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PrEP at the Margins: Towards a Critically Applied Anthropology of Nordic PrEP Access

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In the spirit of this series on a 'critically applied' approach to PrEP, this piece shows how thinking with the concept of marginality can contribute to an analysis of pre-exposure prophylaxis (PrEP), and how this new HIV preventive technology can help us uncover issues of health disparities, even in spaces of affluence with state-provided health care. More specifically, this piece thinks through some of the ways in which PrEP use reveals how sexual and ethnic minorities in Norway are marginalized in global health discourse. The marginalization of these minority groups appears paradoxical, given that Norway often is lauded as a welfare state for its robust universal health care schemes as well as what is often referred to as a public health system that takes care of its citizens from 'cradle to grave'.

In Norway, ethnic minority communities and ethnic MSM and transgender communities in particular have, in recent years, carried the burden of new HIV infections in disproportional relation to other communities in the country. Yet this fact is often overlooked in scholarly literature on the topic and often relegated to the margins when designing initiatives meant to reach these specific communities. This essay argues that PrEP use and PrEP data in Norway demonstrate how, within a robust welfare state, some communities remain at the margins, despite being at the center of discourses on HIV prevention.

Country and Context

Norway has a small but concentrated HIV epidemic. According to data from 2018, the total number of people living with HIV (PLHIV) in Norway is 6,468; of these, 4,382 are men and 2,086 are women[1]. Heterosexual PLHIV account for 3,412, while men who have sex with men (MSM) account for 2,150. People who inject drugs account for a total of 640 while the rest of the 266 PLHIV are bracketed by the categories of 'blood/blood products', 'mother-child transmission', and 'unknown'[2]. While HIV incidences have declined amongst both heterosexual men and MSM in recent years, there are still disparities and unequal rates of infections. Of notable concern is the fact that ethnic minorities accounted in 2018 for 60

per cent of all new HIV infections amongst MSM.

PrEP implementation began in Norway in 2017 through a universal health care scheme wherein patients considered at ‘high risk’ of HIV infection could access the treatment for free through specialist clinics, not through general practitioners (GPs). Indications for PrEP in Norway are similar to other international guidelines on PrEP and mostly target MSM and transgendered women who have had unprotected anal sex with multiple sexual partners as well as a self-reported intention to continue high-risk behavior. STI’s, ‘chemsex’ (the consumption of drugs to enhance sexual performance) and ethnic minority background are also indications for starting on PrEP.

As of Summer 2019, there are approximately 1,150 people using PrEP in Norway; of these, 821 are on a daily dosing regimen (71.3%) while 330 are on an intermittent or event based doing regimen (28.7%). Of interest is that about 98% of all PrEP users in Norway are MSM, a figure that also shows that PrEP use is highly concentrated amongst MSM[3]. Thus, given that HIV epidemic in Norway is concentrated amongst certain communities as well as the fact that Norway has high HIV testing rates, free access to, and follow up of antiretrovirals (ARVs), one could be excused for thinking that Norway seems to be outside the scope of an article focusing on marginality. In fact, in combination with the fact that PrEP is free in Norway, one might even argue that the call for a focus on marginality is misplaced in the Nordic countries. From a pragmatic stand this might be somewhat true, however, this essay makes the case that spaces of such privilege do as much to mask disparities as they do to illuminate how it could be different in other spaces. In particular, this essay argues that Scheper-Hughes notion of a critically applied medical anthropology can contribute to highlighting and thus rectifying inequities in health care. A critically applied medical anthropology of PrEP in Norway provides a highly productive space for looking at how and when ethnic minority communities become marginalized and how the very use of PrEP by certain communities in Norway itself becomes a symptom of PrEP at the margins.

Paradoxical Marginality in Norway

Norway has a long history of providing its citizens with universal health care through a ‘generous welfare state’(Kildal and Kuhnle, 2007, Stephens, 1996). In this respect, Norway seem closer to a utopian space. However, Norway in the context of the HIV epidemic might offer some clues as to why it also can be considered a marginal space. With a relatively small and concentrated epidemic, Norwegian HIV research, be it biomedical or social scientific, is all but invisible in the international literature[4]. Moreover, since the public health system is very generous and robust, access to testing, ARVs, and care, is usually fairly straight

forward and easily managed by most. In this sense, Norway might be conceptualized as a ‘marginal space’ since it is often relegated to the margins as being ‘well-functioning’. It is often assumed that the welfare state shores up any disparities within public health and thus allegedly, offering no space for the *problematization* (Bacchi, 2015, Bacchi, 2012, Foucault, 2001) of the HIV epidemic and in this case, of PrEP specifically. In other words, marginality here is fostered by the perceived success of a small but rich and well-functioning welfare state, thus any ‘problems of the Norwegian welfare state’ is often relegated to the margins of both domestic and international attention.

However, this glosses over the fact that PrEP is also at the margins of various communities in Norway. Case in point; 62 per cent of all new HIV transmissions in Norway in 2018 amongst MSM were in communities of ethnic minority backgrounds. This seems to be a concerning trend as in the years between 2013 and 2019, MSM of ethnic minority backgrounds who tested positive for HIV after arriving in Norway has been close to 30% in each of these years, pointing to the disparity in reaching these communities. This is not counting the 2,304 individuals of immigrant background who live in Norway and who tested HIV-positive prior to coming to Norway. Data on PrEP uptake and access in the newest report on PrEP only disaggregates data according to where PrEP has been prescribed, sexual orientation, hereunder two categories of ‘MSM’ and ‘heterosexual’. Further disaggregation can be discerned by looking at the various clinics that have prescribed PrEP, wherein none of the 19 clinics offering PrEP have prescribed it for cis-women, including sex-workers. As such, the current PrEP data only offers us a partial picture of how PrEP is being rolled out geographically and how it targets MSM. Despite the general lack of attention to the role of marginality in PrEP use in Norway, the report does state that ‘there is a challenge to reach small, but particularly vulnerable groups’ in the country. By linking this recent statement to the long recent history in Norway of problematizing Norway’s ethnic others, we can start to see the contours of another form of ‘PrEP at the margins’.

Ethnic Marginalization

Ethnic minorities in Norway have a long history of occupying what scholars have called ‘a mobile paradoxical space’(Mahtani, 2001). That is, ethnic minorities are both at the center of discourses of HIV and at the discursive margins. In recent years, several white papers, media bulletins and public health initiatives have remarked that ethnic minorities are indeed both disproportionally affected by HIV in Norway, as well as in need of outreach programs that can cater to what are perceived as special needs amongst the various ethnic minority communities. Several media articles and governmental white papers have highlighted the need to reach ethnic

minority MSM and women in HIV preventive work as well as through treatment programs. Popular conversations about HIV in Norway includes claims that 'ethnic minority MSM are 'doubly stigmatized' and made 'invisible both in data and in media discourses'[5]. In particular, concerns about the double stigmatization of ethnic minority MSM and HIV has often been framed in connection to religious beliefs and cultural values.

Ethnic minority women are also noted as being in a precarious situation when living with HIV, as they often lack the support system to access either treatment and care or certain preventive measures. In addition, this groups often experience stigma, as was recently reported by the resource center for ethnic women, MiRA[6]. A report made by *The Norwegian Institute for City and District Research* argued that 'more needed to be done' in reaching ethnic minorities in terms of HIV prevention and treatment. Furthermore, the report highlighted the fact that there are few organizations who specifically works towards ethnic minority communities in regards to HIV preventive work and that several stakeholders have long drawn attention to this lack of work[7].

While calls have been made for more and better programs to reach ethnic minorities within HIV preventive efforts, and while some ground has been made, the latest data shows that; 1) not enough is being done to actually reach and prevent new cases of HIV amongst ethnic minority MSM; 2) that data on PrEP also needs to focus on these communities and insist on some form of 'data visibility'; and 3) PrEP initiatives aim for equitable and transparent programs that make good on the promise of 'leaving no one behind' even in robust welfare state funded programs.

The current predicament of national PrEP programs in Norway highlight the need for a critically applied medical anthropology, one which can 'radicalize medicine' – that is, harness its power, inhabit its knowledges and practices, and orient the entire social institution toward equitable ends (Scheper-Hughes, 1990). The marginality accorded to ethnic minorities in relations to PrEP in Norway can perhaps be better understood against the looming shadow of a perceived well-functioning welfare state. However, people are being 'left behind' and the disparities found in HIV services in Norway today seem to point in the direction of disparities which affect racialized ethnic minority MSM more so than others. Norway has a long tradition of funding HIV preventive efforts through initiatives such as NORAD and now, the Global Fund. Yet, the perceived 'success' of Norway's own contribution to global HIV initiatives as well as the general success of access to treatment and care in Norway might in fact gloss over Norway's own failures in reaching ethnic minority communities *within Norway* when it comes to PrEP and HIV services. This closely resembles Benton et.al.'s statement that

“what is glossed as “global” simultaneously visibilizes the West’s “success” in fighting an epidemic, while it also obscures [racialized and sexual minority communities in the case of Norway] from view in its past and ongoing failures. Conceptualizing these sites and projects as post-colonial offers a corrective to conceptualizations of the “global” in global health that marginalize discussions of health inequalities and social injustice within the West”(Benton et al., 2017:4).

PrEP at the margins is not just a play on words; rather it calls for an analysis and engagement of a critically applied medical anthropology of howmarginality in accessing PrEP within a robust welfare state is taking place, how it affects communities of ethnic and racial backgrounds and finally, how, we can contribute to equitable HIV preventive services even in what seems like a robust health care system.

A critically applied medical anthropology could offer us ways of seeing just how marginality is enacted within perceived centres of affluence, and would enable us to analyse the ways in which PrEP is accessed, how it is used, how it (re)configures networks of intimacies and finally, how we can better view *all* communities, even those that at the current moment are at the margins of the (affluent) centre.

Notes

[1] See the Norwegian Institute of Public Health; https://hivnorge.no/wp-content/uploads/2019/03/Hivarsoppgjor-2018.pdf

[2] For the entire epidemiological data, see the Norwegian Institute of Public Health; https://hivnorge.no/wp-content/uploads/2019/03/Hivarsoppgjor-2018.pdf

[3] These data are from a recent evaluation report of PrEP in Norway conducted by the National Competency Center for Sexually Transmitted Infections (Olafia) and Ullevål University Hospital

[4] For some examples of the Norwegian HIV litterature see; MIDDELTHON, A. L. 2005. A Room for Reflection: Self?Observation and Transformation in Participatory HIV Prevention Work. *Medical Anthropology Quarterly,* 19**,** 419-436, MIDDELTHON, A.-L. & AGGLETON, P. 2001. Reflection and dialogue for HIV prevention among young gay men. *Aids care,* 13**,** 515-526, MIDDELTHON, A. L. 2001. Interpretations of condom use and nonuse among young Norwegian gay men: A qualitative study. *Medical Anthropology Quarterly,* 15**,** 58-83, MIDDELTHON, A.-L. 1997. Infection among Young Gay Men in Norway. *AIDS: Activism and alliances***,** 100, BERG, R. C. 2013. Predictors of never testing for HIV among a national online sample of men who have sex with men in

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[5] See Norwegian newspaper *Aftenposten* for a Norwegian article on the topic:
https://www.aftenposten.no/norge/i/JQ5VR/Den-usynlige-sykdommen

[6] See MiRA centers own webpage,
https://mirasenteret.no/om-mira/nyheter/pressemeldinger/vanskelig-situasjon-for-minoritetskvinner-med-hivaids-let-liv-i-skyggenr/

[7] See the full report here;
https://evalueringsportalen.no/evaluering/mer-maa-til-om-hivrettet-arbeid-overfor-innvandrere/2012-29.pdf/@@inline

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