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# Cultural Conundrums: The Ethics of Epidemiology and the **Problems of Population in Implementing Pre-Exposure Prophylaxis**

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### Abstract

The impending implementation of pre-exposure prophylaxis (PrEP) has prompted complicated bioethical and public health ethics concerns regarding the moral distribution of antiretroviral medications (ARVs) to ostensibly healthy populations as a form of HIV prevention when millions of HIV-positive people still lack access to ARVs globally. This manuscript argues that these questions are, in part, concerns over the ethics of epidemiological science and knowledge production practices. Questions of distribution, and their attendant cost-benefit calculations, will rely on a number of presupposed, and therefore, normatively cultural assumptions within the science of epidemiology specifically regarding the ability of epidemiological surveillance to produce accurate maps of HIV throughout national populations. Specifically, ethical questions around PrEP will focus on who should receive ARVs given the fact that global demand will far exceed supply. Given that sexual transmission is one of the main modes of HIV transmission, these questions of "who" are inextricably linked to knowledge about sex, gender and sexuality. As a result, the ethics of epidemiology, and how the epidemiology of HIV in particular conceives, classifies and constructs sexual populations will become a critical point of reflection and contestation for bioethicists, health activists, physicians, nurses, and researchers in the medical humanities and biomedicine. This paper examines how cultural conundrums within the fields of bio- and public health ethics are directly implicated within the ethics of PrEP, by analyzing the problems of population inaugurated by the construction of the men who have sex with men (MSM) epidemiological category in the specific national context of South Africa.

#### **Keywords**

| Bioethics; Culture; Ethnography; | HIV; MSM; Public | Health Ethics; Pre- | -Exposure Prophylaxis |
|----------------------------------|------------------|---------------------|-----------------------|
| Social Epidemiology; South Afric | ca               |                     |                       |

# INTRODUCTION: EPIDEMIOLOGICAL KNOWLEDGE PRODUCTION AS AN ETHICAL CONCERN

Years before randomized clinical trials were completed that proposed to evaluate the efficacy of using pre-exposure prophylaxis for preventing HIV infection, commonly referred to as PrEP, social science research highlighted the strategy's complexity. One study described this particular approach as, "a problematic intervention," predicting that straightforward acceptance of the prevention strategy would be, "compromised by the anticipation that it is unlikely to be a neat biomedical advance."<sup>2</sup> Evincing such an assessment, in the mid-2000's early PrEP trials faced political challenges from activists in Cameroon and Cambodia, in collaboration with Paris ACT UP, who questioned the design and administration of these trials citing ethical and quality of care concerns.<sup>3</sup> Shortly thereafter, one arm of a multinational Tenofovir trial run by Family Health International, located in Nigeria, was stopped early due to, "logistical difficulties that illustrate the challenge of conducting research in resource poor settings." While it remains unclear whether the political challenges to the Cambodia and Cameroon trials decisively contributed to their early discontinuation, one study describes these actions as "catalysts." Another stated that, "anecdotal reports suggest that the decision to stop the trial may have been to do with the complex political arrangements involved in the governance of Cambodia as well as the confusion surrounding the running of the trial."6

A few years later, some trials were stopped early for biomedical reasons, reporting equivocal results. Still other trials reported evidence indicating that PrEP is a viable strategy for reducing the incidence of HIV in a number of populations globally. 8 Following a scientific and regulatory inquiry and assessment of all available clinical trial evidence evaluating the efficacy of PrEP, in July 2012, the United States Food and Drug Administration approved the antiretroviral (ARV) drug Truvada for use to reduce the risk of HIV in uninfected individuals who are at high risk for contracting the disease and who may engage in sexual activity with HIV-infected partners. 9 The FDA's approval has been handed down despite the wide divergence in reported efficacy of PrEP across clinical trial contexts globally conducted among various localized populations. Such divergence within the intervention is attributed by PrEP researchers themselves to various factors. 10 Rosengarten and Michael offer an intricate "textual analysis" of these two published biomedical analyses of PrEP, which include a large number of PrEP researchers as authors. Their analysis demonstrates that PrEP researchers attribute divergence and multiplicity of the PrEP intervention object to biomedical and anatomical differences in populations, mode of HIV transmission (i.e., vaginal vs. anal intercourse, injecting drug use), as well as the critical importance of sociobehavioral factors, including adherence to the once daily dosing regimen in particular. <sup>11</sup> In other words, these studies a priori presume the unity of this biomedical intervention called PrEP, thereby attributing divergence in the efficacy and effectiveness of this putatively singular object to the populations under study and their sociocultural, biological and economic contexts. Contrary to this biomedical rendering of PrEP as a singular intervention object, this analysis follows Rosengarten and Michael's more nuanced and pragmatic argument that, "underlying the apparent 'complicated simplicities' of a seemingly singular PrEP are the 'contingent complexities', out of which emerge many shifting PrEPs."12

Drawing on the work of philosopher and ethnographer of medical ontology Annmarie Mol, <sup>13</sup> and by examining the vast range of work by epidemiologists and other biomedical and public health scientists in the emerging field of PrEP research, they demonstrate that these researchers reference and implicitly describe, "the immense complexity of PrEP .... Yet there remains in these [researchers'] accounts the underlying presumption of a stable self-identical object imbued with essential capacities that stand apart from its making."14 The political and ethical ramifications of rendering PrEP as ideologically singular, as opposed to pragmatically multiple, are not insignificant. The difference between the two approximates the difference between the pharmacoepidemiological concepts of efficacy and effectiveness. 15 The former being a measure of whether a drug brings about its intended effect under ideal circumstances in a controlled, experimental environment, such as a clinical trial; the later being a measure of whether a drug brings about its intended effect in real-world clinical settings. The various sociocultural realities that condition the possibilities of these multiple PrEPs each have their respective, possible realities for intervention; each have parituclar sociocultural and political contexts that should have some bearing on the ethical implementation of this complex intervention. Importantly, Rosengarten and Michael argue that the constrained bioethical framing of PrEP – typically conceived as limited to two sets of actors: namely PrEP researchers and research subjects - denies the complexity and multiplicity of PrEP in its potential local enactments as an intervention strategy. As such, this sort of narrow bioethical consideration occludes wider sets of actors and additional processes that would necessarily need to be assessed ethically within a public health ethics framework. These would include entire populations of people who are "at-risk" for HIV, how, and according to what norms, these populations were conceived and constructed, and their attendant political, economic and sociocultural contexts, all of which must have some bearing on bioethical and, in particular, public health ethics considerations.

Given the complexity and costliness of this intervention strategy, it is not surprising that the impending implementation of PrEP has prompted complicated ethical quandaries and challenges. <sup>16</sup> In particular, these questions have focused on the ethics of distributing ARVs to ostensibly healthy populations as a form of HIV prevention when millions of HIVpositive people still lack access to ARVs globally. Questions of distribution, and the costbenefit calculations that will ensue, will rely heavily on a number of presupposed, and, as a result, unmarked and under-analyzed normative issues within the science of epidemiology, global practices of epidemiological surveillance, and knowledge about how HIV and AIDS are distributed throughout national populations and sub-populations. In other words, these ethical questions will focus on who will and should receive ARVs given the fact that global demand will far exceed supply. Given that sexual transmission is one of the main modes of HIV infection, these questions of "who" are inextricably linked to knowledge about sex, gender, sexuality, sexual populations and HIV epidemiology. As a result, the ethics of epidemiology – and how the epidemiology of HIV, in particular – conceives, classifies and constructs sexual, or "at-risk," populations will, and in innumerable contexts already has, become a critical point of reflection and contestation for groups affected by HIV and AIDS, bioethicists, health activists, physicians, nurses, and researchers in the medical humanities and biomedicine.

## EPIDEMIOLOGY'S DISUNITY AND EXPANDING ITS ETHICAL FRAME

Structuring explicit questions about the moral distribution and ethics of PrEP are broader, implicit anxieties over the adequacy of narrowly defined bioethical and public health ethics frameworks, and therefore epidemiological modeling and knowledge production practices, to account for the sociocultural, political and economic processes that epidemiologic knowledge, and epidemics themselves, are conditioned by. Notwithstanding, and towards the goal of widening the purview of epidemiology from its blinkered focus on biomedical causality, over the last decades of the twentieth century, the sub-field of social epidemiology has attempted to offer a corrective of the field's normative myopia. 17 These shifts in epidemiology's focus gesture towards something like expanding the ethics of epidemiology through innovative research to elucidate, "the causes of causes," 18 or "the fundamental causes," of disease 19 alternatively referred to as the "social determinants" of health. 20 For instance, some social epidemiologists working in East Asia have argued that cultural, "differences in social inequalities in health will not be captured if we favor Occidental constructs of psychosocial factors, well-being, and social position when such constructs are subject to major cultural and philosophical influences."21 Aside from the problematic "factorization of the concept of culture" that these epidemiologists implicitly enact, <sup>22</sup> it is right of them to point out that the constructs that social epidemiologists, as well as other epidemiologists, use are culturally determined. I will demonstrate why such bracketing of culture becomes an ethically thorny issue regarding the implementation of PrEP and the epidemiology of HIV below, by specifically examining how the men who have sex with men (MSM) epidemiologic category has been enacted in South Africa.

The emergence of social epidemiology, and its concern with how the social sciences can contribute evidence and knowledge deemed valid and admissible within epidemiology, reflects the actual disunity of epidemiology as a field of inquiry. Acknowledging the existence of disunity in the sciences is critical when contemplating how to reorient the ethical frames of epidemiology, public health and biomedicine. Analyzing the historical and contemporary context of disunity across the sciences, the philosopher and historian of science, Peter Galison argues that, "there are disunities to be found between the practice of science in different locales and by different groups of practitioners. Comparative studies ... reveal a locality to scientific knowledge that makes programmatic assertions of 'unity' ever harder to sustain."23 Following Galison's injunction against claims to disciplinary unity, as well anthropological analyses of epidemiology's disunity, <sup>24</sup> the arguments presented here demonstrate the ethical imperatives to first allowing for, and then developing, specificity to epidemiologic knowledge in various national contexts. The aim of nurturing the conditions for this specificity is to develop knowledge production, circulation and application practices that are able to withstand ethical scrutiny in contexts where various categories of epidemiologic research and surveillance are subject to significant sociocultural difference. Relatedly, the arguments developed in this paper follow recent ethical analysis that has argued persuasively for the necessity of ethical review for both public health surveillance as well as research.<sup>25</sup> To be sure, there are unifying aspects to the practice of epidemiology globally. However, the goal of this analysis is to demonstrate the vital importance for allowing a philosophical disunity when conceiving of and representing epidemiology as a

field of inquiry, and the actual multiplicity of its contemporary scientific practices. Acknowledging disunity can both, reorient bioethical concern towards the multiplicity of PrEP as an intervention strategy, and ensure the conditions for locally relevant epidemiologic and public health practices when making knowledge about HIV and AIDS epidemics in various culturally and historically particular contexts.

To contextualize the following arguments for expanding the ethical frame of epidemiology, it is, first, necessary to examine how issues of "culture" are taken up in current bioethical and public health ethics analyses. I will also briefly discuss interventions anthropologists have made with regard to bioethics as well as public health ethics. The present analysis concerns itself primarily with the knowledge production practices of epidemiology. Such a focus places this analysis squarely within the field of public health ethics, given that epidemiology has historically, "developed as the science of public health." Within the emerging field of public health ethics, there has traditionally been an explicit bracketing of cultural matters when developing ethical frameworks.<sup>27</sup> Analyses of interdisciplinary exchanges between anthropology and epidemiology have focused on the more. 28 or less, 29 fraught epistemological and conceptual relationships between these two disciplines than on how to adequately and formally address cultural processes within public health ethics frameworks. However, Veena Das' analysis of the problematic representational practices and distributions of accountability for the success of global immunization programs in India stands as a rare example of anthropology directly addressing concerns in public health ethics.<sup>30</sup> When culture is not overtly excluded from these frameworks, the culture concept and anthropological theory remain largely unexamined in available public health ethics frameworks and analyses. When it is mentioned, "culture" is typically and problematically identified as a "barrier" that public health interventions must address 'out there,' in various lay publics, and not 'within' the cultures of public health, epidemiology and/or biomedicine.<sup>31</sup> Nancy Kass has implicitly acknowledged the significance of cultural processes to public health ethics by remarking that we live in "morally pluralistic" societies, implying that these frameworks must somehow address such plurality, but she does not outline how this might occur. 32 However, most, if not all, existing public heath ethics frameworks stop short of explicitly incorporating a theory of culture, exposing a glaring theoretical blind spot regarding how cultural processes should be integrated and accounted for within these frames. <sup>33</sup> For example, recent analyses have argued for justice, or distributive justice with regard to health resources, as a central ethical principle in public health ethics.<sup>34</sup> All of these analyses implicitly presuppose the adequacy of epidemiologic models and knowledge production practices in order to accurately represent the shape and dynamics of various epidemics as a precondition for attaining distributive justice as an ethical principle. In the next section I will demonstrate how such practices are thoroughly cultural by ethnographically exploring the construction of the men who have sex with men (MSM) epidemiologic category in the context of the South African HIV epidemic. Therefore, public health ethics frameworks that do not explicitly address cultural matters should be interpreted as incomplete, particularly in contexts where sociocultural forces significantly affect critical concepts, constructs and practices of epidemiology as well as key public health ethics principles, such as justice.

As a "public health" intervention, PrEP represents what João Biehl has analyzed as the "pharmaceuticalization of public health." 35 As such, any ethical analysis of PrEP must straddle both the fields of bioethics and public health ethics. Reviewing the anthropological contributions to bioethics, Adriana Petryna has noted that, "anthropological work on the ethics of biotechnology and new medical technologies has shifted attention away from issues of individual autonomy and has deepened the analysis of new biomedical technologies as they affect new patterns of civic, medical, and commercial organization."36 She and other anthropologists have argued that considerations of the ethics of biotechnologies, such as (PrEP), should be widened beyond narrow concerns of individual autonomy, <sup>37</sup> and a myopic focus on informed consent procedures in medical research. <sup>38</sup> Due to PrEPs somewhat novel pharmaco-ethical position spanning the intellectual terrain of both bioethics and public health ethics, this analysis aims to extend anthropological concerns with regard to bioethics to public health ethics by subjecting the cultural practices of epidemiology to ethical scrutiny as the science continues to emerge differentially across and within various national contexts. Therefore, this approach necessitates a more broadly conceived ethical framework that considers how to constitute an adequate understanding of how local cultural knowledge and experience regarding sex, gender and sexuality should condition the production of knowledge about HIV epidemics and the ethical implementation of complex, biomedicalized public health interventions like PrEP.

Given the current limitations of public health ethics paradigms to adequately address cultural concerns, I draw upon Foucauldian moral theory in order to suggest a philosophical orientation for these paradigms to begin to account for cultural matters. It must be noted that this approach should precisely *not* be interpreted as an exercise in making epidemiology "culturally competent." While the concept of cultural competency has largely become a metonym for cultural stereotyping for which anthropologists have felt the need to offer correctives in both medical practice and education, <sup>39</sup> the ethical analysis offered here is a critique of these discourses. Rather, it is a step towards acknowledging and accounting for the reality of cultural difference and processes among the rapidly evolving practices, discourses, subjectivities and spaces of global health. 40 In Foucault's notion of ethics, he conceived of acts, or practices, as distinct from, but inherently related to, a moral code of conduct: "we have to distinguish ... acts and moral code. The acts [conduites] are the real behavior of people in relation to the moral code [prescriptions] imposed on them. ... And there is another side to the moral prescriptions ...: the kind of relationship you ought to have with yourself ... which I call ethics, and which determines how the individual is supposed to constitute himself as a moral subject of his own actions."41 Foucault intended his ethics to correspond generally to individuals in society (i.e., the good citizen), not necessarily to a specific group of individuals, such as epidemiologists (i.e, the good scientist). He also felt that it was, "not at all necessary to relate ethical problems to scientific knowledge," and that given the vast, "cultural inventions of mankind there is a treasury of devices, techniques, ideas, procedures, and so on, that cannot be exactly reactivated but at least constitute, or help to constitute, a certain point of view which can be very useful as a tool for analyzing what's going on now – and to change it."<sup>42</sup> On this point, I am in full agreement. I am not arguing that we relate questions concerning the ethics of PrEP to scientific knowledge and cultural framings per se. Rather, I am arguing just the opposite: for the conduct of epidemiological

surveillance and research to remain ethical in contexts of vast material and social inequalities – which may also index significant cultural difference – it may have to relate itself towards forms of non-scientific cultural experience and knowledge, but nonetheless have significance with regard to the implementation of PrEP. In other words, PrEP researchers must relate themselves not to theoretical, scientific constructs in their closely related disciplines – such as biomedicine or psychology/psychiatry – but rather to other forms of cultural knowledge about concepts, such as gender and sexuality, that have an important bearing on the transmission of disease or distributions of biomedical risk within various populations.

In this way, I argue that it is helpful to widen Foucault's as well as epidemiology's ethical frame of reference. For example, the moral code to which epidemiologists refer would be their theoretical constructs, or set of rules or conventions, for carrying out their work. Such work practices would include constructing risk groups, determining and distributing cases of disease, and calculating distributions of biomedical risk. It is this first practice of epidemiology that is most significant for my analysis and conditions the possibilities of the other practices when mapping HIV epidemics within populations. Typically in epidemiology, given its relative epistemological proximity to biomedicine, psychiatry, and psychology, these theoretical constructs correspond to anatomical, biomedical, biological or behavioral concepts and constructs, such as insulin levels, blood pressure, or sex; here sex can be conceived as both the act/behavior of sex and the concept of anatomo-biological sex. It is also important to note that despite the fact that for "decades now, experts in multiple fields, including medicine, psychology, the social sciences, and the humanities, have distinguished between 'sex' ... and 'gender,'"43 within epidemiology, at times, there is a tendency to use the term, or think, "gender" when what is actually being referred to is the concept of "sex." In the case of the MSM category, for instance, the concept of sex is unconsciously foregrounded, thus effacing or de-emphasizing the gendered relations that exist in many homosexual relations. The significance of this process for my arguments will become evident in the next section.<sup>44</sup> Suffice it to say, this sort of elision makes little difference within populations where sex maps neatly onto gender, such as in many gendercis or homo- and heteronormative groups globally. However, within populations where sex and *perceived* gender or gender identity are disjunct, or the link between the two is complex, or not abiding - such as transgender populations or other types of gender variant populations globally – this type of categorical mistake can significantly affect knowledge of how a disease like HIV is distributed amongst various national populations. Basing the construction of risk groups on anatomobiological sex instead of gender can dramatically change the morphology of risk groups, and therefore, social cartographies of disease. Likewise, not adjusting for socially significant variables, such as gender variance (from sex), in epidemiological models can severely distort distributions of risk for a particular disease agent, such as HIV, that is widely accepted to be affected by such social determinants of health. The effacement or elision of the differences between sex and gender could significantly change how the "causes of causes" are conceived and constituted in a specific population and also how a disease agent is mapped throughout a population. What is at stake here is the integrity and robustness of epidemiological knowledge in what could roughly be described as non-normative sexual cultures.

In the case of the epidemiology of HIV, constituting risk groups typically follows a behavioral paradigm, and almost always references a culturally specific, biomedical understanding of sex, gender and sexuality that privileges anatomical sex in the description of behavioral risk categories. For instance, the risk group, men who have sex with men (MSM), was designed to reference the same-sex aspects of a sexual relation, regardless of whether those in the relation identified themselves as "gay" or "homosexual." This method of grouping typically ignores the possibility that the genders and/or gendered sex roles, of the same-sex sexual partners may be qualitatively different. The use of the "MSM" category is typically used to ostensibly de-contextualize sexual behavior, putatively separating the behavior from its sociocultural context, with the aim of avoiding the sticky issue of social identity. Rather than de-contextualizing, it is clear that the category actually re-contextualizes gendered bodies within a biomedical "culture of no culture," framing of the body, <sup>46</sup> whereby the body's sociocultural aspects are de-emphasized or effaced in lieu of referencing the ostensible "timeless truth" of anatomical and/or biological sex to describe the sexual behavior in question.<sup>47</sup> In many sociocultural contexts the vast range of gendered aspects of homosexual relations are consequential aspects of social and sexual life and are significant markers of social difference. <sup>48</sup> In some cultural contexts the gendered aspects of homosexual pairings could be epidemiologically significant. This appears to be the case among black, South African men categorized using the MSM risk group and will be discussed as a case study in detail below. However, the current epidemiology of HIV among MSM in South Africa, in its present ethical orientation – meaning the relation of epidemiologists creating risk groups (acts) to a biomedical sphere of knowledge that privileges anatomical sex (moral code) – does not create risk groups based on cultural constructs like "gender variance" or "gender identity." One reason for this may be that the current epidemiology of MSM in South Africa does not typically sample according to race, even though the cross-race differences in sexual culture among groups of MSM in South Africa are known to be significant and mediated by other factors such as gendered sex roles and class, particularly among black MSM groups in South Africa.<sup>50</sup> The result is epidemiologic knowledge that reifies the significance of sex in same-sex relations, while simultaneously occluding the gender variant social realities of these sexual pairings, particularly among black MSM. Such occlusions thus efface the possible epidemiological significance of these sociocultural constructs. Why is this important? For instance, the epidemiology of HIV among black MSM could orient itself ethically in another direction, with reference to another sphere of knowledge about sex, gender and sexuality, one that acknowledges the significance of gender variance among these groups. It could do so by creating risk groups and epidemiologic knowledge and variables that reference constructs of gender or gender variance rather than sex, and then determine which of these constructs is most adequate for understanding the dynamics of biomedical risk for HIV among these groups. While the concept of gender as a sociocultural construct is elaborated primarily within a sociocultural or ethnographic epistemic space, the concept of sex is typically understood to be produced primarily within a scientific or biomedical sphere of knowledge. However, feminist philosophy and historical analyses have demonstrated these spheres to be thoroughly cultural spaces of knowing about sex.<sup>51</sup> Exploring the epidemiological significance of gender among black MSM could be one method of expanding bioethical and public health ethics frameworks to apprehend the myriad of social, cultural, political and

economic contexts that biomedical and epidemiological science exists within *and is inevitably shaped by*. I will demonstrate this process in detail below by taking the enactment of the MSM category in the South African context as a case study that illustrates this broader normative concern with the ethics of epidemiology and how it relates specifically to the ethics of PrEP.

# EPIDEMIOLOGICAL FOREKNOWLEDGE AND MAKING UP MSM IN SOUTH AFRICA

The previous section considered expanding bioethical and public health ethics considerations to include how knowledge about health, bodies, and populations are produced through epidemiological science. In order to demonstrate how this broad theoretical discussion takes shape in a concrete context, I will turn my attention to a case study, examining how the MSM epidemiologic category has been constructed and used to make knowledge about the HIV epidemic in South Africa. Exploring how the MSM category is enacted in a specific sociocultural context will illuminate various aspects of the theoretical discussion presented above. After exploring this case study, I will link issues regarding the making of the MSM category to concerns about the ethical implications of the implementation of PrEP

Following Manjari Mahajan, who has analyzed the globalization of HIV risk categories within India's national epidemiological scientific establishment, I read the enactment of the MSM category in the South African context as referencing a "foreknowledge" of HIV epidemics as they have taken shape in other countries. Mahajan develops her notion of foreknowledge by demonstrating that, "the [epidemiologic] models and their encoded foreknowledge invite substitution of data and travel of categories from other societies," adding that, "the presumptions built into epidemiological models obviate the unique features of a society that are relevant to counting but that nonetheless get summarily erased." Like Mahajan, I do not intend to argue against the use of epidemiological modeling, given its usefulness in creating an understanding of the shape and scope of epidemics in various national contexts. However, it is my aim to reorient these scientific practices and subject them to a culturally-informed ethics framework in order to develop better, and more adequate, models, which necessarily, "involve complementing mathematical models with different types of sociological and cultural knowledge." 53

In the case of the MSM category's enactment in South Africa, the type of foreknowledge that Mahajan describes has been mobilized, whereby the MSM category serves as a template for epidemiological evidence making to legitimate new treatment and intervention subject populations of "at-risk" men who have sex with men (MSM). These "men," while ostensibly healthy, are now being figured as in need of or "indicated for" prophylactic treatment with ARVs, evinced by the production of interim guidelines for the administration of PrEP among "high risk" individuals within all groups of MSM in South Africa.<sup>54</sup> In this instance, the interim guidelines reference a number of studies of HIV prevalence among MSM in South Africa and other southern African countries. The studies that are focused on South Africa report a widely varying range of HIV prevalence estimates (ranging from 10% - 50%) for various multi-racial groupings of MSM in various urban and township contexts

throughout South Africa<sup>55</sup> While Baral et al. astutely mention that it is problematic to compare prevalence estimates across various population sampling designs,<sup>56</sup> the variation in prevalence rates calls into question the reliability of the MSM category as a continuous, selfsame and coherent epidemiological object in this context. This is likely due to the fact that within the general MSM category that these researchers constructed, socially and culturally divergent groups, according to race, class and gender variance are collapsed into the same risk group. Despite such heterogeneity, in most of the recent South African HIV prevalence studies, it seems there is some general consistency across studies: black MSM seem to be at highest risk across studies, and those individuals who self-identified as gay had significantly higher HIV prevalence rates and were more likely to be HIV-positive than non-gay-identified individuals.<sup>57</sup> Looking across these studies, gay identity emerges empirically as a significant variable to the distribution of HIV among various, heterogeneous, multi-racial groups of MSM.

Despite the lack of data pointing to the coherence of the MSM category as a useful HIV risk category in the South African context, the national PrEP guidelines paradoxically continue to reference such a category. Referencing Mahajan's concept of foreknowledge, the use of the category can be better understood. In the absence of empirical data on the ground, these epidemiological models and practices continue to reference the undifferentiated MSM category, despite its incoherence and despite the empirical consistency of black MSM and gay-identified men having relatively high HIV prevalence compared to non-gay-identified men. In this case, we can identify a unique feature of South African society that becomes occluded using Mahajan's concept of foreknowledge, animated here through the enactment of the MSM category. What the undifferentiated MSM category occludes is the possibility that something about being gay in these samples of MSM, rather than their anatomical sex, is seemingly epidemiologically significant with regard to HIV and may be a more adequate construct with which to understand the embodied experience of HIV risk and vulnerability in this specific context. The MSM category was historically developed in order to understand situations and contexts of increased HIV risk among men who may not identify as gay. Following this, emphasis was placed on sexual behavior between two anatomically sexed men despite their social (gay, straight, bisexual, etc.) and/or gender variant identities. However, in the South African context, it seems that gay identity has in some way structured HIV risk in ways that men who have sex with men, but do not identify as gay, do not necessarily share by virtue of engaging in sex with other anatomically sexed men. Given the context of the gendered sex roles that exist between black gay men and their sexual partners alluded to earlier, perhaps looking towards cultural knowledge and experiences regarding gender variance among gay-identified men might be more epidemiologically significant.

### **DECONSTRUCTING MSM**

In order to make sense of such a predicament, and in order for epidemiological modeling of the HIV epidemic in South Africa to better reflect the social and sexual realities of South Africans on the ground, perhaps it is best to turn away from foreknowledge of HIV epidemics as it is enacted through the construction of the MSM category in this context. An alternative would be to complement epidemiological models, as Mahajan suggests, "with different types of sociological and cultural knowledge."<sup>58</sup> One possible approach to doing

this is to engage in a simultaneous unmaking and remaking, of the MSM category by drawing upon ethnographic studies of black MSM and gay South Africans as well as the cultural meanings these individuals and groups elaborate about and attribute to their own lives. These ethnographic accounts detail the highly gendered aspects of gay sexual identities among groups of black South Africans who self-identify as such. These accounts further problematize the use of, and destabilize the integrity of, an undifferentiated MSM category in epidemiological representations of the HIV epidemic in South Africa. Graeme Reid's recently published ethnography of emergent gay communities in rural South Africa references the preponderance of 'ladies' and 'gents' gender roles taken on by black gay men in these contexts.<sup>59</sup> Similarly, but less recently, during the last decade of the twentieth century, in the black township context of Soweto, Johannesburg, Donald Donham describes the detailed and complex process of how various black, gay members of the sexual rights organization Gay and Lesbian Organization of the Witswatersrand (GLOW) came to think of themselves as being gay. He focuses on two individuals' narratives of sexual selfunderstanding: Jabu and Linda. Donham writes, "these two analytical dimensions, gender and sex, interrelated in complex ways. While she was growing up, Linda thought of herself as a girl, as did Jabu ... Even though they had male genitalia, both were raised by their parents as girls and both understood themselves in this way."60 In Linda's own description of his understanding of himself, he writes, "Before, I thought I was a woman. Now I think I'm a man, but it doesn't worry me anyway. Although it used to cause problems earlier."61 In the previous passages, one should take careful note the shifting gender referent of the pronouns used to describe Linda both by Linda, himself, and by Donham, over the course of her/his life. Here, I follow George Chauncey in his analysis of male femininity in New York City during the opening decade of the twentieth century in describing this phenomenon as "gender plasticity."62

While the phenomenon of gender plasticity takes shape here in dramatically different ways than is described in Chauncey's historiography, it is nonetheless evinced by the shift in pronouns used to refer to a body whose anatomical sex remains constant despite the plasticity of its gender. Such a phenomenon continues to be prevalent among both gay- and non-gay-identified as well as lesbian- and non-lesbian-identified black South African men and women that I conducted ethnographic research among during the past three years in both Johannesburg and Cape Town, South Africa. A particularly relevant instance of gender plasticity occurred during a conversation I was having with a self-described "straight" male Zulu friend of mine in his mid 20's. He was describing some of his sexual exploits that he remembered from his college years. He was describing a group sex experience that he thought would be important for me to hear about for my research. One night while out with a male friend, he had met a woman at a club and the three of them left to go back to her house. As he retold the story to me, when they arrived at her apartment near campus, there were three other girls there with a gay male friend. As the party developed, he described it to me saying, "things started getting very, very explicit whereby you have to take off your top, you know? And that thing led to us ... now remember we were three guys. So let me say two guys, because that gay guy, okay, we won't count the gay guy. We were two guys, and actually say five ladies."63 In this particular instance I want to draw attention to both the mode and context within which the gay man becomes gendered as a woman. The context in

which the potential risk for HIV transmission is constituted in this sexual encounter is one determined by opposing sexual framings that contrastively interpolate this gay subject as alternately a man, *as well as* a woman. In other words, the gendered status of this subject changes in this sexual situation according to the specific sexual, ethical framing in which my friend viewed the subject. Additionally, we can read a disjuncture between my friend's and an epidemiologist's interpretive framing of this sexual encounter; the gay man was classified as a woman by my friend, and would likely be classified as a man by an epidemiologist.

Across these ethnographic examples, the emergence of the significance of non-scientific cultural knowledge, through the privileging of gender, not sex, is demonstrated through instances of gender plasticity. Conversely and paradoxically, public health or biomedical researchers continue to privilege the anatomical or biological sex of these men by grouping them with other non-differentiated groupings of MSM, whereas many of these "men," as well as their families, and communities, have a much more complex, gendered and culturally mediated relationship to their sexed bodies. Specifically, the complex phenomenon of gender plasticity is effaced in predominant practices of epidemiological knowledge making about the HIV epidemic through the enactments of an undifferentiated MSM category in the South African context.

# MULTIPLE MSM: HIV EPIDEMIOLOGY AND THE ETHICS OF PREP IN SOUTH AFRICA

Close examination of the putatively homogenous, undifferentiated MSM category that epidemiologists and some public health researchers have been referencing and constructing in South Africa exposes what is actually a categorical multiplicity in this context.<sup>64</sup> This type of multiplicity is represented by heterogeneity of types of MSM reflecting variations in race, class, behavior, sexual identity, and HIV prevalence within the ostensibly singular object being constructed by epidemiological and public health researchers. Through deconstructing the category, I demonstrated that groups of black gay men exist within social realities whereby cultural experiences, knowledge and processes work, sometimes antagonistically against these individual's own self-identifications, to cast these anatomically sexed men simultaneously as socially gendered females, rendering the use of the category "MSM" problematic as many "men" in such groupings are, in fact, gendered as female, either by themselves or others. The complexity of this process should be underscored given that many black gay males have a contradictory and complex relationship to their anatomical sex as well as the cultural phenomenon of gender plasticity. At this point, however, it is useful to explore how sociocultural constructs and processes, which construe these men as women, or women-like, may be associated with biological expressions of gender among these men. In other words, such an examination would inquire whether the social phenomenon of gender plasticity might result in biological expressions of gender, such as the feminization of HIV, whereby HIV prevalence estimates of these feminized black men are comparable to other groups of black women who are anatomically female in the South African context.

Of the available HIV prevalence estimates available for South African MSM, only one reports an estimate of 33.9% specifically for gay, black MSM in Soweto, Johannesburg

among a sample of gay black men aged 18-48, the majority of the sample being aged 18-24.65 I flag this figure as observational in nature as it would be spurious to make any generalizations about HIV prevalence among gayidentified black MSM on a national level based on such a non-representative sample. Notwithstanding, it is interesting to note that the figure more closely resembles the national HIV prevalence estimate of 32.7% among black, anatomically female women, aged 20-34, than it does the national HIV prevalence estimate of 9.9% among a heterogeneous category, with respect to both age and race, of MSM. 66 The similarity between the prevalence figures of black gay men and black women is striking, especially given the preponderance of ethnographic as well as cultural knowledge that troubles any homogenous epidemiological coding of MSM. The comparability of these figures is admittedly spurious, and I would not suggest making any conclusions about the shape of the HIV epidemic in South Africa based on such a comparison. However, as an indication of the problematic normative issues regarding the epidemiology of HIV among MSM in South Africa it is informative. It is also arguably less spurious than the practice of constructing a singular, ostensibly homogeneous MSM category in South Africa. This is especially so since such constructions are based upon foreknowledge of HIV epidemics in vastly different national contexts and aim to represent a singular morphology of an MSM HIV epidemic among what is clearly a multiplicity of MSM groups. Rather than purport to represent the actual shape of the HIV epidemic with such a comparison, I make it in order to introduce a measured, yet healthy and necessary, skepticism and critique of the available epidemiology of HIV in South Africa. Given the current, patchy state of the epidemiology of HIV among MSM in this context as well as the highly divergent HIV prevalence estimates among various subgroups of MSM, such a critique is offered in the hopes of generating a more robust and reliable map of the HIV epidemic both among MSM and national HIV epidemics globally.

The comparison also invites an examination of how current epidemiological modeling of the potential cost-effectiveness of implementing interventions like PrEP in South Africa conceives of MSM, or rather does not conceive of MSM, as a potential population for such an intervention. In a recent mathematical modeling study conducted to evaluate the costeffectiveness of PrEP and its impact on HIV transmission in South Africa, researchers used HIV incidence data from the South African national survey, and found that, "PrEP can avert as many as 30% of new infections in targeted age groups of women at highest risk of infection," which following the national survey, <sup>67</sup> they cited as women aged 25-35.<sup>68</sup> In this particular modeling study, the authors are interested in understanding under what conditions PrEP might be considered cost-effective in a generalized epidemic context, like South Africa, where PrEP is targeted to those who are epidemiologically considered to be "most at risk" for HIV. My preceding analysis demonstrates the problematic normative assumptions that silently animate and construct the various epidemiological "facts" about the distribution of HIV throughout various sections of the South African population. The problematic construction of the MSM category in the national survey as a selfsame, continuous object/ category is paradigmatic in this regard. Deconstructing the MSM category and examining its complexity and multiplicity suggests a critical exclusion with respect to this epidemiological modeling study.

This is directly related to how the existing epidemiology of the homogenous category of MSM in South Africa creates a situation whereby black, gay MSM, who may have comparable HIV prevalence estimates to "most at risk" women in South Africa, are normatively excluded from cost-effectiveness modeling studies such as these, thereby potentially limiting their future access to PrEP as a public health intervention if it were to be made available through the national public health system. During an interview that I had with an HIV/AIDS social scientist in South Africa, he confirmed this potential normative exclusion, but contextualized such an exclusion within the context of limited national resources to distribute ARVs adequately to those who are already HIV-positive. His assessment of PrEP as a public health intervention was that it was only being conceived of as a viable prevention strategy among groups of heterosexual South Africans:

"The decision about PrEP in the South African context ... it's [not] likely to be made around PrEP and MSM. I think it will be PrEP and primarily [the] heterosexual epidemic that will be the driver. ... The MSM *populations* are [epidemiologically] important in the Western Cape and ... probably in Gauteng as well but not really anywhere else. Well we haven't looked. ... But probably not, and therefore you know there's no reception; it's not even on the radar. The health department in KZN, they're not even thinking about that. They're struggling to make their targets to get people on treatment. Those people who are already positive ... and how are they going to pay for that? I think it's important, but in practical terms I'm not sure that we're going to do it," (emphasis added). 69

The statements this researcher made about the relative contributions of MSM populations to the national epidemic must be interpreted within the context of the available epidemiologic evidence, which I demonstrated as empirically problematic. Given that the evidence constructed around the putative singularity of an MSM population in South Africa is conceptually flawed, his comments bespeak the incomplete understanding of the epidemiology of HIV generally, and specifically among MSM in particular context. While he deemphasizes the burden of HIV carried by MSM nationally, he simultaneously and paradoxically references the importance of multiple MSM populations to epidemics in urbanized areas of the country. The paradoxical aspects of how a singular MSM population is unimportant while multiple MSM populations are significant can be made sense of if we problematize the category's singularity and look at what might be obviated by such generalizations. And while PrEP, conceived as a public health intervention among "high-risk populations" as opposed to a biomedical treatment for "individuals at high-risk for HIV," is not currently being considered in the public health system among any populations in South Africa, recent studies have reported evidence supporting claims that the treatment of HIVpositive persons is an effective form of *public health* HIV prevention. <sup>70</sup> One study specifically mentions that data such as these may help to provide the evidentiary support to spur on donors to pledge sustainable "treatment as prevention" public health interventions.<sup>71</sup> These types of arguments suggests the strength of the relationship that exists between the production of epidemiologic knowledge and evidence - which I demonstrated above to be a cultural process that should be explicitly addressed within both bioethical and public health ethics frameworks – and the distribution of health resources. Relating these developments to the discussion of the exclusion of MSM in epidemiological modeling studies, the production

of epidemiological modeling evidence in the present, or rather the lack thereof in the case of MSM, can be understood as ethically problematic due to the fact that it may have a critical bearing on future decisions and ethical considerations regarding the implementation of PrEP.

### Conclusion

Specifically, by referencing the cultural knowledge and experiences of gay and gender variant, black MSM in this context, we can begin to see how the dynamics of gendered HIV risk among this group, might mirror the gendered HIV risk among anatomically-sexed women in this same context. Clearly, there would need to be studies to ascertain whether these associations are, in fact, significant. However, the implications of ignoring these possible associations would risk obscuring populations, such as gay and gender variant, black MSM who seem to be most at risk for HIV as well as obfuscate the causes of causes that structure these vulnerabilities. In this case, gender plasticity may be a fundamental driver of HIV risk among various groups of MSM in South Africa and may not be considered or viewed as such due to normative biases in processes of epidemiological knowledge production. These findings may also be relevant in a number of other sociocultural contexts and HIV epidemics globally where nonnormative sexual and gender variant cultures trouble epidemiologic practices that construct behavioral risk groups including, but not necessarily limited to, MSM.<sup>72</sup> It must also be mentioned that if gender variance were in fact a fundamental driver of HIV vulnerability, this type of evidence could open onto other avenues, possibilities and potentialities for public health intervention as well as political and social action that would help mediate blind reliance on "pharmaceuticalized" public health HIV prevention strategies, such as PrEP. This is particularly important given that biomedicalized approaches to HIV prevention structure precarious situations where national health systems can become vulnerable and subject to the vagaries and unpredictability of global pharmaceutical market forces and biocapital as well the shifting mandates of international intellectual property and patent laws.<sup>73</sup> Given the high cost of PrEP and the fact that many MSM and gay groups in, "low and medium-income countries ... [lack] condom availability, ... education and counseling programs, ... [and] nonjudgmental HIV-testing opportunities,"74 any consideration of implementing PrEP will also have to consider whether, and to what degree, other, non-pharmaceutical prevention methods for groups of MSM have been made historically accessible to these groups. In order to conduct itself ethically in contexts where culturally specific social constructs – such as gender plasticity among black, gay MSM in South Africa, for instance – seem to be epidemiologically significant, epidemiology must either incorporate the methods and theoretical orientation of the subfield of social epidemiology or consult other forms of cultural knowledge and experience on sexual matter, be they ethnographic or otherwise. In this way, I demonstrated that ethical concerns for unexamined norms of epidemiological practice were directly related to the ethics of PrEP as an intervention strategy; the ethics of the later implicitly rely on the *cultural* biases, methods and practices of the former. Taking the MSM category in the South African context to be multiple, this analysis indicates that, ethically speaking, following Rosengarten and Michael, 75 the future implementation of PrEP should be *multiply assessed*, taking into account the multiplicitly of various population

groups who may have divergent estimates for HIV prevalence and incidence and varied histories of non-pharmaceutical public health HIV interventions. However, in order to assess the ethical implementation of PrEP, with regard to key public health ethics principles, such as justice, epidemiological knowledge production must first address cultural matters by taking account of and consulting ethnographic and other cultural knowledge and experience regarding sexual populations in various local contexts. Taking South Africa as a case study, I have shown how the enactment of the MSM category within public health and epidemiology mistakenly collapses socially, culturally and epidemiologically disparate groups and communities into a homogenized risk group, thus resulting in distorted representations of the epidemiology of HIV among MSM. These processes have dually contributed to the possibly epidemiological significant "erasure of the [black, gay] sexualminority person,"<sup>76</sup> and therefore population, in public health and epidemiologic research in South Africa. By arguing for the multiplicity of the MSM category in this context, I demonstrated how epidemiology might expand itself ethically towards incorporating the methods of the subfield of social epidemiology or constructs from other forms of available cultural knowledge, such as ethnography or cultural experience, in order to create better epidemiological models, more suited to the social realities of South Africans. I then linked critical questions about the normative constitution of epidemiological knowledge and evidence and the ethical practices of the discipline as they relate specifically to the ethics of implementing PrEP given the particular case study of MSM within the context of a generalized heterosexual epidemic in South Africa. Examining these ethical considerations within this specific case study illustrates how disputes regarding the constitution of risk groups, such as MSM, could potentially incorporate forms of cultural knowledge and experience in place of the use of foreknowledge, in order to create more adequate representations of epidemics within national populations in other contexts. Understanding how these more general processes of knowledge production affect the constitution of "atrisk" populations and epidemiological maps within various populations will help to shed light on many of the manifold bioethical and public health ethics considerations that will invariably arise as the ethical implications of *multiple* PrEPs are debated globally.

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