Decolonising the HIV Care Cascade: Policy and Funding Recommendations from Indigenous Peoples Living with HIV and AIDS

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Indigenous Peoples in settler colonial nations, like Canada, continue to experience intergenerational trauma, racism, socioeconomic disadvantages, and pervasive health disparities resulting from centuries of systemic oppression. Among these, is the disproportionate burden of HIV in Indigenous Peoples in Canada, coupled with a lack of access to care and services. One method of assessing systems-level gaps is by using the framework of the HIV care cascade, which focuses attention on diagnosis of individuals, initiation of antiretroviral treatment, and achievement and maintenance of viral suppression. The cascade, as it stands today, does not yield positive outcomes for Indigenous Peoples living with HIV. In order to close existing gaps, the authors sought to decolonise the HIV care cascade by rooting it in funding and policy recommendations provided directly by Indigenous Peoples living with HIV. This research presents 29 recommendations that arose when First Nations participants living with HIV partook in traditional storytelling interviews to share their life's journey and offer suggestions for improving access to care and services. Said recommendations are to localize testing and diagnosis (while upholding confidentiality), improve access to culturally-appropriate care and services, provide targeted programming for Indigenous women and heterosexual men, and increase funding for provincial disability benefits; important steps in decolonising the HIV care cascade.

Keywords: *Indigenous, First Nations, HIV, AIDS, care cascade, policy, health equity*

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Introduction

Colonialism has a long history of violently intervening into the life of Indigenous Peoples in Canada (a collective term for those who are First Nations, Inuit, or Métis) through policies such as the *Indian Act* (1985), the construction of residential schooling, the 60's scoop, theft of lands, the reserve system, and the overrepresentation of Indigenous Peoples in Canadian prisons (Oliver et al., 2015). Colonial policies have produced inequities across the social determinants of health tied to intergenerational trauma and a persistent lack of funding and services for Indigenous Peoples. Indigenous Peoples continue to resist the processes of colonisation all while remaining resilient to significant adversity and a continued systemic effort to eradicate them as a people. However, socioeconomic disparities are seen across every facet of health, including: heavy infectious disease burdens, significantly shortened life expectancy; diseases and death associated with cigarette smoking; illnesses and deaths linked to misuse of alcohol and other drugs; intimate partner violence; homicide and suicide; obesity, diabetes, hypertension, cardiovascular, and chronic renal disease; and diseases caused by environmental contamination (National Collaborating Centre for Aboriginal Health, 2013, p. 4). Yet another disproportionate health burden facing Indigenous Peoples of Canada and their communities is that from Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS). The estimated HIV prevalence rate for Indigenous Peoples in Canada in 2016 was 362 per 100,000 population which is two times higher than in the general population (Public Health Agency of Canada, 2018). Despite Indigenous Peoples making up only 4.9% of the Canadian population (in 2016; Statistics Canada, 2017), Indigenous women accounted for

30.9% of new HIV cases in Canadian women and Indigenous men accounted for 16.3% of new HIV cases in Canadian men (in 2017; Haddad et al., 2019). However, given significant issues with HIV data collection and reporting, there is limited data on the true impact of HIV and AIDS on this population.

One way to assess gaps in current HIV care and engagement is by using the HIV care cascade, a tool that outlines the stages of care people living with HIV encounter, starting from testing and diagnosis, to initiating antiretroviral treatment, and finally, treatment adherence to maintain viral suppression (Ontario Advisory Committee on HIV/AIDS, 2017). In theory, if everyone living with HIV were able to access and engage with care at each stage of the cascade, the virus would no longer be transmitted. However, individuals can encounter barriers at each step of the cascade due to poor service access, lack of HIV education, stigma and discrimination, poverty, food insecurity, homelessness, and mental health and substance use (Hull et al., 2012), all of which are faced by Indigenous Peoples today. As a result, there is a substantial disconnect between the priorities of the HIV care cascade and the real experiences of Indigenous Peoples living with HIV (Jongbloed et al., 2019).

Concerted efforts are required to decolonise the HIV care cascade, or rather, close the health, discriminatory, and socioeconomic barriers faced by Indigenous Peoples. This large study explored the policies and funding arrangements for HIV/AIDS prevention and treatment in First Nations communities in Ontario, Canada. Particular attention was given to the origin of funding and service delivery, how health and social services are utilized, and the specific role each level of government played in the funding and delivery of services. In this research, 29 First Nations

people living with HIV and AIDS in Ontario provided, through storytelling, their first-hand experiences of the pervasive effects of colonial trauma and how the intersection of racism and HIV stigma has affected their ability to seek confidential, localized, culturally-competent care. Storytelling allows for unmediated sharing of Indigenous experiences and knowledges, and is a pedagogical tool for learning about life (Iseke, 2013). Through participant stories arose a set of 29 recommendations for action at various levels of government and by First Nations communities to re-evaluate current practices of funding and service delivery and diminish Indigenous health inequities across the HIV care cascade.

Methods

This research was conducted alongside Indigenous Peoples living with HIV and followed the Tri-Council Policy Statement on research involving First Nations people, it was approved by the Ryerson University Research Ethics Board (REB 2015-343). Given the legacy of traumatic research conducted upon Indigenous Peoples, it was essential to be respectful of, and give agency to, the knowledge conveyed by participants to researchers. Therefore, this research was developed, directed, and overseen by two Indigenous HIV organisations and a comprehensive reciprocal research agreement was entered into by all parties. Twenty-nine diverse First Nations people living with HIV and AIDS who were or had been living in remote/isolated First Nations in Northern Ontario participated. Due to issues of confidentiality, interviews took place in six cities (Toronto, Thunder Bay, North Bay, and Sudbury, Hamilton, and Chatham) where participants were either now living or visiting in order to receive treatment/services. Participants identified as male (n=13), female (n=12), or Two-Spirit

(n=4). The average age of participants was 48 years, with an average monthly income of \$1,362 CAN. All participants identified as recipients of the Ontario Disability Support Program. Education varied across participants, with 38% (n=11) not attaining higher than grade 9, 10% (n=3) completing grade 10 or 11, 17% (n=5) completing high school, 10% (n=3) completing some college, and 24% (n=7) completing a college or university degree (for a full breakdown of participant demographics, please see [Hillier et al., in press]).

Data were obtained through the Indigenous method of storytelling (Iseke, 2013), which places oral history and ceremony at the forefront. Participants were offered tobacco as a form of consent and paid a \$50 honorarium. The use of tobacco was a cultural connection to traditional medicines, which are critical to storytelling. The storytelling and re-storying process was explained to participants along with their options to withdraw at any point of the research process. Participants were asked six open-ended questions about the impact of HIV and AIDS on their lives, their access to services and treatment, and mitigating factors related to their HIV status that may have forced them to move from their northern communities to urban centres. After transcription, data were de-identified using pseudonyms (chosen by the participant or assigned by the researcher), and six undergraduate students re-storied the transcripts by removing the facilitators' questions and comments. Participants were given the ability to review and change/withdraw their completed stories upon completion of this process, no participants did so. The data were then formatted and edited by the lead author into a set of uniform first-person stories of each participant's life's journey.

Story transcripts were uploaded into the software program NVivo 2017 and

coded. This process was chosen at the request of the two Indigenous HIV organisations, as to better understand, organize, and ascertain patterns in the issues facing First Nations people living with HIV and AIDS. This process uncovered 17 major themes, representing some 143 individually-coded nodes. These themes have been presented, contextualized, and discussed previously in (Hillier et al., 2020). Participants were asked to provide recommendations for improving access to services and treatment for First Nations people living with HIV and AIDS. Twenty-six participants gave recommendations, which have been collated and presented in this research paper. Prior to finalizing the list, it was sent back to participants who consented to be re-contacted by our two Indigenous research partners for feedback and approval. The recommendations each begin with 'we', as they represent a collective request of the individuals and partner organisations who contributed. Our aim was to capture the voices of Indigenous Peoples living with HIV and AIDS and incorporate them into a larger body of knowledge and literature to inform their overall depth. The authors of this study come to this work with their own unique worldviews and experiences that has helped to inform this research. The principal author is a queer mixed Mi'kmaw / settler person who grew up economically disadvantaged in a small isolated community in rural Newfoundland. Co-author Lavallée is an Anishinaabek Qwe registered with the Métis Nation of Ontario and served as the doctoral supervisor of this research, while Winkler is a queer settler who does community-based HIV research with a provincial HIV organisation and is currently a medical student intending to work with Indigenous Peoples.

Results

The recommendations are divided into five calls, each representing a different governing body or collective. First, there is one recommendation directed toward Indigenous Peoples living with HIV and AIDS. Second, recommendations are directed toward the federal government for the overall improvement of funding and access to HIV and AIDS treatment, care, and services amongst First Nations communities. Third and critically, recommendations are directed toward the provincial government who are responsible for many of the services and programs accessed by Indigenous Peoples living with HIV off-reserve. Fourth, recommendations are provided for First Nations communities and political organisations (i.e., Chiefs of Ontario) who can improve the conditions of their people in relation to stigma, education, and access to services within their communities. Fourth, recommendations are provided for non-Indigenous HIV and AIDS community organisations who act as a main resource for many Indigenous Peoples unable to access Indigenous-specific resources. Finally, recommendations are provided for Indigenous HIV and AIDS service organisations to help improve service delivery to their clients.

Indigenous People living with HIV and AIDS

1. We call on all Indigenous Peoples living with HIV and AIDS to seek testing, treatment, services, and programs. We call on them to continue their treatment so as to achieve and maintain an undetectable viral load.

Federal Government

2. We call upon the federal government to resolve jurisdictional confusion surrounding Indigenous HIV and AIDS funding by creating a clear policy that details its responsibility for funding HIV

and AIDS care and services for First Nations people living on reserves in Canada. This policy can take the form of a ministerial directive that will clearly provide direction to the bureaucracy regarding funding allocation to First Nations communities for delivery of programs and services related to HIV and AIDS. This will provide clear guidance so First Nations communities can understand what funding they can access and where they can access it.

3. We call on the federal government to provide sustainable and adequate funding for HIV and AIDS care, treatment, programming, and services in First Nations communities. This funding should be stable and long-term, to avoid creating unnecessary work for communities in having to apply and re-apply for funding on an annual or semi-annual basis.
4. We call on the federal government to continue its commitment to addressing the significant issues affecting Indigenous Peoples across the north including poverty, lack of education, lack of adequate housing, lack of clean drinking water, addressing youth suicide, and the continued trauma experienced by Indigenous Peoples. Without tackling such underlying issues, the incidence of negative coping mechanisms will continue to drive up the incidence of HIV and AIDS within the Indigenous population.
5. We call on the federal government to provide a funding envelope that allows access to culturally-based healing treatment for Indigenous Peoples living with HIV and AIDS. This should include funding for culturally-based programming and services that can be accessed by both Indigenous and non-Indigenous organisations.
6. We call on the federal government to provide a dedicated funding envelope for services and programming, both culturally-based and not, to meet the unique needs of Indigenous women living with HIV and AIDS. This recognizes that Indigenous women face high rates of violence by males in our society and urgently require dedicated space and services to address the high incidence rates of HIV in this sub-population.
7. We call on the federal government to provide a funding envelope for services and programming, both culturally-based and not, to meet the needs of heterosexual Indigenous males living with HIV and AIDS. HIV and AIDS affects Indigenous heterosexual males at higher rates than the general public, and most services and programming are directed toward men who have sex with men and women.
8. We call on the federal government to provide a funding envelope for HIV education in First Nations communities, with a focus on youth. We must remember that HIV prevention is a cost-saving endeavour for everyone. This funding should seek out culturally-based education programs that focus on the unique challenges and risks faced by Indigenous Peoples living in remote and non-remote communities.
9. We call on the federal government to work with provinces to increase access to HIV and sexually transmitted and blood borne infections (STBBIs) testing (including rapid and anonymous testing) along with access to specialists and treatment within First Nations communities. This should include more stringent accountability measures to ensure patient confidentiality.
10. We call on the federal government to provide a funding envelope to increase

access to harm reduction measures within First Nations communities across the north. This includes spaces like safe injection sites for individuals who use drugs.

11. We call on the federal government to do as people ask. Indigenous Peoples living with HIV and AIDS must grapple through bureaucracy to access care, treatment, programming, and services required for survival. Indigenous Peoples must be able to access the care they need in a streamlined fashion, without daunting requirements that take time, resources, and significant effort, with no guarantee that their requests will not be declined. Having a clear policy that lays out what can and cannot be funded, and where to access that funding, can assist in solving this problem.

Provincial Government

This research focused on First Nations in Ontario; however, these recommendations are applicable for other provinces and territories.

12. We call on the provincial government to increase its funding of the Ontario Disability Support Program (ODSP) for people living with HIV and AIDS. Indigenous Peoples already struggle with homelessness; many think their benefits are too little to survive on, and this leaves them facing issues that exacerbate their health problems.
13. We call on the provincial government to provide a funding envelope for provincially-funded AIDS service organisations (ASOs) to provide access to culturally-based healing treatment for Indigenous Peoples living with HIV and AIDS. This should include funding for culturally-based programming and services that can be accessed by both Indigenous and non-Indigenous

organisations. This is in recognition of the fact that many, if not most, Indigenous Peoples are forced to leave their communities for off-reserve treatment by provincially funded ASOs.

14. We call on the provincial government to implement Indigenous cultural safety training for all physicians and medical care professionals within the province. This is in recognition of the treatment participants have received by provincially-mandated and supervised physicians. This recommendation supports the call by the Truth and Reconciliation Commission of Canada to create an environment where culturally appropriate medical care is the standard, whereby all people are treated with respect and their cultural beliefs are acknowledged.

Indigenous Communities and Political Organisations

15. We call on Indigenous communities and political organisations to be receptive to HIV and AIDS education and harm reduction initiatives undertaken by other levels of government and ASOs. This includes actively seeking out funding and opportunities to support such work in their communities.
16. We call on Indigenous communities and political organisations to educate members of their council and respective healthcare teams about HIV and AIDS, issues of confidentiality, stigma, and the supports or services they can provide.
17. We call on Indigenous communities and political organisations to work with their communities to address the issue of HIV and AIDS stigma within their communities. Only by breaking the cycle of stigma and rejection can we begin to eradicate HIV within our communities.
18. We call on Indigenous communities and political organisations to work with

ASOs in accepting community members back after they have passed on to the spirit world. Communities should be prepared to receive their member and allow them a dignified burial in their home.

Non-Indigenous HIV and AIDS Community Organisations

19. We call on Non-Indigenous HIV and AIDS community organisations to undertake initiatives to educate members of their staff about colonisation and the unique issues faced by Indigenous Peoples living with HIV and AIDS.
20. We call on Non-Indigenous HIV and AIDS community organisations to work with Indigenous groups and ASOs to implement culturally-based, competent programming and services for Indigenous Peoples.
21. We call on Non-Indigenous HIV and AIDS community organisations to implement culturally-based, competent programming and services for Indigenous women. This may include dedicated space and time for women's-only programming, in recognition of the disproportionate violence Indigenous women face.
22. We call on Non-Indigenous HIV and AIDS community organisations, especially those in the north, to implement programming and services for heterosexual Indigenous males. This is in recognition of the growing incidence of HIV in this group and a lack of specific resources available to them.

Indigenous HIV and AIDS Organisations

23. We call on Indigenous HIV and AIDS organisations to seek funding to implement programming and services for Indigenous Peoples. This should include education about the cultural

healing practices of their clients and advocating for culturally-based care in accordance with their clients' wishes.

24. We call on Indigenous HIV and AIDS organisations to implement culturally relevant and competent HIV education in First Nations communities and urban areas with a particular focus on Indigenous youth.
25. We call on Indigenous HIV and AIDS organisations to implement culturally relevant and competent HIV harm reduction practices that can be deployed in remote or hard to access First Nations communities alongside urban centres.
26. We call on Indigenous HIV and AIDS organisations to partner with non-Indigenous ASOs to assist in the implementation of culturally-based, competent programming and services for Indigenous People.
27. We call on Indigenous HIV and AIDS organisations to ensure targeted programming and services for women. This may include dedicated space and time for women's-only programming, in recognition of the disproportionate violence Indigenous women face.
28. We call on Indigenous HIV and AIDS organisations to ensure targeted programming and services for heterosexual males, especially in the north. This is in recognition of the growing incidence of HIV in this group and a lack of specific resources available to them.
29. We call on Indigenous HIV and AIDS organisations to work with First Nations communities to assist them in receiving their [deceased] members for burial.

Limitations

A number of limitations are reflected in this research study. Given the timeframe and availability of resources, it was only possible to conduct storytelling interviews

with 29 participants. However, given the target population, the authors believe this was an appropriate sample size to produce the robust recommendations included in this research study.

There were community engagement issues throughout the study, which caused this study to go three years over its anticipated duration. Both community agencies experienced significant staff changes and internal governance challenges throughout, which had a significant impact at the start of the research process and in being able to recruit participants. The loss of multiple executive directors from both organisations was overcome by continued engagement with the new executive directors or the organisation's board of directors.

Discussion

Decolonising the HIV Care Cascade

Recommendations related to Indigenous Peoples are often presented as an act of reconciliation, or a new way forward. The authors reject this approach due to the problematic implication that Indigenous Peoples were once whole, experienced a rift, and can, through reconciliation efforts, become whole again (Stanton, 2011). Indigenous Peoples were never approached as equals, and instead, systematically oppressed, marginalized, and silenced by settler colonialism. This has produced widespread health and socioeconomic inequities and continues to contribute to the disproportionate HIV burden facing Indigenous Peoples. Despite this, Indigenous Peoples have demonstrated persistent strength and resilience in the face of adversity. In their interviews, participants shared a desire to create a better life for younger people and others living with HIV, which can only be achieved with new policy and funding efforts. The recommendations

in this paper, rooted in Indigenous voices, address the inequities faced by Indigenous Peoples living with HIV when seeking confidential testing and diagnosis, sustaining access to antiretroviral treatment, and maintaining viral suppression.

Uptake of Testing and Diagnosis

Decolonising the HIV care cascade must begin with localized rapid diagnostic testing in Northern and remote communities and increased cultural competency towards Indigenous Peoples in urban testing centres. Participants recommended “increased access to HIV and sexually transmitted and blood borne infections (STBBIs) testing (including rapid and anonymous testing) along with access to specialists and treatment within First Nations communities.” Indeed, the largest cohort study of people living with HIV in Ontario placed Indigenous participants at a higher risk for very late diagnosis compared to other populations and concluded that an unmet need is access to HIV testing (Wilton et al., 2019). This recommendation also emphasizes the “stringent accountability measures to ensure patient confidentiality”, as a lack of anonymity in communities is a barrier to testing and diagnosis. Concerns around confidentiality and discrimination towards one's status have been documented in other Canadian research (Woodgate et al., 2017), ultimately pushing Indigenous Peoples living with HIV out of their communities for care. In order to combat the stigma and discrimination experienced within communities, HIV education for “members of their council and respective health care teams about HIV and AIDS, issues of confidentiality, stigma, and the supports or services they can provide” is required alongside a “funding envelope for HIV education in First Nations communities with a focus on youth.” This can be achieved by empowering and supporting peer educators,

as demonstrated in the Taking Action II study, where eighteen Indigenous youth leaders from across Canada shared their stories and promoted change by facilitating peer-led, community arts-based programs and sexual health outreach initiatives (Monchalin et al., 2016).

Access to Treatment and Services

Following testing and diagnosis, people living with HIV require continuous, reliable treatment and care. As recommended, funding for treatment should be stable and long-term so there is no “unnecessary work for communities in having to apply and re-apply for funding on an annual or semi-annual basis.” Indigenous Peoples being treated outside their community should have access to safe, culturally-competent care. These recommendations call for the “implementation of Indigenous cultural sensitivity training for all physicians and medical care professionals” as well as “culturally-based and competent programming and services” at all Indigenous and non-Indigenous HIV and AIDS organisations. Indigenous medicine differs from Western medicine, extending beyond the physical domain to a wholistic (cultural, spiritual) approach grounded in knowledge, belief, and ceremonies. The Western health care system is not always prepared to provide these comprehensive services (Lewis & Myhra, 2018). However, mounting evidence suggests that the integration of Western medicine and traditional medicine is feasible both in communities and larger, urban centres. Traditional medicine has been successfully integrated in a Northern community health centre on Manitoulin Island (Manitowabe & Shawande, 2013), in a rural hospital in Sioux Lookout, where an Elders advisory council provides governance and decision-making around culturally-safe palliative care

treatment (Pierre-Hansen et al., 2010), and an urban primary care clinic in British Columbia, where a culturally-informed, chronic care model for HIV patients has reduced all-cause mortality rates (Klakowicz et al., 2016).

Targeted programming is required for “heterosexual males, especially across the north. This is in recognition of their growing incidence of HIV in this group and a lack of resources available to them.” In a recent analysis of a large cohort of people living with HIV, compared to gay and bisexual men, heterosexual men were more likely to have lower socioeconomic status, a history of injection drug use, greater incidence of Hepatitis C co-infection, and to be Indigenous (Wheeler et al., 2017). Efforts should be made by Indigenous and non-Indigenous service organisations to create programming directed at heterosexual men (in addition to the programming that exists for men who have sex with men or women).

Indigenous women living with HIV should have “dedicated space and time for women’s-only programming, in recognition of the disproportionate violence Indigenous women face.” A history of colonial abuse has left Indigenous women living in poverty and often disconnected from their family and communities (Varcoe & Dick, 2008). Analysis of a cohort of 1,425 women living with HIV found that Indigenous women had higher adjusted odds for a lack of access and delayed access to HIV care (Kronfli et al., 2017). Disproportionate rates of HIV, violence, and involvement in sex work maintain the case that Indigenous women require specific, culturally-safe programming where they feel empowered to access care.

Achieving and Maintaining Viral Suppression

Recommendations call on Indigenous Peoples living with HIV “to

continue their treatment so as to achieve and maintain an undetectable viral load.” Medication adherence can only be maintained with sustained access to antiretroviral therapy and consistent funding for medications. Therefore, these recommendations call on the provincial government to “increase its funding of the Ontario Disability Support Program (ODSP) for people living with HIV and AIDS.” Adherence remains a challenge for those facing precarious housing and addictions issues. As ODSP has only recently extended support to those facing addictions (in the last decade), this recommendation goes hand in hand with “increase[d] access to harm reduction measures within First Nations communities across the north. This includes having spaces such as safe injection sites for individuals to access.” Access to programs like Maximally-Assisted Therapy (MAT), an interdisciplinary care intervention for HIV-positive individuals with a history of addictions and homelessness, has been associated with optimal medication adherence amongst Indigenous participants (Barker et al., 2018) and should be implemented wherever possible.

Unfortunately, as the recommendations highlight, adherence can be complicated by any of the significant issues affecting Indigenous Peoples across the north including:

“poverty, lack of education, lack of adequate housing, lack of clean drinking water, addressing youth suicide, and the continued trauma experienced by Indigenous Peoples. Without tackling [these] underlying issues, the incidence of negative coping mechanisms will continue to drive up the incidence of HIV and AIDS within the Indigenous population.”

Coupled with the racism, stigma, and discrimination faced by Indigenous Peoples living with HIV, the barriers to maintaining

adherence are numerous and require support from all parties outlined in our recommendations. Although Indigenous Peoples display a tremendous amount of resilience in the face of adversity, federal and provincial governments must address the widespread socioeconomic disparities, rooted in colonialism, that persist today. Indigenous communities and Indigenous HIV and AIDS organisations should work hand in hand to ensure communities are educated about HIV and that Indigenous Peoples living with HIV are accepted and have access to treatment. These recommendations also provide a call to action for non-Indigenous HIV organisations to ensure staff are educated about colonisation and trained to provide culturally-competent services. Without changes to policy, funding, community support, and access to culturally-safe services and care, HIV transmission and progression will continue to affect Indigenous Peoples disproportionately, reinforcing the gaps in the HIV care cascade.

Conclusion

This set of recommendations acts as a resurgence of Indigenous voices to claim agency over the funding, cultural competency, and support needed to achieve wholistic well-being and engage in all levels of the HIV care cascade. Resurgence is a way to restore and regenerate Indigenous nationhood (Snelgrove et al., 2014). As such, these recommendations are a tangible collection of principles to stimulate and actualize said nationhood. Due to the colonialism that permeates Canadian society, these recommendations alone cannot impact change; the funding and support of government bodies, Indigenous leaders, Indigenous and non-Indigenous HIV and AIDS organisations is required across all provinces and territories. This is a

call to action to create and sustain equitable access for Indigenous Peoples living with HIV; closing the gaps in the Indigenous HIV care cascade.

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