Decolonizing Methodologies – Indigenous and African Diasporic HIV Research: Findings from a Scoping Review

Lori A. Chambers, Randy Jackson, Tola Mbulaheni, Cathy Worthington, Christine Smillie-Adjarkwa, Nicole R. Greenspan, Ciann Wilson, Renee Mashing, Wangari Tharao and Patrick Brownlee

Acknowledgements: Valerie Pierre-Pierre and Marni Amirault

Session Name: Decolonizing Methodologies: Strengthening Indigenous and African Diasporic Research
November 18, 2013 – 10:55am – McDonald Room
Project Rationale

• Indigenous and African/Caribbean/Black (ACB) diaspora communities are disproportionately affected by HIV

• *Decolonizing, culturally-grounded research approaches* may have profound implications for the ways we understand community engaged, action oriented research related to HIV

• Our team of ACB, Indigenous and allied scholars and community members is working to draw attention to these emerging approaches by re-conceptualizing ways of doing HIV social research in and with ACB and Indigenous communities grounded in traditional world views and practice

• Historical context: Principally inspired by the work of Smith (1999 & 2012) who also drew on the work Said (1994), Sartre (1964) and Memmi (2006)
Original Objectives

• To conduct a scoping review study to review and summarize the growing body of literature on decolonizing, Indigenous methodologies and “diaspora” thought to inform HIV prevention social research

• Produce a working paper/framework for use by SRC members and which could be shared more widely with others engaged in HIV/AIDS research

Definitions

A **scoping review** is a study that maps the literature and is used by researchers and community members to help summarize a range of evidence in order to convey the breadth of a field (Arksey & O’Malley, 2005)

**Decolonizing** (i.e., supports self-determination/challenges colonialism in research), **Indigenous** (i.e., by and for, using techniques and methods drawn from traditions and knowledges of Indigenous peoples), **Diaspora** (i.e., a term linked to imperialism, displacement from homelands and its connection to colonized experience) (Smith, 1999; Evan et al, 2009; Evans Braziel & Mannur, 2003)
Scoping Review: The Journey Begins

• General approach
  – Using (CBR) approach to decision-making

• Search strategy
  – Conceptual understandings of decolonizing/Indigenous/Southern OR Indigenous/African Diaspora cultures AND
  – Worldviews/ways of knowing OR methodology/formalized knowing practices

• Screening Process
  – First pass review to determine clear exclusion
  – Full paper review based on modified inclusion criteria (literature documenting research/knowing practices that were by/with/for Aboriginal/ACB communities)
## Characteristics of Included Literature

<table>
<thead>
<tr>
<th>Topic of Interest</th>
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<tbody>
<tr>
<td>African Indigenous</td>
<td>6</td>
</tr>
<tr>
<td>African Diaspora</td>
<td>3</td>
</tr>
<tr>
<td>Indigenous (Non-African)</td>
<td>44</td>
</tr>
<tr>
<td>Decolonizing Paradigms</td>
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<table>
<thead>
<tr>
<th>Year of Publication</th>
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<tbody>
<tr>
<td>Published since 2008</td>
<td>45 (or 54%)</td>
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<th>Countries of Interest</th>
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<tbody>
<tr>
<td>Published in Canada</td>
<td>25 (or 31%)</td>
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<tr>
<td>Other notable regions:</td>
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<tr>
<td>- U.S.A</td>
<td>21</td>
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<tr>
<td>- Australia</td>
<td>10</td>
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<tr>
<td>- New Zealand</td>
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<tr>
<th>Communities of Interest</th>
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<tbody>
<tr>
<td>Indigenous (non-African) communities</td>
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<tr>
<td>African communities</td>
<td>11</td>
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<tr>
<td>African communities</td>
<td>2</td>
</tr>
<tr>
<td>Other diaspora</td>
<td>3</td>
</tr>
<tr>
<td>N/S</td>
<td>5</td>
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<td>N/A</td>
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### Characteristics of Included Literature

<table>
<thead>
<tr>
<th>Type of Conceptual, Theoretical or Methodological Work</th>
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<tbody>
<tr>
<td>Primary study</td>
<td>32</td>
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<tr>
<td>Methodological</td>
<td>24</td>
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<tr>
<td>Theoretical/Conceptual</td>
<td>23</td>
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<tr>
<td>Commentary/Editorial</td>
<td>3</td>
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<table>
<thead>
<tr>
<th>Method(s) used in Knowledge Gathering/Data Collection*</th>
<th></th>
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<tbody>
<tr>
<td>In-depth interviews</td>
<td>14</td>
</tr>
<tr>
<td>Narrative/storytelling</td>
<td>13</td>
</tr>
<tr>
<td>CBR/PAR</td>
<td>8</td>
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<tr>
<td>Focus Group</td>
<td>5</td>
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<tr>
<td>Sharing Circles (e.g., sharing circles)</td>
<td>11</td>
</tr>
<tr>
<td>Other</td>
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</tr>
<tr>
<td>N/A</td>
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<table>
<thead>
<tr>
<th>Health Issue</th>
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<tbody>
<tr>
<td>HIV/AIDS</td>
<td>3</td>
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<tr>
<td>Non-HIV Health</td>
<td>33</td>
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<tr>
<td>Education/Pedagogy</td>
<td>23</td>
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<tr>
<td>Other</td>
<td>11</td>
</tr>
<tr>
<td>N/A</td>
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* Total for data collection methods exceeds total number of included articles since some studies used multiple data collection methods
Emerging Themes from the Literature

- Community Participation
- Two-Eyed Seeing / Double Consciousness
- Decolonizing Knowing
- Holistic Health
- Cultural Knowing
- Reflexivity
- Ethical Responsibility
- Connectedness
- Ownership and Control
- Cultural Appropriateness of Methods
- Colonialism
- Community Benefit
Emerging Themes from the Literature

- **Decolonizing knowing** centering the issues and worldviews of Indigenous and African populations
- **Colonialism** (processes, practices, histories, ideologies) and its impact on Indigenous/African cultures
- Incorporation of **cultural knowing/knowledge** within research
- **Reclamation of voice** within knowing practice
- **Connectedness** or relational ontology (i.e., relationship to what we know)
- **Holistic health** as tied to decolonized knowing practices
- **Ethical responsibilities** of conducting research
- **Community participation** and active collaboration
- **Culturally appropriate** research methods
- Conducting research of **community benefit**
- Developing research mechanisms that foster community **ownership/control**
- Allowing **reflexivity** (i.e., critical reflection of experiential knowing) to emerge within research
- “Two-eyed seeing”/“double consciousness”— seeing/using the strengths in both Indigenous/Afrocentric and Western ways of knowing
.... And yet ...

Was the research process in which we were engaged decolonizing knowing?
Decolonizing Methodologies - Indigenous and African Diasporic HIV Research: Reflections on a Scoping Review Process

Cathy Worthington, Wangari Tharao, Patrick Brownlee, Randy Jackson, Ciann Wilson, Lori A. Chambers, Valerie Pierre-Pierre, Christine Smillie-Adjarkwa, and Marni Amirault

Acknowledgements: Renee Masching and Nicole R. Greenspan

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The Path Diverges: Evolving Project Method

• Moved to a **collective research process** congruent with decolonizing/Indigenous/ACB world views

• **Two face-to-face meetings**, one with an **electronic oral (video) format** – discussion transcribed to text

• **Themes on our relationships** to the literature coded using an asynchronous/online team approach (sequential coding), with follow-up teleconference for member checking/colleague review

• **(Re)discovering our ways** of knowing as a **collective** through this process
Reshaping Our Scoping Review Process

“In so thinking about how are we changing the scoping review process, I think we abandoned the scoping review process. We certainly know without a ‘pure’ scoping review process.”

“So one of the pieces that I think is interesting in our process for this is when I read the indigenous decolonizing literatures, what we are doing through this personal journey - which has become a group journey - is we're actually mimicking what the indigenous research says that knowledge is. It's something that starts with our individual perspectives, and we share that, and we co-create something that's new. And that's what knowledge is and that's what truth value is.”
Major Discussion Themes

• Tensions with Scoping Review Process

• Our Engagement with the Literature
Tensions with Scoping Review Process: Ontological and Epistemological Disjunctures - Ways of Being in the World and Understanding the World

“... That's one of the biggest tensions I've experienced, this need to validate ourselves to our colleagues, who adhere to Western ways of knowing. And I find that a little tense, for lack of a better word. Because I think validity might mean something different for us and for this way of knowing.”

“When we're doing a scoping review, and we're doing any kind of analysis of the social world, including the social world that includes research, we need to start from a place that understands that information from the worldviews and perspectives of the people who originally created it.”
Tensions with Scoping Review Process:
Concepts and Language

“To jump back to methods, this is powerful self-work. It's also about new self in relation, and co-creating meaning. What does that mean when we try to distill messages down? ... And we can do that, but the words don't cut it. So I struggle with that... What do we do with the words? Words aren't enough.”

“I actually read one article that was a definite exclude. And you know, when you reach the conclusion, and you realize, you know, this actually needed to be said, and to be understood in the context in which we are working. But if I didn't read it, I'd just have left it. And said, you know what, this is not worth including, because it doesn't cover the different topics we are working on. But the conclusions were very relevant to what we are actually doing, and I thought, what are we going to do?”
Tensions with Scoping Review Process:
Reader’s Relationship with the Literature and Beyond

“It's the way this paper teaches me something, or the way that I interpret what they're talking about in this section or in this paragraph... I don't know if a scoping review is supposed to do that. But that mimics the way that I actually learn from the literature outside of this project as well. Sometimes it's the direct content; it's written in the conclusion section. But sometimes it's like, I don't know, the relationship that I build with the author and the journal and the content.”

“If we want to influence and share - perhaps some of the people, the colleagues who we really respect for their great intelligence, for their work, but who haven't been exposed to, who aren't from our cultures, who aren't working with our communities. So how do we present something in a way that's familiar enough for them to pick it up. And do we have to?”
Decolonizing Methodologies: Indigenous and Diasporic HIV Research: Engaging the Literature

Renee Mashing, Valerie Pierre-Pierre, Marni Amirault, Wangari Tharao, Patrick Brownlee, Tola Mbulaheni, Nicole R. Greenspan, Randy Jackson, Cathy Worthington, Christine Smillie-Adjarkwa

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Our Engagement with the Literature: Finding One’s Voice

“It's almost we're caught in this between. And nobody seems to understand, even ourselves, who we have actually become. And if you look at what is actually written about ACB populations, I don't think anybody ever captures the way we have actually re-conceptualized our identities and our ways of thinking within a very different context from where we came from. So it makes me think about what have I become, and really looking critically at how does that impact what I tell people, what I say about myself, and when I'm doing research, what comes out and what stays hidden.”

“Because that's a question I ask myself - the development of knowledge as a journey. The elder I work with told me that. ... it's about accepting that journey we're on, and knowing that we don't have all the answers to allied involvement, and we don't have all the answers to resolve these tensions, even if we wanted to, even if it's appropriate.”
Our Engagement with the Literature: Collaborating across Cultures/Systems

“It's so hard to resolve, not even to resolve the conflict, but to get to a place sometimes of finding a language that we can share, and to ... talk about being spiritual beings, and to shake ourselves out of our heads. And that's the starting point of even understanding what the conflict's about. Much less resolving it, but just kind of naming, or understanding, here's the conflict that we're messing around with.”

“I think it's the bringing more people into the circle, and the circle will get bigger, and of course sometimes we'll condense, occasionally, but I think that is where social justice can occur. What I worry about is when we change the way we speak in order to be listened to and to resolve conflict. And I think sometimes we do this as ACB and Aboriginal researchers.”
Our Engagement with the Literature: Oscillating Locations and Identities

“Cause I only just started researching within my community, whatever that means. Before I was the only non-gay-male, and I was very accepted and I learned a lot. But I've always danced with those tensions of identity, of community, of what that means, of alliances and what that means. Am I imposing my alliance, or have I been asked to be an ally?”

“Yeah, and I have to say that when I read articles, that's my first question all the time, ‘Who is writing this?’ And for me, I don’t want to say there’s a legitimacy to reading — … But I definitely think that that relate-ability to, ‘Whose gaze is this?’”
Our Engagement with the Literature: Literature Similarities and Differences

“The third question, which is how are we talking together, and I think we're having that conversation, right? And it does ... appear in the literature, you know. It's critical race scholarship, right? Which is sort of our bridge. It's all in the same family of critical theories. And we draw from each other.”

“When I work with ACB communities, and even in my own identity, even in my own rhetoric, colonialism never gets taken up. It never gets taken up in the same way, to the same degree [as in the indigenous literature].”
Summary Statements

• The potential impact of this work is far-reaching, as it has already transformed our practice and personal relationships to HIV social research

• As we engage in this journey, (re)discovering our ways of knowing:
  – How do we inhabit (Western, CBR, decolonizing) research spaces as Indigenous, ACB, and/or allied researchers?
  – What do we do with this knowledge yielded thus far?
  – How can we invite others into the circle?
Acknowledgements

• Our team members

• Consultation participants at AIDS 2012 (e.g., Indigenous and African Diaspora scholars)

• Support: The Canadian Institutes of Health Research (CIHR) and the CIHR Social Research Centre in HIV Prevention
Decolonizing Methodologies: Indigenous and Diasporic HIV Research: Engaging the Audience

Ciann Wilson, Nicole R. Greenspan, Christine Smillie-Adjarkwa, Renee Masching, Marni Amirault, Valerie Pierre-Pierre, Patrick Brownlee, Tola Mbulaheni, Wangari Tharao, Lori A. Chambers

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Discussion Questions

• How do decolonizing methodologies change the research process for you and why?

• What are some of the themes in the decolonizing methodological literature that resonate for you and why?

• In what ways are the two bodies of literature (i.e., Indigenous and African Diaspora) talking to each other (or not)?

• What has been your journey using decolonizing methodologies and where do we go from here?