaction, I now utilize CA to demonstrate how those very inferences – and the normative world they invoke – might be resisted. Disclosures of HIV need not necessarily be produced as bad news. In this third and final extract taken from *Me, Myself, and HIV,* Angelikah, a college student from Minneapolis, Minnesota, calls a tattoo parlour to schedule an appointment and inquires about the shop's policies for tattooing someone who is HIV positive.

Extract 3

01 ANGEL: hi I'm calling to set up an appointment to get uh tat↓too,
02 CLT: let me just check our schedule he::re.
03 ((cut))
04 ANGEL: u:m:: I'm HIV ↓positi::ve, .hhh a::nd I'm wondering what your
05 policy is on tattooing for that is:.
06 CLT: we have to treat everybuddy as if they're: HIV positive so
07 tha:t's just fi:ne. your (   ) disclosure u::m but ↑ya.
08 that's not a problem.
09 ANGEL: awesome.

Note the composition of Angelikah's turn on lines 4–5. She first discloses her status "I'm HIV positive" at the beginning of her turn (on line 4) but then maintains the floor. With upward intonation at the end of "positive" (line 4) and with an inhale ("hhh" line 4), followed by a stretched "and" (line 4), she signals her turn at talk is not yet complete. She then requests for the policy on "tattooing for that" (line 4–5). Thus, Angelikah's disclosure is not designed to be treated as a news announcement. She deliberately forecloses an interactional slot that would otherwise allow for receipt and assessment of her status. The disclosure functions as an account for Angelikah's information request for the shop's policy on tattooing people who are HIV positive. Appropriately, the call taker does not treat Angelikah's disclosure as a news announcement and, instead, provides the relevant policy information by way of a report on the shop's practices ("we have to treat everybody as if they're HIV," line 6). The call taker's assessments "that's just fine" (line 7) and "that's not a problem" (line 8) are offered not as a personal stance toward Angelikah's HIV status per se but to indicate that Angelikah's HIV status poses no concerns for tattooing.

Of course, both Angelikah and the call taker orient to each other as engaging in institutional talk by restricting the range of interactional practices they might employ. It would have been inappropriate for the call taker to target Angelikah's HIV disclosure for assessment (though she could have), and it would have been equally inappropriate for Angelikah to call the tattoo shop specifically to announce her HIV status as news to the call taker. Thus, from a CA perspective, one can claim that Angelikah discloses her HIV status to facilitate the institutional business at hand: to ascertain whether and how the tattoo shop accommodates those living with HIV. The call taker forwards the progressivity of that business by responding not with a reaction toward Angelikah's HIV disclosure but with the requested information.

However, from a critical social science perspective, one might characterize Angelikah and the call taker's interaction as a form of "resistance" to HIV-related stigma. The interaction exemplifies how people might respond to HIV disclosures (and how disclosures might be done) in such a way that does not convey negative inferences about HIV. The newsworthiness of Angelikah's disclosure – whether or not it is, in fact, newsworthy for participants – and the stance it might embody are completely irrelevant to the interaction. This, then, is the kind of interaction that normalizes HIV-positive people. It produces a social world where an HIV-positive status is, like homosexuality, disability, or intersex, human variation rather than individual pathology and failure.

Unresolved Issues

I end this chapter with an unresolved dilemma that arises from the competing assumptions that imbue the interactions analyzed in this chapter. On the one hand, HIV disclosures as bad news construct those who have HIV as deficient and unfortunate. On the other hand, HIV disclosures as "not news" (or good news[1]) potentially undermine the logic for HIV prevention. Since talk about HIV propels the assumptions on which HIV prevention and HIV-related stigma campaigns are based, the ways we talk about HIV have implications for the kinds of social policies we prioritize. Where HIV-stigma campaigns set out to proclaim that "we are all HIV equal" (HIVequal.org) in an attempt to challenge the negative inferences associated with an HIV-positive status, HIV prevention maintains and depends on those very negative inferences. In other words, HIV-stigma campaigns seek to normalize HIV, while prevention efforts seek to eliminate HIV. Insisting on particular practices of talk to refuse the stigmatization of HIV would effectively subvert the very assumption that HIV should be prevented and ultimately eradicated.

In this chapter, I have drawn attention to the utility of CA for critical social science in the field of HIV/AIDS. In identifying this dilemma, I now draw attention to CA's limits. We can use CA to articulate how talk-in-interaction constructs a normative social world and how we could change it. CA, however, does not provide an ethic to guide how we should talk and what normative social world we should construct. That is because CA, like ethnomethodology, is not a corrective enterprise (Eglin 2013). It remains indifferent to the practical concerns of a critical social science on HIV/AIDS. In my opinion, it is only through the lens of value-laden inquiry (and the political commitments of the inquirer) that the aforementioned dilemma can be resolved.

This dilemma notwithstanding, I have demonstrated that CA can identify the socio-interactional realities of the participants and the ways HIV might figure in those realities. Through the ways we disclose HIV, we display a stance toward it. By using CA, we can render visible not only the practices through which that stance is asserted and shared but also the ways that stance might be undermined. This stance does not depend on interactants' individual attitudes or personal opinions about HIV but on the interactional organization of talk. Scholars on HIV-related stigma have advocated for greater attention to "structural stigma" (for example, Gagnon 2015). To those scholars, I advise attention to the interactional. As conversation analysts have argued, social organization and broader political structures are built on the ordinary affairs of social interaction, and, as I have shown, it is within these ordinary affairs that foundational assumptions about HIV recur, pervade, and enable.

Appendix A: Jeffersonian Transcription Notation

=	Paired equal signs indicate no break at the end of one turn and the beginning of the next
(0.8)	Length of pause or gap in tenths of second
(.)	A pause or gap less than a tenth of a second
overlapp [ed] [ta]lk	Square brackets mark the onset and end of overlapping talk
.	Closing or falling intonation
,	Continuing or slightly upward intonation
_	Flat intonation
?	Rising intonation
underlined	Underlined talk is emphasized
stre::tched	Colons denote stretch of the prior sound
-	Sharp cut-off of the just prior word or sound
↑rise	Rise in pitch
↓fall	Fall in pitch
<slower>	Enclosed speech is slower than surrounding talk
°quiet°	Enclosed talk is noticeably quieter than surrounding talk

huh	Laughter particles
.hhh	In-breadth
hhh	Exhale
Brehhathy	Breathy talk
( )	Inaudible segment of talk
((eye roll))	Transcribers comments or description
(talk a)/(talk b)	Enclosed talk separated by / denote possible hearings

Notes

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1 None of the instances of HIV disclosures I have collected were produced as good news.

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5

Indigenous Knowing in HIV Research in Canada

A Reflexive Dialogue

Randy Jackson

One of my first recollections of how scientific knowledge can offend came in the form of an early morning call – some twenty or more years ago. An Elder in my community, also my mother's aunt, had just passed to the spirit world. In the years leading up to this moment, I was aware my great aunt was concerned about the loss of traditional knowledge on her death. She agreed to track back into the bush with a Western-trained botanist. On the surface, all seemed in order. The botanist was ahead of current Western research protocol that now informs encounters with Indigenous peoples.[1] The botanist negotiated community access through the band council, spent the appropriate amount of time getting to know the community, secured individual consent, collected the necessary information, produced a community report of findings, and left.

Many years later, long after the death of my great aunt and well into my Western academic training, my mother, while shopping in a bookstore, stumbled on a publication written by this once-visiting botanist. The manuscript showcased the sacred knowledge of flora and fauna in my community's traditional territory. Absent from this publication is any recognition of community involvement in the production of this knowledge. Also absent is an acknowledgment of authority to publish what my mother considers traditional knowledge. The work was published solely under the botanist's name, and my mother was deeply offended. For my mother, the publication represented a theft of Indigenous knowledge. Hearing my mother speak about this issue, I began to lose my sense of naivety about Western research.

Perhaps this is an unremarkable and far too common story of how Western science can offend. For me, however, it is the moment where I began to recognize the West's appropriation of Indigenous knowledges, an appropriation made possible by the subjugation, marginalization, and oppression of Indigenous peoples. These are features of Indigenous experience that can continue to promote the advancement of colonialism. The botanist story is but one example of "researchers extracting data from Indigenous communities and then publishing 'their' research with little benefit to the people" (Kovach 2009, 32). The stories of the West encountering the exotic "Other" are plentiful. Like the experiences of other marginalized and oppressed groups, the West devours knowledge from this "Other" and does so largely for its own benefit. Hearing about the botanist is when I also first recognized that as an Indigenous person I must not only negotiate my cultural identity as an Anishinaabe person, I must simultaneously do so as a member of the Western academy. In practice, this recognition is best described as being far from straightforward, simple, or uncomplicated. Nonetheless, I am compelled to negotiate such a paradox. As Sandy Grande (2008, 234) states, "the colonial tax of Native scholars not only requires a renegotiation of personal identity ... [but] by virtue of living in the Whitestream world, Indigenous scholars have no choice but to renegotiate the forces of colonialism, to learn, understand, and converse in the grammar of the empire as well as develop the skills to contest it."

Many Indigenous scholars have embraced critical approaches in the social sciences that embed decolonizing and Indigenous methodologies. Using these approaches, Indigenous scholars advocate for a critical social science more inclusive of their cultural ways of knowing. A focus on this goal highlights the Western bias in research, the erasure of Indigenous knowledges, and the "pathologization" of Indigenous peoples (Bond 2005; Peltier et al. 2013;

Reading and Nowgesic 2002). Indigenous scholars have also demonstrated how Western research that represents Indigenous peoples negatively shapes the ways in which we think about, and respond to, their health. Decolonizing research recognizes the negative force of colonialism on the health and well-being of Indigenous peoples, emphasizes the reclamation of ancestral ways of knowing (Crofoot Graham 2002), advocates the relevance of local cultural knowledge (Brant Castellano 2000), and favours interpretation and meaning-making processes that reflect cultural knowing (Jackson et al., submitted), culture as intervention (Hall et al. 2015), and holistic and relational models of health care (Brant Castellano 2000; Denzin and Lincoln 2008; Kovach 2009; Smith 2014). Taken together in ways that dovetail with the family of participatory methodologies (Evans et al. 2009), social science researchers over the past decade and longer have begun to fruitfully and meaningfully involve Indigenous organizations and communities in their research programs.

The goal of this chapter is to explore what it has meant to be engaged in Indigenous HIV research. I emphasize how reflexivity, as part of one's critical disposition (Smith 1999), is an active feature of decolonizing and Indigenous methodologies. In this sense, a critical decolonizing and Indigenous methodological approach in HIV research rests on, and compels, not only external, but also internal, epistemic reflexivity. But to engage reflexively recognizes that any learning comes from a deeply personal place (Loppie 2007). As Keyan Tomaselli, Lauren Dyll, and Michael Francis (2008, 368) state, "[to write reflexively] is to implicate [one's self] in the production of knowledge." This chapter provides an overview of decolonizing and Indigenous methodologies and, drawing on a decade of Indigenous HIV research experience, explores some of the strengths and the pressing tensions associated with these approaches in HIV research with Indigenous communities in Canada. From a decolonizing perspective, reflexivity is vital because it serves to remind us that if we are not mindful our research may inadvertently promote the continued rise of hegemonic power structures in research (Cannella and Manuelito 2008). In part, reflexivity in Indigenous research contexts is meant to support

Indigenous self-determination, and, as Linda Smith states (1999, 124), it assists Indigenous and allied researchers "to imagine a world in which indigenous peoples become active participants, and to prepare for the possibilities and challenges that lie ahead."

The Promise of Decolonizing and Indigenous Methodologies

Critical social sciences that take up decolonizing and Indigenous methodologies are flourishing on a global scale. These conceptual approaches to social science research recognize colonialism as a troubling force in the lives of Indigenous peoples. Decolonizing and Indigenous methodologies are meant to work together to interrupt colonialism in social science research by holding space that privileges Indigenous culture, voice, and knowing. In other words, decolonizing critical social sciences are committed to "acts of reclaiming, reformulating, and reconstituting Indigenous culture and languages ... to become self-determining" (Smith 1999, 142). For me, the use of decolonizing approaches, coupled with community-based research principles, has always at least partially focused on the development of techniques of inquiry that strive, taking up the call offered by Karina Walters and colleagues (2009; see also Wilson 2008), to "retraditionalize" the research process through the inclusion of Indigenous knowledges. Indigenous knowledges in research are not meant to reflect the "future centered hope of the Western imagination, but rather, [they express] a hope that lives in contingency with the past – one that trusts the beliefs and understandings of our ancestors as well as the power of traditional knowledge" (Grande 2004, 28).

Although it is important to recognize the diversity of Indigenous knowledge, there is general agreement that these systems are thought to be dynamic and ever evolving (Brant Castellano 2000; Loppie 2007), include oral knowledges that stretch back generations, and are localized in ways specific to one's Indigenous heritage. Indigenous knowledges are also thought to embody a cosmological orientation, and, where knowledge is revealed, the teachings derived almost always involve the interpretative support of a community's healers, Elders, or other spiritual leadership (Brant Castellano 2000; Evans et al. 2009; Kincheloe and Steinberg 2008; Kovach 2009; Peltier et al. 2013; Smith 1999; Wilson 2008). As Marie Battiste (2008, 499) defines it, "Indigenous people's epistemology is derived from the immediate ecology; from people's experiences, perceptions, thoughts and memory, including experiences shared with others; and from the spiritual world discovered in dreams, visions, inspirations, and signs interpreted with guidance of healers or elders" (see also Brant Castellano 2000; Kincheloe and Steinberg 2008). In Indigenous knowledge systems, the knowledge held by individuals and families is considered personal and always correct. At a broader level (for example, community or nation), for knowledge to have social validity across individuals and families, it must be authenticated through collective debate that leads to a high degree of consensus. Knowledge is also thought to express an important relational character in that the meaning derived is always contextualized through one's relationship with one's community and the immediate environment. As Leilani Holmes (2000, 42–43) writes, "knowledge is a gift from a higher power, revealed and contextualized through relationships. [In other words,] knowledge is validated not through the notion of truth value but rather [is affirmed] through connection." A key definition of decolonizing and Indigenous methodologies is offered by Mike Evans and colleagues (2009, 894), who write that such approaches "can be defined as research by and for Indigenous people using techniques and methods drawn from the traditions and knowledges of those people." Incorporating this into critical social science research, scholars have advocated for a decolonized Western academy.

However, the use of Indigenous knowledge can be problematic. As Indigenous scholars, we often hear the critique that the theories we use to develop and guide our research are "inherently Western, are nonindigenous, and … insufficiently grounded in the needs of Native communities" (Simpson and Smith 2014, 1). It has long been recognized that "epistemologies have material consequences" in ways that link with, and support, the continued expansion of the colonial project (3; see also Smith 1999, 2014). This idea embodies the need for Indigenous scholars to critically use decolonizing methodologies to shift Western theory (Grande 2004, 2008). In describing Indigenous knowledges in decolonizing research contexts, scholars generally highlight several common features across diverse Indigenous knowledge systems. Critical social science methodologies that are grounded in Indigenous knowledges are thought of as performative (Denzin and Lincoln 2008; Grande 2004, 2008; Smith 1999, 2014; Swadener and Mutua 2008). Intertwined with a key precept of Indigenous knowledge, decolonizing and Indigenous methodologies are thus best viewed as transformational social action grounded in praxis. They are also considered approaches that tend to emphasize Indigenous community participation in conducting research (Evans et al. 2009; Hall et al. 2015), that commit to acts of cultural reclamation and healing (Smith 1999, 2014), and that guide research processes in ways that leave the approaches used by researchers accountable to the Indigenous peoples represented in the research.

The development of Indigenous knowledges for use in decolonizing research processes involves "methodologies and approaches to research that privilege indigenous knowledges, voices, and experiences" (Smith 1999, 87). Drawing inspiration from critical race theory and interpretative, postmodern, and feminist approaches, these relatively new ways of engaging in research with Indigenous peoples have been reimagined through Indigenous epistemologies (Evans et al. 2009; Grande 2004, 2008; Smith 1999, 2014). What all these approaches have in common is a core set of unifying themes that include a commitment to social justice. Nonetheless, it is important to acknowledge that decolonizing approaches in a critical social science context are relatively new and that some Indigenous scholars remain troubled by approaches that draw on Western foundations. No matter how much we indigenize Western methodologies and methods, the fear is that they will continue to embody colonizing influences (Grande 2008). In other words, while critical social sciences may appear congruent with, and supportive of, efforts to end colonialism, the use of indigenized Western approaches remains problematic. As Grande (2008, 240) notes, "it is important to recognize that revolutionary critical [approaches] remain rooted in the Western paradigm and they're in tension with Indigenous knowledge and praxis." For some Indigenous scholars, the requirement to conform to Western academia feels like "an imposition on [one's] intellect and creativity because [the] focus is shifted from *doing and living* to *talking about* or *explaining*" (Simpson 2014, 113; emphasis in original). Unlike the static edges of objectivity embodied by some Western approaches, "[Indigenous knowledges] are embedded within a larger epistemological framework that values emergence, vision, flux, and dynamic relationship with both human and non-human entities" (112).

My Journey Using Indigenous Knowledge in Decolonizing HIV Research

Long before my introduction to decolonizing and Indigenous methodologies, I had always felt, as a member of the academy, like I had been asked to make a choice. I sensed that I was being asked to choose between identifying as an Anishinaabe person and submitting to Western training as a scholar of HIV research. As an undergraduate student in the early 1990s, little of what I was taught reflected Indigenous knowledges. As a graduate student, despite opportunities to learn about and use Indigenous knowledge, I continued to question whether I was being asked to make a similar choice. In terms of softening the edges of Indigenous consciousness, was I being asked to simply adapt Western research approaches, to use their methods, and to adhere to their ways of creating meaning? As Grande (2008, 234) notes, "one feels compelled to choose between retaining his or her integrity (identity) as a Native person or doing research." Despite advances made by Indigenous and allied scholars and the acceptance of Indigenous ways of knowing by some Western scholars, the pressure to conform to Western standards of truth and validity are considerable, and, in some ways, Indigenous knowledges remains firmly marginalized in the Western academy. Such pressure is exceedingly difficult to untangle, not only in understanding deep-seated emotional reactions but also in respectfully negotiating and claiming space at the Western research table. According to Grande, in examining our own roles within the academic industrial complex, our personal journeys are primarily characterized by "vacillation between wholesale adoption of Anglo-Western theories and the stance that Indigenous scholars need nothing outside of themselves or their communities to understand the world or their place within it" (234).

I have found a resonance, however, in written accounts by other Indigenous scholars – in their stories and their journeys – when considering my own. Before returning to my studies, I was employed by a national Indigenous non-profit organization focused on HIV and AIDS in Indigenous communities. As we built our own internal research capacity, we partnered with trusted Western academics and shared leadership on a variety of projects. These projects explored deficiencies in the provision of health services to Indigenous people living with HIV/AIDS (Jackson and Reimer 2008), the impacts of HIV-related stigma and discrimination in accessing health services by people living with HIV/AIDS (Mill et al. 2009, 2011), experiences and responses to depression among Indigenous peoples living with HIV (Cain et al. 2011, 2013; Jackson et al. 2008), and HIV testing and diagnosis of HIV infection among Indigenous youth (Mill et al. 2008, 2012; Prentice et al. 2011). Although these earlier projects drew on participatory methodologies and were mindful to meaningfully include Indigenous participation, they were not projects that were shaped by Indigenous knowledges. As research teams, for example, we did not consider Indigenous knowledge in ways that might differentially inform our interpretation (for example, the relational connection of participants' stories to the environment). Rather, consistent with participatory research approaches, the roles I primarily assumed on these research teams included responsibility for promotion and recruitment, contributing to the analysis, and community knowledge dissemination activities.

As the research capacity of our organization grew, and once we acquired the opportunity to hold research funding, we also began to understand that research could be made more congruent with

Indigenous world views (Smith 1999; Wilson 2008). We began by designing research that drew on a range of cultural assets of Indigenous communities. Indigenous Elder participation in research, for example, is considered pivotal to the success of our research because Elders are respected as cultural knowledge keepers, are ethical and cultural consultants that help shape research approaches, are mindful of the spiritual needs of both the researchers and participants, and, finally, can conduct ceremonies as part of the research (Flicker et al. 2015).

More recently, we have also worked to develop ways of meaning making that are carefully grounded in Indigenous world views. Across several projects – for example, the resiliency among two-spirit men living long term with HIV (Jackson et al., submitted) and cultural understandings of home in the context of living with, or being at risk of, HIV infection (Greene and Jackson 2015) – meaning making has evolved to where we have drawn on the traditional teachings of the medicine wheel.[2] This work has been carried out at a number of levels: to gather and organize data and to generate interpretations that are relationally embedded in the communities from which the knowledge has been derived (Isaak and Marchessault 2008). The medicine wheel can be used in focus groups to stimulate dialogue among participants. Key quotes found in interview or focus-group data are selected and assigned a unique letter/number combination; quotes are then mapped to the area of the medicine wheel that matches the meaning expressed by the quote. Connections among coded data are then grouped into themes. This approach to data gathering, analysis, and interpretation is meant to maintain the relationship of data to Indigenous peoples. As Shawn Wilson (2008) advocates, Indigenous scholars must remain accountable to Indigenous communities and cautiously consider the research topic, methods of data collection, forms of analysis, and ways that information is being presented. These more recent research projects highlight the promise of Indigenous HIV research in contributing to social change, emancipation, and the use of liberatory and strength-based language. In short, these approaches to Indigenous scholarship suggest a move away from the pathologization of Indigenous peoples to a way of being with, and thinking and writing about, Indigenous peoples. Despite structural challenges that give rise to health disparities, Indigenous peoples as cultural beings are fully capable of achieving health and wellness through the embodiment of Indigenous values and beliefs.

In exploring the use of Indigenous knowledge, I have also become deeply interested in how stories represent theory and how storytelling can be viewed as a culturally dynamic intervention. It is a position that is taken up by Audra Simpson and Andrea Smith (2014, 7) who ask: "How can we critically and intelligently theorize current conditions in diverse spaces inside and outside the academy, and how can we theorize our responses to these conditions?" In the context of my doctoral studies, and toward this end, I have also become increasingly interested in Indigenous methodology as a theory of inquiry that draws on Indigenous methods – poetry, drama, storytelling, critical personal narratives – as performative practices that represent and make Indigenous life more visible. Specifically, I am interested in how stories represent Indigenous theorizing and how the process of storytelling can affect healing trajectories for Indigenous communities confronting HIV and AIDS.

Unlike the Western narrative approaches, Indigenous stories convey embodied meaning, but not through content. Rather, they make visible the context in which the stories originally occurred (Simpson 2014). As Dian Million (2014, 31) writes, "the stories, unlike data, contain the affective legacy of our experiences. They are felt knowledge that accumulates and becomes a force that empowers stories that are otherwise separate to become a focus, a potential for movement." Over the last decade, I have become convinced that Indigenous people might locate their own empowerment through stories and, therefore, find some healing from the ravages of colonialism. As a qualitative researcher who uses an indigenized narrative inquiry in HIV research, like Million (2014, 33), I am buoyed by the prospect of the "power of our everyday stories, the theory of stories as theory, and Indigenism as theory." My interest in Indigenous stories and storytelling springs from a desire to more closely align my scholarship with my tribal genealogy and to work to forge new ground for Indigenous theorizing. As Simpson (2014, 110) similarly writes, "I want my writing and my creative work to do the same thing for others – to pull people into my consciousness" and make the beauty of Indigenous peoples' world views and ways of knowing more visible to outsiders.

The Challenge of Using Indigenous Knowledge in HIV Research

Despite the promise of Indigenous knowledge systems that potentially offer "compelling insights into all domains of human endeavor" (Kincheloe and Steinberg 2008, 135), the use of these approaches remains, as Raewyn Connell (2008, ix) suggests, "a fragile project." Similarly, Smith (2005, 87) describes this space as "tricky ground," which competes within the "internal relations of power, as in any society, that exclude, marginalize, and silence some while empower[ing] others." Although decolonizing and Indigenous methodologies are being widely used in Canadian research (Chambers et al. 2018), their uptake in Canadian HIV research among Indigenous communities is not reflected to the same degree (Peltier et al. 2013). This has serious implications for designing HIV prevention and other HIV-related health services for Indigenous peoples. Perhaps part of the challenge is that it is difficult to raise one's voice, to upset the status quo, and to work to gain legitimacy (Briggs 2005; Kovach 2009; Million 2014). To further the discussion about using Indigenous methodologies in HIV research, I address three critical issues: 1) the question of the master's tools, theoretical overlap, and building confidence to challenge dominant ways of conceptualizing research; 2) questions about two-eyed seeing as a potentially useful construct to alleviate tensions between Indigenous and Western ways of knowing; and 3) the consideration of what makes a critical decolonizing and Indigenous social science an Indigenous science.

The Master's Tools: Theoretical Overlap and Building Confidence

It has never been easy being Indigenous in the academy. It requires operating within systems of power that Indigenous scholarship has helped to critique and transform. The burden of responsibility placed on Indigenous scholars is considerable. Can an Indigenous scholar be both Indigenous and of the academy? As Million (2014, 34) acknowledges, "the struggle of our generation has been to honour our own paradigms, concepts that arise from our lives, our histories, and our cultures while knowing that they are often inextricably mixed with concepts growing from our subjugation." Yet many Indigenous scholars remain troubled by using the tools of the empire to mount resistance to the Western academic project (Briggs 2005; Grande 2004, 2008; Million 2014; Smith 2014). Many express the reasonable fear that if we draw on Western theories and rearticulate them through the lens of Indigenous knowledges, we will always remain guarded by the possibility that we may "unwittingly recapitulate colonial and capitalist assumptions" (Simpson and Smith 2014, 7). As Grande (2008, 234) asks: "Is it possible to engage the grammar of the empire without replicating its effect?" In some ways, it looks and feels like a paradox; to critique Western research as colonial, while, at the same time, drawing on these same theories in Indigenous research, may not necessarily establish intellectual sovereignty. The tension is palatable, and it reaches back to a shared history of colonialism. It is ever present and a site of intense academic interest. Such tension raises other types of questions: if not the master's tools, then whose tools can we use? Do we further develop Indigenous methodologies? It is important to raise these questions.

Although the debate about these ideas – that is, using the master's tools – is largely a public one, I believe that for many Indigenous scholars it is also a deeply personal journey that is not widely shared. My interest in decolonizing Indigenous methodologies is hinged to Indigenous personhood, and it is this connection that both informs and complicates my research. I bring a beautiful and vibrant culture to my research, and it comes from a deeply cultivated sense of connection to Indigenous identity, to a clan system, to a community and nation, to ceremonies, and to customs and protocols. As I described above, I draw on and incorporate Indigenous culture in my research. I also bring some baggage by virtue of having almost been assimilated. My experiences of colonialism, and the damage it has caused, make me highly suspicious, skeptical, and fearful that somehow, no matter how carefully I tread, I will be seduced "into the colonial abyss with [the] promise of [academic] empowerment" (Grande 2008, 234). For me, untangling and understanding the ways I am impacted by colonialism remains a life's project. This project – to decolonize oneself – begins with me acknowledging that I am enmeshed in colonialism. Nevertheless, I choose to mindfully act in ways that draw on Indigenous consciousness to build Indigenous renaissance.

Decolonizing research, when championed with Indigenous knowledges, can uncomfortably stretch Western scholarship by directing practitioners to embody the research process – to involve one's physical being, the emotional self, spiritual energies, and our intellect (Simpson 2011). My research experience suggests that doing so is an uncomfortable process when inside the academy. Yet I also understand that the angst I experience is necessary if Indigenous knowing is to flourish within the academy. According to Elizabeth McIsaac (2000, 100), "for those of us who participate in producing knowledge, there exists a moral imperative to become resituated as learners, and to engage in a process and relationship of learning that is based on indigenous knowledge" (see also Brant Castellano 2000; McLeod 2007).

In a project focused on the resiliencies of two-spirit men living long term with HIV, which I mentioned earlier, we struggled with the idea of internal consistency among our various methodological and epistemological approaches (interpretative, participatory, decolonizing/Indigenous). Using the medicine wheel as a tool to code our data, we were concerned with the idea of internal consistency. Did Indigenous knowledge as a methodological approach fit with how we gathered (that is, focus groups) and understood the data (that is, grounded theory)? We also struggled with the idea of diversity in Indigenous knowledges and whether our research represented our study participants' diverse Indigenous cultures. Similarly, we questioned matters of validity: whether the relational in Indigenous knowing could adequately counter our assessment of the rugged individualism we feel is embodied in Western science. Although we had been trained to resolve tensions in research, we were also cautiously optimistic that such tension, in fact, might be a site of positive and productive methodological development.

In attempting to better understand, we began the process of reframing some important ontological, epistemological, methodological, and axiological implications with ideas that these four aspects often have material, discursive, and transformative qualities. In terms of ontology, for example, we reframed our process as embodied and experiential (that is, drawing on our cultural understanding of health that we shared with our non-Indigenous allied team members). We acknowledged the shared epistemological underpinnings in our methodological approaches (that is, critical, interpretative, empirical). We came to a place that supported the idea that our decolonizing methodology speaks also to our shared experiences of colonization. And, finally, we strove to produce research guided by an ethic that privileged the idea of "retraditionalization" of research with the Anishinaabe principle of *mamowenchike* (that is, mutual respect and responsibility for one another) (Walters et al. 2009).

Although I am buoyed by the notion that Western science has helped me develop the skills to resist Western colonialism in research, I recognize that if I am not acting in ways consistent with my culture these efforts will by stymied and bound to fail. I have reached a place that is supportive of what Simpson and Smith (2014, 9) have labelled "intellectual promiscuity"; the Indigenous project for intellectual sovereignty need not occur in isolation from the West. In fact, there is much common ground. The development of decolonizing research, for example, has been influenced by the family of participatory methodologies and postcolonial, feminist, postmodern, and critical race theories (Cannella and Manuelito

2008). What all of these approaches have in common is a core set of unifying principles that include a commitment to social justice. The resulting dynamic, according to Norman Denzin and Yvonne Lincoln (2008), is a focus on performance, interpretative pedagogies, and the development of theories of power, truth, and ethics. Taken together, some have argued that this is what makes Western theoretical approaches useful, if not congruent, with decolonizing and Indigenous methodologies. Nevertheless, tensions between Western and Indigenous methodologies remain. One promising strategy is the development of two-eyeing as a way of learning to live with methodological angst.

Two-Eyed Seeing: Solution or Red Herring?

A critical social science perspective embraces the idea that there are many ways of knowing the world. Widely considered a new research approach, the principles of two-eyed seeing are gaining popularity among health researchers investigating a range of Indigenous health issues (Hall et al. 2015). Two-eyed seeing in research contexts elevates the idea that "diverse perspectives might work together to answer our most pressing questions about the health of Indigenous people and communities" (Martin 2012, 22). First developed as an approach to providing culturally grounded education for Indigenous students in Western academic settings, two-eyed seeing refers to seeing and understanding the world "from one eye with the strengths of Indigenous ways of knowing, and from the other eye with the strengths of Western ways of knowing, and to use both of these eyes together" (Hatcher and Bartlett 2010, 16; see also Bartlett, Marshall, and Marshall 2012; Hall et al. 2015; Iwama et al. 2009; Marsh et al. 2015; Martin 2012). According to Laura Hall and colleagues (2015, 5), the use of two-eyed seeing in research reflects efforts of health researchers to apply "the tools of Western science from within an Indigenous worldview."

Ultimately, the promise of two-eyed seeing rests on the potential that it holds as a research approach toward supporting Indigenous identity that is grounded in culture and that is tied to the land and to language. Importantly, this framework is used as a strategy to mitigate, manage, or respond to tensions that researchers experience when weaving Indigenous and Western research processes together (Hall et al. 2015). Debbie Martin (2012) recognizes that two-eyed seeing promotes critical appraisal about the ways in which knowledge gets created and inspires approaches that uphold Indigenous world views in research contexts. Indeed, when coupled with reflexivity, the use of two-eyed seeing can promote intellectual promiscuity and draw on the strengths of both Western and Indigenous research traditions. Two-eyed seeing can ultimately work to ground research in the perspectives, values, and world view of those who originally experienced these phenomena (McLeod 2007). In doing so, two-eyed seeing blends disparate forms of Indigenous and Western ways of knowing. Moreover, this approach is invested in developing research "relationship[s] of mutual cultural respect, wherein the benefits of both worldviews are acknowledged as beneficial in healing processes" (Marsh et al. 2015, 5).

Initially, like scholars before me, I was excited by the promise of two-eyed seeing to assist in resolving what I have experienced as tensions between Indigenous and Western ways of knowing. Across a range of projects, my colleagues and I often write two-eyed seeing into our grant applications and use two-eyeing as a conceptual device that allows for the inclusion of Indigenous knowledges. In the resiliency project described earlier, for example, we used grounded theory (that is, open, axial, and selective coding) to assist with mapping data to the medicine wheel. Once mapped, themes and meaning were generated that were consistent with Indigenous knowledge (Jackson et al., submitted). Although the approach proved fruitful and allowed for diverse expertise across Western/Indigenous knowledge systems (Rowan et al. 2015), I had earlier been questioned by a community member about whether I was selling out by ignoring the power of Indigenous ways of creating knowledge. As much as the notion of two-eyed seeing provides some direction about the use of Indigenous knowledge in research contexts, it also raises these kinds of uncomfortable questions: does the use of two-eyed seeing make Indigenous scholars less Indigenous and more likely to favour Western approaches despite rearticulating them through an Indigenous lens? My experience suggests that tensions remain between the desire to conduct Indigenous research fully within Indigenous knowledge systems and the use of Western ways of conducting research. Despite troubling questions, I am supportive of efforts to use two-eyed seeing in research. However, I feel that it needs to be cautiously adopted with a continued focus on the goals of decolonizing methodologies that challenge research as a colonial practice.

What Makes Indigenous Scholarship Indigenous?

For me, the use of Indigenous knowledge in social science research is not easily enacted. Several critical questions can be raised: how do we assess authenticity and validity or verify that Indigenous knowledge has been used in good ways; does Western science offer anything practical in terms of affirming Indigenous identity in research; do principles of two-eyed seeing offer some way of mediating the tensions associated with using Western approaches; and is the use of Indigenous knowledge made more problematic with the concept of two-eyed seeing? Although Western academia is gradually recognizing Indigenous knowledges as a system of philosophy that can be used to know the world (Rheault 1999), bringing social science research into relationship with the lives and experiences of Indigenous peoples remains extremely challenging. Part of the challenge is embracing Indigenous knowing and using that knowing to address the questions posed above. According to Marlene Brant Castellano (2000, 30),

> the holistic quality of knowledge implies that isolating pieces of experience and trying to make sense of them apart from the environment that gave rise to them flies in the face of reality and is bound to lead to frustration. This does not mean that analysis of parts of the circle of life is to be dismissed; it simply means that analysis must be balanced with synthesis – placing the part that we come to know [in] close analysis in the context of all its

> relations, which will continually impact that which we thought we knew, and thereby transform it.

In asking questions about whether research uses and reflects Indigenous knowing, perhaps we have committed a Eurocentric error (Cannella and Manuelito 2008). In other words, the questions may reflect a Western bias we need to "challenge, discard, or transcend" (Strega 2005, 211). Rather, any evaluation of decolonizing and Indigenous methodologies is best when it is grounded and embedded in an Indigenous world view. In terms of self-evaluation, we ask whether the work we have accomplished reflects Indigenous knowing and experience in all phases of the research – from design to dissemination. Here, the idea of "all my relations" proves helpful.[3] In what ways does the research refract Indigenous knowledges? We are extremely interested in evidence of its use in all stages of the research process. In what ways are the participatory aspects of research participatory (that is, the involvement of Elders, community investigators, and so on)? Is participatory involvement supportive of decolonizing efforts to challenge colonialism? Given the cosmological orientation of Indigenous knowledge, if we accept that the development of knowledge is a sacred pursuit, in what ways have we incorporated ceremony into the design of data gathering and analysis? And, finally, are the findings supported by Indigenous peoples? In virtually every project I have been involved in, we have established validity through member-checking processes. We do this with participants and the broader Indigenous community, asking whether we have got it right. Validating Indigenous knowledge within Indigenous knowledge systems is critical toward producing new knowledge that is entirely consistent and supportive of Indigenous identities.

Discussion and Conclusions

In reflecting on my research experience as central to the notion of a critical disposition, I am reminded that reflexivity is a "journey" and not an "end goal." Ongoing reflexivity in Indigenous research contexts is meant to assist with problem solving and encourage the use of critical reasoning to help untangle and move forward. That is, as others have also pointed out, without reflexivity, we may inadvertently "become fixated on a simplistic [decolonization] of Western knowledge and [its research practices]" (Nakata et al. 2012, 120). Reflexivity pushes scholarship in new directions, potentially generates new understanding, and creates new Indigenous knowledges that are grounded in the world views, beliefs, perspectives, and values of Indigenous peoples. As Martin Nakata and colleagues (2012, 120) aptly summarize, such an approach "encourage[s] openness to further inquiry and productive ways of thinking in and through complex and contested knowledge terrains." Reflexivity in Indigenous science matters. Continual assessment of the ways Indigenous scholars apply their craft to complex health and social problems can potentially open space to also consider the ways lived experience is culturally mediated. Such assessment also facilitates appreciating how the meaning of experiences is also culturally mediated.

Critically focused Indigenous HIV research is not a simple matter. Embracing Indigenous HIV research involves navigating complex theoretical tensions between Western and Indigenous approaches, the deft use of two-eyed seeing to address the pull toward the sole use of Western theoretical foundations and challenging issues about assessing validity in the use of Indigenous knowing in social science research. Like Beth Swadener and Kagendo Mutua (2008, 36), I too have "confronted the likelihood that decolonizing research is messy, complex, and perhaps an impossible endeavor – yet have affirmed that attempting to decolonize one's work is a project worth pursuing." As much as learning about Indigenous research and decolonization has been about professional development, it has also inspired personal growth and healing. I have learned that the notion of "intellectual promiscuity" is important but is likely best practised when coupled with two-eyed seeing that embeds the values of sensitivity, humility, and respect as much as maturity, skill, and knowledge (Smith 1999). Having noted this, however, I will not say that I have answers to all of my critical questions about the

Indigenous research endeavour. But I do believe I have gained as much as I offer. Despite tensions, for example, decolonizing participatory and Indigenous research can be a catalyst for real change and the meaningful involvement of Indigenous knowing in research. As Brant Castellano (2000, 33) writes, "the ultimate test of the validity of knowledge is whether it enhances the capacity of people to live well [and whether] new formulations of old wisdom can best be tested in the crucible of everyday life."

Notes

1 The term "Indigenous" is used in this chapter as an umbrella term and is inclusive of First Nations, Inuit, and Métis peoples who are legally defined as Aboriginal under the 1982 Canadian Constitution as the original inhabitants of the territory now known as Canada. The term Indigenous is also used to refer to global Indigenous communities who hold similar or shared knowledges and values as Indigenous peoples in Canada.

2 The medicine wheel, a symbol of Anishinaabe culture, expresses health and wellness as balance and harmony among four aspects of self (physical, emotional, mental, and spiritual) and one's relationships with one's family, community, nation, and universe (Isaak and Marchessault 2008). Used in research, it provides a conceptual tool meant to facilitate close connection between the themes generated in research with Indigenous ontologies.

3 The notion of "all my relations" expresses the sentiment that all things (people, plant life, wildlife, spiritual realm) are interconnected. As researchers, "all my relations" reminds us of our accountability and responsibility to consider this broad context as we develop our research approaches, methods, and analysis.

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PART 2

Empirical Case Studies

6

Thinking Critically about HIV Prevention for Gay and Bisexual Men

Barry D. Adam

The question at hand concerns what the social sciences, and critical social science, in particular, might contribute to the control of one of the major epidemics of our era. After more than thirty years of research and public health practice in the second decade of the twenty-first century, there is a great deal of health science evidence available to make sense of an epidemic where "38.1 million people have become infected with HIV and 25.3 million people have died of AIDS-related illnesses" worldwide (UNAIDS 2015). Progress in the medical sciences has been impressive. In 1981, thousands of people began to die of a mysterious unprecedented illness; today people living with HIV in the global North can have a life expectancy similar to those without HIV. In the global South, UNAIDS estimates that 41 percent of adults are now accessing antiretroviral medication, and the numbers are rising. While there is reason for optimism, nevertheless, even in countries such as Canada, rates remain persistently high among gay, bisexual, and other men who have sex with men, and this group continues to account for 55.5 percent of new HIV infections (Public Health Agency of Canada 2016, 7). The question remains: how do we arrive at effective solutions to HIV transmission? Solutions depend on adequate diagnoses of problems, and diagnoses, in turn, are fundamentally shaped by the presumptions and conceptual paradigms of knowledge producers.

HIV prevention has long relied on a paradigm that calls on the populations most affected by HIV to adopt behavioural modification as the primary strategy to diminish or end the epidemic; safe sex, adopted by all, would bring HIV transmission to a halt. More recently, the introduction of a pharmaceutical pre-exposure prophylaxis (PrEP) adds another behaviour to be adopted by individuals that could make a difference in the transmission numbers. Calling on individuals to adopt protective measures is a strategy that has made real gains in slowing HIV transmission. However, overwhelming reliance on this single paradigm tends to obscure other critical problems in HIV prevention that, if solved, could make considerable headway in attaining the lofty goals articulated by the World Health Organization to bring the HIV epidemic to an end (UNAIDS 2014). On the one hand, a now sizeable social science research literature points to the limitations of, and alternatives to, the behaviour modification paradigm that relies heavily on an appeal to reason as its primary tactic (Adam 2006). On the other hand, persistent focus on individual behaviour absolves health care systems of critical scrutiny of their response to health inequities in the priority populations affected by HIV.

Critical Thinking

Knowledge creation is necessarily a relationship between observers and observed and between observers and the audiences of their observations. A long tradition of reflection and debate in the social sciences points out that these relationships often have a politic (Adorno et al. 1976; Habermas 1968). The social locations of observers, the observed, and research users shape knowledge through the interests, concerns, and sense of relevance each bring to the situation. The observed are most vulnerable to becoming voiceless in the knowledge relationship as observers create narratives to characterize their practices and experiences. Research users may also be the funders or commissioners of research, bringing resources and perspectives that influence the questions asked, the interpretations made of findings, and the ways that results turn into policy and programming. Critical theory, then, has long asked: in whose interests is knowledge produced? And it has questioned the dominance of administrative viewpoints built into a great deal of the world's official reports, media reporting, and, indeed, the conventional wisdom of the larger society. From these discontents have arisen alternative critical knowledge producers organized around Marxism, feminism, postcolonialism, queer theory, critical disability studies, and so on, who seek to re-ground scholarly inquiry in the experiences and practices of subordinated populations, thereby following a logic that is useful and meaningful to them.

A good deal of contemporary scholarship has become particularly interested in the question of neoliberal responsibilization – that is, the late twentieth-century trend in advanced capitalist societies of cutting back state and social services, retreating from income redistribution, and privatizing as much of the public sector as possible (Harvey 2005). This trend is wrapped in a moral rhetoric of individual responsibility, propagating the idea that individuals are responsible for their own successes and failures and must take care of themselves with minimal support from the state or society. Knowledge production has followed along when it has located social problems in the need to change individuals, thereby tacitly exculpating states, corporations, social structures, and institutions of responsibility in the social and health problems of the day. In other words, diagnoses of problems come pre-determined when attention is turned to individuals as the source and solution and not to institutional organizations as the locus of problems (Ayo 2012). The result is entire knowledge systems that simply re-affirm what is, and close off critical reflection on what could be, if the institutional order were to be reformed or rebuilt (Adorno et al. 1976; Smith 1990).

How does this work in health? To take an example that has been subject to widespread public commentary in North America, obesity is often typified as a problem of individual negligence in diet and exercise (De Brún et al. 2013). The responsibilizing message propounded by health authorities and a massive diet industry all point to individuals (or parents) who must take control of their habits and curb potential health-threatening consequences of overindulgence. A more critical eye on obesity questions the taken-for-granted connection between weight and health status and examines the structural environment in which obesity occurs. A multi-billion-dollar food industry massively promotes profitable processed foods likely to result in weight gain, and its promotional budget overwhelms the budgets of health advocates for evidence-based nutrition (Brownell and Horgen 2003). Food distribution is highly uneven with "food deserts" often leaving low-income neighbourhoods with limited food choices (Bedore 2013). Car culture decreases exercise, and a culture of fear that insists that only irresponsible parents allow children to walk in the street results in a generation confined to cars and homes. These kinds of critical observations challenge public discourses that automatically diagnose health problems as problems of individuals and the solution as a moral exhortation to shape up and act responsibly.

In HIV prevention, many of these presumptions and paradigms are also at play. Population and epidemiological studies tend to rely on a form of actuarial reasoning, identifying risk practices and risk populations at a level that makes sense for delineating target populations of administrative concern. Risk profiles developed for very large categories of people such as "men who have sex with men" prove to be notoriously difficult to translate into community or personal practice for the purposes of managing the potential for HIV infection in everyday life (Adam 2011). These studies also take an almost obsessive interest in re-documenting the failure of gay men to use condoms every time since a single instance of sex without a condom over a three- or six-month period typically qualifies them for "high-risk" status. Gay men are repeatedly found wanting in their inability or unwillingness to meet this measure, a standard that is not always easy to carry out in everyday life, as Mark Gaspar's chapter in this volume shows. The amount of research and public health investment in this kind of epidemiological surveillance tacitly identifies anything less than 100 percent adherence to condom use among individuals as the problem in HIV prevention. Much less scrutiny is devoted to the structural environment that implicates the allocation of resources, beyond perfunctory references to global and seemingly intractable "social determinants of health" such as poverty, violence, racism, or homophobia (Public Health Agency of Canada 2015). In sum, a critical perspective demands that the underlying presumptions of biomedical individualism be scrutinized and that the knowledge politic be examined so that the actions of more powerful actors are assessed. While individual behaviour change may be part of the solution, other less visible parts of the solution necessary to meet the challenge of HIV infection require careful examination as well.

Critical perspectives also entail taking seriously the ways in which people on the receiving end of research make sense of their own situations, navigate a structured environment of constrained choices, and take risks along the way. Critical perspectives demand attention to the *emic* (that is, the subjectivity of the observed) rather than the *etic* (that is, information filtered through the rationales of observers). A sociological critique extending from C. Wright Mills's (1959) attack on "abstracted empiricism" to Aaron Cicourel's (1964) ethnomethodology has argued that critical approaches offer greater attention to the empirical, insofar as they come to grips with the everyday lives of people, in contrast to hard-science empiricism that understands people through the medium of aggregated numbers often gathered for administrative purposes. This argument, if applied to HIV-prevention science, would ask what kinds of knowledge about risk are produced by population-level analyses, as opposed to analyses of the diverse narratives spoken by people who must manage the possibility of HIV transmission in their everyday life. Their life worlds and practices provide vantage points from which to look back at administered environments.

These shifts in perspective and politic characteristic of critical approaches, nevertheless, are not always easy to delineate or accomplish. Postmodern reconceptions point out the difficulty of affirming clear boundaries in constructing binary oppositions between structures and individuals. Knowledge producers, research participants, and health authorities may over time overlap or have mutually influential effects on each other. They may become networked or responsive to each other in ways that blur easy distinctions, and some people may circulate from one location in knowledge creation to another. If subjectivity is a discursive position in circulating narratives, then there are no subject locations outside a larger politic of scientific discourse and narrative feedback loops may bind people together in new ways. In HIV prevention, these kinds of actor networks can readily be found. Certainly, the safe sex ethic began in the early 1980s in community mobilizations, well before public health or policy planners were ready to recognize HIV as a public issue. Over time, a great many gay men have reconstructed their practices through responsibilizing narratives that call on the good sexual citizen to be a practitioner of safer sex morality, and research on the views of those most affected by HIV very often picks up widely circulating discourses propounded by authoritative sources (Rangel and Adam 2014). Many community organizations act as pipelines for responsibilizing rhetoric in the name of empowerment and, with only a few exceptions, the treatment action wings of AIDS movements have not hesitated to make alliances with major pharmaceutical corporations to oppose regulation in the interests of getting more and better medication and prevention technologies on the market.

In the HIV sector, a leading resolution to the knowledge politic is "community-based research," which requires the engagement, participation, and consent of community-based organizations with professional researchers to carry out research projects and generate programming. While certainly an important step in ameliorating the balance of power in knowledge production, community-based research, in turn, can push back or bracket such questions as the relationship of community-based organizations to the populations they purport to represent or the use of unreconstructed methodological tools by researchers that leave communities wondering why research results still seem far from their experiences. In short, critical approaches offer tenets and precepts of value in reflecting on knowledge dynamics, but there are no "pure" standpoints from which to assess these dynamics. Certainly, epidemiological research does produce knowledge that is necessary and valuable to understanding epidemics. The nature of sexuality is such that there are many moments of sexual interaction that are routinely outside the purview of exterior administration and, therefore, irreducibly in the control of the individuals involved. But, without critical perspectives, diagnoses and solutions remain incomplete, and ways of doing better are foreclosed.

The Current Prevention Landscape

A now massive HIV research literature, created by a wide range of disciplines around the world, points to two major areas in which advancement can be made to bring down HIV rates. They are biomedical solutions and social/psychological solutions, though a closer look shows how intertwined these two solutions are with each other. Recent research has increasingly clarified the significance of viral load in reducing HIV transmission. HIV-positive people with suppressed viral load appear to have negligible potential to transmit the virus, and 80–90 percent of people on antiretroviral treatment have so little HIV circulating in their bloodstream that current tests (which can detect more than forty copies per millilitre) are unable to detect it (Bavinton et al. 2018; Rodger et al. 2016). The population-level question that arises in light of viral load research is who and how many people are attaining undetectability. Ever since the article by Edward Gardner and colleagues (2011) on the treatment cascade, it has become apparent that the good news about undetectability, both in restoring people living with HIV to health and in greatly reducing transmission, is overshadowed by the sizeable numbers of people who have not attained an undetectable viral load. Gardner and colleagues have stimulated research around the world that has pointed to the gaps between the number of those who have HIV and those who have been diagnosed, between the diagnosed and those linked to care, and between those linked to care and those retained in care.

This analysis also considers those who have attained undetectability through successful treatment. The attrition from one stage to the next is such that 30 to 40 percent of the totality of people with HIV have not reached undetectability in countries such as Canada (Public Health Agency of Canada 2016). Mathematical modelling of numbers in the United States leads to the estimate that 30.2 percent of people with HIV who are undiagnosed are likely the source of forward HIV transmission, another 61.3 percent of HIV transmission comes from people who are diagnosed but not retained in care, and the remainder is from people under treatment for HIV who have not (yet) attained undetectability (Skarbinski et al. 2015). Both individual and structural questions can be posed in the face of these findings: why are so many people not diagnosed or treated; what are the barriers to accessing testing and treatment; what are the experiences of the people located by medical researchers on the cascade timeline; and, as Adrian Guta and Stuart Murray ask in this volume, what disciplinary pressures may be exerted on HIV-positive people to accept treatment regimens? The answers to these questions are incomplete. The thirty-eight nation European Men-Who-Have-Sex-with-Men Internet Survey (EMIS) that attracted 180,000 participants found that 88.1 percent of HIV-positive men who had never taken antiretroviral treatment listed the reason simply as "my doctor says I don't need anti-retroviral treatment at the moment," which points back to the role of the health care system in the treatment cascade (EMIS Network 2013, 77).

Despite enthusiasm for treatment as prevention as the solution to the HIV epidemic (where antiretroviral treatment of HIV disease is proposed to be the primary or even exclusive resolution to HIV transmission) and despite optimistic pronouncements of an upcoming AIDS-free generation at the international AIDS conference in Washington in 2012, grounded largely in gains in reducing heterosexual transmission in the global South, mathematical modelling is showing that treatment as prevention may not be enough on its own to curb the HIV epidemic among gay, bisexual, and other men who have sex with men (Brown, Gill, and Delpech 2013; Muessig et al. 2012; Wand et al. 2010; Wilson 2012). Biomedical solutions often turn out to depend on social and psychological considerations related to the organization of the production and distribution of medication, experience and integratability in the demands of work and home life, and moral precepts regarding respectable or acceptable conduct.

Parallel to the research on the success of treatment in limiting infectiousness among HIV-positive people have been results in 2014 and 2015 from large cohort studies following the use of antiretrovirals as a method of preventing infection among HIV-negative people (Grant et al. 2014; McCormack et al. 2016; Molina et al. 2015). Consistent use of PrEP is proving to be a highly effective method of preventing HIV infection, but the structural barriers to access are formidable. With a corporate pricing scheme that assigns a cost to the consumer more than one hundred times the cost of manufacturing, access to PrEP remains out of reach for all but the best paid and best insured. An increasing number of jurisdictions in the United States, France, Australia, Scotland, and Brazil have taken the lead in providing PrEP to targeted subsets of priority populations, including gay and bisexual men who meet basic eligibility requirements (an instance of which is reviewed by Chris Sanders, Jill Owczarzak, and Andrew Petroll in this volume). Yet few other states have sought either to take on the corporate price structure or remedy barriers to access by providing it to those most likely to benefit from it. In Canada, Quebec's public health regime works to facilitate access to those individuals with medical coverage of prescription drugs through public or private means (REZO 2016). British Columbia, Alberta, and Nova Scotia initiated PrEP programs for people at high risk of HIV infection in 2018.[1] While PrEP was added to Ontario's formulary of publicly funded drugs in September 2017, PrEP may remain out of reach for those not covered by the province's public programs – namely, people between twenty-five and sixty-five years old whose income is above the threshold set by the Trillium Drug Program. Individuals without health insurance – including people without workplace benefits, migrants, or students recently arrived in the province – continue to confront formidable barriers to accessing PrEP.

Social Factors and Vulnerabilities

While epidemiology tends to calculate overall rates of HIV infection over large population categories such as "men who have sex with men," social and psychological research shows a highly uneven impact of HIV within risk populations. Perhaps 10–20 percent of gay and bisexual men are at particularly heightened risk for HIV according to this research, and HIV moves quickly through their networks. In 2003, Ron Stall and colleagues (2003, 941) summed up much of this research work by referring to "additive psychosocial health problems – otherwise known collectively as a syndemic – [that] exist among urban MSM and … the interconnection of these problems functions to magnify the effects of the HIV/AIDS epidemic in this population." Stall and colleagues identified childhood sexual abuse, depression, poly-drug use, and partner violence as syndemic conditions that predispose men to seroconversion. Since then, the interactions and ramifications of these factors and other related conditions, along with psychological research pursuing the "minority stress" hypothesis, which shows somewhat elevated rates of these conditions among gay, bisexual, lesbian, and transgender people in general, have pointed to another major area connected to the ongoing HIV epidemic (Meyer 2013). Each of these conditions is complex and heterogeneous; none can be treated simply as a prime cause without examining antecedents of its own.

The syndemic idea advanced the notion of co-occurring conditions that fuel epidemics and opened a potential new avenue for investigation that broke away from the traditional focus on individual behaviour. Over time, the burgeoning research literature on syndemics, however, has tended to fall back into the dominant paradigm, with each of the syndemic conditions reconceived as individual traits or risk factors, obscuring the social and historical roots that underlie family violence, social isolation, depression, or drug use (Adam 2016). The solutions that typically flow from this kind of psychological research, then, are individual or small-group therapies, and the potential of these solutions has yet to be tested through investment that would be at all comparable to the investment in pharmaceutical remedies. Still, syndemics research raises questions about how underlying conditions might be better identified and addressed.

Childhood sexual abuse may be just one face of a set of adverse childhood experiences that have long-term consequences for later health (Monnat and Chandler 2015). Racist and homophobic bullying also turn out to be predictors of HIV risk (Díaz, Ayala, and Bein 2004; Díaz et al. 2001; Nakamura and Zea 2010; Ryan et al. 2009). Childhood sexual abuse may feed into "depression, confusion and uneasiness about sex, and even loss of control over their love lives, [that] make meaningful self-protection more difficult" (Dorais 2004, 119). Still, even the notion of childhood sexual abuse requires critical scrutiny, insofar as Sonya Arreola and colleagues (2013) have found that youthful sexual exploration that is voluntary actually improves later resiliency and well-being. Both supportive family members and same- or older-aged men who are sexual partners and mentors contribute to "a sense of self and a quality of agency when describing both their childhood and adult sexual episodes, even in the face of virulent homophobic environments" (398). Depression also may index other experiences turned up in the HIV-risk literature such as social isolation, migration, and major stresses such as job loss or death of friends and partners. Problematic substance use appears to be associated with these syndemic factors and may be both a response to them as well as a precursor to HIV risk. Work by Matthew Mimiaga and colleagues (2015) confirms that the analysis of depressive symptoms, heavy alcohol use, stimulant use, poly-drug use, and childhood sexual abuse in a large cohort of gay and bisexual men shows that having two of these conditions leads to a 2.4-fold increase in acquiring HIV, three conditions leads to a 5.3-fold increase, and four or five conditions to a 8.7-fold increase over forty-eight months. These same conditions are also associated with lower adherence to medication and higher viral load among those who are HIV positive (Friedman et al. 2015). Since the proposal of a syndemics perspective on HIV transmission, a burgeoning research literature has repeatedly confirmed the centrality of these conditions for vulnerability to HIV (Halkitis et al. 2014; Herrick et al. 2014; Santos et al. 2014; Tulloch et al. 2015).

Syndemics as Experience

In the interests of a more experience-near portrait of syndemics, two interviews conducted by the author as part of a recent study of the social networks of new seroconverters, drawn from two downtown Toronto clinics, may be illustrative. The first interviewee was fifty-four years old, bisexual, and divorced from his wife for ten years. In the previous six months, he reported having taken a wide range of club drugs and crystal methamphetamine. He had also contracted gonorrhea and chlamydia during that period. He was on long-term disability from work and remarked: "That was before I was diagnosed [HIV positive]. It was due to the depression I was having which also involved drug use but they were not aware of that." He had little experience of gay scenes, and when he decided to explore sexual connection with men in his forties, his access point to gay scenes was through bathhouses. He was well educated and sought information related to the drugs he was taking:

> I also read everything on the internet about it [crystal], all the stories, all the things, even harm reduction sites: ok, if you're still going to do it, here are the ways to mitigate. It got to the point where I was able to come into Toronto, party all night at the bathhouse, leave six o'clock in the morning, drive back to [far suburb], have a shower, grab a coffee, and go to work. I was actually pretty proud of myself for mastering that but of course I wasn't myself at work ... People were like, Why are you so hyper? Why are you talking so fast? ... You'd make excuses.

The second interviewee was twenty-eight years old, gay, employed, and of Caribbean descent. In the last six months, he had also taken a wide range of club drugs, including crystal methamphetamine, and had contracted gonorrhea and chlamydia. On the antecedents to his interest in crystal, he remarked:

> There is a hierarchy of people in this city so you have your white males who assume that because they are white, everyone else should defer ... It was my biggest insecurity in moving here was having to navigate that and I think exclusion is a big part of people's insecurities because people always talk about a community where no one communes ... There is no real need to commune anymore because of the acceptance of homosexuality, and the only real need for gay men to connect is for sex.

Later in the interview, he continued:

> It was wanting to fit in. You know what I think would be great? A big brother program for older gays to mentor younger gays where they could take them on ... If I had known one gay person in high school, my life would have been completely different ... I would not have all these insecurities. I wouldn't try so hard to please people and I wouldn't trade sex for someone to like me. Essentially I have sex with people so I can have a conversation.

Both men spoke eloquently to the difficulties they experienced in making connection with other men, particularly in gay worlds that are increasingly fragmented and deterritorialized in virtual space (Dowsett 2009; Rowe and Dowsett 2008). Their points of contact with gay scenes were shaped by the options perceived to be available, in one instance by a relatively inexperienced man now in his fifties and, in the other, by finding one's way as a black man in a largely white men's scene. Their narratives echo other studies of the party scene. Club drugs or "party drugs" have a long-established role in some sectors of the gay world. One need only look at the 1933 novel *The Young and Evil,* to see how entrenched marijuana and cocaine use were in the Greenwich Village scene in the 1920s (Ford and Tyler 1988). Drug use has been part of a culture of pleasurable exploration and a widespread rite of passage in growing up gay, where many men have been able to control substance use instead of it controlling them (Race 2009). Observers of today's circuit parties and the "party-and-play" scene refer to the "tribalism," "esprit de corps," and sense of communion that attract a segment of the gay and bisexual population (Ghaziani and Cook 2005; Green 2001; Slavin 2004; Westhaver 2005). At the same time, they speak strongly to the costs, disappointments, and dissatisfactions of drug use that have taken over a major portion of their lives and have become interlocked with other life dilemmas.

These experiences affect vulnerability to HIV infection and other health outcomes; they also affect receptiveness to conventional prevention messaging as well as adherence to medication. Accessing the subjectivity of participation in these scenes moves beyond the somewhat opaque statistical relationship of drug use to HIV risk. It opens up questions about the structures of sexual fields, racial hierarchies, and social disruption faced by gay men in growing up as well as the difficulties of building social connection in making sense of syndemic conditions. By doing so, it scrutinizes the social contexts and constrained range of options in which individuals find their way – arenas that otherwise tend to fall into invisibility.

Thinking Critically about Structure

Individualizing and responsibilizing messaging has undoubtedly had considerable effect over the course of the HIV epidemic. HIV rates fell sharply through the 1990s as gay and bisexual men adopted condom use and mobilized to spread the safe sex message as well as to care for and support those already infected. But, in the 2000s, there have been few gains as rates have remained persistently elevated for men who have sex with men. A critical perspective on the current state of HIV prevention raises questions about relying on individual responsibility as the overriding strategy for making a difference and inquires into how institutional actors such as the health care system or the pharmaceutical industry mitigate or reinforce structural inequality.

Few gay, bisexual, and other men receive relevant HIV-related education in schools (Raifman, Beyrer, and Arrington-Sanders 2018). Almost half are not "out" to their health care provider (Dulai et al. 2011, 10). The apprehension or experience of demeaning, judgmental, or simply uncomprehending health care provision inhibits the disclosure of sexual practices to providers. An evaluation of the last major HIV testing campaign in Toronto in 2011–12 found that many individuals travel a considerable distance to access care they perceive to be gay friendly, even bypassing clinics that are closer to home and work to do so (Adam et al. 2016). Physicians rarely ask about the sexual orientation or gender identity of their patients and feel unprepared to provide culturally competent care to sexual minorities. Several studies have documented a desire among physicians for better training in sexual-minority health, but very little is currently included in medical curricula (Ng et al. 2014; Stott 2013). Lack of awareness or cultural competence among providers contributes to a standard of care that is insufficient to reduce HIV and sexually transmitted infections (STI). A recent survey of 590 young men who have sex with men in New York found that, while 46 percent had sought sexual health screening in the previous six months, only 16 percent had ever received a rectal test (Siconolfi et al. 2013). Yet research on gay men has found that "because 53 percent of chlamydial infections and 64 percent of gonococcal infections were at nonurethral sites, these infections would be missed and not treated if only urethral screening was performed" (Kent et al. 2005). Untreated STI are also known facilitators of HIV infection.

These indicators show a significant gap between current practice and the equitable standard of care articulated in reports by the Institute of Medicine (2011), entitled *The Health of Lesbian, Gay, Bisexual, and Transgender People,* and by Harvey Makadon and colleagues (2015), entitled *The Fenway Guide to Lesbian, Gay, Bisexual, and Transgender Health*. While gay and bisexual men do have relatively high rates of testing for HIV in Canada, research on the treatment cascade points to a need to improve the rates of diagnosis, and those rates will improve only through regular and sufficient medical care. A friendly point of entry is just a first step toward access to health services, and a good deal of research points to this as being fundamental to an equitable standard of care for gay and bisexual men and for lesbian, gay, bisexual, transgender (LGBT) communities as a whole. Addressing syndemic conditions and new prevention technologies would require a comprehensive and integrated approach including:

- evidence-based risk assessment services to determine primary care, HIV/STI prevention, and mental health and addiction needs
- timely referrals to appropriate culturally competent primary care and mental health and addiction treatment services, including sexual health clinics; primary care providers; community-based HIV, LGBT and mental health counselling services; community-based psychologists and psychiatrists; and specialized (hospital-based) mental health and addiction services
- evidence-based interventions to meet needs and reduce pressure on existing mental health and psychiatric services
- easy access to PrEP and post-exposure prophylaxis (PEP) provided without cost to those who would most benefit from it
- follow-up to ensure appropriate care is received
- consultation services for primary care, HIV/STI prevention, and mental health providers
- education and training initiatives for primary care and mental health providers
- coordination services to establish and maintain ongoing networks of primary care and mental health providers with expertise in gay men's health care.

Of these initiatives, it is the pharmaceutical measure of providing access to PrEP to those who could most benefit from it that has attracted public health investment and scale-up in a few jurisdictions. In Sydney, Australia, expanded PrEP access has been organized under the auspices of a large research project that has enrolled several thousand men, and, in London in the United Kingdom, improved access has been spearheaded by the comprehensive sexual health clinic, 56 Dean Street.[2] While both of these initiatives are new and remain underway (as of 2018), early epidemiological numbers are promising with HIV rates falling significantly for the first time in two decades (Alcorn 2017; Cairns 2018).

In the United States, leadership in coordinated care takes the form of LGBT health centres in major cities. Fenway Health in Boston is a community health centre specializing in LGBT health care, where health navigators provide a comprehensive health assessment for new patients that identifies underlying and related health and social issues that may limit wellness and inform referrals.[3] Strut in San Francisco offers a comprehensive gay men's wellness centre that co-locates sexual health services, substance use, and mental health counselling services and community-building and support programs.[4] These models point to more systematic, coordinated, and integrated provision of health care services with considerable potential to advance on both the biomedical and syndemic fronts. In Canada, only Winnipeg's Our Own Health Centre has taken the step toward a dedicated gay-friendly health service, while MAX in Ottawa provides linkage to gay-friendly health services.[5]

Conclusion

Critical thinking, then, has much to offer health science and HIV prevention, in particular. In an area long dominated by biomedical individualism and responsibilizing rhetoric aimed at individuals to reform their behaviour, critical perspectives inquire into the larger field of agents and conditions that impact risk and vulnerability. The argument here is not that individualized messaging, which is the hallmark of public health and AIDS service organizations, is "wrong." That messaging is readily understood in a society where responsibilizing discourse is widespread. Moreover, falling HIV rates in the 1990s, before the advent of combination antiretroviral therapy, speak to the effectiveness of that strategy. Nevertheless, a singular focus on that approach too easily lets more powerful actors on the socio-historical stage – such as pharmaceutical corporations, health delivery systems, schools, and state allocation of resources – escape scrutiny in the creation of effective policy. The addition of new prevention technologies such as PrEP into the current situation raises first questions of access but then also whether these technologies are to be conceived as solutions that are to be rolled out through campaigns of health promotion to overcome obstacles to "uptake" and "adherence."

Critical perspectives question the reduction of empirical research to the measurement, counting, and mathematization of population indicators by arguing for the need to take subjectivity seriously. Seeing the constraints and opportunities available to people in the risk populations through their eyes opens the possibility of understanding the role of socio-political environments in contributing to, or detracting from, health. This can take the form of examining proximate institutions directly affecting health service (which is largely the focus here) or extend to more distant structural questions such as the ways in which for-profit medication development system facilitates or limits health, how health promotion reinforces (or undermines) neoliberal ethics of respectable citizenship, how the symbolic politics of innocence and guilt, or worth and unworthiness, enter into the allocation of resources, how gender performance intersects with these systems, and so on. Indeed, school-based anti-bullying programs and gay-straight alliances may in the long run prove to be critical programs in bringing about the kind of structural change that will be fundamental in addressing syndemic conditions. Critical examination, then, need not only be a theoretical exercise, but from it can also flow concrete implications and applications concerning what needs to be done if headway is to be made in facing the HIV epidemic.

Notes

1 "Preventative Medication Will Protect People at Risk of HIV," *BC Government News,* https://news.gov.bc.ca/releases/2017HLTH0114-002108;

"HIV Pre-exposure prophylaxis (PrEP)," *Alberta Health Services,* https://www.albertahealthservices.ca/info/Page16048.aspx; "Nova Scotia Will Fund HIV-Prevention Drug PrEP with Pharmacare," *CBC News,* https://www.cbc.ca/news/canada/nova-scotia/government-increases-access-hiv-prevention-drug-prep-1.4754996.

2 "Epic-NSW PrEP Trial," https://endinghiv.org.au/stay-safe/epic-nsw; "Welcome to 56 Dean Street," http://dean.st/56deanstreet.

3 "Fenway Health," http://www.fenwayhealth.org.

4 "Strut," http://strutsf.org.

5 "Our Own Health Centre," http://www.ourownhealth.ca; "MAX," http://maxottawa.ca.

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7

Undetectable Optimism

The Science of Gay Male Sexual Risk-Taking and Serosorting in the Context of Uncertain Knowledge of Viral Load

Mark Gaspar

In the following chapter, I extend the tradition of critical social science on HIV to examine treatment optimism. Treatment optimism is the epidemiological hypothesis that social actors who believe in the prevention benefits associated with managed or undetectable viral load levels (in particular, gay men and other men who have sex with men) are more likely to take sexual risks (Chen 2012). I draw on the lived experiences of gay men, focusing on the complexity of their sexual practices (an examination of sexual acts in context) in order to question the limitations of ruling forms of knowledge in the field of HIV-prevention science. I then move on to review the scientific literature on treatment optimism to demonstrate that, while epidemiologists and social scientists have tended to be unable to convincingly prove this hypothesis, it has remained a staple narrative in the field. By closely reflecting on the sexual practices of young HIV-negative gay men managing HIV risk in the years prior to 2014, I then challenge the validity and generalizability of the treatment optimism hypothesis and question its implications for HIV-prevention research and education programming.

I demonstrate that while some HIV-negative gay men were incorporating undetectable viral load information into their sexual decision making, this was being done with far more nuance than the treatment optimism hypothesis posits. Indeed, most of the young HIV-negative gay men I interviewed for this project remained skeptical, and some quite critical, of new biomedical information. Many avidly resisted altering their risk management practices, especially when this involved adjusting their preferences for condom use and serosorting (that is, only having sex with partners with the same HIV status; in the case of HIV-negative men, this means only having sex with other HIV-negative men). Numerous intersecting social and structural factors determined how these young men understood undetectable viral load and incorporated or resisted incorporating it into their sexual practices. In addition to offering a critique of the treatment optimism hypothesis, I also elaborate on some of the social and ethico-political tensions surrounding serosorting practices that many HIV-negative gay men faced within a context of changing and highly contested knowledge claims about HIV transmission. I argue that these challenges are often erased from mainstream public health research, despite being central to processes of risk negotiation. By focusing so intently on sexual risk-taking and condomless anal sex, mainstream epidemiological science and public health research can obscure valuable insights into the diverse ways that gay men are being affected by new biomedical prevention technologies. I draw on these observations in the conclusion to consider what these findings mean in our current context where "undetectable equals untransmittable" and the prevention benefits of undetectable viral load are less contested by experts, but no less socially complex.

Critical Social Science and Gay Male HIV-Prevention Science

For over three decades, social scientists have been critically examining the HIV-prevention practices of gay men (Adam 2005; Dowsett 2009; Holt 2014; Kippax 2012; Kippax and Race 2003). They have been particularly interested in the relationship between knowledge-production practices and the everyday experiences of gay men managing HIV risk. Critical work on HIV reflexively engages with existing research in order to avoid contributing to hegemonic power structures through research practice, as noted by Randy Jackson in this volume. By reflexivity, I have in mind a researcher's ability to pose "a set of 'reflexive' questions about a particular research issue: questions concerning the implicit assumptions and ideology underlying the research process, and the role of power, contradiction, and dialectical relationships in theory and research practice" (Eakin et al. 1996, 159). A critical reflexive stance asks how and why particular forms of research about gay men and HIV are being produced. It queries the assumptions underlying these dominant research paradigms, and it destabilizes beliefs regarding what we consider to be valid and significantly consequential evidence about gay men and HIV. As Barry Adam frames it in this volume, critical social science closely monitors the political relationship between the observer (researcher) and the observed (researched) to ask: in whose interest is knowledge being produced?

Part of this critical analysis entails examining dominant research agendas and disciplinary perspectives in HIV-prevention science. HIV-prevention science is a broad field of scientific inquiry spanning the social, behavioural, and biomedical disciplines. It seeks to understand how HIV transmission may be most effectively prevented at the individual, community, and population levels, through surveillance research, risk-factor research (understanding underlying causes for risk-taking), and clinical trials measuring the efficacy of prevention technologies. Many critical social scientists have commented on the hegemonic role of biomedical and public health perspectives, such as epidemiology, within the field of HIV research (Adam 2011; Mykhalovskiy and Rosengarten 2009a, 2009b; Namaste et al. 2012). These research domains have a managerial orientation, often utilizing data collected from large-scale quantitative research projects to produce knowledge for administering health care. While recognizing the necessity of these perspectives, critical scholars have demonstrated how mainstream public health and epidemiological research, with their interest in monitoring individual behaviour and isolating psychosocial factors motivating sexual risk-taking, often produce over-simplified narratives about HIV risk management that, intentionally or not, tend to problematize gay male sexuality

(Adam 2011). Epidemiological research has a tendency to focus intently on the "failure" of "high-risk" gay men to use condoms consistently, often ignoring the social dimensions of risk negotiation and the broader structural factors that may be putting these men at risk of acquiring HIV.

One way that critical social science research on HIV prevention and gay men reintroduces the social is through its emphasis on sexual practice. Susan Kippax and Niamh Stephenson (2005, 363) argue that social and cultural practices are "produced within a particular historical time and place, and embedded in specific locations and formations." As an object of scientific investigation, sexual practice is considered a form of social practice that is distinguishable from sexual behaviour: "Social practices inform particular behaviours or actions by particular individuals on particular occasions in particular locations and context" (Kippax and Race 2003, 3). Thus, sexual behaviours refer to the sexual acts that social actors enact, with minimal consideration of the broader social context in which they occur. Epidemiologists are usually interested in monitoring behaviour – for example, by tracking cases of condomless anal sex or what has until more recently been referred to as unprotected anal intercourse (UAI) – in order to generate theories about why gay men may engage in "high-risk" behaviours in the interest of understanding population incidence rates. Conversely, critical social scientists are interested in the broader context that shapes the meanings associated with specific sexual behaviours and that orient social actors to HIV risk in different ways. They are interested in examining these contexts so that "the ontological claim about 'what sex is' begins to unfold into a series of practical relations: conversations, exchanges, disputes, ruminations, [and] contextualizations" (Race 2014, 259).

By examining sexual practice, critical scholars can provide more nuanced portrayals of HIV risk management in everyday life and offer contrasting perspectives to dominant epidemiological and public health narratives on HIV. This work is critical in a dual sense. First, it highlights the shortcomings of dominant research agendas, demonstrating their limited validity and generalizability and, therefore, their limited ability to positively address the health and well-being of gay men. Second, it demonstrates how particular research models can often ignore, marginalize, or completely erase key social elements of HIV risk management, which can lead to education and service programming that fails to resonate with those at risk, once again undermining their ability to positively impact gay men's health.

In this chapter, I have also been influenced by key components of institutional ethnography (IE), a tradition used by many critical social scientists working on HIV/AIDS in Canada. As described in Daniel Grace's and Colin Hastings's contributions to this volume, the study of people's everyday experiences to investigate ruling forms of knowledge is one of the principle objectives of IE. IE is a "method of inquiry into the social that proposes to enlarge the scope of what becomes visible from that site, mapping the relations that connect one local site to others" (D. Smith 2005, 29). IE pays close attention to the mundane aspects of a social actor's lived experiences as well as examples of ruling relations, those institutional activities that coordinate the social world through texts, documents, policy reports, and administrative forms (Namaste et al. 2012). IE is particularly concerned with how existing scholarly or scientific research operates to give a particular shape to a social problem such that certain elements and social actors are made visible, while others are rendered invisible or marginal (Namaste et al. 2012). By collecting data on the everyday experiences of those less represented in the established literature, scholars using IE can offer perspectives that challenge the dominant narratives circulating in a given research field that come to coordinate the social world through institutional activity. In the following section, I use several key aspects of IE to understand the social effects of a considerable lack of expert consensus on the risk reduction benefits of undetectable viral load on the everyday lives of gay men in order to shed light on the limits of HIV-prevention science and education. I will begin this analysis by describing the treatment optimism thesis, including the specific epistemic and biopolitical contexts shaping its emergence.

The Treatment Optimism Hypothesis

Treatment Optimism and the Uncertainty of Undetectability

The association between a social actor's belief that a managed or undetectable viral load can eliminate the possibility for HIV transmission in the context of serovariant sexual relations (also known as serodiscordant sex, sex between partners with different HIV statuses) with his likelihood of having unsafe sex is known in HIV-prevention science as treatment optimism (Chen 2012). Treatment optimism is an epidemiological hypothesis, or a form of risk-factor research, that has been mobilized by biomedical and social scientists in the field to understand gay male sexual risk-taking. Risk-factor research aims to understand the demographic, behavioural, attitudinal, and psychosocial underpinnings of motivations for higher risk behaviour that may lead to HIV infection in order to influence public health decision making (see also Adam 2011; Dowsett 2009).

Treatment optimism is typically measured in surveys, often through the use of standardized scales (Brennan et al. 2009), by asking a set of questions about sexual risk-taking (usually condomless anal sex or condomless oral sex in earlier research) and beliefs in the risk reduction associated with a supressed or undetectable viral load or the infectivity levels of HIV-positive men who are on treatment. Responses are made into variables and correlated to see if there is a relationship between a willingness to forgo condoms during anal sex and a belief that HIV medications can reduce the risk of transmission during instances of serovariant sex. Specific survey questions may also ask whether research participants use undetectability and viral load information in their decisions to have condomless anal sex. As a research hypothesis, treatment optimism remains deeply entwined with AIDS optimism, the theory that social actors (and, once again, gay men especially) are more likely to have condomless anal sex if they believe that HIV is a "chronic manageable condition" as opposed to a "death sentence" (Adam et al.

2005). Indeed, many of the first published works examined both of these forms of "HIV optimism" at once (Van de Ven et al. 2000).[1]

Before proceeding, it is necessary that I first situate the emergence of the treatment optimism thesis within its specific epistemic and biopolitical context. Both AIDS and treatment optimism emerged as research hypotheses in the HIV field around the end of the 1990s when epidemiologists were trying to explain increasing HIV incidence rates in gay male communities internationally (Crepaz, Hart, and Marks 2004). Importantly, during this period, clinical trial research exploring the extent to which an undetectable viral load could reduce the risk of HIV transmission had yet to commence. Thus, the treatment optimism hypothesis was developed at a time when the risk-reduction benefits of highly active antiretroviral therapy (HAART) were only beginning to be discussed by researchers and some communities of "high-risk" gay men but were not scientifically confirmed (Flowers 2001; Race 2001, 2003). Given the absence of reliable scientific data on the prevention benefits of viral load suppression, all serovariant acts of condomless anal sex, including those where the HIV-positive partner had achieved undetectability, remained, from an epidemiological perspective, unequivocally high-risk sexual acts.

During this period (that is, 1996–2015), the field of HIV research and services was characterized by extreme ambivalence over the role of treatment in prevention practice. On the one hand, many leading experts in the field were avidly enthusiastic about the prevention benefits of HAART. For example, in 2008, the Swiss National AIDS Commission released a statement on viral load suppression and risk that garnered international attention. They argued that an HIV-positive person with a suppressed viral load who is on medication is not sexually infectious (Vernazza et al. 2008). Two large-scale clinical studies, HPTN 052 (Cohen et al. 2011) and the PARTNER study (Jin et al. 2015; Rodger et al. 2016), began measuring the risk-reduction potential associated with HIV treatment, both indicating very favourable correlations between undetectable viral load and a reduced risk of HIV transmission. While the findings from the PARTNER study would eventually usher in a paradigmatic shift in HIV researchers' understanding of undetectable viral load and risk among gay men (discussed in the conclusion of this chapter), the conclusions drawn from HPTN 052 were the ones available at the time of my research. In Canada, researchers at the British Columbia Centre for Excellence in HIV/AIDS were also early to support the correlation between undetectable viral load and the reduced risk of HIV transmission at the population level under the "treatment as prevention" model (Montaner et al. 2010), whose surveillance and biopolitical implications Adrian Guta and Stuart Murray critically dissect in this volume.

On the other hand, many experts were far less convinced about the prevention benefits of undetectability, particularly because of the epistemic limitations of the various clinical trials (HPTN 052, in particular) and, thus, their applicability in everyday life situations. Barry Adam (2011) offers a review of some of these concerns. First, he reminds us that achieving an undetectable viral load is not possible by all HIV-positive people taking antiretroviral medication, including significant majorities of gay men living in Ontario. Second, many of the studies examining viral load measure viral quantities in the blood of HIV-positive persons and not in the genital fluids where viral load may be higher. Third, much of the research on viral load, such as the HPTN 052 study, only collected data from heterosexual couples. These findings are often extrapolated to make sense of gay male sex even though risks from anal sex between men may be higher. And, finally, Adam reminds us that viral blips, temporary moments where viral load levels may spike (for example, when the immune system is combating another sexually transmitted infection [STI]) may also increase risk.

As a result of these concerns, HIV organizations across Canada reacted rather cautiously to research on the lowered risk of HIV transmission associated with undetectability. For example, in response to the Swiss statement, the Canadian AIDS Treatment and Information Exchange (CATIE) released a news bulletin arguing that the report was based on ungeneralizable evidence (Hosein

2008). CATIE followed with more favourable articles about the risk-reduction potential of undetectable viral load (Wilton 2013, 2014). However, they made sure to take a measured approach, recognizing that, while risk may be reduced, it "is not completely eliminated when the viral load is undetectable and no condom is used" (Wilton 2013). Organizations such as the AIDS Committee of Toronto and the Gay Men's Sexual Health Alliance of Ontario also specifically warned gay men about relying solely on viral load levels as a risk-reduction strategy over consistent condom use, reminding gay men that the science was not yet clear (Gay Men's Sexual Health Alliance 2012). Guidelines for service providers in Ontario cautioned against an overly enthusiastic response to undetectable viral load, particularly due to differential levels of virus in the genital tract (Ontario Ministry of Health and Long-Term Care 2008, 2). And, in Vancouver, the progressive Health Initiative for Men's online "Know Your Risk" calculator advised gay men against relying on undetectable viral load to manage risk (Health Initiative for Men 2010).

In the conclusion to this chapter, I will return to examine the relevance of the treatment optimism hypothesis in the current context, where we have more solid evidence supporting the risk-reduction benefits of undetectable viral load for gay men (particularly because of the PARTNER study) and, thus, more expert and community consensus. However, it is necessary that we situate the emergence of treatment optimism research – as well as the narratives coming from the interview data presented later on – within a period of emerging scientific data, but limited expert consensus, on the prevention benefits of undetectable viral load.

Treatment Optimism: Emergence

The exact origins of the treatment optimism hypothesis are tricky to locate with precision, as it appears that various researchers in Australia, Europe, and North America simultaneously became interested in this topic soon after the roll out of HAART in 1996. Early efforts to prove the treatment optimism hypothesis among gay men were generally mixed and, at best, could only partially confirm the relationship between optimistic beliefs and risk-taking among small samples of gay men (Dilley, Woods, and McFarland 1997, 1998; Kalichman et al. 1998; Remien et al. 1998; Vanable et al. 2000). Reflecting on research produced in the late 1990s, Van de Ven and colleagues (2000) argue that no straightforward link between treatment optimism and sexual risk-taking could be firmly established. Many of these research projects found few or no associations between optimistic beliefs in HIV treatment and sexual risk-taking and statistically insignificant findings among small minorities of gay men who reported being treatment optimistic. Importantly, all of these projects were unable to report on causality – that is, that "unsafe" sexual behaviour may be associated with, but may not necessarily be caused by, optimistic beliefs in HIV treatments (Crepaz, Hart, and Marks 2004; Van de Ven et al. 1999).

Nonetheless, research aiming to confirm the treatment optimism hypothesis continued to proliferate throughout the 2000s. While some level of treatment optimism behaviour among gay men was observed, much of this work continued to either complicate or contradict the hypothesis, while other studies offered statistically insignificant findings (Crepaz, Hart, and Marks 2004; Elford, Bolding, and Sherr 2002; International Collaboration on HIV Treatment 2003; Koblin et al. 2003; Williamson and Hart 2004; Vanable, Ostrow, and McKirnan 2003). Indeed, one study disproving the hypothesis argued that optimistic beliefs in treatment actually tended to proceed from a history of sexual risk-taking rather than optimistic beliefs being a causal factor in sexual risk-taking (Huebner, Rebchook, and Kegeles 2004). Having optimistic beliefs in treatment tended to serve as a "post-hoc rationalization" after a social actor has had condomless anal sex (Huebner and Gerend 2001).

When I conducted my empirical qualitative study on gay men and HIV risk in 2013, treatment optimism remained a contested, yet important, concept with equivocal evidence to support its claims. Indeed, after the Swiss report was released, researchers and service providers speculated that more gay men would start to become overly reliant on viral load information as part of their risk management strategies and would begin to engage in condomless anal sex once one or more partners had achieved an undetectable viral load (Hosein 2008). In response to these concerns, the Ontario HIV Treatment Network (OHTN) produced a summary sheet of research projects on viral load addressing the treatment optimism hypothesis in order to help researchers, policy makers, and service providers make sense of this ostensible problem (Rapid Response Service 2014). Following the language of IE, we can consider this to be an example of a ruling relation, an institutional document that is meant to coordinate the social by influencing how researchers, policy makers, and prevention educators respond to at-risk clients' interest in undetectable viral load.

A significant portion of treatment optimism research highlighted by the OHTN examines the issue from the perspective of HIV-positive men (Chen 2012). Some studies have found some association between increased sexual risk-taking behaviours and treatment optimism among HIV-positive men (Brennan et al. 2010). A study in Australia confirmed that some HIV-negative men in serovariant relationships do use undetectable viral load information when choosing to have condomless anal sex with their HIV-positive partners (Prestage et al. 2009). However, both groups of HIV-positive men examined in the study, those with detectable and undetectable viral loads, were just as likely to engage in condomless anal sex with their HIV-negative partners. A US study looking at HIV-positive men argues that treatment optimism leads to more condomless anal sex in the context of casual serovariant sexual relations (Joseph et al. 2010). The OHTN report contends that, as a whole, these studies suggest that treatment optimism can lead to sexual risk-taking, especially among HIV-positive gay men.

No doubt, treatment optimism is an important concept that, despite an ambiguous relationship to empirical evidence, has played a key role in organizing the field of HIV prevention. The belief that biomedical technologies may inadvertently support increased HIV incidence is a staple idea that has appeared in countless grant applications, conference presentations, and scientific publications on gay men's health and HIV prevention. The treatment optimism hypothesis has thus been a core lens by which we have come to understand gay men's health, well-being, and risk negotiation strategies in the context of the HIV epidemic.

Critical Inquiry into Treatment Optimism

It should not come as a surprise that recent research addressing the treatment optimism hypothesis tends to indicate that HIV-positive men are more likely to be treatment optimistic than HIV-negative men since positive men are likely to be more familiar with the concept of viral load as a result of their diagnosis. Those more proximate to the HIV/AIDS service industry will also have a much greater awareness of HIV-prevention terminology than those further removed (Namaste et al. 2012). Moreover, HIV-positive men also have more at stake in believing in the risk reduction potential of undetectable viral load since this association recasts their position as posing a high risk into one of posing little to no risk of transmitting HIV to their sexual partners.

Nonetheless, treatment optimism research, like a significant bulk of research interested in HIV prevention and gay men, zooms in on the narratives of those who have taken sexual risks, and, in particular, those who have recently had instances of condomless anal sex (see Barry Adam in this volume). Quite literally, scientists select out those who have not had condomless anal sex with partners with mixed or unknown HIV statuses in their attempts to understand the effects of undetectable viral load. While this interest in understanding the underlying motivations for "high-risk" behaviour may be logical – at least from an epidemiological point of view – it misses an important opportunity to understand how information on undetectable viral load may be influencing sexual practice more broadly and what role it might be playing in risk management. Moreover, when we focus mostly on the risk-related narratives of those engaging in "higher-risk" practices (that is UAI), we may be ignoring the diverse ways in which gay men are negotiating and being affected by HIV risk. If only a small minority of gay men are actually demonstrating treatment optimistic risk behaviours, what might there be to learn from the stories of the majority of gay men who are not? What are the diverse ways that those who are at risk interpret and incorporate undetectability into their sexual practice? How exactly is information about undetectable viral load changing risk negotiations and sexual ethics?

In line with IE perspectives on HIV prevention, we can investigate the narratives of social actors that are not as commonly included in the literature in order to answer these questions and to add critical nuance to our understandings of the relationship between scientific research and people's everyday lives (Namaste et al. 2012). Below I focus on the narratives of young HIV-negative identified gay men (aged eighteen to thirty-five) who have had one or more experiences where they were uncertain about their serostatus. A recent history of engaging in condomless anal sex was not a requirement for participating in the study. The data was collected from thirty-three in-depth semi-structured interviews following an active interview format (Holstein and Gubrium 1995). The interviews were conducted in Montreal and Toronto in the fall of 2013 and were examined using interpretative phenomenological analysis (J. Smith 2004). The interviewee names presented below are pseudonyms. In order to tap outside of the established epistemic communities governing knowledge production in Canada – that is, to think beyond the network of professionals and expert community collaborators who are routinely responsible for producing and disseminating valid knowledge about HIV prevention – the interview participants could not have participated in a previous qualitative research project about HIV/AIDS or have had an active volunteer or working relationship with an AIDS service organization (ASO) (Holt 2014). Community-based research paradigms in Canada often require researchers to directly align with existing organizations in order to generate research questions and recruit research participants (Namaste et al. 2012). This epistemic tendency to work only in and through such organizations means that we are often collecting and evaluating research among networks of people who may be more "in the know." Focusing on HIV-negative men who are not all active sexual risk-takers (that is, barebackers) and who have had marginal or non-existent relationships to ASOs, offers us new perspectives that will allow us to enlarge our view of relevant social processes and critically re-examine some of the debates on undetectability.

During the interview, participants were asked to reflect on moments where they felt that they were at risk for HIV, for whatever reason (including instances of low- and negligible-risk sex and even to recount extended periods of abstention), and how they managed and were affected by risk in those contexts. The broader goal of the study was to determine how HIV-negative gay men were being affected by serostatus uncertainty and to detail the intersecting social and structural factors that fostered a social actor's tolerance or aversion to serostatus uncertainty over time. The following discussion focuses specifically on those narratives where undetectable viral load played a role in a participant's interpretation of risk events and how it came to influence his sexual practice.

Arguably, the use of qualitative methods to explore sexual health matters within a scientific field dominated by quantitative evidence-based medicine can be inherently critical. Flexible qualitative methods, such as active interviewing, provide research participants with more agency to shape a research project's priorities, as interviewees can choose how to engage with the interviewer and subject matter. Rather than setting out a predetermined list of hypotheses, which are then quantitatively measured, semi-structured qualitative interviews can open up the potential to address social dynamics not previously considered by the researcher (or the research field as a whole). The treatment optimism hypothesis, as it is commonly measured in quantitative surveys, suggests that the most important thing to know about undetectability is how it influences UAI. Qualitative research that asks gay men to reflect on how they have been affected by serostatus uncertainty, under the context of uncertain knowledge claims about undetectability, destabilizes this assumption and questions what we should be prioritizing in our research practices in the first place. It is a fundamentally different entry point into the field, one that is in line with IE scholarship that emphasizes the need to start investigations from the point of view of social actors' lived experiences rather than from the "objectifying discourses" that dominate a scientific field (D. Smith 1990).

Realities of Treatment Optimism among HIV-Negative Gay Men

Treatment Pessimistic Beliefs and Serosorting

The participants in my study shared experiences and opinions that offered clear challenges to the treatment optimism hypothesis. First, some of the participants could not be considered to be treatment optimistic as they had no idea what undetectable viral load meant. This finding mirrors earlier research on treatment optimism that indicated low awareness of the benefits of HIV treatments among HIV-negative men (Koblin et al. 2003). Drawing this conclusion, once again, more than a decade later is somewhat distressing. It certainly indicates that prevention education on undetectability has not been reaching all groups of gay men in Canada and that discussions on undetectable viral load may be less ubiquitous beyond the epistemic communities governing HIV knowledge production and service delivery.

Other participants expressed a greater awareness of undetectable viral load and understood (to varying degrees) its implications for prevention. Here is an example from Mario who was aware of undetectability but confused about its benefits:

> MARIO: What always has intrigued me, or is intriguing me lately, because I tried to go online dating last year before Martin came around and people kept writing something called "undetectable." I didn't know what that was in the beginning. But I'm like, so you have HIV? I still don't quite understand why people say undetectable. Like, I don't understand that logic and where that stemmed from.

Mario's comments illustrate that some gay men are not treatment optimistic in part because they do not fully comprehend the concept of undetectable viral load. For some, the concept of undetectability is complex and confusing. When I further explained undetectability to Mario during the interview, he replied that it would not change his discomfort with having serovariant sex and that he would not be able to sustain an erection because of his risk aversion. Others with more awareness of undetectability expressed similar opinions. For example, Sebastian was aware of undetectable viral load but still relied on serosorting to manage risk:

> SEBASTIAN: I'd still be uncomfortable [relying on undetectable viral load]. Yeah. Even rationally knowing that like, the risk is like, so reduced, it would still make me uncomfortable.

Thus, for some HIV-negative men who rely on serosorting as a form of risk management, new knowledge about undetectability may not change their views on what they consider to be effective HIV prevention. These men can see all serovariant relations, regardless of what sexual acts are performed or whether condoms are used, as posing a higher degree of risk.

For other participants, there was a higher degree of skepticism and even some hostility directed toward those who may be too optimistic about the risk reduction of undetectable viral load. For example, Jonathan discussed the issue of viral load and HIV status disclosure – not as a specific legal issue (see Colin Hastings in this volume), but as a broader ethical issue:

> JONATHAN: So, this really is why it's getting spread so much. Cause people don't really, you know what I'm saying, they don't let the sexual partner who doesn't have anything [that is, who is HIV negative] make the choice of taking the risk or not. Do you know what I'm saying? And that's like, practically cruel,

> you know? Yeah, it's undetectable, but undetectable for me is like, yeah you have it, cause you have it.

Rather than being treatment optimistic, men such as Jonathan were treatment pessimistic, as they vehemently refused to accept undetectable viral load information as part of a viable risk-reduction strategy. Beyond rejecting the benefits of undetectable viral load, some of these participants went as far as to blame HIV-positive men who factored in undetectability into their risk-reduction practices for actually increasing risk to gay male communities, especially when undetectability was used to justify the non-disclosure of HIV-positive serostatus. This finding follows in the tradition of critical social science by focusing on evidence that is excluded from ruling forms of investigation. All of the examples above come from men sharing stories involving choices to proceed with protected and lower-risk sex, not condomless sex. Consequently, we are able to witness dynamics that are marginalized in mainstream epidemiological research focused on understanding gay men's health principally through their proclivities to have condomless anal sex.

All of the participants who preferred to serosort as a form of risk management believed that someone who is HIV positive posed a risk of infection regardless of their viral load status and, consequently, deemed serostatus disclosure to be a moral imperative. A discomfort with serovariant sex, which many interviewees considered to be high risk regardless of condom use or other risk-reduction methods such as strategic positioning,[2] shaped how these men came to interpret information on undetectability. These findings mirror research conducted in Australia, which has demonstrated that some gay men remain unconvinced about the role of relative risk reduction strategies such as factoring in undetectable viral load information and that some struggle to find any form of sex to be "safe enough" (Prestage et al. 2012). Thus, awareness of relative risk reduction practices is not, at least in and of itself, enough to modify sexual practices.

Rather than seeing emerging biomedical information influence sexual decision making, this study demonstrates that pre-existing beliefs about risk and prevention shaped how emerging biomedical information was interpreted. Those who were reliant on serosorting as a risk management practice tended to be less open to changing their sexual practices on the basis of viral load information, since they found serosorting to be absolutely imperative to managing sexual risk. For these men, serosorting was effective HIV prevention. The social dimensions of HIV prevention (in this instance, aiming to maintain seroconcordant sexual relationships and fearing serovariant relationships) influenced the interpretation of the biomedical evidence rather than the reverse.

Undetectable Viral Load and Social Context

Among interviewees less convinced about the prevention benefits of undetectable viral load, the social context by which they were introduced to undetectable viral load information played a significant role in how they interpreted and applied such information. For example, Jonathan developed a strong risk aversion to serovariant sex due to a prior experience of taking post-exposure prophylaxis (PEP) after having condomless anal sex during a one-night stand (with an individual who was only later on confirmed to be HIV negative). Jonathan experienced severe side effects from the treatment and was bedridden for weeks. This episode made him extremely averse to further sexual risk-taking and distrustful of the benefits of HIV medication as a form of risk management. Francis also took PEP after a condom break during a hookup and experienced severe side effects, leading to an increased aversion to sexual risk-taking. Months later, Francis began dating an HIV-positive man who disclosed that he had an undetectable viral load. He was aware that this meant a reduced risk of transmission, but, at the time, he was not comfortable with having serovariant anal sex and requested that they use condoms for oral sex. This request put a strain on the relationship, which soon ended. After some time had passed, Francis reflected on his risk management decisions and considered himself to have been too risk averse and serophobic. He began to question his preference for serosorting and his expectation that HIV-positive men should always disclose their serostatus.

Another factor motivating Francis's risk aversion was his immigration status, an issue brought up in several interviews. Since 2002, an HIV test has been a requirement for those applying for Canadian permanent residency. Thus, participants who were applying for permanent residency worried extensively about how an HIV-positive diagnosis would affect this process. Take, for example, Karun's comments about his immigration status and serovariant sex:

> KARUN: I'm hoping that my permanent residence will arrive within the next month or so.
>
> INTERVIEWER: Do you think that's going to change [things]?
>
> KARUN: I think it would, I think it would. I'd feel a lot more comfortable and secure ... And if a HIV-positive person were to approach me and tell me that "This is who I am and these are the risks involved," I'd be a lot more open to listening to that person than right now. Right now, if someone were HIV positive and they were to tell me, and they'd say "I really would like to have sex with you even though I'm undetectable, so there would be no problem, blah blah blah," I just wouldn't listen at this stage.

Although very sexually active for several years, Karun had not been particularly concerned about his HIV status. He thought he was effectively serosorting, and, since he was only having oral sex, he considered his risk levels to be negligible. However, when he contracted an STI and realized that his serostatus could play a role in his immigration process, Karun became very concerned about HIV, to the point of developing a severe anxiety disorder.

Immigration policy does not alter the scientific evidence on undetectable viral load. However, the social significance that Karun placed on achieving Canadian citizenship, and the perception that this goal might be threatened by his sexual risk-taking, played a role in determining how he interpreted information about viral load.

Karun also found out that some of his former sexual partners who he thought were HIV negative were, in fact, HIV positive. While these men explained to him that they had undetectable viral loads, Karun's concern over his immigration status made him extremely risk averse. Greatly fearing that he would be deported back to a homophobic climate, he was unable to accept undetectable viral load information as part of a viable risk management strategy. He was also shocked that these men had not disclosed their serostatuses earlier, and this sense of betrayal made him distrust the information on undetectability that they presented to him. Karun had also grown exceedingly tired of casually hooking up and was struggling to find a longer-term romance. This led him to develop self-esteem issues, to moralize all of his sexual activity in a negative fashion, and to develop hostile reactions to gay male sexuality, all of which fuelled his risk aversion and altered his perception about undetectability and serovariant sex.

The experiences of Karun, Francis, and Jonathan highlight the critical value of focusing on sexual practice over behaviour, and on factoring in the broader social contexts that determine how these men apply meaning to sexual acts. The issue is not reducible to the decision to have condomless anal sex. A variety of other experiences, such as taking PEP, going through the immigration process and reacting to instances of HIV status non-disclosure, come to shape how these social actors respond to changing ideas about sexual risk-taking.

Sexual Relationships and the Ethics of Serosorting

The type of sexual relationship and the politicization of serosorting also played a key role in interpretations of risk and undetectable viral load. As an illustration, take these comments from Fred on serosorting and undetectability:

> FRED: Someone, someone who wanted to have a hookup, and it was specifically a hookup. We've been communicating online on dudesnude. And he said "I have HIV." And I sat down like, "Do I want to do this? Do I?" I wasn't willing to do it. Um, and, it would be hard if I was in that situation where, like, someone I knew who I was close to and they were really emotionally involved or something and I saw that they were getting hurt by it. And it was like, do I take the risk? Or, do I [act] supposedly irrationally? Like, I actually feel almost [that a] kind of social pressure [exists] that if a person then is at viral load at zero [i.e. that is, undetectable] then I'm supposed to have sex with them because my anxiety is irrational and I'm not supposed to be participating in this stigma or something like that.

Fred was unable to have serovariant sex in the context of a casual hookup because the transitory nature of this relationship did not seem worth the perceived serostatus uncertainty that would follow. However, he realized that his decision to serosort could shift in the context of a more intimate relationship where the social connection would be stronger. Social bonds profoundly influence the perception of risk (Körner, Hendry, and Kippax 2005a, 2005b). Fred's comments echoed other participants who remained conflicted about how their preferences for serosorting could minimize opportunities for social and romantic connections with HIV-positive men. Furthermore, Fred felt that by acting on his anxiety rather than "rationally" processing the biomedical risks associated with serovariant sex, he was not managing risk in a socially preferred manner. Indeed, he argued that he felt social pressure to overcome his fears and his preference for serosorting. If treatment optimism research has been concerned about men being too risk tolerant, we see here that some gay men are concerned with being too risk averse, as "excessive" risk avoidance can be seen as fostering stigma.

By changing the degree of risk associated with serovariant sex, undetectability has also challenged men such as Fred to reconsider the ethical implications of serosorting (see also Flowers 2001). Thus, there is a treatment optimism script circulating in gay male communities – namely, the idea that well-informed, ethical, politically conscious, HIV-negative men accept the risk reduction potential of undetectable viral load and do not stigmatize HIV-positive men through serosorting. According to this script, failure to accept the benefits of undetectable viral load and a reliance on serosorting are considered morally flawed. Nick's comments highlighted this dynamic:

> NICK: Some people, especially in the more lefty-activist communities look on my "Hmm, HIV, let's not have sex," as like really not cool and prejudiced. And they'll be like, that's a value you need to change, sort of thing. They'll be like that, for any number of reasons, it's discriminatory. It would be the same as saying, "I don't sleep with Asian people," which you think is horrible and racist; this isn't any different. And so, like, you need to check your privilege or the stereotypical bullshit you're buying into and address that.
>
> INTERVIEWER: And, what's your response to kind of, [to] that?
>
> NICK: I mean, I'm not saying it's [a good one], but, "Bite me"? Like, I get the argument. I do. And I admit, as we discussed earlier, that it is prejudiced. But it's also where I am. And I don't feel the need to justify that or to change that really.

While Nick recognized serosorting as a form of sexual discrimination and was aware of the risk reduction capacity of undetectable viral load, he refused to adjust his sexual practices and considered serosorting justifiable.

Thus, on the one hand, the participants' accounts challenged the generalizability of the treatment optimism hypothesis by offering us examples of men unwilling to accept the benefits of undetectable viral load and refusing to adjust their preference for serosorting. These men were concerned about all serovariant sexual relations, regardless of condom use and viral load levels. On the other hand, a preference for serosorting and a refusal to accept the benefits of emerging information on undetectability were framed as morally and politically flawed (Dean 2009). HIV-negative gay men may continue to serosort as a form of risk management, but they acknowledged that some of their peers may frown on them for doing so.

Optimistic Beliefs and Serovariant Sex

Some men did express more optimistic opinions about undetectability and did not hold such strong preferences for serosorting. Information about undetectable viral load has made some men who used to serosort more comfortable with serovariant sex. For example, Paul shared his opinions on serovariant sex when condoms are used:

> PAUL: I mean, learning that an HIV-positive person who takes his medication and has an undetectable load, viral load, learning that that person has a very low chance of transmitting the disease, makes it, you know, you sort of look at it from a different perspective. Then you're like, well, then these people are, they are no longer people who need to be ostracized from the sexual community.

However, no man interviewed for this project discussed being comfortable with having condomless anal sex with a casual partner or with a partner of opposite serostatus as a result of undetectable viral load. For the HIV-negative men interviewed for this project, there was far more nuance in how undetectable viral load was adopted into risk management practices. For example, Vincent researched the benefits of undetectability thoroughly and talked about the risks with his physician before he started having serovariant sex with a condom. At the time of the interview, he had knowingly had serovariant sex once with someone he knew well, which is something he felt that he needed to do as part of his sexual growth. Despite this, Vincent remained ambivalent about having more serovariant sexual relations in the future and considered HIV status disclosure to be morally obligatory. Similarly, Michael only had serovariant sex with HIV-positive men with undetectable viral loads who were close friends. With casual partners, he serosorted or relied on forms of lower-risk sex such as oral sex and mutual masturbation. Meanwhile, Ben was comfortable having sex with HIV-positive men regardless of the nature of their relationship, but he preferred to use condoms for anal sex even when a HIV-positive partner had an undetectable viral load. Condomless anal sex was negotiated only with close friends who had recently confirmed their serostatus as negative. For Tim, the viral load status of his HIV-positive partners was irrelevant since he always used condoms with each partner and considered that to be effective prevention.

Among the participants who had longer-term serovariant relations, information on undetectable viral load was used to help negotiate risk, though these men still relied on condoms or lower-risk forms of sex, such as oral sex, as their primary risk-reduction strategies. Finally, none of the participants who had condomless anal intercourse with partners whose serostatuses could not be confirmed as HIV negative, or who were later revealed to be HIV positive, stated that undetectable viral load was the motivating factor for their sexual decision making. This is not to deny that there are men, including HIV-negative men, who do use undetectable viral load information to negotiate condom use (Grace et al. 2014). However, the findings from this study illustrate that this behaviour does not represent the realities of all gay men and that there is tremendous nuance in how gay men are incorporating biomedical knowledge into their sexual practices.

For the men in this study with more optimistic beliefs, information about undetectable viral load made serosorting, but not necessarily condoms, unnecessary. Rather than using new biomedical knowledge to justify having condomless anal sex, these men used knowledge about undetectable viral load to shift their perceptions about the risks associated with serovariant sexual relations when condoms were being used. Other participants, however, were comfortable with condoms and found serosorting, regardless of serostatus, unnecessary. For these men, undetectable viral load information was helpful but did not alter their sexual practices much. Participants who did not serosort, or who recently changed their opinions on serosorting, also tended to display significantly more comfort with having frequent casual sexual relations. Conversely, those participants who relied on serosorting generally tended to view frequent casual sexual relations with multiple partners and sexual risk-taking less favourably (even if they themselves engaged in such acts). All social actors moralize their sexual activity, which then guides their perception of the risks associated with sexual acts (Adam 2005, 2006; Douglas 1992; Gaspar 2017). The more positive a social actor's opinions are of his sexual behaviour, the more comfortable he will tend to be with the risks associated with his sexual decision making. Thus, the risk aversion of some participants tended to be rooted, at least in part, in a more negative view of casual sexual relations, whereas the risk tolerance of other participants was rooted in a more positive appreciation of casual sexual relations. This aversion or tolerance then shaped how these men interpreted new biomedical information such as undetectable viral load, which then influenced their decisions to continue to serosort or not.

Conversant with an already well-established literature in the social sciences on health decision making and risk management, the findings from this study demonstrate that the choices of everyday social actors cannot be reduced to epidemiological risk factors or the health belief model (Cockerham 2005; Crammond and Carey 2016; Douglas 1992). Complex social and structural factors orient social actors to health risk information differently and, thus, reflexively determine agency (Giddens 1984, 1991). Gay men's sexual practices are influenced by various matters such as immigration status, social bonding, ideas on casual sex, past experiences with HIV treatments (that is, PEP), previous experiences getting tested for HIV, and so on (Gaspar 2017).

Undetectable Optimism: Conclusion

The effects of the treatment optimism thesis have to be reassessed in our current moment, where we now have less ambiguous evidence on the risk reduction of undetectable viral load in the context of homosexual relations (Jin et al. 2015; Rodger et al. 2016). Organizations such as CATIE and l'Institut National de Santé Publique du Québec have changed their opinions on undetectability from a more apprehensive stance (as discussed above) to a more encouraging one where undetectability poses "negligible risk" (Canadian AIDS Treatment and Information Exchange 2015; Institut National de Santé Publique du Québec 2014). The "undetectable = untransmittable" (U=U) education campaign has gained widespread support by many ASOs across Canada. Given this paradigmatic shift, a critical reflection on treatment optimism may seem antiquated.

However, the intention of this chapter is less about rehashing the legacy of treatment optimism research – another risk-factor hypothesis thrown aside along with AIDS optimism and condom fatigue – than about stimulating a necessary dialogue on the effectiveness of HIV-prevention science more generally. The diverse ways undetectable viral load information was used (and resisted) by the participants in this study not only destabilizes the generalizability of the treatment optimism hypothesis but also throws into question the validity of risk-factor research that aims to isolate the sources of sexual risk-taking. Even if the treatment optimism hypothesis were proven to be statistically valid and generalizable as a theory to describe population-level behavioural patterns, the acts of condomless anal sex associated with these optimistic beliefs would never have been truly biomedically "high-risk" acts and, consequently, could never have been used to sufficiently explain population-level HIV incidence trends among gay men – that is, the very goal of treatment optimism work.

This is a rather humbling thought. Vast amounts of energy, human resources, and research dollars have gone into proving a theory on risk-taking that was not only tenuous in its ability to describe behaviour but that was also based on what was eventually proven to be incorrect biomedical risk logic. Of course, in the absence of convincing knowledge on undetectability's risk reduction, the treatment optimism hypothesis was indeed a plausible and reasonable theory. However, even though an idea may be reasonable and popular, it may not, in fact, be correct or helpful. It is thus important that we reflect on the limitations of treatment optimism research, not simply for the sake of offering critique but also to recognize how certain research questions and theories become standard or ruling forms of knowledge in a given field, which can then displace other forms of inquiry that may be better suited for addressing the health and well-being of social actors. Popular arguments and "objectifying discourses" that are disconnected from everyday reality may actually do more harm than good by distracting us from doing work that could have more tangible impacts on gay men's health and well-being.

At this moment in the epidemic, we should recognize that the recent paradigm shift to U=U may alter how many HIV-negative gay men have sex with HIV-positive men. Over time, we are likely to witness a generalized increased awareness of undetectability, with many accepting it, along with the benefits of pre-exposure prophylaxis (PrEP), as a valid prevention option that might render condoms obsolete for some. In other words, we may indeed see a higher prevalence of "treatment optimism behaviours" (though, importantly, their links to HIV incidence will be negligible, and the data from this chapter indicates that resistance to undetectable viral load may still be strong among many gay men). Yet the core problematic being addressed in this chapter is less of a targeted attack on treatment optimism per se (indeed, hypotheses are set up to be proven/disproven) and more the epistemological conditions that determine what qualifies as significant or quality HIV-prevention science. With humility, we must acknowledge how these conditions have supported a theory of behaviour that, for over a decade, has been unable to describe gay male sexual practices or help gay men and service providers manage risk in any significant way. Failure to do so means that we run the very real risk of producing more behavioural theories in the future that are unable to improve the health and well-being needs of gay men.

Indeed, we have arguably reached a saturation point on research trying to understand the motivations for condomless anal sex. In a manner similar to arguments made by Barry Adam (2011; and in this volume), Gary Dowsett (2009) and Mark Gaspar (2017) contend that quantitative risk-factor research such as that motivated by the treatment optimism hypothesis has a very limited capacity to describe real-life situations in ways that may be advantageous to so-called at-risk social actors. While some studies reviewed above have shown that there are gay men who do incorporate undetectable viral load information into their decisions to have condomless anal sex, it is unlikely that viral load information remains the principal motivating factor behind these decisions. Most likely, treatment optimism remains but one element among a range of psychosocial and material forces, noted by Barry Adam in this volume that produces vulnerability to health risks and encourages condomless anal sex. Nonetheless, this avid focus on the motivations for risk-taking prevents us from addressing structural issues that may really matter for gay men, including expanding and improving sexual health and mental health services or offering men access to affordable PEP and PrEP (Gaspar 2017).

What has made the treatment optimism hypothesis insidious is its implication that many gay men may lack the reflexivity necessary to interpret the benefits of new biomedical knowledge. This type of thinking can then serve as a justification to minimize prevention education that would unambiguously highlight the prevention benefits of undetectable viral load. Moreover, while not explicitly stated, the constant concern that gay men may be relying on undetectable viral load information, provides a caution against serovariant sexual relations, which is somewhat hypocritical coming from a field that has also been devoted to problematizing the perpetuation of HIV stigma and questioning how such stigma may also facilitate risk-taking and seroconversion (Earnshaw and Chaudoir 2009).

However, one of the principle contributions of this chapter to HIV-prevention science is the finding that HIV-negative men are far from uncritically adopting information on undetectability into their sexual practice and that many, particularly those who serosort, are, in fact, resisting incorporating this knowledge into their sexual practice. This finding is key as we move into an era where U=U. Educating at-risk communities more directly about the risk reduction benefits of undetectability will not automatically lead to the abandonment of condoms (and, thus, a spike in STIs) since this knowledge is always going to be processed through the risk aversion or tolerance of social actors. Put differently, those who are not going to use condoms will probably not use condoms regardless of our education efforts on undetectable viral load. The real benefit of education on undetectable viral load, however, is less about reducing risk-taking and more about helping reduce oppressive levels of HIV stigma as well as the anxieties many HIV-negative gay men have with sex and serovariant relations more specifically.

Perhaps the reason why the treatment optimism hypothesis has endured in the field despite so much contradictory evidence is because it is a simplified understanding of the relationship between sex and biomedicine that is easy to collect in larger-scale surveys and easy to analyze – we either see the correlation between optimistic beliefs and increased sexual risk-taking or we do not. However, the examples brought forth in this chapter demonstrate that the relationship between sex and biomedicine is far more complex in everyday life, as a myriad of intersecting factors contribute to whether or not a social actor is willing to accept the prevention benefits of undetectable viral load.

Notes

1 The terms “treatment optimism,” “AIDS optimism,” and “HIV optimism” are sometimes used interchangeably. However, for this chapter “treatment optimism” refers specifically to beliefs related to the risk reduction associated with undetectable viral load; “AIDS optimism” to the beliefs about HIV being a chronic manageable condition; and “HIV optimism” to the combination of both of these hypotheses.

2 This is an HIV-prevention strategy where the HIV-negative partner selects to be the penetrative anal sex partner (i.e., the top) instead of the receptive anal sex partner (i.e., the bottom) to reduce risk. Strategic positioning can be implemented in instances of serovariant sex (i.e., sometimes referred to as seropositioning) or when the HIV status of a sexual partner cannot be confirmed. It can be implemented with or without condoms.

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8

A Critical Case-Study Analysis of the Logic and Practices of Prescribing HIV Pre-Exposure Prophylaxis (PrEP) to At-Risk Adolescents

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This chapter considers the role of critical social science in public health research settings, where intervention studies are undertaken to prevent and manage diseases, injuries, and other health conditions at the population level. We present a brief case study of the Urban Health Center (UHC) youth clinic, an inner-city family medicine and sexual health clinic in the United States, where HIV pre-exposure prophylaxis (PrEP) is prescribed to urban youth deemed to be at high risk of acquiring HIV. Driven by the goals of the medical director, a PrEP prescription and monitoring policy has been implemented that attempts to address specific social and structural challenges faced by the clinic's predominantly African American lesbian, gay, bisexual, transgender, and queer (LGBTQ) patients. This clinic presents a compelling case study of the front-line implementation of a biomedical HIV intervention for at-risk, underprivileged people. The case also presents an interesting example of the "pharmaceuticalization of public health," which promotes access to medications as a primary public health intervention strategy (Bell and Figert 2012). We argue that straightforward analysis of this example is complicated by the troubled relationship between the African American community and various US public health organizations due in part to historical incidents of maltreatment such as the Tuskegee syphilis study[1] and, more recently, the case of Henrietta Lacks.[2]

In biomedical terms, PrEP involves using antiretroviral therapy (ART) to prevent HIV among HIV-negative people. Currently, Truvada® (tenofovir and emtricitabine) is the US Food and Drug Administration-approved drug combination for this purpose. As a once-per-day pill, it has become a promising HIV-prevention intervention as it aims to address limitations of traditional behavioural approaches and the challenges of structural interventions (see Conniff and Evensen 2016). PrEP is viewed by many as a particularly viable option in urban settings where many at-risk groups, such as injection drug users and men who have sex with men (MSM), especially African American MSM, are disproportionately affected by HIV. The drug is manufactured by Gilead Sciences and was selected for HIV prophylaxis because it has fewer side effects compared to other HIV antiretroviral drugs. Generally speaking, PrEP is recommended for people who are HIV negative but who are considered at high risk for HIV infection. Typically, this includes people who have condomless penetrative sex outside of monogamous seroconcordant relationships, people who have been diagnosed with a sexually transmitted infection (STI) within the past six months, people in an ongoing sexual relationship with an HIV-positive partner, and people who share drug injection equipment (Centers for Disease Control and Prevention 2014). The Centers for Disease Control and Prevention's (CDC) monitoring guidelines recommend quarterly blood tests to check for HIV infection and renal function and quarterly provider visits to assess such things as patient adherence and risk behaviours.

Prescribing PrEP remains controversial among many providers, despite research demonstrating that PrEP can be highly effective in preventing HIV and that it has considerable promise as a public health HIV-prevention intervention (Grant et al. 2010; Petroll, Staden, and Westergaard 2016). Commonly cited arguments against widespread PrEP prescription include the high cost of the drug, the perceived challenges of medication adherence, concerns about safety, and possible "risk compensation" wherein people increase risk behaviours because they overestimate the protective benefit of the drug (Agot et al. 2015; Grov et al. 2015; Liu et al. 2013; Marcus et al. 2013; and, for a social science critique of the related concept of "treatment optimism," see Mark Gaspar in this volume). Despite these concerns, PrEP demand is growing, and providers are increasingly prescribing the drug.

The rise in demand for PrEP among patients along with the growing willingness of providers to prescribe the drug also taps into mounting concerns about the pharmaceuticalization of society, in which social, behavioural, or bodily conditions are increasingly cast as problems requiring treatment or enhancement via pharmaceuticals (Abraham 2010; Bell and Figert 2012; Williams, Gabe, and Davis 2008). Relatedly, debates between supporters and critics of PrEP have recently erupted among members of the LGBTQ community and AIDS service organizations (ASOs). A recent journalistic account of competing perspectives indicates that, while some champion PrEP as ushering in a new era of sexual liberation and responsibility among gay men in particular, others decry it as a "party drug" that may promote sexual irresponsibility and exacerbate STI risk behaviour, especially were it to become widely viewed as a substitute for condoms (Glazek 2013). This debate recalls earlier concerns surrounding the birth control pill (May 2010; Watkins 2012) and, more recently, the HPV vaccine (Connell and Hunt 2010; Wailoo et al. 2010), in which social anxieties over sexual norms, health risks associated with long-term use, and rises in STI rates took centre stage (Myers and Sepkowitz 2013).

Still, scholars have pointed out that the promise of PrEP has yet to be fully realized and that social science methods are ideally suited to evaluate the impact of the drug beyond questions of biomedical efficacy and public debates that are steeped in binary perspectives (Auerbach and Hoppe 2015). Indeed, social scientists have begun to weigh in critically on questions about the use of PrEP, its prevention potential, and socio-cultural concerns that embattle the drug. One trajectory of analysis has focused on the promise of PrEP and to what extent its potential can be extrapolated beyond the clinical setting. Marsha Rosengarten and Mike Michael (2009) interviewed scientists involved in developing PrEP trials who were also likely to inform future policy decisions in order to better understand expectations about the drug's potential and whether this potential was likely to extend beyond the particular set of research questions that the trials were designed to address (for example, risk compensation, viral resistance, and gender use). Indeed, despite the stakeholders' seemingly "fixed" or narrow vision of the drug, the study findings point to a wider array of uses that encourage broader discussion of PrEP's biomedical prevention potential (1054).

PrEP's potential, however, is at the same time beleaguered by concerns about the limitations of the drug's potential in a global context. Cindy Patton and Hye Jin Kim (2012), for example, observe that community activist demands for gender-specific clinical trials have created a faith in PrEP as a global panacea for women at risk of HIV, which fails to adequately take into account the complexities of risk and HIV facing women in developing nations. Eric Roberts and Derrick Matthews (2012) similarly caution against placing too much stock in pharmaceuticals such as PrEP to solve public health problems, as biomedical interventions still rely heavily on individual behaviour change and drug adherence to be successful. While these authors are all optimistic that PrEP will prove to be one among many options in the HIV-prevention tool kit, they maintain that resources should remain focused on efforts to better understand reasons for the gaps in behaviour and structural interventions.

Other social scientists have attended to questions of user uptake. Martin Holt (2015), for instance, sought to understand why, given the perceived promise of PrEP, there appeared to be a slow uptake of interest in using the drug among certain groups, even when prescription access and pharmaceutical coverage were not obstacles. Using an analysis of pharmaceutical industry research reports, he found that the initial profile of the typical PrEP user was influenced by assumptions about vulnerability and risk behaviour. It was generally felt that the once-per-day pill regimen and regular monitoring would be either too difficult or undesirable for most people at high risk of HIV infection. Thus, narrow expectations about who was likely to use PrEP and for what reasons inadvertently tainted the drug's early marketing at the outreach. Tim Dean (2015, 229) adds that, for gay men in particular, what may be involved in regarding oneself as being "at risk" of HIV infection often is less straightforward than what public health agencies appear ready to concede. Seeking a prescription for PrEP tacitly acknowledges a desire for a kind of sex – that is, condomless – which runs counter to community safer-sex norms. He notes that this may be felt as a sign of "failure or uncomfortable confession" that discourages some from seeking a prescription for the drug, thus limiting PrEP's full potential as an HIV-prevention strategy (30). In short, these critical social science analyses provide valuable insights about the configuration of PrEP users during the earliest developmental and conceptual phases, prior to efforts to implement widespread usage of the drug.

By contrast, our project centred on the front-line implementation of PrEP at the community level, in particular, through hospitals and community health clinics. While some studies have focused on PrEP awareness among at-risk individuals (King et al. 2014), little attention has been paid to health care providers' ability and willingness to prescribe PrEP or to the clinic-level logistical barriers and facilitators that support PrEP provision. We devised a mixed methods study to examine providers' awareness of, and knowledge about, PrEP, experience prescribing the drug, and barriers to prescribing it to vulnerable demographic groups. The goal of the study was to develop interventions targeting the specific barriers faced by providers and to incorporate findings from site visits that reveal how clinics have successfully overcome barriers in order to begin prescribing PrEP. The present analysis focuses on a specific site visit that produced important case-study insights into some of the realities facing front-line providers who widely prescribe PrEP to historically underserved and marginalized communities.

In this analysis, we draw on Bent Flyvbjerg's (2001) phronetic case-study approach to examine underlying questions about the reasoning and clinical practices at the heart of prescribing PrEP at the UHC youth clinic. By emphasizing people's day-to-day knowledge and experiences, this approach applies four value-oriented questions to examine and critique the goals, desirability, and outcome of practices in a local setting. Specifically, we explore how and why the clinic's PrEP prescription policies have developed in a particular context. We also consider the implications for widespread prescription of this drug in light of criticisms made about the pharmaceuticalization of public health. Finally, we reflect on the historical relationship between racialization and biomedicine and, in doing so, use a critical social science perspective to enrich the application of Flyvbjerg's case-study approach.

Methodological Overview

This chapter draws on data from a US-based study assessing health care providers' current awareness of, knowledge about, and attitudes toward prescribing PrEP. The study employed a nationwide online survey of 500 medical providers followed by site visits and qualitative interviews at five clinics where PrEP is being prescribed. The goals of the study were to assess the providers' knowledge and attitudes toward PrEP and to identify barriers to providing PrEP that exist in different organizational settings as well as strategies for overcoming those barriers. Providers who were interested in participating in a site visit were able to provide contact information at the end of the online survey. The survey asked providers for estimates of how many PrEP patients they currently serve so that we could identify sites where the drug was being widely prescribed. Approximately forty survey respondents indicated that they were willing to host a site visit. From this list of potential hosts, we first sought geographic diversity by including clinics from different regions of the United States. We also sought representation from multiple types of clinic settings such as specialty hospital-based clinics, private primary care clinics, and public health clinics or community health centres. The inclusion of diverse clinic settings revealed how PrEP implementation was accomplished in settings facing different logistical barriers (for example, knowledge, community support) and resources (for example, staffing).

The three authors visited the present site over a two-day period in March 2015. The purpose of the site visit was to learn more about the organizational structure, patient demographics, and clinic policies and protocols related to prescribing and monitoring the use of PrEP. Over the two days, we toured the health clinic and several affiliated support agencies. In addition to meeting numerous clinicians and staff, we conducted in-depth interviews with the medical director, three nurse practitioners, two volunteer medical students, the youth program director, and the health clinic's administrative director. Additionally, we conducted two focus groups with four to five people each, one with staff and volunteers from the health clinic and the second with staff and volunteers from the youth drop-in centre. These interviews and focus groups enabled us to speak at length with seventeen people in distinct roles in the PrEP prescription process, including those involved with patient intake, prescription insurance assistance, youth outreach, and the discussion of PrEP and risk-reduction counselling beyond the clinical setting. We audio-recorded all of the interviews and focus-group sessions and took field notes throughout the site tour. At the end of each day, we met to discuss our field notes, impressions of interviews, and to reflect on questions that we had about what we learned about this case.

By using a case-study approach to analyze the data, we sought to explore underlying questions about the purpose and desirability of PrEP prescription practices at a particular health clinic. Case studies offer a detailed understanding of a complex issue or setting relevant to the research focus. As a method of empirical inquiry, case studies investigate a unique phenomenon within a real-life context when the boundaries between the phenomenon and context are not clearly evident (Yin 2008). Case-study approaches vary in design and purpose. A case may be chosen because it is an exemplar or because it is an outlier. Case studies, however, are observational in nature and often complement other methods of data collection, thus they typically take the form of a story or narrative that conveys a sequence of events to a broad audience (Thomas 2011). Depending on a researcher's epistemological stance, a case-study approach may be positivist by striving for generalizability of findings (Yin 2008) or take a constructivist bent by developing inductive social theory or a heuristic example (Stake 2005).

Our analysis takes a constructionist approach; we draw specifically on Flyvbjerg's (2001) "phronetic" case-study approach, a model that rehabilitates Aristotelian epistemology by privileging the "practical wisdom" or experiential knowledge that can be gleaned from a single case. In Flyvbjerg's estimation, the phronetic approach stands apart from others as it offers insights into the unique structure of a problem in a particular setting. This approach is situated among the constructivist traditions as it provides intricate understanding rather than predictive power; it differs from established comparative case-study methods in that the end goal is not the pursuit of absolute "truth" but, rather, local knowledge. By fleshing out a context-specific understanding of reasoning and practices in particular situations, the phronetic approach is meant to contribute to ongoing dialogue about social problems. In short, validity does not result from research design or generalizability but, instead, from authentic insights gained from a novel case.

To this end, Flyvbjerg (2001, 60) puts forward a set of four normative questions for researchers to address in case-study analyses: where is the case going; is this desirable; what should be done; and who gains and who loses? In his view, addressing these questions enables researchers to move beyond case description and arrive at situational-dependent conclusions about a particular social problem. We use these four questions as a framework to explore the reasoning and practices used at the UHC youth clinic. Our critique points to some of the challenges in addressing these questions and demonstrates the importance of integrating a critical social science perspective into this type of case-study research.

The UHC Youth Clinic

The UHC is a comprehensive ASO consisting of a conglomerate of health centres and social service agencies. According to the agency website, its mission is to provide state-of-the art, culturally competent primary care to low-income members of the local community, including HIV specialty care, consumer education, advocacy, social services, and outreach to people living with HIV as well as to those who are at high risk of infection, including family members, communities with high rates of HIV, the formerly incarcerated, and young people at risk of STIs and HIV infection. Most of the affiliated agencies are located within a short walking distance of one another in the inner-city downtown area, increasing convenience and accessibility for clients.

One of the UHC constituent agencies – the youth clinic – offers free or low-cost primary care and family planning services for adolescent and young adults aged thirteen to twenty-four years old. Primary care includes preventive medicine, vaccinations, physicals, and referrals to medical specialists as needed. Family planning services include STI testing, birth control and emergency contraception, pregnancy testing and counselling options, pelvic and breast exams, pap tests and HPV screening, and PrEP prescription and monitoring. The youth clinic sees young people for medical services regardless of their health insurance status and supports uninsured patients by providing insurance navigation and enrolment. Rapid HIV testing and pre- and post-test risk-reduction counselling are also provided onsite.

In total, the clinic sees approximately 400 patients for medical services. A handful of HIV-positive patients receive care at the clinic, though most are referred to a medical clinic specializing in HIV treatment and care. Approximately 95 percent of patients are more or less evenly distributed across the eighteen-to-twenty-four-year-old range, while 5 percent are under the age of eighteen. The PrEP clinic, however, only offers PrEP to patients aged eighteen years old or older. At the time of our site visit, the youth clinic had been prescribing PrEP for about two years and already had over fifty patients receiving the medication, with a steady increase of new patients receiving prescriptions on a weekly basis. Approximately 90 percent of PrEP patients at the clinic are male, mostly gay or bisexual, and, most significantly, all, but one, are African American. The primarily African American clientele makes this clinic an important site for case analysis, as specific attention to this demographic is largely absent in the literature.

According to clinicians and staff, the health clinic is the primary – and, in many cases, the only – source of health care available to the inner-city youth who access the services. They noted that because the patients tend to be relatively healthy and free of the types of chronic illnesses that manifest later in adulthood, much of the care revolves around matters of sexual health. HIV prevention, testing, and risk-reduction counselling therefore have been integrated as part of the standard clinical practice during all patient visits, including the introduction and discussion of PrEP with patients as a routine part of medical appointments. In essence, providers assert that PrEP should be treated as a standard sexual health option, akin to birth control pills or HPV vaccinations, instead of as a specialty service.

The clinic is located in an inner-city urban neighbourhood with a mix of apartment buildings, townhomes, and small businesses. The clinic is concentrated on a single floor of a six-floor brownstone building, casual attire is the norm among clinic personnel, and we learned that many of the patients are on a first-name basis with the clinic staff and providers. The clinic offers both appointments and walk-in hours on a daily basis where patients can come for all health concerns. Although patients can find information about PrEP and seek prescriptions at any time, Monday evenings are reserved exclusively for PrEP services. The clinic is staffed by one physician who is an infectious disease specialist and exclusively sees PrEP patients during the weekly clinic hours. In addition, there are three full-time nurse practitioners specializing in paediatric and family medicine. Two medical students volunteer at the health clinic during regular hours as part of their professional training; they also see patients at the weekly PrEP clinic. A research assistant is employed part time; among her duties is assisting patients with enrolling in health care insurance to cover the approximate $1,200 monthly cost of the drug. All of the PrEP patients receive the medication at low or no cost. A clinic director oversees and manages the agency during operating hours. Finally, several UHC outreach personnel who work out of a youth drop-in centre are also regular fixtures at the health clinic as they help with referrals and counselling.

Evidence, Protocols, and PrEP

A key feature of contemporary medical practice is evidence-based medicine, a movement that emerged in the 1990s to base clinical decision making on clinical trial research, epidemiological research, and systematic reviews of research evidence (Timmermans and Berg 2003). The UHC youth clinic is no exception, as the primary evidence-based tool that shapes how the providers prescribe and monitor PrEP is the CDC guidelines (Centers for Disease Control and Prevention 2014). While the CDC guidelines provide comprehensive information for the use of daily oral PrEP to reduce the risk of acquiring HIV infection, they are not intended to be rigid but, rather, to be modified to suit local circumstances. What we noted at the UHC youth clinic is a process of adapting the CDC standards. Based on these guidelines, the medical director has put in place a PrEP policy and set of procedures that take into account both the perceived needs of the clinic patients and the challenges of serving this particular community. For example, monitoring for STIs is enhanced; instead of taking quarterly blood work to test for infections, as recommended by the guidelines, patients are tested monthly. Prescriptions for the drug are filled at the clinic on a weekly or biweekly basis rather than monthly or quarterly prescription fills. All of the providers and staff that we spoke with supported the clinic's PrEP policy and procedures. Several added that they had participated in the original clinic-wide meetings to discuss implementing PrEP. They also noted that the decision to prescribe PrEP met little, if any, resistance from the UHC board members or from members of the local community, who contributed to their ability to integrate PrEP practice and the weekly clinic into the youth health centre. Thus, there appears to have been a clinic-wide buy-in of the policy from the outset, which suggests, from Flyvbjerg's case-study perspective, a clear direction in clinical practice that is deemed desirable to the director, providers, and staff alike.

As per the youth clinic's protocol, patients seeking information about PrEP meet with a provider and receive a rapid HIV test. Then the patients are assessed to determine whether they need prescription insurance assistance. Patients requiring assistance are referred to the clinic's research assistant for help with insurance enrolment and scheduled for a return appointment in two weeks at which time a baseline HIV serology test is completed. Patients who do not require assistance receive baseline testing on the same day and are immediately prescribed the drug. Interestingly, the clinic's PrEP policy establishes a relatively "low threshold" for prescribing the drug. We were told that, for all intents and purposes, any patient who seeks the drug and meets the testing guidelines – that is, provides an HIV-negative result – will be prescribed the drug and will be able to receive it at little or no cost through the clinic. The clinicians that we spoke with could only think of a handful of patients to whom they had denied a PrEP prescription. In one case, the patient was assessed as having mental health concerns that were likely to interfere with medication adherence. Instead, the provider determined that the patient should be referred for counselling services and re-evaluated for PrEP at a later date. In a second case, a patient was ineligible for PrEP after being found to be HIV positive.

When we asked the director and clinicians about the low threshold for prescribing the drug, they shared with us a number of perspectives. According to one, "this is a population at high risk of acquiring HIV, and therefore patients who ask for PrEP most likely need it." According to another, the clinic serves an underprivileged African American population for which "many behavioural interventions are ineffective, and PrEP is their best option for avoiding HIV infection for those who are able to maintain adherence." The providers were also confident that their "patients know their own sexual behaviour better than what they're sometimes willing to share with physicians," meaning that some patients find it easier to ask for PrEP than to admit engaging in risky sexual behaviour. In addition, we were told that according to clinic records, "approximately 75 percent of the patients had tested positive for a rectal or vaginal STI within the past five years," further pointing to a population at high risk for HIV acquisition. In short, the providers' willingness to offer PrEP is predicated on a combination of public health surveillance data on HIV incidence for the city, data from the clinic records, and individual risk assessments made during medical appointments.

PrEP Distribution and Monitoring

We were also interested to learn that the clinic's PrEP policy includes a more rigorous monitoring protocol than is recommended by the CDC. For example, whereas the CDC guidelines recommend that PrEP be prescribed in one- or three-month allotments that are filled through pharmacies or online prescription services, the UHC youth clinic directly administers PrEP prescriptions to patients on a weekly or biweekly basis depending on the client's housing situation or other personal circumstances. One of the clinic staff separates weekly or biweekly doses and packages the pills in resealable plastic bags for patients to pick up. Typically, the prescriptions are distributed on "PrEP night" at the clinic, although patients who are unable to attend this night can receive their medication on a walk-in basis at other times. According to the providers, one benefit of this strategy is that patients visit the clinic on a regular basis to receive their medication and check in with providers with updates or questions about the treatment. Further, rather than relying solely on a quarterly HIV baseline test in order to receive a prescription renewal, the UHC youth clinic requires a monthly HIV rapid test in addition to the quarterly serology tests. According to the providers, this practice enables additional opportunities for pre- and post-test counsellors to address any new patient concerns about PrEP.

From the perspectives of the director and clinicians, this medication distribution procedure resolves a number of concerns specific to this local population. First, the youth population that the clinic serves often have unstable housing arrangements, sometimes "couch surfing" at the homes of friends and relatives and, other times, living on the streets for periods of time. Under these conditions, the patients may have poorer adherence as a result of stress, trauma, or because their medication has been lost or stolen. Weekly and biweekly medication pickups reduce the likelihood that patients will lose large quantities of the medication or, in the event this occurs, it limits the amount of time the patient is without the medicine. Second, by requiring patients to come to the clinic more regularly, the providers and staff are able to visit with patients and conduct brief assessments to determine if there are any problems with adherence, side effects, or the like. If concerns arise, clinicians can halt a patient's PrEP prescription until the problems can be resolved or further assessed.

Reflecting for a moment, we see a policy that implements a more rigorous standard of monitoring and medication distribution in an effort to address structural conditions and social circumstances commonly faced by the clinic's patient population. This practice points to some potential limitations of the CDC guidelines – namely, that they do not articulate specific recommendations for agencies like the UHC youth clinic. Though the federal guidelines are intended to be generally applicable to providers, they do not attend to the unique and complicated structural challenges and risk environments faced by many low-income inner-city youth who are likely to benefit most from PrEP. In terms of Flyvbjerg's investigative questions, one could tentatively conclude that this is a desirable course of action both with respect to individual care and broader HIV prevention.

Promoting PrEP

Also setting apart the UHC youth clinic from other organizations in our study are the clinical processes through which PrEP is advertised and prescribed to at-risk youth and then administered to patients on an ongoing basis. First, the introduction of PrEP has been integrated into the triage process that occurs when patients initially visit the clinic during normal operating hours. When the patient checks in for an appointment, the intake person might ask: "Have you heard of PrEP?"[3] This question presents an opportunity to enter into a short dialogue about the medication regardless of how the patient responds. If, for example, the patient confirms that he or she has heard of PrEP, the intake person might follow up with a clarification to the effect of: "So you're aware it's an effective HIV-prevention medication that we offer here at the clinic?" Statements of this sort are crafted to ensure that the patient is indeed thinking of the correct medication as well as confirming the medical efficacy of the drug. If the patient indicates that he or she is unfamiliar with PrEP, the intake person might respond: "[PrEP] is an HIV-prevention medication, think of it like a condom that you can put over your blood cells to prevent HIV infection." This type of statement tries a different tactic by attempting to employ a familiar condom metaphor to refer to how the medication functions to prevent viral acquisition and replication. Our interviews suggest that intake personnel do not use this opportunity to enter into in-depth discussion about PrEP but, rather, attempt to raise awareness and then direct patients to ask providers for further information about the drug if they are interested.

A second clinical process that engages patients in discussion about PrEP occurs during regular medical appointments. A patient who comes to the clinic for a medical appointment or for STI testing, for example, will typically be assessed for sexual risk behaviour as part of the counselling component of the visit. The providers we spoke with habitually ask all patients about sexual health and risk factors due to the perceived high risk associated with the patient population. Patients who are assessed as being candidates for PrEP are asked if they are familiar with the drug, how it is prescribed and monitored, and whether they are interested in learning more about the drug or receiving a prescription. Patients who are interested are scheduled for a follow-up and, if needed, referred to the PrEP research assistant for help with insurance enrolment. According to providers, this practice is part of the overall clinic strategy of integrating risk assessment and discussion about PrEP as often as possible and to as many patients as possible. It is important to stress that, according to providers, the goal is not to pressure patients into seeking PrEP but, rather, to encourage regular discussion of HIV risk-reduction strategies, including PrEP, as a component of standard care and sexual health awareness. The providers further noted that this practice is important because their patients often assume that PrEP is unattainable due to its high cost or because they are uninsured. Thus, from the providers' perspectives, frequently discussing PrEP assures patients of its feasibility and affordability and, if needed, provides a space where patients can immediately connect with onsite resources and support to receive a prescription.

A third type of clinical engagement with PrEP occurs through proxy via the youth drop-in centre that is part of the UHC conglomerate. The drop-in centre gives adolescents and young adults, aged thirteen to twenty-four years old, access to resources that fulfill basic needs such as showers, a meal, laundry services, personal care items, and clothing. The centre is described as a LGBTQ "safe space" as well as an entry point for youth to be connected to the UHC's many other programs and services, including the youth health clinic. Informational posters and fliers about PrEP are available. We learned that the drop-in centre has weekly support groups where LGBTQ youth, in particular, regularly come to interact with one another for reasons ranging from networking to seeking sexual health information and risk-reduction counselling. The outreach personnel who oversee the drop-in centre and facilitate the discussion groups confirmed that PrEP is a regular topic of discussion among the attendees. They highlighted for us two ways that this frequently occurs.

First, discussion of PrEP often arises organically during the weekly discussion groups. Matters of sexual health and STI risk reduction, for example, are commonly broached for open discussion. Providers suggested that this gives attendees an opportunity to share their experiences, ask questions, and learn from the experiences and questions shared by others. Many of the youth who attend the drop-in centre have been referred from the youth health clinic and vice versa; furthermore, many attendees are either taking PrEP or reportedly know someone who takes the drug and are interested in learning more about it. The outreach specialists have all received training on PrEP and can either guide an informed discussion or answer specific one-on-one questions to ensure the accuracy of information. The outreach specialists shared several examples of misinformation about PrEP that surfaced during discussion groups, including the conspiracy belief that "Truvada causes HIV infection," and a range of concerns about extreme side effects such as "bleeding stomach ulcers" allegedly caused by the medication.

A second way that the discussion of PrEP emerges out of the youth drop-in centre occurs when attendees talk freely about their experiences with taking the drug. One example that the outreach personnel shared involved an attendee (who is also a patient at the youth clinic) walking into the drop-in centre and announcing to the group: "Check out my 'blue pill' everyone, I'm taking PrEP." In this instance, the person proudly displayed the bag of "blue pills" for all who were present to see. Outreach personnel shared similar examples in which taking PrEP reportedly is deemed by the youth as an exciting and "hip" development in their lives. One interviewee described this phenomenon as a "club membership" where people advertise their status as PrEP users and describe themselves as contributing to "science, to community health, or to the end of HIV." In this respect, the youth drop-in centre may have a peer effect that indirectly promotes PrEP through social interaction and the sharing of personal stories among attendees, which, it seems, further frames the drug as something that is both attainable and desirable. It is worth noting that the participants also mentioned that not being on PrEP may have the potential to make someone an outsider among their peers, which raises questions about over-prescription and the medically unnecessary use of the drug.

In order to follow up, we asked the clinicians whether they thought that this social facet of the youth centre culture might be encouraging people to seek PrEP who might actually be at no or low risk of HIV infection. In other words, we wondered whether they felt it was a problem that there may be instances where patients are receiving PrEP who do not need it? Further, is it a problem that peer pressure, as opposed to risk behaviour, may be influencing PrEP use? The clinicians we spoke with had a different approach to addressing these questions in that they focused on how quickly sexual behaviours change among adolescents. One participant reasoned, for example, that "a patient who is not sexually active today could easily become sexually active tomorrow" and engage in risk behaviour, in which case that patient would benefit from being on PrEP despite previously not being sexually active. This reasoning is consistent with the clinic's overall approach to treating PrEP as a standard sexual health option and not a niche medication.

Finally, we concluded our interviews by asking how the providers and staff felt about the feasibility of their clinic's approach to prescribing PrEP. We were particularly interested in the issue of feasibility given the increased monitoring and medication distribution practices that have been put in place at the clinic. Since they were now two years into widely prescribing PrEP, we felt it was an ideal time for feedback on this question. The clinicians and staff with whom we spoke agreed that, at their clinic at least, implementation of the PrEP policy and practices were relatively straightforward and, according to their current projections, sustainable into the next few years.

Reflecting Critically on the Case of the UHC Youth Clinic

At the centre of Flyvbjerg's (2001) phronetic approach is an engagement with four value-oriented questions aimed at examining a course of action, the desirability of its outcome, the guiding perspectives, and the power relations among those involved. According to Flyvbjerg, these questions position the case-study enthusiast to arrive at an advanced understanding of social actors and their practices as well as normative assessments within the specific context

(60). Put another way, using these questions as an analytic framework produces knowledge that is most relevant to people and policy makers, particularly at the local or community level. This approach enables social scientists interested in PrEP to grapple with issues concerning PrEP that go beyond what Judy Auerbach and Trevor Hoppe (2015) describe as the mere question of how to "get drugs into bodies."

We have used the spirit of Flyvbjerg's four questions to guide the qualitative analysis above; using this framework alone, it is perhaps reasonable to conclude – on biomedical grounds at least – that the UHC youth clinic is moving in a positive direction by emphasizing a biomedical HIV intervention as part of standard care. However, our analysis indicates that introducing the clinic's PrEP policy as a standard of care is not as straightforward as it may initially appear. From a critical social science perspective, this study also points to ways that medical, social, and cultural relations become mutually constitutive in this setting. It is important, for instance, that we not lose sight of the troubled historical relationship between race and biomedical research and health care in the United States (Mays 2012; Thomas and Quinn 1991). Historians and bioethicists continue to speak of the Tuskegee syphilis study, in particular, as a lasting metaphor of racism and paternalism, one that ought to guide medical decisions and analysis moving forward (Reverby 2010).[4] Further, it is believed that this troubled history has fostered lasting distrust among racial and ethnic minorities toward medical and pharmaceutical technologies as well as toward the vital physician-patient relationship (Scharff et al. 2015). With this in mind, this case study inspires deeper reflection on what we learned about the particular reasoning and practices underlying widespread prescription of PrEP at this clinic, particularly given concerns about the pharmaceuticalization of society and serving historically marginalized groups in matters of health care.

To begin with, the clinic's PrEP policy and procedures belie some of the local realities of prescribing PrEP while, at the same time, illustrating the challenge of Flyvbjerg's normative case-study approach from a critical social science perspective. We learned, for example, that two related claims inform the clinic's policy to widely administer PrEP to patients. The first claim is that, from the perspective of these providers, "if you're African American and living in [the inner city], then you should be taking PrEP." This claim is predicated on public health surveillance data that reports on the high prevalence of HIV among the local inner-city youth, particularly African American MSM. The second claim is that, from the perspective of these providers, "if a patient comes asking for PrEP, then he or she likely needs it." This claim is based on the providers' sense of confidence that patients are accurately assessing their own HIV risk, even if they do not accurately disclose all risk information to their providers. Widely prescribing PrEP is therefore seen as a desirable practice because it meets the HIV prevention needs of both individual patients and a particularly vulnerable community of African American MSM living in an area of high HIV seroprevalence. At the same time, the claims reveal how patients at the community level become further targets of biomedicine and illustrate how this tension is managed by evidence that PrEP is effective and not harmful.

On the one hand, these claims reflect both a sense of hope and desperation at the heart of promoting the widespread use of PrEP. Rosengarten and Michael's (2009) analysis of the expectations attached to PrEP similarly speak to the many ways that the drug can be framed as an emergent entity in the pursuit of biomedical solutions to HIV prevention. Their analysis suggests that the biomedical possibility, or "promise," of the drug is that it has the potential to address multiple risk scenarios that bedevil HIV prevention in different cultural and geographic settings. Similarly, at the UHC youth clinic, PrEP is viewed as being beneficial for patients regardless of their current "risk" status because even currently low-risk patients are considered to be at potentially high risk of HIV infection in the immediate future. In this local context of care, widely prescribing PrEP is considered far from wasteful or unnecessarily costly as it offers preparedness in light of risk uncertainty among these patients, regardless of whether one embraces a population- or individual-level perspective.

On the other hand, the claims illuminate how HIV risk has become racialized in this local context as a particular group of people is considered categorically in need of PrEP. This calls to mind the example of BiDil, the first "race-specific drug" approved to treat heart disease in African Americans. Jonathan Khan's (2010) analysis of the biomedical reasoning and practices that resulted in the widespread promotion of BiDil cautions that, while it is laudable to call attention to the needs of the medically underserved, it is also important to avoid reifying assumptions of bodily or racial difference that obscures structural forces that drive health disparities. Janet Shim (2010, 222–23) similarly argues that social differences of race and class can inadvertently transform into markers of behavioural risk. In other words, the cautionary tale offered by each author is that, while the presumed beneficiaries of attention to difference are racial minorities, there is also the danger that risk factors come to carry connotations of race, culture, and class. Such social effects are not a desirable outcome of disease prevention practice. Just as some argue that PrEP as a pharmaceutical intervention constructs new identity categories such as "Truvada whore" in the social context of gay and bisexual relationships (Calabrese and Underhill 2015; Glazek 2013), our study indicates ways that PrEP may contribute to the social construction of race. In particular, our analysis sheds light on ways that ART drugs and notions of risk and race become mutually constitutive through the practice of PrEP as a pharmaceutical-based public health intervention. Thus, we contend that the phronetic approach is an invaluable methodology as it encourages researchers to challenge power relations by directing analytic focus to what Flyvbjerg, Todd Landman, and Sanford Schram (2012, 288) call "tension points" or emergent fault lines. In this instance, the emerging tension points are the medical practices, epidemiological knowledge, and population health goals that reveal uncertain practices, contestable knowledge, and potential conflicts that warrant closer reflection and consideration as we move forward.

The two claims above also speak to the relationship between individual- and population-level approaches to HIV prevention. In the first example, the broader community health concern resonates with what has been described as the "pharmaceuticalization of public health" in research on biomedical HIV prevention in areas with high levels of poverty and HIV prevalence (Biehl 2006, 2007). In this research conducted in Brazil, the federal government made ART universally available to people living with HIV as part of a national primary health prevention strategy. Providing free treatment as prevention was seen to be less costly in terms of long-term care than behavioural approaches, which were seen to be less reliable and more labour intensive to maintain. Thus, as a public health intervention, ART was seen to promote lasting health and productivity for people living with HIV, while also reducing onward viral transmission to the larger population. Although PrEP is prescribed to HIV-negative people, a similar public health logic surfaces in prescription practices at the clinic. The providers feel that liberally prescribing PrEP to their patients serves needs that go beyond individual patient care. Widely prescribing the drug is viewed as a biomedical solution to curbing the disproportionately high rate of HIV incidence in the community, thereby helping to justify the cost of treatment as a long-term benefit. To follow this reasoning through to its logical conclusion, however, returns us to the question of whether the pharmaceuticalization of society is indeed a desirable approach to combatting HIV or whether it distracts from broader structural factors that underlie disproportionately high HIV prevalence in impoverished urban communities (Friedman, Cooper, and Osbourne 2009).

We also learned that the health clinic's close affiliation with the youth drop-in centre presents an opportunity to connect with an at-risk, difficult-to-reach population. On the one hand, attendees of the drop-in centre who learn about PrEP during group discussion or from fellow attendees can be easily referred to the health clinic where they can seek a PrEP prescription or, for that matter, seek general health care. This arrangement may be viewed as efficient from a clinical perspective and convenient from a patient perspective. On the other hand, this arrangement potentially blurs the boundaries between health care services and the youth outreach program, particularly as the clinic itself was described as a place where patients openly socialize with one another and staff in much the same fashion as they do at the drop-in centre. That PrEP reportedly has a status as a hip and fashionable drug, which may inspire awe and interaction among the youth, suggests it exhibits qualities of what Suzanne Fraser, Kylie Valentine, and Celia Roberts (2009) describe as a "living drug." Drugs, in this sense, are not simply innocuous pills that are the purview of the medical clinic. Rather, they saturate culture by permeating our ordinary daily lives, social relationships, and, in some cases, social and political activism mobilized to improve the public's health. Since we take drugs, worry about them, share our experiences using them, and pin our hopes and futures on them, Fraser, Valentine, and Roberts argue that drugs are imbued with "agency" insofar as they frame our lived reality and shape people's lives on an ongoing basis (124). In the UHC youth clinic, the allure of PrEP may inspire some attendees of the youth drop-in centre to visit the health clinic and become PrEP patients, thus providing a compelling example of how PrEP has become a living drug in which culture and medicine overlap. This raises questions about the risk of over-prescribing PrEP, particularly among adolescent populations, though we can only offer tentative thoughts on this matter as we were unable to speak directly with patients during the site visit.

Finally, we learned that at this clinic PrEP is distributed in weekly or biweekly doses rather than the standard monthly prescription allotment that is more commonly prescribed at other clinics. This practice was enacted to address a series of medical concerns shared among the clinic providers. Among these concerns is the providers' need for additional opportunities to interact with patients and monitor their adherence to the drug. This clinical practice also enables providers to perform HIV/STI testing and counselling on a monthly basis rather than quarterly as advised by the CDC (Centers for Disease Control and Prevention 2014). From an implementation perspective, these clinical practices reflect the importance of flexible guidelines for prescribing and monitoring PrEP. Other providers interested in implementing PrEP programs at their clinics are well advised to carefully reflect on community needs and structural barriers in advance of implementing a similar type of PrEP clinic. Admittedly, this flexibility also raises questions about how often providers may veer from the CDC guidelines by being either too strict or too lenient and what implications might result. Increased monitoring, for example, runs the risk of binding patients' lives to restrictive medical routines, making other normal daily events and tasks in life, such as work or school, more challenging.

In closing, it is important to acknowledge the limitations of our approach. First, our case analysis does not benefit from discussions with past or current patients, attendees of the youth drop-in centre, or upper-level hospital administrators or board members of the clinic. Speaking with PrEP users, in particular, undoubtedly would have enhanced our understanding of clinic practices from a patient perspective. Second, though ours is not a comparative study, the analysis of the racialization of risk could be enriched by additional case studies of inner-city clinics serving predominantly racial and ethnic populations as well as those serving predominantly white populations (for example, Magnet sexual health services in San Francisco). Despite these limitations, our case findings of front-line clinical practices and reasoning are of use to social and health scientists interested in case-study research as well as to providers working in similar organizational settings who may be considering developing a PrEP clinic within their clinical practices. Further, our analysis of the relationship between pharmaceuticals, health care, and racialization offers an example of how critical social science can enrich case-study research on clinical practice in local contexts. As interest in the widespread implementation of PrEP intensifies in both biomedical and diverse community settings, the need for critical social science research has never been greater.

Notes

1 The Tuskegee syphilis experiment (1932–72) was a clinical study conducted by the US Public Health Service to determine the effects of untreated syphilis in African American men. The study enrolled impoverished sharecroppers living in rural Alabama under the guise of receiving free health care and continued long after penicillin was known to treat the disease (Jones 1981). The case was fundamental to the *Belmont Report* (1979), which established respect for persons, beneficence, and justice as the three fundamental ethics principles of human subjects research.

2 Henrietta Lacks (1920–51) was an African American woman who became an unwitting donor of cells from a cervical tumour that was biopsied during treatment. Unbeknownst to Henrietta and her family, the cells were then cultured and used in medical research over the course of several decades, leading to the development of the "immortal cell line" known as HeLa (Gold 1986). The case has raised ethical-legal issues concerning consent, medical privacy, and property rights over bodily cells; the case also has led to wider recognition of the Lacks family's contribution to biomedical research (Skloot 2010).

3 This quotation, along with the two quotations that follow, are typical examples given by the staff of the general script that they follow in their daily work. They noted that there is variability in what they say depending on the staff person, the patient, and the particular circumstances.

4 The Tuskegee syphilis study illustrates the historically exploitative relationship between race and science, particularly with respect to treatment of African American sexuality. Physicians leading the study, for instance, believed that African Americans were sexually promiscuous and that the study participants knowingly engaged in sexual relations with other people infected with syphilis (Jones 1981; Reverby 2010). In reality, the subjects were not informed of their syphilis diagnosis. Instead, they were told that they had general illnesses that could be treated by participating in the study. This case was instrumental in the establishment of research ethics institutional review boards to closely regulate the use of deception in research and ensure voluntary participation.

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9

The Social Relations of Disclosure

Critical Reflections on the Community-Based Response to HIV Criminalization

Colin Hastings

Our conversations about the critical in critical social science research are most often centred on complete, published works and take place after the research design is complete, the data has been collected, and the analysis written. This chapter reflects, instead, on how I am thinking through the design of an ongoing, critical, ethnographic study of community-based agencies that organize responses to the criminalization of HIV non-disclosure in Ontario. More precisely, I address an ongoing dialogue about the relationship between research informed by Foucauldian studies of governmentality and Dorothy Smith's (1987, 1990, 2002, 2005) approach to the study of the social organization of knowledge known as institutional ethnography (IE). This case study considers the analytic and practical implications of each perspective for the form that "the critical" takes within my project. I reflect on how these approaches to critical social science offer different possibilities for thinking about and critiquing the work of particular community-based groups that respond to the criminalization of HIV non-disclosure by trying to shape the disclosure practices of people living with HIV.

At the outset of my critical inquiry into these community-based initiatives, I engaged with Foucauldian studies of governmentality that direct the sociologist's vision to the reasoning and techniques that these community-based organizations utilize to manage the way that people living with HIV disclose their status (see Adrian Guta and Stuart Murray in this volume for a thorough account of how the Foucauldian-informed literature on governmentality has been taken up in critical studies of HIV). As I "tried on" the Foucauldian perspective as a way to understand the disclosure interventions that each community-based group promotes, I recognized that the governmentality literature provides sociologists with a largely incomplete approach to critical inquiry. As Pat O'Malley, Lorna Weir, and Clifford Shearing (1997) argue, it impedes a critical understanding of the relations and effects of rule. While working to develop critical and applied scholarship on HIV disclosure, I came to require a framework that positions me to add to the community-based advocates' understanding of the social relations, social processes, and institutions that shape HIV disclosure (Weir and Mykhalovskiy 2010, 18). That is the work I set out to do in this chapter.

In order to overcome the critical limits of Foucauldian literature on governmentality, I have modelled my inquiry on the work of critical sociologists who have evoked institutional ethnographic approaches to extend the Foucauldian perspective. For example, Lorna Weir and Eric Mykhalovskiy (2010, 17) position their study of global public health knowledge of infectious disease outbreaks as a dialogue or "joint project" between Foucauldian research and studies in the social organization of knowledge (SSOK). The authors describe SSOK as an approach that privileges an investigation into how knowledge "works" and shapes how things get done. Thus, studies of the social organization of knowledge "facilitate inquiries about what Foucault's work refused: the distribution and effects of a discourse at the level of social relations" (26). Here, I draw on a model of inquiry that employs IE to extend Foucauldian-informed studies of governmentality to investigate how these community-based interventions are hooked into, and socially organized by, broader processes of rule. Such an approach to inquiry, which maps the social relations in which social movements are involved, adds to a trajectory of institutional ethnographic research that intends to develop knowledge "for social movements and for activists" (Kinsman 2006, 135; G. Smith 1990). In this chapter, an exploration of the social relations in which community-based HIV advocates work provides a grounding for reflexive and critical dialogues with advocates that concern the social effects of their disclosure interventions. Such a level of critical engagement is significant because it can enhance understandings of how community-based advocacy groups do their work. This sort of critical dialogue is largely foreclosed by studies of governmentality.

This chapter is organized into three parts. I first set out the context of the criminalization of HIV non-disclosure in Canada and identify some of the ways that critical social scientists and community-based advocates have responded to HIV criminalization. Second, I present segments of interviews with advocates who work with dissimilar community-based HIV agencies. Two people that I interviewed co-organize a social group for people living with HIV and another facilitates a public education campaign about HIV disclosure, while another is the executive director of a large AIDS service organization. While each of these community-based HIV groups has a unique focus, they share a common intention to inform the way that people living with HIV disclose their status. Third, I identify some of the tensions between understanding these community-based disclosure interventions through the lens of Foucauldian-informed studies of biological citizenship and institutional ethnographic analysis. In this final section, I devote particular attention to the forms of critical engagement that SSOK position the researcher to take part in.

The Criminalization of HIV Non-Disclosure in Canada

Under current Canadian criminal law, people living with HIV can be charged with aggravated sexual assault and prosecuted if they do not disclose their HIV-positive status to their partner(s) before having sex. Since 1989 in Canada, there have been at least 184 people charged in 200 cases of HIV non-disclosure (Hastings, Kazatchkine, and Mykhalovskiy 2017). The legal obligation to disclose one's HIV status was first established by the Supreme Court of Canada in 1998 in its judgment in *R. v Cuerrier*.[1] The Supreme Court of Canada's decision in *Cuerrier* established that people living with HIV have a duty to disclose their status to sex partners where sexual activity poses a "significant risk of serious bodily harm."[2] The criminalization of HIV non-disclosure intensified in 2012 when the court decided in *R. v Mabior* and *R. v D.C.* that people living with HIV must disclose their status before engaging in sexual activities that pose a "realistic possibility of HIV transmission."[3] The court has characterized acts that carry even very small risks of HIV transmission as posing "a realistic possibility" of transmission (Canadian HIV/AIDS Legal Network 2014).

In this study, I am attentive to the ways that the Supreme Court of Canada's decision in *Mabior* and *D.C.* becomes present in the talk and actions of community-based HIV/AIDS organizations. I am looking for the ways that the criminal law operates as a text that coordinates "the work done by different people not only in that setting but in other settings so that the work done in one place is coordinated with that done elsewhere and at other times" (D. Smith 2005, 101). The court's decision can be thought of as a "boss text" that instructs specific people to carry out specific practices and coordinates organizational relations in such a way that people's work is brought into conformity with the requirements set out by the text (D. Smith 2010, cited in Bisaillon 2012, 610). While I remain mindful that interpretations of criminal-legal decisions shift,[4] my analysis in this chapter concentrates on how the Supreme Court of Canada's decision in *Mabior* and *D.C.* has been taken up by community organizations.

There has been a sustained community-based response to the criminalization of HIV non-disclosure in Canada. Much of this mobilization has been organized around initiatives that aim to intervene in the criminal-legal process. For instance, the HIV/AIDS Legal Clinic Ontario (2013) and the Canadian HIV/AIDS Legal Network (2012, 2013, 2014) have been working to mitigate the negative consequences of HIV criminalization by intervening in Canadian court proceedings, supporting defence attorneys, and assisting people living with HIV. They also have been engaging policy makers, community-based AIDS service organizations, health care workers, and journalists who work on this issue.[5] Activist collectives such as AIDS ACTION NOW!, the Ontario Working Group on Criminal Law and HIV Exposure, and the Canadian Coalition to Reform HIV Criminalization have been organizing against criminalization through direction action, public demonstrations, community education initiatives, and meetings with policy makers. AIDS service organizations (ASOs) that provide support, outreach, and education to people living with HIV have been working on issues related to disclosure since these organizations were formed in the 1980s. Before the first HIV-related criminal cases surfaced in Canada in the late 1980s, ASOs were instructing people living with HIV on how to inform others of their HIV-positive status and often understood HIV disclosure to be an empowering practice. Today, support workers at ASOs are also instructing people living with HIV on their legal obligation to disclose their HIV-positive status prior to sex and helping to connect them to resources published by organizations such as the HIV/AIDS Legal Clinic Ontario and the Canadian AIDS Information and Treatment Exchange. Recently, critiques of HIV criminalization have been extended to more mainstream settings. In December 2016, the minister of justice and the attorney general of Canada issued a statement that criticized "the over-criminalization of HIV non-disclosure [that] discourages many individuals from being tested and seeking treatment, and further stigmatizes those living with HIV or AIDS" (Department of Justice Canada 2016).

Community-based interventions that aim to intervene in the socio-legal contexts in which people disclose their HIV-positive status have largely defined the response to criminalization in Canada. However, this case study focuses on a unique type of community-based disclosure intervention that responds to HIV criminalization not by challenging the criminal law but, rather, by informing the ways that individuals living with HIV disclose their HIV-positive status to sexual partners, family members, friends, and co-workers. Investigating the empirical site of these individual-focused disclosure interventions extends current social scientific critiques of HIV criminalization by considering how such an intervention may be producing a new ethics of how one is to disclose his or her HIV-positive status.

Critical Social Science on HIV Disclosure

Much of the literature on HIV criminalization investigates the ways that people living with HIV experience or perceive the law. Research calls attention to ways that criminalization increases HIV stigma, negatively influences interactions between people living with HIV and health care providers, and ultimately violates the human rights of people living with HIV while failing to enhance HIV-prevention efforts (Mykhalovskiy 2015; O'Byrne, Bryan, and Roy 2013; Sanders 2015). This chapter aims to correct that gap through a case study of a particular segment of the community-based response to criminalization that encourages people to disclose their HIV-positive status.

A strand of critical social science that devotes careful attention to the social worlds in which people disclose their HIV-positive status informs my study of community-based disclosure interventions. This includes the work of Lenore Manderson (2014, 6), which treats HIV disclosure as a complex and challenging process that not only reveals one's health status but also "routinely index[es] other forms of sexuality, sexual practices, drug-related behaviour and so on." Because one's HIV disclosure can also reveal stigmatized activities, researchers have underlined that HIV disclosure enhances the forms of medical, social, and personal governmentality and surveillance to which one is subject. Corinne Squire (2014, 144) argues that, in such a context, disclosure is never freely provided but, rather, is always part of a contract in which things such as "services, citizenship, relationship, or personhood are given back." These accounts of HIV disclosure are valuable because they work to critique and to disrupt the common assumption that the implications of HIV disclosure are universal. As Manderson (2014, 6) writes, "while there is an illusion of relative equality when disclosures are made between the one who discloses and the one who receives disclosure ... gender, age, and other social structures destabilize presumed equality and sharpen concerns of what might be at stake in any disclosure." My analysis in this chapter seeks to build on Manderson's understanding of HIV disclosure in order to account for the social relations that organize people's disclosure practices.

I model my approach to critical social science on the work of researchers who have developed critiques of social structures that shape people's everyday social realities. For instance, Luc Boltanski (2011) argues that the main difference between critical theory and traditional theory is that critical work is able to be reflexive, is adept at incorporating social actors into its analysis, and is capable of understanding the discontent of everyday social actors. This perspective squares with that of institutional ethnographers who have problematized the ways that sociological accounts that are not attuned to "the site of experience, the presence of actual subjects, and the actualities of the world [people] live in" produce "objectifying discourses" (D. Smith 1990, 12). Objectifying discourses are a concern for institutional ethnographers because they erase the actual contexts in which living individuals act. People disappear within objectifying discourses, and, as a result, "we cannot see what is going on" (55). This case study calls attention to the ways that community organizers often have produced an objectifying discourse of disclosure and, in so doing, broadens the ways that researchers and advocates understand the impacts of criminalization.

Interviews with Community Advocates

This chapter is primarily based on five institutional ethnographic interviews with people based in HIV organizations who contribute to community-based HIV disclosure interventions (Devault and McCoy 2004; D. Smith 2005). Each group's intervention focuses mainly on the disclosure activities of gay men. Because institutional ethnographic inquiry begins with the local experiences of social actors, the experiences of other groups located outside of the context of gay men living in urban centres will likely yield different results than those presented here. The interview participants were each linked to groups in Toronto that respond to HIV criminalization through initiatives that encourage individuals living with HIV to act in a particular way around disclosure. The interviewees have gone about this work in slightly different ways. For instance, I conducted three interviews with people who co-organize a group that arranges social gatherings for people living with HIV. I refer to the co-organizers of this social group by the pseudonyms Chris and David. The co-organizers are open publicly about their HIV-positive status and have been involved with the group for about two years. Their social group encourages members to be open about their HIV-positive status in a wide range of social settings, such as with family, friends, co-workers, and people they meet at parties. The social events that they organize include dance parties, brunches, and group trips to popular attractions in Toronto. I also interviewed a person who lives with HIV and volunteers in an ASO. This individual, who I refer to as Tony, was part of a team of facilitators who oversaw the collaborative production of a guidebook about how to manage HIV disclosure. The guidebook is the result of a meeting in which almost ninety people living with HIV came together to translate their disclosure experiences and advice into a document that was distributed to ASOs. Finally, I spoke with the executive director of a large ASO that provides support services, education, and counselling for people living with HIV. The executive director, who I refer to as Bill in this chapter, described the variety of ways that concerns related to disclosure shape the organization's outreach and counselling programs.

The interviews lasted forty-five to eighty minutes, were tape-recorded, and transcribed in full. In addition to the interviews, I also studied how various texts (websites, blogs, brochures, resource manuals) that the interviewees' organizations produce actively coordinate how people living with HIV understand and "do" disclosure. Furthermore, I attended community events and meetings in which community-based organizations discussed and planned interventions around HIV disclosure. Together, these empirical data sources provided a basis for me to understand how the community-based response to criminalization is socially organized.

A close reading of participants' accounts of their work reveals that these community-based projects frame disclosure in similar ways. First, each of the initiatives pivot on the idea that disclosure is an individual choice made by an individual rational actor. The intervention of each group is centred on efforts to inform a person's decision about how, when, or whether to disclose his or her HIV-positive status. Second, each participant described how his group focuses on disclosure activities that are not formally regulated by the criminal law. In an effort to bolster ways of thinking about disclosure that are not captured by the criminal law obligation to disclose before sex, each group concentrates on activities such as disclosing to friends and family, colleagues, or being publicly open about one's HIV-positive status. In the sections that follow, I set out the ways in which the interviewees produce disclosure as an individual choice and an act that takes place outside of the social relations of criminal-legal authority.

A Social Group to Encourage Disclosure

Chris and David's descriptions of their work with a social group for people living with HIV make visible how an understanding of disclosure as an individual decision that is external to the relevancies of the criminal law takes form. Chris recounted a conversation that he had with a group member who was hesitant about widely disclosing his HIV-positive status. As Chris described, a member of the social group "became very agitated and said, 'well I'm not sure if I can be a member of this group anymore' and I said, 'you have to pick a team, you're either negative or you're positive, but don't tell two different stories.'" In this statement, Chris produces one's HIV disclosure as a choice that is like deciding which team to play on. The decision to disclose one's status seems to place one on the side of people living with HIV, while it is implied that the decision to conceal one's status positions one in opposition to people living with HIV. In this conversation, disclosure is produced above all else as a choice that a person living with HIV has to make. Particular social contexts that might make it difficult, undesirable, or unsafe for one to choose the HIV "team" fall out of view in this account.

The co-organizers of the social group produce disclosure as a decision that individuals should eventually progress toward as they grow and evolve as people. During my interview with David, the co-organizer made a distinction between group members' "bad behaviour" and "good behaviour," with the latter described as "using I statements and sharing the air ... respecting others' differences and looking for similarities." He added: "Eventually I think disclosure will be one of the ones [behaviours] we try and bring out." In this instance, David produces disclosure as a form of conduct that is aligned with well-mannered, respectful ways of being. The "decision" to disclose or not is essentially made into a choice that one makes between "good behaviour" and "bad behaviour."

Since Chris and David produce disclosure as a decision, they make an effort to locate the decision-making process outside of the social relations of criminal-legal authority. The social group encourages people to be open about their HIV-positive status, not because of concerns about the criminal law but, rather, on the grounds that it will improve their sense of self and enhance their interpersonal relationships. Chris explained that being open about one's HIV-positive status enables one to "stop living a double life" and allows one to "stop trying to remember who knows? Who doesn't know? It [non-disclosure] stilts your conversation, it stilts your ability to be carefree and friendly." Here, Chris constitutes disclosure as an activity that is fulfilling and even enjoyable. As he explained, "you disclose not because it's the law, you disclose because it's going to make your life better and easier and more fun." Other community-based initiatives attend to the socio-legal contexts in which people disclose their HIV-positive status by clarifying the criminal-legal obligation to disclose, assisting people living with HIV to navigate the criminal law or by mobilizing opposition to criminalization. Chris and David described a different type of community-based intervention that concentrates on disclosure activities that are external to the relevancies of the criminal law altogether.

A Guidebook to Inform How People Living with HIV Understand Disclosure

Tony's description of the work that he did to help facilitate the production of a guidebook about HIV disclosure also produces disclosure as an individual choice that is made for reasons that are not related to complying with the criminal law obligation. Tony spoke about the type of environment that he and his co-facilitators tried to cultivate at the writing meeting where the guidebook was crafted. His understanding of disclosure displays a greater sensitivity to the social conditions that shape people's disclosure activities than was evident in Chris and David's account. As a facilitator of the meeting, Tony emphasized that "not disclosing should be an option because we don't live the same cookie cutter life. I am lucky that I am gay and I can have the freedom to disclose every single day ... not everyone can." In this statement, Tony acknowledges that disclosure is not a uniform experience, and he calls attention to the social conditions that can limit the opportunities that one has to be open about one's HIV status. He hopes that the guidebook on which people living with HIV have collaborated will inform the ways that support workers in ASOs counsel people on issues related to disclosure. In particular, he wants support workers to be more aware of the complex social situations that people living with HIV confront and to be a better resource for people living with HIV who have to make strategic decisions about disclosure that fit the contexts of their everyday social lives. He hopes the guidebook will be a useful tool for someone living with HIV who is facing complicated questions such as: "I can't disclose to my dad right now because he's paying my tuition, so maybe when I graduate? Is that wrong? Is that sneaky?" Tony produces disclosure as a type of decision that comes to bear on different relationships in one's social life in unique ways.

Much like Chris and David's social group, the disclosure guidebook is premised on efforts to critique a social context in which people believe a criminal-legal discourse has "hijacked" discussions of disclosure. Tony emphasized that he finds talking about disclosure as a social practice that is not fully captured by the criminal law to be empowering for people living with HIV. He explained that, in his experience, when groups of people living with HIV gather to discuss disclosure the criminal-legal obligation to disclose hinders productive dialogue. For instance, he identified that in workshops about disclosure "people don't know how to have a conversation other than 'the law tells me I have to wear a condom.'" In addition to the sexual encounters that the criminal law is concerned about, Tony wants people to recognize that "there are many other areas where disclosure happens or doesn't happen and disclosure needs to be put back into the hands of the person living with [HIV] and it should be their choice to [disclose] or not to." Tony's disclosure intervention seeks to instill a way of thinking about disclosure as something broader than the criminal law obligation to disclose before sex.

HIV Disclosure Initiatives at an ASO

Bill, the director of a large ASO, echoed much of Tony's perspective on disclosure. Like each of the other interviewees, he produces disclosure as an individual decision that occurs beyond the criminal-legal obligation. As he described how disclosure issues arise in the ASO's counselling and outreach services, he produces disclosure as a practice that can be productive in some situations: "For some people disclosure can be an empowering thing." He also acknowledged that disclosure is different for everyone who lives with HIV. He explained that his organization's initiatives around disclosure are "not trying to say you need to be completely out about your status because that person who is out may have a very different you know, where they're socially located or what's going on in their life that they can actually do that." This approach to disclosure contrasts significantly from the approach that Chris and David employed in their social group where testimonials from people who have disclosed to loved ones feature prominently as models for how members of the social group should disclose.

Like the other interviewees, Bill emphasized the importance of moving the discourse on disclosure away from criminalization to “think of disclosure as a process” and to “shift to taking a more holistic approach to disclosure.” For Bill, being more “holistic” seems to involve devoting greater attention to contexts where disclosure happens that the criminal law is not concerned about. He made a distinction between “there’s that legal thing, and there’s the rest of your life too.” Bill described disclosure initiatives at the ASO that concentrate on the social lives of people who access services rather than the legal dimension of one’s disclosure practices. He explained that the ASO is “trying to shift that discourse away from a very legal, heavy hand of the law to, okay, practically, what does [disclosure] mean as someone living with HIV?” As part of this shift, the ASO runs a “psycho-educational workshop series where guys come in and learn things such as how to manage your health, how to get connected to a doctor, there’s a whole component on sexual health which obviously includes negotiating safer sex or disclosure … not just physical health but mental health and sexual health.” Much like Chris, David, and Tony, the disclosure interventions that Bill described focus mostly on aspects of people’s individual social lives other than the criminal-legal obligation to disclose prior to sex.

The interviewees’ descriptions of their work reveal two types of disclosure interventions that focus on the individual. The first type, articulated by Chris and David, urge people to make the decision to be open about their HIV-positive status in a wide range of social settings, not because the criminal law tells them to but, rather, because disclosing will improve their social lives and help them to become better, fuller versions of themselves. The second type of individual-focused disclosure intervention, exemplified in the work of Tony and Bill, also produces disclosure as a decision, but it devotes more attention to the social conditions in which one makes choices about disclosure. The work of these groups concentrates on advising people living with HIV on how to effectively manoeuvre these social situations rather than working to challenge or protest against them. Studies of governmentality and SSOK offer the critical sociologist different possibilities for thinking through and critiquing these community-based interventions. I examine the political implications of utilizing both perspectives to understand these responses to criminalization in the next section of this chapter.

Critically Engaging with Interview Transcripts

The perspective that critical sociologists use to understand community-based initiatives, such as the disclosure interventions that I study here, not only produce distinct trajectories of critique, but they also position the researcher to have particular dialogues with community-based advocates. Foucauldian-informed studies of biological citizenship and IE bring different aspects of these disclosure interventions into view and shape the extent to which the researcher can contribute to the community-based advocates' understanding of HIV criminalization.

Biological Citizenship as a Perspective to Understand Community-Based Disclosure Interventions

The most frequently cited Foucauldian-informed work on biological citizenship is Nikolas Rose and Carlos Novas's (2005) chapter, "Biological Citizenship." The authors argue that in the biomedical era a new form of biological citizenship is emerging throughout the West that is shaped by "new subjectivities, new politics, and new ethics" (36). Biological citizenship is a perspective from which to examine how one's biological identity (including one's health status) comes to bear on one's social and political identity. The framework can be a useful strategy to investigate how people who share a biological identity come together in order to claim rights, to gather information, or to gain access to medical care, treatments, or other resources. In short, biological citizenship can get us thinking in interesting ways about how the social and the biological are connected.

There are two ways in which biological citizenship can serve as a useful perspective for understanding community-based disclosure interventions. First, studies of biological citizenship call attention to diffuse and overlapping forms of governance that people living with HIV confront. Studies of biological citizenship are part of a trajectory of research that has demonstrated the power dynamics at play between medical authorities and people who politically mobilize their health status in order to obtain rights, resources, and services. Such a project relies on Michel Foucault's particular understanding of power and governance. Rose (1993, 286) argues:

> Michel Foucault's notion of governmentality has a significance for us today because it is an alternative way of thinking the activity of politics. The forms of power that subject us, the systems of rule that administer us, the types of authority that master us – do not find their principle coherence in a State ... The force field with which we are confronted in our present is made up of a multiplicity of interlocking apparatuses for the programing of this or that dimension of life, apparatuses that cannot be understood according to polarization of public and private or state and civil society.

In this quotation, Rose helps us to understand the community-based disclosure interventions as apparatuses that are part of a broader force field that encourages people living with HIV to act in a particular way around disclosure. Foucauldian-informed studies of biological citizenship help illuminate how this form of governance is exercised through community-based organizations as opposed to being a coherent form of authority enacted by a centralized state body alone. For example, interview segments included in this chapter illustrate that people's disclosure practices are shaped not only by the heavy hand of the criminal law but also by techniques as diverse as social outings to parks, collaborative writing projects by people living with HIV, and workshops that focus on the mental and sexual health of people who live with HIV. These types of governance that community-based disclosure interventions enact are overlooked if social scientific analysis concentrates solely on the practices and techniques of the criminal justice system and public health authorities. Understandings of biological citizenship call attention to the techniques that interviewees employ to produce a new and expanded set of ethical demands for people living with HIV.

Studies of biological citizenship also reveal how these governing techniques come to bear on people's conception of "the self." The central point of interest for Rose and Novas (2005, 21) is what they identify as "a new informed ethics of the self" that is associated with biological citizenship. The authors conceptualize biological citizenship as a set of techniques for governing and managing one's everyday life in relation to a condition and in relation to expert knowledge. Active and responsible biological citizens are understood to have obligatory responsibilities that include activism, being informed about one's condition, and adjusting diet, lifestyle, and habits to maximize health.

In the context of this study, the biological citizenship perspective illuminates how the governing techniques of disclosure interventions act on "the self." For example, this is particularly evident in the ways that Chris and David's social group produces a "right" way for one to disclose his or her status: "The reality is that you have to be educated about the illness, you also have to be positive and optimistic about the outcome ... when you disclose you don't leave the person feeling like they're in a position to care for you." Here, the person living with HIV is not only expected to be open with his or her status but also to be informed, confident, and mindful of the person to whom they disclose. These types of expectations raise the already high stakes that are attached to disclosure. Rose and Novas (2005, 22) warn that, as the enactment of responsible behaviours becomes the norm, those who refuse to identify themselves with this responsible community of biological citizens will come to be viewed as "problematic persons." Understanding Chris and David's social group through the perspective of biological citizenship brings into view how the normative character of the group encourages people living with HIV to alter and align their conduct around disclosure with the model of "responsibility" that the social group's organizers produce.

While the Foucauldian project directs the sociologist's vision to the "conduct of conduct" within community organizations, its capacity to incite critical dialogue is incomplete as it emphasizes the "mentality of rule" over the "messy actualities of governance" (O'Malley, Weir, and Shearing 1997; Weir and Mykhalovskiy 2010). Thus, the critical potential of Rose and Novas's conception of biological citizenship is limited because it restricts the researcher to making observations about the techniques that organizations employ to shape the conduct of people living with HIV instead of the social effects of their interventions. A more politically productive, albeit challenging, critical sociological project is to map for community-based advocates how their interventions are organized by, and hooked into, broader social relations, such as the criminal law. Such a critique that is concerned with systems of social organization and their social effects produces a more stable ground for reflexive, critical engagement with the organizers of community-based disclosure interventions.

SSOK as a Perspective to Understand Community-Based Disclosure Interventions

An institutional ethnographic approach positions the critical sociologist to develop an analysis of the social organization of these community-based interventions rather than a study only of their rationalities of rule (Campbell 2010). In the remainder of this chapter, I call attention to two ways in which an IE-informed study of these community-based initiatives is politically and critically productive. First, I display how an IE study can bring into view the broader social relations with which these disclosure interventions are connected. SSOK position the researcher to explore "with people their experience of what is happening to them and their doings and how those are hooked up with what is beyond their experience" (D. Smith 2005, 41). Second, I concentrate on how an IE approach can be utilized to inform critical analyses that illuminate the social effects of these disclosure interventions. Such dialogues can enhance advocates' understanding of criminalization's social effects as IE incorporates the perspectives of social actors to show how ruling relations are (re)produced, resisted, and reformed in the activities of actual people (Nichols 2014, 8). Together, these two contributions of IE-informed sociological inquiry highlight the distinct type of reflexive and critical engagement that studies of social organization position the researcher to take part in.

First, studying transcripts of interviews with community-based advocates with an eye to social organization makes visible how their activities are coordinated by broader social relations, specifically extra-local criminal-legal texts (Mykhalovskiy, McCoy, and Bresalier 2004; Nichols 2014, 183). For example, the collaboratively produced HIV disclosure guidebook that was described through Tony's interview states that it is responding to a situation in which "we as a community have been sitting on disclosure and feeling powerless for some time, especially as criminalization has taken the spotlight. We have finally pushed back on this together." This "pushback" is centred on redefining disclosure "as a lifetime experience and not just an act required by the law in some circumstances" (8). Most of the material in the guidebook was developed by people living with HIV at the collaborative writing meeting; however, the opening pages of the guidebook detail that "the material developed at the [group name] meeting is supplemented by evidence from research literature on disclosure" (9). In most cases, this "research evidence" promotes the benefits of being open with one's HIV-positive status while overlooking the particular social worlds in which people disclose. For example, "from the literature" sections link disclosure with positive outcomes such as gaining support, reducing stress, gaining self-acceptance, sharing knowledge, reconciling with family and friends, and diminishing feelings of loneliness and isolation. Like each of the disclosure interventions described in this chapter, the guidebook not only addresses disclosure within intimate relationships with which the criminal law is concerned but also provides broader instructions for disclosing to friends and family, within the workplace, to health care providers, to children, and "going public."

Conducting an empirical investigation into the ways that the criminal law operates as a "boss text" that coordinates the talk and actions of community-based advocates brings into view the paradoxical way that the criminal law coordinates the interviewees' participation in an objectifying discourse of disclosure. Advocates often emphasize the importance of "pushing back" against criminalization by moving discussions about disclosure to spaces that the Supreme Court's decision in *Mabior* and *D.C.* does not address. In so doing, these groups increasingly intervene on people's individual personal lives and provide instructions that urge people living with HIV to disclose to one's family, friends, and co-workers. In effect, these disclosure interventions may actually broaden and create more spaces in which people living with HIV are expected to disclose their status. Thus, the expanded expectation that people will disclose their HIV-positive status in their personal lives is coordinated by the disclosure obligation produced by the Supreme Court. The criminal law is actively organizing community-based responses that are designed to counter the criminalized discourse of disclosure.

In an effort to oppose a discourse that produces disclosure as an activity required by the criminal law, people form groups and construct interventions to turn disclosure into a process – a choice that an individual makes in his or her personal life. As the empirical findings in this chapter have displayed, these groups often neglect the social contexts that make one's HIV disclosure such a complex activity. While Rose's (1993) conception of governmentality positions the researcher to understand a disclosure intervention as part of a broader force field of governing bodies that shape the conduct of people living with HIV, the institutional ethnographic approach offers the critical sociologist a perspective for understanding how the social relations of criminalization actually take form in the activities of community-based advocates. An empirical study of social organization makes possible a grounded and material critique of community-based organizations that is foreclosed by studies of governmentality. This form of critique can enhance community advocates' understandings of the circumstances that their disclosure interventions address (McCoy 2008).

A second critical contribution made possible by reading interview transcripts for social organization is that the approach provides the researcher with a stable foundation for developing a reflexive critique that can enhance community advocates' understanding of the social effects of their interventions. The objectifying discourse of disclosure that community-based interventions routinely produce is a social effect of criminalization to which a Foucauldian study of the "conduct of conduct" would be blind. An IE perspective can illuminate for community-based advocates the ways that their interventions are hooked into the broader social relations, social processes, and institutions that shape HIV disclosure. This is a critically productive contribution that may enhance their understanding of not only the social effects of criminalization but also the (potentially harmful) social effects of the objectified account of disclosure that they tend to mobilize. Dorothy Smith (1990, 55) cautions that these types of objectifying discourses are harmful because, "we cannot see what is going on." We cannot see the various ways that people's social realities (such as the social conditions of one's relationships, employment status, or access to medical care, social supports, and housing, to name a few) come to bear on the way that one either discloses or conceals one's HIV-positive status. Of course, such a critical and reflexive dialogue is challenging and even uncomfortable for a critical sociologist to have with those involved in the response to criminalization. However, the political potential of these dialogues extends the Foucauldian project that positions the researcher as merely echoing back to advocates the descriptions of the techniques that they employ to shape the conduct of people living with HIV. This tension can be a productive way to support and enhance advocates' knowledge of the wide-reaching effects of criminalization and to stimulate interventions that respond to the social contexts that make disclosure difficult in the first place rather than the personal, individual decisions of people living with HIV.

Conclusion

In this case study, analyses of governmentality and SSOK provide the researcher with different possibilities for thinking about and critiquing particular initiatives that aim to intervene in the arena of HIV disclosure. IE has been shown to be a perspective that is adept at developing critiques that can enhance advocates' understanding of social relations and produce detailed descriptions of the institutional processes that activists address. This research can add to the critical inquiry on criminalization by calling attention to the ways in which the criminal law obligation to disclose prior to sex not only impacts the realms of public health, health care, and criminal law but also the activities of local community-based organizations (McCoy 2008). This analysis of an objectified discourse of disclosure mobilized by people working with community-based groups can further contribute to institutional ethnographic research that is concerned with objectifying discourses. This account of objectifying discourses that circulate at the local level can extend IE studies of ways that objectifying discourses operate in professional, formal, managerial settings such as health care, education, and the social service sector – in what Dorothy Smith (1990, 14) calls "the total complex of activities by which our kind of society is managed and administrated." This study suggests that institutional ethnographers need not limit their investigations of objectifying discourses to managerial settings. IE can also be evoked to reveal how people's everyday work is governed and brought into coordination with organizational courses of action that operate outside of formal, managerial spaces.

Notes

1 *R. v Cuerrier,* [1998] 2 SCR 371.
2 Ibid., para. 128.
3 *R. v Mabior*, [2012] SCC 47, para. 94; *R. v D.C.*, [2012] SCC 48, para 29.
4 It is important to be mindful of the distinction between the wording of the Supreme Court of Canada's decision and how the decision is interpreted.

For example, in 2013, a trial court in Nova Scotia did not accept that the Supreme Court's decision had definitively foreclosed different interpretations of "realistic possibility of HIV transmission" (Canadian HIV/AIDS Legal Network 2014, 2). The court acquitted a young man who engaged in unprotected sex based on evidence that his undetectable viral load meant that the risk of transmission was approaching zero. *R. v J.T.C.,* 2013 NSPC 105.

5 See Canadian HIV/AIDS Legal Network, aidslaw.ca.

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10

Epidemiology, the Media, and Vancouver's Public Health Emergency

A Critical Ethnography

Denielle Elliott

> *The tradition of the oppressed teaches us that the "state of emergency" in which we live is not the exception but the rule.*
>
> *– Walter Benjamin, 1940 (quoted in Taussig, 1992)*

IN 2006, COLLEAGUES VISITING from Scotland for a medical anthropology conference asked if I would be willing to take them to Vancouver's Downtown Eastside, a community they had come to know through media and research accounts as a space plagued by disease, addiction, and criminality. Later when we walked around the community, they were surprised that in fact the neighbourhood seemed quite safe and mundane, not at all what they had expected given the accounts they had read. Descriptions that reported on shooting galleries, a public injection drug scene, an open street-level sex trade, and sky rocketing rates of HIV had created an imaginary for them that was dangerous, dark, and destitute. Though clearly a space marked by poverty, it was not the inner-city "ghetto" or "slum" they expected. Such sensationalist media accounts and research reports were common through the late 1980s, 1990s, and much of 2000s as Vancouver's Downtown Eastside wrestled with many of the issues facing large urban centres – poverty, homelessness, illegal drug use, sex work, and crime. Researchers documented the rise of HIV and those at risk of HIV in Vancouver – men who have sex with men, sex workers, and injection drug users – and the media relayed their findings to the public. This chapter explores the ways in which research reports and media shaped a particular imaginary of the Downtown Eastside, one that was largely incongruent with the everyday reality of those who lived there.

One of the key moments that drew this national attention to the Downtown Eastside was when the Vancouver/Richmond Health Board (VRHB) declared a public health emergency in 1997 in response to reports that suggested illicit drug use and HIV infections were both dramatically increasing. Framed as a humanitarian intervention for the urban poor, and backed by a rights discourse for illicit drug users, the public health emergency was meant to offer much needed health care and social welfare programming to those living with HIV or to those seen as being at risk of HIV. Declaring a public health emergency was both discursive practice and political action, resulting in a whole series of commitments and interventions from all three levels of state that would have both intended and unintended consequences. To date, it remains the one and only emergency declared for Vancouver, British Columbia, and, twenty years later, the state of emergency officially remains in place, never having been cancelled.[1] It signalled an important shift politically as it became a rationale for an assemblage of dense, interwoven, sometimes contradictory, political, and biomedical technologies that governed, regulated, and shaped the everyday lives of the urban poor.

Epidemiological knowledge, in particular, defined the emergency and the epidemic and continues to influence what is known about the community and its residents today. Although not the only research being conducted in the Downtown Eastside, epidemiological studies have the most salience and influence provincial and regional policy and clinical guidelines and garner the most amount of media attention. This chapter considers the potential value of critical ethnography in our attempts to understand how particular HIV communities become known through epidemiology. I consider epidemiological knowledge in its original research form and as it is taken up in dispersed form by the media, asking how these representations shape how the public has come to know the Downtown Eastside. In doing so, the chapter speaks more generally to the ongoing limitations of risk-factor epidemiology in understanding complex illness trends such as HIV/AIDS.

In the following pages, I consider two specific questions. First, I explore how epidemiological ways of knowing shaped a particular understanding of the Downtown Eastside as diseased and drug addicted: which stories were being told through the dominant epidemiological discourse and which stories were eclipsed and how did these stories get taken up in the media? Second, I reflect on the disjuncture between what is "known" about the Downtown Eastside and what is lived by examining the everyday experiences of Indigenous women and men in clinical care settings. In answering these questions, I focus largely on the Vancouver Injection Drug Users Study (VIDUS) and media reports following the public health emergency. Although there were other research projects and other narratives circulating, VIDUS researchers at the British Columbia Centre for Excellence in HIV/AIDS (Centre for Excellence) were key in defining the public health emergency. Epidemiological evidence emerged as politically compelling knowledge in a community plagued by controversy and contestation, and it was employed by politicians, scientists, and advocates alike.

A Critical Ethnography

Critiques of well-intentioned interventions, whether they are of technologies, programs, or epidemiological research, raise their own risks of being used as a rationale to limit resources for the disadvantaged. What then might a critical ethnography of the public health emergency and epidemiological studies of the Downtown Eastside offer to an understanding of HIV/AIDS? As Didier Fassin (2013, 121) has argued in his own study of AIDS in South Africa, a critical ethnography that examines the "confrontation" of intersecting forces – in this case, of patients and doctors, research subjects and epidemiologists, and suffering, science, and media – leads to deeper and more nuanced understandings of HIV. A critical ethnography of epidemiology, in particular, works to displace or disturb the "behaviour" or "individual choice" model that blames Downtown Eastside residents for their ill health and HIV status with an analytic that highlights the ways in which the HIV epidemic has been fundamentally shaped by larger political, economic, and historical forces, whereas a non-critical approach may simply document and describe those models. The historical reflexivity demanded of critical ethnography forces us to consider how histories of colonialism, violence, exploitation, segregation, capitalism, medicine, and other powerful global forces shape, every day, the health and well-being of the urban poor and urban indigenized communities such as the Downtown Eastside. What may seem at first glance as "strange" behaviour seems logical once we make visible these historical and contemporary forces at play. Critical ethnographic approaches also force researchers to contend with their own positionality and complicity in power relations that may be a part of the larger biomedical assemblages we study, the scholarly fields we are embedded within, or the institutions where we work (Madison 2011). This is particularly important as we think about the historical legacy of both medical and anthropological research with Indigenous communities. Critical ethnography works to unsettle how we think about addictions, epidemiological research, and Indigenous communities by listening to Indigenous voices (see the section on clinical care below).

Fassin (2013; see also 2007) provides an example from his fieldwork in South Africa where few seemed to understand the ways in which the HIV epidemic evolved or how the state responded to the AIDS crisis in the 1990s. A popular and uninformed perspective portrayed Africans as polygamous, sexually promiscuous, or uneducated about HIV risks. But Fassin's critical lens and long-term ethnographic fieldwork make visible the relationships between HIV infection rates and racialized labour practices in the context of apartheid, displacing myths about sexual promiscuity among African men. Men are displaced from their homes, forced to live segregated from their families for long durations, in male-only housing on farming and mining projects, creating the contexts where men may engage in sexual relations with other partners. Such decisions are shaped by structural forces and are not "cultural" or necessarily individual choices (Fassin 2004). Following his lead, this chapter aims to interrogate the conventional narratives about Downtown Eastside residents, produced by the media and epidemiological knowledge, as inherently drug using and HIV positive. A critical ethnographic approach in this case provides a view into the ways in which meanings about the Downtown Eastside are produced by the media and research but do not always align with the lived experience of residents who make the Downtown Eastside their home.

This chapter is drawn from a larger multi-sited ethnographic project that I carried out in 2004 and 2005, which focused on the production of scientific knowledge, everyday clinical practice, and the political economy of anti-HIV medicines in the Downtown Eastside.[2] By 2000, the community had become publicly defined by HIV and addictions as well as by these circulating epidemiological and media discourses. HIV prevention and treatment are a central concern in the lives of many Downtown Eastside residents, although they are just some of the many health issues afflicting the community. Diabetes, malnutrition, various forms of cancer, oral hygiene, tuberculosis, sexually transmitted infections, chronic pain, and untreated mental illnesses are among the issues that many patients have highlighted as being their health priorities. In fact, many patients were begging their doctors during appointments for treatment, care, or referrals to specialists to sort out non-HIV-related health issues. In some cases, doctors would attempt to address these other concerns, but, too often, they focused solely on addictions (even when patients did not suffer with addictions) and questions of HIV/AIDS. In fact, there is very little clinical care for chronic diseases in the community. As Julie Livingstone (2012) has discussed in reference to Botswana, HIV occurs alongside many other pressing diseases, particularly cancer, which are often eclipsed due to an international prioritization on HIV/AIDS. During my interviews and conversations with clinic patients, many voiced intense frustration that their other health concerns were not being taken seriously. For instance, Mike, an Indigenous man in his late thirties, was plagued by pain resulting from hip failure and desperately required two hip replacements.[3] I watched as years passed by as we worked together as he limped, often unable to walk due to the pain. My suggestion here is that epidemiological ways of knowing the Downtown Eastside, which define the community as being plagued by HIV/AIDS and illicit drug use, combined with the media's repetition of such knowing, has shifted the focus of clinical care away from chronic disease and primary care to focus overwhelmingly on HIV and addictions. While these were genuine issues for some, many residents in the Downtown Eastside were neither HIV positive nor drug users.

Vancouver's Inner City

A few blocks away from Vancouver's prosperous downtown core and lush Stanley Park is a neighbourhood that is a space of ruin, an intimation of Canada's colonial past (Stoler 2008). The community is scarred by the effects of neoliberal policies and practices that un-house the poor, de-institutionalize the mentally ill, and pathologize the sick. But, unlike many other urban ghettos that have been forgotten or abandoned by neoliberal states, this community experienced a surge of attention and resources after the public health emergency was declared (Biehl 2005). "There is nowhere else like it," "it's a place like no other" – these are epithets commonly used to describe the Downtown Eastside. It is a place of vibrant energy, of compassion, hope, love, and heartbreak, a place of generosity, and a place of social suffering and marginalization. The heart of the neighbourhood is the intersection of Hastings Street and Main Street or, what many locals refer to as, "Pain and Wastings." This moniker conjures up images more commonly associated with the neighbourhood, characterized all too frequently with reference to the illicit drug trafficking, public use of injection drugs and inhalation of crack cocaine, intense poverty, crime, and violence, and concentrated street-level sex industry. Its residents include displaced Indigenous peoples, deinstitutionalized mentally ill, working-class men, and impoverished new immigrants who are too poor to relocate to Vancouver's upscale neighbourhoods.

The 2010 Olympics spurred an intense gentrification project that rendered the community almost unrecognizable as hipsters, artists, students, and middle-class urbanites flocked to the neighbourhood for housing and upscale boutique shopping. Many of the urban poor live in substandard housing or sleep on the street, their lives bundled up in shopping carts. Estimates from 2013 suggest that there were over 1,600 people living on the street or in temporary shelters in Vancouver (Vancouver Homeless Count 2013). This number does not reflect the thousands of other local residents who live in single room occupancy hotels or in the various social housing projects. The inner city is, as Nicholas Blomley (2004) has carefully illustrated, an inherently political space marked with street marches, vigils, demonstrations and protests for (or against) affordable housing, missing women, human rights, policing, the Olympics, and gentrification. Informal "red zones" designate where women in the sex industry are allowed to work; they are forced further and further into unsafe areas, industrial neighbourhoods deserted at night, where they are more vulnerable to those who prey on the disadvantaged (Robertson 2007).

Although a distinctly "urban" community located within a metropolitan city with a population of 2.2 million, it would be amiss not to recognize the ties between the Downtown Eastside and rural and reserve communities. In the Downtown Eastside, as in Canada more generally, a colonial history plays a central role in understanding current health and illness disparities. The process of colonization has been a pivotal force in the construction of contemporary Indigenous health. Today, Indigenous peoples live with the contemporary effects of the history of colonial relations, coupled with existing discrimination, continual struggles for self-determination, and poverty. While not all Canadian Indigenous people face these contemporary struggles, they are more likely to. Many Downtown Eastside residents are members of First Nations living with the historical legacy and contemporary limitations of the *Indian Act*.[4] It is a distinctly colonial space within a city unwilling to acknowledge its violent history. But the community is more than just home to Indigenous peoples. The land is traditional Coast Salish territory, appropriated by the Canadian state, which then relocated and displaced Indigenous peoples to reserves. And yet, the history of colonialism and its contemporary effects on Indigenous peoples – the dispossession and violence – are eerily eclipsed in most discourses about Vancouver's inner city (Barman 2007; Culhane 2003).

The colonial histories of this space and the land itself are usually erased from contemporary debates and discussions about the community or its residents' health. In public health, "traditional healing practices" and "Indigenous medicine" are often deployed as nostalgic signifiers and refer to medicine wheels, healing circles, sweat lodges, Elders, and smudging ceremonies, which may or may not be relevant to the diverse Indigenous peoples living in the inner city.[5] The Downtown Eastside might be best thought of as an "indigenized urban space," one where colonial histories, contemporary Indigenous lives, and marginality intersect, shaping urban policy, health care, and subjectivities (Culhane 2003). Although many researchers, activists, and public health administrators may understand the links between health inequities and colonial histories, the epidemiological literature published about the inner city oddly speaks only to indigeneity as a risk factor. As I will show in this chapter, the narrow focus of research on injection drug use and HIV effectually erases the history of colonialism and the contemporary forces that similarly shape urban Indigenous lives. The discussion in this chapter enters into dialogue with Randy Jackson (in this volume), who encourages us to interrogate how we know Indigenous issues as well as what we know in this regard.

Knowing the Downtown Eastside

In response to research from VIDUS and the provincial coroner's report indicating that deaths from heroin overdoses and HIV infections were both dramatically increasing in the inner city, the City of Vancouver declared a public health emergency on 25 September 1997 (British Columbia 1994). It was a declaration of a state of emergency, and it defined a special circumstance that required extraordinary action by multiple levels of state (Agamben 1998). The public health emergency worked very quickly to mobilize a whole series of funding commitments. The BC provincial government promised $3 million to help address the HIV epidemic. The federal minister of health announced that his office would contribute $1 million. The City of Vancouver subsequently developed a revitalization and community development project for the Downtown Eastside. Then, in 2000, the Vancouver Agreement, which allocated $13.9 million for a range of interventions aimed at decreasing the co-epidemics, was announced.[6] These were impressive commitments, and some would draw accolades from international organizations such as the United Nations. Combined, they touched on every part of life, including employment, education, retraining, mental health, addiction, capacity building, HIV, food, housing, policing, and morality.

The emergency was reported in national and international news sources, such as the *New York Times,* and it focused attention on the human suffering (Munro 1997). In some ways, the attention was much needed, and it forced funding for many programs that residents still benefit from today. Yet, too often, the media reports were not factual representations of the epidemiological studies they reported on, and such research reports tended to focus on the worst of the community, eclipsing large parts of everyday life in the Downtown Eastside and contributing to negative representations. The focus on HIV, injection drug use, and deaths from drug overdoses framed the way in which the public saw the Downtown Eastside and its residents, and sometimes this trickled down into clinical encounters with doctors and nurses working in the area.

Historically, the community has been understood as a largely working-class, male space, and it has maintained a relatively marginal space in the city (Roe 2009; Sommers 2001). But, with the public health emergency, combined with epidemiological and media accounts focusing on illicit drugs and HIV risk, the community took on new meaning – as a space dominated by drug addiction and disease.[7] This meant renewed attention on all sorts of levels, including at the level of epidemiology. The media reported: "Vancouver's raging HIV epidemic most rampant in developed world" (Munroe 1997, A1). Even the agenda for the VRHB on October 16, 1997 read: "Vancouver has the highest known rate of HIV among the injection drug users in the Western world." The action plan from the VRHB that accompanied the public health emergency outlined new strategies for addressing early detection of HIV, easier access to clean syringes, making HIV reportable, and increased epidemiological surveillance (Jimenez 1997). In theory, the action plan addressed the larger social determinants of health and included a focus on the determinants of disease and illness such as housing, transportation, and nutrition, which would have benefited all Downtown Eastside residents. But, as the years followed, the focus for change remained almost solely on the behaviours and lifestyles of injection drug users.

VIDUS and the Provincial Coroner's Report

Chief Coroner Vince Cain's 1994 report to the attorney general was one of two reports that played an important role in the emergency. Vince Cain had been appointed to head a provincial task force to investigate an unusually high number of heroin overdoses resulting in death by the minister of health and the attorney general in 1993. The report was a result of eight months of consultation with key stakeholders and included quantitative and qualitative research, the latter what Cain called "anecdotal" (British Columbia 1994, vi). The report is over one hundred pages long, but Chapter 2, "The Epidemiology of Overdose Deaths in BC," which reported the statistics of community health, included the most powerful data (drawn from the British Columbia Coroners Service [BCCS]).[8] Cain concluded that the number of deaths resulting from drug overdose rose so dramatically that it might be considered "epidemic" (5). Deaths from overdoses continued to increase, peaking in 1998, according to the BCCS. Cain wrote that he hoped the findings of his report would be "received in the spirit it was conceived" and that it was meant to enhance 1) "community and government responses to the social, economic, and health care needs of people addicted to the use and abuse of illicit narcotic drugs" and 2) "the delivery of service programs affecting particularly, but not exclusively, the disaffected, children, youth, women, First Nations people, and mentally disabled people in British Columbia" (vii). The data that were extracted from the report and that made the news addressed a very small minority of the urban poor – injection drug users consuming heroin – but this minority was often taken to represent all of the local residents.

Three years later, Steffanie Strathdee and her VIDUS colleagues (1997) published what would become a seminal paper for the attention it focused on HIV incidence in the Downtown Eastside. VIDUS was a comprehensive epidemiological study, involving multidisciplinary collaborators that aimed to explore HIV incidence among injection drug users in the community. Operating out of a storefront office, it was a prospective cohort study of 1,500 injection drug users (1996–2005); in 2006, it became a prospective cohort of 1,000 HIV-negative injection drug users; and then it was newly funded in 2009 by the US National Institutes of Health. VIDUS collects data through self-reported surveys conducted by junior research assistants, graduate students, and staff nurses. Today, it operates with a sister study, ACCESS, which follows HIV-positive injection drug users. Participants provide blood samples and are interviewed about their drug use behaviours (including frequency, types of drugs, injection practices), health status, sexual practices (condom use, sex work, partners), demographics, and access to general health and social service programming (Strathdee et al. 1997). Blood samples are screened for HIV and Hepatitis C, and, if patients are positive, they are screened for cluster of differentiation 4 (CD4), plasma viral load, and resistance monitoring. Participants are also given an abbreviated depression survey and asked questions about their mental health status (including suicide ideation, histories of mental illness, and sexual abuse) (Strathdee et al. 1997). The VIDUS survey asks about drug use, sexual practices, and collected biological data, which is then linked to provincial administrative databases through the provincial medical services plan (universal health care) (Schechter 1997).

The VIDUS paper reported that a "rapid increase in HIV infection among IDU [injection drug use]" had been documented in Vancouver between 1994 and 1997, in spite of a well-developed needle-exchange program that, at the time, was considered to be the largest in North America (Strathdee et al. 1997, F60). The study results suggested that of the 1,008 injection drug users that were enrolled, almost 25 percent had HIV and 88 percent had Hepatitis C. During the first follow-up visit six months later, the researchers found twenty-four new seroconversions from the original 257 research participants who had been HIV negative at baseline, an incidence rate of 18.6 percent, which they concluded was higher than other drug-using populations in cities such as Baltimore, Montreal, and New York and represented a "serious outbreak of HIV infection among IDU in Vancouver" (F63).

Strathdee and colleagues Martin Schechter (lead investigator on the grant) and Michael O'Shaughnessy (centre director in 1997) received a lot of media attention for this paper, and they advocated for an urgent and immediate response to the epidemic (see, for instance, Munroe 1997; Walker 1997). Their research results were widely taken up in the media and influenced the VRHB to declare the public health emergency. Although Strathdee and her colleagues specified that the HIV rates they reported were specific to injection drug users, the statistics and numbers from their study came to define the whole community, particularly as they mutated through their circulation in the media and public discourses. One might add that, in some circumstances, their data came to define large segments of the Canadian population, outside of the local community. For instance, they published papers on HIV incidence differences between Indigenous and non-Indigenous injection drug users that were used as evidence to suggest (incorrectly) that, nationwide, Indigenous peoples were twice as likely as non-Indigenous people to become HIV positive (see, for instance, Craib et al. 2003). This discursive pattern bears resemblance to the biomedical and other knowledge practices that Randy Jackson describes in this volume as being central to the "pathologization of Indigenous peoples" and their lives. Similarly, Caroline Tait's (2008) work on fetal alcohol spectrum disorder (FASD) and Indigenous women has highlighted how Indigenous infants are often diagnosed with FASD without any medical evidence. The critical ethnographic approach here helps make visible the ways in which Indigenous peoples are disproportionately targeted by addiction policy in Canada, whether through discourses of biological susceptibility (Waldram 2004) or by "culturalizing" Indigenous subjects by assigning particular behavioural "risky" practices to all Indigenous peoples (Fassin 2004, 173).

Combined, the Cain report and the VIDUS research created a dominant and restrictive narrative about the Downtown Eastside. In many respects, such epidemiological reports represent a moral science for the ways in which they shape national discourses about those living with HIV (Hacking 1991). Many of the urban poor have become practised at recounting stories of trauma, violence, and risk for the consumption of state actors, whether these be nurses, doctors, and/or scientists.[9] Epidemiological studies about HIV transmission ask intimate questions about sexual habits and preferences, illegal economic activities involving drugs and sex, and the micro-practices of drug ingestion. The questions demand exhaustive and intimate details on illegal, underground activities, eclipsing other chronic health issues or questions about mental health, hunger, or malnutrition. Their answers, and complex lives, are translated into epidemiological categories and quantified for public circulation, reinforcing their status as "addicts" and, thus, that they are in need of monitoring and control.[10] By not asking about family, love, friendship, arthritis, cancer, or other chronic diseases, the quantitative surveys demand the subject to represent the self in the terms defined by the Centre for Excellence (as drug users or at risk of HIV). Reflecting larger discursive patterns in harm reduction and drug policy, the "IDU" emerges; not the injection drug user but, simply, an abbreviated "IDU," which materializes as a category of analysis and a new way of knowing and defining inner-city residents (Fraser et al. 2004). The epidemiological categories of analysis both include and exclude and are both political and scientific. In their exclusion, they limit what is known about the Downtown Eastside and its residents.

Media

These epidemiological discourses and research reports were taken up in the media, where they were sometimes misconstrued and misrepresented to the larger public. News sources picked up quickly on the statistics being reported by the VIDUS researchers and further contributed to alarmist accounts of death and dying in the inner city. The *Globe and Mail*'s cover story on May 4, 1996 reads: "In this 15-block area, a stroll from the city's five-star hotels, more than 500 people died of overdoses in the past 3 years. This year, public health officials will distribute more than 2 million free needles to try to prevent a crisis fuelled by the fusion of poverty and drugs" (Cernetig 1996). Journalists understood that while the epidemiological data were powerful signifiers, so too were descriptions of the sensational, such as the "frightening new dimension" of the city. Reporting on VIDUS in 1997, the *Vancouver Sun* ran a story on the front page that read: "Nearly half the 6,000 to 10,000 addicts in Downtown Eastside are infected, AIDS expert says" (Munro 1997). The *Times Colonist* reported: "Just across the water, Vancouver's drug ghetto has the highest rate of HIV transmission (18.6 percent) in the industrialized world" (Dickson 1997).

The research report details took on incongruous new meanings as the media took them up. The researchers compared the epidemiological reports from the Downtown Eastside with other inner-city communities and injection drug-using populations. The 1997 VIDUS paper suggested that the incidence rates were "much higher than that observed among prospective IDU studies in Baltimore, Montreal, Amsterdam and New York" (Strathdee et al. 1997, F63). Strathdee was quoted by the *Toronto Star* in October 1997, the month following the declaration of the public health emergency: "It's like Dundas and Sherbourne Sts. times 10 down here. *Our studies are showing this is the highest rate of HIV infection among drug users in the developed world*" (Walker 1997, A1; emphasis added). The *Toronto Star* reported that the community had "become the worst drug epidemic of any city in the developed world," not what the scientists had concluded (A1).

The way in which epidemiological "facts" are taken up and then move and mutate to popular media (and, later, to clinical practice) suggests a shift in discourse that is more about the social imaginaries of the Downtown Eastside than about the lived experience of its subjects or the research data. Consider, for example, a 1997 article by the national Canadian newspaper, the *Globe and Mail,* which reported that the VRHB had "mixed-up statistics" when they reported that 713 people had newly tested positive for HIV in Vancouver, rather than 713 province wide (Matas 1997, A4). The VRHB was left awkwardly to make sense publicly of their counting error. When questioned, the response from the VRHB's director of communications was simply to reaffirm what the original numbers suggested: "There's no question that there is an HIV and AIDS epidemic in the downtown east side [*sic*] and the board acted on that advice" (A4). The same news article continues on to discuss other incompatible data about HIV and the Downtown Eastside. Matas reported:

> Dr. McLean presented other statistics to the board that were at odds with numbers used during debate about the medical emergency. Dr. McLean said the Vancouver Injection Drug Use Study, which is the only current research study of Vancouver injection-drug users, found that the HIV incidence rate has fallen to 4 percent, from 18.6 percent in the first few months of 1996 ... The study ... may have overestimated the HIV incidence at the beginning of the study and underestimated the most recent numbers, he added. (A4)

Although the epidemiological quantifiable data being reported were inaccurate ("overestimated" and "underestimated") and were not as dramatic as originally reported, they took on new meanings and gained momentum as they began to circulate in the media.[11]

The process of concluding that the Downtown Eastside has the highest rate of HIV among injection drug users in the Western world and the process of representing this finding in the popular media are socially and politically mediated.[12] Strathdee declared to the media that her research suggested the community had a higher rate of HIV infection among injection drug users in the world, but what the media reported was that Vancouver had the highest rate of HIV infection in the Western world. To this day, news and researchers incorrectly report the Downtown Eastside as having the highest rate of HIV infection in the Western world (global North). The context of HIV infection in Canada is put into perspective by Alan Whiteside and Julia Smith (2009), who explain that 0.4 percent of Canadians are infected with HIV, compared to 26 percent of adults in Swaziland. In Canada, there are localized epidemics that are very context specific – such as that which has been noted for Vancouver's Downtown Eastside – further supporting how important it is to read data, including HIV rates and mortality rates, in the socio-political context in which they are collected and produced. The power of statistical evidence and scientific objectivity is that they are assumed to be immutable and not context specific (Latour 1987; Law and Mol 2001). Yet, without the context, the data and the numbers exclude important information about the health and wellness of the lives of the urban poor and, thus, render local residents as disobedient bodies (making bad choices or engaging in bad health behaviours).

But it was not only the inaccurate sensationalist stories that circulated. The original detail also became an oft-repeated fact from the scientific source itself – the Centre for Excellence – which worked to reify the Downtown Eastside as a space of drug use and HIV risk. For instance, it reported: "Vancouver's downtown eastside [*sic*] has one of the highest HIV rates among injection drug users in the developed world" (Miller et al. 2005, 108). And the

Centre for Excellence's website (now removed) announced in 2011: "The DTES [Downtown Eastside] has the lowest national life expectancy and the highest HIV prevalence in the Western world, reaching 27 percent among injection drug users."[13] There is a performative value in this particular narrative, which is perhaps evidenced in its life of almost two decades, which results from its productive function to demand additional surveillance and study. The data from VIDUS provide the state with a comprehensive system of surveillance and regulation because the evidence collected was part of a biopolitical assemblage that justified particular health care policies and practices in the community, as I will illustrate in the next section. Susan Shaw (2012) argues that post-welfare states such as the United States and Canada govern "populations" through numerically based forms of expertise. She notes that they rely increasingly on medical and epidemiological research conducted with urban poor groups such as Indigenous peoples, injection drug users, and sex workers, which constructs these groups as being in need of caring and control. In the context of the Downtown Eastside, epidemiological discourses reinforce negative representations of the community and residents as diseased, disordered, and dangerous, which were not at all how the local residents saw themselves.[14]

This presentation of the relationship between media and epidemiological discourse draws on a long tradition of critical social science in relation to HIV and representations, which was particularly popular in the 1980s. Emerging from a framework of cultural studies, a number of different investigations sought to demonstrate not simply how the media represents the social world but, indeed, also how the world is constructed and constituted in and through media discourse (Brantlinger 1990). Specifically with regard to HIV, scholars drew on this tradition to consider the fundamental role of meaning in the HIV/AIDS epidemic. Simon Watney (1987a, 1987b), for instance, showed how representations of HIV in the press consolidated an association of HIV/AIDS with gay men in the British context. Similarly, Paula Treichler (1987) explored the central role of language and media in her analysis of the AIDS crisis, demonstrating how biomedical science itself often constituted specific social and cultural world views. Taking up media reports of HIV affecting men more than women, Treichler showed how cultural assumptions about gender informed how scientific evidence was presented. In a similar vein, and more firmly located within the context of critical ethnography that informs this chapter, Paul Farmer (1992) explored how media representations associating Haitians with AIDS in the 1980s in the United States impacted the everyday lives of Haitian Americans, compromising their access to employment and housing. In all of these studies, there is a consideration of the relationship between the media and the social: how public discourse influences our understandings of disease, of whom is affected by specific diseases, and of how these understandings influence public policies as well as everyday interactions among people. More recent scholarship continues this tradition, as evidenced in a recent report on media, immigration, and race with regard to HIV criminalization in Canada, demonstrating how media coverage of HIV criminalization cases constitutes immigrants as dangerous outsiders to be considered as a threat to the nation (Mykhalovskiy et al. 2016).

Building on this tradition, this chapter considers how epidemiological knowledge and "facts" are presented and misrepresented, both within the realm of research itself as well as within the media. These framings of facts and evidence circumscribe what is known about the Downtown Eastside and simultaneously constitute what can be done at the level of social policy and clinical care. There is a parallel here to Mark Gaspar's research in this volume that examines the ways in which risk-factor epidemiology creates categories of risk in particular ways that limit what can be known about gay men and that is at odds with the experiences of the young gay men who Gaspar interviewed. The media reports of the Downtown Eastside, appealing to select forms of epidemiological data, shape our understandings of this neighbourhood and its inhabitants in particular ways. The following section of this chapter demonstrates how these framings of the community, and the epidemic, organize clinical care in particular ways.

Clinical Care

In this final section, I illustrate the awkward disconnect between how the Downtown Eastside was known in the media and in epidemiological research and the everyday lived experiences of Downtown Eastside residents, as evidenced in everyday clinical encounters. The VIDUS report and the media accounts tell a specific story about the Downtown Eastside resident, conjuring her or him as inherently a drug addict and, thus, not trustworthy. This framework influenced urban health clinic policies, medical practice, and therapeutic encounters (see also Woodward 1999). For instance, Florence, an Indigenous woman in her late fifties, told me that her doctor insisted that her liver disease must have been a result of alcoholism, even though she had never been a drinker. She said she felt like a "number" and that her providers "forgot she was a person." Skin cancer, cervical cancer, pain, and acute psychiatric conditions often went untreated, and were perhaps diagnosed too late, as health care professionals focused on addictions and HIV care. An infectious disease specialist who worked weekly in one of the AIDS clinics commented on how absurd it was that there were so many people living in the neighbourhood with serious mental health issues but no psychiatric care offered. Some patients commented that the clinics in the Downtown Eastside offered no care, only prescriptions for drugs that never really treated the underlying issues. The years following the public health emergency resulted in a proliferation of services for injection drug users, such as the injection site, on-site detox and transitional housing, and methadone maintenance therapy. However, there were scarce services for primary care and chronic diseases like those Florence and others needed.

These epidemiological discourses and subsequent media narratives were taken up in local clinics in different and uneven ways. At one urban clinic, the medical assistants photocopied all prescriptions after the appointment concluded as a way to keep track of patients' drug use patterns (and concerns about prescription drug misuse). Clinics posted signs on their doors that stated they did not prescribe narcotics. Some family practitioners refused to get licensed for methadone so they could avoid dealing with addicted patients who might seem suitable for methadone replacement therapy. During clinic observations, I observed patients asking for treatment for back pain, arthritic knees, giardia, nausea, anxiety, sleeplessness, and broken limbs from falling, violence, or accidents. Many health care professionals often interpreted complaints about pain inevitably as requests for narcotics and deemed this as "drug-seeking" behaviour. Clinicians often refused patients' requests for Tylenol 3, or "T3s," even though they can be purchased over the counter in British Columbia.[15] Some doctors demanded "medication contracts" with their patients to help manage long-term narcotic use. One doctor explained to me, after negotiating a contract with an Indigenous male patient in his sixties, that such contracts were "important to foster responsibility," a reflection of circulating discourses that constructed Downtown Eastside patients, especially those who were Indigenous, as childlike and irresponsible with their own health. Another nurse, talking about the patients at her clinic (particularly an Indigenous man in his thirties), said: "Their brains are forgetful." When I asked if she could explain what she meant, she said that it was because they were drug addicts and that the drugs damaged their brains.

Yet many patients at her clinic were not drug users (not to mention that her statement was a gross oversimplification of scientific theories about how certain drugs alter the structure and function of the brain). In other situations, I observed doctors trying to prescribe methadone to patients who, exasperated, tried to explain to their doctors that they were not drug users, or not opiate users, and therefore did not require methadone. In another case, I watched a doctor discuss a new HIV diagnosis with a patient. The patient, a working-class Indigenous man in his late twenties, was confused by the diagnosis and could not imagine how he had become infected. The doctor asked if he had been a drug user or if he had sex with men. The patient said "no" to both. In the ensuing discussion, the doctor continued to insist that the patient must have been an injection drug user, despite the patient's adamant denial. The drug-using trope that circulates in the media is so encompassing that the urban poor patients are often unable to escape it, despite their efforts to resist.

One particular clinical interaction stood out for me. A tall, Indigenous man in his late thirties whom I had interviewed asked me to attend a doctor's appointment that he had scheduled for the next week. Joe was a gentle, very soft-spoken, and reflective man. He needed to receive the results from a lung X-ray he had had the week prior. As we waited for the doctor, he told me how worried he was about getting lung cancer. His dad had died of lung cancer, and his older brother was recently diagnosed with it. He was visibly concerned. During the appointment with the doctor, people continued to interrupt, knocking on the door, cutting through the office. The doctor's mobile phone rang, and she talked on it, while also being on the other phone trying to get the X-ray results that had not yet been delivered to her office. At one point, she asked Joe what he was doing for the rest of the day, and, in response, he talked about having some friends come by his place. In response, she queried him if they were friends that "used"? He said "no," explaining that he also had his teenaged nieces staying with him. Seemingly ignoring his reply, she then told him that he needed to stop using cocaine. All the while, he sat there patiently, nervously, waiting for the results from his chest X-ray.

A couple of weeks later, I attended another appointment with him to see the same doctor. A few days before, a friend of Joe's had died a tragic death on the street, and many in the community were grieving.[16] As he sat waiting for the doctor to review the chart, he said to her: "Too bad about Frank, hey?" She responded: "Some people make bad choices." Joe did not say anything. It was a painful interaction to watch because I also knew Frank and the circumstances of his death could hardly be blamed on "bad choices" but, rather, on histories of colonialism, a residential school system, a lifetime of discrimination, and other forms of structural violence (Elliott 2015). She then asked about a support group that she had told Joe to attend to help him "stay clean"; he told her the group had lost funding and so was no longer functioning. Regardless of how Joe tried to shape his clinical encounter with this physician, focusing it on grief or cancer, she continued to see and treat him as a drug addict, seemingly unaware of the larger structural forces influencing Joe's well-being.

The delivery of antiretrovirals (ARVs) was also closely tied to the perception of patients in the Downtown Eastside as being drug addicted. Nurses and doctors both made individual evaluations regarding the suitability of a patient for HIV treatment based on a host of factors, including how acute their drug use history was, housing, and individual personality quirks. Clinical measures, such as low CD4s, which ideally should have been the main predictor of treatment, were often trumped by personal assessments. A nurse would regularly describe patients to me that were "too chaotic, too unstable" and, on occasion, "too nuts" to start the ARV regimen. In part, clinicians made this evaluation with a concern that poor adherence would lead to viral resistance, but, in fact, it was evident that these clinical evaluations of patients' lifestyles were largely based on an imaginary – not the everyday – reality of patients' lives, and I was able to witness this disconnect as an ethnographer. I observed doctors refusing to prescribe ARVs to patients who they believed were using illicit drugs too much or too frequently, even when patients pleaded to be started on anti-HIV medicines. Clinicians' historical experiences of working in the community also contributed to their construction of patients as being addicted, or drug-seeking, but the larger public discourse that emerged from the public health emergency and the media worked more generally to paint the community with one large brush stroke, framing community members as addicted and diseased. Epidemiological studies such as VIDUS are not the only force of power in clinical encounters, but, as their results move and mutate, they are decisive entities, with influence on clinical management and treatment decisions.

Conclusions

A non-critical ethnography of the public health emergency might simply applaud the efforts of the state and epidemiological surveillance for highlighting and documenting serious diseases and unusually high death rates in the Downtown Eastside, noting the ways in which new interventions, new funding commitments, and new health care policies were being rolled out in support of those living with addictions without consideration of the unintended consequences. But critical ethnography furthers our understanding by contextualizing and connecting such media misrepresentations and epidemiological knowing with historical practices that stigmatize, alienate, and blame the urban poor (Watney 1987b). The knowledge that emerges about the Downtown Eastside is a cluster of both formal epidemiological data (in itself problematic for its sole focus on disease and addiction) and informal misinterpretations, which combined, do not reflect the lived reality of Downtown Eastside residents. Yet such discourses shape how the public, policy makers, clinicians, and others throughout the world know the entire Downtown Eastside.

Critical ethnography can include attention, as in this chapter, to how meanings constitute our understandings of the world and our actions within it. The epidemiological knowledge produced about the Downtown Eastside and its misrepresentation in the media function to organize what we understand about Downtown Eastside residents. As demonstrated in the section on clinical care, these frameworks have implications beyond the world of ideas; they inform treatment and the delivery of services. The meanings about the Downtown Eastside that circulate foreclose clinical practice itself. This chapter demonstrates not simply the disjuncture between the clinical experiences of the Downtown Eastside residents and the knowledge produced by HIV/AIDS researchers, but it also shows how such experiences are informed by, and constituted through, epidemiological and media knowledge. This analysis complements particularly well some of the other contributions in this volume, notably Randy Jackson's reflections on how colonialist ways of seeing Indigenous people reduce the complexity of their experiences and needs. There is also a connection to the chapter by Chris Sanders, Jill Owczarzak, and Andrew Petroll in this volume, which considers the ways in which African American young gay men can be understood to be a population at high risk of acquiring HIV and, thus, a prime site for the rollout of pre-exposure prophylaxis antiretroviral medications. They raise important questions about the overdetermination of racialized groups in this process, such that public health interventions might be embedded in broader relations of surveillance between racial communities and the state. This chapter considers the question of Indigenous communities as a similar site of public health focus, considering how, despite such attention, the primary health care needs of members of the Downtown Eastside remain unaddressed.

Combined with other epidemiological evidence, including the Cain report on mortality, scientific data compelled the VRHB to call a public health emergency. This epidemiological knowledge has contributed to old and tired representations of a community that is intensely complex, rich in history, and so much more than the "poorest postal code" and a place of "the highest rate of HIV in the developed world." Yet, as critiques of risk-factor epidemiology have argued, knowing individual behaviours or risk factors has largely not influenced disease patterns, for such an approach does not account for the social or historical conditions that shape individual behaviours and risks. The negative representations of the community that have inadvertently emerged from these data, combined with a historical national narrative that has defined Indigenous peoples as "childlike" and non-citizens, are used to demand or justify more surveillance in the community, increased policing, an intensification of regulatory biomedical programming, coercive housing policies, and an assemblage of medico-administrative technologies and surveys that manage the urban poor (Million 2013; Warry 1998).

In other ways, these discourses are productive; they produce subjectivities, they garner resources, and community residents and activists take them up to advocate for more resources (such as a supervised injection site). What the data fail to represent are the ways in which HIV and addictions are exacerbated by colonial histories, current federal policies (such as the *Indian Act*), racism, economic inequalities, and the everyday experience of politically, economically, and socially marginalized lives in Canada. This is not to deny that the Downtown Eastside has been plagued by suffering, ill health, poverty, or disease. Rather, the question that arises is: what disservice have we done to the community by highlighting the drugs, the HIV, and the deaths, instead of the structural and symbolic violence that operates through the very institutional systems that aim to ameliorate them?

Notes

1 In September 2016, doctors in Saskatchewan requested that the province similarly declare a public health emergency in response to a localized HIV epidemic, but the province refused (Vogel 2016).

2 My own ethnographic focus on anti-HIV medicines and programs must be considered as part of this larger assemblage of research that focused on HIV at the expense of other key health or social issues in the community. However, my research sought to document how AIDS interventions were being used to regulate and govern Downtown Eastside residents in a manner that was eerily similar to twentieth-century colonial practices.

3 All names used here are pseudonyms to protect the identity of research participants.

4 *Indian Act*, RSC 1985, c. I-5.

5 Although there has been a demonstrated need to incorporate Indigenous (or culturally appropriate) healing practices in contemporary medical practice in the community, there is little recognition of the immense diversity of Indigenous peoples living in the community and the fact that many do not share healing traditions. Smudging, for instance, becomes a "pan-Indian" healing practice that all Indigenous peoples in the community are expected to engage in and respect.

6 Vancouver Agreement, http://www.vancouveragreement.ca/TheAgreement.htm.

7 The missing and murdered women and the criminal trial case of Robert Pickton, charged with the murder of forty-nine of the women, later brought more negative attention to the Downtown Eastside, specifically defining it as a criminal and dangerous space and later as an Indigenized space for

the focus on the Indigenous heritage of many of the missing and murdered women. For more on the missing women, media coverage, and Indigenous identity, see Culhane 2003; Gilchrist 2010; Pratt 2005.

8 The British Columbia Coroners Service is part of the provincial Ministry of Public Safety and Solicitor General.

9 On the "confessional" nature of HIV research, see Boellstorff 2009; Nguyen 2013.

10 For kindred critiques of epidemiological discourse, see Bibeau 1997; Lupton, McCarthy, and Chapman 1995; Petersen and Lupton 1996.

11 For more on HIV/AIDS in the media, see Lupton 1999; Watney 1987a, 1987b; Mykhalovskiy et al. 2016.

12 Ludwig Fleck ([1934] 1979, 23) examines the construction and history of scientific concepts – of how we come to know scientific facts. He argues that there is no "complete truth" or "complete error" in science and that facts are made collectively, often arising from "somewhat hazy," relatively unsubstantiated pre-ideas.

13 BC Centre for Excellence in HIV/AIDS, http://www.cfenet.ubc.ca/our-work/information-hiv-aids (accessed June 22, 2011).

14 In interviews with Downtown Eastside residents, I began by asking research participants to tell me about who they were. They responded with stories of nationhood, kin relations, and work. For instance, "I'm from Lillooet Nation, I used to fish, but I moved here when I was sixteen. I have five brothers, but only one is living." Or, "I'm from Prince Rupert and I love the Boston Bruins. I'm a huge hockey fan." Very rarely did participants describe themselves as addicts or defined by an illness or disease.

15 Tylenol 3 purchased with a prescription would be covered by the province or the federal government (depending on whether or not the patient was a status Indian or not), whereas over-the-counter purchases are not.

16 On the night of December 3, 2005, the temperature dipped below the freezing mark to −2.0 degrees Celsius. On Hastings Street, outside the recycling depot, paramedics responded to an emergency call just after 11:30 p.m. to attend to a man in a wheelchair. Newspaper reports suggest that the man, who may have had pneumonia, refused treatment from the paramedics, that he did not want to go to the hospital, and so they finished the call and left. The next morning, the paramedics received another call to the same block of Hastings Street to find the same man lying on the street, now deceased.

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Conclusion

Viviane Namaste and Eric Mykhalovskiy

This volume explores questions about the relationship between critical social science and knowledge about HIV/AIDS. We brought the collection together out of a concern about the closure of spaces for critical research on HIV/AIDS and its devaluing by the HIV/AIDS industry. We wanted to create a discursive home that showcases rigorous, critical social science research on HIV/AIDS by Canadian scholars, including the work of a generation of emerging researchers. In this book, we do not use the term "critical social science" to refer to a pre-given, delineated set of authorized "critical" approaches to social research. Instead, we have in mind various modes of social inquiry that call into question, and stand as alternatives to, the authoritative forms of knowledge through which HIV/AIDS is governed. These modes of inquiry challenge taken-for-granted assumptions about how best to respond to the HIV/AIDS epidemic and commit to struggling against social injustice, inequality, and human suffering. In this conclusion, we highlight some of the contributions of the anthology and offer reflections about the future of critical social research on HIV.

The two sections of this book, "Critical Dispositions" and "Empirical Case Studies," distinguish in general terms the chapters that treat a given tradition of inquiry and its relationship to critical work on HIV as an object of discussion ("Critical Dispositions") from the chapters that apply a given tradition of inquiry to a particular empirical site of research ("Empirical Case Studies"). Chapters included in the first section of the book offer extended narratives about the conceptual foundations, characteristic analytic strategies, and techniques of inquiry associated with various traditions of social science inquiry. Rather than simply invoking the *a priori* critical status of a given tradition of inquiry, authors reflect on what form critical inquiry takes within the disposition they write about and consider its possibilities and limitations for social science research on HIV. In doing so, they offer readers points of entry for developing a broader understanding of a range of social science approaches, how they formulate problem spaces, the contours of thought to which they commit practitioners, and the HIV-related topics of research for which they are best suited. The chapters included in the second section of the book contribute examples of the form that theoretically informed empirical research on HIV can take when it is unfettered by the managerial and applied logics of the HIV/AIDS industry. No edited collection can comprehensively address all areas of inquiry within its focus; ours is no exception. While the case studies in this book address a range of topics, they make a particular contribution to critical analyses of the limitations of established public health and biomedical approaches to HIV prevention.

As part of developing this anthology, we invited all of our contributors to push beyond the limits of negative critique and its penchant for pointing out problems and illuminating absences (Rebughini 2018). We challenged authors to balance the culture of negative critique with explicit normative claims-making and to commit to articulating a positive vision of alternative futures. Considered as a whole, this volume offers an example of a broad practice of critical social science that includes the burden of articulating better ways of responding to the challenges of the HIV/AIDS epidemic, beyond the impulse to negate. The chapters in this anthology pierce through the established power-knowledge relations of the mainstream HIV response. They raise fundamental questions about the nature and organization of various forms of authoritative knowledge and their use by policy makers, government officials, health providers, community workers, people living with HIV/AIDS, researchers, and others involved in responding to HIV/AIDS. The collection helps us to understand the exclusions and effects of the forms of knowledge too often privileged in public health worlds. It also invites us to contemplate the relationship between knowledge and action and how alternative ways of knowing HIV can help us differently intervene in the epidemic.

The theoretical models, methodological influences, and intellectual vocabularies employed by the authors in this book vary widely. Including chapters that cover a wide array of approaches to critical social science on HIV/AIDS makes at least two important contributions. First, it expands on the "usual suspects" that are typically brought to mind as exemplars of critical social science. This book encourages us to think about perspectives such as conversation analysis and actor-network theory that, in many intellectual circles, would not be considered to be particularly useful for progressive, socially engaged responses to HIV/AIDS. Second, it encourages ways of knowing that bring different approaches to critical social science into relationship with one another. How best to attend to the specificity of a tradition of inquiry while remaining mindful of principles of combination and dialogue across traditions promises to invigorate future critical social science on HIV/AIDS.

Future Possibilities

One way to speak about future possibilities for HIV/AIDS research is to identify new topics for social science inquiry and to suggest promising avenues of theoretical engagement. However, as Viviane Namaste notes in this volume and elsewhere (Namaste et al. 2012), the future of critical social science research on HIV/AIDS in Canada is less about the pursuit of novel substantive areas or the use of any given theoretical tradition and more about cultivating conditions that permit emerging scholars to continually question how we come to know about HIV/AIDS and reflect on how, and for whom, knowing HIV/AIDS differently matters.

In the introduction to this volume, we described the institutional relations of knowledge that imperil critical social science research on HIV/AIDS. The HIV/AIDS industry and its emphasis on biomedical and epidemiological knowledge for governing the epidemic, state funding relations that favour applied health science research on HIV/AIDS, and, more broadly, the corporatization of universities and the new accountability relations that define academic careers and shape the settings in which we work all make the practice of critical scholarship on HIV/AIDS difficult. Cultivating a critical disposition to HIV/AIDS among emerging scholars will require remaking the institutional and knowledge practices that have contributed to the discursive closure of critical social science HIV/AIDS research.

Most obviously, we need new funding relations to support future critical social science research on HIV/AIDS. In Canada, recent developments at the Social Sciences and Humanities Research Council that suggest a renewed openness to fund health research are a welcome change. But more needs to be done. We need to think boldly and creatively about alternatives to applied, multidisciplinary, large-scale, team-funded research that defines the funding landscape for HIV research in Canada and about the forms of knowledge that such grants encourage, such as the absolute favouring of high-impact journal articles and increasingly cookie-cutter approaches to knowledge translation initiatives that emphasize a narrow set of key stakeholders. Too often, critical social scientists are absorbed into team grants with a token status that promotes a service relationship between social scientists and health researchers and offers little institutional support for social scientists to pursue independent scholarly inquiry. We need to continue to emphasize the epistemological specificity of critical social science research on HIV/AIDS and its value for responding to the epidemic. We need to insist on conditions for the review of grants that respect this specificity and to encourage strategic funding that targets critical social science research on HIV/AIDS. Small research grant opportunities that do not have built-in expectations for multidisciplinary team research and that provide social scientists with time and funds to engage in intensive research and writing are among the funding arrangements that might help strengthen critical social science HIV/AIDS research in Canada.

A peculiar feature of the Canadian funding landscape for HIV/AIDS research is the emphasis placed on community-based research (CBR). Canadian scholars have noted that a strong association has been created between social science research and CBR to the extent that, in some settings, social science research and CBR are treated as equivalent. They have further argued that some social scientists have opted out of pursing HIV/AIDS research because of concerns that such research must conform to normative expectations about CBR, including favouring participatory action research over other modalities and the requirement for research to be directed by community-based advisory committees (Mykhalovskiy and Cain 2008).

We recognize the value of HIV-related CBR but are also aware of how the absorption of CBR into the Canadian funding apparatus can perversely narrow the space for pursuing critical social science research on HIV. Again, there is a need for critical social scientists to argue for the specificity of social science scholarship on HIV. While we steadfastly support the role and voice of community members in the HIV/AIDS response, we identify a need to encourage perspectives that may not be known, or commonly articulated, within community-based responses to the epidemic. We can imagine critical work on HIV/AIDS enacting (at least) a double move: 1) uncovering forms of knowledge integral to community members as necessary conditions for thinking about how to respond to HIV/AIDS and 2) reflecting on what some of the blind spots of community organizations might be in their response to the epidemic, how those responses might be embedded in broader relations of inequality, and how they might be reoriented. Canada has a rich history of community responses to HIV/AIDS. As critical social science on HIV/AIDS evolves, further reflection on the knowledges and potential limits of community responses to the epidemic is warranted.

As we contemplate the future of critical social science on HIV/AIDS, we underline the need to develop, experiment with, and implement new models for networking and fostering dialogue among critical social scientists. The recent revitalization of the Association for Social Sciences and Humanities in HIV and the decision of the Governing Council of the International AIDS Society to establish an independent social and behavioural science track at the International AIDS Conference are important developments at the international level. But we need to further explore the potential of smaller-scale gatherings, workshops, and dialogue sessions for cultivating new ways of knowing HIV/AIDS. In the introduction to this volume, we noted the importance that such gatherings have played in promoting critical social scholarship on HIV/AIDS in Canada. Following this tradition, the process of developing this anthology did not engage established knowledge relations that organize mainstream research on HIV/AIDS. We did not proceed by securing a Canadian Institutes of Health Research grant but, instead, relied on smaller sources of funding. We did not produce a multidisciplinary team of participants or require our initiative to be vetted by community partners.

Instead, we extended an invitation to emerging and established social scientists who were within our extended networks and invited them to meet together on two occasions. On the first occasion, we explored some general ideas and themes related to the practice of critical social science, and, on the second occasion, we developed and strengthened chapters emerging from the previous conversation. It was a slow, careful process that disrupted the conventional pace of the emerging scholarly marketplace and metrics of scholarly productivity. We asked contributors to take their time, to welcome revisions to their work, and to push the boundaries of their own thinking. The "output" for authors was not a quickly produced, peer-reviewed article with a high-impact factor but, rather, a book chapter. The collaborative nature of the writing process, and the extended narrative form of the written chapters, has resulted in something very different from mainstream applied HIV research. Critical social scientists, particularly those with established access to resources, would do well to invest in developing models of scholarly collaboration, dialogue, teaching, and mentorship that cultivate the theoretically reflexive and engaged ways of knowing that are the hallmarks of critical social science research on HIV.

If the problems associated with mainstream public health knowledge have been elucidated in this volume, there is perhaps further reflection needed on how to encourage dialogue between critical social scientists and more mainstream public health scholars and practitioners. If we are to avoid a stance of negative critique, in which we simply point out problems, we will need to develop a more robust discussion about how social scientists working in a critical tradition can meaningfully engage with those who work with more mainstream public health approaches. How can we work with epidemiologists and public health officials without absorbing mainstream epidemiological conceptualizations of race, class, gender, sexual orientation, and other social relations as individualized demographic variables (Shim 2010)? How can we work with public health and medical practitioners to recognize the importance of biomedical HIV prevention, while also acting on the fundamental social, economic, and political determinants of the epidemic? Developing practical strategies for working through the epistemological and political tensions that arise at the interface of critical social science and conventional public health reasoning and practice will help contribute to a robust practice of critical social science research on HIV/AIDS (Mykhalovskiy et al., forthcoming).

There is a long tradition of critical social science research on HIV/AIDS in Canada and beyond. We hope that this book contributes to a renewed commitment to the project of a critical social science on HIV/AIDS, helping us to understand, and to act with, meaning and impact. We hope that it inspires both established and emerging scholars, researchers, and community workers to take up the challenge of producing knowledge as a necessary contribution to responding to the complexity of HIV/AIDS.

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