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'Culture' as HIV Prevention: Indigenous Youth Speak Up!

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2014

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This article was originally published at:

<http://epress.lib.uts.edu.au/journals/index.php/ijcre/article/view/4802/5575>

Citation for this paper:

Wilson, C., Oliver, V., Flicker, S., Native Youth Sexual Health Network, Prentice, T., Jackson, R., ... Mitchell, C. (2016). "Culture" as HIV prevention: Indigenous youth Speak Up!, *Gateways: International Journal of Community Research and Engagement*, 9(1), 74–88. doi: 10.5130/ijcre.v9i1.4802

'Culture' as HIV prevention: Indigenous youth speak up! | Wilson

Indigenous Youth Speak Up!

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Gateways: International Journal of Community Research and Engagement
Vol 9/No 1 (2016)

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DOI: <http://dx.doi.org/0.5130/ijcre.v9i1.4802>

ISSN 1836-3393

Published by UTS ePRESS

<http://epress.lib.uts.edu.au/journals/index.php/ijcre/index>

One rainy spring evening, our research team was preparing for a community report-back session on the Taking Action community-based participatory action research project in Kahnawà:ke, a Mohawk reserve located near Montreal. We presented our major research findings by showcasing several of the arts-based products (e.g. murals, paintings, hip hop songs and videos) produced by youth participants during the project, linking structural inequity to HIV vulnerability (Flicker 2012; Flicker et al. 2014a, b). The event culminated in a conversation with the audience on the issues raised in the project. During the discussion, one man asked: 'Why are Aboriginal youth into hip hop, wearing baggy clothes and acting Black?' Many of the youth present were frustrated by the question. They tried to explain that Indigenous cultures are not static; rather they are fluid and change over time. They felt that expression through hip hop and 'new' forms of art were mediums as

powerful as drumming circles or pow-wows for conveying their health promotion messages to their peers. One of the adults in the room chimed in, stating, 'Ya, I do photography. That is not often seen as a traditional Aboriginal art form, but what does it mean to be "authentically" Aboriginal?' Not completely sure if he was satisfied with the answers he had received, the man sat back in his seat mulling over the responses.

The discussions in this community exemplify the challenges between representations of Indigenous identity and traditional and contemporary Indigenous cultures. They highlight the ways in which Indigenous identity is often thought to be synonymous with 'static', 'primitive' and 'unchanging' traditions that are often juxtaposed with 'contemporary' practices (King 2011). This vignette also demonstrates how Indigenous identity expression has taken on political, historical, racial and nationalist signification and remains a site of much tension, both within and outside Indigenous communities in Canada.

In this article, we explore (a) the ways Indigenous youth involved in an HIV intervention take up and reclaim their cultures as a project of defining self, and (b) the way Indigenous culture can be used as a tool for resistance, HIV prevention, and health promotion more generally. Here, we draw on Simpson's (2011) definition of culture as a series of interrelated processes (e.g. activities, ceremonies) that engage our full beings and require our full presence (mental, physical, spiritual, etc.) in order to survive, live full lives and grow.

BACKGROUND

Tensions surrounding Indigenous culture and identity are situated in the nation-building history of Canada, in which racial classifications were layered upon legal definitions and were deemed necessary for socially constructing a 'strong' white settler society as superior to, and separate from, Indigenous communities and other racial minorities (Mawani 2002). The very existence of settler society and its stake in the ownership of land and resources were dependent on defining and legislating 'Aboriginality' and maintaining a racial apartheid that defined who could lay claim to nationhood and access resources (Banton 2000; Das Gupta 2009; Furedi 2001; Lawrence 2003; Mawani 2002). Towards this end, Aboriginal identification (i.e. Indian status) was made synonymous with race, blood quantum, prescriptive physical and phenotypic characteristics, and a political-legal relationship to the state (Lawrence 2003). Legislation like The Indian Act (which was enacted in 1876 with the goal of assimilation through institutions such as residential schools and land regulation) resulted in very real differences in the experiences of 'Nativity' in Canada and exemplifies the countless ways Indigenous identity has been highly politicised and embedded in systems of power along the intersections of race, gender and class (Lawrence 2003).

In this article, the terms 'Aboriginal' 'Native' and 'Indigenous' are used interchangeably, reflective of the inconsistent use and broad disagreement on the legitimacy of appropriate labels for the identity of the first peoples of Turtle Island – an Indigenous term used to refer to North America (Adelson & Olding 2013). The definition of the term 'Indigenous' signifies descendants of peoples who originally inhabited a geographical region in pre-colonial times and maintain distinctive cultural, economic and political ties to their land (Amadahy & Lawrence 2009). It is important to note, however, that these legislated definitions were meaningless to Indigenous nations prior to colonisation; they are thought to have homogenised hundreds of diverse Indigenous tribes, nations and cultures; forcibly replaced traditional Indigenous ways of identifying the self, which relied on a relationship to land, space, place and community identity; and afforded the Canadian government substantial control over definitions of Indigeneity (LaRocque 2011; Lawrence 2003).

The operation of historic and ongoing forms of systemic oppression and colonisation, such as racism and social, economic and political disenfranchisement, have not only resulted in contentious debates about definitions of Indigenous identity and sovereignty, but have had an impact on every aspect of Indigenous life, including health inequities. Indigenous communities are over-represented in many poor health outcomes, including the HIV epidemic (Adelson 2005; Reading & Wien 2009). Aboriginal communities account for 4.3 per cent of the Canadian population and yet account for 15.9 per cent of the reported HIV cases (Public Health Agency of Canada 2013). Aboriginal youth are at greater risk than their non-Aboriginal counterparts, with 32.6 per cent of the positive HIV test reports from 1998 to 2008 being among Aboriginal youth aged 15–29, as compared with 20.5 per cent among those of other groups (Public Health Agency of Canada 2010). Indigenous youth are also diagnosed with HIV and AIDS at younger ages (Public Health Agency of Canada 2010). Existing health promotion practices in public health often focus on individual models of risk (Flicker et al. 2014a). However, when left un-contextualised by the social determinants of health, 'risk models' and HIV statistics help to sensationalise stories about the primitive, 'culturally backward' Native (or racialised other) who is unable to control his/her instincts, emotions and sexual desires (Lawrence 2003, 2004; Mawani 2002; Richardson 2008). Inherent to these dominant narratives is the portrayal of Aboriginal (and racialised) bodies as public health hazards, vectors of disease and pollutants. Indigenous people are thought to lack the knowledge and behavioural mannerisms of a 'proper Canadian', the rational and collected White person who

occupies a role of purity, authority and normalcy in dominant discourse (LaRocque 2011; Richardson 2008). By contrast, contextualised models of health promotion understand health disparities as a direct consequence of compounding factors such as inequitable socio-geopolitical histories (Flicker et al. 2014a; Kaufman et al. 2007a; McIvor, Napoleon & Dickie 2009; Ricci et al. 2009; Steenbeek 2004; Steenbeek et al. 2010).

Behaviour change interventions need to move beyond the individual to address interpersonal, social, environmental, cultural and structural factors, which can be potent forces in prevention efforts (Devries et al. 2009; Kaufman et al. 2007a; Wilson & Miller 2003). Numerous studies have found that health and wellbeing are integrally connected to culture (Fagan & McDonnell 2010; Kaufman et al. 2007b; Leston, Jessen & Simons 2012; Mooney-Somers et al. 2012; Ricci et al. 2009; Rushing & Stephens 2012; Wilson & Miller 2003), and this is especially true for Indigenous communities where culture and language act as buffers/protective factors against negative effects of risk (McIvor et al. 2009). Many Indigenous youth value working with and seeking counsel from trusted adults and elders as these approaches are holistic and build bridges for intergenerational communication and knowledge exchange (Bouris et al. 2010; Ricci et al. 2009). Strategies that centre on cultural reclamation, reconnection and re-engagement can focus on the knowledge, skills, talents and capacities of youth, as well as highlight the preventive measures young people are already taking. These approaches are strengths based, promote positive identity formation and counter stereotypes of the health issues facing Indigenous communities by highlighting their resilience and ability to flourish (Mooney-Somers et al. 2012; Restoule et al. 2010).

In this article, we focus on how youth see and understand their culture in relation to their identities and health. We do so as a first step to reimagining HIV prevention possibilities that offer an alternative to conventional public health practice which seeks to isolate behaviours (e.g. condom use) from social, political and historical contexts. In doing so, we hope to offer a counter narrative to the ways in which health promotion can be achieved.

METHODS

Arts-based approaches have been widely used in HIV research and health promotion inquiry and advocacy (Catalani & Minkler 2009; Cole & Knowles 2008; Denzin & Lincoln 2011; Markus 2012; Wang & Burris 1997). Following in this tradition, the *Taking Action Project: Using Arts-Based Approaches to Develop Aboriginal Youth Leadership in HIV Prevention* explored (a) the potential for using the arts to engage Indigenous youth in HIV leadership and health promotion activism, and (b) how they linked structural inequality with individual risk through their art. In-depth methodological details are provided elsewhere (Flicker et al. 2014a, b; Oliver et al. 2015), however we provide a brief overview here (Figure 1). The project underwent ethical review at the four participating universities (York, McGill, McMaster and the University of Toronto); the study design was also reviewed by participating Indigenous communities and, where appropriate, community consent was sought.

Figure 1: Taking Action methodology summary



We adopted a community-engaged, sex positive, strength-based approach premised on the idea that Indigenous youth are strong, resilient and knowledgeable, and many have the capacity required to be leaders in their communities. We hired, trained and supported youth coordinators from six different Indigenous communities across Canada to lead customised arts-based weekend workshops for their peers which explored the links between structural inequality and HIV (Yee et al. 2010). Each workshop offered a mix of traditional art-making activities such as carving, painting, throat singing and drumming, along with more contemporary

art forms such as hip hop, theatre and photography. As the workshops happened sequentially, art created in one community was shared with subsequent sister communities to both spark dialogue about HIV and inspire the creative process. We also engaged in a variety of interactive games and activities to support HIV education, such as 'Sexual Health Bingo', which simultaneously encouraged networking and discussions about HIV among workshop participants; 'Connect it!' where, using post-its, participants wrote words they linked to HIV and colonisation and then tried to link them graphically; and condom-on-banana relays (Yee et al. 2010). Elders were available throughout the workshops as supports and ceremonial facilitators. Elders are respected culturally knowledgeable individuals who are skilled at translating knowledge within communities (Flicker et al. 2015). They provided ceremonial and ethical guidance to assist the research process (Flicker et al. 2015).

Across the six communities, over 100 young people (aged 13–29) participated in art-making; 88 of these youth filled out demographic surveys and consent forms, and 70 subsequently participated in private 1:1 in-depth follow-up interviews conducted by the research team to reflect on their experiences (six to eight weeks after the workshops). Youth were provided with free meals and art supplies at the workshop and received a \$20 honorarium for participating in the follow-up interview. Interviews focused on how they felt about the workshop, their understandings of the reasons for the elevated rates of HIV among Aboriginal youth and what could be done about it, and their thoughts on the art pieces created at the workshop. All interviews were audio-recorded and transcribed verbatim. This article draws on the data derived from these interviews.

Data were coded using NVivo qualitative data management software by a team of five graduate students, who received group training from the principal investigator on how to thematically code data in accordance with the codebook collaboratively created by the research team (Flicker & Nixon 2014). Students worked in pairs to review paper copies of transcripts, cut them up with scissors, and organise excerpts according to the codebook categories. Coded data were then analysed and discussed in a collaborative participatory fashion at a retreat in which all co-investigators and the six Youth Coordinators participated. The analysis presented below reflects discussions around the major 'Culture' code.

The project team operationalised the Ownership, Control, Access and Possession (OCAP®) Principles – a protocol that supports Aboriginal self-determination and ownership over all research concerning Aboriginal people (First Nations Centre 2007; <http://fnigc.ca/ocap.html>). Participants had full ownership of their artwork and consented to its reproduction and sharing in print and online formats. Additionally, a 'Youth Story' manual was created by the youth coordinators and shared with their communities at local community events.

LIMITATIONS

Our sample was self-selected. It is possible that only those youth leaders interested in art and/or HIV volunteered to participate. As a result, care must be taken in interpreting results. Culture-based interventions may not work for all Indigenous youth in all contexts. However, we worked with a diverse cross-section of young people from various cultures, regions and walks of life (often voices that are rarely heard) that overwhelmingly supported this approach.

RESULTS

Aboriginal Identity and Cultural Reclamation

Drawing on data from the youth interviews, we foreground the voices of young people as they explain the role of their identities, and particularly culture, in their narratives of self-affirmation, health, healing and wellbeing. For some youth, their identity was linked to race and legislated ideas of Indigeneity such as status cards. This was often directly connected to their ancestry, their appearance and (in)ability to 'pass' or 'look' Aboriginal.

When I was younger, it used to bug me a lot, like not looking Aboriginal, like on reserve and stuff. But now I am more confident in my identity ... I started getting more involved in the traditional and ceremonial stuff, I was like, I know I am Aboriginal, like I have my Indian status in my wallet, so I am not worried about that.

However, as described in the quote above, for many youth being Aboriginal was much more than simply appearance, blood quantum or status card. It also related to the importance that culture played in identity formation, as a continuous and ongoing process. As one youth described:

If you forget the stories and songs, we forget the past. And if we forget the past, then there's no history. If there's no history then there can't be a future.

The Complexity of Culture

For youth participants, culture was a complex construct that included reconnecting to their land, body, history, family, community, language, tradition and ceremony, among other elements. [Table 1](#) provides a more detailed look at the ways in which participants took up and defined the importance of culture. Many youth regarded elders as integral stewards for imparting, teaching and disseminating culture and traditional ways of knowing and doing to the younger generation. Some youth spoke passionately about the personal importance, impact and pride of being involved in cultural practices, events and ceremonies. Others talked about learning their language as important for intergenerational healing, empowerment, staying healthy, and combatting ills like HIV and substance use (see [Table 1](#)).

Table 1: The importance of culture

Theme	Examples
Elders as knowledge keepers	<p>'We should talk to our elders about more because they have our culture and tradition and we need to learn it more because really, that is the future.'</p> <p>'We see how our grandparents were raised: they were in the snow, they were in the canoes, they were cutting fish and everything like that and then the next ... generation had screens and TVs and everything like that and they were not on the land and they were not being taught the same morals.'</p> <p>'We have to get our culture back we have to find some other spiritual strength that our ancestors had. In order to do that we need to go back to the land, yes the land, it's all important.'</p>
Learning language and culture	<p>'I want to learn Native language. I want to be able to speak it, I just want to learn it. Like I am more into it than I was before.'</p> <p>'I want to learn more stuff about my culture because I'm in a different school now and we can't learn anything because there's no Mi'kmaq classes. So, I want to, somehow, like, get to know more about my culture and stuff.'</p> <p>'Yeah, so yeah, I am really in touch with it, I go to longhouse and festivals and stuff like that and I was named in the longhouse. I am really in touch with it, I am not fluent in the language but I would really like to be.'</p> <p>'Culture is important because in our culture you can understand the language and what they are saying when they're drumming, like information about HIV and stuff like that.'</p>
Art as culture	<p>'Art is part of our culture or just part of any culture really: it actually is culture.'</p> <p>'Because [the hip hop song] ... just catches you, catches your attention ... Because mostly everybody on the reserve listens to music.'</p> <p>'Like, I like traditional Aboriginal art, I have always found it especially beautiful and interesting. Maybe something inherited.'</p> <p>'Lots of people look at art, especially Native people, because they have, like, really unique art styles.'</p>
Culture and wellbeing	<p>'Because people will be, like, I wish I could remember my culture and then start like going out with friends and family hunting and stuff and it will cut down on drinking and all that a little bit, and then they will be like just yeah.'</p> <p>'Yeah, [ceremony] gets your mind off doing things like drugs and alcohol and hanging out with your own crowd. You get to learn more.'</p> <p>'I like doing cultural things like fishing, cleaning some fish that my grandma catches. Helping her with stuff like that and yeah. Because your mind will be set on, like, to do something good for your culture [not] destroying it by drinking.'</p> <p>'Culture can tell you how to keep your body healthy, like through praying and other medicines.'</p> <p>'Get more involved in culture, medicine, keeping the body healthy, and not, like, learning it is not cool to party and stuff.'</p>
Culture, sexuality and prevention	<p>'Way back in our youth, we would be educated about our sexuality. So I think just like going back to having the facts, being educated at a young age ... Yeah, I think that, if [we] were still in our culture then we would not have that much, like our numbers wouldn't be out there, we would be doing our traditions of what we do.'</p> <p>'People with culture they try to get it away so there would be a separation of culture and HIV when you are talking to them, but I don't think that should be because I think culture should</p>

Theme

Examples

be an emphasis on what it means to be like a human.'

'Culture is a big deal because if you know about your culture you will respect your body more rather than not knowing anything and doing whatever you see or hear people do.'

'I was talking to my auntie who is in a fasting camp. And she mentioned that, like, way back before like colonization, that people were really frank about sexuality and that they thought that that was the best way to protect people because then they knew like, they knew the facts. And I think that is important also.'

Central to the conversation about culture and sexual health was that the youth had a very good understanding of the role colonialism played in suppressing conversations about sex and sexuality, which otherwise would have been normalised conversations and topics that reaffirmed self-knowing in their traditions.

A number of youth resisted dominant narratives and conceptions of Aboriginal culture as being static and unchanging. They discussed the importance of art as a medium for self-expression and an important example of the fluidity and malleability of Aboriginal cultures and traditions that are able to evolve to incorporate new ways of knowing and doing, such as video-making and photography.

Although youth placed great importance on and pride in their cultures, many discussed the detrimental impact of colonialism, the residential school system and assimilation on their cultures, communities and lived realities. These factors and processes often contributed to their inability to piece together fragmented narratives about silenced histories, cultures, traditions, languages and knowledges.

Um, I learned that a big part of the reason why a lot of us lost our language was cause they – we weren't allowed to speak it in the residential schools and they would get, like, whipped or whatever if they tried to talk our language – and then, that's kind of a reason why we lost it. And, that's pretty bad, cause a lot of people don't know how to speak their language.

Furthermore, some youth made complex connections between these colonial processes and the ongoing challenges their communities face, including the spread of HIV among Aboriginal peoples.

I guess in a way residential schools ... all that physical, sexual and mental abuse and then when we were able to go home they did not know much of the culture anymore and they just felt like crap, I guess, and then they went to alcohol and drugs, I guess, and yeah.

The problem with Aboriginal people is just like the isolation that they have to go through: isolation from each other, from their communities, from their traditional ways. I think that can have all sorts of negative repercussions, and I think that HIV is one of them.

Many of the youth participants felt that coming together and having an opportunity to engage, reclaim, redefine and reimagine their culture and heritage was not only important for their positive identity formation, but was also a 'good way' to talk about HIV prevention.

DISCUSSION

Youth expressed frustrations with the role of colonial processes in silencing, fragmenting and erasing aspects of their cultures, histories, traditions, languages and knowledges. Many connected this erasure to the social and health ills prevalent in their communities, including HIV. As demonstrated in [Table 1](#), youth understood how colonisation resulted in social isolation, the breakdown of community and familial connections that are vital for living in a good way, the loss of language and cultural knowledge, and increased substance use. Colonialism has led to legislative attacks on every aspect of Indigenous life, including spiritual and ceremonial life, cultural genocide through assimilation in the residential school system, and Indigenous ownership of land (Mikkonen & Raphael [2010](#); Simpson [2004](#)). Identifying these factors and the resulting traumatic stress is critical for understanding the historical and contemporary health crises of Indigenous peoples in Canada. For instance, when it comes to the sexual health of Aboriginal communities, many of the 'high-risk' behaviours that are displayed by some Indigenous people are linked to intergenerational trauma (and sexual trauma more specifically), unresolved grief, and the shaming of sexuality and cultural identity – much of which is a legacy of the residential school system, as depicted in the narrative accounts of the youth (Mitchell & Maracle [2005](#)). The intergenerational trauma of colonisation is a determinant of health with grave implications for the overall health and wellbeing of Indigenous peoples, resulting in increased vulnerability to infectious and chronic illnesses (Czyzewski [2011](#); LaRocque [2011](#); Lawrence [2004](#); Simpson [2004](#)).

The narratives of cultural pride shared by the youth are important because they mark a counter-discourse that does not centre on grief and colonisation. Much like the responses of the youth who challenged their elders' ideas of authentic Indigenous identity at our feedback session in Kahnawà:ke, these narratives are framed around resistance, resilience, self-determination and self-definition. Overwhelmingly, the youth located their identities in cultural survival rather than a legislated national identity or racial identification. Further, for many youth, Indigenous culture and identity was understood as being fluid and open to evolution, change, and the incorporation of new art forms and mediums for expression and understanding the self. The youth conceived of identity and culture as processes one could learn and re-learn, build and re-build, as well as redefine to reflect cultural practices and art forms, such as hip hop and film, with which they are familiar. While such cultural identifications may seem arbitrary to some (Nederveen Pieterse 1992), they offer us a starting place that focuses on strengths (rather than the dominant narratives of deficits) within Indigenous communities. Narratives where youth believe they have the power to shape, challenge, reclaim and create new cultural norms and traditions that fit with their own personal and communal visions for change are particularly empowering.

Many youth viewed reclaiming their cultures as key to combating HIV because traditional practices teach values like respect for and knowledge about one's body, healthy sexuality, sexual pride, and living a balanced life (Simpson 2009). In other words, for these youth, culture serves as a protective factor against risks of health ills such as HIV (McIvor, Napoleon & Dickie 2009). Many of the youth discussed how participation in cultural practices was important for their self-conception, empowerment and healing, as well as transmitting information about HIV and keeping them engaged in something affirming to their identities, while distracting them from harmful activities such as substance use. Towards this end, many youth spoke excitedly of their attempts to learn and reclaim their languages and cultures despite barriers. Reclaiming Indigenous cultures, stories, languages and ceremonies helps to nurture the hearts and minds of future generations, as it teaches youth that it is 'ok to be Indian' (Simpson 2011). This is integral to ending the cycles of victimisation, perpetuated through dominant narratives of colonial abuse, and combatting hopelessness by reconnecting Indigenous peoples to stories of resistance and survival. Reclaiming is the ultimate form of decolonisation: it can include processes such as storytelling, language speaking, ceremony, singing, dancing and doing (Simpson 2009).

CONCLUSION

Our research process and findings show that the incorporation of culture, community, history and tradition is important for effective HIV prevention and health promotion initiatives for Aboriginal youth. Equally important are approaches that are: a) strengths-based; b) sex positive – encouraging informed and candid conversations about sexual health among youth and trusted adults; c) culturally safe (Mooney-Somers et al. 2012; Ricci et al. 2009; Rushing & Stephens 2012); and d) incorporate Indigenous models of health promotion (Mikhailovich, Morrison & Arabena 2007). These approaches can aid in creating strategies that move beyond individual behaviour change models. Individual and community health are vastly interconnected, so health interventions that focus on individual behaviour models of HIV risk, while failing to address the long-term impact of social, political and economic domination, and cultural genocide experienced by Indigenous communities are problematic and inadequate (Anderson 2011; Mitchell & Maracle 2005). There is a need for collective healing within Indigenous communities based on self-determination, intergenerational connections, and traditional and cultural ways of knowing and doing (Anderson 2011). Towards this end, a level of cooperation between health service providers, community members and traditional healers needs to be established (Kaufman et al. 2007a; Steenbeek et al. 2010). Aboriginal community members know best the needs of their communities and should be a central part of leading the development of sexual health service delivery and needs assessment (Ricci et al. 2009; Steenbeek 2004; Steenbeek et al. 2010; Thompson, Greville & Param 2008). Lastly, this work may be useful in research and activist spaces beyond the Canadian context where Indigenous peoples have experienced similar forms of structural violence.

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