

Following Tanya's Lead

The mirage and hope of social medicine research

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Abstract

Entrenched structural inequalities raise challenging questions of how socially-oriented research initiatives are likely to improve health for marginalised people. The recent inclusion of transgender women in the National HIV Behavioral Surveillance (NHBS), an ongoing initiative funded by the Centers for Disease Control and Prevention (CDC) to study the HIV epidemic in the US, is designed to redress the exclusion of transgender people from past HIV research and to confront the disproportionate burden of HIV on transgender women through the production of specific knowledge about HIV risk factors in this population. The hope is that such research will ameliorate the burden of HIV among transgender women. Building on a decade-long ethnographic engagement with transgender activists and health practitioners, I delve into tensions between the health research that sustains this horizon of hope and what I call the 'mirage' of social medicine research. My interlocutors call out this mirage of scientific optimism in which 'all the answers are already known', suggesting that health research oriented towards social justice simply begets more research. Nonetheless, my interlocutors engaged with me, a physician-anthropologist trainee, in order to insist on the ethical necessity of including transgender people in health research even as they exposed the limits of such inclusion and, more broadly, the limits of medicine's power to redress social injustice. We should follow their lead, embracing neither futility and hopelessness nor the mirage of medical salvation, in order to build collaborative relationships in the service of a more caring social medicine.

Keywords

Social medicine, transgender health, HIV/AIDS, community-centred research.

Introduction

I was meeting Tanya for the first time. A Black trans woman and activist in her 50s, she had been introduced to me by another activist. Soon after, she had invited me to her home in West Philadelphia to interview her as part of an ongoing nationwide study of the HIV epidemic that sought to take trans women's perspectives into account. The study is technically known as the formative assessment phase of the trans women cycle of the National HIV Behavioral Surveillance (NHBS), funded by the US Centers for Disease Control and Prevention (CDC) and administered by local health departments across the US.¹ At the time, I was primarily conducting ethnographic research with children and adolescents engaged in gender-affirming care, and I was hired to work with the study's Philadelphia-based researchers as an ethnographer. Tanya was one of the trans women who volunteered to share their experiences with me, and it was in this context that she would critique HIV prevention research and trouble the optimistic logic of health disparities scholarship.

As we sat in her living room, I began our conversation by thanking Tanya for graciously sharing her experiences with me. I explained that although I would ask questions from the interview guide I had developed, I was more interested in the information that Tanya herself felt was important for me to know. Tanya talked first about her experiences as a long-time activist in Philadelphia, where she organised support groups and mutual aid for trans people. I asked her some questions about communities of trans women in Philadelphia and the resources she felt were most needed. Like the majority of people I interviewed for this study, she emphasised that housing was the most urgent need, but we also talked about food security and healthcare. She told me about the discrimination that she had faced at large health institutions in the city and went on to criticise other large trans-serving organisations in Philadelphia, explaining, 'They started out wanting to help people, but now it's just a business.'

When I started to ask about how best to engage trans women as part of the HIV research that the health department was going to conduct, Tanya stopped me. She asked if I could explain again the purpose of the study that I was facilitating. I told her that the CDC wanted to understand the specific factors that shape the HIV epidemic among transgender women in order to design better prevention

1 Each NHBS cycle includes a formative assessment in advance of data collection. Described in the guidance distributed by the CDC as ethnographic, this assessment principally entails interviews with 'key informants' (professionals in healthcare and other fields with expertise on the population in question) and 'community key informants' (members of the community—in this case, trans women). There is much more to say about the construction of a 'population at risk' in the context of this study, but it is beyond the scope of this essay. There were extensive debates at the local and national level about the coherence of the category 'trans women' and the stakes of excluding trans men, non-binary, or other non-normatively gendered people; by embracing the specificity of the category of trans women, participants and researchers were partially contesting but also partially embracing the problematic exclusions of the umbrella meaning of transgender (see Valentine 2007).

strategies. She leaned back in her chair and sighed. 'You already know the answers to those questions,' she said. 'What happened is that somebody got a grant and they sent you here to talk to me, and now here you are.'

In this Position Piece, I explore the challenge Tanya makes to the optimism of community-based HIV research among trans women. Her comment struck me in part because she insisted on the spuriousness of my questions while at the same time seeming to indicate that she trusted me to understand her critique and thought it worth her time to engage in this research despite its flaws. Tanya engaged with my position as a physician-anthropologist trainee—one who stands for health institutions and their failings but who might also listen and respond. She insisted on the ethical necessity of including transgender people in health research, even as she was sceptical of such inclusion. For the remainder of this essay, I will follow Tanya's lead as she points the way beyond the extremes of naïve optimism and fatalism.

Following another's lead is a central concept in my larger work on gender-affirming care in childhood (Franklin 2020). I use it to refer to the shared commitment of clinicians, families, and anthropological interlocutors to defer to young people's own knowledge of their gender identities. Here, I suggest that following Tanya's lead helps us understand the limits of medicine's power to redress social injustice without succumbing to fatalism and allows us to instead imagine social medicine in more collaborative and critical terms. By devoting her time to working with researchers, Tanya suggests that this is possible, but she nonetheless highlights the flaws of research that does not centre on the experiences of affected communities.

The unknown of HIV research

At first glance, the questions that the Centers for Disease Control and Prevention (CDC) posed in this study seem indeed to be urgent ones. The prevalence of HIV infection is much greater among trans women than among the population as a whole, with recent estimates suggesting that trans women are nearly 50 times more likely to be infected. This risk is even higher among transgender women of colour and particularly acute among young trans women (Baral et al. 2013; James et al. 2016; Frank et al. 2019; Garofalo et al. 2012; Jin et al. 2019). While the US National HIV Behavioral Surveillance (NHBS) was created in 2003, it did not specifically include transgender women until 2018.

Yet, as these data demonstrate, the impact of HIV on trans women has already been the focus of much health research, as have the social and structural contexts of this persistent epidemic. Trans women's discrimination and mistreatment in many settings mean they are also unable to access HIV treatment or prevention

services, or indeed other forms of healthcare. The 2015 US Transgender Survey (James et al. 2016) found that 23% of respondents had not sought healthcare during the preceding year due to fear of mistreatment, while 33% of those who had received healthcare in the preceding year had gone through at least one negative experience related to being transgender. As Tanya indicated, health outcomes are shaped by structural inequalities that manifest in the domains of housing, education, and employment, as well as in the effects of 'minority stress', all of which produce high rates of mental illness and substance use (Bockting et al. 2013; Nealy 2017). These interlocking vulnerabilities continue to drive high rates of HIV among other illnesses, as the disproportionate impact of COVID-19 has demonstrated.

All of this is to say that the literature certainly supports Tanya's contention that the HIV epidemic among trans women has already been studied to a significant extent by different researchers—so much so that such research tacitly equates HIV with trans women. If health research on the subject of trans women's health—and the impact of HIV in particular—has created this conflation, framing trans women as a population at risk, we should return to Tanya's question and ask what the purpose of specifically including trans women in HIV research is. If we already know that communities of trans women are vulnerable to HIV, then what is the unknown that such research seeks to illuminate?

When research becomes a self-justifying cycle, it can run ahead of itself, losing touch with its subjects and turning into a 'perversion of knowledge' (Benjamin 2019, 116). Adriana Petryna elucidates this process in the areas of global clinical trials and runaway climate change. Her concept of 'horizoning work' is meant to recoup a possibility of response through 'local and highly practical forms of research that attempt to bring an unknown or runaway future into the present as an object of knowledge and intervention' (2018, 573; see also Petryna and Rendell, this issue). Uncertainty in this case is not the result of a 'problem requiring more data' (Petryna 2015, 163); rather, it is intrinsic to the politics and interests of maintaining an unknown as the steady state in research, hovering over those most at risk, in a way that forecloses a translation of knowledge into action. Here, in HIV research among the trans community, we see how invocations of the unknown prevent science from being brought to bear on an urgent problem: the reasons that HIV continues to disproportionately impact transgender women. As Tanya suggests, however, the answers to those questions are *known*; the research itself

(and the funding bureaucracy that mobilises it), productive of the unknowing, hinders that which it seeks to address.²

Optimism and action

There is a tension between the necessity and the redundancy of the questions that research poses about the social factors that perpetuate the HIV epidemic among transgender women. Tanya and other trans women I interviewed did not object to the trans women cycle of the National HIV Behavioral Surveillance (NHBS) and often framed the value of such a project in terms of inclusion. From the beginning of the formative assessment, many of my interlocutors told me that they were experiencing or had experienced research fatigue. They went on to explain that they were willing to endure such fatigue (trans women felt that they had been exhaustively studied and even objectified) if researchers asked the right questions. The perception was that they rarely, if ever, did. In particular, research did not make space for the narratives of trans women themselves. Furthermore, research rarely returned to the community, either in the form of data or health promotion. As Tanya's statement illustrates, none of this should come as a surprise in light of substantial social sciences scholarship that has examined the objectifying impulse of medicine and health research (e.g., Gill-Peterson 2018; Good and DeVecchio Good 1993; Holmes and Ponte 2011).

But supplementing this data with trans women's narratives is not necessarily a remedy—inclusion itself is a 'cunning' mechanism of liberal governance (Povinelli 2002). And, as anthropologist David Valentine illustrated, the category 'transgender' itself affords the possibility of recognition in public arenas at the cost of continued race- and class-based marginalisation (2007). In light of these dynamics, Tanya's sceptical critique exposes a kind of mirage by drawing our attention to the implausibility of the implicit promise made by medicine. Rather than finding a point of reference to cope with the unforeseen dangers of changing circumstances, health research here sustains the illusory hope—the aforementioned mirage—that knowledge will ameliorate the burden of HIV among transgender women. This optimistic investment in the transformative possibilities of science belies the reality (obvious to community members and well-documented by researchers) that trans women are more at risk of HIV and many other health problems due to structural inequalities in healthcare access, housing, education, and employment engendered by pervasive anti-trans discrimination.

2 Owing to Michel Foucault and many others, the productivity of scientific knowledge is not a new observation. See, for example, *Imagining Transgender* (Valentine 2007) on the way that medical discourses have shaped contemporary conceptions of transgender identity in relation to gender and not sexuality. What is interesting about this case is not simply that trans health disparities research is productive, but that it creates a particular orientation towards the future.

Of course, the CDC and local health researchers are not ignorant of the body of existing literature that explores the HIV epidemic among transgender women; on the contrary, it is what motivated the creation of the trans women cycle of the NHBS. My purpose here is not to suggest that this or any other particular instance of HIV research is inadequate in relation to any particular theoretical ideal, nor to parse the utility of knowledge creation from the point of view of public health practitioners (although such a critical evaluation would be valuable [Biruk 2018]). Instead, I follow Tanya's lead and question whose hope is sustained by this mirage of medical knowledge? Whose optimism is placed in these knowledge-making efforts?³ What does this mirage conceal? And what must happen for the knowledge that is produced by such research to become actionable? Ultimately, this research transforms anti-trans structural violence into an ordinary sort of public health problem, but what is not acknowledged is the limit of medicine's unclaimed power to redress social injustice. Most disconcertingly, given the commitments of health researchers to pursuing work that serves trans women, research oriented toward social justice may, as Tanya suggests, simply beget more research, sustaining a techno-scientific optimism at the cost of truncating its own horizon of actionability.

Conclusions

In understanding the logic of this kind of mirage—that is, the illusory hope implicit in HIV research among transgender communities which fixes our gaze on the future and negates the past—I find psychoanalyst Donald Winnicott's unfinished and posthumously published paper 'Fear of Breakdown' (1974) useful. In it, he wonders if what may be experienced as fear of some future event is actually 'the fear of a breakdown that has already been experienced' (idem, 104). Near the end of his essay, in a phrase that expresses his clinical perspective on a certain experience of breakdown but might just as easily describe our collective failures to confront HIV (and COVID-19), Winnicott remarks, 'It is necessary to think not of trauma but of nothing happening when something might profitably have happened. It is easier [...] to remember trauma than to remember nothing happening when it might have happened.' (Idem, 106.) What Winnicott elegantly elucidates, despite writing about a different topic, is a kind of logic that powerfully characterises medical science's affective investment in the future, which (i.e., the investment) is tied to its inability to apprehend and acknowledge the anti-trans violence of the past and present (Gill-Peterson 2018).

3 I do not necessarily see this as a form of 'cruel optimism' (Berlant 2011) as I would not go so far as to argue that optimistic investments in trans health research sustain the conditions of anti-trans violence. To do so risks a kind of flattening equivalence and, more importantly, reproduces exactly the fantasy of medical omnipotence that lies at the heart of medical optimism itself. Yet the fact that inclusion in medical research is justifiably seen as a victory should not preclude a critique of the broader project; see Savannah Shange on the 'win' in progressive education in San Francisco (Shange 2019).

In other words, one problem with the attempt to make use of medicine as a tool of social justice is that this approach seeks in vain a foundational injury, which it then overrepresents as the determinant of present inequity. (By injury, I mean a pattern of violence that research could re-present as a problem to be remedied by medicine.) This method involves pushing the moment of violence into the past, making it impossible to acknowledge that it is not merely historical neglect but also present violence that trans women must contend with, a fact that medical research may merely obfuscate. Tanya helps us understand the futility of searching for such a foundational injury using the tools of health research, reorienting us instead to the 'nothing' that happened when 'something' might have, if only it could have been profitable. We should follow her lead, embracing neither futility and hopelessness nor the mirage of medical salvation, in order to build collaborative relationships in the service of a more caring social medicine.

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