

Who Counts as “Transgender”?

Epidemiological Methods and a Critical Intervention

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Abstract This article draws on the work of Michel Foucault to critique epidemiological methods in general and transgender HIV prevention research in particular. Funding for transgender HIV prevention research and programs is often directly connected to widely accepted, yet often problematic, practices of data collection and analysis. The authors believe that attending to the needs of those who do not conform to a binary gender system requires analyzing the ways in which epidemiology research produces and reifies the gender system itself. In order to understand the relation between a trans “identity” and a trans “population,” the article employs as analytics Foucault’s concepts of normalizing power and biopower. It reviews the history and techniques of epidemiology and then briefly the ways in which normalizing power produces specific identity categories such as gender and gender identity as inherent to an individual, followed by an examination of how those socially produced identities operate at the level of population regulation. Finally, it explores some resistant practices that both epidemiologists themselves and the targets of their research might engage in order to at least mitigate some of these difficulties.

Keywords transgender, biopower, normalizing power, critical epidemiology, population, HIV prevention

This article is a critical engagement with research aimed precisely at “making transgender count” in the global fight against HIV/AIDS. Recognizing the dearth of HIV prevention resources accessible to those referred to as “transgender,”¹ this work critiques epidemiological research that seeks to respond to this lack of resources. Through the generation of quantitative data, the research provides evidence in support of prevention resources aimed specifically at persons referred to as “transgender women.” We identify two main problems with this approach, one methodological and one philosophical: the first questions particular uses of epidemiological methods that invoke a “transgender population” in order to make inferences. Here we argue that these methods reproduce specifically Western gender categories, in contexts where they may not fit, with detrimental effects of restigmatization and a reification of transgender as a type of

individual universally at high risk for HIV. We argue here that even on its own terms and with its own goals in mind, epidemiology fails to serve the individuals it claims to be serving. The second problem we address is about the power-laden nature of identity categories themselves: the very insistence that particular persons be classified and counted as transgender positions them as abnormal and subject to greater scrutiny and social surveillance within the binary gender system. We approach both problems through Michel Foucault's work on biopower and normalizing power, drawing attention to the discursive and material practices involved in the creation of subjects, or individuals with particular identities, as well as to the categories that render them objects of scientific knowledge and targets of population control and political and biomedical technologies.

We understand the high stakes of the research we critique here: funding for both HIV prevention research and programs is often directly connected to the practices of data collection that we call into question. But we believe that attending to the needs of those who do not conform to a binary gender system requires analyzing the ways in which research produces and reifies the gender system itself, even if that means challenging accepted epidemiological practices. Put differently, it is imperative to examine how statistical and medical knowledge about gender-nonconforming persons, as well as the biopolitical grid that circumscribes it, may perpetuate the forms of invisibility and violence it aims to remedy. One question that emerges, then, is how epidemiology as a field might respond to the problems we identify. To that end, we explore some resistant practices that both epidemiologists themselves and the targets of their research might employ in order to at least mitigate some of these difficulties.

Epidemiological studies on transgender HIV prevention invariably and problematically assume an a priori transgender population. While this research has the laudable goal of trying to promote health and expand services to individuals whom HIV prevention research tends to overlook, the means by which it attempts to identify those individuals perpetuates the very problem it seeks to address. It assumes that a trans identity is both natural to an individual and globally universal; such an assumption leads to problematic data collection practices that erase trans and gender-nonconforming people's needs and lives and perpetuate global dynamics of injustice and inequality. In order to understand the relation between a trans "identity" and a trans "population," it is key to analyze the mutually reinforcing interactions of normalizing and biopower. We will first review the history and techniques of epidemiology and then briefly review the ways in which normalizing power produces specific gender identity categories as inherent to an individual. We will then turn to examining how those socially produced identities operate at the level of population regulation.

Epidemiology, the Population, and (Ab)Normality

Epidemiology is generally understood as the study of the distribution of health and disease among various human populations (Aschengrau and Seage 2008; Szklo and Nieto 2007). Though its logics can be traced to the seventeenth century and the scientific revolution, epidemiology emerged as a science in the nineteenth century and then as an academic discipline in the early twentieth century (Aschengrau and Seage 2008; Krieger 2012). According to Nancy Krieger (2012), social scientists extrapolated mathematical principles from astronomy in order to infer notions of the “average man.” The key difference, however, was that “for a star, the location of the mean referred to the location of a singular real object, whereas for a population, the location of its population mean depended on how the population was defined” (642). Krieger’s essay “Who and What Is a Population?” traces the problematic ways in which epidemiology has continued to deploy the “population” as an a priori fact, simultaneously neglecting to define it with any precision or acknowledge the relational, extrinsic, and dynamic qualities that shape populations (660). Statistics, etymologically defined as the science of the state, is a primary epidemiological technique to derive means, probabilities, and complex risk profiles from sufficiently large samples to make comparisons between and inferences about various imprecisely defined populations as well as subgroups within a population. Without conceptual precision, the statistics derived from population research are, at best, approximations of societal patterns and, at worst, dangerous and essentialist knowledge claims.

The problem is widespread, and it is clear that from the beginning, epidemiology has operated in biopolitical and normalizing ways. Krieger (2012) and other scholars (Lorway and Khan 2014; Spade and Rohlf, forthcoming) have highlighted how epidemiology and its use of statistics have progressed in the context of specific social, economic, and political developments such as the eugenics movement in the early twentieth century and the Gates Foundation’s global epidemiological research that has merged with Harvard Business School metrics in the early twenty-first century. In both contexts, epidemiology and statistics are deployed to make visible populations with distinct sets of bodily and behavioral traits that are linked to potential illness or potential threats to national and economic security. Here, too, the pathologizing mechanisms of normalizing power operate implicitly and largely invisibly, precisely by leaving unquestioned the ways in which so-called abnormal populations are created through the techniques used to measure and “fix” them.

Consider Geoffrey Rose’s seminal work *Preventive Medicine* ([1993] 2008), which fails to provide a nuanced definition of population despite the centrality of the construct to his argument (for a more in-depth critique of Rose’s conceptualization, see Krieger 2012). Rose famously makes the case that health

promotion and disease prevention are most effectively and efficiently achieved via population-based analyses of and interventions on what he terms the “normal majority” rather than via an approach that targets those few who are most at risk and what he refers to as abnormal (94). Foucault’s (1990) analysis of normalizing power suggests that leaving unexamined the use of the very terms *normal* and *abnormal* masks complex systems of social, economic, cultural, and political power relations that actually create and enforce the very categories so named. Extending Rose’s approach to HIV prevention research today, one can easily anticipate the ways in which epidemiological analyses may exclude the most vulnerable or, alternatively, encourage the construction of “abnormal populations” in order to justify research and interventions on the social margins.

Indeed, in the latter half of the twentieth century, epidemiology devoted its resources to large cohort studies that examined health risks and behaviors of predominantly white, middle-class America and Europe such as the Framingham Heart Study and the British Doctors Study. This methodological approach exemplifies Rose’s prioritization of what he deems a “normal majority.” In so doing, it advances social and economic interests of the state through the quantification and normalization of health and behaviors without any identification of the ways in which state apparatuses may harm the health of persons in its wake, particularly those on the margins.

Epstein (2003, 2007) illuminates how, in the wake of the civil rights era, advocates on the social margins, rather than respond to the erasures and potential harms that state-centered methods and population-based research created, lobbied instead for state-centered research on “special populations,” including women, persons of color, and lesbian and gay ones initially, and much later, bisexual and transgender ones. He argues that this “state-centered approach takes categorical identities to be the foundation of a health promotion and biomedical research strategy” (2003: 132). Janet Shim (2000) argues that, through this emphasis on individual characteristics of a sample—assumed to be fixed and static categories—such as race, class, and gender and their relationship to poor health outcomes, population-based methods place the burden of change upon individuals, masking and even reproducing the power relations that circumscribe the health disparities in question. Shim observes, for example, how nonwhite and poor racial and class statuses are routinely cited as individual, additive risk factors for poor health outcomes, while white and middle-class statuses are viewed as protective factors (179). This framework, though it may acknowledge the role of social stigma and discrimination, casts intersections of race, class, gender, and sexual orientation as individual and essential rather than as a relational and social process.

Excluded by lesbian and gay as well as HIV research agendas, transgender health and HIV prevention research have navigated a unique trajectory. In “Counting

Us In,” Hanssmann (2010) reviews this trajectory thoroughly and highlights the community-based research conducted by US researchers—including trans community members—in the 1990s and early 2000s that estimates HIV disease burdens, among other health risks, unique to US urban transgender communities. In the twenty-first century, many of these small studies have been pooled into a meta-analysis (see Herbst et al. 2008) so as to achieve a sufficiently large sample and establish population-level evidence on which to justify the funding of state-centered HIV prevention programs and research. Based on the ostensible success of the 2008 study by Herbst and colleagues, researchers concerned with transgender HIV prevention have gone global with the meta-analysis, attempting to make visible and declaring an HIV crisis among a global, universal transgender population (Baral et al. 2013). The use of the meta-analysis has become widely accepted in transgender health research (see also Operario, Soma, and Underhill 2008). Unfortunately, through its construction of population-level data about trans and gender-nonconforming bodies, it perpetuates the problems of normalization and social control. To illustrate this problem and to explore transgender health research issues in depth, we turn first to Michel Foucault’s work (2007) and then to the 2013 meta-analysis of Stefan Baral and colleagues in the following section.

Biopower: Epidemiology and Reifying Transgender

It is in the Baral and colleagues’ 2013 global meta-analysis and its cascade of effects that understanding the connection between normalizing power and biopower becomes crucial. Whereas normalizing power targets individuals for social surveillance and control, biopower targets “the population.” Biopower regulates subjects with a goal of promoting overall health. In order to do so, it collects data and enumerates events like mortality, birth, teenage pregnancy, drug use, criminality, and, of course, the spread of disease. The data seem like objective evidence of what they track, but Foucault’s analysis makes clear that the data collection processes themselves create the populations they claim simply to identify. Biopower, he argues, is a mechanism of governmentality, the construct known as a population itself being a tool of management and containment, functioning as a mechanism to manage the health and life of its members, whose bodies are generally viewed as an economic resource that requires governing. He provides a helpful way of thinking about public health’s slippery use of this construct (2007). Foucault observes that the population is not a natural taxonomy to be discovered, ordered, counted, and made visible. Rather, the population is produced through statistics, which are understood to make visible “a set of elements in which we can note constants and regularities even in accidents, in which we can identify the universal of desire . . . and with regard to which we can identify a number of

modifiable variables on which it depends” (75). Those statistical effects help produce a “nature” inherent to the population and against which the state can intervene and manage individuals. Interventions and management arise from multiple sites within the state, of course, including government-funded research but also nongovernmental projects and corporations with a perceived stake in the issue at hand. In relation to HIV/AIDS, biopower flows through various government agencies and private foundations that track data and fund research projects at local, national, and international levels as well as through the World Health Organization (WHO) and various pharmaceutical companies involved in HIV/AIDS treatment and prevention. In this case, being considered a legitimate member of the priority population is key to receiving services; when normalizing identities become part of data collection, normalizing power’s exclusionary and coercive mechanisms may induce more harm than good.

To underscore the work of normalizing power and biopower, we turn to the *Lancet* and Baral and colleagues’ 2013 “Worldwide Burden of HIV in Transgender Women: A Systematic Review and Meta-analysis.” This study exemplifies the methods by which a transgender population and its nature are produced ex post facto through the work of the study itself. The authors define transgender through a reification of the sex and/or gender binaries whereby the gendered subject is viewed as fixed, coherent, and nonambiguous. They posit, “Transgender women [are] defined here as people who were assigned male at birth but who identify as women” (Baral et al. 2013: 214) and then later, with no explanation, as “people who were born male but identify as a different gender” (215). The authors pool the results of thirty-nine studies conducted in fifteen different countries in order to determine the “relative burden of HIV in all transgender women worldwide” (214). Several of the studies do not describe the research participants as transgender at all and suggest contextually and temporally specific sets of classifications and comparisons that shine light on additional conceptual ambiguities. For example, Altaf (2008) compares *hijras* with male sex workers whereas Shaw and colleagues (2011) compare *hijra* sex workers with male sex workers in urban Pakistan. A 2008 study in Ho Chi Minh City that recruited men who have sex with men from popular sites for public or commercial sex compares “four distinct groups: transvestites (. . . known as ‘bong lo’), non-transvestites (. . . known as ‘bong kin’) . . . , bisexuals who had both male and female partners (known as ‘da he’) . . . , and sex workers (heterosexuals selling sex to men to earn money)” (Nguyen et al. 2008: 3). In South America, Grandi and colleagues (2000) recruited male sex workers in São Paulo, Brazil, between 1992 and 1998—as much as fourteen years prior to Shaw and colleagues—and compared the HIV epidemiology of transvestites to hustlers; in Montevideo, Uruguay, in 1999, Russi and colleagues (2003) conducted a seroepidemiologic study of 200 male transvestite commercial sex workers.

The vast amounts of slippage across time, space, and social categories call into question the basic legitimacy of the conclusions. The notion that throughout the world today transgender women's odds of having HIV is forty-nine times that of the general population is questionable precisely because of the assumptions and techniques used to "count" them. Indeed, the researchers themselves seem to understand the problem here when they note that "gender identities are complex and fluid"; yet despite contradictions with the original definition, they maintain that "a full explication of gender identities is beyond the scope of this text" (Baral et al. 2013: 214). This acknowledgment masks the insidious nature of the category of transgender in this context, erasing culturally specific experiences of gender and conflating a broad range of gender expressions and experiences into one term that is supposed to capture them all.

The *hijra* category in Pakistan and India, for example, long precedes the late twentieth-century category of transgender and has operated in contexts that others have argued are quite different from those of the Western gender binary (see, for example, Cohen 2005 and Reddy 2005). Yet this study reorganizes *hijra* as a subset of a global transgender population. The accuracy and function of the term *transgender* thus become highly suspect. There are quite practical effects of such categorizing that undermine the very goals of the researchers doing the study. Similar to Cohen (2005), anthropologist Aniruddha Dutta (2012) observes that HIV-prevention funding streams for nongovernmental organizations (NGOs) in India have now been parsed in the same way as in the United States, despite a very different understanding and set of practices around sexuality and gender. Funders have been eager to separate gender and sexuality in India, where they have been understood as intertwined, overlapping, and fluid, and to standardize Western models of "MSM" (men who have sex with men) and "transgender" funding streams. Dutta notes, "The MSM-TG division may not only exclude people who do not 'fit' these labels, but also splinter existing marginalized communities of gender/sexually variant people into narrow identitarian groups. This particularly affects communities and community-based organizations in non-metropolitan and rural areas, which are more dependent on such funding than metropolitan middle class LGBT groups."

Consider as well WHO, the authority on health for the United Nations, which recently released its HIV prevention, treatment, and care guidelines for key populations, "Values and Preferences of Transgender People: A Qualitative Study" (Schneiders 2014). Based on interviews with only fourteen "transgender men and women" from six of the seven WHO regions, the guidelines also cite Baral and colleagues (2013) and another US-focused meta-analysis (Herbst et al. 2008) as key evidence for transgender persons' disproportionately high HIV burden. Noting a failure to use condoms consistently despite availability, the guidelines

restate the recommendations of Baral and colleagues for more research on biomedical interventions such as pre-exposure prophylaxis (PrEP) and post-exposure prophylaxis (PEP) for HIV-negative transgender persons (Baral et al. 2013; Schneiders 2014). These recommendations target those perceived as trans-identified individuals throughout the world for greater scrutiny from governmental organizations, NGOs, and researchers as well as from pharmaceutical corporations, not to mention those informed by the (mis)interpretations of these studies’ findings by mainstream and LGBT media sources.

Epidemiologists Greta R. Bauer and Ayden I. Scheim attempted to intervene on the flattening and stigmatizing effects of Baral and colleagues’ study. In a letter to the *Lancet*’s editor (Bauer and Scheim 2013), they flag both the sampling bias—that the Baral analysis pooled only studies that focused almost exclusively on street-based sex workers—as well as their extrapolation of the study results to all transgender women rather than to transgender, street-based sex workers (832). They do not, however, question the Eurocentric, positivist use of the category itself.

In a subsequent article, Bauer (2014) builds on the work of Krieger and proposes that epidemiologists adapt intersectionality theory in order to address inequality more precisely. Kimberle Crenshaw (1989, 1994), among other black feminist scholars, developed intersectionality theory for use in qualitative and legal research to identify and intervene, not upon populations or individuals, but upon the contextually (e.g., legally) specific ways in which marginalized persons, such as black women, experience systemic erasures that can result from the notion of unitary categories of identity (1994). Bauer calls for a quantitative adaptation and more precisely specified, multilevel models that account for intersecting social identities, social positions, and related social policies in order to “reduce measurement bias and improve construct validity” and, ultimately, advance health equity on a population level (2014: 15). Bauer offers a more critical epidemiology as she recommends models that account for unstable identities, encourages triangulation with qualitative results, and makes room for structural interventions such as policy change. Nonetheless, this intersectional approach—that quantifies and compares ever more data about types of people—continues along the path of individualizing people into narrow identitarian subpopulations and runs “the risk of continuing to reinforce the intractability of inequity” (12).

It is important to remember that normalizing power is a tool of biopower: the specification of individuals allows them to be more readily controlled and regulated through the various social bodies—medicine, law, psychiatry, as Foucault suggests, but also WHO and various other bodies monitoring and managing health within nations and around the globe. Our analysis suggests that while these various bodies are trying very hard to do good in the world, they

ultimately perpetuate the problems of stereotyping and oppression that they aim to overcome. And they do so precisely by using the terms of normalizing and biopower: fixed identities, invasive scrutiny of individuals, and the imposition of dominant cultural norms on individuals who often do not fit into them. As noted above and by others (Dutta 2012; Lorway and Khan 2014), many individuals are not “counted” precisely because they do not fit the definitions of identity categories at play. Valentine’s (2007) ethnographic research in New York City identified how “transgender” only gained traction as an identity among primarily white, college-educated, activist trans women in the 1990s, a pattern that emerged simultaneously with its use in social-service agencies, where the same trans-identified women may have worked as peer counselors and outreach workers. Meanwhile, he observed that among persons of color, particularly within ball culture, it was “more common to hear participants refer to themselves as gay, fem queens, girls, and sometimes (though often jokingly) as women” (105). These multiple forms of self-identification can be seen as resistance to a system that requires conformity to the identity “transgender.” The solution is not to specify individuals ever more carefully—that is the path of ever-increasing normalization. The solution, rather, is to question the system itself.

Conclusion

We believe that research aimed at expanding resources for trans individuals should itself seek to understand the various biopolitical and normalizing social, economic, and political components that contribute to the marginalization and invisibility of trans and gender-nonconforming individuals within the HIV prevention and treatment complex rather than merely acknowledge structural problems as complicating the process. That is, if social stigmatization and economic marginalization contribute to a lack of access to resources, as numerous trans health and HIV studies have suggested, then those practices need to be understood, challenged, and changed. It seems clear here that simply being gender nonconforming cannot explain an individual’s exclusion from resources; the system and the research that position the individual as abnormal are complicit in the problem. So first, researchers need to ask a different set of questions that might include: How are identities produced within the sex/gender binary as abnormal? How do funding streams assume these identities as a foundation? How can we work across disciplines to interrogate with more precision how socioeconomic and geopolitical inequalities intertwine with the gender binary system and the exclusions it generates? This means that researchers should be educated about our own role in broad social, political, and economic power relations, and we should also lobby for changes in the research system along these lines. In short, researchers themselves need to find modes of resistance to the system of which we are a part.

Second, if researchers need to understand what drives sex work or intravenous drug use, a structural analysis of poverty is in order rather than a classification of identities. Focusing research on understanding structures and structural violence, coupled with broader engagements with gender-nonconforming individuals as partners in the mutual task of undermining structural oppression, may begin to move research beyond biopolitical and normalizing mechanisms of regulation and social control. Relatedly, researchers need to pay more attention to the resistances that inevitably arise from participants themselves, who may either implicitly or explicitly resist the research in which they agree to participate. While these forms of resistance may not transform the normalizing and biopolitical systems they seek to alter, they may mitigate some of their worst effects and open up spaces of questioning within the research itself.

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Note

1. Throughout the article, we use the terms *transgender*, *trans*, and *gender nonconforming* to refer to any individual who violates the alignment of sex-assigned-at-birth and gender expression of their culture. Similar to Christoph Hanssmann (2010) and David Valentine (2007), we intentionally vary our usage of these terms, knowing well that any term we choose poses potential problems and does not necessarily resonate with those to whom we have applied them.

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